


BMJ Open Psychometric validation of a Patient-Centred Quality of Cancer Care Questionnaire in Mexico

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ABSTRACT

Objectives To develop and validate a Patient-Centred Quality of Cancer Care Questionnaire in Spanish (PCQCCQ-S) appropriate to the Mexican context.

Design Psychometric validation of a questionnaire.

Setting Two public oncology hospitals in Mexico City.

Participants 1809 patients with cancer aged ≥18 years.

Source of information Cross-sectional survey.

Methods The validation procedures comprised (1) content validity through a group of experts and patients; (2) item reduction and evaluation of the factor structure, through an exploratory factor analysis based on the polychoric correlation matrix; (3) internal consistency using Cronbach's alpha; (4) convergent validity between the PCQCCQ-S and supportive care needs scale; (5) correlation analysis between the PCQCCQ-S and quality of life scale by calculating Spearman's rank-correlation coefficient; and (6) differentiation by 'known groups' through the Wilcoxon rank-sum test.

Results The PCQCCQ-S has 30 items with the following five factors accounting for 96.5% of the total variance: (1) timely care; (2) clarity of the information; (3) information for treatment decision-making; (4) activities to address biopsychosocial needs; and (5) respectful and coordinated care. Cronbach's alpha values ranged from 0.73 to 0.90 among the factors. PCQCCQ-S has moderate convergent validity with supportive care needs scale, revealing that higher quality is correlated with lower patient needs. PCQCCQ-S has acceptable ability to differentiate by 'known groups', showing that older patients and those with low levels of education perceived lower total quality of care as compared with their counterparts.

Conclusion PCQCCQ-S has acceptable psychometric properties and can be used to measure quality of patient-centred cancer care in Mexico and serve as a reference to develop PCQCCQ-S in other Spanish-speaking countries.

INTRODUCTION

Cancer is a set of complex chronic diseases and a leading cause of morbidity and mortality worldwide. It disproportionately affects people in low-and-middle-income countries (LMICs) where 70% of deaths from cancer occur.^{1 2}

Strengths and limitations of this study

- The study addresses an important gap in the literature of scarcity of psychometrically rigorous patient-reported experience measures for assessing patient-centred quality of cancer care in low-and-middle-income countries and in languages other than English.
- The multidisciplinary group of clinical experts and patients validated the content of the Patient-Centred Quality of Cancer Care Questionnaire in Spanish (PCQCCQ-S).
- The PCQCCQ-S psychometric properties were validated in a large sample of patients with haematological (n=467) and solid (n=1342) cancers.
- The PCQCCQ-S validation was performed in a group of patients treated at two public oncology hospitals in Mexico City, possibly limiting generalisability of the results.

In Mexico, cancer is the fourth cause of hospitalisations and the third cause of death among adults.^{3 4} Patients with cancer in LMICs face access and financial barriers to healthcare, largely caused by shortages of trained health professionals, equipment and palliative care services.^{5 6} These deficiencies reduce patients' chances of receiving high-quality, patient-centred care needed to satisfy their healthcare needs and face the mental and social challenges associated with the disease.⁷⁻⁹

Patient-centredness is a core component of high-quality healthcare.¹⁰ It calls on providers to respect patients' values and preferences, facilitate access to continuous and coordinated care, address patients' physical and emotional needs, and provide adequate information to enable patient participation in healthcare-related decision-making and self-care.^{1 2} Patient-centred care can improve healthcare utilisation, efficiency, quality of care and patient satisfaction.¹¹⁻¹³

Patient-reported experience measures (PREMs) are important metrics of patient-centred quality of care that are complementary to process and outcomes measures. PREMs aim at informing health system policy and improvement initiatives on user perspectives and experiences with health services.¹⁴

There are few studies evaluating the quality of cancer care from the patient-centredness perspective in LMICs,⁷ and based on our literature review, none from Latin American countries has explored Patient-Centred Quality of Cancer Care (PCQCC) using validated PREMs. Existing PCQCC tools are designed for high-income countries and in English.¹⁵ The gap in the literature might be explained by the scarcity of validated psychometrically rigorous tools for LMICs and in Spanish, for measuring PCQCC.¹⁵

This study aims to address this gap by validating a Patient-Centred Quality of Cancer Care Questionnaire in the Spanish language (PCQCCQ-S) appropriate to the Mexican context.

METHODS

We conducted a psychometric validation of a PCQCCQ-S. The validation procedures comprised two stages: (1) development of the PCQCCQ-S and assessment of its content validity; (2) evaluation of the PCQCCQ-S factor structure, internal consistency and construct validity through convergent validity, correlation analysis and differentiation by 'known groups'.

Stage 1

We performed a literature review of existing PCQCC measurement instruments. We identified one comprehensive PCQCCQ developed in Australia¹⁶; the 48-item self-report questionnaire covers 10 domains around treatment delivery and decision-making, coordinated and integrated care, emotional support, timely care, follow-up care, respectful communication, patient preferences and values, cancer information and equitable care. The Australian PCQCCQ showed acceptable content and construct validity, and internal consistency based on a validation of the scale for patients with haematological cancer.¹⁶ Recognising the strengths (focus on patient-centred care characteristics and rigorous psychometric validation) of the Australian PCQCCQ, we used it as a reference to develop and validate a Spanish-version questionnaire applicable to patients with different types of cancer. This decision was justified by the relevance of the common patient-centred care principles measured by the Australian PCQCCQ to the quality of cancer care independently of cancer type.

The Australian PCQCCQ was translated into Spanish in accord with Mexican usage by a bilingual translator. A group of experts comprising eight oncologists, one psychologist, one nurse, one social worker, two health systems researchers and eight patients with cancer (one for each cancer included in this study) was assembled. All health professionals in the expert group had at least

≥10 years of experience in cancer care and in validation of health assessment tools. Experts assessed language appropriateness and whether the PCQCCQ items were representative of the concept they intended to measure by rating each item as: 1='not relevant', 2='useful but not relevant, or not feasible' or 3='relevant'. Experts' responses were grouped and those items rated as 'relevant' were counted; a content validity index (CVI) was then calculated for each item as $(n_c - N/2) / (N/2)$, where ' n_c ' is the number of experts who indicated the item as 'relevant' and N is the total number of experts.¹⁷ Items rated poorly were revised or removed from the initial list. As a result, four items related to the choice of medical provider were eliminated, as patients receiving care in the public health institutions in Mexico cannot choose their medical doctor.

Two new items were proposed for inclusion in the questionnaire: 'The staff at the hospital provided clear information about the cancer diagnosis' and 'The staff at the hospital treated the patient as a person and not as a medical case'. Also, due to the generally low educational level of Mexican patients, the self-report questionnaire was modified to be administered by an interviewer.

Following these adjustments, a pilot of the Mexican PCQCCQ-S was performed with 25 patients with cancer to assure its comprehensibility for patients of different educational backgrounds. We included five patients for each of the following educational levels: none or incomplete elementary school, completed elementary school, completed secondary school, completed high school, university degree. As a result, a negatively worded statement, "I had to wait too long," was changed to "I had to wait for a short length of time", and additional minor editions were proposed at this time.

At the end of the first stage, we included 46 items in the psychometric testing (44 originated from the Australian PCQCCQ and 2 new items).

Stage 2

From April 2018 to April 2019, a cross-sectional survey was conducted in two oncology hospitals in Mexico City, one that belongs to the Ministry of Health (MoH) and another to the Mexican Institute of Social Security (IMSS). The hospitals included in this study were selected by convenience sampling and are the largest oncology hospitals in Mexico that provide care for patients with any type of cancer who live in Mexico City or nearby states.

Approximately 90% of the Mexican population receives healthcare at the MoH or IMSS facilities. Formal sector workers and their families are covered by mandatory social health insurance under IMSS, which has 65 million affiliates.¹⁸ Meanwhile, the federal MoH institutions and the MoH local health secretariats in every Mexican state provide healthcare to 54 million people without social security.

The study population comprised outpatient patients with cancer aged ≥18 years with one of the eight most frequent types of cancer in Mexico: leukaemia, lymphoma

and multiple myeloma, breast, cervix, colon, lung or prostate cancer. These cancers account for 62% of hospital discharges and deaths.¹⁹ We included patients with at least one hospitalisation during the last year, ≤ 5 years since diagnosis and without mental impairment.

Four registered nurses participating in the fieldwork received a 1-week training course covering participant identification, recruitment and questionnaire implementation. During the study period, the nurses interviewed all patients who met the inclusion criteria, agreed to participate and signed informed consent forms. The interview took place immediately after patients' medical consultation. After the interview, two field coordinators reviewed patients' health records to verify diagnosis and treatment. Also, the coordinators screened each questionnaire for missing values and verified them with patients on the same day of his/her participation. This strategy resulted in the absence of variables with missing values in the study analysis.

Sample size was based on the practice of ensuring a person-to-item ratio of 10:1.²⁰ The initial estimated sample was 460 patients per institution for haematological and solid cancer groups. The largest possible sample size is recommended to run the factor analysis because adequacy of the sample size cannot be determined until after data have been analysed.²¹ Thus, the final sample was also based on availability of patients and included 1241 IMSS patients and 568 MoH patients comprised of 467 patients with haematological cancers and 1342 with solid cancers. Sequential sampling was used to complete the sample in each hospital.

Statistical analysis

We carried out a descriptive analysis to depict patient characteristics and identify the distribution of each PCQCCQ-S item. We performed the item reduction and evaluation of the factor structure, through exploratory factor analysis based on the polychoric correlation matrix, due to the asymmetric distribution of most items.²² We identified the number of factors as those with Eigenvalues larger than 1.00. We used Promax oblique rotation based on the assumption that the factors relate to one another. Factor loadings >0.4 were considered significant. Based on this criterion, we excluded items with lower factor loading and those associated with more than one factor.²³ Additionally, we calculated the percent variance explained by each factor and communality of each item.

We performed five separate factor analyses: (1) all observations treated as a single group; (2) patients with haematological cancers; (3) patients with solid cancers; (4) IMSS patients; and (5) MoH patients. The results for these five analyses were similar, and therefore, we present only the whole sample analysis.

The score for each PCQCCQ-S factor (domain) was calculated by adding all subscale items and dividing them by the number of items in each factor as suggested by Tzelepis *et al*, with a minimum score of 1 and maximum of 4 per domain and for a total PCQCCQ-S score.¹⁵

We used Cronbach's alpha to measure the internal consistency of the items under the same domain, considering alpha coefficients >0.7 as acceptable.²⁴ We assessed convergent validity among each PCQCCQ-S factor scores and the supportive care needs scores⁸ by calculating Spearman's rank correlation coefficient; $r < 0.35$ was considered to represent weak correlation, $r = 0.36-0.67$, moderate correlation, and $r = 0.68-1.0$, strong correlation.²⁵ Convergent validity is the 'degree to which scores on a new questionnaire are related to measures of another scale that can be expected on theoretical grounds to be close to the one measured by a new questionnaire'.²⁶ We considered the supportive care needs scale as an indirect measure of the quality of care. We assumed that the PCQCCQ-S would have a moderate negative correlation with supportive care needs scale, as the highest quality of care would be correlated with the lowest supportive care needs.

In addition, we performed a correlation analysis between the PCQCCQ-S and health-related quality of life (HRQoL) scale to determine the relationship between existing HRQoL measure and newly developed PCQCCQ-S. We hypothesised that the PCQCCQ-S would have a moderate positive correlation with HRQoL, expecting that higher quality of care would be correlated with better quality of life.

Wilcoxon rank-sum test served to evaluate the ability of the Mexican PCQCCQ-S to differentiate between subgroups of patients with cancer such as by sex, age group, schooling, healthcare provider, cancer type and stage. This test compared the medians of the score domains of different subgroups of patients. Based on previous research on quality of cancer care,¹⁰ we hypothesised that patients who were male, aged ≥ 60 years, had lower education levels, had comorbidities and had haematological cancer, were at advanced cancer stages, and/or who attended MoH hospitals would receive lower quality of care compared with their counterparts.

For the analysis, we used Stata V.14.0 (Stata, College Station, Texas, USA) and considered $p < 0.05$ as statistically significant.

Study covariates

Other study variables included general patient characteristics (sex, age, place of residence, schooling, marital status, type of healthcare provider) and clinical history (length of time since diagnosis, type of cancer and stage, cancer treatment in the last month, supportive care needs and HRQoL).

To measure supportive care needs, we used the Short-Form Supportive Care Needs (SCNS-SFM) questionnaire previously validated in Mexico,⁸ which consists of 33 items grouped into five domains: (1) psychological needs; (2) needs related to information about the health system environment, continuity of care and provision of information; (3) physical and daily living needs; (4) sensitivity of healthcare professionals to patients' physical and emotional needs; and (5) sexuality-related needs. Each item has a 5-point Likert response option scale, where 1

corresponds to the absence of need and 5 to high need for support. Scores for each domain were calculated according to the McElduff *et al* scoring recommendations.²⁷ The final standardised scores ranged from 0 (no need) to 100 (high need).

HRQoL was measured using the European Organization for Research and Treatment of Cancer (EORTC QLQ-30) quality of life questionnaire, which consists of 30 items grouped in an overall health subscale, five functional subscales (physical, role, emotional, cognitive and social functioning). Each item has a 4-point Likert response option scale, and two overall health questions have a 7-point response option scale. We transformed each subscale linearly to a score of 0–100, with 100 representing the best for overall health and functional status. EORTC QLQ-30 was validated previously in Mexican Spanish.²⁸

Patient and public involvement

Patients were engaged in the expert group that performed content validity of the Mexican PCQCCQ-S, and they participated in the pilot testing of the questionnaire; yet, patients were not involved in the design and conception of the present study.

RESULTS

Out of 1965 eligible patients with cancer, 1809 (92%) agreed to participate. The main reasons for not participating were lack of time; no interest; and fatigue, weakness or pain.

Most participants were women (57.8%), 59 years or younger (57%), residents of Mexico City (58%) or the State of Mexico (27.6%), with low educational level (secondary school or lower, 59.7%) and/or were living with a life partner (65.7%). IMSS provided care to most patients (68.6%). They were most often diagnosed <1 year prior to the study (65.5%). Breast (25.4%) and colorectal cancer (17.7%) were the most common. 66.9% had an advanced disease stage. During the last month, 16% of patients had undergone surgery, 68.0% chemo or radiotherapy, and 47.8% other types of treatment. Physical and daily living needs (mean 45.2 points) were the most frequent supportive care needs, whereas patient care (21.4 points) scored the lowest. Furthermore, the mean score for overall health was 59.5, ranging from 77 points for cognitive functioning to 56.4 for role functioning (table 1).

The descriptive statistics of PCQCCQ-S revealed that the statements showing the highest percentage of ‘strongly disagree’ responses were about staff providing or helping patients’ family or friends find information on ‘how to find others in a similar situation to talk to’ (68.6%), ‘how to deal with being worried, upset, or sad’ (64%), ‘information to take home’ (63.8%) and ‘helping to deal with spiritual needs’ (59.6%), ‘changes in personal relationships’ (54.2%) and information on ‘whom to contact with questions about patients’ care’ (48.7%). The statements

Table 1 General patient characteristics, clinical history, supportive care needs and health-related quality of life (n=1809)

	%
General patient characteristics	
Women	57.8
Age, mean (SD)	55.4 (14.6)
60 years or older	43
Place of residence	
Mexico City	58
State of Mexico	27.6
Other States	14.4
Schooling	
None or incomplete elementary school	12.8
Elementary school	18.6
Secondary school	28.3
High school degree	24.8
University degree or higher	15.5
Marital status	
Married or free union	65.7
Single or divorced or widowed	34.3
Health care provider	
IMSS	68.6
MoH	31.4
Clinical history	
Length of time since cancer diagnosis	
<1 year	65.5
≥1 and <3 years	29.5
≥3 and ≤5 years	5.0
Type of cancer	
Leukaemia	8.7
Lymphoma	12.1
Myeloma	5.0
Breast cancer	25.4
Cervical cancer	8.3
Prostate cancer	15.7
Colorectal cancer	17.7
Lung cancer	7.1
Cancer stage	
Early (I–II)	33.1
Advanced (III–IV)	66.9
Cancer treatment in the last month*	
Surgery	16.0
Chemotherapy and/or radiotherapy	68.0
Other (hormonotherapy, immunotherapy, among others)	47.8
Supportive care needs	
Health systems and information	Mean (SD) 42.5 (27.4)

Continued

Table 1 Continued

	%
Physical and daily living	45.2 (27.7)
Psychological	38.5 (28.4)
Sexuality	23.6 (31.2)
Care and support	21.4 (23.0)
Quality of life	
Overall health status	59.5 (19.8)
Functional scales	
Cognitive functioning	77.0 (25.8)
Emotional functioning	69.1 (27.7)
Physical functioning	66.7 (25.8)
Social functioning	63.6 (31.6)
Role functioning	56.4 (34.5)

*'Cancer treatment' variable describes all types of treatment that the patient received in the last month; consequently, the sum of treatment categories exceeds 100%.

IMSS, Mexican Institute of Social Security; MoH, Ministry of Health.

showing the highest percentage of 'strongly agree' responses were the following: 'staff showed respect for the patient' (74.5%); 'coordination of the appointments, so the patient did not have to go the hospital more than necessary' (64.7%); and 'staff attended to pain or discomfort promptly' (63.9%) (table 2).

The results of the factor analysis indicate that 5 factors and 30 items were retained for the final version of the PCQCCQ-S (table 3). We excluded 16 items due to their low factor loading, or their association with more than one factor. Table 3 depicts the item loadings for the rotated factor solution and the variance and Cronbach's alpha for each factor of the final version of the PCQCCQ-S. The five factors identified through the analysis accounted for 96.5% of the total variance. We presented the factors based on the logic of the care continuum. We termed the first factor 'timely care'; it contains three items and $\alpha=0.79$. The second factor, 'clarity of the information,' also includes three items ($\alpha=0.82$). The third factor, 'information for treatment decision-making' contains five items ($\alpha=0.83$). The fourth factor, which we termed 'activities to address biopsychosocial needs,' consisted of 13 items ($\alpha=0.90$) and focused on psychological (eg, worries, sadness, changes in personal relationship) and spiritual needs; self-care needs (eg, information on day-to-day tasks and leisure activities), financial support, among others. The fifth factor, which we termed 'respectful and coordinated care,' contained six items ($\alpha=0.73$). Finally, the Cronbach's alpha of the total number of PCQCCQ-S items was 0.90.

Table 4 presents the results of the convergent validity and correlation analysis. Moderate statistically significant negative correlation was observed between the 'health systems and information' domain of SCNS-SFM

and PCQCCQ-S factors of 'clarity of the information' ($r=-0.38$), 'information for treatment decision-making' ($r=-0.40$), 'activities to address biopsychosocial needs' ($r=-0.45$), 'respectful and coordinated care' ($r=-0.39$) and total PCQCCQ-S score ($r=-0.55$). Additionally, the SCNS-SFM 'care and support' domain correlated with the 'respectful and coordinated care' ($r=-0.45$) factor and the total PCQCCQ-S score ($r=-0.37$). In addition, we found weak correlations among EORTC QLQ-30 domains and PCQCCQ-S factors.

The results of the analysis of differentiation of PCQCCQ-S by 'known groups' indicate that men, patients 60 years and older, those with haematological cancer and in advanced cancer stages, and those who received care at IMSS reported a lower score for timely care (table 5). Clarity of the information and information for treatment decision-making was low for those without a high school level of education. The perception of respectful and coordinated care was lower at MoH hospitals compared with IMSS hospitals. Furthermore, older patients with low education levels had a lower score in the factor of 'activities to address biopsychosocial needs' and a lower total PCQCCQ-S score.

Online supplementary file 1 presents the final PCQCCQ-S.

DISCUSSION

A validated measurement tool to assess patient-centred cancer care is a prerequisite for quality assessment, accountability and improvement and hence key to improving access to cancer care. Yet, these tools are severely lacking in LMICs and in languages other than English. This study provides evidence for the acceptable content validity, factor structure, internal consistency and construct validity of a PCQCCQ-S in patients with haematological and solid cancers in two public health institutions in Mexico.

The reference for PCQCCQ-S was an Australian 48-item PCQCC questionnaire that focuses on characteristics of patient-centred care validated in patients with haematological cancer.¹⁶ However, to be used in another population, an adapted tool should be tested to show adequate psychometric properties.²⁹

The group of experts convened for this research reviewed content validity and excluded four items that did not apply to the Mexican context, proposed two additional items and modified others to assure their clarity for Mexican cancer patients with diverse educational backgrounds. Furthermore, the exploratory factor analysis retained only 5 factors and 30 items. The resulting PCQCCQ-S has 30 items and 5 factors: (1) timely care; (2) clarity of the information; (3) information that helps treatment decision-making; (4) activities to address biopsychosocial needs; (5) respectful and coordinated care. The first three factors are comparable with those in the Australian PCQCCQ; factors related to equitable care and patient preferences of the Australian PCQCCQ were eliminated

Table 2 Descriptive statistics of Patient-Centred Quality of Cancer Care Questionnaire in Spanish (PCQCCQ-S) (n=1809)

Items	Strongly agree (%)	Agree (%)	Disagree (%)	Strongly disagree (%)	Not applicable (%)
Waiting short length of time...					
Q1: from the first visit with the general practitioner about cancer-related symptoms to getting screening tests	44.4	24.2	12.3	19.1	0
Q2: getting reference to a cancer doctor	48.4	26.5	9.7	15.3	0
Q3: getting confirmed cancer diagnosis	53.1	29.5	8.8	8.6	0
The staff at the hospital...					
Q4: talked to the patients in a way he/she could understand	56.6	29.9	10.9	2.6	0
Q5: provided the information about cancer that was easy to understand	48.6	32.1	14.4	4.9	0
Q6: provided clear information about cancer diagnosis	54.2	28.6	12.9	4.3	0
The doctors at the hospital explained...					
Q7: all of the treatments that the patient could have	40.9	24.3	15.3	19.6	0
Q8: the consequences of not having treatment	44.7	19.7	12.4	23.2	0
Q9: the short-term side effects of each treatment option	48.2	24.4	10.8	16.5	0
Q10: the long-term side effects of each treatment option	27.3	16.2	22.1	34.4	0
Q11: how each treatment option might affect length of life	33.8	20.1	17.4	28.7	0
The staff at the hospital helped to deal with...					
Q12: being worried, upset or sad	16.3	19.6	18.1	45.9	0
Q13: spiritual needs	9.5	10.2	20.6	59.6	0.1
Q14: changes in personal relationship	10.0	12.7	23.1	54.2	0
The staff at the hospital provided information about...					
Q15: cancer and treatments to take home (eg, booklets, websites)	9.0	6.5	20.7	63.8	0
Q16: how to deal with day-to-day tasks (eg, childcare, housework)	15.0	15.5	22.2	47.2	0.1
Q17: whom to contact with questions about patients' care	14.3	14.8	22.2	48.7	0
Q18: what could be done as leisure activities to feel well	18.2	14.5	19.8	47.5	0
Q19: available financial support for patients with cancer	8.2	8.1	17.8	65.0	0.9
Q20: how to organise transport to and from the hospital	4.5	4.0	20.3	70.4	0.8
Q21: get parking close to the hospital	1.5	2.2	18.7	75.8	1.7
Q22: find other patients with cancer to talk to about their cancer	8.9	8.3	18.6	64.2	0
The staff at the hospital provided information to patient family or friends...					
Q23: how to deal with being worried, upset or sad	9.2	8.5	18.3	64.0	0
Q24: how to find others in a similar situation to talk to	4.5	6.5	20.4	68.6	0
The staff at the hospital...					
Q25: showed respect for patient	74.5	22.1	2.6	0.8	0
Q26: treated patient as a person and not as a medical case	63.3	23.8	7.2	5.7	0
Q27: attended promptly to pain or discomfort	63.9	26.8	5.6	3.6	0.1
Q28: coordinated appointments so that the patient did not have to go to hospital more than necessary	64.7	24.2	6.4	4.7	0
After hospital treatment had ended staff at the hospital helped...					
Q29: with formalities to move back home	57.6	27.2	8.7	6.5	0
Q30: with formalities/ necessary information to move to / follow-up in other hospitals/clinics	37.9	22.8	17.9	21.0	0.4

Table 3 Factor analysis of Patient-Centred Quality of Cancer Care Questionnaire in Spanish (PCQCCQ-S) (n=1809)

Factors and items	Factor loadings	Community	% of the total variance	Cronbach α
F1: Timely care			10.8	0.79
Waiting short length of time...				
Q1: from the first visit with the general practitioner about cancer-related symptoms to getting screening tests	0.87	0.75		
Q2: getting reference to a cancer doctor	0.89	0.80		
Q3: getting confirmed cancer diagnosis	0.60	0.49		
F2: Clarity of the information			16.2	0.82
The staff at the hospital...				
Q4: talked to the patients in a way he/she could understand	0.71	0.59		
Q5: provided the information about cancer that was easy to understand	0.85	0.78		
Q6: provided clear information about cancer diagnosis	0.84	0.71		
F3: Information for treatment decision-making			17.0	0.83
The doctors at the hospital explained...				
Q7: all of the treatments that the patient could have	0.55	0.53		
Q8: the consequences of not having treatment	0.71	0.63		
Q9: the short-term side effects of each treatment option	0.86	0.67		
Q10: the long-term side effects of each treatment option	0.80	0.68		
Q11: how each treatment option might affect length of life	0.86	0.71		
F4: Addressing biopsychosocial needs			41.1	0.90
The staff at the hospital helped to deal with...				
Q12: being worried, upset or sad	0.69	0.59		
Q13: spiritual needs	0.81	0.68		
Q14: changes in personal relationship	0.78	0.72		
The staff at the hospital provided information about...				
Q15: cancer and treatments to take home (eg, booklets, websites)	0.57	0.48		
Q16: how to deal with day-to-day tasks (eg, childcare, housework)	0.68	0.60		
Q17: whom to contact with questions about patients' care	0.62	0.48		
Q18: what could be done as leisure activities to feel well	0.57	0.56		
Q19: available financial support for patients with cancer	0.75	0.51		
Q20: how to organise transport to and from the hospital	0.88	0.69		
Q21: get parking close to the hospital	0.84	0.62		
Q22: find other patients with cancer to talk to about their cancer	0.80	0.61		
The staff at the hospital provided information to patient family or friends...				
Q23: how to deal with being worried, upset or sad	0.84	0.75		
Q24: how to find others in a similar situation to talk to	0.89	0.74		
F5: Respectful and coordinated care			11.4	0.73
The staff at the hospital...				
Q25: showed respect for me	0.48	0.39		
Q26: treated patient as a person and not as a medical case	0.66	0.61		
Q27: attended promptly to pain or discomfort	0.63	0.46		
Q28: coordinated appointments so that the patient did not have to go to hospital more than necessary	0.69	0.51		
After hospital treatment had ended staff at the hospital helped...				

Continued

Table 3 Continued

Factors and items	Factor loadings	Community	% of the total variance	Cronbach α
Q29: with formalities to move back home	0.77	0.50		
Q30: with formalities/necessary information to move to / follow-up in other hospitals/clinics	0.65	0.40		

after expert group content evaluation and factor analysis. In addition, as a result of factor analysis, the remaining factors of the Australian PCQCCQ were consolidated into two: activities to address biopsychosocial needs and respectful and coordinated care.

The characteristics of the study population and the provision of healthcare in Mexico could have influenced the results of the content and construct validity. For instance, patients at MoH and IMSS do not choose their hospital and healthcare provider. Moreover, patients with low educational attainment predominated in the sample. In our study, 12.8% of participants had not completed elementary school and 18.6% had only completed elementary school; in the Australian study, only 3.2% had an elementary school level of education. Furthermore, our population included patients with both solid and haematological cancer receiving healthcare in public hospitals, while the Australian study focused on patients with haematological malignancy and patients with private health insurance (68.8% of their sample).

Internal consistency of the Mexican PCQCCQ-S was acceptable with Cronbach's α values ranging from 0.73

to 0.90 for the different factors. It also showed moderate convergent validity with the supportive care needs measure, particularly with its 'health systems and information' and 'care and support' domains. The correlations between these two scales were negative, signalling that higher quality of care is correlated with lower patient needs. The study from Australia did not investigate the convergent validity of their PCQCCQ.

The analysis of PCQCCQ-S differentiation by 'known groups' revealed a perception of lower quality among patients >60 years and in those with low levels of education. In addition, failures in timely care were perceived by men, older patients, IMSS affiliates, patients with haematological cancer and patients at early cancer stages. In contrast, in Australia being younger and having had a recent diagnosis were associated with perceived lower quality of care by patients with cancer.³⁰ Several studies have found that older adults and those with lower levels of education are at greater risk for receiving low quality healthcare, which may be attributed to their limited capacity to demand quality due to inadequate health literacy.^{7 31 32}

Table 4 Convergent validity and correlation analysis of Patient-Centred Quality of Cancer Care Questionnaire in Spanish (PCQCCQ-S) (n=1809)

PCQCCQ-S domains	Timely care	Clarity of the information	Information for treatment decision-making	Addressing biopsychosocial needs	Respectful and coordinated care	Total score
SCNS-SFM domains	Convergent validity					
Health systems and information	-0.17*	-0.38*	-0.40*	-0.45*	-0.39*	-0.55*
Psychological	-0.16*	-0.24*	-0.20*	-0.16*	-0.25*	-0.27*
Care and support	-0.19*	-0.30*	-0.26*	-0.20*	-0.45*	-0.37*
Physical and daily living	-0.12*	-0.20*	-0.19*	-0.28*	-0.03	-0.28*
Sexuality	-0.04	-0.07**	-0.05**	-0.09*	-0.08**	-0.10*
EORTC QLQ-30	Correlation analysis					
Overall health status	0.12*	0.20*	0.21*	0.22*	0.18*	0.28*
Physical functioning	0.11*	0.11*	0.12*	0.18*	0.01	0.18*
Role functioning	0.10*	0.12*	0.13*	0.20*	0.02	0.19*
Emotional functioning	0.15*	0.21*	0.17*	0.15*	0.18*	0.23*
Cognitive functioning	0.17*	0.14*	0.10*	0.10*	0.17*	0.18*
Social functioning	0.08**	0.16*	0.19*	0.20*	0.06**	0.23*

Spearman's rank correlation coefficient: * $p < 0.0001$; ** $p < 0.05$.

EORTC QLQ-30, European Organization for Research and Treatment of Cancer ; SCNS-SFM, Short-Form Supportive Care Needs Questionnaire.

Table 5 Differentiation of Patient-Centred Quality of Cancer Care Questionnaire in Spanish (PCQCCQ-S) by 'known groups' (n=1809)

Variable	Categories	Timely care	Clarity of the information	Information for treatment decision-making	Addressing biopsychosocial needs	Respectful and coordinated care	Total score
Sex, median*	Female	3.3	3.3	2.8	1.5	3.5	2.4
	Male	3.0	3.3	2.8	1.5	3.5	2.5
Wilcoxon rank-sum test	Z statistic (p value)	2.85 (p=0.004)	-1.07 (p=0.283)	-1.29 (p=0.197)	0.09 (p=0.924)	-2.09 (p=0.036)	-0.26 (p=0.793)
	Age, median	3.3	3.3	2.8	1.5	3.5	2.5
Wilcoxon rank-sum test	<60 years	3.0	3.3	2.8	1.4	3.5	2.4
	>60 years	2.38 (p=0.017)	1.93 (p=0.053)	1.22 (p=0.224)	2.73 (p=0.006)	-2.61 (p=0.009)	2.16 (p=0.031)
Schooling, median	≤Secondary school	3.3	3.3	2.8	1.4	3.5	2.4
	>High school	3.3	3.7	3.0	1.6	3.5	2.5
Wilcoxon rank-sum test	Z statistic (p value)	-0.84 (p=0.399)	-4.52 (p=0.00001)	-2.92 (p=0.003)	-2.50 (p=0.013)	-1.004 (p=0.3156)	-2.66 (p=0.008)
	Chronic comorbidity, median	3.3	3.3	2.8	1.5	3.5	2.4
Wilcoxon rank-sum test	Yes	3.3	3.3	2.8	1.5	3.5	2.5
	No	3.3	3.3	2.8	1.5	3.5	2.5
Wilcoxon rank-sum test	Z statistic (p value)	-1.44 (p=0.149)	-0.92 (p=0.359)	-0.08 (p=0.933)	-1.44 (p=0.149)	-0.15 (p=0.879)	-1.44 (p=0.150)
	Healthcare provider, median	3.0	3.3	2.8	1.5	3.5	2.5
Wilcoxon rank-sum test	IMSS	3.3	3.3	2.8	1.4	3.3	2.5
	MoH	-6.00 (p=0.000)	0.34 (p=0.735)	0.90 (p=0.369)	1.87 (p=0.061)	5.86 (p=0.00001)	0.94 (p=0.349)
Cancer type, median	Haematological	3.0	3.3	2.8	1.5	3.5	2.5
	Solid tumours	3.3	3.3	2.8	1.5	3.5	2.5
Wilcoxon rank-sum test	Z statistic (p value)	2.16 (p=0.031)	0.37 (p=0.710)	-0.75 (p=0.455)	-0.27 (p=0.788)	-1.57 (p=0.117)	-0.15 (p=0.882)
	Cancer stage, median	3.3	3.3	2.8	1.5	3.5	2.5
Wilcoxon rank-sum test	I-II	3.0	3.3	2.8	1.5	3.5	2.4
	III-IV	2.87 (p=0.004)	0.59 (p=0.557)	0.54 (p=0.585)	-0.56 (p=0.576)	0.58 (p=0.561)	0.80 (p=0.422)

The bold values highlight the statistically significant Z statistic and p values.

*Median of domain scores.



Our analysis revealed that activities that address patients' biopsychosocial needs had the lowest scoring, reflected in inadequate provision of information on how patients can deal with being worried, upset or sad, as well as their spiritual needs and changes in their family relationships. These results are different from the Australian study findings that 80% of patients had their psychological needs addressed. However, similar to the Australian study, other neglected aspects of care included a lack of support from hospital staff in finding other people with similar experiences with whom patients can talk.³⁰ Quality improvement efforts should focus on these areas.

The primary limitation of this study is that the Mexican PCQCCQ-S validation was performed in a group of patients treated at two hospitals (IMSS and MoH) in Mexico City, possibly limiting generalisability of the results. Therefore, it is important to perform confirmatory analysis of the factor structure of this instrument on different samples of patients with cancer in Mexico and other Spanish-speaking countries. Additionally, it would be worthwhile to assess whether it is sensitive to detecting changes in quality of care over time and its test-retest reliability.

Furthermore, the study included patients with at least one hospitalisation during the last year; therefore, the results do not represent quality of care of those who only received outpatient care. Yet, most patients with cancer require hospitalisation(s) to perform complex diagnostic and therapeutic procedures, to deal with adverse events of surgery and/or chemoradiotherapy, and for symptom control in patients with advanced cancer.

CONCLUSION

The PCQCCQ-S has acceptable psychometric properties and can be used as PREM to assess quality of patient-centred cancer care in Mexico, to assure health professionals accountability through continuous monitoring of healthcare quality and to inform quality improvement initiatives through feedback on specific user experiences. It can also serve as a reference to develop PCQCCQ-S in other Spanish-speaking LMICs and hence contribute to patient-centred health system strengthening and improve access to higher quality cancer care.

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Contributors SVD conceptualised the study, conducted the literature review, performed statistical analysis and wrote the manuscript. IPM-V participated in the pilot testing of PCQCCQ-S, coordinated the fieldwork and critically reviewed the manuscript for significant intellectual content. CI-C participated in the process of content validity and critically reviewed the manuscript for significant intellectual content. MG-D-I-B, CEA-F, AM and LG-L coordinated the fieldwork and critically reviewed the manuscript for significant intellectual content. FMK and RP-C participated in study conceptualisation and critically reviewed the manuscript for significant intellectual content. All authors read and approved the final version of the manuscript, have participated sufficiently in the work to take public responsibility for appropriate portions of the content and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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REFERENCES

- 1 Stewart BW, Wild CP, eds. *World cancer report 2014*. Lyon: International Agency for Research on Cancer, 2014.
- 2 Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018;391:1391-454.
- 3 International Agency on the research on cancer, World Health Organization. GLOBOCAN 2012: estimated incidence, mortality and prevalence worldwide in 2012. Cancer-Factsheets. Available: http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx.
- 4 Instituto Nacional de Estadística Y Geografía. *Anuario estadístico de Los Estados Unidos Mexicanos*. México: INEGI, 2014. http://www.inegi.org.mx/prod_serv/contenidos/espanol/bvinegi/productos/integracion/pais/aeum/2013/AEGEUM2013.pdf
- 5 Torres Vigil I, Aday LA, De Lima L, et al. What predicts the quality of advanced cancer care in Latin America? A look at five countries: Argentina, Brazil, Cuba, Mexico, and Peru. *J Pain Symptom Manage* 2007;34:315-27.
- 6 Estrada EE. Improving the quality of care in a public hospital in Guatemala. *Int J Gynecol Cancer* 2019.
- 7 Kruk ME, Gage AD, Arsenault C, et al. High-Quality health systems in the sustainable development goals era: time for a revolution. *Lancet Glob Health* 2018;6:e1196-252.
- 8 Doubova SV, Aguirre-Hernández R, Gutiérrez-de la Barrera M, et al. Supportive care needs of Mexican adult cancer patients: validation

- of the Mexican version of the short-form supportive care needs questionnaire (SCNS-SFM). *Support Care Cancer* 2015;23:2711–9.
- 9 Doubova SV, Casales-Hernández MG, Pérez-Cuevas R. Supportive care needs and association with quality of life of Mexican adults with solid cancers. *Cancer Nurs* 2018;41:E1–12.
 - 10 Institute of Medicine. *Delivering high-quality cancer care: charting a new course for a system in crisis*. Washington, DC: The National Academies, 2013.
 - 11 Liang H, Tao L, Ford EW, et al. The patient-centered oncology care on health care utilization and cost: a systematic review and meta-analysis. *Health Care Manage Rev* 2018. doi:10.1097/HMR.0000000000000226. [Epub ahead of print: 17 Oct 2018].
 - 12 An J, Lau A. Economic evaluation of patient-centered care among long-term cancer survivors. *Am J Manag Care* 2018;24:e292–9.
 - 13 Jayadevappa R, Chhatre S, Gallo JJ, et al. Patient-Centered preference assessment to improve satisfaction with care among patients with localized prostate cancer: a randomized controlled trial. *J Clin Oncol* 2019;37:964–73.
 - 14 Bull C, Byrnes J, Hettiarachchi R, et al. A systematic review of the validity and reliability of patient-reported experience measures. *Health Serv Res* 2019;54:1023–35.
 - 15 Tzelepis F, Rose SK, Sanson-Fisher RW, et al. Are we missing the Institute of medicine's mark? A systematic review of patient-reported outcome measures assessing quality of patient-centred cancer care. *BMC Cancer* 2014;14:41.
 - 16 Tzelepis F, Sanson-Fisher RW, Hall AE, et al. Development and psychometric evaluation of the quality of patient-centered cancer care measure with hematological cancer survivors. *Cancer* 2015;121:2383–92.
 - 17 Veneziano L, Hooper J. A method for quantifying content validity of health-related questionnaires. *Am J Health Behav* 1997;21:67–70.
 - 18 Instituto Mexicano del Seguro social. Informe al Ejecutivo federal Y al Congreso de la Unión sobre La situación financiera Y Los riesgos del Instituto Mexicano del Seguro social 2017-2018, 2018. Available: <http://www.imss.gob.mx/sites/all/statics/pdf/informes/20172018/21-InformeCompleto.pdf>
 - 19 Hernández-Ávila JE, Palacio-Mejía LS, González-González L, et al. Utilization of hospital services for cancer care in Mexico. *Salud Publica Mex* 2016;58:142–52.
 - 20 Worthington R, Whittaker T. Scale development research: a content analysis and recommendations for best practices. *The counseling psychologist* 2006;34:806–38.
 - 21 Henson R, Roberts J. Use of exploratory factor analysis in published research: common errors and some Comment on improved practice. *Educ Psychol Measurement* 2006;66:393–416.
 - 22 Mislavy RJ. Recent developments in the factor analysis of categorical variables. *Journal of Educational Statistics* 1986;11:3–31.
 - 23 Hair JF, Anderson RE, Tatham RL, et al. *Análisis Multivariante*. 5th edn. Madrid: Prentice Hall Iberia, 1999.
 - 24 Jaju A, Crask MR, American Marketing Association. *The perfect design: optimization between reliability, validity, redundancy in scale items and response rates*. , 1999: 10, 127–31.
 - 25 Taylor R. Interpretation of the correlation coefficient: a basic review. *Journal of Diagnostic Medical Sonography* 1990;6:35–9.
 - 26 Boateng GO, Neilands TB, Frongillo EA, et al. Best practices for developing and validating scales for health, social, and behavioral research: a primer. *Front Public Health* 2018;6:149.
 - 27 McElduff P, Boyes A, Zucca A, et al. *Supportive care needs survey: a guide to administration, scoring and analysis*. Australia, Newcastle: Centre for Health Research & Psycho-oncology, 2004.
 - 28 Oñate-Ocaña LF, Alcántara-Pilar A, Vilar-Compte D, et al. Validation of the Mexican Spanish version of the EORTC C30 and STO22 questionnaires for the evaluation of health-related quality of life in patients with gastric cancer. *Ann Surg Oncol* 2009;16:88–95.
 - 29 Borsa JC, Damásio BF, Bandeira DR. Cross-Cultural adaptation and validation of psychological instruments: some considerations. *Paidéia* 2012;22:423–32.
 - 30 Tzelepis F, Sanson-Fisher RW, Hall AE, et al. The quality of patient-centred care: haematological cancer survivors' perceptions. *Psychooncology* 2015;24:796–803.
 - 31 Kossovsky MP, Sarasin FP, Louis-Simonet M, et al. Age and quality of in-hospital care of patients with heart failure. *Eur J Public Health* 2004;14:123–7.
 - 32 Asch SM, Kerr EA, Keesey J, et al. Who is at greatest risk for receiving poor-quality health care? *N Engl J Med* 2006;354:1147–56.