

Common ethical dilemmas of family caregivers of palliative patients in Indonesia

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Abstract

Family caregivers, especially in Asian countries, have a profound role in caring for a sick family member. However, there are wide variations between the Asian and western world in terms of culture and facilities. Therefore, the problems and needs of family caregivers between those two regions may also be distinct, and it is important to explore and elaborate based on our empirical evidence. In Indonesia, motives and values in caregiving and religion become the wheel-power of the family caregivers in providing care. This affects action and consequences for caregivers. This paper attempts to elaborate on common ethical dilemmas that usually face by family caregivers in Indonesia. Unfortunately, family caregivers typically are not prepared to make those challenging decisions. Therefore, we recommend not only that family caregivers need to be involved in the caring process, but also their issues and ethical dilemmas should be assessed and addressed by health care professionals, especially nurses, who have the most frequent contact with patient and family caregiver.

Keywords

Asia; caregivers; religion; health personnel; caring; ethics; nursing; Indonesia

Prolog

Without a good understanding of what it is like to be overwhelmed by the experience of illness - one's own or that of a loved one - how can the doctor or ethicist (or other health care professionals) appreciate the human situation the doctor must address?" (Dresser, 2011).

This implies that understanding the lived experiences of patients and family caregivers is an essential key to take care of patients with a terminal illness. Accordingly, we would start this perspective essay by presenting three real cases.

Case one

Roy, 25 years old, a young man we interviewed in a chemotherapy clinic in Yogyakarta, Indonesia, was accompanying his mother, diagnosed with breast cancer.

He took it hard when we asked what his life activity was. Finally, he said: *'Well, I was a happy newly graduate entering my first day of work, but then mom called me almost every hour that day. She asked what time would I be home. That night I could not sleep. I thought it should be fine to postpone my life for 1-2 years to be her caregiver. My life can wait, but my mother's treatment cannot. I then submitted a resignation letter at the end of that week.'*

Case two

Celine, 34 years old, who has been married for ten years, was looking forward to having a child of her own. She used to live in Singapore, but since last year, she moved back to Jakarta to take care of her mother, diagnosed with tongue cancer, and her father, a diagnosed Alzheimer's patient. Celine has an older sister who lives nearby; however, she said she was already too busy to take care of her own three kids. Therefore, it should be Celine who becomes their

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mom's caregiver since Celine has no kids. Coming from a wealthy family, they set up a proper home care plan fully equipped with nurses and a visiting doctor. However, it has been three months since she could go anywhere. One time she went to the gym, but she received a phone call from her husband asking how she could leave their parents at home in that condition. She was then stuck at home, bored and depressed.

Case three

Maria, almost 50 years old, decided to be her sister's caregiver, Anna, since five months ago. In doing so, she needed to leave her family and job in Kalimantan, Indonesia, which was such a tough decision to make. Anna, 36 years old, was diagnosed with breast cancer around three years ago. She has fought bravely, and now she suffered from constant pain and a large malignant wound on both of her breasts. She also suffered from anemia and needed to go to the hospital for a transfusion. Nevertheless, Anna is a cheerful lady with a bright personality. She knew exactly what is going on with her condition and was ready for the worst scenario. Her concern was only for her daughter, Lia (16 years old). Lia never knew who her father is since she was born. Since Lia goes to school and Anna was bound to bed rest, Maria's heart was moved. Actually, Maria and Anna had such opposite characters; they had argued in many ways since they were little. Maria decided to be Anna's caregiver because she could not be on her mother's side during her last moment in life. This guiltiness haunted her for many years. She was expecting that by becoming one of Anna's caregivers, her guiltiness would fade away. When we asked: "*With whom would Lia stay with when something happens to Anna?*" With her soft voice, she said that this is the most important topic, but she could not initiate it with Anna. She does not know how and when to start this discussion.

These cases illustrate that caring for the loved ones (who are ill) affects the patients and may also change the family caregivers' life. Accordingly, the [World Health Organization \(2010\)](#) defines palliative care as an approach to enhance not only the quality of life (QOL) of patients but also their family caregivers. This definition relates to the Indonesian situation where caring for the family member is considered part of Asian culture ([Funk, Chappell, & Liu, 2013](#)).

This perspective paper aims to elaborate experiences of family caregivers in Indonesia and to identify some common ethical dilemmas in their palliative experiences.

Family Caregivers

The family caregiver has various definitions. The most common meaning refers to people who provide care to their loved ones with or without blood relations, including in-laws and neighbors ([Kilic & Oz, 2019](#)). This person may or may not live with the care recipient, but they provide care for at least 6 hours a day. However, the most common differentiation with the formal caregiver is that there is no

financial compensation from the care recipient to this family caregiver.

Family caregivers' circumstances are varied between Western and Asian regions. In the Western world, independence (or lack of dependency) is highly appreciated. The government responds by providing various formal facilities such as long-term, hospice care, nursing homes, and many other institutions in order to maintain the individual sense of independence for people with chronic and terminal illnesses. On the other hand, in Asian countries, including in Indonesia, taking care of family members is part of the culture. In this setting, there are many important lessons that we have learned from generation to generation—taking care of our family, especially our parents, may be the only way we know how to appreciate life and our inheritance. In Javanese culture, for example, *tabon* is a term that refers to a child that is assigned to take care of a parent ([Keasberry, 2001](#)). According to this culture, *tabon* will be granted ownership of the house once the parents are passed away ([Keasberry, 2001](#)).

In relation to financial compensation, some developed countries have various schemes. For example, in the Netherlands, people are able to self-assign a '*mantelzorg*' (family caregiver in Dutch). They put this information on legal government documentation. When something happens to their health, this *mantelzorg* will provide direct care, including taking the patient to the hospital, facilitating their groceries, and other daily activities. The Dutch government offers a financial scheme to compensate for the time spent by the *mantelzorg* in providing this care. There is a limited amount of Euros per day that can be accessed by the *mantelzorg* and applied as an invoice ([Alice, Inger, & Mirjam, 2019](#)).

Considering the wide variations in the Western and Asian cultures, this implies that we need be careful about directly or thoughtlessly adapting ideas or interventions from the Western countries to Asian ones. Cultures are a form of intergenerational heritage that actively shapes people's lives, including the family caregiving condition. Since one of the most suitable policy types is supported by empirical evidence, research on family caregivers in Asia, including Indonesia, is essentially needed.

Family Caregivers in Indonesia

When one of the authors (MSK) started PhD study in 2015, funded by the Dutch government, evidence was limited concerning family caregivers in Indonesia. Fortunately, research on this topic has been growing progressively in the past five years. A study revealed that family caregivers have a profound role in patient care even during hospitalization ([Effendy et al., 2015](#)). This finding implied that family caregivers must have important tasks at home. They should be supported. They should be part of the care. The next question is, how can we provide the support and care that they need?

This initiated me to start my first study by comparing the experiences of family caregivers of patients with cancer and patients with dementia. We found more similarities than differences in the problems in caregiving, actions of caregivers, and beliefs in caregiving. Some differences were also identified (Kristanti, Engels, Effendy, Utarini, & Vernooij-Dassen, 2018). Family caregivers of people with dementia revealed that direct contact with health care professionals was highly appreciated. People with dementia are usually cared for by either gerontologists or neurologists, then the communication and coordination can be much simpler. On the other hand, care for most patients with cancer is done by multi-disciplines, including oncologists, internists, surgeons, and many other parties, depending on their needs. This lack of simple, one-to-one involvement increases the risk for friction and miscommunication issues.

However, family caregivers of people with dementia revealed that they sometimes felt a loss of connection with the patient even when the patient was still beside them. *"She doesn't know me anymore; she doesn't know anyone anymore"* [Husband].

Meanwhile, family caregivers of patients with cancer often described a stronger family cohesiveness. For example, one participant said that she (55 years old) had only talked to her older brother (57 years old), who lived in a different city once or twice a year since they were busy with their own life, family, and work. But since she has been looking after their mother, they keep in touch on a daily basis, sometimes just to ask how they are doing. As a result, they found a reconnection during this caregiving process (Kristanti et al., 2018).

The next study then elaborates on the experiences of family caregivers of patients with cancer (Kristanti, Effendy, Utarini, Vernooij-Dassen, & Engels, 2019). Data were collected from three major cities in Indonesia: Jakarta, Surabaya, and Yogyakarta. Belief in caregiving is the core phenomenon (Kristanti et al., 2019). It is the wheel-power of caregivers. It consists of spiritual and religion, values, and motives in caregiving. This wheel-power influences the actions of family caregivers and the consequences they received. The more constructive their belief in caregiving, the better the consequences it impacted on them. Those with this spirit eventually found themselves as a better person and vice versa.

Common Ethical Dilemmas

These empirical data can help us reflect on ethical dilemmas that the family caregivers must face in the caregiving process or their relationships with patients and other family members. In general terminology, extensive medical literature used ethics, dilemma, and moral distress interchangeably (Yildiz, 2019). In the nursing profession, an ethical dilemma may be alleviated by utilizing a scientific ethic, that is, by placing people (or the care recipient) at the center and interacting with family members and their

network, by considering their values, uniqueness, dignity, and inherent human rights (Yildiz, 2019).

In the case of the family caregivers' journey, based on our empirical data (Kristanti et al., 2019; Kristanti et al., 2018), one of the most frequent dilemmas was 'hiding'. Family caregivers tend to hide their emotions and burdens in front of the patient. They thought that their feelings were not relevant and should stay hidden. They would pose a cheerful, brave, and tough face in front of the patient. Another hiding is about revealing diagnoses. When the patient is younger (below 50 years old), the doctor mostly revealed diagnoses directly. However, when the patient is older and maybe illiterate (unable to understand), the family caregiver is the first to receive the diagnosis. The doctor then would request the family to inform the patient, or in some cases, the family would ask the doctor and nurses not to reveal the diagnoses until the patient is ready. When the patient was not aware of their diagnoses, the condition became the most problematic situation for the family caregivers. One of the participants in our study revealed that once she broke the news of the diagnosis to her mother, it felt like 'a mountain had been removed from her shoulders' (Kristanti et al., 2019).

The second ethical dilemma was the perception of voluntary vs. obligatory actions in the caregiving tasks. In many Western publications, Asian countries are framed negatively that caregiving is a mandatory action. Our study in Indonesia showed that we framed 'this obligation' in a positive way so that we see this as a chance to make some payback to our loved ones. It is described as 'a chance in disguise' or some opportunities and benefits while facing some challenges (Kristanti et al., 2019).

The third dilemma was that most caregivers were the so-called 'first-time players' with no training (Dresser, 2011), meaning that they are 'newbies' (in caregiving role), and they may need time to grasp information, to have second or third opinions, to make (some immature) decisions and/or to change their decision. It is because nothing is harder than making decisions about treatment and caring, resulting in life and death consequences. Family caregivers also felt like living as a shadow. Their presence was mostly overlooked by healthcare professionals or other family members. While all the spotlight is on the patient, the family caregiver is also the one who needs to be taken care of.

The decision-making process is another dilemma that we identified. Some caregivers need to decide to continue or stop treatment when the patient can no longer participate in this decision. The decision for resuscitation can be a life-long traumatic memory for them. The guilty feeling to stop the treatment can also become their burden of guilt for the rest of their life. In order to reduce unnecessary guilty feeling, British Medical Association reminds us to apply the ethical principles of ordinary and extraordinary. The obligation of healthcare workers is to provide ordinary care, while extraordinary care is not an obligation (British Medical Association, 2007). One is not obliged to use all resources to defend human life. Extraordinary care is a situation in

which we have to say “enough” and not prolonging treatment or care.

The last dilemma is the appreciation concerning the formal facilities. Some palliative care experts in Indonesia are still discussing if hospice care is suitable for our culture. Would we dare to let our loved ones stay in the hospital at the end of their life? Can we ignore what people say to us if we put our loved ones in a nursing home? or do we prefer to have them stay with peace in their familiar place: at home? What is the formal facility to support both patients and caregivers that suits our economic condition, social status, and culture?

Ethical Considerations in Involving the Family

As nurses, sometimes we need to decide to involve or not involve family caregivers as part of our caring team. Becoming part of the team means that we may have an equal number of tasks and responsibilities. One of the important tasks of healthcare workers (including nurses) is to foster autonomous decision-making of the patients or their proxy (Beauchamps & James, 2019). As healthcare workers, nurses have an ethical obligation to give all necessary information so that patients or their prox may make autonomous decisions. In many cases, the final decision is a shared-decision making between family caregivers and nurses. We may refer to the four *prima facie* principles in making the decision: respect for autonomy, beneficence, non-maleficence, and justice (Beauchamps & James, 2019).

Principles of beneficence must take positive steps to help others, not merely refrain from harming them (nonmaleficence). It is an ethical obligation to do good for patients and their families, including family caregivers. Involving family caregivers in patient care will enhance the collaborative aspect. We then need to identify who is the daily ‘family caregiver’ and who is the ‘key person to make a decision for the patient’ because their roles are different. They can be the same person. But in Indonesia, this is not always the case. There are cases where the main decision-maker is living in another part of the world. They can be the one who is funding the treatment or the eldest ones in the family. Nurses need to identify this hierarchy so that they can speak the right topic to the right person.

Non-maleficence relates to the previous principles. The principle of nonmaleficence obligates us to abstain from causing harm to others. This principle is identical to the famous maxim *Primum non nocere*: “Above all [or first] do no harm.” Although this principle does not appear in Hippocratic writings, it is regarded as a fundamental principle in the Hippocratic tradition. It was found that that the most dilemmatic problem in family caregivers is their unbounded tasks (Dresser, 2011). They do everything every time. In some cases, family caregivers of dementia passed away when the patient was still alive. Nurses should assist them in setting up targets and boundaries to maintain the family caregivers’ own QOL.

The third *prima facie* is justice. Traditionally justice means that equals must be treated equally, and unequal must be treated unequally. This traditional definition is attributed to Beauchamps and James (2019) added an important notion, justice means fair, equitable, and appropriate treatment in light of what is due or owed to affected individuals and groups. This implies that services offered by nurses for caregivers should have the same quality and standard. We should provide the support that is systematic and structured. Intervention such as providing basic care training is effective to maintain the QOL of patients in terminal illness (Kristanti, Setiyarini, & Effendy, 2017). Also, interventions offered should not only be for the patient’s QOL but also maintain the caregivers’ well-being.

The last principle is respect for autonomy. Respect for autonomy is to acknowledge patients’ right to hold views, make choices, and take actions based on their values and beliefs. It means that nurses or other healthcare workers have to respect the autonomous decision of patients. The opposite is true: the decision by a non-autonomous person should not be respected. Respecting the autonomous decision of patients means that nurses should obtain people’s agreement for any decision and any medical interventions relate to them, keep confidentiality and promises, and not deceive others (Gillon, 1994). This principle may relate to the decision-making process in palliative care. Knowing how challenging the decision-making process in palliative care could be, advanced care planning (ACP) should be implemented soon in Indonesia. ACP is a discussion between the doctor, patient, and family (and nurses) for planning the treatment and future decisions. The patient should be in good condition physically and psychologically following a procedure. The discussion during ACP may include if the patient accepts or refuses resuscitation when it is needed. ACP will make the treatment and next step in the process easier for everybody and prevent a traumatic event due to the obligation to provide a decision in a short moment for family caregivers.

Implication for Nursing Practice

Nurses are part of health care professionals who have the most frequent contact and interaction with patients and families. Therefore, nurses have an important task to observe patient's and family's situations and needs. In addition, knowing some of the ethical dilemmas that may be faced by the family caregivers, nurses need to assess and provide sufficient support for them. Patients and families are one unit in caregiving. By providing care to the family caregivers, we support the patients in facing difficult moments in life due to their illness.

Conclusion

Family caregivers have profound roles in caregiving for patients with chronic and terminal illnesses. Some ethical dilemmas along the journey were identified as signposts. Accordingly, nurses can utilize the four primary ethical

principles of caregiving to provide support for family caregivers and enhance the family caregivers' sense of well-being.

Declaration of Conflicting Interest

None declared.

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Authors' Contributions

MSK was responsible for initiating the concept, writing, and drafting and had the ownership of data. K and CE provided important intellectual content and contributed feedback while writing a manuscript draft. All authors have provided final approval and agreement to be accountable for all aspects of the work regarding content.

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