

Evaluation of quality of life in a palliative care context: an integrative literature review¹

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The use of scales that have been validated and standardized for different cultures is very useful for identifying demands in the field of Palliative Care and implementing the most appropriate care. This integrative literature review focuses on instruments assessing the Quality of Life of patients under Palliative Care through a journal search in electronic databases. The study consisted of 49 papers identified in Medline/PubMed, of which 18 met the inclusion criteria previously defined. Information concerning the selected studies is presented and later categorized, with a greater emphasis on the analysis of the psychometric properties of validations of the Palliative Outcome Scale, conducted in three countries. This review enabled the identification of instruments already developed and validated for different cultures, increasing the possibility of knowledge in the field.

Descriptors: Palliative Care; Review; Quality of Life; Validation Studies.

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Avaliação de qualidade de vida no contexto dos cuidados paliativos: revisão integrativa de literatura

O uso de escalas padronizadas e validadas para diferentes culturas é de grande utilidade na identificação de demandas e implementação de atenção mais adequada no campo dos cuidados paliativos. Esta revisão integrativa de literatura científica teve como foco os instrumentos de avaliação de qualidade de vida de pacientes em cuidados paliativos, através da busca de publicações em periódicos indexados em bases eletrônicas de dados. O material do estudo constituiu-se de 49 artigos identificados na base de dados MEDLINE/PubMed, sendo que 18 atenderam os critérios de inclusão previamente definidos. Na análise dos dados, foram apresentadas informações referentes às publicações dos estudos selecionados, sendo posteriormente categorizados, com maior ênfase na análise das propriedades psicométricas das validações da escala Palliative Outcome Scale, realizadas em três países. Esta revisão permitiu a identificação de instrumentos de avaliação já desenvolvidos e validados às diferentes culturas, possibilitando ampliar conhecimentos nesse campo.

Descritores: Cuidados Paliativos; Revisão; Qualidade de Vida; Estudos de Validação.

Evaluación de la calidad de vida en contexto de los cuidados paliativos: revisión integradora de literatura

El uso de protocolos estándares y validados para distintas culturas es de gran utilidad para la identificación de demandas y para cuidados más ajustados en el campo de los cuidados paliativos. Esta revisión integradora de la literatura científica pone énfasis en instrumentos de evaluación de la calidad de vida de pacientes en cuidados paliativos, con la búsqueda de la publicación en periódicos indexados en bases electrónicas de datos. El material del estudio consiste en 49 artículos identificados en la base de datos Medline/Pubmed, siendo 18 adecuados a los criterios de inclusión previamente definidos. En el análisis de los datos, fueron presentadas informaciones respecto a las publicaciones de los estudios seleccionados, clasificados en categorías, con énfasis en el análisis de las propiedades psicométricas de las validaciones de la escala Palliative Outcome Scale, ejecutadas en tres países. Esta revisión permitió la identificación de los instrumentos de evaluación ya desarrollados y validados para las diversas culturas, haciendo posible ampliar conocimientos en ese campo.

Descriptores: Cuidados Paliativos; Revisión; Calidad de Vida; Estudios de Validación.

Introduction

With changes in lifestyle and technical/scientific advancements in the field of health and increased life expectancy, chronic diseases became more frequent as did the discomfort that accompanies the affected individuals and their families. In this context, Palliative Care is a philosophy of care whose efforts improve the quality of life of patients and their family members in the process of coping with death through early identification, prevention and relief of suffering, evaluation of treatment appropriate to physical, psychosocial and spiritual problems⁽¹⁾.

The evaluation of Quality of Life (QOL) of patients in Palliative Care is an important procedure in the identification of a patient's overall condition as well as in the evaluation of the quality of service provided. Despite a lack of consensus as to the definition of the term "Quality of Life"⁽²⁻³⁾, there are various instruments intended to measure such a construct from different perspectives⁽⁴⁾. Evaluation scales have been developed and/or culturally adapted and validated in different contexts and situations.

Brazilian health care services use standardized scales not adapted or validated to the Brazilian culture, the results of which cause a significant impact on the determination of procedures to be implemented and on the evaluations of care provided to patients. However, the scientific advancements in this field require the systematization and standardization of evaluation procedures to better measure results, to acquire better intra- and inter-professional group communication and consolidate evidence-based practices.

In this context, studies have been developed to validate instruments to evaluate QOL in the field of Palliative Care. Some recent studies identified such instruments through systematic reviews in the scientific literature⁽⁴⁻⁵⁾. However, it was not possible to identify a study evaluating the process of developing, translating, cultural adapting and/or validating such an instrument.

Objective

To analyze Brazilian and international studies concerning cultural adaptations and validations of instruments evaluating Quality of Life of patients in Palliative Care and discuss the use of these instruments in the Brazilian context.

Methods

The stages recommended in the literature⁽⁶⁾ to carry out integrative reviews were complied with. This study's guiding question was: "Which instruments evaluating Quality of Life in patients in Palliative Care have been already validated and published?"

To determine the sample, a search was conducted of scientific papers published in periodicals annexed in the Lilacs, Scielo, PubMed/Medline and IBECs databases from April to July 2010. The descriptors *Hospice Care*, *Palliative Care* and *Terminal Care* were associated, through the Boolean connector "AND", with the descriptor *Quality of Life* and its respective descriptors

in Portuguese and Spanish. The search was restricted to Validation Studies.

A total of 49 papers were found in the PubMed/Medline database, though seven were duplicated under more than one descriptor. Based on a detailed reading of titles and abstracts, 18 papers that met the following criteria were selected: a) published from 1999 to 2010; b) the study's full text was available on line; c) developed, translated, culturally adapted and/or validated an instrument to evaluate the QOL of patients in the context of hospice care. This selection and number of papers meet the recommendations found in the literature, which require that at least 30% of papers meet the established inclusion criteria⁽⁷⁾.

The remaining papers were excluded because they either did not validate instruments (n=8), did not address people under palliative care (n=2), or the instrument did not evaluate the QOL of patients (n=21).

A specific evaluation instrument⁽⁸⁾ was adapted to interpret and analyze the selected papers in order to extract the information required to answer the study's question.

Results

All the selected papers were methodological investigation studies, which present different means to prove hypotheses, methods of data collection, and data analysis measures and techniques.

The studies were conducted in Africa, Korea, Spain, and the United States (11.1% each), in countries in Western Europe (33.3%), Asia (16.7%) and South America (5.6%). Most are published in periodicals whose theme is Palliative Care and/or Pain (50%) followed by those related to Quality of Life (22.2%), cancer (16.7%) and medical/clinical periodicals (11.1%). The average impact factor of these periodicals is 2.753 (1.231-5.418).

Figures 1 and 2 present publication data of these studies.

Year of publication	Title	Author	Periodical	Impact Factor	Instrument	Other instruments used
2001	Cross-cultural validation of the McGill Quality of Life questionnaire in Hong Kong Chinese.	Lo RS, Woo J, et al	Palliat Med	2,031	McGill Quality of Life questionnaire - Chinese version	SIS measuring, Spitzer Quality of Life Index
2003	Quality of life for oncology patients during the terminal period: Validation of the HRCA-QL index.	Llobera J, et al.	Support Care Cancer	2,089	Hebrew Rehabilitation Center for Aged QL	KPS, Independence in of daily living activities

(The Figure 1 continue in the next page...)

Year of publication	Title	Author	Periodical	Impact Factor	Instrument	Other instruments used
2004	Adapting the Lung Cancer Symptom Scale (LCSS) to mesothelioma: using the LCSS-Meso conceptual model for validation.	Hollen PJ, et al.	Cancer	5,418	Lung Cancer Symptom Scale (LCSS)	KPS
2004	The "Palliative Care Quality of Life Instrument (PQLI)" in terminal cancer patients.	Mystakidou K, et al.	Health Qual Life Outcomes	2,456	Palliative Care Quality of Life Instrument (PQLI)	ECOG; EORTC QLQ C-30 and Quality of Life in Palliative Care
2004	Validation of the Spanish version of the Palliative Care Outcome Scale	Serra-Prat M, et al.	Medicina Clinica – Barc	1,231	Palliative Care Outcome Scale – Spain	EORTC QLQC-30, KPS and Barthel Index
2005	Validation and clinical application of the German version of the Palliative Care Outcome Scale.	Bausewein C, et al.	J Pain Symptom Manage	2,423	Palliative Outcome Scale—Germany	ECOG
2005	Validation of the McGill Quality of Life Questionnaire in home hospice settings in Israel.	Bentur N, Resnizky S.	Palliat Med	2,031	McGill Quality of Life Questionnaire – Israel	None
2005	The feasibility, reliability and validity of the McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF) in the palliative care population.	Lua PL, et al.	Qual Life Res.	2,376	McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF)	General Health Status extracted from SF-36 and MQOL
2006	Edmonton symptom assessment scale: Italian validation in two palliative care settings.	Moro C, et al.	Support Care Cancer	2,089	Edmonton symptom assessment scale	Symptom Distress Scale; KPS

Figure 1 – Studies included in the literature review according to publication data between 2001 and 2006

Year of publication	Title	Author	Periodical	Impact factor	Instrument	Other instruments used
2007	Validation study of the Korean version of the McGill Quality of Life Questionnaire.	Hyun Kim S, et al.	Palliat Med	2,031	McGill Quality of Life Questionnaire - Korean version	EORTC QLQ C-30; Sense of Dignity; General Health Perception; ECOG
2007	Validation of the Missoula-Vitas Quality-of-Life Index among patients with advanced AIDS in urban Kampala, Uganda.	Namisango E, et al.	J Pain Symptom Manage	2,423	Missoula-Vitas Quality-of-Life Index (MVQOLI)	Karnofsky, socio-demographic questionnaire
2007	Validity, reliability and clinical relevance of EORTC QLQ-C30 and LC13 inpatients with chest malignancies in a palliative setting.	Nicklasson M, Bergman B.	Qual Life Res.	2,376	EORTC QLQ-C30 and LC13	Hospital anxiety and Depression Scale; Brief Pain Inventory; Karnofsky; WHO Scale; O ₂ Saturation and Spirometry
2008	Use of the palliative outcome scale in Argentina: a cross-cultural adaptation and validation study.	Eisenchlas JH, et al.	J Pain Symptom Manage	2,423	Palliative Outcome Scale	EORTC QLQ C-30; ECOG

(The Figure 2 continue in the next page...)

Year of publication	Title	Author	Periodical	Impact factor	Instrument	Other instruments used
2009	Validation of the European Organization for Research and Treatment of Cancer QLQ-LMC21 questionnaire for assessing patient-reported outcomes during treatment of colorectal liver metastases.	Blazeby JM, et al.	Br J Surg	4,007	QLQ-LMC21	Karnofsky
2009	Reliability and validity of the Hospice Quality of Life Scale for Korean cancer patients.	Kim SH, et al.	J Pain Symptom Manage	2,423	Hospice Quality of Life Scale	ECOG Performance Status; QLQ C30 e McMaster QLS
2009	Reliability and validity of the Functional Assessment of Chronic Illness Therapy-Palliative care (FACIT-Pal) scale.	Lyons KD, et al.	J Pain Symptom Manage	2,423	Functional Assessment of Chronic Illness Therapy-Palliative care (FACIT-Pal) scale	Trial outcome index (TOI); Edmonton Symptom Assessment and Center for Epidemiological Studies-depression (CES-D)
2009	Reliability and validity of Japanese version of the McGill Quality of Life Questionnaire assessed by application in palliative care wards.	Tsujikawa M, et al.	Palliat Med	2,423	McGill Quality of Life Questionnaire – Japanese version	Performance Status;
2010	Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale.	Harding R, et al.	Health Qual Life Outcomes	2,456	APCA African Palliative Outcome Scale.	Missoula Vitas QoL Index and ECOG

Figure 2 - Studies included in the literature review according to publication data between 2007 to 2010

The selected studies were classified into three categories according to the type of development proposed: New instruments; Development of specific modules based on generic instruments; Adaptation to specific populations.

New Instruments

Four papers were included in this category and are presented based on the constructed instrument.

The McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF)⁽⁹⁾ – This short version includes only eight items of the 17-item McGill Quality of Life Questionnaire. It includes physical, psychological, existential wellbeing, and the domains of social and family support. In this study conducted in Malaysia, the instrument was jointly applied with the questionnaire's original version to 55 patients who were monitored in an outpatient clinic, 48 in hospice facilities, and 86 in hospitals, all with a diagnosis of advanced cancer under palliative care. The new version was answered in less

time and was considered by the patients to be clear. The authors concluded in the data analysis that MQOL-CSF is a simple yet reliable instrument to evaluate the QOL of patients in Palliative Care.

The Hospice Quality of Life Scale (HQLS)⁽¹⁰⁾ – An instrument composed of 40 questions distributed into 13 domains. Aiming to address specificities of Eastern culture, these questions were re-categorized into another six clinical sub-scales: physical, psychological, and spiritual aspects, family and social economy and global aspects. It was applied to a sample of 188 cancer patients under Palliative Care to verify its psychometric proprieties, presenting values that indicate its efficiency in evaluating of the quality of care of these patients.

Palliative Care Quality of Life Instrument (PQLI)⁽¹¹⁾ – Developed in Greek and contains 28 items. One of its questions is open and evaluates the overall QOC of patients under Palliative Care and the remaining questions are closed with a gradual scale of three items. The instrument comprises the dimensions of

functionality, symptoms, choice of treatment (what is the most important thing for the patient), psychological dimension and overall quality of life. The instrument was applied to a sample of 120 patients with diagnosis of terminal cancer in order to check its psychometric properties, which, according to the study's authors, demonstrated good validity, reliability and sensitivity.

African Palliative Outcome Scale [POS] (APCA)⁽¹²⁾ – This scale was developed in Africa based on the Palliative Outcome Scale (POS), which evaluates the QOL of patients in Palliative Care. The scale's original version was significantly adapted and the new scale comprises 14 items and includes as key-domains: pain and relief of symptoms, access to medication, spiritual and emotional support, acceptance of sadness, family support and a family basis for planning advanced care. The African scale's final version was applied to 80 individuals with a diagnosis of cancer or HIV/AIDS, cared for in home care or monitored in an outpatient clinic. After its psychometric properties were verified, the authors concluded that the APCA was sensitive to changes over time such that it is possible to evaluate multiple domains of patients with HIV/AIDS or cancer in Palliative Care and considered it to be the first scale with relevant results in this field in Africa.

Development of specific modules based on generic instruments

Three papers were included in this category based on the developed instruments.

Functional Assessment of Chronic Illness Therapy – Pal (FACIT-PAL)⁽¹³⁾ – Composed of a sub-scale of Palliative Care based on the Functional Assessment of Chronic Illness Therapy - G (FACT-G), a generic and multi-dimensional instrument that evaluates Health Related Quality of Life. A total of 256 individuals diagnosed with advanced cancer in the United States answered the 46 items of the instrument: 27 from the FACT-G and 19 from the FACIT-PAL in order to check its psychometric properties. The study's authors concluded that it is a valid and reliable instrument to evaluate QOL of patients under Palliative Care.

Quality of Life Questionnaire – LC13 (QLQ-LC13)⁽¹⁴⁾ – Specific module of the Quality of Life Questionnaire instrument - C30 (QLQ-C30) to evaluate the QOL of patients with lung cancer. It was developed by the European Organization for Research and Treatment of Cancer (EORTC) and its psychometric properties were tested on a sample of 112 patients with advanced lung cancer or pleural mesothelioma under Palliative Care in

Sweden. The authors concluded that the instruments are valid and clinically relevant in the field of Palliative Care with this population.

Quality of Life Questionnaire – LMC21 (QLQ-LMC21)⁽¹⁵⁾ – The QLQ C-30 instrument's module for liver cancer, developed to evaluate the QOL of hepatectomized patients or patients under Palliative Care due to the hepatic metastases of colorectal cancer. This study was conducted in England and used a sample of 356 patients who completed the QLQ-C30 and the QLQ-LMC21, before and three months after the hepatectomy or at the beginning of the palliative treatment. The authors observed that the instrument presents good sensitivity and concluded, through psychometric tests, that it also presented good reliability and clinical, criterion, and construct validity, being valid and reliable to be used jointly with the QLQ-C30 in this population.

Adaptation to specific populations

Eleven papers were included and are described based on the adapted and validated instrument.

Missoula-Vitas Quality of Life Index (MVQOLI)⁽¹⁶⁾: The authors stated that this is the only instrument in Uganda that includes the domain "existential transcendence" in the evaluation of QOL of people with advanced diseases in the context of Palliative Care. The instrument was originally developed in the United States and uses a subjective language to reflect and measure the nature of the experience of patients and adaptation to their circumstances. The scale is composed of 25 items and can be divided into five domains of people's subjective experience: symptoms, functional state, interpersonal relations, emotional well-being and transcendence. To verify the validity of the Uganda's version, the authors used a sample of 200 patients with advanced AIDS. The instrument presented good psychometric results and the authors concluded that new the MVQOLI version is viable, valid, and reliable to measure QOL in this population.

Edmonton Symptom Assessment Scale (ESAS)⁽¹⁷⁾ – In order to measure the QOL of patients under Palliative Care, this instrument evaluates the severity of various symptoms: pain, tiredness, nausea, depression, anxiety, somnolence, appetite, wellbeing and shortness of breath. To validate the Italian version of this instrument, the authors used a sample of 83 inpatients and 158 patients cared for in home care, all with a diagnosis of terminal cancer and in Palliative Care. Based on psychometric analysis, the authors considered the ESAS Italian version to be reliable, valid and viable to evaluate

physical symptoms of patients in the context of Palliative Care and to be sensitive to the different contexts of care.

The Lung Cancer Symptom Scale-Mesothelioma (LCSS-Meso)⁽¹⁸⁾ – This study aimed to adapt this scale to a population with malignant pleural mesothelioma in Palliative Care in the United States. The instrument is composed of nine visual analogue scales including the dimensions of physical and functionality (physical, cognitive and social aspects) and Overall QOL (Cognitive, psychological, social and spiritual). It was applied to 495 patients with mesothelioma under Palliative Care to verify its psychometric proprieties. The symptoms most prevalent in this population were included in one of the instrument's items, which the authors considered to be valid, reliable and sensitive to changes related to the QOL in this population.

Hebrew Rehabilitation Center for Aged-QL (HRCA-QL)⁽¹⁹⁾ – This instrument is a version of the Spitzer Quality of Life Index and was especially adapted to patients with advanced cancer. It contains five questions scored from 0 to 2, hence a total score ranges from 0 to 10. These questions include mobility, activities of daily life, health, support and prospects. The authors concluded, based on psychometric tests performed with 200 patients with terminal cancer, that the instrument's Spanish version is valid and reliable to evaluate the QOL of this population.

McGill Quality of Life Questionnaire (MQOL-HB)⁽²⁰⁾ – Multi-dimensional instrument to evaluate the QOL of patients in Palliative Care including the domains physical, psychological, existential wellbeing and social support, comprised in the perception of QOL. It comprises 17 questions scored through a visual analogue scale from 0 to 10. The study's authors considered it appropriate for the Israeli population in all stages of terminal diseases. Its psychometric proprieties were tested in a sample of 160 patients with advanced cancer (invasive and metastatic) admitted to a hospice facility active at the time in Israel. The results indicated that the Hebrew version of MQOL is valid and appropriate for the Israeli culture.

McGill Quality of Life Questionnaire (MQOL-K)⁽²¹⁾ – The Korean version of this instrument was applied to 140 patients in Palliative Care with a diagnosis of terminal cancer to verify its psychometric proprieties. The authors

confirmed the Korean version was adequate, valid and reliable to measure the QOL of patients in Palliative Care.

McGill Quality of Life Questionnaire (MQOL-HK)⁽²²⁾ – The instrument was translated for and adapted to Hong Kong. It was applied to 462 patients with advanced cancer admitted into Palliative Care. The authors state that the sub-scale of existential wellbeing is the most important one to measure QOL in the studied population given the Asian culture. Psychometric tests confirmed the instrument was valid and reliable, though they indicated the need to incorporate questions related to people's empathic skills toward patients, and in relation to patients' diet and sexual lives.

McGill Quality of Life Questionnaire (MQOL-J)⁽²³⁾ – The Japanese version was applied to a sample of 60 patients with a diagnosis of advanced cancer to verify psychometric proprieties. The authors indicated its validity and reliability and also considered the spiritual and psychological dimensions to be closely related to QOL for the studied population given its culture. The authors state that the instrument requires physical and mental effort from patients and should be applied only to those in a condition to answer it.

Palliative Outcome Scale (POS)⁽²⁴⁾ – This scale was developed in England and results from a multi-dimensional evaluation of QOL of people under Palliative Care. It presents two versions: a self-applied version, directed to patients, and a proxy version, directed to health workers, enabling identical and reliable measures. It contains 11 questions, one of which is an open question to indicate the main problems experienced by patients while the remaining are scored on a Likert scale of five points. It addresses aspects related to physical and psychological symptoms, spiritual considerations, practical and emotional concerns, in addition to the psychosocial needs of patients and their families. POS's total score results from the sum of the ten questions, both for the staff and patients, ranging from 0 to 40 points. A score 40 indicates that those under treatment are experiencing the greatest harm⁽²⁵⁻²⁷⁾.

Following, we present papers that were cultural adaptations of POS validated in Germany⁽²⁵⁾, Argentina⁽²⁶⁾, and Spain⁽²⁷⁾ (Figure 3). Studies validating the scale in Portuguese, Italian, Urdu and Punjabi were also mentioned on the King's College in London website⁽²⁸⁾.

Year	Country	Sample	Validity	Internal consistency – Cronbach's alpha	Reliability
2004	Spain	200 patients with a diagnosis of advanced cancer	<p>Concurrent validity (r_s) Correlation with global QOL EORTC QLQ C-30 – correlates with 5 items</p> <p>Correlation with the Karnofsky's scale</p> <p>Correlation with the Barthel's index – with 3 items of POS from Spain</p>	<p>Staff's version: Cronbach's alpha = 0.62</p> <p>Patients' version: Cronbach's alpha = 0.64</p>	<p>Correlation between the two versions CCI ranged from 0.75 to 0.38 Kappa ranged from 0.51 to 0.75</p> <p>Test-retest reliability CCI ranges from 0.61 to 0.89 Weighted Kappa index ranged from 0.36 to 0.57</p>
2005	Germany	118 patients with a diagnosis of advanced cancer	<p>Content validity and consensus validity Analysis of the interviews</p>	Not reported	<p>Correlation between the two versions Spearman's correlation ranged from 0.11 to 0.54 Kappa ranged from 0.9 to 0.39</p>
2007	Argentina	65 patients with a diagnosis of advanced cancer	<p>Content validity IVC_{patient}=0.86 (r=0.52-1) IVC_{staff}=0.84 (r=0.55-1)</p> <p>Construct's validity QLQ C-30 - rho=0.74 p<0.0005</p>	<p>Staff's version Cronbach's alpha ranges from 0.66 to 0.73</p> <p>Patients' version Cronbach's alpha ranges from 0.68 to 0.69</p>	<p>Correlation between the two versions Kappa >0.3 (acceptable concordance) Spearman's correlation ranged from 0.38 to 0.82</p> <p>Test re-test reliability k>0.8</p> <p>Sensitiveness Wilcoxon-Signed Rank Test) ranged from 0.0 to 1.0</p>

Figure 3 – Presentation of the studies concerning the cultural adaptation and validation of POS

The Palliative Outcome Scale (POS) is an instrument that measures the effectiveness of Palliative Care, taking into account the main difficulties experienced by patients from a multi-dimensional perspective. It also enables an appropriate evaluation of the QOL of individuals in this context of care and the efficiency of Palliative Care delivery from the perspective of individuals and the staff.

The authors verified the psychometric properties of the POS's German version⁽²⁵⁾ after its translation and linguistic and cultural adaptation. The new version was applied at three different points in time: only once to 118 patients; twice to 55 patients; and three times to 36 patients. Another instrument, the EORT QLQ-C30, was applied jointly with POS. It evaluates the QOL of patients with cancer. The authors concluded that the German version of POS is a valid measure well accepted by patients and health professionals.

In the pre-test of the Argentine version⁽²⁶⁾, the last stage of the cultural adaptation process, the authors used a sample of 85 individuals (65 patients with advanced cancer and 20 health professionals). They concluded that the POS's Argentine version is valid and reliable to measure Palliative Care provided to patients with cancer.

Jointly with the EORTC QLQ-C30, Karnofsky Performance Status (KPS) and Barthel's Index, the Spanish version⁽²⁷⁾ was applied to a sample of 200 patients with advanced cancer. The first two indexes are intended to evaluate functional capacity. The study's authors concluded the Spanish version is a valid and reliable scale.

The POS's validation studies concluded that it is easy to apply and well accepted by health professionals and patients. We note the importance of the proxy version of this instrument, which distinguishes it from the remaining instruments in this category.

Discussion

A total of 13 different instruments intended to evaluate the QOL of patients under Palliative Care were identified in this integrative review. Two of the four studies identified in the category of development of "new instruments" were based on existing instruments. Two studies in the category "Development of specific modules based on generic instruments" refer to different modules of the same generic instrument, EORTC QLQ C-30 – evaluation of QOL of patients under Palliative Care. Four of the six instruments identified in the last

category "Adaptation to specific populations" are cultural adaptations and validations of MQOL in other countries and three of POS.

The growing use of self-applied instruments is explained by the feasibility of patients reporting facts and feelings from their perspective. However, the impossibility of patients to fully answer the instrument due to the evolution of their clinical conditions requires the development of a proxy version (directed to the staff).

The number of questions is also a factor that influences answers. An average of 18.69 (5 to 46) questions among the 13 analyzed instruments was identified. We believe that opting for instruments with a small number of objective questions that are easy to understand should be a priority, so that questions can be answered in the shortest period of time possible. In this way, patients might avoid being overwhelmed when they are already in a vulnerable situation.

Most of the instruments found (94.4%) seek to evaluate the QOL of patients from a multi-dimensional perspective including physical, emotional, social, economic, spiritual aspects and the patient's relationships with family and the staff. We understand that the needs and suffering of patients with no possibility of being cured should be identified in an integral manner in order to implement measures to relieve suffering and improve QOL.

Only two studies used samples of patients with non-oncological^(14,18) diagnoses, while the remaining included advanced cancer, which indicates the need to validate new instruments to evaluate the QOL of individuals with non-oncological diagnoses under palliative care that might present characteristics different from those found in cancer patients.

The studies validating the POS in the three countries mentioned did not follow the same methodological trajectories and the authors found the versions to present good levels of reliability and validity and were well accepted by patients in palliative care. We stress the importance of verifying all types of validity and reliability so that psychometric properties are ensured. The authors state that low values of the Kappa coefficient and Cronbach's alpha are explained by the small number of questions, even though it is characterized as a multi-dimensional instrument. Further studies addressing the broadened use of POS and adaptation to other cultures, as well as in clinical research, are needed.

Final considerations

This review enabled the identification of evaluation instruments already developed and validated for different cultures, as well as identifying a lack of instruments to evaluate the QOL of patients under palliative care validated in Brazil, published and indexed in international databases. From this perspective, another study is being developed in Brazil to translate, culturally adapt and later validate the Palliative Outcome Scale (POS), because this is an international scale with a multi-dimensional nature useful both in research and in clinical practice that permits broadening knowledge in the field.

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