



PATIENT CONCERNS INVENTORY FOR HEAD AND NECK CANCER – BRAZILIAN CULTURAL ADAPTATION

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Keyword:	Quality of life, surveys and questionnaires, head neck neoplasms, reliability and validity, outcomes research

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ABSTRACT

Objective: The purpose of this study was to translate, culturally validate and evaluate the Patients Concerns Inventory - Head and Neck (PCI- H&N) in a consecutive series of Brazilian patients. **Methods:** This study included adult patients treated for upper aerodigestive tract (UADT) cancer. The translation and cultural adaptation of the PCI-H&N followed internationally accepted guidelines and included a pretest sample of patients that completed the first Brazilian-Portuguese version of the PCI. The use/feasibility/acceptability of the PCI was tested subsequently in a consecutive series of UADT cancer patients that completed the final Brazilian-Portuguese version of the PCI and a Brazilian-Portuguese version of the University of Washington Quality of Life Questionnaire (UW-QOL). Associations between physical and socio-emotional composite scores from the UW-QOL and PCI were analyzed. **Results:** Twenty patients participated in the pretest survey (translation and cultural adaptation process), and 84 patients were analysed in the cultural validation study. Issues most selected were: fear of cancer returning, dry mouth, chewing/eating, speech/voice/being understood, swallowing, dental health/teeth, anxiety, fatigue/tiredness, taste and fear of adverse events. The three specialists most selected were speech therapist, dentist and psychologist. Statistically significant relationships between PCI and UW-QOL were found. **Conclusions:** The translation and cultural adaptation of the PCI for Brazilian-Portuguese language was successful, and the results demonstrate its feasibility and usefulness, making this a valuable tool for use within the Brazilian H&N cancer population.

Keywords: Surveys and Questionnaires; Quality of life; Head and neck neoplasms; validity and reliability; outcomes research

RESUMO

Objetivo: O objetivo deste estudo foi traduzir, adaptar culturalmente e avaliar o Inventário de Preocupações dos Pacientes - Cabeça e Pescoço (IPP-CP) em uma série consecutiva de pacientes brasileiros. **Métodos:** Este estudo incluiu pacientes adultos tratados por câncer do trato aerodigestivo superior (TADS). A tradução e adaptação cultural do IPP-CP seguiu diretrizes internacionalmente aceitas e incluiu uma amostra piloto de pacientes que completaram a primeira versão em Português do IPP-CP. O uso/viabilidade/aceitabilidade do IPP-CP foi testado posteriormente, em uma série consecutiva de pacientes com câncer do TADS que completaram a versão final em Português do PCI e uma versão em Português do questionário de qualidade de vida da Universidade de Washington (UW-QOL). As associações entre os escores físicos e sócio-emocionais do UW-QOL e IPP foram analisadas. **Resultados:** Vinte pacientes participaram da pesquisa piloto (processo de adaptação cultural tradução), e 84 pacientes foram analisados no estudo de validação cultural. Questões mais selecionadas foram: medo do câncer voltar, boca seca, mastigação/comer, fala/voz /ser compreendido, deglutição, saúde dental/dentes, ansiedade, fadiga/cansaço, paladar e medo de eventos adversos. Os três especialistas mais selecionadas foram fonoaudiólogo, dentista e psicólogo. Relações estatisticamente significativas entre IPP e UW-QOL foram encontrados. **Conclusões:** A tradução e adaptação cultural do IPP para o Português foi bem sucedida, e os resultados demonstram a sua viabilidade e utilidade, tornando esta uma ferramenta valiosa para uso na população brasileira câncer de CP.

Palavras-chave: Questionários; Qualidade de vida; qualidade de vida relacionada à saúde; câncer de cabeça e pescoço; adaptação cultural; inventário

Introduction

Worldwide, approximately 650 000 people per year are diagnosed with head and neck cancer¹[1]. The city of São Paulo has one of the highest incidence rates of laryngeal and oral cancer worldwide²[2].

Head and neck cancer and its treatment can cause significant changes in vital functions related to feeding, communication and breathing of affected patients as well as to individual's self-imaging. Such alterations can have devastating consequences on the patient's quality of life and also on their families³⁻⁵[3-5]. The current focus of head and neck oncology is to eliminate cancer, prolong survival, obtain better functional outcomes and preserve or restore the quality of life (QOL) of affected patients. Studies of QOL using generic or specific measures usually generate data and information about disease and treatment consequences on patient's life, including data that could be used to improve treatment support, optimize patient care, define rehabilitation necessity and goals, identify patients problems and preferences and also could facilitate communication between patients and doctors⁶⁻⁹[6-9].

In conjunction with the Merseyside Regional Head & Neck Cancer Centre Support Group, ROGERS et al. (2009)¹⁰⁻¹¹[10,11] and GHAZALI et al. (2011)¹²[12] developed the Patients Concerns Inventory – Head and Neck (PCI-H&N), which have been included in the British H&N National Annual audit (DAHNO) as an indicator of quality of care. It consists of an inventory based on the synthesis of items from various health-related quality of life (HRQOL) questionnaires. The PCI is a carefully designed H&N cancer specific checklist intended to be used in consultations as part of routine outpatient care. It is holistic, self-administered and designed to give a more patient-focused and patient-directed consultation leading to more shared decision-making and potentially better patient support and outcomes. Patients select items from the checklist that they want to discuss during the consultation and also select from a list of health professionals those they would like to see during their outpatient visit or to be referred to.

The purposes of the present study were to adapt and culturally validate the Patients Concerns Inventory – Head and Neck (PCI-H&N) to Brazilian-Portuguese language and to evaluate its use in a series of patients treated for

head and neck cancer in a referral cancer center in Brazil.

Materials and Methods

The instrument description

The first part of the original English version of the PCI has 57 items grouped into 5 domains: physical and functional well-being (29 items), treatment-related (4 items), social assistance and welfare (9 items), psychological, emotional and spiritual well-being (14 items), and other (free text). The second part consists of a list of 17 specialists, also grouped into 5 domains: physical and functional well-being (8 specialists), treatment-related (3 specialists), social assistance and welfare (3 specialists), psychological, emotional and spiritual well being (3 specialists), and others (free text). In both parts of the inventory, patients can select as many items and specialists as they would like.

It is important to highlight that the PCI is a checklist of issues that patients wish to talk about in their clinical consultation and is not a measure of the level of concern per se. Patients can have concerns and still not want to discuss them. It has no rating or score.

Translation and adaptation process

The translation and cultural adaptation of the PCI followed internationally accepted guidelines¹³⁻¹⁴ [13,14]. Initially, two bicultural experts and translators, who were experts in the area of healthcare, translated the original English version of the PCI into Brazilian-Portuguese language. A third bicultural expert compared the two versions, and a consensus version was reached. The consensus-translated version of Brazilian-Portuguese PCI was then back-translated into English by two additional bicultural experts and translators who were native English speakers in collaboration with one of the authors (SNR). To confirm the cross-cultural equivalence of the original and translated versions for semantic, idiomatic, experiential and conceptual aspects, a committee formed by three healthcare professionals with experience in head and neck cancer (HNC) revised the final version, comparing it to the original one. Any discrepancies between the original and

back-translated versions were resolved by repeating the process as needed.

A pretest survey was performed.

Pretest survey

The inclusion criteria for the pretest survey were: patients 18 years of age or older who were treated for upper aerodigestive tract (UADT) cancers regardless of the histological type or tumor staging. Exclusion criteria: patients with a thyroid cancer diagnosis, medical diagnosis of neurological changes and/or deficits in comprehension and/or ability to communicate as well as individuals who reported being physically and/or psychologically unable to answer the questionnaire.

A series of 20 eligible patients completed the Brazilian-Portuguese PCI version for the pretest survey. Informed consent was obtained from all patients enrolled in this pretest survey.

During this pretest survey patients were asked about any difficulty in the interpretation of any words or expressions translated in the Brazilian version of PCI, as well as any limitation to complete the questionnaire. If any specific difficulty to complete the inventory were reported for more than one patient, a consensus conference among the research team members (Brazilian authors) was performed to adapt and modify such item as needed.

Cultural validation study

A consecutive series of UADT cancer patients, with the same inclusion and exclusion criteria of the pretest survey, completed the final version of the PCI (see Appendix) and also the Brazilian-Portuguese validated form of the University of Washington Quality of Life Questionnaire (UW-QOLv4)¹⁵⁻¹⁶ [15,16]. Informed consent was also obtained from all enrolled patients.

Based on the literature available for this type of research, there is no consensus and no general criteria for the required sample size for a patient reported outcome instrument validation study. A sample size of at least 50 to 100 participants is generally recommended. These numbers of subjects ensure stability of the variance covariance matrix¹⁷.

A valid measure will assess what it is meant to be measured, and the PCI evaluates whether patients want to discuss items - in practice they either

want to discuss an item or they don't. Then, due to its "checklist" pattern, PCI is not suited for psychometric testing in the usual sense applied to the majority of HRQOL survey instruments. The translation and cultural adaptation can be considered the most important step to be achieved to assure its properties in other language. In this setting, content validity is the most relevant of PCI properties. Content validity reflects the belief that the questions adequately cover the content of the field of study, and it was established with a rigorous approach to item development in the original form⁸⁻¹⁰ [8-10] and can be maintained by a rigorous process of translation and back-translation into Brazilian-Portuguese language.

However, even considering that the most important step of cultural validation of PCI in Brazilian-Portuguese language is the rigorous process of translation and back-translation, we decide to test the construct validity of the Brazilian version comparing its results with the UW-QOL scores. Construct validity is present if the scale behaves according to hypothesized relationships. We hypothesized that the composite score of the UW-QOL should be associated and correlated with the number of issues selected for discussion by the patients on the PCI.

The Brazilian Portuguese validated form of the University of Washington Quality of Life Questionnaire (UW-QOLv4) was used because it is a disease-specific, concise and well-validated QOL questionnaire and because its domains overlap with many of the concerns listed on the PCI. Each domain item on the UW-QOL scale is scored from 0 to 100, with the composite score being the mean of the 12 domains. Higher scores are indicative of better QOL. In this study the UW-QOL results were analyzed by considering two composite scores: "physical function" (simple average of the domain scores for swallowing, chewing, speech, saliva, taste and appearance) and "socio-emotional function" (simple average of the domain scores for activity, recreation, pain, mood, anxiety and shoulders)¹⁵ [15].

Statistical analysis

The nonparametric Mann-Whitney test (two categories) or Kruskal-Wallis test (three categories) were used to evaluate the association between the number of items/specialists selected and the patient characteristics. The

Mann-Whitney test was also used to associate the composite scores of the UW-QOL (physical, socio-emotional) with the specific items/specialists selected by the patients. The associations between the scores of the UW-QOL and age, time of diagnosis and the number of items/specialists selected were assessed using Spearman's correlation coefficient. Associations between the specific items/specialists selected and patient characteristics were evaluated using the chi-square test or Fisher's exact test. The level of significance was set to 1%. The software used was R version 3.0.1. (R is a language and environment for statistical computing and graphics. R provides a wide variety of statistical and graphical techniques, and is highly extensible. It is available as Free Software under the terms of the Free Software Foundation's GNU General Public License in source code form).

Results

Translation process and pretest survey

As part of the translation and adaptation process we conducted a pretest survey with 20 patients with UADT cancers (8 oral cavity, 6 larynx, 2 oropharynx, 3 nasopharynx, and 1 maxillary sinus) and they completed the Brazilian-Portuguese version of the PCI.

There were no significant discrepancies between the translation and back-translation versions, despite the grammatical and cultural differences between the Brazilian and English populations.

However, in the pretest survey some patients did not understand the meaning of the following terms in the first translated version: mucous, deglutition, smell, taste, percutaneous gastrostomy (PEG), fear of adverse events and coping strategies. The terms home care/Family Health Program (originally described as home care/district nurse) were erroneously interpreted as any family member or person providing help/medical assistance. The term "activity" was interpreted differently by patients, being understood as physical exercises or as activities of daily living. Patients were also confused by the terms salivation and dry mouth and were unable to distinguish and clearly define them.

Following the adequacy of equivalence and adaptations for the

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6 Brazilian population, the consensus research team then constructed a final
7 version into Brazilian-Portuguese language. This final version was defined
8 replacing or supplementing the terms that were not well understood,
9 misinterpreted or indistinguishable, for phlegm/secretions, swallowing
10 (deglutition), olfaction (smell), taste (sense flavor), feeding tube, fear of
11 adverse events and strategies to cope with the illness and treatment, care
12 from specialists in the home, physical activity and too much salivation.
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16 In the pretest survey, among the specialists listed in the original PCI
17 version, dental hygienist and chaplain were not easily identified by patients,
18 as well as emotional support therapists (a clinical specialty just below the level
19 of a psychologist that exists in the United Kingdom). For the final consensus
20 version, the specialty dental hygienist was removed, chaplain was replaced by
21 the religious authority/leader of their religion, and psychologist and
22 psychiatrist were added (see Appendix).
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28 **Cultural validation study**

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30 A consecutive series of 84 patients with UADT cancers were enrolled
31 between February 2013 and June 2013 for this study and they completed the
32 final Brazilian-Portuguese version of the PCI and the Brazilian-Portuguese
33 version of the University of Washington Quality of Life Questionnaire (UW-
34 QOL v4). Most patients were male (74%), mean age of 62 years (range from
35 36 to 89 years), with low education level (57%) and histologically confirmed
36 squamous cell carcinoma (SCC) (89%). Tumor sites were the oral cavity in 35
37 patients (42%), larynx in 20 patients (24%), oropharynx in 19 patients (23%),
38 nasopharynx in 3 (4%), hypopharynx in 3 (4%), nasal and paranasal sinuses
39 in 2 (2%) and occult primary tumors in 2 (2%). Most patients presented with
40 tumors at an advanced stage: T3 in 19 patients (23%) and T4 in 25 (30%).
41 Half of the patient sample was clinically negative for lymph node involvement
42 (50%), and almost all patients were clinically negative for distant metastasis
43 (96%). Regarding time interval between treatment and completing the
44 questionnaires, 25 patients (30%) had less than 12 months, 22 patients (26%)
45 between 12 and 36 months and 37 patients (44%) for 36 months or more.
46 Thirty-four patients (40%) underwent surgery and radiotherapy, 29 patients
47 (35%) underwent primary radiotherapy and 21 (25%) underwent only surgery.
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6 Thirty-five patients (42%) underwent chemotherapy at some point during their
7 treatment.
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9 The time required to fill out the PCI ranged from 6 to 20 minutes
10 (mean, 13 minutes). The frequency of the items indicated on the PCI is
11 described in Figures 1 and 2. Among the listed items in the inventory, issues
12 selected most frequently by patients for discussion included the following: fear
13 of cancer returning (57%), dry mouth (45%), chewing/eating (44%),
14 speech/voice/being understood (43%), swallowing (40%), dental health/teeth
15 (36%), anxiety (31%), fatigue/tiredness (30%), taste (sense flavor) (30%) and
16 fear of adverse events (30%) (Figure 1). The three specialists most selected
17 by patients were speech therapist by 22 patients (26%), dentist by 20 patients
18 (24%) and psychologist by 15 patients (18%) (Figure 2). The median
19 (interquartile range - IQR) number of PCI items selected was 8 (5-13), ranging
20 between 0 and 42 items, with 75 patients (89%) selecting at least one item.
21 The median (IQR) number of specialists indicated was 1 (0-2), ranging
22 between 0 and 8 specialists, with 30 patients (36%) selecting at least one
23 specialist.
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25 The number of concerns and specialists selected correlated weakly
26 with the time of diagnosis (-0.29 , $p=0.007$ and -0.28 , $p=0.01$) with more
27 items selected as shorter was the interval between the end of treatment and
28 participation in the study, while patient age correlated with the number of
29 specialists selected (-0.28 , $p=0.009$) with younger patients selecting a
30 greater number of specialists (Table 1). There were no other significant
31 association of clinical variables studied with the number of items and
32 specialists selected.
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34 The mean composite score for the UW-QOL was 73 [standard
35 deviation (SD), 20]. For the physical and socio-emotional domains, the scores
36 were respectively, 78 (21) and 67 (24). The physical and socio-emotional
37 domains of the UW-QOL were significantly correlated with the number of
38 concerns selected (-0.46 and -0.45 , both $p < 0.001$) and with the number of
39 specialists selected (-0.46 , $p < 0.001$ and -0.33 , $p = 0.002$). The worse the
40 UW-QOL scores more PCI items that were selected.
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42 Significant associations of specific issues and specialists selected with
43 patient characteristics and with the physical and socio-emotional domains of
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6 the UW-QOL were detected. Patients under 55 years of age selected more
7 items of dental health (50%) and fear of cancer returning (75%) than older
8 patients. Females were more than twice as likely as males to select sleep and
9 anxiety, with 8/22 (36%) and 12/22 (55%), respectively. Patients treated for
10 twelve months or less selected considerably more items than patients further
11 from diagnosis in regard to appetite (40%), cancer treatment (48%), use of a
12 feeding tube (32%), wound healing (16%) support for the family (16%), and
13 specialists of dietician (28%) and speech therapist (52%). Appetite (42%) and
14 appearance (46%) were about three times more likely to be selected by
15 patients who had more extensive neck disease (N2-N3). Individuals
16 undergoing reconstruction indicated more frequently excessive salivation
17 (22%) compared to those without reconstruction (3%). The item dry mouth
18 was indicated by 16 (35%) of patients who underwent radiotherapy and 17
19 (81%) of those who did not undergo surgery. In addition, 19 patients (66%)
20 who underwent primary radiotherapy (RT) selected dry mouth, and one-third
21 of those who underwent surgery without RT selected salivation and
22 depression (33%), and one-quarter selected strategies to confront the disease
23 and the treatment (24%) and mood (29%). The physical domain score was
24 significantly associated with the selection of items for appetite, mouth
25 opening, pain in head and neck, swallowing, swelling, recreation,
26 relationships, speech/voice/being understood and fear of adverse events as
27 well as selection of dentist, speech pathologist and oncologist/radiotherapist.
28 The socio-emotional domain score was significantly associated with the items
29 for appetite, chewing/eating, mouth opening, swallowing, taste, feeding tube,
30 speech/voice/being understood and memory as well as speech pathologist
31 and oncologist/radiotherapist. Patients with UWQOL composite scores of
32 below 50 were particularly affected.

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46 Additional concerns and specialists that were not present in the original
47 instrument were suggested by the patients under the item "others". These
48 items and specialists included the following: spouse/partner (twice),
49 gastroesophageal reflux, follow-up, hair loss, choking, dementia, quality of life,
50 transportation to hospital (displacement/cost), health insurance, dependent on
51 others to provide support in general, diabetes, alternative treatments, burning
52 tongue, sensation of suffocation, geriatrician, professor of physical education
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specialized in oncology, otorhinolaryngologist, neurologist, acupuncturist, hematologist, vascular physician, dermatologist (four times), gastroenterologist, nephrologist, ophthalmologist, and orthopedist.

Discussion

The assessment of HRQOL of patients with HNC is typically measured using specific questionnaires that cover a complex conceptual framework involving physical, psychological and social domains¹⁸ [17]. Worldwide, the most widely used questionnaires are the EORTC QLQ-H&N35¹⁹ [18], the UW-QOL^{3,15,16} [3,15,16] and FACT the H&N²⁰ [19].

The conception and main goals of the PCI are different from HR-QOL questionnaires available in Brazil, since it enables the health team to know in real time the priorities and concerns raised by patients, helping them to target and structure consultations and promote shared decision making and multidisciplinary care¹⁰ [10]. Moreover, the PCI encompasses a wide range of different concerns in diverse areas of the patient's life, which may be affected by the disease and/or treatment. Given the importance of this topic as well as the increased survival of individuals with HNC, the availability of a specific and easy-to-use clinical tool is necessary in the Brazilian-Portuguese language to allow physicians to identify the concerns that permeate the lives of these patients during and after their treatment and to expedite any referrals or clarifications they require. Mainly in busy referral medical centers, this instrument could help to focus the clinical consultation on the patients needs, promote a more comprehensive multidisciplinary care, which could result in a more personalized approach.

Although the study consisted mainly of patients with tumors of the oral cavity, oropharynx and larynx with a few cases of nasopharynx, hypopharynx, nasal cavity, maxillary sinus, and other HNC sites, the patient sample was fully represented by different tumor stages, treatment modalities and time intervals from diagnosis. Several other concerns and other specialists not in the original instrument emerged during this study, which should be considered in future refinements of the PCI, a factor already considered by the original author (SNR) since the initial conception of the PCI¹⁰ [10].

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Generally the impressions about the PCI from patients were largely favorable, as illustrated by the following comments: "Sometimes the doctor is unwilling to talk about some subjects; I do not know if it is lack of time or because they don't want to trouble the patient... many doctors want to protect the patient..." "All that I feel is written there...!" "This questionnaire was very important to me; it could produce an explanatory leaflet about everything that can happen to us because of the treatment..." "From the common concerns and common cases, group meetings could be established for patients and families..." "... This questionnaire is like an anticipated dialogue with the doctor...!" "This was the first time someone listened to me and asked how I felt. I have already taken this initiative with respect to the hospital, but it is the first time someone from the hospital has taken this initiative in relation to me..." "...In several years of continuous treatment at the hospital, this is the first time I've been formally consulted on topics related to the treatment. I think that with this, I could contribute more with my experiences to enhance the hospital services..." "It's gratifying to have people worried about their neighbor. Thank's for this! "

The item selected most often by patients was the fear of their cancer returning (also named fear of recurrence- FoR), followed by dry mouth and chewing/eating and the indication for a speech therapist and dentist. Other studies that used the PCI-H&N have also found the FoR to be the most common concern that patients with HNC want to discuss in clinics^{10,21,22} [10,20,21], specially in patients aged less than 65 years, who seemed to experience more significant FoR^{23,24} [22,23], which is in accordance with the findings of the present study. The use of the PCI during the clinical routine seems to "allow" and facilitate patients to talk about this heavy burden with the clinical team, which is usually not addressed during consultation and that may cause detrimental effects on patients psychological well-being²⁵ [24].

For the PCI validation we considered that the most important step of cultural validation of PCI in Brazilian-Portuguese language was the rigorous process of translation and back-translation as well as the cultural adaptation of some words and expressions not well understood or misinterpreted by Brazilian patients. However, we decide to test the construct validity of the Brazilian version comparing its results with the UW-QOL scores. The results

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6 showed important associations between the Brazilian-Portuguese version of
7 PCI with the UW-QOL scores. Patients with low UW-QOL scores had higher
8 number of issues selected for discussion on PCI, confirming the hypothesized
9 scenario of low QOL scores were related to the number of issues raised on
10 PCI.
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13 Overall, the results of the present study demonstrated good user
14 feasibility/acceptability of the PCI and have shown that there are significant
15 correlations of PCI with clinical variables and the UW-QOL, which is in
16 accordance with the expectations related to this instrument and support the
17 usefulness of the PCI in our population.
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22 The incorporation of the PCI-H&N into clinical practice has the potential
23 of offering patients the freedom to choose whether they wish to address some
24 of their concerns at any point during treatment with members of the clinical
25 team, supporting the adoption of appropriate strategies and referrals, which
26 may in turn minimize the impact of the disease and its treatment in different
27 areas of the patient's life. In its original conception in the UK, the PCI and
28 UW-QOL were completed by patients using a touch-screen computer (TST)
29 and the responses were networked into the consultation room. In the present
30 study, touch-screen technology was not available and patients received a
31 printed version of the translated PCI. The concomitant use of a HRQOL
32 instrument like UW-QOL, allows patients with any dysfunction to be identified
33 and thus promote an opportunity for the clinician to discuss aspects where
34 patients are performing badly even though the patient might not have selected
35 related items on the PCI for discussion. In this scenario, PCI can be used by
36 itself either on paper or via touch screen and can be used together with a
37 HRQOL questionnaire prior to consultation.
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47 **Conclusion**

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50 In conclusion, the PCI is the only clinical tool in this class now available
51 for patients with HNC that is fast, easy to administer and can be used alone or
52 in conjunction with HRQOL questionnaires. The translation and adaptation of
53 the PCI into Brazilian-Portuguese can be considered successful, and the
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results demonstrate its applicability and sensitivity, making the Portuguese version a valuable tool that can be used within the Brazilian population. International comparison would give valuable insight into the cross-cultural patients experience of HNC survivorship.

Further studies using the Brazilian-Portuguese version of the PCI must evaluate the adherence of the clinical staff to this new tool, evaluate the optimization of the communication between the clinician and the patient, verify if the previously undiagnosed concerns of the patients were actually identified and discussed, assess if there were any changes in the number of referrals to other members of the multidisciplinary team and explore the changes in patient concerns over time.

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For Review Only

Table 1: Patients characteristics and the number of items and professional specialists selected in the PCI (n=84)

		Number of issues selected				Number of professionals selected				
		n	Median	IQR	%	5+ items		2+ professionals		
						n	Median	IQR	%	n
Age ⁺	<55	20	9	5-12	80	16	2	0-4	60	12
	55-64	27	7	4-12	67	18	1	0-3	37	10
	>=65	37	9	5-14	78	29	0	0-1	22	8
Gender	Male	62	8	5-13	76	47	0	0-2	31	19
	Female	22	10	4-15	73	16	1.5	1-4	50	11
Site	Oral Cavity	35	8	4-13	71	25	1	0-3	31	11
	Oropharynx	19	9	5-15	79	15	1	0-3	47	9
	Larynx	20	8	5-10	75	15	0	0-2	30	6
	Others	10	10	7-13	80	8	1	0-2	40	4
Time from diagnosis ⁺ (months)	<12	25	13	7-15	84	21	2	0-4	60	15
	12-36	22	9	4-12	73	16	0.5	0-2	36	8
	>=36	37	7	4-11	70	26	0	0-1	19	7
T <u>stage</u>	T1_2	38	7.5	4-12	66	25	1	0-2	37	14
	T3_4	44	8.5	6-14	82	36	0.5	0-3	34	15
N <u>stage</u>	N0_1	59	7	4-12	69	41	0	0-2	27	16
	N2_3	24	11	8-15	88	21	2	0-3	54	13
Reconstruction	no	38	8.5	4-12	68	26	1	0-2	34	13
	yes	46	8	5-14	80	37	1	0-3	37	17
RT	no	16	8.5	4-16	63	10	1	0-2	38	6
	yes	68	8	5-13	78	53	1	0-2	35	24
Treatment	Surgery , no RT	21	10	4-17	67	14	1	0-3	48	10
	Surgery & RT	34	7	5-11	76	26	0	0-1	21	7
	Primary RT	29	9	6-13	79	23	1	0-3	45	13
Physical function (UW-QOL) ⁺⁺⁺	<50	9	9	8-16	100	9	3	2-4	89	8
	50-74	19	12	9-16	84	16	1	0-5	47	9
	75-89	26	9	4-13	73	19	1	0-2	38	10
	90+	30	6	3-9	63	19	0	0-1	10	3
Social-emotional (UW-QOL) ⁺⁺	<50	20	12	8-15	90	18	1.5	0-4	50	10
	50-74	27	9	6-14	85	23	1	0-3	48	13
	75-89	20	6	4-10	70	14	0	0-1	20	4
	90+	17	4	2-8	47	8	0	0-1	18	3

+0.001!p<0.01 Spearman correlation for the number of issues selected; *0.001!p<0.01 Spearman correlation for the number of specialists selected; ++p<0.001 Spearman correlation for the number of issues selected; **p<0.001 Spearman correlation for the number of specialists selected; None of the other patient characteristics were associated at p!0.01 with the number of issues or specialists selected according to the Mann-Whitney test (Gender, clinical T, N, Reconstruction, RT, Surgery) or Kruskal-Wallis test (Site, Treatment). RT = Radiotherapy

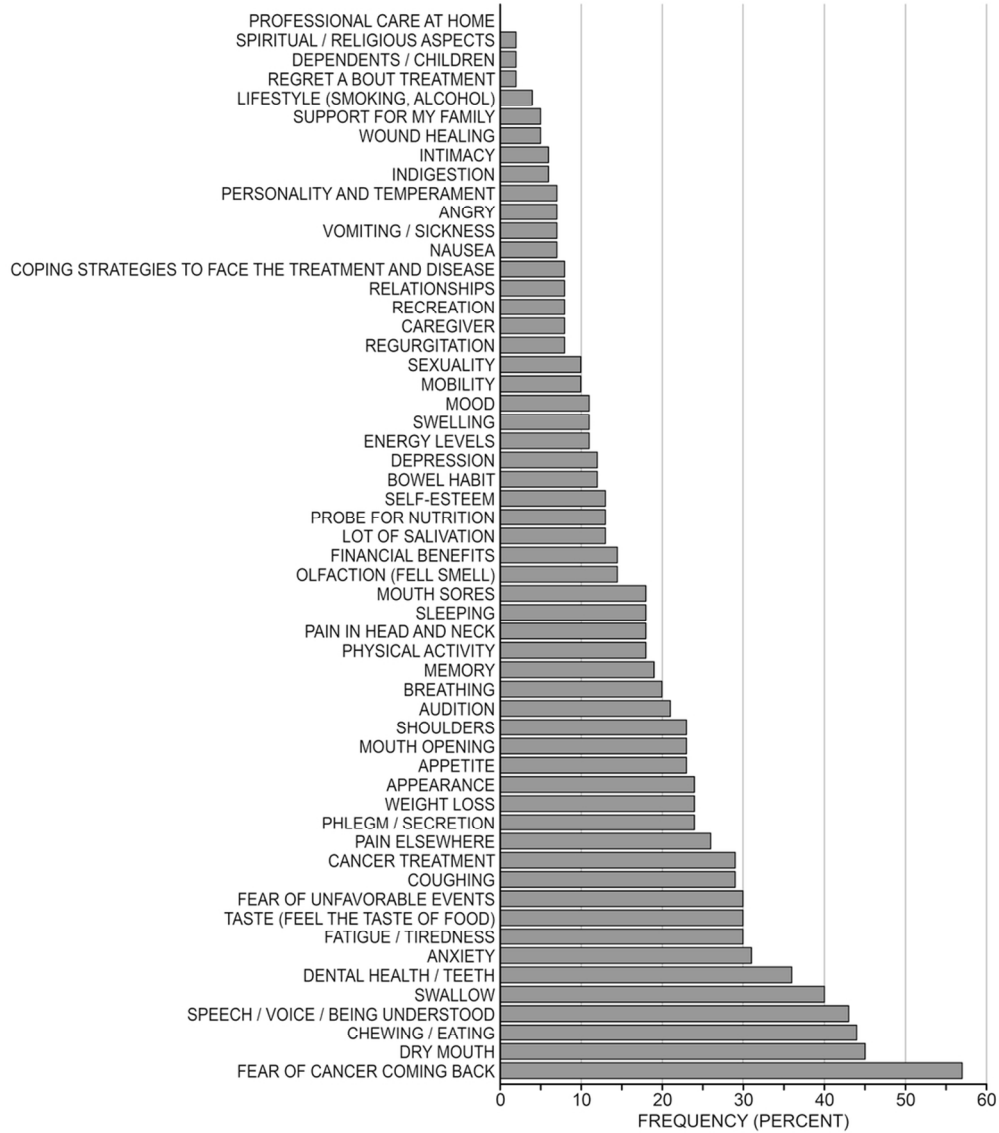


Figure 1 - The frequency of the items indicated on the PCI

47x53mm (600 x 600 DPI)

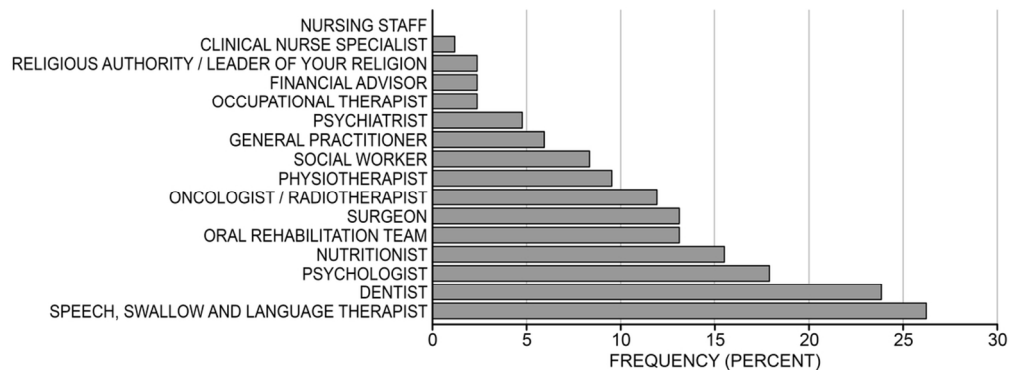


Figure 2 - The frequency of the specialists indicated on the PCI

51x19mm (600 x 600 DPI)

Review Only

APPENDIX

Inventário de Preocupações dos Pacientes – IPP

Nome: _____

Idade: _____

Sexo: Fem () Masc ()

Data: _____

Por favor, escolha nesta lista os temas que lhe preocupam e sobre os quais você gostaria especificamente de falar em sua consulta clínica hoje. Você pode escolher mais de uma opção.

Bem-estar Físico e Funcional

- () Atividade Física
 () Apetite
 () Hábito Intestinal
 () Respiração
 () Mastigar/comer
 () Tosse
 () Saúde dental/dentes
 () Boca seca
 () Níveis de energia
 () Fadiga/cansaço
 () Audição
 () Indigestão
 () Mobilidade
 () Abertura de boca
 () Catarro/secreção
 () Náusea
 () Dor na cabeça e pescoço
 () dor em outro lugar
 () Regurgitação
 () Muita salivação
 () Ombros
 () Sono
 () Olfato (sentir cheiro)
 () Feridas na boca
 () Engolir
 () Inchaço
 () Paladar (sentir sabor)
 () Vômitos/ mal-estar
 () Perda de peso

Relacionadas ao Tratamento

- () Tratamento do câncer
 () Arrependimento pelo tratamento
 () Sonda para alimentação
 () Cicatrização de feridas

Assistência e Bem-estar Social

- () Cuidador
 () Dependentes / crianças
 () Benefícios financeiros
 () Atendimento de profissionais à domicílio
 () Estilo de vida (fumo/álcool)
 () Recreação
 () Relacionamentos
 () Fala/voz/ser entendido
 () Suporte para minha família

Bem-Estar Psicológico, Emocional e Espiritual

- () Aparência
 () Raiva
 () Ansiedade
 () Estratégias para enfrentar a doença e o tratamento
 () Depressão
 () Medo do câncer voltar
 () Medo de acontecimentos desfavoráveis
 () Intimidade
 () Memória
 () Humor
 () Auto-estima
 () Sexualidade
 () Aspectos espirituais/religiosos
 () Personalidade e temperamento

Outros (por favor, indique)

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Por favor, indique os profissionais com os quais você gostaria de conversar durante seu dia de consulta no hospital ou para os quais você gostaria de ser encaminhado. Você pode indicar mais de uma pessoa.

Marque um X

Bem-estar Físico e Funcional

- Dentista
- Equipe de reabilitação oral
- Nutricionista
- Fisioterapeuta
- Fonoaudiólogo
- Terapeuta Ocupacional
- Equipe de enfermagem

Relacionados ao Tratamento

- Cirurgião
- Oncologista / Radioterapeuta
- Enfermeira clínica especialista

Assistência Social e Bem-estar

- Assistente Social
- Clínico Geral
- Assessor financeiro

Bem-estar Psicológico, Emocional e Espiritual

- Autoridade Religiosa / Líder da sua religião
- Psiquiatra
- Psicólogo

Outros (por favor, indique):

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