

PALLIATIVE CARE FROM THE PERSPECTIVE OF RELATIVES AND PATIENTS

Improving understanding and better recognition of experiences of patients and their family members through interprofessional education

Introduction

According to the World Health Organization (WHO), palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering. The palliative care support system is offered to help patients live as actively as possible until death, and offers a support system to help the family cope during the patient's illness and in their own bereavement.

Therefore, palliative care patients' and their family members' perceptions of the quality of care in terms of their views to different aspects of care are at the core of developing palliative care services (Sandsdalen et al., 2015). The perspective of patients and family caregivers places their emotional experience of palliative care in the center. The meaning that patients and family caregivers attribute to their experience of palliative care is fundamental to the provision, practice and evaluation of optimal care (Sampson et al., 2014).

The importance of listening and responding to the views of service users is recognized by healthcare professionals and policy makers (Conner et al., 2008). Not only for the evaluation of the quality of care, but also for developing genuinely patient- and family-centered care, and thus accountable and appropriate care services. At the same time, we need to develop the required abilities and sensitivity of professionals to better recognize and acknowledge the experiences and preferences of the patients and their family members regarding participation in decision making and concerning the place of care (Woodman et al., 2016).

The development of the professionals' understanding, attitudes and values towards patient- and family-centered care begins during their undergraduate education, continues through to postgraduate education and finally to experiences in palliative care in their career. Developing education is essential to facilitate improvements in clinical practice and patient care (Grant et al., 2009). Therefore, to develop the quality of palliative care and patient- and family-centered care, initiatives on improving professionals' basic and specialized education are warranted.

Background

The structure of how palliative care is organized differs between countries (EAPC, 2009) and people are cared for in various settings at the end of their lives (de Boer et al., 2017). However, the principles of palliative care are similar and at the core of care is the patient and his or her family. Dying in the setting that the patients and family members prefer is one indicator of good palliative care quality (de Boer et al., 2017). In relation to preferred place of care, greater understanding is needed to identify how best to support families at the end-of-life and to ensure that more patients are cared for in the place they prefer (Gomes et al., 2013; Woodman et al., 2016). When the care is provided at home, healthcare professionals need to provide support to the family caregivers to ensure successful care, thus improving end-of-life experiences for families (Woodman et al., 2016). Regardless of the place of care, common values of palliative care according to the EAPC (2009) and a consensus paper by Junger et al. (2012) are autonomy, dignity and collaborative relationship between staff, patient, and family. In optimal palliative care, quality of life is the central goal of care and it is provided by a multi-professional approach. As a multi-professional approach, the field of palliative care includes medicine, nursing, social work, psychology, nutrition, and rehabilitation, although depth of support available from each discipline varies (Grant et al., 2009).

Good palliative care according to Sampson et al. (2014) is distinguished by characteristics such as expertise of professionals, enablement and efficiency within the context of respectfulness. In the development and research of palliative care, health care professionals' perspectives on care have been well documented, however less focus has been placed on patients' and families' perceptions and experiences (Ciemiński et al., 2015). To provide truly patient-centered palliative care, we need to understand and acknowledge the perspectives and experiences of patients and families.

The above highlights the importance of understanding the emotional experience of care to patients and their family members, and provides insight into examples of where and how this care occurs. In Ciemiński et al.'s (2015) study, Presence, Reassurance, and Honoring Choices emerged as central themes linked to satisfaction of patients and their family members with palliative care services. Family members may experience that they need to advocate for their

As Joan Smith (2014) has highlighted, patients receiving palliative care mention that communication is certainly key in helping them to cope with their severe illness. The methods the professionals use to help the patient and family members can often be quite simple, such as a friendly introduction of oneself or holding the patient's hand when he or she is afraid. For the family, the same simple methods can support their coping and feelings of security.

dying relatives (Shield et al., 2010). In a study by Sampson et al. (2014), specific expectations from the perspective of patients and family members were professionalism, expertise and facilitation. Patients value health professionals who have expertise in palliative care to support feelings of security (Conner et al., 2008). According to patients and family, professionals need to be compassionate, empathetic and possess skills in listening, connecting, and interacting with patients and families. Indeed, communication with patients and families about end-of-life care is essential (EAPC, 2009; Johnson and Bott, 2016). Good communication is also the core element of a well-established palliative care culture (Reitinger et al., 2018).

Open and frequent communication among the patients, family members, and healthcare professionals emerged as being essential for the satisfaction of all participants at the end of life, also in Jackson et al.'s (2012) study. Families desire frequent updates about the patient's status as well as on the care being provided to their loved one. Caring and highly experienced staff members allow families to feel secure and comfortable with the care their loved ones are receiving.

Thus, the ability to communicate and sensitively listen to and acknowledge patients' and family members' expectations and preferences are important aspects of care provision, and need to be embedded into training of all professionals working in palliative care. One of the premises in palliative care education should also be the care philosophy of patient- and family-centered care. Through education we can enhance the abilities of professionals' communication skills and better acknowledge experiences and preferences of patients and their family members in palliative care.

The EduPal project

In Finland, the Ministry of Education and Culture launched an initiative and funding program for the universities to develop multidisciplinary education and collaboration among the universities. The «Developing palliative nursing and medical education through multidisciplinary cooperation and working life collaboration EduPal 2018–2020» project was one of the projects to which funding was granted. The development of palliative care and services in general has been seen as one of the priorities in Finnish health care. In this project,



Fig. 1 Palliative care education – adapted values and principles.

the focus is on developing palliative care education from the undergraduate education to postgraduate education in nursing and medicine. Altogether 15 universities of applied sciences (nursing education) and five universities (medical education) are taking part in this three-year project.

The ultimate goal of the project is to increase the quality of palliative care by developing educational preparation of professionals working with palliative care patients. More precisely, the aims of the project are a) to explore the current state of the education in palliative nursing and medicine in Finland and to compare it to the international recommendations, b) to create a competency description for palliative nursing and medicine for basic and specialist levels in multidisciplinary cooperation with experts from the clinical field, and c) to create national education recommendations for undergraduate nursing and medical education and for postgraduate education in palliative care.

Our focus is on education and we are aiming for concrete outcomes. We have started by evaluating current curricula of undergraduate nursing and medical education. We have also organized interprofessional workshops all around Finland, to explore the professionals' opinions on competence requirements for different professions. In addition, we are currently collecting survey data from nurses and physicians specialized in palliative care on competence requirements and education. We also wanted to gather people's opinions on a large scale and therefore there is an online survey for citizens on our project's webpage. We intend to use this information to define the competence requirements on different levels of palliative care, and to develop the curriculum for undergraduate as well as postgraduate education in palliative nursing and medicine. At the end of the project we hope to have an active network of palliative educators and professionals working together to provide excellent interprofessional palliative care education, in which the patient and family are at the core.

How to develop educational preparation of professionals

There are no simple answers on how to address the challenges in palliative care and education to promote patient- and family-centered care. In the EduPal project we have an excellent opportunity to create genuinely interprofessional education that is based on the competence requirements of working life. To understand patients' and families' perspectives, we have included patient organizations and societies in our project as stakeholders and have opened up the survey to all. However, when we proceed with the project,

we are also aiming to use other methods to fully recognize their experiences and preferences by organizing public events. We also intend to integrate bachelor's and master's theses into the project.

However, if we simply focus on what we could do in the education of professionals, there are many ways to enhance students' and professionals' abilities to listen and be more sensitive to patients' and family members' experiences and preferences. Contemporary simulation and clinical practice environments create good opportunities. Nowadays there is online material that is already available to use for learning such as recorded stories and documents of patients and families. We also have educated experts with experience in patient associations and health care organizations, who can deliver training for students. The methods above enhance students' reflective learning and encourage them to think about their own values, attitudes and experiences. To develop multi-professional cooperation, we need to create opportunities for the nurse and medical students to work together during their education. In figure one, we have summarized some of our ideas about values and principles in palliative care education based on the EAPC (2009) and Junger et al. (2012) description of core values and principles of palliative care. One practical tool for structuring the education we will adapt for the project in the future are the domains of the consensus paper by the Joint Commission for the Accreditation of Hospitals.¹ The eight domains are Structure and Process of Care, Physical Aspects of Care, Psychological and Psychiatric Aspects of Care, Social Aspects of Care, Spiritual, Religious and Existential Aspects of Care, Cultural Aspects of Care, The Imminently Dying Patient and Ethical and Legal Aspects of Care integrating patient- and family-centered care as a core content.

Conclusion

At the core of high-quality palliative care is the patient and the family. As professionals, we need to appraise their experiences of and preferences to care. To provide genuinely patient- and family-centered palliative care services, we need to work together for better recognition and sensitivity towards their experiences and wishes. As part of developing more patient- and family-centered care, the educational preparation of professionals needs to be developed through interprofessional education and by bringing in the voices of patients and family members into education.

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¹ Currently The Joint Commission TJC available at <https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/12/Clinical-Practice-Guidelines-Domain-Summary-1.pdf>

References

de Boer, D., Hofstede, J.M., Veer, A.J.E. de, Raijmakers, N.J.H., and Francke, A.L. (2017). Relatives' perceived quality of palliative care: Comparisons between care settings in which patients die. *BMC Palliative Care*, 16(1), 41. <https://doi.org/10.1186/s12904-017-0224-x>

Ciemins, E., Brant, J., Kersten, D., Mulette, E., and Dickersson, D. (2015). A qualitative analysis of patient and family perspectives of palliative care. *Journal of Palliative Medicine* 18(3), 282–285.

Connor, A., Allport, S., Dixon, J., and Somerville, A-M. (2008). Patient perspective: what do palliative care patients think about their care? *International Journal of Palliative Nursing* 14(11), 546–552.

European Association for Palliative Care (EAPC) (2009). White Paper on standards and norms for hospice and palliative care in Europe: part 1. Recommendations from the European association for Palliative Care. *European Journal of Palliative Care* 16(6), 278–89.

Gomes, B., Calanzani, N., Gysels, M., Hall, S., and Higginson, I.J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care* 12:7. doi: 10.1186/1472-684X-12-7

Grant, M., Elk, R., Ferrell, B., Morrison, R.S., and von Gunten, C.F. (2009). Current Status of Palliative Care, Education, and Research. *CA: A Cancer Journal for Clinicians* 59(5), 327. doi: 10.3322/caac.20032

Jackson, J., Derderian, L., White, P., Ayotte, J., Fiorini, J., Hall, R., and Shay, J. (2012). Family Perspectives on End-of-Life Care: A Metasynthesis. *Journal of Hospice and Palliative nursing* 14(4), 202–211.

Johnson, S., and Bott, M.J. (2016). Communication with residents and families in nursing homes at the end of life. *Journal of Hospice and Palliative Nursing* 18(2), 124–130.

Junger, S., Payne, S., Brearley, S., Ploenes, V., and Radbruch, L. (2012). Consensus Building in Palliative Care: A Europe-Wide Delphi Study on Common Understandings and Conceptual Differences. *Journal of Pain and Symptom Management* 44(2), 192–205.

Reitinger, E., Schuchter, P., Heimerl, K., and Wegleitner, K. (2018). Palliative care culture in nursing homes: the relatives' perspective. *Journal of Research in Nursing* 23(2–3), 239–251.

Sampson, C., Finlay, I., Byrne, A., Snow, V., and Nelson, A. (2014). The practice of palliative care from the perspective of patients and carers. *BMJ Supportive and Palliative Care* 4(3), 291–298. doi: 10.1136/bmjspcare-2013-000551

Sandsdalen, T., Rystedt, I., Grøndahl, A., Hov, R., Høye, S., and Wilde-Larsson, B. (2015). Patients' perceptions of palliative care: adaptation of the Quality from the Patient's Perspective instrument for use in palliative care, and description of patients' perceptions of care received. *BMC Palliative care* 14: 53. doi: 10.1186/s12904-015-0049-4

Shield, R.R., Wetle, T., Teno, J., Miller, S.C., and Welch L.C. (2010). Vigilant at the end of life: Family advocacy in the nursing home. *Journal of Palliative Medicine* 13(5), 573–579.

Smith, J. (2014). Palliative care: a patient's perspective. *International Journal of Palliative Nursing* 20(4), 164.

World Health Organization (WHO) (2018). WHO Definition of Palliative Care. Retrieved <http://www.who.int/cancer/palliative/definition/en/>

Woodman, C., Baillie, J., and Sivell, S. (2016). The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. *BMJ Supportive and Palliative care* 6(4), 418–429.

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