Development and Psycometric Validation of Cancer-Q: Questionnaire about Cancer Patient's Knowledge of their Disease

Construção e Validação Psicométrica do Câncer-Q: Questionário de Conhecimentos da Doença para Pacientes com Câncer
Construcción y Validación Psicométrica del Cáncer-Q: Cuestionario de Conocimientos de la Enfermedad para Pacientes con Cáncer

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Abstract

Introduction: Cancer is one of the leading causes of death in the world and is considered one of the fastest growing diseases in Brazil, it is estimated that about 600 thousand new cases of cancer are diagnosed between the years 2018 and 2019. **Objective:** To develop an validate the instrument "Questionnaire of knowledge of the disease for cancer patients" and asses the level of knowledge of cancer patients. **Method:** The instrument was developed by analyzing the specific literature for presentation to a multidisciplinary team of health care, who answered the validation of clarity and content of the instrument. Then, its generated the pilot version. After the pilot study analysis, the instrument was tested in 71 cancer patients of Center of Oncology Research (Cepon). The reproducibility was obtained through the intraclass correlation coefficient of test-retest method. **Results:** The final version had 14 questions and presented an clarity index of 8,63±0,75. The intraclass correlation coefficient was 0,858 and Cronbach's alpha, 0,611. Factor analysis indicated five factor related to areas of knowledge. The final scores were compared with the characteristics of patients and concluded that low education and low income are associated with lower scores of knowledge. **Conclusion:** The instrument has satisfactory clarity and validity indices and can be used to asses the cancer patient´s knowledge.
Palavras-chave: Neoplasms; Patient Health Questionnaire; Knowledge; Patients.

Resumo

Introdução: O câncer é uma das principais causas de morte e é considerado uma das doenças que mais cresce no Brasil. Estima-se que cerca de 600 mil novos casos de câncer sejam diagnosticados entre 2018 e 2019. **Objetivo:** Construir e validar o instrumento "Questionário de conhecimentos da doença para pacientes com câncer", avaliar o nível de conhecimento de pacientes com câncer sobre sua doença e relacionar o nível de conhecimento com a idade, sexo, renda familiar e escolaridade. **Método:** O instrumento foi construído com base na literatura específica do câncer. Os itens foram apresentados a uma equipe multidisciplinar da área da saúde para julgamento quanto à clareza e ao conteúdo do instrumento. Em seguida, gerou-se a versão-piloto e, após as análises, o instrumento foi aplicado em 71 pacientes com câncer do Centro de Pesquisas Oncológicas (Cepon). A reprodutibilidade foi obtida por meio do coeficiente de correlação intraclasse do método de teste e reteste. **Resultados:** A versão final do instrumento obteve 14 questões e apresentou um índice de clareza de 8,63±0,75. O valor do coeficiente de correlação intraclasse foi de 0,858 e do alfa de Cronbach, 0,611. A análise fatorial revelou cinco fatores, e os escores finais foram comparados com as características dos pacientes, sendo a baixa escolaridade e a baixa renda relacionadas a baixos escores de conhecimento. **Conclusão:** O instrumento possui índice de clareza satisfatório e de validade adequado, podendo ser utilizado para avaliar o conhecimento de pacientes com câncer sobre sua própria doença.
Key words: Neoplasias; Questionário de Saúde do Paciente; Conhecimento; Patientes.

Resumen

Introducción: El cáncer es una de las principales causas de muerte en el mundo y es considerada una de las enfermedades que más crece en Brasil, se estima que cerca de 600 mil nuevos casos de cáncer se diagnostican entre los años 2018 y 2019. **Objetivo:** Construir y validar el instrumento "Cuestionario de conocimientos de la enfermedad para pacientes con cáncer" y evaluar el nivel de conocimiento de pacientes con cáncer sobre su propia enfermedad y relacionar el nivel de conocimiento con la edad, el sexo, la renta familiar y la escolaridad. **Método:** El instrumento fue construido con base en el estudio de la literatura específica del cáncer para la presentación de los ítems a un equipo multidisciplinario del área de la salud, que juzgaron los ítems de acuerdo con la claridad y contenido del instrumento. A continuación se generó la versión piloto y después de los análisis del estudio piloto, el instrumento fue aplicado en 71 pacientes con cáncer del Centro de Investigaciones Oncológicas (Cepón). La reproducibilidad fue obtenida por medio del coeficiente de correlación intraclase del método de prueba y reteste. **Resultados:** La versión final del instrumento obtuvo 14 preguntas y presentó un índice de claridad de 8,63 ± 0,75. El valor del coeficiente de correlación intraclase fue de 0,858 y del alfa de Cronbach, 0,611. El análisis factorial reveló cinco y los escores finales se compararon con las características de los pacientes y se concluyó que baja escolaridad y bajos ingresos están asociados a bajos escores de conocimiento. **Conclusión:** El instrumento posee índice de claridad satisfactorio y de validez adecuado, pudiendo ser utilizado para evaluar el conocimiento de pacientes con cáncer sobre su propia enfermedad.
Palabras clave: Neoplasias; Cuestionario de Salud del Paciente; Conocimiento; Pacientes.

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INTRODUCTION

Cancer is one of the leading causes of mortality in the world, accounting for 8.2 million deaths in 2012. According to estimates, in 2030 there will be 27 million new cases of cancer worldwide; of these, 17 million people may die of cancer[1]. Cancer is considered one of the fastest growing diseases in Brazil, and an estimated 600 thousand new cases will be diagnosed in 2018 and 2019[2].

Since cancer is a chronic degenerative disease, it is one of the main causes of most problems for patients and their families and is thus a public health problem[3]. It is thus important to develop strategies to reduce cancer-related morbidity rates. One such strategy is to educate patients concerning their disease[3-5]. Studies have demonstrated that comprehensive knowledge of the disease contributes directly to its treatment[4,5]. The focus of patient education should be to expand knowledge related to health and the disease, thus allowing patients to better understand the relevant health measures and to make informed decisions concerning their illness[1,3-5].

According to Bonin et al.[5], patients' lack of knowledge contributes significantly to worse quality of life, promotes social isolation, increases comorbidities, leads to lack of selfcare, contributes to ignorance of signs and symptoms, and raises barriers to treatment adherence, due largely to ignorance of the potential benefits of adequate knowledge.

Patient education is thus important, since most people either have no information at all or are poorly informed of the disease, since cancer has multiple factors[3]. In order for patients to understand their disease better, it is essential to assess their level of knowledge[3,4]. Assessment tools are already available in areas like cardiology and allow healthcare professionals to identify and measure patients' level of knowledge and potential changes of attitude towards the disease[5].

However, there are no records in the literature on validated instruments capable of assessing cancer patients' level of knowledge in Brazil. The current study thus aimed to construct and validate the Questionnaire on Cancer Patients' Knowledge of Their Disease (Cancer-Q).

METHOD

This was a cross-sectional study using three intentional, non-probabilistic samples, conducted from June 2014 to June 2015. The study was performed at the Center for Cancer Research (*Centro de Pesquisas Oncológicas - CEPON*) in Florianópolis, Santa Catarina State, Brazil.

Group I consisted of healthcare professionals with expertise in oncology, hereinafter the experts, and was responsible for validating the research instrument's clarity and content in relation to the various target areas of knowledge: pathophysiology, cancer signs and symptoms, risk factors and life habits, diagnosis, treatment, medication, selfcare, and physical exercise. Group II consisted of ten cancer patients and participated in the validation of clarity and reproducibility phases during the pilot study. Group III consisted of cancer patients who participated in the construct validity and internal consistency phases.

Patients in groups II and III met the proposed inclusion criteria: clinical diagnosis of cancer, adults 18 years and older, and with no record on their medical charts of diagnosis of depression or cognitive impairment that would hinder application of the questionnaire. Primary location of the patients' tumors was based on data recorded in the patient identification forms at CEPON.

The study was approved by the Institutional Review Board of the State University of Santa Catarina (UDESC) under case review number 959.526/15 and by the Institutional Review Board of CEPON under case review number 975.591/15. The study complied with the ethical principles regarding personal autonomy, as specified in Resolution no. 466/12 of the Brazilian National Health Council (CNS 196/96) and CONEP (National Commission for Research Ethics), adopting and complying with the standards and guidelines regulating research in human subjects.

All participants signed a free and informed consent form and were assessed by a single researcher, properly trained, a Master's student in the Graduate Studies Program in Human Movement Sciences at the State University of Santa Catarina. Patients received introductory instructions concerning the questionnaire and completed an identification form with data on age, sex, type of cancer, time since diagnosis, comorbidities, family income, and level of schooling.

The questionnaire was applied next and was completed by patients themselves. Before starting the completion, all doubts concerning the questionnaire were cleared up, such that the researcher did not intervene during the questionnaire's completion itself. The collected data were maintained in complete secrecy and only used for the purposes of this study.

Elaboration of the questionnaire's items was divided according to the specific content of the oncology field, namely: concept, pathophysiology, signs and symptoms; risk factors and life habits, diagnosis, treatments, physical exercise, and selfcare. Each question had four possible multiple-choice alternatives: a correct answer, an incomplete answer, an incorrect answer, and "I don't know".

Elaboration of the questionnaire on cancer patients'

knowledge consisted of three stages: theoretical, empirical, and analytical[4-6]. The theoretical stage involved the theoretical basis and its adaptation to a construct to be followed in elaborating the questionnaire, based on the specific literature in oncology. The empirical stage was the application of the test or pilot version and data collection to assess the instrument's properties. The analytical stage included statistical analyses for validating the instrument[4-7].

Cancer-Q was developed by the research group in Physical Exercise and Health at the Center for Health and Sports Sciences at the State University of Santa Catarina, which has instruments that have been developed, validated, and published on health education for chronic and degenerative diseases, such as the Questionnaire on Patients' Knowledge of Coronary Artery Disease (Cade-Q), developed and validated by Ghisi et al.[4], and the Questionnaire on Patients' Knowledge of Heart Failure, developed and validated by Bonin et al[5].

Definition of the sample size followed the prerequisites described in the literature, recommending five to ten subjects per proposed item[6]. As suggested by Hair et al.[8], extraction of the instrument's factors should capture at least 60% of the variance.

Table 1 shows the classification of the level of knowledge used in this study, based on Ghisi et al.[4].

Table 1. Classification of level of knowledge in a sample of cancer patients (n =71)

Points	Percentage of correct answers	Classification of the knowledge
38 to 42	90 to 100%	Excellent knowledge
30 to 37	70 to 89%	Good knowledge
21 to 29	50 to 69%	Fair knowledge
13 to 20	30 to 49%	Little knowledge
< 13	< 30%	Insufficient knowledge

Source: Ghisi et al., 2010.

To validate the clarity and content, the experts were asked to analyze the items semantically in order to verify whether all the items were consistent with the study population, and as to the content, the aim of which was to verify the adequacy of the attributes' presentation[6]. For each question that was tested, a scale was organized ranging from 1 to 10: from 1 to 4, the question was considered confusing; 5 to 7, unclear; and 8 to 10, clear[4-7]. Below each component there was a space for suggestions on the proposed items' content and semantic analysis. The clarity index was obtained as the mean of the sum of the scores assigned by the experts[4,7].

Questions with a clarity index less than eight were reworded and replaced with other terms pertaining to the same concept in order to avoid altering the instrument's structure. After adjustments, the instrument was presented again to the same experts to generate a second version of the questionnaire. After the experts had validated the content and assessed the clarity, the second version of the questionnaire was applied to ten patients to verify the clarity index and mean completion time. Questions with a clarity index less than eight were adjusted again, generating the instrument's final version, submitted to validation of the construct and reproducibility.

Assessment of the study instrument's reproducibility used the test-retest method. The questionnaire was reapplied 14 days after the first application, after which statistical analysis of the data was performed using the intraclass correlation coefficient (ICC), with values greater than 0.8 as the basis[4-7].

Construct validity was analyzed via exploratory factor analysis of the instrument's data. This method was chosen because the questionnaire's factors are relatively independent. Factor analysis was performed with orthogonal rotation, using the Equamax method, which is a combination of Varimax, which simplifies the factors, and Quartimax, which simplifies the variables. The Keiser-Meyer-Olkin (KMO) test and Bartlett's test of sphericity were used to confirm the items' adequacy and suitability [7-9].

Principal components analysis was used to extract the factors, considering only those with eigenvalues greater than 1.0 and factor loads greater than 0.3. Once the values were selected, a factor matrix was generated in which we observed the relations between the items and factors via the factor loads[4,5,7-9]. Internal consistency was assessed by Cronbach's alpha in all the study participants, with a minimum value of 0.6 as the basis[6-9].

Descriptive analysis was used to characterize the participants and included the following items: sex, age, time since diagnosis, type of cancer, family income, and level of schooling (in years)[7]. Descriptive statistical resources were used, such as absolute and relative frequencies, means, and standard deviations.

The Kolmogorov-Smirnov normality test was used for the variables age and instrument score and showed the data's non-normality. Nonparametric tests were thus used[7]. Spearman's correlation test was used to verify the existence of correlation between level of knowledge on the disease and the other variables (schooling, family income, comorbidities, age, and time since diagnosis). For all the analyses, statistical significance as set at 0.05 ($p<0.05$).

RESULTS

Group I consisted of 17 healthcare professionals, as follows: five physicians, four physical therapists, four physical education professionals, two psychologists, one pharmacist, and one nutritionist. Group II included ten cancer patients from CEPON, with mean age of 48.9±12.1 years. Group III consisted of 71 patients, of whom 47 were women and 24 men, with mean age of 50.99±9.22 years. Mean time since clinical diagnosis of cancer was 29±7.31 months.

Initially, 24 items were elaborated and the experts assessed each question for clarity, as follows: clear (scores from eight to ten), unclear (scores from five to seven), and confusing (scores from one to four). There was a space for comments and suggestions. Mean clarity score was 8.87±0.46.

Two questions scored less than eight, requiring adaptation to improve the understanding in the context of grasping the proposed item. The other questions obtained satisfactory indices, but all the experts' comments were incorporated. They suggested the exclusion of one question and the grouping of others into a new question, without altering the initially proposed items. The number of questions was thus decreased from 24 to 18. The question that was excluded referred to the medications used in the treatment, and due to the terminology's complexity, the experts suggested excluding the question.

To finalize the questionnaire, we presented it again to the same experts. This final instrument contained all the expert suggestions to the initial version, and the order of the questions and answers remained the same, with 80% agreement in the items assessed. Mean clarity score was 9.04±0.21.

The ten patients selected for the pilot study completed the questionnaire, signaling what they considered most correct out of four possible answers, and then indicated the choice and the score that best classified the set of questions and answers in the context of understanding the proposed item's clarity, thus generating the instrument's clarity index, which was 8.63±0.75. Mean completion time was 16.5±5.2 minutes.

The patients that participated in the pilot study answered the questionnaire in two distinct stages in order to assess the reliability. In both stages, they marked only one choice for each question, that which they considered the most correct. The scores determined for the choices were: correct = 3; incomplete = 1; incorrect = 0; I don't know = 0. The maximum score was established according to the final number of questions answered, generating a final score. The instrument's total ICC was 0.858, obtained via the final scores. The ICC was calculated for

each individual question; four questions failed to reach the score of 0.8 proposed by the literature and were thus excluded from the instrument, for a final total of 14 questions (Annex I). The excluded questions were one each on cancer symptoms, drugs used in the treatment, physical exercises, and selfcare.

Participants in the final version of the questionnaire consisted of 71 patients (47 women and 24 men), with a mean age of 50.99±9.22 years, all with a clinical diagnosis of cancer, and mean time since diagnosis of 29 months. Table 2 shows the participants' characteristics. Since the study had 71 participants, it met the minimum of 70, considering that the instrument's final version has 14 questions. The ratio of patients to item was 5.07.

In the sum of the 14 questions answered by patients, the instrument showed a total score of 35.66±4.9, with a median of 37 (the instrument has a minimum of zero points and a maximum of 42, as shown in Table 1). As shown in Table 3, the predominant classification was "good knowledge".

Participants' characteristics were also analyzed as a function of the total score. There was no significant difference when comparing the knowledge scores between men and women (p=0.161). There was a predominance of "excellent knowledge" in men (50%), followed by "good knowledge" (37.5%). Women showed mostly "good knowledge" (51.1%), followed by "excellent knowledge" (40.4%).

Positive correlations were found between level of knowledge and the sociodemographic variables schooling (rho=0.807; p<0.001) and family income (rho=0.655; p<0.001). No association was found between the variables in relation to type of cancer and level of knowledge (p=0.075).

When analyzed individually, question number 8 reached the highest number of correct answers, followed by questions 1, 4, and 5, respectively. Question number 3 reached the highest number of partially correct answers, followed by questions 9, 14, and 13, respectively. Question number 11 reached the highest number of incorrect answers and/or "I don't know", followed by questions 13, 6, and 7, respectively, as shown in Table 4.

Construct validity was analyzed via exploratory factor analysis of the data, shown in Table 5. The KMO normality test and Bartlett's sphericity test indicated that the data are suitable for factor analysis (KMO=0.616 and Bartlett *p*<0.001), emphasizing that they are necessary prerequisites for such analysis. Factors loads greater than 0.3 were considered[4,5,7].

Five factors were found to exist, such that each factor attributed at least two items, meeting the principle of equilibrium in the rules of item construction. These five

Table 2. Characteristics of the sample of cancer patients

Variable	Category	f (%)
Sex	Male	24 (33.8)
	Female	47 (66.2)
	Obesity	19 (26.4)
	Diabetes mellitus	11 (15.3)
Comorbidities	Systemic arterial hypertension	8 (11.1)
	Dyslipidemia	7 (9.7)
	Chronic obstructive pulmonary disease	1 (1.4)
	Up one minimum wage*	4 (5.6)
	1.1 to 2 times the minimum wage	28 (39.4)
	2.1 to 3 times the minimum wage	23 (32.4)
Family income	3.1 to 4 times the minimum wage	11 (15.5)
	4.1 to 5 times the minimum wage	4 (5.6)
	More than 5 times the minimum wage	1 (1.4)
	1 to 5 complete years	33 (46.5)
	6 to 11 complete years	26 (36.6)
	More than 11 complete years	12 (16.9)
	Breast	24 (33.8)
Schooling	Lung	11 (15.5)
	Colorectal	10 (14.1)
	Uterine cervix	5 (7.0)
	Prostate	5 (7.0)
	Liver	4 (5.6)
	Stomach	3 (4.2)
	Multiple myeloma	2 (4.9)
	Pancreas	2 (2.8)
	Skin	2 (2.8)
Type of cancer	Non-Hodgkin's lymphoma	1 (1.4)
	Ovary	1 (1.4)
	Gallbladder	1 (1.4)

* one minimum wage = approximately U$250/month

Table 3. Overall scores on cancer patients' knowledge of their own disease

Score	%	Classification of knowledge	f (%)
38 to 42 points	90 to 100	Excellent	31 (43.7)
30 to 37 points	70 to 89	Good	33 (46.5)
21 to 29 points	50 a 69	Fair	6 (8.5)
13 to 20 points	30 a 49	Low	1 (1.4)
> 13 points	> 30	Insufficient	0 (0)

Table 4. Performance on Questionnaire on Cancer Patients' Knowledge of Their Disease

Questions	Don't know/ incorrect f (%)	Partially correct f (%)	Correct f (%)
1	3 (4.2)	0 (0)	68 (95.8)
2	5 (7.0)	3 (4.2)	63 (88.7)
3	4 (5.6)	25 (35.2)	42 (59.2)
4	2 (2.8)	1 (1.4)	68 (95.8)
5	1 (1.4)	2 (2.8)	68 (95.8)
6	8 (11.3)	4 (5.6)	59 (83.1)
7	8 (11.3)	14 (19.7)	49 (69.0)
8	1 (1.4)	1 (1.4)	69 (97.2)
9	5 (7.0)	19 (26.8)	47 (66.2)
10	1 (1.4)	8 (11.3)	62 (87.3)
11	10 (14.1)	9 (12.7)	52 (73.2)
12	0 (0)	14 (19.7)	57 (80.3)
13	9 (12.7)	16 (22.5)	46 (64.8)
14	2 (2.8)	19 (26.8)	50 (70.4)

factors jointly accounted for 62.7% of the items' total variance.

The first factor, called the "general factor", encompassed four items, involving the following areas of knowledge: treatment, medications, concept, pathophysiology, and risk factors, accounting for 14.3% of the total variance, while the other factors made a smaller contribution to this variance. The second factor encompassed three items, involving the following areas of knowledge: diagnosis, life habits, treatment, medications, and selfcare, called the "treatment factor", accounting for 14.8% of the total variance. The third factor encompassed two items in the following areas: physical exercise, signs and symptoms, and risk factors, called "selfcare", accounting for 12% of the total variance. The fourth factor, with three items, covered the following areas of knowledge: selfcare, physical exercise, treatment, and life habits, called "physical exercise factor", accounting for 12.4% of the total variance. The fifth factor covered two items in the following areas: treatment, selfcare, and life habits, called the "miscellaneous factor", accounting for 9.1% of the total variance. The instrument as a whole showed internal consistency, with Cronbach's alpha = 0.611.

DISCUSSION

The study aimed to develop and validate an instrument to assess cancer patients' knowledge, and it confirmed the instrument's validity. As far as we know, this was the first study seeking to assess cancer patients' knowledge of their own disease. Content validity was established via expert assessment, aimed at analyzing the representativeness

Table 5. Factorial structure of the instrument

Question	Area	Factors				
		1	2	3	4	5
6	Treatment	0.717				
7	Treatment medication	0.702				
2	Risk factors	0.627				
1	Concept and pathophysiology	0.511				
8	Treatment medication selfcare		0.886			
5	Treatment		0.803			
4	Diagnosis Life habits		0.449			
9	Treatment Physical exercise			0.873		
3	Signs and symptoms Risk factors			0.514		
13	Selfcare Life habits				0.724	
11	Treatment Physical exercise				0.711	
14	Treatment Physical exercise				0.467	
12	Treatment Selfcare Life habits					0.833
10	Selfcare					0.498
% of variance		14.3%	14.8%	12%	12.4%	9.1%

of the items (questions) in relation to the concept and theoretical relevance[10,11]. Validity was based on the theoretical frame of reference and was defined according to the expert opinion of individuals with theoretical knowledge and based on the respective literature on the topic and in the field, in this case oncology[7].

In the theoretical analysis of items, it is recommended to have a minimum of six experts[6], and the current study had 17. Lee et al.[12] included ten experts for the development and validation of an instrument to assess the efficacy of self-monitoring by breast cancer patients. The study by Shimet et al.[13] included 11 experts for the construction and validation of an instrument to assess cancer patients' overall needs.

According to the experts in charge of assessing the clarity and content, as well as the patients in the pilot study, the Cancer-Q instrument met the structural prerequisites, as well as simplicity, clarity, balance, and credibility, via items expressing a single idea for the instrument[6], as presented previously in the Cade-Q[4] and IC-Q instruments[5]. The experts suggested semantic reorganization in the wording and expressions used, due to the patients' personal, social, cultural, and educational heterogeneity. The experts' opinions were taken into account, since the goal was to promote patients' adequate understanding of the questions and answers as a whole. The instrument thus proved to be clearly comprehensible[4-7].

Analysis of the instrument's reliability used the test-retest method in the pilot study. The instrument's total ICC was 0.858, corroborating the value suggested in

the literature (minimum of 0.8), demonstrating the instrument's stability and reliability and providing evidence that successive applications of this instrument will produce the same or similar results[6], as seen in instruments from other studies in the field of oncology with reliability and stability in the instrument based on the test-retest method[14-17].

Construct validity was assessed by exploratory factor analysis. Although the KMO normality test and Bartlett's sphericity test indicated that the datasets presented the prerequisites for factor analysis, they showed that the instrument displayed multidimensional characteristics, mostly covering more than one area of knowledge[4,7,9]. This instrument's exploratory factor analysis resulted in five factors, covering a total of nine areas of knowledge[6]. Each factor in an instrument should convey a meaning pertaining to the study's underlying theories. The factors should be verified for stability, interpretation, and production of a useful construct for future studies[4-7]. In this study, some questions were repeated in more than one factor, although they always belonged to just one factor at a higher factor load.

Thus, the items' higher factor load was considered for retaining items in the factors, since significant loads should not participate in the interpretation of more than one factor. Retention of items takes into account the loads' values and the variables' practical significance[8].

The five factors covered a diverse quantity of items in each domain. Still, the factor analysis in the study met the principles in the construction rules, with the five factors accounting for 62.7% of the items' total variance,

as suggested by Hair et al.[8] for extracting factors that should capture at least 60% of the variance. The study also considered loads greater than 0.3, as demonstrated in studies of other diseases with multifactorial etiologies[4,5].

Chung et al.[15] developed an instrument with 50 items to assess quality of life in prostate cancer patients, and factor analysis confirmed four factors. Likewise, Bairati et al.[16] developed an instrument on knowledge concerning mammography for early detection of breast cancer, and Morales-Sanchez et al.[20] developed a questionnaire on knowledge of risk factors for skin cancer. Lee et al.[12] found five factors in an instrument developed and validated for work with breast cancer patients.

All the above studies showed factor loads similar or close to those observed in our study. Some instruments were developed with more than five factors, such as Shim et al.[13], with seven factors in 59 items to assess cancer patients' needs, and Defossez et al.[17], with 12 factors in their instrument. Our study addressed factors that were similar to those of Shim et al.[13] and Defossez et al.[17], such as selfcare and life habits.

Studies in oncology that have used factor analysis for the distribution of items have shown that the number of factors in the instruments is determined by the fact that cancer has a multifactorial etiology, including genetic, environmental, and lifestyle factors[8]. Our questionnaire thus showed similarities to the instruments in the other studies cited in the literature, resulting specifically from the areas of knowledge, both in the amount of items[12,20] and the number of factors across which the items are distributed[12,15,16,20].

We found that questions 6, 7, 11, and 13 were the items with the highest proportion of incorrect answers and/or "I don't know", with lack of knowledge predominantly in areas related to the consequences of inadequate treatments and especially physical exercise. The literature suggests that physical exercise has positive psychological, physiological, and physical effects in cancer patients, but it must be prescribed correctly in order to ensure its efficacy and safety[21].

Physical inactivity and lack of knowledge concerning physical exercise have reached epidemic levels in developed countries and are considered a serious public health problem. Individuals with sedentary lifestyle (an important risk factor for various chronic diseases) are specifically prone to cancer, a leading cause of mortality. Educational interventions are necessary for people to understand the significance of sedentary lifestyle, besides serving as a public health policy for creating programs to prevent physical inactivity[18,21].

The items with the highest proportion of correct answers were 8, 1, 4, and 5, related to the areas of concept, pathophysiology, diagnosis, and treatments. This shows the importance of educational programs in the care of cancer patients, but such measures are hindered by the high costs of health programs[18,22-25].

As for level of knowledge, the study's results showed that higher family income and schooling were associated with higher scores by participants, corroborating previous studies in oncology that associated increased schooling and family income[19,22-25] with lower rates of development of the disease and relapses. This is because people with higher income and schooling tend to have more access to information on the disease, avoiding important risk factors, especially excessive alcohol consumption and smoking, as well as physical inactivity and inadequate and inappropriate eating habits[1,2].

Increased educational level is reflected directly in patients' greater knowledge of their disease (i.e., knowledge is mediated by individuals' educational and cultural levels). Socioeconomic factors can thus substantially impact the quality of life of persons diagnosed with cancer[37]. This was also shown in the instruments on which the current study was based, such as Cade-Q, in which Ghisi et al.[4] demonstrated that socioeconomic status (measured by family income and level of schooling) influences the acquisition of knowledge.

Patients' age showed a weak negative correlation with total knowledge scores. However, the results indicate that younger cancer patients tend to have slightly better knowledge. No correlation was found between level of knowledge and time since diagnosis of the disease. This is due to the patients' heterogeneity. The more heterogeneous a population, the more difficult it is to correlate factors that may alter levels of knowledge, leading to an inadequate understanding of the disease[4,5].

The priorities in teaching and learning should obviously be patient-centered, especially in educational programs in oncology. The development of instruments to assess knowledge of the disease can thus be an interesting strategy with a low operational and logistic cost to work with this population[3-7].

This study presents the following limitations: the results are generalizable to all types of cancer, which can reduce the outcomes' precision. The Cancer-Q questionnaire was developed and validated on the basis of consensuses and guidelines reporting various themes related to cancer, and the entire process took place in a single institution (albeit one of the most important of its kind in Brazil). The study did not reach the recommended minimum (consisting mostly of female patients) of 50 assessed in the test-retest procedure. The instrument's high scores may have been generated by the relatively long mean time since diagnosis (29 months), which can

contribute to the patients' level of knowledge. The absence of depression and cognitive impairment was obtained from the patients' medical charts, which the institution authorized us to consult. Therefore, future studies are necessary to determine whether Cancer-Q is sensitive to changes over time, assessing patients' knowledge before and after health education programs.

CONCLUSION

The Cancer-Q instrument is valid for application in cancer patients, aimed at studying their level of knowledge concerning their own disease. The questionnaire needs to be reproduced in a larger population of cancer patients, and more studies are needed in the area of health education and cancer in order to determine the patients' real needs for knowledge.

CONTRIBUTIONS

Moacir Pereira Junior and Magnus Benetti contributed to the research project's conception and planning and the data collection, analysis, and interpretation. Rafaella Zulianello dos Santos, Ana Paula Ramos, Alexandro Andrade, and Luiz Roberto Medina dos Santos contributed to the data analysis and interpretation, elaboration of the results, and discussion of the study.

CONFLICT OF INTEREST:

None.

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ANNEX I. QUESTIONNAIRE ON CANCER PATIENTS' KNOWLEDGE OF THEIR DISEASE

QUESTIONNAIRE ON CANCER PATIENTS' KNOWLEDGE OF THEIR DISEASE

Instructions for use by study participants

You are being asked to complete this questionnaire because you have a clinical diagnosis of cancer. The questionnaire is confidential, and participation is voluntary.

The aims of this study are:
- To assess your knowledge of cancer.
- To identify specific topics in this knowledge (development of the disease, signs and symptoms, diagnosis, risk factors, lifestyle, treatments, physical exercise, evolution of the disease, diet, care with the disease, and medication).

Thank you for your collaboration.

Instructions for completion of the questionnaire:
1. Please complete *all* the questions.
2. Each question has four possible answers:
- A *correct* answer, showing complete knowledge of the disease.
- A *correct* answer showing incomplete knowledge of disease.
- An *incorrect* answer showing incorrect knowledge.
- An alternative *"I don't know"* showing lack of knowledge on the disease.
Check only one answer, the one you think is the answer that shows *complete knowledge* on that question.

Questionnaire on Cancer Patients' Knowledge of Their Disease

1. What is cancer?
a) Cancer is a disease that affects older people due to weakening of the body's defense system.
b) Cancer is disordered growth of cells that invade tissues and organs and can spread to other parts of the body.
c) Cancer is an exclusively hereditary disease, transmitted from parents to children.
d) I don't know.

2. Which risk factors have the most influence on the development of cancer?
a) Low schooling and low family income.
b) Age over 65 years and obesity.
c) Lifestyle (smoking, alcohol, unhealthy diet, physical inactivity) and genetic predisposition.
d) I don't know.

3. What are the most common symptoms in a person with cancer?
a) Cancer symptoms vary and depend on the part of the body that's affected.
b) A person with cancer doesn't feel anything.
c) The most common symptoms are chills, fatigue, night sweats, and weight loss.
d) I don't know.

4. Which of the following is the best approach for early detection of cancer?
a) Urine test.
b) Regular medical checkups, physical examination, blood tests, and imaging tests.
c) Treadmill stress test.
d) I don't know.

5. Which treatments are used the most to cure cancer?
a) Chemotherapy, radiotherapy, surgery, and sometimes immune therapy.
b) There is no treatment, since cancer is a genetic disease.
c) Hormone replacement.
d) I don't know.

6. Which interventions in cancer treatment can provide better quality of life for patients?
a) Quit work and abandon family, drug treatment, surgical treatment, and prolonged and absolute bed rest.
b) Drug treatment and surgical treatment when necessary.
c) Drug treatment and surgical treatment when necessary, lifestyle change, and prevention of risk factors that exacerbate the disease.
d) I don't know.

7. The role of drug treatment for cancer is:
a) To improve the patient's physical and psychological condition.
b) To avoid infectious diseases.
c) To prevent the diseased cells from growing and multiplying rapidly, out of control, and aggressively.
d) I don't know.

8. What are the most common side effects of the drugs used in cancer treatments?
a) Fatigue, diarrhea, insomnia, hair loss, nauseas, and vomiting.
b) Pain in them muscles, bones, and joints.
c) Improved sexual performance, increased appetite, and weight gain.
d) I don't know.

9. In relation to physical exercise by cancer patients:
a) Cancer patients should never do physical exercise, since it increases the risk of death.
b) Physical exercise should be included in the treatment when the patient is clinically stable.
c) Physical exercise is part of the treatment, since it can improve physical conditioning and muscle strength and relieve the symptoms.
d) I don't know.

10. In relation to selfcare by cancer patients, it is important to know that:
a) Patients should have knowledge of their disease.
b) Patients and their families should know about the disease, since the knowledge can improve the patients' quality of life and help their treatment.
c) It is not important to know about the evolution and treatment of the disease, because that is the healthcare team's responsibility.
d) I don't know.

11. Physical exercise for cancer patients should:
a) Begin immediately after diagnosis.
b) Respect the patient's needs, which will be analyzed by the healthcare team and prescribed individually.
c) Physical exercise should be the same for the same age, both for men and women, since this group has the same physical conditioning.
d) I don't know.

12. What is the best diet for cancer patients?
a) A diet high in fiber and vitamins, fruits, vegetables, and whole grains.
b) A normal diet, sour and salty to stimulate the appetite.
c) A low-salt, low-fat diet.
d) I don't know.

13. Check one of the consequences of inadequate cancer treatment:
a) Increased depression, tiredness, and weakness.
b) Weakening of the body's defense system, with worsening of the symptoms and risk of death.
c) Appearance of other diseases, such as diabetes.
d) I don't know.

14. What are the most important effects of physical exercise for cancer patients?
a) Maintenance of blood glucose and decreased resting heart rate and body fat.
b) Increased pulse rate, increased blood sugar, and increased cholesterol.
c) Strengthens the body's defense cells, improves quality of life, and improves depression and fatigue.
d) I don't know.