

Journal Watch

Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients

Peter Hudson, R.N., B.N. (Hons), Ph.D., Cheryl Remedios, B.A. (Hons), DPsych (Health), Rachel Zordan, B.Sc. (Psych), GDipSc (Psych), Ph.D., Kristina Thomas, BPsych (Health), Doctor of Psychology (Health), Di Clifton, M.B.B.S., BMedSci (Hons), M.P.M., FRANZCP, Michael Crewdson, B.A., BBehSci (Hons Psych), M.Sc., Christopher Hall, M.A., GDipAdChPsych, B.Ed., Tom Trauer, B.A. (Hons), Ph.D., Amanda Bolleter, B.A., B.S.W., David M. Clarke, MBBS, M.P.M., Ph.D., and Catherine Bauld, B.A. (Psych), GDipAdolPsych, Ph.D.

Journal of Palliative Medicine 2012;15(6): 696-702

Prepared by: Cheryl Nekolaichuk, PhD, R. Psych.

Reviewed: Tertiary Palliative Care Unit 43, Grey Nuns Community Hospital
September 24, 2013

Abstract

Background: Support for family caregivers, including bereavement follow-up, is a core function of palliative care. Many caregivers acknowledge positive aspects associated with the role; however a considerable proportion will experience poor psychological, social, financial, spiritual, and physical well-being and some will suffer from complicated grief. Many family caregivers have unmet needs and would like more information, preparation, and support to assist them in the caregiving role. There is a shortage of evidence-based strategies to guide health professionals in providing optimal support while the caregiver is providing care and after the patient's death.

Purpose: To develop clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients.

Methods: (1) Literature review; (2) focus groups and structured interviews with key stakeholders within Australia; (3) national and international expert opinion to further develop and refine the guidelines using a modified Delphi process; and (4) endorsement of the guidelines from key palliative care, caregiver, and bereavement organizations (national and international).

Results: The guidelines were developed for multidisciplinary health care professionals and clinical services commonly involved in caring for adult patients receiving palliative care in a variety of care sites throughout Australia. These consensus-based guidelines have been endorsed key Australian and international organizations.

Conclusions: The guidelines may prove valuable for the international palliative care community and for generalist health care providers who occasionally care for palliative care patients. Research is recommended to explore the uptake, implementation, and effectiveness of the guidelines.

Strengths:

- Rigorous study design (i.e. clearly described process)
- Systematic approach for grading evidence to support guidelines (use of well-recognized national grading system; inclusion of two additional levels of evidence – qualitative, expert opinion; initial review by 1 reviewer – 50% of rated literature was randomly selected and reviewed by two of the authors who were blinded to the initial review)
- Although developed in Australia, the guidelines provide a general framework which may be adapted for local needs and contexts in international settings

Weaknesses:

- Low participant recruitment rate ($52/82 = 63\%$) and completion rate ($26/52 = 50\%$)
- Potentially biased sample: Most participants were female ($n = 19, 73\%$), working in major urban centres ($n = 20, 77\%$) and academics ($n = 20, 77\%$)
- Lack of high evidence in the field – inclusion of qualitative and expert opinion for some of the evidence which could potentially be considered a weakness but also a strength

Relevance to Palliative Care:

Family support is a core value of palliative care, in which the patient and family are considered the unit of care. Follow-up bereavement support is generally lacking in palliative care programs. The development of guidelines for the psychosocial and bereavement support of family caregivers can assist palliative care clinicians to identify caregivers who may be at risk and to prioritize their services.