



RESEARCH ARTICLE

THE EXPERIENCES OF NURSES IN PROVIDING END OF LIFE CARE: A REVIEW

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ABSTRACT

Background: Non Communicable Diseases is the main cause of 70% death worldwide may also cause various signs and symptoms so the affected person can suffer and their families have more burdens. This situation can decrease the quality of life, increase the families or caregivers' burdens, and provide less guarantee towards the dignity of the death. Therefore, the provision of qualified palliative care and end of life care are very important. The key question of this literature review is the experiences of nurses both in palliative care specialization and outside palliative care settings in delivering end of life care including the pain management.

Methods: The search strategies of the literature review generated 51 English articles from many backgrounds, with 34 studies met the inclusion criteria. All of these studies were identified from various computerized databases, the university journals, bibliographies, and reference lists between the years 2006 and 2016.

Results: The experiences of the nurses can be generated into four categorizations as the needs of the patients and caregivers, the perceptions towards palliative care, the challenges in delivering end of life care, and the sources needed in delivering end of life care.

Conclusion: There are numerous commendations of efforts that are very useful for nurses and the institutions to improve the quality of end of life care. It is hoped that through these efforts, the essence of caring end of life clients and the caregivers could be expanded over and over.

INTRODUCTION

The life changes recently have influenced the people's quality of life. The consumption of nicotine, lesser physical activities due to the use of modern utilities, alcohol, and imbalanced diet are the most responsible factors of Non Communicable Diseases (NCDs) as heart diseases, stroke, cancers, diabetes, and chronic lung diseases (WHO, 2016). WHO (2016) added that NCDs is the main cause of 70% death worldwide. NCDs may also cause various signs and symptoms so the affected person can suffer and their families have more burdens. The most uncomfortable symptom testified by people living with life-threatening illness is pain. Pain is the main symptoms claimed by almost all patients in palliative care units or End of Life (EoL). Many other symptoms are reported by the patients as well but mostly come along with pain in any health condition of the patients (Wilkie & Ezenwa, 2012). A study by Smith *et al* in 2000 identified that pain described by 60% respondents (Wilkie & Ezenwa, 2012) and in their follow up research in 2010, pain was still described by 46% respondents at the end of their life (Reynolds, *et al.*, 2013). As a result, pain can decrease the quality of life, increase the families or caregivers' burdens, and provide less guarantee towards the dignity of the death. Therefore, pain management is a very important component in the area of palliative care and EoL.

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RESEARCH METHODS

This study is a literature review. The key question of this literature review is the experiences of nurses both in palliative care specialization and outside palliative care settings in delivering EoL including the pain management. The search strategies of the literature review generated 51 English articles from many backgrounds, with 34 studies met the inclusion criteria. All of these studies were identified from computerized databases including google, google scholar, SAGE, Sciedu Press, IISTE, PubMed, Medline, Scholar Commons, NCBI, Gardner, BMC, Wiley, Science Direct, Ebscohost, and CareSearch. The search for unpublished studies were done through the university journals such as Southern Cross University, University of Wisconsin Milwaukee, and University of South Florida. Studying bibliographies and reference lists were applied as well. The articles studied were limited between the years 2006 and 2016. Individual case reports are excluded from the review.

RESULTS AND DISCUSSION

The needs of the patients and caregivers

There is evidence that working in palliative care settings caused emotional challenges and very stressful as clients and the caregivers may have a very complex situations due to the disease (Rose, 2008).

Clients with life-threatening illness feel most uncomfortable symptoms that cause deterioration and limitation in daily living or other physical activities. As a result, clients and the caregivers may need emotional supports, information, comfort, self-care, life style choices, assertiveness (Rose, 2008), emotional, physical, and spiritual care (Kaasalainen, *et al.*, 2014).

The perceptions towards palliative care

The attention to palliative care particularly in developing countries remains at a low level due to the infectious disease and malnutrition problems which have a higher health care priority (Crane, 2010). Whereas, approximately 80% of the global NCD deaths that occur annually are in low- and middle-income countries (WHO, 2008). The lack of Palliative Care services in developing countries has also been associated with the lack of trained staffs, funding, infrastructure, research, academic links, and misunderstanding regarding health issues (Clemens, 2007). Generally, researchers found that knowledge and attitude of nurses towards palliative care remains at low level (Kassa, *et al.*, 2014). It may associate to the low consideration of the nursing schools' curriculum (Miller, 2012; Fadare, *et al.*, 2014; Ayed, *et al.*, 2015). The multiple roles of nurses, perceptions, and misconceptions of palliative care may also responsible in the development of palliative care in several countries (Chuah, *et al.*, 2016). Another study shows that there is issues related to the nurses and physician relationship and that the philosophy of palliative care may have impact to the delivery of palliative care services (Roche-Fahy & Dowling, 2009).

The challenges in delivering EoL care

• The general challenges of EoL care

End-of-Life care practices need various skills that require the competence of the nurses. Some challenges related to the nursing practices in palliative care include the evolution of palliative care and EoL care (Montgomery, *et al.*, 2016), the challenge in administering analgesia (Davis, 2014), EoL practices itself (Abudari, *et al.*, 2016), and the complexity of the skills (Hendricks-Ferguson, *et al.*, 2015). Lack of training (Chuah, *et al.*, 2016) and gaps in knowledge (Fadare, *et al.*, 2014) for nurses in delivering EoL care seems to be the most challenge issues in this service. For some nurses who deliver EoL care in community settings, long distance and bad weather could be the most important difficulties (Kaasalainen, *et al.*, 2014).

From the institution's side, an absence of palliative care integration (Abudari, *et al.*, 2016), unavailability of members in interdisciplinary (Wallerstedt & Andershed, 2007), and organizational stress (Gélinas, *et al.*, 2012) are the main issues in the provision of EoL care. On the other hand, health care providers may also have challenges to wards the various background of the family matters, cultural values, religions practices, and family approach (Abudari, *et al.*, 2016). Moreover, evidence proved that it is not easy to talk about death (Beck, *et al.*, 2012). Another study acknowledged that there is a lack of awareness of cultural diversity in delivering EoL care (Wallerstedt & Andershed, 2007). A research by Brazil, *et al.* (2010) has tried to investigate the role of informal caregivers as well in the establishment of EoL care.

• The feelings of the nurses delivering EoL care

Some studies identified that ethical dilemmas (Karlsson, *et al.*, 2010) and moral distress (Hamric & Blackhall, 2007) could be the most issues faced by nurses in EoL care. Moreover, nurses may consider their own mortality and have to deal with their own emotions in the caring of terminally-ill clients. Accordingly, some nurses reported helplessness, being more sensitive, frustration (Karlsson, *et al.*, 2010), and emotional stress (Hendricks-Ferguson, *et al.*, 2015).

The sources needed in delivering EoL care

• The needs of the nurses working in palliative care

Before take a part into EoL practices, a nurse should be validate themselves that they are ready to care terminally-ill clients (Rose, 2008), have high level of commitment, feeling prepared and putting themselves forward (Mishelmovich, *et al.*, 2016), self-confidence (Pennbrant, *et al.*, 2015), also the sense of meaning and purpose to their work (Ablett & Jones, 2007). In the caring of the clients, nurses should have compassion and dedication to care (Bam & Naidoo, 2014), ambition (Wallerstedt & Andershed, 2007), kindness, warmth, and genuineness (Johnston & Smith, 2006). Nurses have likewise need to be trusted by their clients (Hendricks-Ferguson, *et al.*, 2015). To decline the emotional burden in the caring of EoL clients, nurses should consider to balance life style between work and their own private life (Pennbrant, *et al.*, 2015).

• Sources needed in delivering EoL care

Communication skills, including breaking the significant news' skill (Mishelmovich, *et al.*, 2016), are the most important nursing competence in EoL care, but some studies identified that the nurses' skill in this area was very poor (Tait, *et al.*, 2015; Pennbrant, *et al.*, 2015). Despite the communication skills, awareness, participations, and safety in pain management should be applied by the nurses as well (Miller, 2012; Unné & Rosengren, 2013). Other sources needed are collaboration, experience, working in team (Jansen, *et al.*, 2016; Mishelmovich, *et al.*, 2016), skill of knowing, and leadership (Montgomery, *et al.*, 2016).

Recommendation for further practices

Considering that knowledge and skills of nurses need to be improved, training (Rose, 2008), debriefing, regular coaching, guidance on reflective practice (Reid, 2013), more education (Fadare, *et al.*, 2014; Johnston & Smith, 2006), interactive learning and practice development (Jansen, *et al.*, 2016), and curriculum (Ayed, *et al.*, 2015) were recommended by the researchers. As a team approached is valued (Phillips, *et al.*, 2008), the experienced nurse as a committed advocate will be very helpful because it is ascertained that they have more positive attitudes (Montgomery, *et al.*, 2016). Nurses should also advance the skills in the pain assessment (Rustøen, *et al.*, 2009), pain management, and the documentation (Fadare, *et al.*, 2014). To provide culturally competent care (Wallerstedt & Andershed, 2007), nurses should be given formal cultural education (Johnston & Smith, 2006) so that they can value individual response to grief (Montgomery, *et al.*, 2016). It is better for the institution to provide professional counselling, stress management service (Bam & Naidoo, 2014), and integrated service structured (Reid, 2013) to improve the

service for both health care providers and clients. Learning in the challenging environment as in palliative care can also be gained from scheduled meetings or everyday encounters (Johnston & Smith, 2006) for nurses so that they have time for reflections (Pennbrant, *et al.*, 2015), giving information and sharing knowledge (Rustøen, *et al.*, 2009).

Conclusion

To conclude, the experiences of the nurses can be generated into four categorizations as the needs of the patients and caregivers, the perceptions towards palliative care, the challenges in delivering EoL care, and the sources needed in delivering EoL care. From the review can also be analyzed that some studies have tried to propose numerous commendations that are very useful for nurses and the institutions to improve the quality of EoL care. It is hoped that through these efforts, the essence of caring EoL clients and the caregivers could be expanded over and over.

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