Original Article

A New Italian Questionnaire to Assess Caregivers of Cancer Patients' Satisfaction With Palliative Care: Multicenter Validation of the Post Mortem Questionnaire-Short Form

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Abstract

Context. Caregiver satisfaction with palliative care is a crucial indicator of its effectiveness. In light of the lack of validated or reliable Italian instruments, the Post Mortem Questionnaire-Short Form (QPM-SF), a self-report questionnaire, has been developed to assess home and inpatient hospice care.

Objectives. The present study was designed to evaluate the psychometric properties of QPM-SF and assess for differences in quality of palliative care between hospice and home care settings.

Methods. A total of 584 caregivers of terminal cancer patients completed QPM-SF one month after the death of the care recipient. To assess test-retest reliability, a subgroup of 50 caregivers completed the questionnaire a second time, one month later.

Results. QPM-SF showed good internal consistency and temporal stability and a four-factor structure: "Integrated home care," "Hospice," "Physical care-Information-Global evaluation," and "Needs."

Conclusion. QPM-SF may be considered a valid, reliable, and well-accepted self-report instrument for examining and implementing palliative care interventions. J Pain Symptom Manage 2014;47:298–306. © *2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words
Palliative care, satisfaction, cancer, terminal phase, end-of-life care

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Introduction

The terminal phase of cancer is a crucial period for both the dying person and their caregivers because it truly tests a health care service's ability to provide comprehensive, compassionate, and coordinated care. As defined by the World Health Organization,

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"palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."[1p. 94] In response to increasing awareness of the needs of terminally ill cancer patients, medical institutions have begun to develop specialized palliative care programs, which typically include, according to El-Jawahri et al.,[2p. 87] "a multidisciplinary team of clinicians specially trained in managing symptoms, enabling informed decision making by offering education about prognosis and the potential benefits and risks of treatments, as well as providing psychological, social, and spiritual support."

To develop and refine effective and efficacious palliative care teams, assessment of the clinical usefulness of current palliative care interventions is essential.[3] A crucial aspect in the evaluation of palliative care is the assessment of patients' and families' reported satisfaction with care.[4] Indeed, satisfaction with care likely integrates multiple aspects of both the patients' and the caregivers' experience of care.[5] Qualitative research has demonstrated that patients and families attribute great importance to satisfaction.[5]

Although there is overlap between the domains/themes of palliative care satisfaction and those of general satisfaction, there are also elements that are relatively unique to this field. As such, outcome measures should assess constructs reflecting the specific goals of palliative care, such as improvement of patients' quality of life and quality of death, symptom control, family support, and satisfaction.[3,6] Dimensional analysis of the literature demonstrates that the unique consequences of palliative care are personhood and identity and quality of death rather than quality of life.[7]

Although the patient is the most appropriate source of information on his/her own condition, family caregivers are considered an alternative or complementary source of information. For example, they may play an important role when the patient is no longer able to complete a questionnaire or to communicate because of declining health. Indeed, in this situation, either the patient may refuse to complete the questionnaire or the multiprofessional team may be reluctant to request it. As such, an assessment tool designed to evaluate caregiver satisfaction may provide valuable information related to the benefits and limitations of extant palliative care services.

Despite methodological limitations, research demonstrates that palliative care interventions improve patients' quality of life, satisfaction with care, and end-of-life outcomes.[2] Kane et al.[8] were among the first to analyze satisfaction with care and found that both patients and caregivers reported higher satisfaction with palliative care compared with those receiving usual care. Subsequent research has demonstrated that palliative care and hospice teams improved satisfaction. However, the majority of studies did not assess satisfaction of outcome directly. Moreover, the type of service delivered by each team varied considerably.[5,9–12] Although the evidence supports the capability of these interventions to improve important aspects of end-of-life care, future study designs need to account for the limitations described previously. Specifically, standardized outcome measures designed for end-of-life care satisfaction should be used.[13,14] Moreover, given the variety of settings and procedures that provide palliative care services, the identification of ideal service delivery conditions is essential. Because of the inconsistency of results across the few studies that have compared different locations of palliative care delivery, generalizability of findings, particularly to service delivery in other countries, is limited.[2,15]

Importantly, there is a paucity of research on measurement tools assessing quality of care and families' need.[4,16] Few instruments have been developed or validated to assess clinical practice, evaluation studies, quality assessment, or improvement of interventions. Moreover, many commonly used instruments have not been specifically tested in end-of-life populations, where psychometrics, burden, or applicability may be very different. Studies that used general measures of satisfaction often resulted in ceiling effects within a palliative care setting.[4] Furthermore, as reported by Teno, none of these measures emerged as a "gold standard."[16] Finally, there are no validated or reliable instruments in the Italian language.[16]