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ORIGINAL ARTICLE

VALIDATION OF INSTRUMENT FOR REGISTRATION OF SIGNS AND SYMPTOMS BY THE CAREGIVER IN HOME PALLIATIVE CARE[1]

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ABSTRACT

Objectives: to develop and validate an instrument for recording signs and symptoms by caregivers of patients in palliative cancer care at home. **Method:** methodological study with two stages: 1) integrative review of the literature for the generation of items and content composition through synthesis of evidence, setting up the "Patient Symptoms Record"; 2) content validation with 11 specialists in home palliative cancer care, who answered a questionnaire containing the Likert scale in the months of June and July 2020. We performed a preliminary test of the instrument with 15 caregivers. In the analysis, the content validity index > 80% was considered, calculated in three groups: header; signs and symptoms; design — and overall instrument. **Results:** after three rounds of evaluation, the content validation rates achieved for the three groups and for the overall instrument were respectively: 95.5%, 95.58%, 86.5% and 92.52%. Cronbach's alpha coefficient was 0.925. **Conclusion:** the content validity of the Patient Symptoms Record was verified by designing a new tool for palliative cancer care. Its application represents a contribution to effective communication between caregivers and the health team, with the potential to directly impact the quality of life of patients and families/caregivers.

Keywords: Home care. Palliative care. Validation study. Oncology nursing.

INTRODUCTION

Among chronic non-communicable diseases, cancer is one of the main public health problems in the world, responsible for millions of deaths annually(1). In 2020, according to estimates by the Global Cancer Observatory (Globocan), there were 19.3 million new cases of cancer worldwide(2). Faced with the diagnosis of this disease that threatens life and causes suffering, it is necessary to apply palliative care with the main objective of controlling the signs and symptoms arising from the disease and/or its treatments, in an integral way, based on a multiprofessional approach(3). Such care should be able to be provided wherever the person needs or wishes to be, so it is critical that health services are able to provide home care (HC).

This distinction of environment for the provision of palliative care, that is, that emphasizes the home context, meets its precepts related to the promotion of quality of life and respect for human dignity, with emphasis on palliative care in the final stages of life. In view of the main needs derived from serious diseases, such as cancer, palliative care is defined by the World Health Organization (WHO) as an approach that improves the quality of life of patients and their families in the face of problems related to life-threatening diseases, and this approach is done through the early identification, evaluation and treatment of pain and other health, physical, psychosocial and spiritual needs(4).

Studies show that, given the incurability and progression of serious diseases, a growing portion of the population prefers to receive quality care at home, which is the place chosen

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for death. However, the lack of structure of both health services and families, including qualified human resources and the presence of a capable caregiver, can make this practice unfeasible and direct the event of death to the hospital, which is fraught with greater suffering(5-8). This weakens health systems and threatens their economic sustainability. Thus, important changes in health care have sought to prioritize the expansion of services towards the patient's home(7), an environment that enables the reduction of the use of emergencies, hospitalizations, and favors the continuity of care(8).

There are different models of practice that integrate palliative care in the context of the community, using resources from Primary Health Care and hospital resources, such as those from home internment programs, which differ in the capacity to assist the most complex cases based on the mode of integration of generalist palliative care, or palliative approaches, with specialized palliative care(5-6,9). These can be accessible in the main types of care, that is, home, outpatient or hospital, applicable in each case according to the individual needs of patients and families.

In this study, based on the authors' experience and the practice model of the investigated scenario, HC is directed to people with incurable cancer and with clinical conditions that prevent them from attending the outpatient clinic. Thus, they receive a multiprofessional team at home, with an average interval of five days between consultations, depending on the need of each case. The fundamental criterion for referral of the patient to this modality is the presence of a capable caregiver, that is, who guarantees the continuity of home care in the interval between consultations, based on the guidelines received and telephone support to manage, mainly, any changes in signs and symptoms that commonly occur in advanced cancer. At this juncture, caregiver is the person who directly provides care to the patient at home on a continuous or regular basis, whether family or not(6).

We emphasize, supported by the authors' experience and by scientific evidence, that the control of signs and symptoms of patients with advanced cancer at home is a challenge(10). To overcome this, it is essential to apply strategies that facilitate the management of care, among which is the training of the caregiver to recognize and know how to communicate the changes of these signs and symptoms. The agility and sensitivity with which this communication happens(11) direct the response of the doctor and/or nurse in a timely manner, determine the good result of the therapeutic conduct in a unique way(12) and favor the confidence and safety of the caregiver and the patient to remain at

home.

The communication of changes in signs and symptoms, mainly professional-professional, currently has attributes of different tools and scales that help the prognosis and decision-making in palliative care, such as the Edmonton Symptom Assessment System(ESAS), which evaluates and monitors nine physical and psychological symptoms of the patient(13).

However, we believe that professional-caregiver communication in HC can be facilitated with the proposal of an analogous instrument to record the patient's signs and symptoms in the interval between consultations, with the differential of placing the caregiver as the target audience. Thus, the elaboration of the instrument based on this hypothesis was given in response to the following guiding question: “What information should compose an instrument for daily recording, by the caregiver, of the signs and symptoms manifested by the patient with advanced cancer at home?” Therefore, we aimed to develop and validate an instrument for recording signs and symptoms by caregivers of patients in palliative cancer care at home.

METHOD

Methodological study developed in two stages(14), namely: 1) elaboration of the instrument; and 2) content evaluation by health specialists and caregivers. In the first stage, the items were collected to compose the content of the instrument through the synthesis of evidence from the integrative literature review (ILR), published in “Signs and symptoms manifested by patients in palliative cancer care in home care: an integrative review”(10), and the first prototype of the instrument entitled “Patient Symptoms Record” (PSR) was assembled.

For the assembly of the instrument prototype, we decided to organize it into sections. The first section of the header was structured using general information considered necessary to identify the patient. The second section consisted of columns containing the signs and symptoms identified in the evidence of ILR(10), with the addition of representative images for each of them, prepared by the first author. Finally, the third section consisted of the area of capturing answers, "yes" or "no", objectively, aiming to make the filling feasible and little influenced by the sociodemographic characteristics of caregivers.

Subsequently, a semi-structured questionnaire was created, divided into two parts. The first was to characterize the profile of specialists, considering: sex, age, education and professional performance, time of graduation, higher academic degree, scientific production, area of scientific production, time of experience in oncology, palliative care and HC. The second part contained the items of the instrument for the specialists' assessment of relevance, conciseness, accuracy, relevance and clarity, using a four-point Likert scale with the options: Strongly agree, Agree, Disagree and Partially disagree. For the participation of caregivers in this stage of evaluation of the instrument content, preliminary tests were performed with a small sample, which represented about 10% of patients under follow-up in HC during the data collection period.

In the second stage of the study, data collection occurred in the months between June and July 2020, at the HC service of a federal public hospital, specialized in palliative cancer care, located in Rio de Janeiro, Brazil. The choice of this scenario was due to the fact that it is considered a national reference in palliative cancer care, having a structured and organized HC service, with the necessary infrastructure for its operationalization and significant quantity of home consultations. In 2019, this HC service carried out an average of 777 consultations per month, totaling 9,327 consultations in the year. In addition, the hospital has a stimulating environment for teaching and research, dedicated specifically to palliative care, as well as is committed to the training of new palliative professionals and the promotion of networking to expand palliative care at the national level.

Health professionals with ties to the study scenario who reached a minimum of 5 points based on the Fehring criteria (15), adapted to the study context, were considered to compose the group of specialists, among them: having clinical practice in the topic addressed (1 point per year/with a maximum of 3 points); having a master's degree in any health area (2 points); having a master's degree with a dissertation in the oncology area and/or in palliative care (3 points); having published a scientific article, book or chapter in the oncology area and/or in palliative care and/or home care (2 points); having training (specialization) in the oncology area and/or in palliative care (2 points). Professionals who had not worked in HC for more than two years from the beginning of the data collection period were excluded.

The caregivers selected to perform the preliminary tests were those in whom the HC had been established for at least 15 days, considering data available at the service on the mean length of stay of patients of 47 days in the HC; aged 18 years or more; with a basic level of education that would enable them to read and understand the instrument and the guidelines for its completion. Caregivers of patients with imminent death in the next 24 hours or who were overwhelmed and emotionally very shaken were excluded.

To define the minimum necessary sample of specialists, the statistical formula applicable to validation studies was adopted, $n = Za2 * P * (1 - P)/e2$, in which "Za" refers to the confidence level adopted, "P" represents the expected proportion of specialists indicating the adequacy of each item, and "e" symbolizes the difference of acceptable proportion in relation to what would be expected(16).

The specialists and caregivers were intentionally invited by the first author, through individual personal contact, in the study setting or at the home consultation, respectively. For specialists, the deadline for returning the evaluation of the content was 14 days. The document could be returned by hand to the first author or left in a folder identified in the HC sector, allowing greater convenience to the participant.

For caregivers, the instrument version after the specialists' validation rounds was presented at the end of the home consultation by the previously trained HC nurse; in the subsequent consultation, this completed instrument was collected and delivered to the authors for analysis and preparation of the final version of the instrument presented in this study. At the same time of this subsequent consultation, the HC nurse established an informal conversation with the caregiver seeking to perceive facilities or difficulties in filling, as well as the potential for acceptance for their inclusion in the caregiver's daily care routine.

The statistical treatment of the data occurred through the Microsoft Excel® program and the IBM SPSS® statistical software platform — the latter, specifically to calculate Cronbach's alpha coefficient. It is noteworthy that the qualitative data from the justifications of the specialists were grouped by comparison and quantification of the themes, confirmed by the data from the observation of the instruments completed by the caregivers and the reports transmitted by the nurses of the HC.

Descriptive statistics were applied to the profile characterization data of the specialists with simple frequency and percentage. To analyze the proportion of specialists agreeing on the elements of the instrument's prototype, the Content Validity Index (CVI) was used, considering CVI > 80% for each item to be considered validated (17). The calculation of the CVI of the items was based on the number of specialists who evaluated the item as “3” (Agree) or “4” (Strongly agree), dividing the result by the total number of specialists. The overall CVI of the instrument was obtained by summing the CVI of the three groups (header, signs and symptoms, and design) divided by three.

Items assessed as 1 (Disagree) or 2 (Partially Disagree) have been revised, replaced or deleted. The data obtained from the justifications of these scores, as well as from the observation of the completion by the caregivers and their reports on this experience, were grouped by the semantic criterion and analyzed in contrast to the literature, to decide on the maintenance, exclusion or review of each item.

The Cronbach's alpha coefficient was also calculated to evaluate the internal consistency of the instrument and, therefore, its reliability, considering satisfactory when $\alpha \geq 0.70$, being classified as high ($0.75 < \alpha \leq 0.90$ and very high reliability $\alpha \geq 0.90$ (18).

This study respected the precepts of Resolutions No. 466/12 and No. 580/18 of the National Health Council; it was submitted to the Research Ethics Committee of the Anna Nery Nursing School/São Francisco de Assis Health Care Institute, the Federal University of Rio de Janeiro (CEP-EEAN/HESFA/UFRJ) and the Research Ethics Committee of the José Alencar Gomes da Silva National Cancer Institute (CEP-INCA), with approval under respective CAAE 23266719.4.0000.5238 and 23266719.4.3001.5274. All participants signed the Informed Consent, guaranteeing their anonymity.

RESULTS

With the results of the ILR(10), the first stage of the study was concluded. In the second stage, 12 health professionals participated initially. However, one of them returned the questionnaire with several items without completion in the first round of data collection, characterizing possible impairment in the analysis, and was excluded from the study. Fifteen caregivers performed the preliminary test of the instrument.

Regarding the characterization of the 11 specialists, 9 were female and 3 were male. The predominant age was between 36 and 45 years (45%). Regarding the professional category, the group consisted of six nurses (55%), two physical therapists (18%), two physicians (18%) and one psychologist (9%). Regarding the time of training, there was a predominance of specialists with more than ten years of academic training (91%); eight professionals had *Lato Sensu* specialization (73%) and three *Stricto Sensu* specialization (27%).

About the professional performance, nine specialists worked in the area of oncology and in palliative care for a period equal to or greater than ten years (82%). Regarding the duration of work in HC, one had a period equal to or greater than 10 years (9%), four between 7 and 9 years (36%), five between 4 and 6 years (45%) and one between 1 and 3 years (9%). Ten of the specialists claimed to have scientific production (publication of scientific article and/or books), whose main themes were: oncology (4); palliative care (8) and/or HC (3).

Three rounds of evaluation by the specialists were necessary to validate the content of the PSR instrument. It is noteworthy that, since the first round of evaluation, despite the reach of the CVI above 80%, upon suggestion to change any item even if by only one expert, it was decided to carry out careful analysis and adjustments when considered relevant for improvement. Regarding the observation of the instruments, we identified completion of all sections by the caregivers, without apparent difficulty and, among the reports, we observed potential for acceptance of the instrument in the daily care routine by the caregiver. The evaluations of these caregivers did not indicate additional adjustments in the PSR instrument.

Table 1. Content Validity Index by PSR group in the three evaluation rounds — Rio de Janeiro, Brazil, 2020

<table>
<tr><th colspan="6">DESIGN EVALUATION</th></tr>
<tr><td>Evaluation round</td><td>Evaluation round</td><td colspan="2">Evaluation round</td><td>Evaluation round</td><td>Número de itens</td></tr>
<tr><td>1st</td><td>1st</td><td colspan="2">1st</td><td>1st</td><td>64%</td></tr>
<tr><td>2nd</td><td>2nd</td><td colspan="2">2nd</td><td>2nd</td><td>64%</td></tr>
<tr><td>3rd</td><td>3rd</td><td colspan="2">3rd</td><td>3rd</td><td>64%</td></tr>
<tr><td colspan="4">Total group CVI*</td><td colspan="2">Total group CVI*</td></tr>
<tr><th colspan="6">HEADER EVALUATION</th></tr>
<tr><td>Evaluation round</td><td>Evaluation round</td><td colspan="2">Evaluation round</td><td>Evaluation round</td><td>Precisão do item</td></tr>
<tr><td>1st</td><td>1st</td><td colspan="2">1st</td><td>1st</td><td>91%</td></tr>
<tr><td>2nd</td><td>2nd</td><td colspan="2">2nd</td><td>2nd</td><td>91%</td></tr>
<tr><td>3rd</td><td>3rd</td><td colspan="2">3rd</td><td>3rd</td><td>91%</td></tr>
<tr><td colspan="4">Total group CVI</td><td colspan="2">Total group CVI</td></tr>
<tr><th colspan="6">EVALUATION OF ITEMS THAT CONTEMPLATE SIGNS AND SYMPTOMS</th></tr>
<tr><td>Evaluation round</td><td>Evaluation round</td><td>Evaluation round</td><td>Evaluation round</td><td>Precisão do item</td><td>Representatividade da imagem</td></tr>
<tr><td>1st</td><td>1st</td><td>1st</td><td>1st</td><td>91,81%</td><td>77%</td></tr>
<tr><td>2nd</td><td>2nd</td><td>2nd</td><td>2nd</td><td>91,81%</td><td>82,81%</td></tr>
<tr><td>3rd</td><td>3rd</td><td>3rd</td><td>3rd</td><td>91,81%</td><td>94,27%</td></tr>
<tr><td colspan="4">Total group CVI</td><td colspan="2">Total group CVI</td></tr>
<tr><td colspan="4">Total CVI of PSR**</td><td colspan="2">Total CVI of PSR**</td></tr>
</table>

* CVI - Content Validation Index; ** PSR - Patient Symptoms Record.

In the first round, nine items reached validation consensus among specislists with CVI above 80%, comprising: in the evaluation of the design – “logic of the organization of items”; in the evaluation of the header – “clarity and conciseness of title”, “item relevance”, “item conciseness” and “item accuracy”; in the evaluation of the items that contemplate the signs and symptoms – “clarity and conciseness of title”, “item relevance”, “item conciseness” and “item precision”.

The synthesis of the specialists' suggestions included: changing the title, increasing the size of the letter, adding items, adding a descriptive section "Others", reviewing the structures/graphic design of the images representing the signs and symptoms and changing the item referring to the location of the patient's home in the header. After analysis, all changes were considered relevant and met, so that we proceeded to the second round of evaluation.

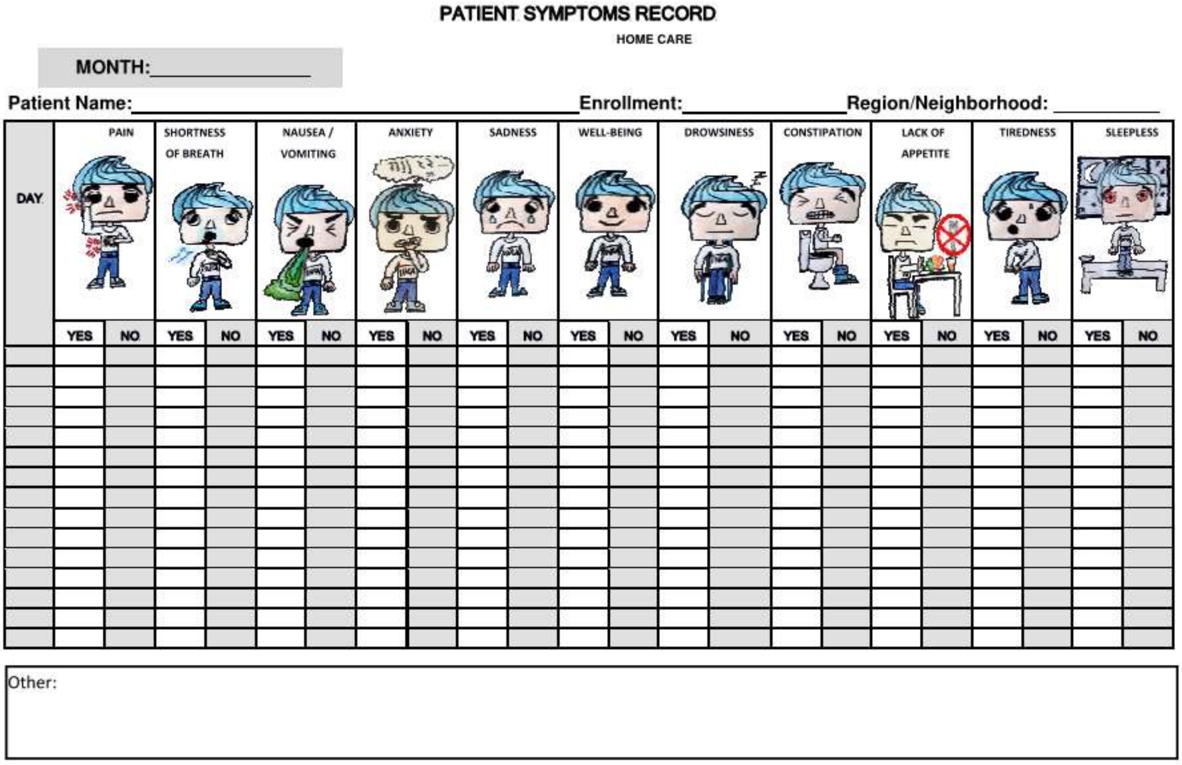
In the second round of evaluation, 12 items reached validation consensus among specialists with CVI above 80%, comprising: in the evaluation of the design – "clarity and conciseness of title", "logic of the organization of items" and "text size"; in the evaluation of the header – "clarity and conciseness of title", "item relevance", "item conciseness" and "item accuracy"; in the evaluation of the items that contemplate the signs and symptoms – "clarity and conciseness of title", "item relevance", "item conciseness", "item accuracy" and "representativeness of image".

The synthesis of specialists' suggestions covered in the second round: new title change, reduction of header letter size and review of structures/graphic design of representative images of signs and symptoms.After analysis, all changes were considered relevant and met, moving on to the third round of evaluation.

In the third round of evaluation, the CVI results remained the same, exception the item "image representativeness", in the evaluation that contemplates the signs and symptoms, which increased from 82.81% to 94.27% after changes according to the suggestions.

It is noteworthy that the item "number of items", of the design evaluation group, remained with a CVI of 64% in all evaluation rounds. This is due to the disagreement between increasing or reducing the number of signs and symptoms covered in the instrument. After careful analysis, it was decided to maintain the quantity according to most specialists, which did not affect the overall CVI of the PSR instrument, which reached 92.52%.

Regarding Cronbach's alpha test, the result occurred after applying the data generated in the Microsoft Excel® program and in the IBM SPSS® statistical software platform, resulting in $\alpha = 0.925$.



PATIENT SYMPTOMS RECORD

HOME CARE

MONTH:______________

Patient Name:________________________________ Enrollment:____________ Region/Neighborhood: __________

DAY	PAIN		SHORTNESS OF BREATH		NAUSEA / VOMITING		ANXIETY		SADNESS		WELL-BEING		DROWSINESS		CONSTIPATION		LACK OF APPETITE		TIREDNESS		SLEEPLESS	
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO

Other:

Figure 1. Final version of the instrument for daily registration of caregivers.

From the final version of the constituted PSR, it is worth describing that, in the section entitled "header", the title of the instrument is included followed by the area for registration of the current month. Soon after, the identification part of the patient follows, where there is a place to fill in the name, registration number and region/neighborhood of residence. This last item refers to a division of patient groups by geographical areas according to the household address, necessary for logistical planning.

It is important to mention that the delimitation of the neighborhoods guides the appointment schedule according to the itinerary to be traveled, saving time for the professional to travel, since the time for patient care added to the time of travel in HC can impact the service.

The second section contemplates 11 signs and symptoms distributed in columns in which each is associated with a representative image. The third section contains lines to fill in the days sequentially. The marking of answers is objectively ("yes" or "no"), referring to the presentation or not of the signs and symptoms on the corresponding date.

At the end of the instrument, after the main table, there is a space for free registration by the caregiver with the title “Others”, which, in the observation of the completed instruments, we perceive the expression of other symptoms, such as the odor in the wound and the presence of pressure injuries. Among the most reported signs and symptoms, in descending order, we highlight: pain, drowsiness, shortness of breath, lack of appetite and vomiting.

DISCUSSION

The first stage of the study, in which the ILR (10) was performed, allowed the identification of the main signs and symptoms presented by patients in palliative cancer care in HC, generating information to compose the content of the instrument prototype for this study. It is noteworthy that the proposal to elaborate this instrument meets the premise that caregivers need assistance and guidance both on the evolution of the disease and on the necessary care to be offered(19). In this sense, health professionals should be able to communicate effectively with caregivers to achieve care goals.

Regarding the second stage of the study, the validation of the instrument by the specialists obtained global CVI of 92.52% and Cronbach's alpha coefficient of 0.925, confirming the validation of its content and very high level of reliability, compared to studies involving elaboration and validation of instruments(17-18,20-21). We emphasize the importance of the space called "Others", since, even in a small sample of caregivers for the preliminary test, the complexity of the clinical profile of patients and their individualities require singular attention for the management of cases and control of signs and symptoms.

In home services with availability of telephone contact for guidance, as in the study scenario, it is possible to point out needs based on the identification of the presence and frequency of signs and symptoms that generate discomfort and make it difficult for the patient to stay at home. Consultations by telephone allows the adoption of measures early, as it facilitates the evaluation and management of signs and symptoms at home, configuring a strategy that benefits cancer patients in palliative care by reducing the demand for emergency services and hospitalizations(22).

From this perspective, the PSR proposes to assist caregivers and health professionals in monitoring the clinical status of patients in palliative care at home, allowing them to obtain more complete information to identify real needs. Communication is paramount for health care, especially with the patient who no longer benefits from disease-modifying treatments. In palliative care, good communication is essential for prevention and relief of signs and symptoms, which requires efficiency in the coordination of the care process(7).

It is known that, among the reasons that can lead cancer patients in home palliative care to attend the emergency sector, is the inadequate control of symptoms(24). In this sense, the use of the PSR aims to facilitate communication between caregivers and health professionals; thus, it reduces the volume of unstructured and disjointed information in relation to care and provides the opportunity for proper management of signs and symptoms at home.

In addition, it should be considered that many cancer patients in low- and middle-income countries receive a late diagnosis of the disease, increasing the possibility of intense suffering associated with pain, respiratory and gastrointestinal problems, loss of consciousness, among others(23). With the progression of the disease and the proximity of death, adequate control of the patients' symptoms should be tried at the place of their preference, which is usually the home; therefore, avoiding emergency care is the will of many patients because they make the relationship between suffering and frequent need for hospitalization(22).

Within the scope of HC, a partnership between health professionals and caregivers is essential, enabling the management of care in a shared way, through clear dialogues and respect for decisions. Patient-centered communication and shared decision-making at the end of life are a critical part of care delivery; with this in mind, assessment of practice against standards can inform quality improvement initiatives (24).

In the understanding that improving health by avoiding suffering is an essential component when dealing with high-quality health systems (25), the importance that should be given to communication is emphasized, considered an essential element in care, but at the same time a great challenge(19).

It should be noted that findings of the ILR (10) highlight the application of the Edmonton Symptom Assessment System (ESAS) instrumentas a tool to guide health professionals in care planning, initially composed of eight visual analog scales from 0 to 100 mm in order to indicate intensity of pain, activity, nausea, depression, anxiety, drowsiness, appetite and sense of well-being(26). It is worth notingthat, since its elaboration in 1991, ESAS has been validated and translated into more than 20 languages, including Brazilian Portuguese, and also upgrading with new editions. However, some limitations pointed out were: its application makes assessment focusing on the intensity of symptoms; some items are not well defined(26); and there is no direct favor of professional-caregiver communication.

The proposed PSR differs by highlighting the caregiver as a target audience for its completion, contemplating the marking of objective answers, the choice of an easy-to-understand written language, as well as the use of representative images associated with each of the signs and symptoms. This configuration aims to facilitate the understanding/completion by caregivers of different educational levels and by those with visual difficulty, contributing to the adequate completion and consequently to the effective communication between caregivers and HC professionals. This allows us to identify the frequency of the main signs and symptoms presented by patients in palliative cancer care. Images can be used to demonstrate and explain procedures, elucidate ideas and thus facilitate the natural fluidity of information, allowing to guide the reading of the instrument as a whole(27).

The guidance of the practice of health professionals responsible for consultations in HC programs in palliative cancer care occurs based on the identification of the main signs and symptoms manifested by patients at home(10). In view of the above, the PSR will enable the improvement of health care management, since the systematized information of signs and symptoms manifested by the patient can serve as a basis for defining intervals of consultations, indication of care by a certain professional category and priority interventions. Consequently, it will allow adapting the multiprofessional work process in HC, especially of the nursing team.

The limitations of the study involve the performance of validation in only one hospital that treats patients in palliative care, as well as the preliminary test with a small sample, which may impair the generalization of results to other institutions.

CONCLUSION

The development of the study followed strict recommendations according to the scientific literature, following the steps to verify the validity of the content. The evaluation of psychometric properties occurred through the calculation of CVI, with three rounds of data collection. In addition, we counted on the participation of caregivers in the preliminary test, which did not indicate additional adjustments in the instrument and pointed to its good acceptance in the daily care routines with patients at home, in alignment with the performance of the multidisciplinary team of specialized palliative care.

The content validity of the instrument was verified in a clear, precise, concise, relevant and pertinent way in its items, in line with the study objective. In this understanding, the application of the “Patient Symptoms Record” in the practice of home care in palliative cancer care has the potential to contribute to effective communication between caregivers and health professionals. It serves to monitor the clinical status of the patient, enabling greater agility in the actions that are necessary and, consequently, for the proper management of signs and symptoms at home, aiming to contribute to the quality of life of patients and families/caregivers.

However, it should be emphasized the need for a next phase of the study for the actual application of the instrument in a representative sample. For this, we consider essential to develop an experimental study with randomization of the sample so that it is possible to evaluate the effects of the intervention to introduce in practice the use of the instrument for "Patient Symptoms Record".

VALIDAÇÃO DE INSTRUMENTO PARA REGISTRO DE SINAIS E SINTOMAS PELO CUIDADOR NO CUIDADO PALIATIVO DOMICILIAR

RESUMO

Objetivos:elaborar e validar um instrumento para registro de sinais e sintomas por cuidador dedoentes em cuidados paliativos oncológicos nodomicílio. **Método:** estudo metodológico com duas etapas: 1) revisão integrativa da literatura para a geração de itens e composição do conteúdo mediante síntese de evidências, montando o “Registro de Sintomas do Paciente”; 2) validação de conteúdo com 11 especialistas em assistência domiciliar de cuidados paliativos oncológicos, que responderam,nos meses de junho e julho de 2020, questionário contendo escala Likert.Realizamos teste preliminar do instrumento com 15 cuidadores. Na análise, foi considerado o índice de validade de conteúdo >80%, calculado em três grupos: cabeçalho; sinais e sintomas; design— e global do instrumento. **Resultados:** após três rodadas de avaliação, os índices de validação de conteúdo alcançadospara os três grupose para o globaldo instrumento foram respectivamente: 95,5%, 95,58%, 86,5% e 92,52%. O coeficiente alfa de Cronbach foi 0,925. **Conclusão:** a validade de conteúdo do Registro de Sintomas do Paciente foi verificada concebendo nova ferramenta para os cuidados paliativos oncológicos.Sua aplicação representa contribuição para a comunicação efetiva entre cuidadores e equipe de saúde, com potencial para impactar diretamente a qualidade de vida dos doentes e familiares.

Palavras-chave: Assistência domiciliar. Cuidados paliativos. Estudos de validação. Enfermagem oncológica.

VALIDACIÓN DE INSTRUMENTOS PARA EL REGISTRO DE SEÑALES Y SÍNTOMAS POR PARTE DEL CUIDADOR EN CUIDADOS PALIATIVOS DOMICILIARIOS

RESUMEN

Objetivos: elaborar y validar un instrumento para registro de señales y síntomas por cuidador de pacientes en cuidados paliativos oncológicos en el domicilio. **Método**: estudio metodológico con dos etapas: 1) revisión integradora de la literatura para la generación de ítems y composición del contenido mediante síntesis de evidencias, elaborando el "Registro de Síntomas del Paciente"; 2) validación de contenido con 11 especialistas en asistencia domiciliaria de cuidados paliativos oncológicos, que respondieron, en los meses de junio y julio de 2020, cuestionario que contenía escala Likert. Realizamos pruebas preliminares del instrumento con 15 cuidadores. En el análisis, fue considerado el índice de validez de contenido > 80%, calculado en tres grupos: encabezamiento; señales y síntomas; diseño - y global del instrumento. **Resultados**: después de tres rondas de evaluación, los índices de validación de contenido alcanzados para los tres grupos y para el global del instrumento fueron respectivamente: 95,5%; 95,58%; 86,5% y 92,52%. El coeficiente alfa de Cronbach fue 0,925. **Conclusión**: la validez del contenido del Registro de Síntomas del Paciente fue verificada diseñando una nueva herramienta para los cuidados paliativos oncológicos. Su aplicación contribuye a la comunicación efectiva entre cuidadores y equipo de salud, con potencial para impactar directamente la calidad de vida de los pacientes y familiares.

Palabras clave: Atención domiciliaria. Cuidados paliativos. Estudios de validación. Enfermería oncológica.

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