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Review

Patient reported outcome measures of quality of end-of-life care: A systematic review

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ABSTRACT

End-of-life (EoL) care[1] is increasingly used as a generic term in preference to palliative care or terminal care, particularly with reference to individuals with chronic disease, who are resident in community and long-term care (LTC) settings. This review evaluates studies based on patient reported outcome measures (PROMS) of quality of EoL care across all health-care settings. From 1041 citations, 12 studies were extracted by searches conducted in EBSCO, Scopus, Web of Science, PubMed, Cochrane, Open Grey and Google Scholar databases.

At present, the evidence base for EoL care is founded on cancer care. This review highlights the paucity of studies that evaluate quality of EoL care for patients with chronic disease outside the established cancer-acute care paradigm, particularly in LTC. This review highlights the absence of any PROMs for the estimated 60% of patients in LTC with cognitive impairment. Patient-reported outcomes (PROs) are critical to understanding how EoL care services and practices affect patients' health and EoL experience. PROMs describe the quality of care from the patient's perspective and add balance to existing clinical or proxy-derived knowledge on the quality of care and services provided.

Contents

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[1] The term EoL care has evolved as an umbrella term that encompasses all aspects of care related to death and dying provided towards the end of life [2]. There is no consensus in the literature regarding the time-frame it is applied to; definitions range from care in the last year of life, to care from time of terminal diagnosis until death. However, it is generally accepted as representing a broad continuum of care for people who are living with, or dying from terminal illness [1]. This wide focus lends itself to the description of care for patients with non-malignant chronic diseases where disease trajectories are more protracted, and prognostication less certain than for patients with cancer.

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1. Introduction

1.1. Rationale

By 2050, there will be 392 million people worldwide aged 80 years and over; more than three times the current number [3]. In developed countries, this demographic transition is underpinned by an epidemiological transition from high infant and maternal mortality, and high infectious disease rates, to low premature mortality and a predominance of chronic, non-communicable disease [4]. In congruence with population ageing, societies are ageing, and social environments are changing. Traditional, family-based options for EoL care are becoming less common [5]. Family size is decreasing and perspectives on intergenerational care of older people are shifting [6]. People are dying later in life, increasingly from chronic disease, and more frequently in LTC than at home [7].

Chronic diseases include cardiovascular disease, hypertension, stroke, cancer, diabetes, arthritis, chronic obstructive pulmonary disease (COPD), dementia, and depression. Cardiovascular diseases account for the majority (46%) of chronic disease deaths globally, followed by cancers (22%), respiratory diseases (10.5%) and diabetes (4%) [8].The prevalence of these diseases typically increases with age, and multi-morbidity is a common feature. Approximately 80% of older adults have at least one chronic disease, and 68% have at least two [9]. Chronic diseases are the leading cause of mortality worldwide, representing 60% of all deaths globally [10].

The proportion of U.S. deaths in LTC was 23% in 2008, this figure is projected to rise to 40% by 2040 [11]. This trend is mirrored elsewhere, in New Zealand [12], Australia [13], Canada [14], Ireland [7], and the U.K. [6]. A study of prevalence of chronic medical conditions in older residents in LTC in the U.S. found that the leading three chronic diseases were; hypertension (men 53%, women 56%), dementia (men 45%, women 52%), and depression (men 31%, women 37%) [15]. A study of patterns of chronic co-morbid medical conditions in older residents in LTC in the U.S. found that the most frequent two co-morbid disease combination in both men and women was hypertension and dementia [16]. It is estimated that as many as 60% of patients in LTC have cognitive impairment or dementia, many of whom do not have a formal diagnosis [17–20].

Evaluating EoL care for patients with cancer presents fewer methodological challenges than for other chronic disease populations. In comparison to other leading chronic diseases, cancer has a more predictable trajectory towards death, and more certainty in prognostication [21–23]. Consequently, much of the research to-date in evaluating EoL care has focused on patients with cancer in its associated care settings. Originally, PROMs of EoL care focused on the evaluation of physical symptoms, recently, their scope has broadened to include psycho-social factors, well-being, spirituality, mental health, communication and quality of life [24]. There are several condition-specific PROMs for patients with different types of cancer; typically these measures focus on symptoms such as pain, dyspnea, and nausea, in addition to subjective aspects of the patients' experience of EoL care.

While many of the physical symptoms experienced by cancer patients are common to other chronic disease populations, the patient experience at EoL is often different. Patients with non-malignant disease experience more burdensome symptoms in the last year of life than those suffering from cancer, not only because of the greater number of symptoms, but also because of the more protracted trajectory of decline in chronic conditions [25,26]. A gradual deterioration in functioning, punctuated by intermittent acute episodes is typical in conditions such as COPD and heart failure. Frail elderly patients and those with dementia typically experience a prolonged and progressive functional decline from an already low baseline of physical and cognitive function [27]. As a result, many of these patients use multiple healthcare settings for EoL care.

1.2. Objectives

Currently, the evidence base for EoL care is founded on the cancer-acute care paradigm [28]. Development of the evidence base necessitates measurement of the patient experience beyond these confines. The objectives of this review were to identify, describe and critically evaluate existing PROMs of quality of EoL care, for patients with chronic disease, in various healthcare settings.

2. Methods

2.1. Eligibility criteria

Papers were identified based on the following inclusion criteria:

1. Primary research studies based wholly or partially on PROs of EoL care, or that validate PROMs of EoL care
2. Sample of adults (18 years of age and over) with any chronic disease or condition
3. Conducted in any type of health-care setting
4. Using assessment measure(s) with described psychometric properties
5. Reported in English and published between January 2006 and July 2016 (inclusive)

The following exclusion criteria were used:

1. Studies based on samples where cancer is the sole diagnosis
2. Clinical trials and studies addressing technical interventions, physiological, laboratory-based, or radiological outcomes
3. Descriptive, non-clinical articles (e.g., reviews, discussion pieces, reports, expert statements)

2.2. Information sources and searches

A systematic review of the literature was conducted during July 2016. Searches were conducted in Academic Search Complete, CINAHL Plus with full text, PsycINFO, Scopus, Web of Science, PubMed, and Cochrane databases. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Guidelines were used in this systematic review [29]. The search strategy included a combination of free text and controlled vocabulary (MeSH) terms. The search strategy used three groups of terms combined with AND: "end of life care", "patient reported outcomes", and "scale". Details of the electronic search strategy, including search terms used are shown in Table 1. The grey literature was searched using Open Grey and Google Scholar databases.

Studies were examined for inclusion in a two-step process, with an initial screening of titles and abstracts, followed by screening of full-text articles against the inclusion criteria to identify relevant studies.