

Review Article

How Are Palliative Care Cancer Populations Characterized in Randomized Controlled Trials? A Literature Review

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Abstract

Context. The difficulties in defining a palliative care patient accentuate the need to provide stringent descriptions of the patient population in palliative care research.

Objectives. To conduct a systematic literature review with the aim of identifying which key variables have been used to describe adult palliative care cancer populations in randomized controlled trials (RCTs).

Methods. The data sources used were MEDLINE (1950 to January 25, 2010) and Embase (1980 to January 25, 2010), limited to RCTs in adult cancer patients with incurable disease. Forty-three variables were systematically extracted from the eligible articles.

Results. The review includes 336 articles reporting RCTs in palliative care cancer patients. Age (98%), gender (90%), cancer diagnosis (89%), performance status (45%), and survival (45%) were the most frequently reported variables. A large number of other variables were much less frequently reported.

Conclusion. A substantial variation exists in how palliative care cancer populations are described in RCTs. Few variables are consistently registered and reported. There is a clear need to standardize the reporting. The results from this work will serve as the basis for an international Delphi process with the aim of

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reaching consensus on a minimum set of descriptors to characterize a palliative care cancer population. *J Pain Symptom Manage* 2014;47:906–914. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, literature review, randomized clinical trial, cancer, patient characteristic, generalizability, publication standard, basic data set

Introduction

Balfour Mount introduced the term “palliative care” in 1973.¹ Today, at least 37 English and 26 German definitions of palliative care have been identified.² Most of the definitions agree about the holistic nature of the palliative care approach and the central objectives of “quality of life” and “relief of suffering.”^{2,3} The definitions show much less agreement as to the target group, and whether a limited prognosis is a central patient characteristic.² This may be illustrated by the two most frequently used definitions, the World Health Organization definitions of 1990⁴ and 2002,⁵ respectively. The first describes the target population as “patients whose disease is not responsive to curative treatment,” whereas the second has extended the population to “patients and their families, facing the problems associated with life-threatening illness.”

The difficulty in defining the target population for palliative care is getting more pronounced as more diagnostic groups are included and as the palliative care approach is implemented at an earlier stage in the disease trajectory. Indeed, palliative care patients are usually defined by the fact that they receive palliative care.⁶ This might serve a classification purpose on a pragmatic level, but it creates considerable problems for research purposes. Palliative care populations may differ extensively for age, diagnosis, symptom burden, functional status, and survival. Most patients admitted to palliative care programs in Europe are cancer patients,⁷ and the heterogeneity only within this diagnostic group is well documented. A large cross-sectional study performed by the European Association for Palliative Care Research Network in 2000⁷ showed that the samples varied considerably for demographic characteristics, places of care, expected survival, type of analgesics, and treatment modalities.^{8,9} This

heterogeneity requires a thorough description of the study sample to be able to judge the external validity of results from clinical trials; that is, if the study results can be generalized to groups and settings beyond those in the trial.¹⁰

In recent years, palliative care has been increasingly expanded to include patients with advanced illness other than cancer. Other patient groups have been shown to have similar symptom burdens and palliative care needs to cancer patients¹¹ and, therefore, to share some of their characteristics. However, increasing the spectrum of diagnoses also adds to the heterogeneity of the palliative care population.

The need to reach international consensus on how to describe and classify a palliative care population has been recognized by several investigators.^{6,7,12–15} In a recent workshop on clinical priorities, barriers, and solutions in end-of-life care research across Europe, the challenge in describing and classifying the palliative care population was perceived as an important barrier to conducting high-quality research in end-of-life care.¹⁶ The lack of common descriptors makes it hard to get a clear picture of the populations and consequently to compare results across studies and apply the findings in clinical settings.

At least one initiative has been taken to define a framework of variables to describe a palliative care population.¹² The proposed checklist for reporting patient population and service characteristics in hospice and palliative care research has recently been revised.¹⁷ A limited number of demographic variables were proposed, including age, gender, socioeconomic indices, ethnicity, life-limiting illness, performance status, and days from referral until death. The list is limited, especially for disease-related variables, but it may be a starting point for establishing a common way for reporting study materials.

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