



EVALUATION TOOLS OF QUALITY OF LIFE IN PALLIATIVE CARE: AN INTEGRATIVE REVIEW

INSTRUMENTOS DE AVALIAÇÃO DE QUALIDADE DE VIDA EM CUIDADOS PALIATIVOS: REVISÃO INTEGRATIVA

HERRAMIENTAS DE EVALUACIÓN DE LA CALIDAD DE VIDA EN CUIDADOS PALIATIVOS: REVISIÓN INTEGRADORA

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ABSTRACT

Objective: characterizing the national scientific production about the use of instruments for evaluating health-related quality of life (HRQOL) in palliative care. **Method:** an integrative review, guided by the question: Which tools are used to evaluate HRQOL in palliative care? held in BDEF, LILACS, in the virtual library SCIELO and in the electronic portal CAPES databases, from 2003 to 2013. The sample consisted of 15 publications. It was used the adapted instrument Critical Appraisal Skills Programme and the Hierarchical Classification of Evidences for the Evaluation of the Studies. **Results:** there were identified the following instruments: generic used in patients with any disease; generic for cancer patients; and specific for cancer patients in palliative care. **Conclusion:** it is recommended to use specific tools to evaluate the HRQOL of patients in palliative care containing a number of reduced issues. **Descriptors:** Palliative Care; Quality of Life; Nursing.

RESUMO

Objetivo: caracterizar a produção científica nacional acerca da utilização de instrumentos para avaliação de qualidade de vida relacionada à saúde (QVRS) em cuidados paliativos. **Método:** revisão integrativa, norteadada pelo questionamento: quais os instrumentos utilizados para a avaliação de QVRS em cuidados paliativos? Realizada nas bases de dados BDEF, LILACS, na biblioteca virtual SCIELO e no portal eletrônico CAPES, no período de 2003 a 2013. A amostra foi constituída por 15 publicações. Utilizou-se o instrumento adaptado do *Critical Appraisal Skills Programme* e o de Classificação Hierárquica das Evidências para Avaliação dos Estudos. **Resultados:** identificados instrumentos: genéricos utilizados em pacientes com qualquer doença; genéricos para pacientes oncológicos; e específicos para pacientes com câncer em cuidados paliativos. **Conclusão:** recomenda-se utilizar instrumentos específicos para avaliação da QVRS dos pacientes em cuidados paliativos contendo um número de questões reduzidas. **Descritores:** Cuidados Paliativos; Qualidade de Vida; Enfermagem.

RESUMEN

Objetivo: caracterizar la producción científica nacional acerca del uso de instrumentos para evaluar la calidad de vida relacionada a la salud (CVRS) en los cuidados paliativos. **Método:** una revisión integradora guiada por la pregunta: ¿qué herramientas son utilizadas para evaluar la CVRS en los cuidados paliativos? efectuada en las bases de datos BDEF, LILACS, biblioteca virtual SciELO y portal electrónico CAPES, entre 2003 y 2013. La muestra estuvo constituida por 15 publicaciones. Se utilizó el instrumento Critical Appraisal Skills Programme y la Clasificación Jerárquica de las Evidencias para la Evaluación de los Estudios. **Resultados:** instrumentos identificados: genéricos utilizados en pacientes con cualquier enfermedad; genéricos para pacientes con cáncer; y específicos para pacientes con cáncer en cuidados paliativos. **Conclusión:** se recomienda el uso de herramientas específicas para evaluar la CVRS de los pacientes en cuidados paliativos que contienen un número de cuestiones reducidas. **Descriptores:** Cuidados Paliativos; Calidad de Vida; Enfermería.

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INTRODUCTION

The technical and scientific advancement in the field of health has promoted an increase in life expectancy of patients with chronic diseases, generating, however, intense and comprehensive discomforts that affect the individual and his family. In this context, emerge the palliative care, with the purpose to introduce measures to encourage improvements in the quality of life (QOL) of patients and their families in the coping process at the end of life, through early identification, prevention and relief of suffering, adequate evaluation and treatment of physical, psychosocial and spiritual problems.¹

The similarity of the various concepts espoused in the literature by various authors, the World Health Organization¹ defines QOL as the individual's perception of his position in life, taking into account the cultural aspects and the system of values that covers, considering his objectives, expectations and interests.

Concern about the QOL of people has been highlighted notably in the area of health sciences, adopting the terminology Health-Related to Quality of Life (HRQOL), when assigned to various aspects of life of an individual affected by damage or influences resulting from diseases or injuries and treatments perceived through physical, psychological and social limitations.²

The evaluation of HRQOL of patients in palliative care is the primary goal of care at the end of life, considered as an important procedure to identify and assess the impact on quality of life of patients in physical, psychological, social and spiritual domains.

For healthcare professionals often it becomes difficult to accurately assess the QOL of sick people, due to the absence of a suitable tool, thus resulting in the need to seek validated and specific instruments to assess HRQOL of patients in palliative care, as shown in some studies.³ Thus, the use of these tools helps to identify the overall condition of the individual despite the proximity to terminality.

In Brazil, most HRQOL assessment tools used by care services are not adapted and validated to the country's culture, and the results obtained through these can produce distortions in determining actions to be taken and assessments of care offered patients. However, some studies have been developed on the national scene to validate HRQOL assessment tools in the field of palliative care.

Hence the importance of research aimed at investigating the scientific production in Brazilian literature about the use of tools for HRQOL assessment in palliative care. In this context, this study aimed to:

- Characterizing the national scientific production about the use of instruments for evaluation of health-related quality of life (HRQOL) in palliative care.

METHODOLOGY

This is an integrative review that includes the construction of an extensive literature review, evidence-based. This type of study is premised synthesize research previously carried out about a specific phenomenon entailed in guiding question that signals the literature search.⁴

The present review was prepared on the following steps: issue identification and elaboration of the guiding question; establishment of inclusion and exclusion criteria of studies; databases of choices and search of scientific production; analysis of the studies included in the review; discussion of the results; and finally, the knowledge synthesis of the main results of the analysis evidenced the articles included.

This literature review was guided by the following question: Which tools are used to evaluate HRQOL in palliative care? Faced with this question went to the second stage whose objective was the establishment of the search strategy in the literature.

The survey material to form the integrative review was carried out in March 2014, through on-line search in the Virtual Health Library (BVS), in the database of the Latin American and Caribbean Literature in Health Sciences (LILACS), the Scientific Electronic Library Online (SciELO), the Nursing Database (BDENF), in the portal of CAPES and the Digital Library of the University of São Paulo (USP). To search for articles was used in health terminology consulted on Descriptors in Health Sciences (DeCS/Bireme) "quality of life" and "palliative care", with and without the use of the Boolean operator AND, together with the selected terms, such as: palliative care and quality of life.

Inclusion criteria for material selection were: studies that addressed the use of patient QOL instruments in palliative care, indexed studies in selected databases for the study and the Virtual Library SciELO, published in the 2003-2013 period, in Portuguese, in the original article mode, dissertation or thesis. Regarding the exclusion criteria there were considered: a review in

duplication without abstracts available and those who, despite having the selected descriptors, not directly addressed the proposed theme.

By using these criteria there were selected 157 studies of which 26 were excluded because they are repeated in the SciELO and LILACS and BDENF bases and 17 for not having the available summaries. After reading the abstracts of the remaining studies, 75 were excluded for not meeting the inclusion criteria for this review. Then proceeded to strict reading of the article in full, and then deleted 24 for not having answers to the research question and objective proposed for the study on the screen. Against the criteria established for sample selection, 15 studies were selected.

To assessing the quality of the selected studies we used the adapted instrument *Appraisal Critical Skills Programme (ACSP)* - Program in critical reading skills, prepared by the University of Oxford in 2002.⁵ Based on this instrument, the studies are classified according to the following scores: 06 to 10 points (good methodological quality and reduced bias) and a minimum of 5 points (satisfactory methodological quality, but with increased risk of bias); therefore, it was decided to use only the articles classified 6-10 points.

In respect of the level of evidence classification there was used a second instrument, the Hierarchical Classification of evidence for studies of evaluation⁶: 1 - systematic reviews or meta-analysis of relevant clinical trials; 2 - evidence of at least one randomized controlled clinical trial clearly delineated; 3 - well-designed clinical trials without randomization; 4 - cohort studies and well-designed case-control; 5 - systematic review of descriptive and qualitative studies; 6 - evidence derived from a single descriptive or qualitative study; 7 - opinion of authorities or expert committees including information interpretations not based on research.

Based on the recommended criteria in these two instruments, made up the corpus of this integrative review all 15 studies since they were classified as having good methodological quality work.

After obtaining the final sample readings were taken each minute of study, in order to structure the relevant information to the development of this review. At this stage, it proceeded to a critical assessment of the selected studies, considering the instrument used, containing the following items: lead author, vocational training, study title, study

mode, database/virtual library/portal, title the journal, year of publication, objectives, methodology and results.

The data analysis stage was guided by the thematic analysis or inferred by categorical content analysis technique⁷. Thus, the object and results of studies under evaluation were grouped and integrated, which established the following categories for analysis and discussion: Category 1 - generic instruments to assess HRQOL of patients with any disease; category 2 - generic instruments to assess HRQOL of patients with oncological diseases; and category 3 - specific instruments to assess HRQOL of patients in palliative care.

Inserted studies were presented in figures, in order to allow a better view in this review.

RESULTS

♦ Characterization of the studies

Figure 1 below highlights the title of the studies included in this review, publication of authorship, emphasizing lead author and vocational training, mode of study, journal name and the year of publication, methodology, methodological quality score of the study and level of evidence.

Study (E)	Title	Authors/ Training	Modality	Database/ Virtual Library/ Portal / Journal/Year	Methodology	Score	Evidence
E1	The knowledge of cancer diagnosis does not lead to depression in patients under palliative care	Diniz, RW (Physician)	Original article	LILACS Rev Assoc Med Bras 2006	Cross-sectional study, observational and prospective, with 62 cancer patients receiving palliative care.	6-10	Level VI
E2	Study of the effects of massage therapy in relieving pain and improving the quality of life in cancer patients under palliative care	Ferreira, ASM, (Physician)	Original article	SciELO Rev Dor 2007	Randomized controlled, prospective, involving 34 patients with advanced cancer.	6-10	Level II
E3	Neoplastic pulmonary Lymphangitis: impact of palliative therapy on quality of life and prognosis	Dettino, ALA (Physician)	Doctoral thesis (FMUSP)	LILACS 2008	Prospective cohort study, with 52 patients with neoplastic pulmonary Lymphangitis.	6-10	Level IV
E4	Quality of life in women with advanced disease stage cancer	Silva, CHD (Physician)	Master's thesis (UNICAMP)	Portal CAPES 2008	Cross-sectional study, involving 277 women in advanced cancer stage.	6-10	Level VI
E5	Symptom control and nutritional intervention. Factors that interfere in the quality of life of cancer patients in palliative care	Silva, PB (Nutrition ist)	Original article	LILACS Rev Dor 2010	Longitudinal, prospective clinical study, including 50 cancer patients under palliative care.	6-10	Level VI
E6	Evaluation of the effectiveness of a dental care protocol to relieve pain, oral symptoms and improves quality of life in patients with head and neck cancer in palliative care: non-controlled clinical trial	Jales, SMCP (Dentist)	Doctoral thesis (FMUSP)	LILACS 2011	Uncontrolled clinical trial, conducted with 40 patients with advanced head and neck cancer in palliative care.	6-10	Level III
E7	Cancer patients on palliative chemotherapy : profile and relationship between symptoms,	Souza, RS (Nurse)	Master's thesis (UFMG)	Portal CAPES 2011	Descriptive study with cross-sectional delineation, quantitative, with 70 patients on palliative	6-10	Level VI

	functional capacity and quality of life					chemotherapy		
E8	Bio-ethics and palliative care: decision making and quality of life.	Wittmann -Vieira (Nurse)	Original article	LILACS Rev Paulista 2012	Acta	Descriptive, transversal, quantitative study, with 89 patients with advanced stages of the disease.	6-10	Level VI
E9	Self-care needs to the quality of life of customers with head and neck cancer: nursing's contributions	Luca, MD (Nurse)	Master's thesis (UERJ)	Portal CAPES 2012		Descriptive, quantitative study, with pre-experimental design (with intervention - for self-care during the nursing consultation), with 77 cancer patients.	6-10	Level III
E10	Translation, cultural adaptation and initial validation in Brazil of Palliative Outcome Scale (POS)	Correia, FR (Nurse)	Master's thesis (EERP/USP)	Portal Capes 2012		Methodological study, descriptive, transversal, quantitative character, involving health professionals (experts) and patients with cancer.	6-10	Level VI
E11	Quality of life for Brazilian patients with advanced cancer: validation of the European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire Core15-Pal - EORTC QLQ-C15-PAL	Nunes, NAH (Nurse)	Master's thesis (UNG)	Portal CAPES 2013		Methodological study, descriptive, transversal, involving 104 patients with advanced cancer.	6-10	Level VI
E12	Palliative care in primary health care: new challenges.	Paz, CRP (Nurse)	Master's thesis (EEUSP)	Digital Library of the University of São Paulo, 2013		An exploratory, descriptive research, documental, includes records of 160 patients with advanced chronic-degenerative disease.	6-10	Level VI
E13	Occupational therapy modulating pain in cancer patients under palliative care.	Takeda, N (Occupational Therapist)	Master's thesis (Unesp Botucatu)	Digital Collection of UNESP, 2009		Randomized and controlled, prospective, involving 59 patients with advanced malignancy.	6-10	Level II
E14	Evaluation of quality of life and toxicities in patients	Forones, NM (Physician)	Original article	LILACS Arq Gastroenterol 2006		Descriptive, prospective study, with the	6-10	Level VI

	with colorectal cancer treated with adjuvant chemotherapy based on fluoropirimidin .				participation of 45 patients with diagnosis of colorectal cancer.		
E15	Advanced esophageal neoplasm - still very late diagnosis	Ferrari, AP (Physician)	Original article	LILACS Arq Gastroenterol 2006	Descriptive, prospective study, with 38 patients with advanced cancer.	6-10	Level VI

Figure 1. Characterization of scientific production, regarding the title of the study, lead author and training mode of publication, database, journal and year of publication, methodology, study methodological quality score and level of evidence. João Pessoa-PB, 2013.

Regarding the main authors of the studies expressed in Figure 1 the stand-nurses and doctors, both categories with six publications; nutritionist, dentist and occupational therapist with an output each. The increase in scientific production of nurses on HRQOL shows interest of these professionals in order to get valid and reliable tools that can serve as a framework for planning of patient care and their families, promoting the binomial relief of suffering and comfort in terminally life.

Regarding the study mode, six original articles integrated the corpus of this integrative review, seven dissertations and two doctoral theses. And seven studies LILACS database, electronic library SciELO and five bank theses and dissertations CAPES Portal. In addition to these, there were found two dissertations being an originating bank of theses and dissertations of the Digital Library of the University of São Paulo (USP) and one of the digital collection of the Paulista State University (UNESP).

Original articles that have addressed the issue related to this review were published in nationally circulated periodicals, distributed as follows: one in the Journal of the Brazilian Medical Association, two in the Journal of Pain and in the journal Acta Paulista. Regarding the year of publication it points to the year 2012 and 2006; with three studies in 2013, 2011, 2008 with two publications respectively; and production in 2007, 2009 and 2010. The fact points to a growing concern among health professionals about the importance of HRQOL measurements of patients in palliative care, in order to seek therapeutic strategies and promote a dignified and respectful care to the human being terminally ill.

With respect to the characterization of the design methodology of the publications that have integrated this literature review that identified with respect to interference in the study, eight were die observational and interventional five; two works were the

methodological type. As for handling direct interventions on the investigated object, three surveys were the clinical type, a study was characterized as quasi-experimental and ten studies were not experimental. Furthermore, document has a publication using the secondary data representing the originality of the study. Among these studies, it is highlighted that 11 present level of evidence VI.

With regard to the epidemiological survey profile, eight were descriptive six analytical and controlled; regarding the temporal tracking of the nine studies were longitudinal and prospective cross-six; and all studies were quantitative.

Regarding the participants of the studies analyzed, 13 were patients with some type of advanced cancer receiving palliative care in referral hospitals for cancer treatment, amounting to a total sample of 917, with an average of 83.3 patients. In this universe of study are added 83 patients with cancer participated in two clinical trials. Another study was conducted with 58 patients with advanced cancer and a survey consisted of 160 users of the Basic Health Units Services, able to receive palliative care.

With regard to the research site, stand out eight studies conducted in São Paulo, two in Rio de Janeiro, the other three in Parana, Minas Gerais and Rio Grande do Sul, respectively.

In the analysis of studies using assessment tools HRQOL and CP, as arranged in Figure 2 was possible to identify three thematic categories: generic instruments to assess HRQOL of patients with any disease (E3, E4, E8, E13); Generic tools to evaluate the HRQOL of patients with oncological diseases (E2, E6, E9, E10, E11, E14, E15) and specific instruments to assess HRQOL of patients in palliative care (E1, E5, E11, E7, E10, E12).

With respect to the objectives proposed in this review, there were observed in the analysis of studies using several assessment instruments, among these stand out sociodemographic characteristics, pain assessment, functional assessment, clinical assessment, evaluation of HRQOL among others.

Figure 2 shows the synthesis of the instruments identified in the studies selected for the proposed revision.

Study	Objective	Instrument de QVRS/CP	Other instruments
E1	Profile and identify the prevalence of depression in patients under palliative care in Oncology service of the Faculty of Medicine of ABC.	Palliative Care Quality of Life Instrument) - PQLI	Socio-demographic characterization of Beck Depression inventory
E2	Evaluate the effect of massage therapy on analgesia and the quality of life in patients with cancer pain and bone metastases.	European Organization for Research and Treatment of Cancer - EORTC QLQ-C30 version 3.0	Numerical analog scale for pain
E3	Evaluate the clinical aspects, treatment, quality of life and survival of patients with LPN.	Medical Outcomes Study 36-item Short-Form Health Survey (SF-36)	Saint George´s Respiratory Questionnaire (specific to respiratory disease)
E4	Assessing QOL in women with advanced cancer, treated at a hospital in palliative care, Oncology reference in Brazil.	WHOQOL-BREAF	Sociodemographic and clinical characterization
E5	Analyze, through previously validated questionnaire, as nutritional intervention and the control of symptoms interfered in the quality of life of cancer patients in palliative care.	European Organization for Research and Treatment of Cancer, EORTC QLQ-C15-PAL	Questionnaire for socio-economic assessment Zubrod scale - ECOG
E6	Characterize the orofacial clinical condition of patients with advanced head and neck cancer in palliative care; evaluate the functionality, HRQOL and the effectiveness of a dental care protocol, in control of orofacial pain and complaints, in the quality of life, prognosis and survival of these patients.	Quality of life, the University of Washington - UW-QOL (Version 4.0)	Chart for dental assessment pain visual analogue scale for Functional Performance of Karnofsky scale
E7	Compose the profile of palliative chemotherapy patients answered at an outpatient clinic in Belo Horizonte sociodemographic and clinical characteristics and relations between symptoms, functional capacity and quality of life.	Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-PAL - Version 4).	Sociodemographic and clinical Scale characterization of personal capacity palliative (Palliative Performance Scale) Symptoms experience index
E8	Evaluate the decision-making process and the quality of life of adult patients, Oncology, admitted to palliative care unit	WHOQOL-BREF and WHOQOL-OLD	Performance Scale of Karnofsky (KPS)
E9	Identify the socio-demographic profile and Nosological with head and neck cancer seen in the clinic for palliative care; identify the QOL of those people through consultation of nursing; assess changes in the system of self-care, whereas nursing intervention.	European Organization for Research and Treatment of Cancer, EORTC QLQ C-30 EORTC QLQ H&N-35 (specific module)	Category and evaluation clinic nursing assessment form (SAE)
E10	Perform the translation, cultural adaptation and initial validation of the POS for Brazil (POS-BR)	European Organization for Research and Treatment of Cancer - EORTC QLQ C-30	Performance Scale of Karnofsky (KPS)
E11	Evaluate the psychometric properties of the European Organization for Research and Treatment of Cancer, EORTC QLQ-C15-PAL, to evaluate patients' QOL Brazilians with	POS-BR European Organization for Research and Treatment of Cancer - EORTC QLQ C-30	Karnofsky Performance scale (KPS) demographic Characterization brief Pain Inventory Beck Depression Inventory

advanced cancer.		EORTC QLQ-C15-PAL	
E12	Discuss the incorporation of CP in primary health care (PHC).	Karnofsky Performance scale (KPS)	Socio-demographic characterization Program of dispensing supplies for urinary incontinence/Fecal evaluation scale of functional incapacity of the Spanish Red Cross
E13	Evaluate the results of an occupational therapy program applied to cancer patients under palliative care, with respect to the modulation of pain and improves the symptoms of anxiety and depression and quality of life.	Karnofsky Performance scale (KPS) 12-Item Short-Form Health Survey (SF 12)	Socio-demographic characterization intervention and control Groups of occupational therapy Protocol Visual analogue scale (EVA) opioid consumption assessment hospital anxiety and depression scale (HADS)
E14	Assess in patients with colorectal cancer on chemotherapy with 5-FU and AF, the toxicity of treatment and quality of life.	WHOQOL-BREF	Chemotherapy scheme Mayo Clinic Table of recommendations for acute and subacute toxicity of SKEEL and GANZ clinical and laboratory Assessment
E15	Evaluate the quality of life and the alleviation of dysphagia obtained with different types of treatment offered to patients with advanced esophageal neoplasia.	Karnofsky Performance scale (KPS)	Clinical evaluation of surgical treatment

Figure 2. Presentation of the objectives and instruments of the selected studies. João Pessoa-PB, 2013.

DISCUSSION

♦ Generic instruments for measuring HRQOL of patients with any disease

This category of analysis includes the instruments classified as generic that propose to evaluate the HRQOL of patients with diseases in general. These instruments were used in four studies that have integrated this literature review, described below.

♦ Medical Outcomes Study 36-item Short-Form Health Survey (SF-36)

This instrument was used in a study (E3) held with 52 patients diagnosed with neoplastic pulmonary Lymphangitis, recruited from hospitals in the state of São Paulo-SP, prospective cohort, with application of the SF-36 instrument associated with a specific instrument for patients respiratory disease has been answered by 46 patients. In this study, the author chose not to use all the items of the SF-36, reducing its dimensions to a single value - the index of the SF-36 (ISF) calculated as the average of the items. However, the author makes no description of the facility and/or difficulties in applying the instrument, but also on the reliability of the instrument for patients with advanced cancer.

The Short Form - 36 (SF-36) is a generic health evaluation questionnaire consisting of 36 questions divided into nine areas: physical activity, social activity, limited by physical disability, the emotional capacity limitations, mental health, vitality, pain, perceived health in general and perception of improved

particular problem in health. The score ranges from 0 to 100 and higher score means better health and less pain. This questionnaire was validated in Brazil for patients with rheumatoid arthritis, and later used for evaluation of patients with chronic lung diseases, cardiac, kidney disease, people with ALS, among others.⁸

Some studies that used the SF-36 in patients with cancer, admit it is a useful measure for evaluating the quality of life of patients with lung cancer, has adequate psychometric properties, with good responsiveness, however, proved more sensitive to detect the worsening of quality of life than its improvement.⁹⁻¹⁰

♦ World Health Organization Quality Of Life - WHOQOL-BREAF e World Health Organization Quality Of Life - WHOQOL-OLD

The instrument was used in two studies in the sample of this review. One (E4) was a cross-sectional study involving 277 women with advanced breast cancer, to evaluate the QOL of these women who received care in palliative care in oncological reference hospital in Brazil. In this study, the author reveals that the WHOQOL-BREAF applies well in situations that require participation with lower overhead patient and time constraints.

The second study (E8) that used the WHOQOL-BREAF instrument was also cross-sectional, with the participation of 89 adult patients with advanced cancer without therapeutic possibilities of cure, cancer

treated in hospital in Porto Alegre - RS, in order to evaluate the process of decision making and the quality of life for them. In the assessment of QOL were also used the WHOQOL-OLD and Psychological Moral Development Instrument to assess the ability of decision making of the patient. The author emphasizes the importance of Psychological and Environment domains for assessment of QOL.

Considering the importance of the assessment of QOL, the World Health Organization created the Quality of Life Group (WHOQOL Group) to develop acceptable evaluation measures in an international context, adapted to different cultures, validated and disseminated. Thus was created a tool containing 100 questions - the WHOQOL-100, which includes the physical, psychological, social relationships and environment.¹¹

Later, this group has produced a shortened version of WHOQOL-100, the WHOQOL-Bref, consisting of 26 questions, among which items 1 and 2 focus on the overall quality of life, with responses distributed in Likert scale, 1-5 which, the higher the score, the better the quality of life. The remaining 24 facets comprise four domains: physical, psychological, social relationships and environment. Each domain consists of questions whose scores of responses also vary between 1 and 5.

The WHOQOL-Bref instrument was used in the E14, consisting of 45 patients with colorectal adenocarcinoma and in particular chemotherapy regimen with different cycles. The results indicated a decline in quality of life, characterized by lower mean scores in the physical and social, especially at the beginning of chemotherapy, which may be due to the toxicity of drugs and disease progression.

It is noteworthy that this instrument was validated in Brazil by research that showed good psychometric performance and practicality of its implementation. The version in Portuguese language WHOQOL-Bref has been applied in different samples of cancer patients, whether on an outpatient basis, which is in hospitals, showing satisfactory psychometric performance, good accessibility, with proper understanding and time for answers.¹²

The WHOQOL-OLD is an instrument created by the Quality group of the World Health Organization of Life, considered a complementary tool on QOL in the elderly. It consists of 24 items divided into six facets. Every facet has four items with score values

can fluctuate from 4 to 20. The scores of these six facets can result in an overall score for QOL in the elderly. The high scores represent a high quality of life and lower scores representing a lower quality of life.¹³

The use of questionnaires WHOQOL-BREF and WHOQOL-OLD promoted a more comprehensive assessment of the quality of life of patients, especially important for this last facet of death and dying, sensory abilities, autonomy, past activities, present and future and intimacy (E8).

♦ 12-item Short-Form Health Survey (SF-12)

The SF-12 was used in the E13, in groups of cancer patients in palliative care. The results were satisfactory for the HRQOL of those participating in therapeutic activities. The instrument is an abbreviation of the SF-36 and has been validated to measure physical and mental health status.¹⁴ In a study with adolescents it was predictive of a good standard in QOL related to the physical and mental dimensions.¹⁵

Thus, the SF-12 is a potential tool to assess QOL in the general population, with emphasis on the physical and mental aspects, due to satisfactory levels of sensitivity, reliability, construct validity and the SF-12 questionnaire structure.¹⁶

♦ Generic instruments for assessing HRQOL of patients with oncological disease

This category of analysis will be presented the instruments classified as generic that purport to assess HRQOL of patients with cancer, used in six studies the integrative review, as described below.

European Organization for Research and Treatment of Cancer - EORTC QLQ-C30 version 3.0.

The EORTC QLQ-C30 instrument was found in four studies that have integrated this literature review.

In the first study (E2), the authors evaluated the effect of massage therapy on analgesia and on the QOL of 34 patients with lung cancer, breast or prostate cancer pain and who had bone metastases, allocated in the State of São Paulo. To assess QOL used the EORTC QLQ-C30 instrument, but there has been no discussion about the applicability of the instrument in the study population itself.

The second work (E9) was conducted with 77 patients with head and neck cancer receiving outpatient palliative care and registered in the National Cancer Institute (INCA) in Rio de Janeiro, to evaluate the QOL

of these patients after based nursing consultation the theory of Dorothea Orem. In the assessment of QoL were used the EORTC QLQ-C30 and EORTC specific module H & N35 for head and neck cancer. The author of the study underscores the importance of using instruments mentioned the possibility of identifying aspects that negatively affect the QOL of patients in palliative care, providing subsidies for health care and individualized planning aimed at improving their quality of life.

The EORTC QLQC-30 instrument was used in the third study (E10) that category analysis that aimed to carry out the translation, cultural adaptation and initial validation of a specific instrument for patients in palliative care, the Palliative Outcome Scale - POS for the Brazil (POS-BR). And, while the fourth category (E11) that used the EORTC QLQ-C30 instrument was developed with the objective of evaluating the psychometric properties of the specific module to evaluate the QOL of Brazilian patients in palliative care, the EORTC QLQ-C15-PAL. It should be noted that details on the E10 and E11 studies will be presented later in the third category of analysis of integrative review.

It is noteworthy that the EORTC, Quality of Life Questionnaire (QLQ) is an instrument copyrighted, prepared by the Quality of Life Group created by this organization in 1980, after being recognized as a valid and reliable scale to assess QOL of a wide people with cancer. So far been translated and validated in 81 languages.

It is noteworthy that the latest version of this tool is the EORTC QLQ-C30 Version 3.0, with multidimensional, self-report feature, containing 30 items aimed at assessing patients in the last two weeks, integrating questions about physical functioning, symptoms, side effects treatment, psychological distress, social interaction, sexuality, body image, global health, QOL and satisfaction with medical care, as well as two issues where patients rate their overall health and quality of life. Questions 01-28 are arranged in Likert Scale four points, with answers ranging from no (score value = 1) to very (score value = 4). Questions 29 and 30 also arranged in similar scale, but with seven points, one corresponding to a lousy seven great. The combination of these two scores results in an overall health score.¹⁷⁻⁸

The measurement score of the items varies score from 0 to 100. The highest score of the scale is a higher level of response; namely, a high score for a functional scale is a healthy level of operation; a high score for the state

of global health/QOL represents a high quality of life; However, a high score for symptom scale, represents a high level of symptoms and poorer quality of life.¹⁹

The quality of life group has presented to the scientific community instruments modulated with items specific to certain types of cancer, such as lung, breast, head and neck, colorectal cancer,²⁰⁻³ prostate (EORTC QLQ PR25), ovary (EORTC QLQ OV28), multiple myeloma EORTC QLQ MY20, hepatocellular carcinoma and primary liver cancer (EORTC QLQ HCC18). In addition to these, cervical cancer (EORTC QLQ CX24), brain (EORTC QLQ BN20) and recently, cancer patients in palliative care (EORTC QLQ C15PAL).

The QLQ-H & N35 questionnaire is a specific module for evaluation of patient QOL with head and neck tumors, developed by EORTC, it has been validated in several languages, should apply in addition to the questionnaire core QLQ-C30 from EORTC for evaluation domains global and specific. Its use predominantly in Western countries has shown good validity and reliability. It consists of 30 questions with four possible answers Likert 4-point-five questions with binary answers, type yes or no. It is considered long application because, when used along with the core questionnaire QLQ-C30, 65 questions must be answered in full. The assessment is based on scores of measures ranging from 0 to 100, with the higher the score, the worse the intensity of the problem in the assessed area.²⁴

♦ Quality of life at the University of Washington - UW-QOL (Version 4.0) (01)

The UW-QOL instrument was used in a study (E6) of the sample of this integrative review, which aimed to evaluate the functionality, HRQOL and effectiveness of a protocol of dental care for pain control and QOL of 75 patients with cancer Head and neck and exclusively in palliative care, held at the Hospital of the Medical School of São Paulo - SP. Several other instruments for evaluation of the clinical conditions of the patients were used. The author of the study makes no mention regarding the applicability of the tool to participants.

The questionnaire from the University of Washington was created in 1990 by *Ernest A. Weymuller Jr*, from the perspective of a specific instrument for patients with head and neck cancer, containing nine questions (or domains). In 2001, a fourth version was defined since added two emotional domains (mood and anxiety). Version 4.0 has been

validated for the Portuguese language and aims to assess important aspects of the patient in the last seven days. It was composed of 12 questions related to the specific functions of the head and neck (appearance, swallowing, chewing, talking, shoulder, taste, and saliva), activity, recreation, pain, mood and anxiety.

In that instrument, each issue contains three to five response categories with scores ranging from 0 (worst) to 100 (best), and the total score, which is the average of the 12 domains. It also consisting of three general questions about their overall quality of life and health-related and an open question that gives opportunity to the individual to report his comments. It has been considered a short instrument, easy to understand and quick to perform, using an average of five minutes to answer the questionnaire. The psychometric validation procedure was obtained reaching up significant amounts of reproducibility and constructed validity, and then recognized as an instrument adapted and validated in Portuguese.²⁵

◆ Specific instruments for measuring HRQOL of patients in palliative care

In this category of analysis will be presented to follow the instruments classified as specific to assess HRQOL of patients in palliative care, used in five studies the integrative review.

◆ Palliative Care Quality of Life Instrument - PQLI

The PQLI instrument was used in only one study (E1) of the sample that RIL, aiming to profile and identify the prevalence of depression in 62 patients under palliative care, assisted at the Department of Oncology, Faculty of Medicine of ABC Paulista, São Paulo - SP and from their results suggest conditions for improving the QOL of these patients. This was an observational and prospective cross-sectional study. According to the author, because the instrument has not yet been validated for the Portuguese language, its use aimed to qualitatively chart a patient's profile.

The *Palliative Care Quality of Life Instrument* (PQLI) refers to an instrument developed in Greece, consisting of 28 items; of which one is open to assess the overall quality of life of patients in palliative care and the other consist of closed answers on a gradual scale three items. Integrate the functionality of dimensions, symptoms, choice of treatment, psychological and overall quality of life. To check its psychometric properties, the instrument was applied to a

sample of 120 patients diagnosed with terminal cancer, demonstrating good validity, reliability and sensitivity, according to the study authors.²⁶ It is noteworthy that, to date, the instrument was not validated for the Portuguese language.

◆ European Organization for Research and Treatment of Cancer, EORTC QLQ-C15-PAL

The EORTC QLQ C-15 instrument-PAL was found in two studies members of this category of analysis. The first study (E5) analyzed, this was a prospective longitudinal study, which aimed to analyze the nutritional intervention and the control of symptoms interfere in the QoL of 50 patients with advanced cancer in palliative care. However, in this study there is no description regarding the application of the study.

The second work (E11) aimed to evaluate the psychometric properties of the specific module to evaluate the QOL of Brazilian patients in palliative care, the EORTC QLQ-C15-PAL. This is a methodological study, involving 104 patients, diagnosed with cancer and metastases. Other instruments such as *Karnofsky Performance Status Scale*, Beck Depression Inventory and Brief Pain Inventory, were also used in this study. The author points out that the EORTC QLQ-C30 has a wide application to assess HRQOL of patients specifically with cancer in general, but many of their items are inappropriate for patients in palliative care, as well as the instrument extension, making it impractical for application these patients.

The EORTC QLQ-C15-PAL is a specific tool to assess QoL of cancer patients in palliative care, drafted in English, validated and translated into Portuguese in Brazil by itself EORTC group. Its psychometric properties have been validated in the country in 2013. The instrument consists of 14 questions related to the patient's QOL during the last week, with questions about activities, autonomy, and shortness of breath, difficulty sleeping, weakness, fatigue, appetite, nausea, constipation, pain, depression, overall quality of life and how much pain interferes in carrying out daily activities.²⁷ Thus, the instrument has adequate psychometric properties to assess the HRQOL of cancer patients and palliative care.

◆ Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-PAL - Version 4)

The FACIT-PAL instrument, version 4, was used in a cross-sectional study (E7), conducted with the participation of 70 cancer

patients who underwent palliative chemotherapy in a hospital in Belo Horizonte - MG, in order to compose the profile of these patients as sociodemographic and clinical characteristics and relationships between symptoms, functional capacity, quality of life. These assessments were used other instruments as its specificity.

This instrument is constituted as a subscale of palliative care developed from the *Functional Assessment of Chronic Illness Therapy - G* (FACT-G), generic, multidimensional measure to assess HRQOL. To check its psychometric properties in the US, 256 people diagnosed with advanced cancer completed the 46 items of the instrument, and 27 of the FACT-G and 19 FACIT-PAL. The study authors concluded that it is a valid and reliable instrument for assessing the QOL of patients in palliative care.²⁸

Functional assessment of QOL of cancer patients in palliative care indicates the need for understanding of the preservation or maintenance of functional capacity and better control the patient's symptoms, by the members of the therapeutic team, favoring the better HRQOL for patients and their family.

◆ Palliative Outcome Scale - POS-Br

It is a cross-sectional study (E10), which aimed to develop the initial validation for the Portuguese of Brazil, Palliative Outcome Scale - POS-BR, for cancer patients in palliative care, with the participation of 18 professionals health and 68 patients with advanced cancer receiving such care. In the study, the author briefly describes the characteristics and properties of the EORTC QLQ-C30 scale, noting that it is a specific tool to assess QOL of patients with cancer and in various evolution stages of the disease and justifies its use for support the validation of POS, because it is a well-established scale and validity in several countries.

The POS instrument was developed by Irene Higginson of the Department of Palliative Care and Policy at King's College London, described as a specific instrument for the assessment of HRQOL in patients receiving palliative care, and to evaluate the results of palliative care. Therefore, it consists of two versions, one intended for patient self and a proxy for the health professional. It is recognized as easy to understand and apply, averaging ten minutes in execution, containing ten items that address the main areas of palliative care, involving physical, social, psychological and spiritual life of the people and the provision

of palliative care, time window of three days prior to the application.²⁹ The total score of the POS is obtained by adding the points of the ten issues, both for the team and for patients and may have a zero variation (better HRQOL) to forty points (worse HRQOL).

◆ Karnofsky Performance Scale - KPS

The Karnofsky Performance Scale was used in the studies (E12, E15). It consists of an elaborate instrument initially to facilitate the identification of patients with cancer likely to palliative care. This scale is useful for assessing the performance of patients as their basic activities of life and enables the planning directed to palliative care and the evaluation of the clinical outcome of patients.

In the E12, the results of applying the KPS signaled the need for palliative care for patients with high level of health care dependence and self-care, due to the involvement of various diseases, especially neurological, vascular and chronic degenerative diseases.

Regarding the study (E15) were evaluated 38 advanced neoplasia in patients with esophageal and who underwent palliative surgical interventions and nutritional support. The instrument was used by oncologists as an indirect measure reflecting the need for assistance in accordance with the clinical conditions that interfere with the QOL of patients.

It is known that the diversity of instruments aims to consolidate some subjective perceptions of QOL from objective data, enabling a better interpretation for health research.¹⁶

CONCLUSION

This integrative review identified the use of instruments characterized as generic nature in HRQOL assessment of patients with any disease; characterized as generic instruments to evaluate the HRQOL of patients with neoplastic disease; and tools to evaluate the HRQOL of patients with oncological diseases in palliative care.

It was observed that, with the increase of palliative care in assisting the patient with cancer without curative therapeutic possibilities, it has been growing concern among health professionals to evaluate the HRQOL of these people.

In this sense, it should be emphasized methodological studies for translation, cultural adaptation and validation of specific tools for palliative care, which have recently been addressed by the scientific community, as shown by the studies analyzed, such as the

EORTC QLQ C15-PAL, the FACIT-PAL and the POS-BR, which involved about 350 cancer patients and palliative care; and the PQLI and the UW-QOL, although they have not yet been validated for the Portuguese language in Brazil.

It was also found that the instruments to be applied in patients under palliative care, have reduced the number of items seen which, if considered exhaustive, may hinder the fulfillment by the participants.

The analysis of studies involving HRQOL assessment tools showed that in cancer patients with palliative care indication is recommended to use specific instruments containing a number of relatively small issues, among 11-28 items and to consider the clinical condition of patient avoiding physical and emotional stress during the interview. Furthermore, they consider issues that could signal detection or symptoms that may affect QOL of patients, emphasizing their physical and emotional limitations.

It is noteworthy that the study has some limitations, including the inability to generalize the results, since this is a review study with a small number of publications that refer to the subject investigated. It is suggested that further studies be conducted using the methodology of systematic review with a view to seeking stronger evidence regarding the properties of HRQOL assessment tools for cancer patients in palliative care.

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