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## Last Chance to Care: An Autoethnography of End-of-Life Care in Indonesia

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### Abstract

In Australia, palliative care is an accepted and expected part of contemporary health care service provision. Efficacious palliative care focusses on managing pain and symptoms and making the patient as comfortable as possible (World Health Organization Definition of Palliative Care (WHO, 2010). As well, palliative care focusses on the spiritual and psycho-social dimensions of life (Martina, 2017), providing the opportunity for the patient and their family to continue to be engaged with life and self-determined decision making throughout palliation. In this account, utilizing the qualitative research method of autoethnography the Australian author describes her experience of caring for her Indonesian father-in-law in the last week of his life. She explores emerging tensions associated with local end-of-life care and Western care which trigger deeper feelings associated with losing a loved one, complicated by the recent and sudden loss of her own parents. Narration is a powerful tool for capturing the verisimilitude of everyday experiences, evoking in the reader a powerful resonance into a very personal inner life which is often not spoken about in academic texts. This account, a cultural story of dying in East Java, Indonesia, also provides insight into the author's expectations, as an Australian and concludes with some reflections about the emerging position of palliative care services in Indonesia.

### Keywords

Palliative Care, Death, Dying, Indonesia, Autoethnography, Narrative

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I thank with all my heart all those individuals who have failed to extend their minds to understand the power of autoethnography and for the structural processes which have worked to hamper my efforts. I am forever grateful to you for helping me to harness my passion and channel my courage to express my creativity regardless. It has made me a better writer. Thank you.

## **Last Chance to Care: An Autoethnography of End-of-Life Care in Indonesia**

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*In Australia, palliative care is an accepted and expected part of contemporary health care service provision. Efficacious palliative care focusses on managing pain and symptoms and making the patient as comfortable as possible (World Health Organization Definition of Palliative Care (WHO, 2010). As well, palliative care focusses on the spiritual and psycho-social dimensions of life (Martina, 2017), providing the opportunity for the patient and their family to continue to be engaged with life and self-determined decision making throughout palliation. In this account, utilizing the qualitative research method of autoethnography the Australian author describes her experience of caring for her Indonesian father-in-law in the last week of his life. She explores emerging tensions associated with local end-of-life care and Western care which trigger deeper feelings associated with losing a loved one, complicated by the recent and sudden loss of her own parents. Narration is a powerful tool for capturing the verisimilitude of everyday experiences, evoking in the reader a powerful resonance into a very personal inner life which is often not spoken about in academic texts. This account, a cultural story of dying in East Java, Indonesia, also provides insight into the author's expectations, as an Australian and concludes with some reflections about the emerging position of palliative care services in Indonesia. Keywords: Palliative Care, Death, Dying, Indonesia, Autoethnography, Narrative*

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Palliative care is 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. (WHO, 2010, n.p.)

### **Introduction**

The prospect of dying is, for most people, something to avoid thinking about. In many developed nations, the average person can go through most of their life and have very little, if any, first-hand experience of death (Field & Cassell, 1997; Freeman, DasGupta, & Fitch, 2015). Children grow up without attending funerals or being in close proximity to someone getting old and dying. Such is the modern, clinical lifestyle that the dying are kept out of sight— hospitalized or admitted to hospice care. Relatives can become ill and die without being seen until their coffins or ashes are revealed at the funeral or memorial service. The practice in the first half of the last century of keeping the deceased in the front parlor on show is far removed from the way most death is dealt with in Western societies today (Field & Cassell, 1997). In traditional cultures, families continue to care for their dying family members, and in Indonesia are strongly committed to doing so (Effendy, Rizmadewi Agustina, Kristanti, & Engels, 2015). It is only Western societies which separate them from their usual life, their homes and families in order to take care of them, often being guided by

a medical model and the expertise of health professionals (Kellehear, 2009). For many people, religion is an important part of end of life care. For Muslims, a belief in Allah means that the decision about their death is not in their hands; that Allah will decide when it is time to die and He will take care of them during the journey. In the case of Javanese Muslims, the purpose of life is explicitly to prepare for the afterlife (Webster, 2009). During the last phase of life, relatives constantly sit with the dying relative and recite Koran verses, known as *sura*, to comfort them and see them through to the next life with all the blessings they need to make the journey comfortable, but many of them suffer because they do not receive care to alleviate symptoms (Effendy et al., 2015; Rochmawati, Wiechula, & Cameron 2018).

### Review of the Literature

Palliative care in Indonesia is a relatively new addition to medical care, having been introduced as a concept around 1990 (Soebadi & Tejawinata, 1996). At this time, the Ministry of Health convened the National Cancer Control Committee, which in turn created a Palliative and Cancer Pain team. The team's objective was to offer pain relief, support to care givers and family during the illness and bereavement period, support the patient to celebrate life, contextualize death as a natural process, and develop a community-based service which could provide family-oriented care in the patient's home (Soebadi & Tejawinata, 1996). This pilot was developed into a service model which commenced in 1992 in Surabaya, East Java by Dr. Sunaryadi Tejawinata (Martina, 2017). In 1999, the Indonesian Palliative Care Society (*Masyarakat Palliatif Indonesia, or MPI*) was established and comprises health professionals with an interest in palliative care, including "medical practitioners, nurses, pharmacists, psychologists, social workers, religious personnel and volunteers" (Effendy et al., 2015, p. 99).

At the time of writing, Indonesian palliative care focuses on providing comfort to oncology and pediatric patients but is currently limited to seven urban hospitals on the islands of Java, Bali and Sulawesi (Effendy et al., 2015). The hospitals are located in large urban centers: Surabaya, Jakarta, Yogyakarta, Bandung, Semarang, Denpasar and Makassar (Effendy et al., 2015) These hospitals offer comprehensive palliative care including home visiting and telephone support. Rural areas do not have access to tertiary palliative care at all (Putranto, Mudjaddid, Shatri, Adli, & Martina, 2017), rather they utilise strong networks of community-based services to fill the gaps. These services are not necessarily informed by palliative care best-practice or coordinated with other support services (Effendy, 2015; Effendy, et al., 2015; Witjaksono, Sutandiyo, & Suardi, 2014). Whatever care is provided, it is strongly supplemented by family care (Effendy et al., 2014; Kristanti, Setiyarini, & Effendy, 2017; Ibrahim, Haroen, & Pinxten, 2011).

Because palliative care is in the early stages of development in Indonesia (Effendy et al., 2015; Martina, 2017), there is a small group of leading practitioners who have contributed to the literature to date emanating from their work in hospitals. Palliative care researcher, Christantie Effendy and her colleagues undertook research with AIDS and Cancer patients in the advanced stage of disease at the time of seeking medical intervention (Effendy, 2015). They focused their investigations on the effectiveness of the patient's needs assessment and whether those needs were ultimately met (Effendy et al., 2015). This research resulted in a basic care training booklet and video for family caregivers, but the research was predominantly informed by the high rate of cancer and AIDS in the population and the advanced stage of disease at the time of seeking medical intervention (Effendy, 2015) so there remains a need for comparable resources for aged care and other degenerative and neurological diseases. Dr. Effendy continues to promote oncology-focused literature about palliative care in Indonesia and advocate for high quality services available to all Indonesians

but she acknowledges the field requires more pioneers and resources (Kristanti, Setiyarini, & Effendy, 2017; Witjaksono, Sutandiyo, & Suardi, 2014). This article highlights the need in small, rural communities that do not have access to palliative care services.

### Method

Positioning myself in the center of this narrative (Walker, 2017), I initially wrote about my father-in-law's death as a way of coming to terms with the experience, particularly in relation to the tensions which arose in supporting him at the end of his life. This approach freed me from making my experiences "fit" with theoretical frameworks. Instead, it allowed me to create meanings from my lived experience and offered me the space to sit with my discomfort and convey that in a legitimate way to readers (Ross Kuby, 2013). Ferrell and Hamm (1998) refer to this type of research as working at the edge and highlight its benefits as including honesty, subjectivity and risk, and Rutherford Behar famously advocated for heartfelt or heartbreaking ethnography (Behar, 1996). The central theme of talking about what hasn't been talked about before, what isn't easily expressed, is of interest here: the idea that medicine has colonized death and palliative care without exploring the subjective experiences of patients or carers (Fox 2015). Richardson (2000a) has named the genre of reflective ethnographies, such as autoethnography (AE), as being subject to creative analytic practices which differentiates them from biography and fiction. For me, the use of autoethnography is empowering because it gives authority to the voice of lived experience and provides a window into the internal human world, as well as describing social and cultural phenomena which may not yet have been mined (Ellis, 2004). This is a particularly useful method for phenomena which are sensitive and/or difficult to talk about publicly. Death and dying is one such topic. When dialogue is open, people become empowered to speak frankly about their lived experience, and this can be a powerful method for exploring nuances of human emotion and experiences.

The literature about palliative care in Indonesia focusses largely on palliative care as provided by healthcare professionals (Jones, Podolsky, & Green, 2012; Martina, 2017) or describes traditional practices of dying (Chambert-Loir & Reid, 2002). There are few first-hand narratives describing the experience from an observational ethnographic perspective, and none that focus on the lived experience of caring for a Javanese elder. In Java, dying is not simply a medical or biological process; it is also a spiritual process which involves loved ones and family. There are cultural and legal aspects to consider, and there are practical matters and existential challenges to overcome. It is ethical that no one professional discipline "owns" dying (Freeman et al., 2015; Glover, 1977; Singer, 1994).

A proponent of AE, Carolyn Ellis (2004) believes that this method for conveying human experience provides the opportunity for writers to position themselves in the center of the narrative and for readers to identify their own parallel experiences within that story, creating a palpable relatedness and self-understanding. Richardson (1990) agrees, proposing that this is the aspect the readers are most interested in because they can relate to the story and in reflection upon it, their own experiences are normalized. This is empowering for readers. This builds on Hollway and Jefferson's notion of *unconscious subjectivity*, which recognizes that the researcher is not separate to the research field and that their research is defined by their relationships with those whom they are observing in the field (Hollway & Jefferson, 2000).

AE emerged from the method of ethnography; the aim of which is to create thick description (Geertz 1973) by using the data to create evocative, relatable accounts of cultural life. AE is an approach used to study culture which endeavours to look deeper than simple observation; it aims to convey people's intentions, thoughts, feelings and inner reflections

and is dependent upon the researcher's ability to reflect on her/his lived experience by focusing on their own reactions, most private thoughts and feelings, and their in-the-moment analysis of events (Bochner & Ellis, 2016). Autoethnographers capitalize on their own experiences to contribute to knowledge about the phenomenon under study, often in a space which hasn't been previously well documented at this stage (Ellis, Adams, & Bochner, 2011; Pitard, 2017).

This approach relies upon the autoethnographer being able to reflexively track their thoughts, senses, feelings and reactions in the moment, and then critically analyze and reflect upon their experiences, subsequently reporting them in a rational and coherent way (Ellis, 2004). It can depend upon a narrative approach which allows the writer to viscerally convey the complexity of human emotion and the sometimes, conflicting thoughts and feelings that emerge in such situations, but which are often not written about (Ellis 2004). Ordinarily, it is not necessarily represented in a chronological format, however, on this occasion I found it helpful to tell the story as it occurred.

While it may seem as though AE is a highly subjective method, it is important to note that phenomenological study of social life, particularly from the perspective of the inner world, can only be reported subjectively (Bille & Steinfeldt, 2013). This does not detract from its value and contribution to scholarship, rather it generates a deeper layer of meaning which can be generalized to others (Giorgi, 2009) and which is not made to fit existing theories. Dahlberg proposes that there is merit in reserving judgement about the phenomenon under investigation so that understanding emerges throughout the observation (Dahlberg, 2006).

Qualitative research, like all research, must adhere to qualitative standards. These include: rigor, authenticity and resonance, generalizability and whether it achieves its goal (Bochner, 2000; Bochner, 2002; Ellis, Adams, & Bochner, 2011; Richardson, 2000b). Although this paper did not emerge from research, its objective is to take the reader along on my journey caring for my elderly father-in-law, Babak, during his last days. I want to create a sense of verisimilitude for the reader in the sense of haste my family had in being with him, the frustration in not being able to provide the resources to care for him the way I wanted to. If readers believe the story I am telling to be one of genuine truth and can either relate it to their own experience of loss or imagine what that might be like, then the paper has achieved its purpose and, in the process, further evidence for the value of AE as an appropriate vehicle for telling life stories will occur.

Because of the autobiographic and narrative nature of AE, the job of the autoethnographer is to ensure that ethical standards are maintained throughout the writing process (Bochner & Ellis, 2016). Relational ethics is particularly pertinent for stories which focus on people in the author's circle (Ellis, 2007). For me, this included my father-in-law, my husband, my children and other villagers and relatives. Seeking permission from my husband and children was central to the process because without this permission, I could not have embarked on the process of preparing my journal reflections for publication in a peer reviewed journal. To protect people's privacy, I have de-identified all the individuals and the places which might cause readers to recognize the people in this article. As my university (where I am completing a PhD) does not support my publication of AE articles using my own name, I am able to further protect the identities of those I write about by using a pseudonym.

Narrative vignettes are woven throughout this paper to simultaneously convey the experience and my meaning making. This provides an opportunity for the reader to viscerally engage in the story and walk with me as I try to make sense of what is occurring, to support Bapak, to support my husband and children, to provide practical help to Bapak and to come to terms with my own complex grief. It is a lot to try and make sense of, but ethnographic fieldwork does not frequently occur in calm environments—sense must be made out of chaos

(Behar, 1996; Shaffir & Stebbins, 1991). This narrative began its life as a way for me to make sense of a chaotic experience, particularly because I wanted to capture the cultural elements of death in Indonesia. I have used AE for other projects, including a master's thesis. I find it a powerful method for personal journal writing and contributing cultural perspectives. I also wanted to capture the inner tensions I experienced in drawing on my professional experience as a Palliative Care Social Worker some years ago to relieve the discomfort and pain of losing someone I loved dearly. AE provides the author with a tool to capture in-the-moment feelings, emotions and thoughts (Ellis, 2004) so often left out of discussions about death and dying.

### **Positioning Myself**

I am a white Australian social worker married to a Javanese man. We have lived in Australia for the duration of our 21-year marriage, spending several months out of the year in Java where we have a house. Although I work in a different field now, I have worked in hospital aged care and cancer and palliative care treating teams. Eighteen months prior to my father-in-law's death, I cared for my parents in Australia who died in quick succession to each other: my mother from Pancreatic Cancer and my father from a complex aetiology and what seemed to be a broken heart. Apparently, this is not unusual (Souter, 2018). My Javanese father-in-law was a widower in his 80s who remarried, and they lived a fairly impoverished life without ready access to medical care. He was a traditional man who made do with what he had and did not seek what he believed was unattainable to him. In many respects, this is where the story starts.

### **Death in Java**

The Indonesian Ministry of Health reported in 2015 that there were 2488 hospitals in Indonesia, of which only 1593 are public (Ministry of Health, 2016). There is a total of approximately 305,000 beds in private and government hospitals. That is 1.21 beds per 1000 inhabitants (Ministry of Health, 2016). There are 0.2 medical practitioners per 1,000 people and 1.2 nurses and midwives per 1,000 people (The World Bank, 2018). One does not need to be an expert to see that health care services are not easily accessible.

### **Findings**

About seven weeks before he died, Bapak fell over at home while attempting to sit in a chair; missing the chair and landing heavily on his left hip. He did not seek medical intervention despite experiencing a gradual decline in mobility and wellness. Family members accepted his decision to remain at home without medical intervention and his seemingly terminal fate. This is a phenomenon I have observed many times in the last 25 years visiting Indonesia. Many people, young and old, have told me that they do not access medical intervention during illness and/or injury due to expense, access, family support and service reliability. Faith also plays a role in people's ability to accept their fate and not challenge Allah by seeking interventions which might prevent their ascendancy to the next life. It is at this juncture that we found Bapak lying on a hard rattan day bed in a bedroom with moldy and crumbling rendered walls, concrete floor, a rusty tin roof and open timber shutters. Mosquitos buzz around and there is a small wasp's nest on the rafter. Other than my sting-prone 13-year old son, no one seems perturbed by this. Bapak is lying on a sagging rattan day bed, only a sheet of linoleum between his back and the slats. He is wearing a sarong and stained singlet. He looks small, thin and very uncomfortable, and I struggle to

imagine how this bed is helping him to recover. When I first see him, my emotions get the better of me and I leave the room in tears, not wanting him to see me cry. “I can’t do this again”—I say, having buried my own parents only 15 months earlier. In a reverse of roles, my oldest son gives me a cuddle and utters soothing words before we return to the room together.

Bapak recognizes us, squeezing our hands and crying but he has that distant look in his eyes that I recalled dementia patients often have before they die. His wife brings some *soto*— a clear broth with rice, chicken and carrots—and we all take it in turns to feed him. I am encouraged by his appetite, but discouraged by his exertion, cries and pained expression. My social work experience seems to intuitively filter through from the dark recesses of my mind, and I tell my husband that I think Bapak needs palliative care, but he doesn’t know what I mean. I tell him he must be made comfortable and have some medical care to build him up a little before we leave in nine days and that I don’t believe this can occur in this environment. I suggest we admit him to the local private hospital because I think he is dehydrated, confused and experiencing strong pain. My husband agrees and begins to discuss the plan with his father’s wife. She starts to cry, and we tell her that it’s a chance for her to have some respite as well. This does not seem to alleviate her distress and that bothers me, but right now I am more concerned with Bapak’s discomfort. In spite of her reaction, she complies by giving my husband Bapak’s medical entitlement card and ID.

My husband tells me he must also discuss the plan with his brothers. We leave with a tentative plan and, though I feel relieved that he is still alive, it is challenging to see him so run down.

Later in the morning, the family holds a meeting and it is agreed to admit Bapak to hospital, and an ambulance is booked to transfer him. We talk to the Emergency Room nursing staff and doctors to see what their initial diagnosis and prognosis is. It is too early to tell us much. They order blood tests, a urine test and X-rays. A cannula is inserted into his right wrist and a saline drip and hydrochlorothiazide drip for his kidneys are attached. He has an oxygen tube. He also has a naso-gastric tube inserted for feeding and a catheter which reveals deep strawberry red urine. This alone signals alarm—I realize he has kidney failure and there are no resources here to alleviate this problem. It is not difficult to imagine his discomfort.

We wait quietly and soberly with my brother-in-law for Bapak to be taken to and return from X-ray and watch the people who are watching us—white people in this small, local Javanese hospital. A curious distraction from the reality of their unfortunate presence here today. We follow the orderlies and a nurse as they wheel Bapak’s bed past the rooms along the open verandas of this tranquil hospital amongst the rice paddies to his room, already occupied by a relatively young but ill looking man. There are only centimeters between the two beds. The young man’s family is lying on the floor at the foot of the bed with their possessions: small tables with food and a pillow. The TV is on and the volume loud.

When his bed is put in place, we settle in close to Bapak. My husband takes his hand and hovers over him speaking loudly and clearly to explain what is occurring and asks him repeatedly whether he wants anything. Afterwards I pull up a chair beside him and stroke his arm. He gestures that he wants to hold hands, and this is the way we sit for most of the time during my shifts over the following week. I notice he has a dry mouth and ask the nurse whether we can swab his mouth. She agrees but advises the hospital won’t provide the swabs or water, so I instruct the children as to what I’m trying to do and send them to a small supermarket up the road so that we can fashion some kind of mouth swab. They return with a packet of straws, but no cotton wool and I reluctantly abandon the idea. I don’t have time to feel disappointed and quickly engage in problem solving to try and alleviate his dry mouth.

My husband recommends dripping the water into his mouth using the straws until we can think of something better. I also notice he seems to be lying on his injured back and I worry about bed sores and his pain. My husband and I discuss whether he can locate a physiotherapist who could come to the hospital, but he tells me we can't bring one into the hospital. Fortunately, the next day a physiotherapist has been to visit and props up his shoulder with a pillow to relieve the pressure on his lower back, the site of injury. We wash him with wet tissues and cuddle him to convey our love. The next six days are spent like this. We cry together, but mostly he seems incoherent and confused. He grasps for something or someone in mid-air and twists the sheets in his hands, just like my father did in his last days. I don't know whether he knows me, whether he thinks I'm his missing daughters or deceased first wife, or whether he is even aware of being in hospital. I speak Indonesian with him to try to ascertain his needs, but he doesn't seem to understand. My husband has more luck speaking Javanese. Nevertheless, I do not leave his side during my shifts and must diligently monitor him as he tries to pull out his catheter and tubes. I also need to call the nurses regularly to empty the blood-red urine bag when it fills and replace the drips as they empty. Blood pressure observations and temperature is measured frequently, and much ado is made of variations. I am mindful that none of this really matters with the dying, but politely thank the nurses for their care. I realize that the nurses, though doing their very best, are not trained in palliative care (Tarihoran, 2013) and don't have the resources that would provide patients with comfort (Martina, 2017).

For approximately the first three days he remains restless, writhing around in pain and seeming to be hallucinating, but after this, he takes on the peacefulness that the terminally ill often do, and settles finally. My husband reads this as a sign that he is improving, but I tell him we are close to the end now and advise him to prepare himself. "I am ready" he states emphatically, over and over again, and I sense that he is bracing himself for the worst. I am torn between focusing on the practical needs of the situation and providing emotional support to my husband, which I fear will overwhelm me emotionally and render me useless to provide a level head and practical support to Bapak. I cannot let myself fall apart right now.

On our last day in Java we discuss with the family whether he can remain in hospital, but they are reluctant as they can't stay with him due to their employment commitments. Coincidentally, the doctor advises us he is ready for discharge and so, once again, I begin instructing my husband and his brothers about what is needed at home. Certainly, the rattan bed needs a mattress and I am concerned about pressure sores so enquire amongst people we know where we can get a pressured air mattress and something soft to lie on, like a sheep skin, but nobody knows. Again, I try to think laterally but don't come up with anything. It is frustrating not being able to buy things that will make him comfortable at this time. I am fleetingly annoyed with myself for not having brought these things from Australia.

Bapak is transferred home by ambulance and we visit him the next morning. I am relieved to find that my brother-in-law has put a thin, cotton mattress on his bed. He is surrounded by his wife and villagers who've come to visit, and we bustle our way in. The visitors leave the room but hover in the doorway watching us, and I feel self-conscious about showing my grief and emotion so publicly. I learn that Indonesian custom doesn't privilege the dying and their family to privacy. My husband and sons read *Yaasin*, Islamic prayers, with Bapak for 40 minutes, the visitors joining in. All the while, Bapak remains quiet and resigned and, though he is mouthing *Yaasin* verses, he is looking into the distance. When we say goodbye, he becomes animated again—wriggling around and crying. It's heart breaking to leave him at this vulnerable and sensitive time, but we must embark on our return flights to Perth.

At 11.:30 p.m. my husband receives a message that his father has died and wakes me to tell me. I offer him my love and condolences and then sob into my pillow. His pain has ended—finally—but ours begins now.

### Discussion

As mentioned earlier, palliative care as a concept is relatively new in Indonesia and not yet accessible by most of the population. In Bapak's experience, the key principles of palliative care were not comprehensively considered or offered. If we examine the qualities of palliative care and compare with Bapak's experience, we can see many opportunities for development of Indonesian palliative care services.

The Indonesian custom of family members providing care met, to some extent, Bapak's social and spiritual needs; however, this really only commenced during the admission period; previous to this he was isolated at home without medical intervention and his wife as sole carer.

One of the most important aspects of palliative care is that there is a continuous and coordinated assessment of physical, mental, cultural, social and spiritual needs and that care is provided by professionally trained staff (Palliative Care Australia, 2018). Whilst the hospital provided a bed, medical support and nursing care, a large part of the care fell to family members, including my need to alert nursing staff of drips emptying and urine bags filling. This is partly due to cultural conventions. It is difficult to say whether hospitals are responding to cultural needs of the patient or whether the family are expected to provide support and care in the absence of hospital resources.

Another principal of palliative care is that the patient, their carer(s) and family should be involved in planning and decision making (Mitchell, 2011). This was not our experience. The medical staff assessed Bapak behind closed doors, did not seek input from family members and apart from brief discussions with some family members during triage assessment and prior to discharge, communication did not provide the opportunity to discuss diagnosis, treatment options or prognosis. There seemed to be an unspoken understanding that all family members and nursing staff knew that Bapak was dying and that family would care for him at home following discharge. Once again, this may be a cultural *morè*, emanating from the Islamic belief that only Allah knows when someone is dying and discussion about imminent death is not the norm. Once discharged from hospital, private services may have been able to provide ongoing care, however these are expensive and for those without resources in Indonesia, such services remain unavailable, hence the primary caring role fell back to his wife and children who had to return to their work, adding further burden to their stress and grief. In any case, there was no discharge assessment or canvassing by hospital personnel regarding which services he might need at home nor were referral options provided to us.

In a health system which is not comprehensive or holistic in itself, the challenge is to coordinate and integrate holistic care (Ross & Walsh 2014). Essentially, you can't provide resources you don't have, and this was our experience in regard to material resources such as a pressurised air mattress, sheep skin to deter bed sores and mouth swabs to aid hydration. These are standard items in any Australian hospital and their scarcity in Java led to my great frustration.

Efficacious pain relief is another core component of palliative care (Palliative Care Australia, 2018) because control of pain as a symptom allows the person to feel more comfortable which enhances their quality of life. It also promotes dignity and means non-professional carers, such as extended family members, are better placed to care for the individual in their home and to attend to other needs (Rosser & Walsh, 2014).

Another factor of good palliative care is that careers are supported throughout the process and during bereavement (Palliative Care Australia, 2018). Although my father-in-law received very diligent and kind nursing care and had family support, the benefits of holistic and coordinated care may have improved his quality of life and provided the opportunity for earlier interventions (Martina, 2017). My greatest distress occurred when I saw Bapak in great physical pain, and this is mainly due to the unavailability of efficacious pain relief.

### **Conclusion**

Although the body of scholarship is small, it is well evidenced that palliative care services in Indonesia are in the early stages of development and require more resourcing, strategic planning and public health leadership in order to flourish (Martina, 2017). At the time of writing, there were eight palliative care services attached to oncology wards of major hospitals located in urban areas mainly on Java and Bali (Effendy, 2015; Witjaksono, Sutandiyo, & Suardi, 2014) and one pediatric hospice (Rachel House, n.d.). There are numerous community services which provide care to the dying for a fee, though they are not necessarily called palliative care. The danger of this is that services are not accredited nor coordinated, and coordination is one key factor of efficacious palliative care. Martina reports that dedicated inpatient palliative care units and community palliative care non-government organizations are expected to be operational by the end of 2018 (Martina, 2017). By way of example, Australia's palliative care services commenced in the 1980s and also initially focused on adults with cancer (Hudson, 2017), but now extend to life limiting illnesses and disabilities, so it is hoped that Indonesia will continue development of the sector in coming years. Perhaps the first step in the process is raising awareness.

Indonesian nursing lecturer and palliative care advocate, Dame Elysa Tuty Arna Uly Tarihoran (2013), undertook research to evaluate palliative care knowledge amongst Indonesian nurses and concluded that lack of specialist knowledge and training is the main barrier to qualitative palliative care being provided in Indonesia. She acknowledges that palliative care training is currently only provided informally in clinical settings and recommends that palliative care education be formalized and improved in both clinical and community settings and that government resourcing and policy development must also occur across the country.

The Indonesian Palliative Society recommends a top down approach to establishing palliative care in Indonesia beginning with the creation of government-initiated policies, improving undergraduate and postgraduate education in palliative care for health professionals, reforming existing attitudes of health professionals and more generally improving social conditions (Mitchell, 2011; Witjaksono, Sutandiyo, & Suardi, 2014). The Society also recommends that psychological, social and spiritual aspects of life are crucial factors in the provision of qualitative palliative care. This model acknowledges the plight of the average Indonesian in a rural area and the lack of awareness people have which preclude them from seeking palliative care (Witjaksono, Sutandiyo, & Suardi, 2014).

The average Indonesian citizen dies at home with minimal medical intervention, due in part to service availability and in part to affordability and the culture of end of life care being the responsibility of family (Kristanti et al., 2017). Indonesians, particularly the elderly, accept death as a normal part of the life cycle, and as such, that it will occur at home in familiar surroundings with loving family members around to care for them. Martina (2017) suggests that retaining the care of family members whilst supplementing it with formal palliative care, will not only enhance the palliative care measures undertaken by professionals but serves to unburden the health care system because patients require fewer and shorter admissions.

This paper did not emanate from research, but this does not diminish its value. Borne from my lived experience as a privileged, white Australian woman with some knowledge of palliative care and Indonesian culture, I wanted to express my frustrations in caring for my beloved father-in-law during his last week of life. By using a narrative method and the critical analysis of AE, I hoped to create what Ruth Behar refers to as heartbreaking ethnography (Behar, 1996), to capture the essence of the complex emotions associated with end of life: the frustrations, sadness, expectations, disappointments, and finally, mine and my family's despair throughout. The purpose of AE is to convey a sense of verisimilitude so that others may relate to the experience. This is no small feat: stories such as this are a powerful method for conveying human emotion and the internalization of experience, and have the potential to reassure, normalize and provide insight for others. For this reason, my experience of Bapak's death cannot be generalized to a broader group or population. To do so would contradict the purpose of AE which values the individual's introspection and meaning-making of their experiences (Ellis 2004). Some might argue that it is also unethical and disrespectful to try to make this story "fit" with a dominant narrative (Ellis 2004). For these reasons, this story stands alone—its strength lies in its ability to resonate with readers.

This narrative illustrates a tension between my desire to provide comfort to my father-in-law, Bapak, and the lack of resources to enact this, but it also highlights that Indonesians accept the discomfort that awaits them during this period and instead focus on the spiritual process. Though I wasn't surprised by his stoicism, I was surprised that medical care depends upon it, albeit in the absence of palliative care, which can provide comfort without compromising the person's traditional ways of managing death because it focusses on a holistic, bio-psycho-social model of care which considers the person's wishes. Given the Indonesian context that many people, and cancer patients in particular, do not seek medical support until advanced stage, the benefits of palliative care are largely about quality of life, rather than extending life in the final days and weeks (Effendy, 2015; Effendy et al., 2014; Soebadi & Tejawinata, 1996) and this can be achieved relatively simply with education and resources (Putranto et al., 2017). As Indonesia embeds its palliative care services more, my hope is that comfort can be offered to all Indonesians who need it.

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### **Author Note**

Petra is currently completing a PhD exploring cultural identity in cross cultural marriages using traditional ethnographic techniques though she did complete her master's dissertation using autoethnography. Unfortunately, her university does not permit her using AE in writing about her experiences of life in Indonesia, therefore she must use a pseudonym to convey these important stories of lived experience. Correspondence regarding this article can be addressed directly to: [petrabwessner@gmail.com](mailto:petrabwessner@gmail.com).

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