

Review

Spiritual Assessment within Clinical Interventions Focused on Quality of Life Assessment in Palliative Care: A Secondary Analysis of a Systematic Review

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Abstract: One of the most crucial palliative care challenges is in determining how patients' needs are defined and assessed. Although physical and psychological needs are commonly documented in patient's charts, spiritual needs are less frequently reported. The aim of this review was to determine which explicit, longitudinal documentation of spiritual concerns would sufficiently affect clinical care to alleviate spiritual distress or promote spiritual wellbeing. A secondary analysis of a systematic review originally aimed at appraising the effectiveness of complex interventions focused on quality of life in palliative care was conducted. Five databases were searched for articles reporting interventions focused on QoL including at least two or more QoL dimensions. A narrative synthesis was performed to synthesize findings. In total, 10 studies were included. Only three studies included spiritual wellbeing assessment. Spirituality tools used to assess spiritual wellbeing were different between studies: Hospital QoL Index 14; Spiritual Needs Inventory; Missoula-Vitas QoL Index; and the Needs Assessment Tool: Progressive Disease-Cancer. Only one study reported a healthcare professional's session training in the use of the QoL tool. Two out of three studies showed in participants an improvement in spiritual wellbeing, but changes in spiritual wellbeing scores were not significant. Overall patients receiving interventions focused on QoL assessment experienced both improvements in their QoL and in their spiritual needs. Although spiritual changes were not significant, the results provide evidence that a spiritual need exists and that spiritual care should be appropriately planned and delivered. Spiritual needs assessment precedes spiritual caring. It is essential that interventions focused on QoL assessment in palliative care include training on how to conduct a spiritual assessment and appropriate interventions to be offered to patients to address their spiritual needs.

Keywords: palliative care; spiritual care; complex intervention; quality of life

1. Introduction

Recent guidelines on the quality of palliative care indicate that spirituality is a crucial dimension to consider when assisting patients nearing the end of life [1]. Moreover, in its definition of palliative care, the World Health Organization (WHO) draws attention to the various needs of the patient, including that of the spiritual dimension [2].

There is no single, agreed-upon definition of spirituality. Although spirituality has much in common with religiosity, and the two terms are often erroneously used as synonyms [3], they are not

the same thing. Specifically, in the spiritual dimension the predominant concept is that of giving sense and meaning to one's life [3]; in the religious dimension, by contrast, the prevalent concepts are the belief in, and worship of, a supernatural divine power that controls human destiny. Religion is also an organized system of beliefs and practices that follow a moral code. In a more modern perspective, religion is seen as a component of spirituality [4].

Recognition of, and support for, spiritual needs on the part of healthcare professionals is associated with a reduction in care interventions and aggressive treatments and an improvement in the quality of life of patients in the advanced stages of disease [5]. In cancer patients, it has been shown that the utilization of religious beliefs to facilitate end-of-life management is predictive of the greater implementation of aggressive, life-prolonging treatments [6]. Moreover, the results of a recent meta-analysis indicate that patients who utilize religious beliefs and spirituality in order to face up to their disease generally have better outcomes [7]. As a result, more research is needed to address these issues definitively.

The spiritual dimension has been identified as one of the dimensions constituting the multi-dimensional construct of quality of life during palliative care [8]. Indeed, the importance of spiritual assistance within the sphere of palliative care has been amply acknowledged [1]. Nevertheless, attention to this dimensional quality of life is somewhat limited in clinical practice. Although patients may be willing to talk about spirituality, clinicians tend to overlook this aspect and to focus on physical and psychological needs [9].

Several tools are available to measure quality of life, including its spiritual dimension, during palliative care [10]. Moreover, various studies of outcome measurements in palliative care have recently been published [11].

Nevertheless, a recent report claimed that interventions carried out in clinical practice with regard to the management of spirituality in palliative care were either lacking or too weak to support an evidence-based practice approach [12].

Moreover, as assessment-oriented interventions could be easily implemented across diversely resourced settings and according to recent guidelines concerning distress screening in the psychosocial and palliative care literature, we were interested in understanding how the measurement of spirituality is described in the literature. Thus, the purpose of the present secondary analysis was to determine, drawing from all the interventions previously identified and discussed in a systematic review, and with the focus to measure at least two dimensions of quality of life in palliative care practice, which explicit, longitudinal documentation of spiritual concerns would sufficiently affect clinical care to alleviate spiritual distress or promote spiritual wellbeing. Although the latter question was very narrow, we reckon that this secondary analysis could contribute to assist practical clinical decision-making and promote new, specific research queries in this area of palliative care, as well as promote the assessment of spirituality in palliative care practice.

2. Methods

This was a secondary analysis of a systematic review originally conducted in order to evaluate the efficacy of complex interventions aimed at measuring at least two dimensions of quality of life during palliative care [13].

We assumed that, in any palliative care clinical setting, the common distressing symptoms within the domain of physical wellbeing are commonly assessed and incorporated into the plan of care. We, therefore, sought to systematically identify clinical interventions focusing on the assessment of at least two quality of life domains.

The main review was conducted in accordance with the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [14].

2.1. Data Sources

In order to conduct this review, we consulted the following databases: Medline, Embase, Cinahl, PsycINFO, and Cochrane. We then conducted a "hand search" of the references provided by the studies

included. For this secondary analysis we conducted the search of the databases from its inception to March 2015.

2.2. Selection

Studies were eligible for inclusion if they fulfilled the following criteria, which were developed according to the PICO model [15]: (a) any adult patient—aged 18 years or more—with palliative care needs according to the WHO definition and regardless of primary disease in any palliative care clinical setting; (b) any clinical intervention focused on QoL measurement including at least two or more QoL dimensions; (c) any objectively measured patient outcome; (d) any experimental, quasi-experimental, or observational analytical studies; and (e) research published in English, regardless of the year of publication.

Studies focusing on psychometric properties of quality of life measurements, or focusing solely on caregivers' quality of life measurements or on the prognostic value of measuring quality of life, were excluded.

The authors independently reviewed the titles and full abstracts, and then the full texts of the studies identified through the search. Agreement between reviewers was greater than 80%, and discrepancies were resolved by means of discussion.

2.3. Data Extraction and Quality Assessment

Data abstraction was conducted by means of a standardized form, including aim, sample, intervention, outcome measure, and results, designed by the authors.

The Edwards Method Score for experimental and observational studies was used to score the methodological quality of the studies included [16]. At this stage, two authors independently scored the studies and a third author checked for accuracy and correctness. In accordance with the Edwards Method Score, the authors used scores between 0 and 2. For experimental studies, the total maximum score is 22 and, for observational studies, 16. The higher the scores, the better the quality of the studies included.

3. Results

The main findings (*i.e.*, effectiveness of the interventions focused on quality of life assessment in palliative care) of this systematic review and the process of study identification, screening, and inclusion according to the PRISMA guidelines [14] are reported elsewhere [13].

This paper reports the results of the secondary analysis regarding which explicit, longitudinal documentation of spiritual concerns would sufficiently affect clinical care to alleviate spiritual distress or promote spiritual wellbeing in clinical interventions focused on quality of life assessment in patients with palliative care needs. Table 1 provides details of the characteristics of the included studies (Table 1).

The following main results were found:

- (a) Three out of ten studies included spiritual wellbeing assessment [17–19];
- (b) A total of 1000 adult advanced cancer patients participated across the three studies included in this analysis. The study populations ranged from 72 to 709 participants, the median sample size being 219;
- (c) The interventions were delivered either in outpatient [19], inpatient [17], or home care [18];
- (d) Study comprised one quasi-experimental design [17], one interrupted time-series design [19] and one randomized controlled trial (RCT) [18];
- (e) The quality of the evidence was found to be moderate for the RCT [18] and the interrupted time-series [19], with quality scores of 15 out 22 and 13 out 16, respectively. The quality of the quasi-experimental design was low, with a quality score of 11 out 16 [17]. The internal validity of these studies was negatively affected by the omission of how sample size and power had been determined [17,18] and the small sample size [17,19]. The attrition rates were high in all three studies, which negatively affected their external validity;

- (f) Spirituality tools differed among the studies: Hospital QoL Index 14; Spiritual Needs Inventory; Missoula-Vitas QoL Index; and Needs Assessment Tool: Progressive Disease-Cancer;
- (g) Only one study reported a healthcare professional's session training in the use of the quality of life tool [19];
- (h) Two [17,19] of the three studies revealed that participants reported an improvement in spiritual wellbeing, but changes in spiritual wellbeing scores were not significant.

Table 1. Characteristics of the included studies (N = 3).

| Author, Year, Country | Study Population | Study Design | Aims/Intervention | Outcome Measures | Results |
|--------------------------------------|---|--|---|--|---|
| Waller <i>et al.</i> (2012), UK [19] | - 219 outpatient advanced cancer patients. - Mean age (SD): 66 (10.7) years. | - Interrupted time series design - Power (%): 80% - Sample Size: 407 | <p>Aim</p> <p>- To assess the impact of the systematic and ongoing use of the Guidelines and NAT: PD-C on patient outcomes.</p> <p>Intervention</p> <p>Systematic use of Palliative Care Needs assessment Guidelines and NAT: PD-C.</p> <p>1. Patients completed CATIs every 2 months over a period of 18 months or until their death or withdrawal: trained interviewers performed the CATI in assessing unmet needs, depression, anxiety, and QoL.</p> <p>2. Healthcare professionals received an individual (medical staff) or group (nursing, allied healthcare professionals) training in the use of NAT: PD-C and the Guidelines after patients had completed at least two baseline CATIs including purpose, structure, potential barriers and strategies to address them.</p> <p>3. Trained clinical staff, staff members from SPCs and patients' general practitioners completed NAT: PD-C monthly during their patient consultations.</p> <p>4. Patients continued to complete bimonthly CATIs following the introduction of the intervention.</p> | <p>Needs Assessment Tool: Progressive Disease-Cancer (NAT:PD-C): one page health professional-completed tool assessing patient wellbeing, the ability of the caregiver/family to care for the patient and caregiver wellbeing.</p> <p>- Section 1: 3 items to fast-track a review by a SPCS: that the patient has a caregiver available; that the patient or caregiver has requested a referral to a SPCS; or the health professional needs assistance in managing care</p> <p>- Section 2: 7 items to assess the patient's well-being across the physical, daily living, psychological, information, spiritual/existential, cultural and social, financial, and legal domains;</p> <p>- Section 3: 6 items to assess the ability of the caregiver/family to care for the patient across the physical, daily living, psychological, information, financial, legal, and family and relationship domains;</p> <p>- Section 4: 2 items to assess the caregiver's wellbeing in relation to their own physical, psychological, and bereavement issues.</p> <p>- Reliability: YES - Validity: YES - Developed in palliative care patients.</p> | <p>- Pre-intervention: highest health system and information needs.</p> <p>- Post-intervention: statistically significant reduction at T1: $p < 0.05$, T2: $p < 0.05$, and T3: $p < 0.01$</p> <p>- Participants reported an improvement in spiritual wellbeing, but changes in spiritual wellbeing scores were not significant.</p> <p>- Attrition rate: 58%.</p> |

Table 1. Cont.

| Author, Year, Country | Study Population | Study Design | Aims/Intervention | Outcome Measures | Results |
|-----------------------------|--|---|--|---|--|
| McMillan et al. (2011), USA | <ul style="list-style-type: none"> - 709 advanced cancer patients and caregivers in home palliative care services. - Mean age (SD) (12.1) years. - Patients: 72.6 (13.8) years. - Caregivers: 65.4 (13.8) years. | <ul style="list-style-type: none"> - RCT - Power (%): N/A - Sample size: N/A | <p>Aim</p> <ul style="list-style-type: none"> - To determine the efficacy of providing systematic feedback from standardized assessment tools for hospice patients and caregivers in improving hospice outcomes compared with standard care. <p>Intervention</p> <ul style="list-style-type: none"> - Both groups completed the same standardized assessment by the research assistants and not received suggestions for changing care plans. - Patients and caregivers were assessed upon admission and then weekly. - Intervention group: team members received structured reports at two staff meetings from the research assistants. The oral report lasted less than 4 min - Control group: team member did not receive any reports. | <p>Patient tools</p> <ul style="list-style-type: none"> • Memorial Symptom Assessment Scale-revised - 25-item tool measuring severity and distress of the symptom rated with separate 4-point Likert-type scales - Reliability: YES - Validity: YES - Developed for use with palliative care cancer patients. • Hospice Quality of Life Index 14 (HQLI-14) - 14-item tool measuring overall QoL: psychophysiological wellbeing, functional wellbeing, and social/spiritual wellbeing. Items scored on a 0-10 point scale - Reliability: YES - Validity: YES - Developed for use with palliative care patients. Patients and caregivers tools • Spiritual Needs Inventory - 17-item tool made up of 2 main parts: one scored from 1 to 5, and one by ticking YES or NO - Reliability: YES - Validity: YES - Developed for use with end of life patients and their caregivers. • The Boston short form of the Center for Epidemiological Studies - Depression - 10-item true-false instrument measuring depression - Reliability: YES - Validity: YES - Developed for use in clinical practice (not in palliative care patient) | <ul style="list-style-type: none"> - Results showed improved patient depression ($p < 0.001$) as a result of the intervention, and improvement in both groups in patient quality of life ($p < 0.001$); - Spiritual needs (patient and caregiver) were not differ over time in the 2 groups Attrition rate: 51% |

Table 1. Cont.

| Author, Year, Country | Study Population | Study Design | Aims/Intervention | Outcome Measures | Results |
|--------------------------|--|---|--|---|---|
| Hill (2002), New Zealand | - 72 inpatient terminally ill patients. - Patients' age: range 20-89 years. | Quasi-experimental design - Power (%): NA - Sample size: NA | Aim To compare changes in self-rated QoL in two patient groups in hospice setting before and after the intervention. Intervention 1. In both groups, QoL self-assessment using the MVQOLI questionnaire at T1 (within 3 days) and T2 (7–10 days later). 2. Intervention group: T1 assessment used as a basis of care planning by patients and nurses. 3. Control group: standard therapy that includes the formation of care plans by nurses alone. | • The Missoula-Vitas Quality of Life Index (MVQOLI) - 15-item tool measuring symptoms, function, interpersonal, wellbeing, transcendent, overall QoL. - Reliability: NO - Validity: NO - Developed in palliative care patients. | QoL changes no statistically significant differences in the QoL subscales and overall QoL between groups. Changes within group, statistically significant improvement for - Intervention group: symptoms ($p < 0.05$, ES = 0.47), function ($p < 0.05$, ES = 0.48), overall QoL ($p < 0.001$, ES = 0.40). - Control group: symptoms ($p < 0.01$). - Patients in both groups reported an improvement in transcendent domain, not statistically significant Attrition rate: 39% |

Key Studies Characteristics

McMillan *et al.* [18] recruited 709 dyads of patients and caregivers and examined the effect of a systematic feedback from standardized assessment tools in hospice home care. The authors found that the intervention significantly improved patient depression in the intervention group compared to the control group, and patients' QoL in both groups. Spiritual needs (patient and caregiver) did not differ over time in the two groups.

The quasi-experimental study with a before-and-after design compared changes in self-rated QoL in two patient groups (72 patients) in an inpatient hospice unit. The study was concerned with using baseline QoL assessment as a basis of care planning by patients and nurses. Change of QoL scores between groups at baseline and 7–10 days later were not significantly different. A statistically significant QoL improvement was shown within groups for symptoms (both groups), function, and overall QoL (intervention group only) [17]. Patients in both groups reported a not statistically significant improvement in the transcendent domain.

In an interrupted time-series study, Waller *et al.* [19] examined how outcomes changed in 195 outpatients prior to and following the implementation of the Palliative Care Needs Assessment Guidelines and the Needs Assessment Tool: Progressive Disease-Cancer (NAT: PD-C). The authors found that "health system and information" and "patient care and support" needs were significantly improved in the intervention group. Participants reported an improvement in spiritual wellbeing, but changes in spiritual wellbeing scores were not significant.

4. Discussion

Overall, patients receiving interventions focused on QoL assessment experienced improvements in their QoL. Although there was no significant difference in spiritual wellbeing, the results provide evidence that a spiritual need exists and that spiritual care should be appropriately planned and delivered.

In the setting of palliative care, research into spiritual wellbeing is increasing. Our secondary analysis, which was aimed to investigate which explicit, longitudinal documentation of spiritual

concerns would sufficiently affect clinical care to alleviate spiritual distress or promote spiritual wellbeing in clinical interventions focusing on quality of life measurement, revealed that the number of studies was small and that their quality was modest.

In all, we identified three studies, with different study designs, which aimed to evaluate at least two dimensions of quality of life, one of which was spirituality. Only one of the three studies had an RCT design [18]. This study had been conducted with a view to improving outcomes in a home-care program through the standardized assessment of quality of life and the sharing of the results through a structured report presented to staff during meetings. While the intervention significantly reduced depression, the spiritual wellbeing between groups did not differ over time. This result may suggest the utilization of a structured assessment that includes the spiritual domain. Although interventions designed to tackle conditions of compromised spirituality were not described in the study, the fact that encouraging patients and their families to share their spiritual needs appeared to be beneficial suggests that the study of specific interventions to assess spirituality should be continued, in order to encourage patients to explore those aspects of spirituality that are important to them. Moreover, the results of this study provide indications regarding both the influence of spirituality on the psychological wellbeing (*i.e.*, depression) of patients and the comfort that healthcare workers inevitably transmit during quality-of-life evaluation. These results, therefore, support those of other studies [20,21].

The longitudinal study by Waller *et al.* [19] indicated an improvement, albeit not statistically significant, in the spiritual dimension following implementation of the guidelines on the management of needs and on their structured evaluation in an outpatient department receiving cancer patients in an advanced stage of disease. It is noteworthy that this study attempted to implement a quality of life assessment tool in clinical practice, together with the application of the guidelines for the management of patients' unfulfilled needs.

Two of the studies identified used validated tools for the assessment of spirituality. Specifically, in the study by McMillan *et al.* [18], the measurement tools used were the Hospice Quality of Life Index 14 and the Spiritual Needs Inventory. Waller *et al.* [19] used six items concerning spirituality from the Needs Assessment for Advanced Cancer Patients. In the third study analyzed [17], in which patients reported an improvement not statistically significant for transcendent domain, a version of the Missoula-Vitas Quality of Life Index was used; at that time, however, it had not been validated.

The results of this secondary analysis suggest some practical recommendations. Structured recording (*i.e.*, via a questionnaire) of patients' needs and the sharing of results with all team members, in order to plan the best possible care, may have a positive influence on the patient's spiritual dimension. Similar to results reported in a former systematic review aimed at evaluating the effects of routine screening cancer patients for psychological distress on distress outcome [22]; it might be premature to recommend implementation of interventions focused on routine screening palliative care patients for spiritual needs.

Using quality of life assessment interventions alone is not sufficient to improve spiritual wellbeing of patients identified as having a spiritual need, as this would involve offering an appropriate intervention to address such a need, and having an organized integrated spiritual wellbeing system for evaluation and case management by integrating "the best research evidence with clinical expertise and patient values" [23,24].

Although only one of the three studies included in this analysis envisioned training healthcare professionals in the assessment and management of needs, this is one of the key elements to consider in the implementation of interventions aimed at assessing the spiritual domain and quality of life in the setting of palliative care. Another key element that responds to our review query regarding how spirituality is evaluated within quality-of-life assessments is that of timing. Although the three studies were not homogeneous in this regard, hospitalized and home-care patients were assessed weekly, and outpatients monthly.

The above-mentioned findings suggest that further, well-designed, efficacy-based research initiatives should be undertaken, in order to implement clinical and healthcare interventions aimed at measuring quality of life, including spirituality, in patients needing palliative care.

5. Conclusions

Out of three studies included in the analysis, only two reported an improvement, albeit not significant, in spirituality following the implementation of intervention aimed at measuring the quality of life in patients with palliative care needs. The small number of experimental studies and the low/modest quality of the three studies included mean that caution should be exercised in interpreting the results of this secondary analysis.

Despite the limitations of the studies identified, some crucial implications emerged with regard to the sphere of palliative care in clinical practice. As it is of fundamental importance to improve the spiritual dimension and the overall quality of life of patients needing palliative care, regardless of the healthcare setting, we need to consider the key elements involved in clinical intervention aimed at measuring quality of life. Specifically, in addition to the use of validated tools for outcome measurement, several other aspects require attention: the training of healthcare professionals, the choice of assessment timing, the sharing of results among staff members, and the availability of appropriate interventions and evidence-based protocols for the management of patients' unfulfilled needs. These are simple specifications that are inexpensive to implement, though they do require organization.

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Conflicts of Interest: The authors declare no conflict of interest.

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