

GUEST EDITORIAL

## **Palliative and End-of-Life Nursing Research Now and in the Future**

**Wendy Duggleby**

The face of palliative and end-of-life care is changing (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009), and so is nursing research in this critical area. *CJNR* published its first focus issue on palliative and end-of-life care in 2005 (Vol. 37 N° 2). The guest editors were Susan McClement and Lesley F. Degner. That focus issue included one research study — I was first author (Duggleby & Wright, 2005). It also included many wonderful articles on methodological and conceptual research issues and translating evidence to inform palliative and end-of-life nursing practice. I have the privilege of being the guest editor for this current issue, and it was exciting to see both the number of research studies submitted and the quality of those studies. It was very difficult to select the five articles that would be part of this issue. Without a doubt, there has been an increase in nurse researchers leading multidisciplinary teams conducting and publishing research in palliative and end-of-life care since 2005. Whatever the reasons for this change, it has been inspiring to see where palliative and end-of-life nursing research has been and where it is now and to contemplate where it might be in another 5 years.

In the 2005 focus issue, Linda Kristjanson (2005) was invited to write the Discourse. Kristjanson made several recommendations for future research. She suggested that research to inform nursing practice should focus on increasing our understanding of the unique needs of diverse palliative populations and that investigators would need to utilize innovative research approaches to reach this goal. In this current focus issue, several of the articles reflect innovative research with diverse populations. For example, Brenda L. Cameron and her colleagues use participatory action research to study palliative care health professionals in Chile and Canada. A mixed-methods approach is used by Genevieve N. Thompson and her colleagues to ask family caregivers of persons in nursing homes, the majority with dementia, about respect and kindness. Parents of pediatric palliative care patients and their relationships with nurses are the focus of

a phenomenological study by Judy Rashotte and her colleagues. Kelli I. Stajduhar and her colleagues look at the relationship of nursing home care professionals and family members using interpretive description. The processes of care of persons with heart failure at the end of life are the focus of a qualitative study by Sharon Kaasalainen and her colleagues. Mary Hampton and her colleagues have worked for 7 years in Saskatchewan to increase awareness of appropriate Aboriginal end-of-life health care among non-Aboriginal health-care providers; in the *Happenings* contribution they describe unique research approaches and partnerships they have formed with this population. All of these articles not only increase our understanding of diverse populations at the end of life, but also mirror the diversity of palliative and end-of-life nursing practice.

The articles also reflect some of the essential aspects of palliative nursing practice. In her *Discourse* contribution, Stajduhar quotes Cicely Saunders (2006) as saying that nurses enable people to find relief, support, and meaning at the end of their lives. Kaasalainen and her colleagues describe how persons with heart disease, their families, and health professionals strive together to find relief and reduce suffering from symptoms. Both Cameron and her colleagues and Stajduhar and her colleagues describe how palliative nurses empower others through engagement and the sharing of knowledge. Rashotte and her colleagues describe the importance of receptivity and attentiveness as moral considerations in clinical judgement and decision-making that support the preferences of parents. As well, the importance of respecting and valuing persons at the end of life is described by Thompson and her colleagues.

Nurses providing palliative and end-of-life care bear witness to the deepest issues of humanity, suffering, and mortality. Their moral ethic demands that they have the knowledge and skills necessary to provide comfort and care at a very important time of life. Palliative nurses use specialized knowledge from all fields of inquiry, such as physiology, psychology, and sociology, and work with multidisciplinary teams to improve the quality of life of the persons they care for. However, only through nursing research, examples of which are presented in this focus issue, can we begin to understand that palliative nurses also require knowledge and skills to deal with the complex moral dilemmas associated with empowering persons who are suffering.

### **Where Will We Be 5 Years From Now?**

In the next 5 years, nurse researchers will be working within networks of palliative care researchers to develop innovative and flexible research

designs and approaches that are specific to palliative populations. Research designs are typically determined by the research question being asked. However, in choosing a research design it is important to also consider the population that is the focus of study. For example, Hampton and her colleagues clearly demonstrate, in their *Happenings* contribution, the importance of their research approach in working with Aboriginal populations. In the next 5 years, palliative and end-of-life research will have to focus on other diverse populations, such as people who are homeless and those with disabilities. As a result, there will be an escalating need for even more innovative approaches to research.

As suggested by Stadjuhar in her *Discourse*, innovative models and systems of palliative and end-of-life care should also be a research focus over the next 5 years. It is imperative, however, with research focused on improving systems of care, that the ultimate goal of providing care not be forgotten. The goal of palliative care as defined by the World Health Organization (2011) is to improve quality of life for persons with life-threatening illnesses and their families. Enhancing quality of life is an essential goal of palliative and end-of-life nursing research and should not be lost in our focus on systems of care. I was recently asked by the Oncology Nursing Society to develop, with my colleague Pat Berry (University of Utah), research priorities for palliative and end-of-life care. Through an extensive literature review and discussion with nurses, it was evident that there is a great need for research on all aspects of quality of life (psychosocial, spiritual, physical, mental, and environmental) (Oncology Nursing Society, 2011). This research needs to focus on diverse populations in terms of ethnicity, language, and culture, as well as specific age groups, such as older adults and children.

The research articles in this focus issue also remind us that future research should focus on the essence of palliative and end-of-life nursing practice, as this is at the heart of improving quality of life for persons with life-threatening illnesses. Examples of future research questions might be the following: How can we best ensure that nursing care is provided respectfully and with kindness in complex, impersonal organizational environments? How can we enhance quality of life where suffering and loss are part of the person's experience? How can nurses reach those who may not have access to palliative and end-of-life care?

It has been a great pleasure to be the guest editor of *CJNR*'s 2011 focus issue on palliative and end-of-life care. I am looking forward to the next focus issue 5 years from now. At that time, I hope, we will see the number of nurse researchers in the field continuing to grow, along with the development of knowledge that will inform palliative and end-of-life nursing practice.

## References

- Duggleby, W., & Wright, K. (2005). Transforming hope: How elderly palliative patients live with hope. *Canadian Journal of Nursing Research*, 39(2), 70–84.
- Grant, M., Elk, R., Ferrell, B., Morrison, S. R., & von Gunten, C. F. (2009). Current status of palliative care: Clinical implementation, education and research. *CA Cancer Journal*, 59, 327–335.
- Kristjanson, L. J. (2005). Directions in palliative care nursing research: Impeccable care, timing and complexity. *Canadian Journal of Nursing Research*, 37(2), 13–20.
- Oncology Nursing Society. (2011). *Oncology Nursing Society research priorities update 2009–2013*. Retrieved May 31, 2011, from <http://www.ons.org/Research>.
- Saunders, C. (2006). Foreword. In Betty Ferrell and Nessa Coyle (Eds.), *Textbook of palliative nursing* (2nd ed.). New York: Oxford University Press.
- World Health Organization. (2011). *WHO definition of palliative care*. Retrieved July 4, 2011, from <http://www.who.int/cancer/palliative/definition/en/>.

---

*Wendy Duggleby, PhD, RN, AOCN, is Professor and Endowed Nursing Research Chair in Aging and Quality of Life, Faculty of Nursing, University of Alberta, Edmonton, Canada.*