

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

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Aim: To review healthcare literature in relation to the provision of palliative care in Indonesia and to identify factors that may impact on palliative care development.

Background: People living with life-limiting illness benefit from access to palliative care services to optimize quality of life. Palliative care services are being expanded in developing countries but in Indonesia such services are in their infancy with many patients with life-limiting illnesses having access to appropriate health care compromised.

Methods: Relevant healthcare databases including CINAHL, PubMed, Science Direct and Scopus were searched using the combinations of search terms: palliative care, terminal care, end-of-life care, Indonesia and nursing. A search of grey literature including Internet sites was also carried out.

Results: Nine articles were included in the review. Facilitating factors supporting the provision of palliative care included: a culture of strong familial support, government policy support, volunteering and support from regional organizations. Identified barriers to palliative care provision were a limited understanding of palliative care among healthcare professionals, the challenging geography of Indonesia and limited access to opioid medications.

Conclusions: There are facilitators and barriers that currently impact on the development of palliative care in Indonesia. Strategies that can be implemented to improve palliative care include training of nurses and doctors in the primary care sector, integrating palliative care in undergraduate medical and nursing curriculum and educating family and community about basic care. Nurses and doctors who work in primary care can potentially play a role in supporting and educating family members providing direct care to patients with palliative needs.

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

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Conflict of interest

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Introduction

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

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

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

Indonesia faces a challenge regarding the growing incidence of non-communicable disease including cancer, diabetes and cardiovascular disease (World Health Organisation (WHO) 2010). Consequently, the number of patients who need palliative care is increasing. Generally, palliative services are provided to people in the late stage of disease (Utari 2008). In 2014, the estimated rate of adults who needed palliative care at their end of life in the South East Asia region which includes Indonesia was approximately 234–353 per 100,000 population (WHO 2014a). The greatest need was for progressive non-malignant disease, followed by cancer and HIV/AIDS. In Indonesia, palliative care services were initiated in 1990 through the establishment of pilot palliative services provided in existing health institutions (Al-Shahri 2002; Soebadi & Tejawinata 1996). A global overview identified that Indonesian palliative care services are currently classified as level 3a, i.e. not fully integrated into mainstream healthcare services (Lynch et al. 2013).

This leads to the following questions: How is palliative care currently provided in Indonesia? What are the barriers and are there any facilitating factors in providing palliative care?

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

Background

Health care in Indonesia

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

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

In January 2014, a new universal health coverage; the *Badan Penyelenggara Jaminan Sosial Kesehatan* or *BPJS Kesehatan* (Healthcare and Social Security Agency) which covers the cost of primary and referral care was implemented (BPJS Kesehatan 2014; Kwok 2014). The impact of the new policy is

not yet known as its implementation is relatively new and there is no published evaluation at this time.

Methods

Aim

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

Search strategy

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

Inclusion and exclusion criteria

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

Result

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

Of these nine articles, three were primary research reports written by Indonesian nurses ($n = 2$) and a British physician ($n = 1$). Two were descriptive surveys; one study examined the role of family, nurse and physician in dealing with palliative patients' symptoms and the other investigated learning needs of healthcare professionals in relation to palliative care. The third article was a qualitative study exploring the need

for home-based palliative care for people living with HIV/AIDS. All three articles also included information on barriers and facilitating factors for palliative care in Indonesia.

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

Palliative care in Indonesia – major findings

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

Current progress

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

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

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

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

Table 1 Continued

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

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

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

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

Facilitating factors

This review identified several facilitating factors. These factors included support from regional authorities (Effendy et al. 2015; Witjaksono et al. 2014), individual families (Effendy et al. 2014; Soebadi et al. 1996) and the involvement of the community (Saleh et al. 2008; Soebadi et al. 1996). The government's support for palliative care was shown when the national policy on palliative care were enacted by the Ministry of Health in 2007 (Effendy et al. 2015; Witjaksono et al. 2014). Effendy et al. (2015) reported that this policy stated that palliative services should be available in the five main cities of Indonesia including Jakarta, Yogyakarta, Surabaya, Denpasar and Makassar. The policy should have a positive impact on palliative care services as it encourages all types of healthcare organizations to provide palliative care services. Witjaksono et al. (2014) and Effendy et al. (2015) however suggest the need for palliative care services is evident but the

available palliative facilities are limited. Witjaksono et al. (2014) suggest that the national palliative care policy has not been applied in the healthcare system due to the absence of palliative care guidelines and standards, an appropriate referral system and lack of resources. Although there is criticism of government support at the national level, one publication highlighted support from local authorities through conducting basic palliative care training for healthcare professionals in hospitals and primary health centres (Witjaksono et al. 2014).

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

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

Challenges

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

The limited use of opioids has been a significant challenge to the provision of palliative care. When palliative care services were first developed in Indonesia there was limited availability of oral morphine. Weak opioids were used in the

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

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

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

Discussion

This review of the literature has outlined the past and recent provision of palliative care services including the type of care and the facilitators and barriers in relation to palliative care services in Indonesia. The current provision of palliative care is still in its infancy. According to the six levels of palliative care development described earlier, palliative care activity in Indonesia is at level 3a where the provision of services is isolated (Lynch et al. 2013). Although the Indonesian healthcare context may be different from developed nations, in both contexts the need for palliative care is growing (WHO, 2014a) However, in developed countries, palliative care services are generally well established and integrated within

mainstream healthcare systems, while in Indonesia the scope of palliative care activity is still patchy (Lynch et al. 2013) and the referral system to the existing palliative care services has only recently commenced (Effendy et al. 2015). In low- and middle-income countries and particularly in Indonesia, the availability of palliative care services is still limited and in many parts of the country is simply not available. In this review, we found there were 10 hospice and palliative organizations and service providers as reported by Lynch et al. (2013). In considering the size of population and geographical location of services, clearly there are significant constraints in terms of the number of palliative care services available. Data collected in 2011 provides a telling comparison where the indicative ratio of palliative care service to the population in Indonesia was 1:22,996,000 and for Australia was 1:67,000 (Lynch et al. 2013). Consequently, the quality of life for those living with life-limiting illness whether in Indonesia or other developing nations remains relatively poor. This present review highlights that the progress of palliative care in Indonesia has been slow. It is not clear why palliative care has not been given a higher priority but clearly there is a great need.

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

In Indonesia, family and community support are viewed as having a significant role in providing care to the sick and dying. This reflects findings from other developing countries in Asia such as Malaysia (Namasivayam et al. 2011) and India (Shanmugasundaram et al. 2006) where providing care for the sick and dying is a moral obligation for family members. Indonesian culture stresses the important role that family members play in providing care for their loved ones (Effendy et al. 2014). This is also reflected in a study reporting on the assistance given by relatives to women post mastectomy with

families providing physical and spiritual support (Anggraeni & Ekowati 2011). Although only one study identified addressed in detail community involvement in palliative care activities (Saleh et al. 2008), it has been recognized that community involvement has been a feature of the Indonesian healthcare system more generally (Joint Committee on Reducing Maternal and Neonatal Mortality in Indonesia, National Research Council & Indonesian Academy of Sciences 2013). Given the level of family and community support that currently exists for family caregiving in cancer care, research is required to determine how best to support families and community groups in the provision of palliative care in Indonesia.

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

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

Another major constraint is Indonesia's geography. Half of Indonesian population live in rural areas (Central Bureau of Statistic (Badan Pusat Statistik/BPS) 2010) while only ten palliative care services are available in seven larger cities (Effendy et al. 2015; Witjaksono et al. 2014). This situation results in very limited access for Indonesian people living in rural areas to obtain palliative care. Australia also has difficulties in providing specialist health services in rural areas. Several strategies have been implemented to

improve access to palliative care in rural areas including capacity building for non-specialist practitioners (Recoche et al. 2014), integrating palliative care to primary care services (Palliative Care Australia 2005) and increasing involvement of general practitioners in developing local palliative care services (Phillips et al. 2006). Some of these strategies could also be implemented to improve access to palliative care in Indonesia. For example, shifting the focus from educating specialists in palliative care to educating generalist nurses and doctors working in the community, in the form of continuing professional education, would have considerable potential. It is likely most specialists in palliative care would continue to be based in larger cities not in rural areas. Such education then needs to focus on building non-specialist doctors' and nurses' capabilities in palliative care. These doctors and nurses would then be able to directly implement better palliative care to their patients.

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

Limitations

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

Implications for nursing and midwifery policy, education and practice

Palliative care provision encourages an interdisciplinary approach in delivering the service. Among health professionals, however, nurses have the potential to play a more central role in the provision of palliative care. Nurses are more

engaged with patients and their families particularly in the provision of care such as symptom management. This provides an opportunity to educate patient's families in how to provide basic care at home.

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

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

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

Implications for research

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

nursing care, developing or adapting tools to measure changes in health status, and patient satisfaction with palliative care provision.

Conclusion

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

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Study conception and design: ER, RW, KC.

Literature review/analysis: ER.

Manuscript draft writing: ER.

Study supervision: RW, KC.

Critical revisions for important intellectual content: RW, KC.

References

- Al-Shahri, M. (2002) The future of palliative care in the Islamic world. *Western Journal of Medicine*, 176 (1), 60–61.
- Amery, J. (2012) Mapping children's palliative care around the world: an online survey of children's palliative care services and professionals' educational needs. *Journal of Palliative Medicine*, 15 (6), 646–652.
- Anggraeni, M. D. & Ekowati, W. (2011) Family role in the achievement of post radical mastectomy self integrity patients. *International Journal of Public Health Research* 1 (special issue), 163–168.

- Bararah, V.F. (2014) *Treating and Managing Uncurable Illness (menangani penyakit yang tidak bisa disembuhkan)*. Available at: <http://health.detik.com/read/2010/10/07/153528/1458146/775/menangani-penyakit-yang-tak-bisa-disembuhkan> (accessed 22 January 2015).
- BPJS Kesehatan (2014) *Benefits of Healthcare and social security agency (Manfaat BPJS Kesehatan)*. Available at: <http://bpjs-kesehatan.go.id/statis-13-manfaat.html> (accessed 31 July 2014).
- Central Bureau of Statistic (Badan Pusat Statistik/BPS) (2010) *2010 Population census (Sensus Penduduk 2010)*. Available at: <http://sp2010.bps.go.id/> (accessed 08 October 2012).
- Effendy, C., et al. (2014) Dealing with symptoms and issues of hospitalized patients with cancer in Indonesia: the role of families, nurses, and physicians. *Pain Practice*, **15** (5), 441–446.
- Effendy, C., Agustina, H.R., Kristanti, M.S. & Engels, Y. (2015) The nascent palliative care landscape of Indonesia. *European Journal of Palliative Care*, **22** (2), 98–101.
- Gómez-Batiste, X., et al. (2010) Effectiveness of palliative care services in symptom control of patients with advanced terminal cancer: a Spanish, multicenter, prospective, quasi-experimental, pre-post study. *Journal of Pain and Symptom Management*, **40** (5), 652–660.
- Ibrahim, K., Haroen, H. & Pinxten, L. (2011) Home-based care: a need assessment of people living with HIV infection in Bandung, Indonesia. *The Journal of the Association of Nurses in AIDS Care*, **22** (3), 229–237.
- Indonesian Cancer Foundation (Yayasan Kanker Indonesia/YKI) (2012) *About ICF (Tentang YKI)*. Available at: <http://yayasankankerindonesia.org/> (accessed 08 October 2012).
- International Agency on Research on Cancer (IARC) (2012) *GLOBOCAN 2012: Estimated cancer incidence mortality and prevalence worldwide in 2012*. Available at: http://globocan.iarc.fr/Pages/fact_sheets_population.aspx?country=360# (accessed 31 July 2014).
- Joint Committee on Reducing Maternal and Neonatal Mortality in Indonesia, National Research Council & Indonesian Academy of Sciences (2013) *Reducing Maternal and Neonatal Mortality in Indonesia: Saving Lives, Saving the Future*. The National Academies Press, Washington, DC.
- Komurcu, S. (2011) Current status of palliative care in Turkey. *Journal of Pediatric Hematology/Oncology*, **33** (supplement 1), S78–S80.
- Kwok, E. (2014) *BPJS Kesehatan: A new medicare system?* Available at: <http://www.kpmg.com/ID/en/IssuesAndInsights/ArticlesPublications/Documents/IES-Bulletin-February-2014.pdf> (accessed 26 November 2014).
- Lickiss, J.N. (1993) Indonesia: status of cancer pain and palliative care. *Journal of Pain & Symptom Management*, **8** (6), 423–424.
- Lynch, T., Connor, S. & Clark, D. (2013) Mapping levels of palliative care development: a global update. *Journal of Pain and Symptom Management*, **45** (6), 1094–1106.
- Murtagh, E.E., et al. (2014) How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*, **28** (1), 49–58.
- Namasivayam, P., et al. (2011) Nurse-family interaction in Malaysian palliative care settings: a focused literature review. *International Journal of Palliative Nursing*, **17** (10), 507–513.
- O'Brien, M. (2014) *Indonesia: need of pain relief*. Available at: <http://treatthepain.org/Assets/CountryReports/Indonesia.pdf> (accessed 08 August 2014).
- Paiva, C.E., et al. (2012) Effectiveness of a palliative care outpatient programme in improving cancer-related symptoms among ambulatory Brazilian patients. *European Journal of Cancer Care*, **21** (1), 124–130.
- Palliative Care Australia (2005) *A Guide to Palliative Care Service Development: A Population Based Approach Canberra*. Palliative Care Australia, Canberra.
- Phillips, J.L., et al. (2006) Enhancing palliative care delivery in a regional community in Australia. *Australian Health Review*, **30** (3), 370–379.
- Recoche, K., et al. (2014) Building palliative care capacity in rural health: a collaborative approach. *Australian Nursing Midwifery Journal*, **21** (10), 38.
- Saleh, M.S., Danantosa, T. & Kusumawardhani, C. (2008) Palliative care in Balongsari Primary Health Center Surabaya: efforts to bring outpatient services to patients with advanced cancer (Perawatan paliatif di Puskesmas Balongsari Surabaya: upaya mendekatkan layanan rawat jalan kepada pasien kanker stadium lanjut). *Indonesian Journal of Cancer*, **1**, 27–29.
- Shad, A., Ashraf, M.S. & Hafeez, H. (2011) Development of palliative-care services in a developing country: Pakistan. *Journal of Pediatric and Hematology Oncology*, **33**, s62–s63.
- Shanmugasundaram, S., Chapman, Y. & O'Connor, M. (2006) Development of palliative care in India: an overview. *International Journal of Palliative Nursing*, **12** (4), 241–246.
- Shields, L. & Hartati, L.E. (2006) Primary care in Indonesia. *Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community*, **10** (1), 4–8.
- Soebadi, R.D. & Tejawinata, S. (1996) Indonesia: status of cancer pain and palliative care. *Journal of Pain and Symptom Management*, **12** (2), 112–115.
- Tjindarbumi, D. & Mangunkusumo, R. (2002) Cancer in Indonesia, present and future. *Japanese Journal of Clinical Oncology*, **32** (supplement), 17–21.
- Utari, D. (2008) *The service of palliative care and hospice home care in the Indonesian Cancer Foundation (Pelayanan paliatif dan hospice home care Yayasan Kanker Indonesia)*. Available at: <http://indonesianjournalofcancer.org/2008/2008-workshops> (accessed 05 August 2014).
- Witjaksono, M., Sutandiyo, N. & Suardi, D. R. (2014) *Regional support for palliative care in Indonesia*. Available at: <http://www.ehospice.com/Default/tabid/10686/ArticleId/11661/> (accessed 19 August 2014).
- World Health Organisation (WHO) (2010) *Country Cooperation Strategy at a Glance*. World Health Organization. Available at: <http://www.who.int/countries/idn/en/> (accessed 23 September 2012).

World Health Organisation (WHO) (2014a) *Global Atlas of Palliative Care at the End of Life* Worldwide Palliative Care Alliance and World Health Organization. Available at: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf (accessed 11 September 2014).

World Health Organisation (WHO) (2014b) Strengthening of palliative care as a component of integrated treatment throughout the life

course. *Journal of Pain & Palliative Care Pharmacotherapy*, **28** (2), 130–134.

World Hospice and Palliative Care Day (2014) *World Hospice and Palliative Care Day in Indonesia*. Available at: <http://www.worldday.org/events/printable-list/?entryid45=50760>. (accessed 19 September 2014).