

Special Article

Improving the Evidence Base in Palliative Care to Inform Practice and Policy: Thinking Outside the Box

Samar M. Aoun, BSc(Hons), MPH, PhD, and Cheryl Nekolaichuk, PhD, RPsych
School of Nursing and Midwifery (S.M.A.), Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia; and Division of Palliative Care Medicine (C.N.), Department of Oncology, University of Alberta, Edmonton, Alberta, Canada

Abstract

The adoption of evidence-based hierarchies and research methods from other disciplines may not completely translate to complex palliative care settings. The heterogeneity of the palliative care population, complexity of clinical presentations, and fluctuating health states present significant research challenges. The aim of this narrative review was to explore the debate about the use of current evidence-based approaches for conducting research, such as randomized controlled trials and other study designs, in palliative care, and more specifically to 1) describe key myths about palliative care research; 2) highlight substantive challenges of conducting palliative care research, using case illustrations; and 3) propose specific strategies to address some of these challenges. Myths about research in palliative care revolve around evidence hierarchies, sample heterogeneity, random assignment, participant burden, and measurement issues. Challenges arise because of the complex physical, psychological, existential, and spiritual problems faced by patients, families, and service providers. These challenges can be organized according to six general domains: patient, system/organization, context/setting, study design, research team, and ethics. A number of approaches for dealing with challenges in conducting research fall into five separate domains: study design, sampling, conceptual, statistical, and measures and outcomes. Although randomized controlled trials have their place whenever possible, alternative designs may offer more feasible research protocols that can be successfully implemented in palliative care. Therefore, this article highlights “outside the box” approaches that would benefit both clinicians and researchers in the palliative care field. Ultimately, the selection of research designs is dependent on a clearly articulated research question, which drives the research process. J Pain Symptom Manage 2014;48:1222–1235. © 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, research design, evidence-based medicine, randomized controlled trials, complex interventions, mixed methods

Drs. Aoun and Nekolaichuk contributed equally to the article.

Address correspondence to: Samar M. Aoun, BSc(Hons), MPH, PhD, School of Nursing and Midwifery, Faculty of Health Sciences, Curtin

University, G.P.O. Box 1987, Perth 6845, Western Australia, Australia. E-mail: s.aoun@curtin.edu.au

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Introduction

*Each science must develop a set of techniques, methods, procedures and theories, which are appropriate for understanding the characteristics of the subject matter of the discipline.*¹

To influence clinical practice in palliative care, clinicians need to have access to the “best” evidence. However, acquiring this evidence presents particular problems, and the discipline of palliative care urgently requires a wider evidence base. Aoun and Kristjanson^{2,3} examined the debate about best evidence within the public health literature. They proposed that similar arguments and concerns exist with respect to the use of current evidence-based approaches for implementing research and evaluating the literature in palliative care.

More recently, Hui and colleagues^{4,5} examined the quality, design, and scope of the palliative literature in a systematic review of 1213 articles, spanning two time periods: 6 months in 2004 and 6 months in 2009. The four most common study designs from the evidence hierarchy (Fig. 1) were case report/series (51%), cross-sectional surveys (18%), qualitative studies (11%), and cohort studies (9%). Randomized controlled trials (RCTs) comprised only 6% of all studies, the majority of which focused on interventions for physical symptoms with a median sample size of only 70 participants. Other aspects of palliative care, including communication, decision making/ethics, education, research methodology, and spirituality represented 5% or less of all RCTs. The authors concluded that there are critical concerns about the current state of knowledge conception with the overall methodological quality of RCTs being poor.

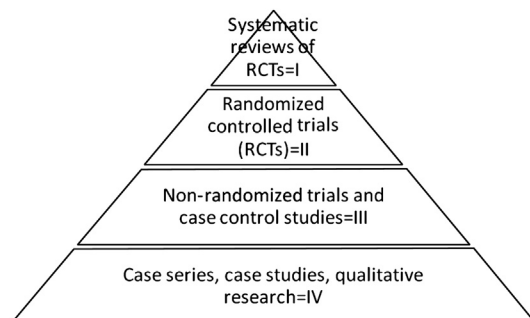


Fig. 1. The hierarchy of evidence (Levels I–IV).⁷⁵ RCT = randomized controlled trial.

The Cochrane systematic reviews in palliative care failed “to provide good evidence for clinical practice because the primary studies are few in number, small, clinically heterogeneous, and of poor quality and external validity” (p. 8).

The most recent Cochrane review on the effectiveness of home palliative care services has raised similar methodological concerns.⁶ Based on a review of 23 studies (37,561 patients and 4042 caregivers), there was strong evidence to demonstrate that these services supported an increased number of patients dying at home and reduced symptom burden, without increasing caregiver grief. However, the evidence was not conclusive on nine other patient and caregiver outcomes because of a number of methodological issues. Therefore, there is a great need for high-quality evidence to support everyday clinical practice and a need to conduct more studies on caregivers, health-care professionals, and psychosocial-spiritual topics in palliative care.

Over the past two decades, numerous concerns regarding methodological issues and debates about the role of evidence-based approaches in palliative care research have been raised.^{7–21} The purpose of this narrative review was to further explore the debate about the use of current evidence-based approaches, such as RCTs, for conducting research and evaluating the literature in palliative care, by addressing the following three questions:

- What are some myths about palliative care research?
- What are the challenges of conducting palliative care research?
- What strategies can be used to address these challenges?

We will begin with a description of five myths associated with palliative care research, followed by a summary of specific research challenges and strategies. To illustrate some of the challenges and corresponding strategies, we will present examples of research projects undertaken in different settings at the regional and international levels over the past 10 years.

What Are Some of the Myths About Palliative Care Research?

Five myths that have potentially held back advances in the number, quality, and diversity of

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