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A validation study of the Dutch version of the Quality of Life – Cancer Survivor (QOL-CS) questionnaire in a group of prostate cancer survivors

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Abstract

The primary objective of this study was to validate the Dutch version of the Quality of Life – Cancer Survivor (QOL-CS) questionnaire using a group of Dutch prostate cancer survivors. The QOL-CS was specifically designed to measure the quality of life of long-term cancer survivors. We performed a population-based, cohort study of 784 prostate cancer survivors who were diagnosed with prostate cancer between 1994 and 1998. To determine the test–retest reliability, second questionnaires were sent to 109 participants, of whom 103 (94%) returned the forms. The quality of life in Dutch long-term prostate cancer survivors was adequately measured by the physical, psychological and social well-being subscale and can be used in order to measure the specific aspects of quality of life important to cancer survivors. However, as the subscale spiritual well-being showed a low internal consistency, which could be related to cultural background, it seems to be appropriate to evaluate the validity and reliability of the QOL-CS in other cultural settings.

Key words: Cancer survivor, Prostate cancer, Cancer, Quality of life, Validation

Introduction

Prostate cancer is the most common male cancer in the Western world [1]. In past decades the incidence and survival of prostate cancer have increased tremendously, resulting in a rising number of cancer survivors. It is therefore important to understand how the disease affects the quality of life among survivors (QOL) [1]. Most QOL instruments focus on the effects of diagnosis and initial cancer treatment [2] whereas the specific concerns and needs of long-term survivors are seldom measured. The Quality of Life – Cancer Survivor (QOL-CS) is one of the few instruments that has been designed specifically for the assessment of QOL in long-term cancer survivors and has been validated or used in several American studies [3–9].

The objective of this study was to validate the Dutch translation of the QOL-CS questionnaire using a group of long-term prostate cancer survivors.

Methods

Participants

The population-based Eindhoven Cancer Registry (ECR) was used to select all men diagnosed with

prostate cancer between 1/1/1994 and 31/12/1998 who were alive at time of data collection. In addition, the selected men had to be disease-free and 75 years or younger at time of diagnosis. The ECR routinely collects data on tumor characteristics like date of diagnosis, subsite, histology, stage and treatment and patient characteristics like gender, date of birth and co-morbidity at time of diagnosis.

Instruments

The QOL-CS was developed by researchers of the City of Hope National Medical Centre in California USA, to measure the QOL of long-term cancer survivors [3]. It examines issues of particular concern to long-term cancer survivors such as fear of a second tumor, recurrence or metastasis, survivorship guilt and the role of spirituality and religion [5]. The QOL-CS is a 45-item visual analogue scale, based on a scale of 0 (worst outcome) to 10 (best outcome). The instrument consists of four scales: physical, psychological, social and spiritual well-being. A 'forward–backward' procedure was used to translate the English-language version of the QOL-CS into Dutch.

The SF-36 questionnaire was used to measure health-related quality of life [10]. For this validation study we only used three subscales (physical and social functioning, and emotional well-being). The Revised version of the Illness Intrusiveness Ratings Scale (IIRS) [11] was used to assess the impact of the respondent's 'illness and/or its treatment' on life domains important to quality of life [12]. The four domains included for this validation study were physical health, mental health, relationship with friends and religious expression.

Data collection procedure

The Institutional Review Board of Máxima Medical Centre in the Netherlands approved the study-protocol. After approval, questionnaires were sent to all long-term prostate cancer survivors who fulfilled the inclusion criteria, by their (former) specialists. After 2 months a reminder was sent to all participants who had not returned the questionnaire. A completed questionnaire was considered to imply informed consent.

Reliability and validity

The internal consistency was measured using Cronbach's α coefficient. To measure test–retest reliability, the first 109 participants, who returned the survey and wanted to participate in further studies, received a second set of questionnaires.

In order to measure convergent validity, correlations between comparable dimensions of the QOL-CS and the IIRS-R and between QOL-CS and the SF-36 were computed. Criteria for quantitative significance of correlations were based on the recommendations of Burnand et al. [5]. These recommendations were; <0.30 negligible; 0.30–0.45 moderate; 0.45–0.60 substantial; and >0.60 high.

Finally, item-discriminant validity of the QOL-CS scales was tested. The correlation between each item of the scale and its own scale was compared with the correlations between that item and every other scale. The item to own scale correlation should be higher if the categories within the QOL-CS questionnaire are valid.

Statistical analyses

Because of the non-normal distribution of the QOL-CS questionnaire, Spearman's rank was used as correlation measure for the test–retest reliability and convergent and divergent validity. Chi-square was used to evaluate the differences between people who did or did not want to participate a second time. For all analyses, SAS (Version 8.02, SAS Institute Inc., Cary, North Carolina, USA) was used.

Results

In total, 966 prostate cancer survivors were sent a questionnaire, of which 784 (81%) returned a completed questionnaire (Figure 1). Of the 109 patients who received a second questionnaire, 103 (94%) completed the QOL-CS for the second time, 2 months after their first response.

Participant's characteristics

Table 1 presents medical and sociodemographic data for the total group of participants ($n = 784$)

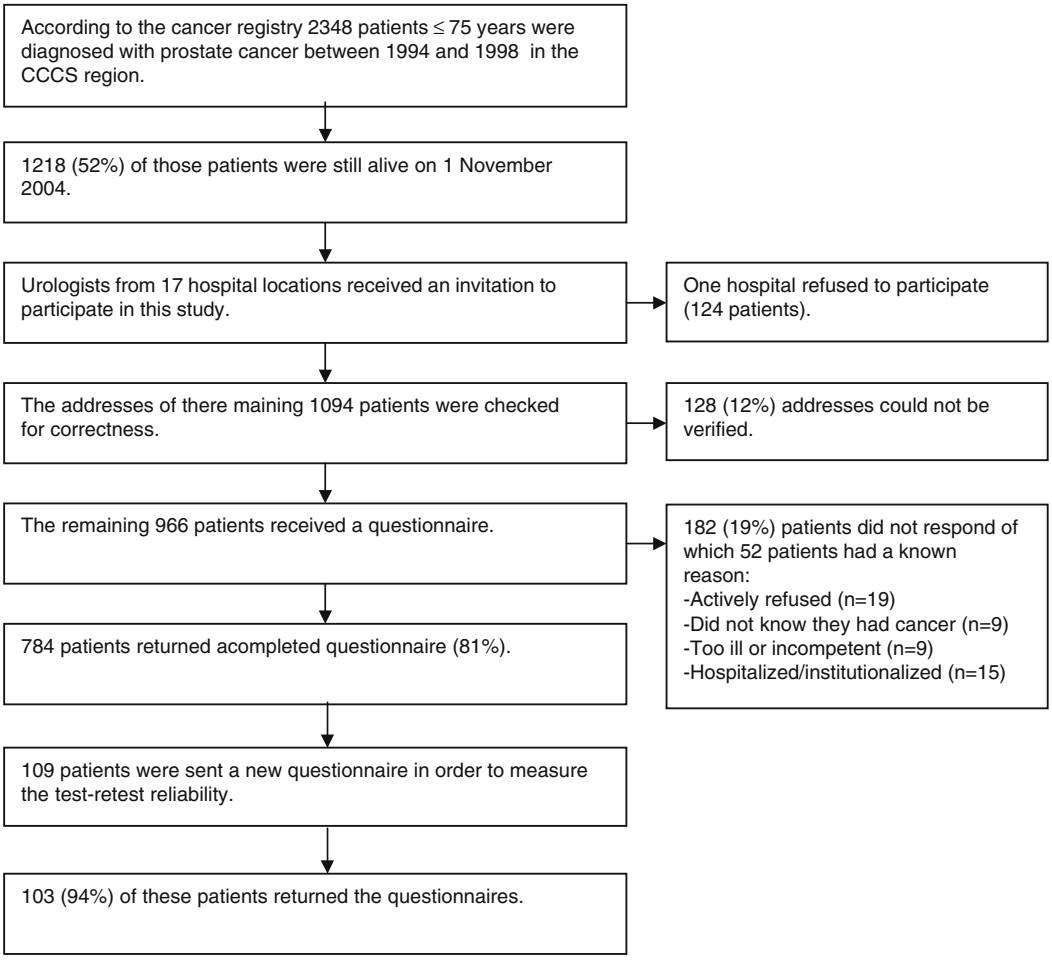

Figure 1. Flow-chart of the data collection process.

and the test–retest group (n = 103). Men who completed the questionnaire twice were diagnosed more often with stage II disease and more often underwent prostatectomy, compared to the total group of participants.

Reliability and validity

Internal consistency was high for all scales (Chronbach's $\alpha > 0.70$) except for the spiritual well-being scale (Chronbach's $\alpha = 0.49$). The overall scale had an internal consistency of 0.91 (Table 2).

For a few items, correlation with their own subscale was low (items of social well-being and spiritual well-being), but most of the item-to-subscale correlations were moderate to high (Table 2). The item-to-subscale correlations for two items ('uncertainty future' and 'survivorship guilt') in the spiritual well-being scale were negative. When the two items were deleted, Chronbach's α for the spiritual subscale increased to 0.67.

Item-discriminant validity was measured by comparison of the item-to-own scale correlation with the item-to-other scales correlation values (Table 2). For the subscales physical and social well-being, all items exhibited a higher correlation with their own scale than with the other subscales. For the subscales psychological and spiritual well-being, a few items exhibited a higher correlation with one or more of the other scales. The items 'uncertainty future' and 'survivorship guilt' exhibited a substantially higher correlation with all other subscales then with their own (Table 2).

Table 1 Sociodemographic and medical characteristics of questionnaire respondents

	N = 784	%	N = 103	%
Age at time of survey (years)				
< 70	192	(24)	25	(24)
70–74	212	(27)	31	(31)
75–79	248	(32)	34	(34)
80 +	132	(17)	13	(13)
Stage				
I	164	(21)	16	(15)
II	428	(55)	65	(63)
III	96	(12)	13	(13)
IV	45	(6)	5	(5)
Unknown	51	(6)	4	(4)
Treatment				
Prostatectomy	257	(33)	58	(56)
Radiotherapy	323	(41)	30	(29)
Hormonal therapy	94	(12)	8	(8)
None	73	(9)	6	(6)
Unknown/other	37	(5)	1	(1)
Comorbidities				
None	279	(36)	38	(37)
1	275	(35)	39	(38)
2 +	230	(29)	26	(25)
Marital status				
Married	609	(81)	84	(83)
Single	20	(3)	4	(4)
Divorced	26	(3)	4	(4)
Widowed	98	(13)	9	(9)
Living arrangement				
Living together	559	(81)	81	(85)
Living alone	123	(19)	14	(15)
Educational level				
Low	178	(24)	20	(20)
Middle	407	(55)	55	(55)
High	158	(21)	25	(25)
Occupation				
Unemployed due to disability	20	(3)	2	(2)
Retired	661	(88)	87	(87)
Employed <33 h/w	42	(5)	9	(9)
Employed 33 + h/w	13	(2)	2	(2)
Other	13	(2)	0	(0)

Table 3 shows the correlations between the four subscales and the overall scale. The correlations between spiritual and physical well-being, between spiritual and psychological well-being and between spiritual and social well-being were negligible (resp. $r = 0.09$, $r = 0.15$ and $r = 0.00$). Note that the moderate correlation between spiritual well-being and the overall scale ($r = 0.31$) is in contrast to the high correlations between the other subscales and the overall scale ($r \geq 0.79$).

The overall QOL-CS test–retest reliability assessed among 103 participants was 0.79. Physical, psychological, social and spiritual well-being had reliability coefficients of 0.69, 0.75, 0.70 and 0.71, respectively. All item-to-item correlations were in the range of 0.38–0.87, except the item 'fertility' in the social well-being scale, which had a test–retest correlation of 0.22. Additional subgroup analyses showed that test–retest reliability was high among participants in different stages or different therapies.

Convergent validity was measured between the QOL-CS and the SF-36. Table 4 reveals substantial to high correlations for most of the scales. The overall QOL-CS correlation with the total SF-36 scale was 0.67. Table 4 also shows the correlations between the QOL-CS scales and the IIRS-R of which most were moderate to substantial. There was a negligible negative association between social well-being and relationships with friends ($r = -0.07$). The QOL-CS and the IIRS-R were weakly positively but significantly associated ($r = 0.28$).

Discussion

Results show that the physical, psychological and social subscales of the QOL-CS have good psychometric properties. The subscale spiritual well-being had low internal consistency and the subscale to scale correlation was below acceptance. Furthermore, analysis of convergent validity showed that correlations between the spiritual well-being scale and the associated IIRS-R scale were too low. In contrast, a US validation study showed that this scale was more reliable and valid in the USA [3]. This is thought to be due to differences in culture and population. Religious and spiritual elements also appeared to be less relevant in childhood cancer survivors in the USA [5]. Because the items 'uncertainty future' and 'survivorship guilt' both had extremely low and even negative item-to-own correlations, we recommend dropping these items from the Dutch version of the QOL-CS for prostate cancer survivors. This will raise the internal consistency. The performance of the QOL-CS without these two items needs to be addressed in future research.

Table 2 Internal consistency, item-to-own scale correlations and item-to-other scale correlations

Scale	Number of items	Chronbach's α	Item-to-own scale	Item-to-other scale
Physical well-being	8	0.86	0.48–0.73	−0.01–0.56
Psychological well-being	18	0.89	0.38–0.69	−0.03–0.61
Social well-being	10	0.73	0.04–0.58	−0.08–0.57
Spiritual well-being	8	0.49	−0.16–0.44	−0.35–0.61
Overall quality of life	44	0.91		

Table 3 Interscale correlations[a] of the QOL-CS

QOL-CS	Physical well-being	Psychological well-being	Social well-being	Spiritual well-being	Overall quality of life
Physical well-being	–				
Psychological well-being	0.65	–			
Social well-being	0.54	0.68	–		
Spiritual well-being	0.09	0.15	0.00	–	
Overall quality of life	0.79	0.93	0.79	0.31	–

[a]Spearman rank correlations.

Table 4 Convergent validity of the QOL-CS and the SF-36 and of the QOL-CS and the IIRS-R[a]

	QOL-CS			
	Physical well-being	Psychological well-being	Social well-being	Spiritual well-being
SF-36				
Physical functioning	0.62*	0.41*	0.37*	0.06
Emotional well-being	0.55*	0.62*	0.41*	0.15*
Social functioning	0.60*	0.52*	0.45*	0.07*
IIRS-R				
Physical health	0.44*	0.29*	0.18	0.15
Mental health	0.30*	0.31*	0.20*	0.29*
Relationship with friends	0.11	−0.04	−0.07	0.08
Religious expression	0.10	−0.10	−0.12	0.41*

[a]Spearman rank correlation.
*p-value < 0.05.

The study had several limitations. The QOL-CS results were based on a group of Dutch prostate cancer survivors. Nevertheless, we found similar reliable and valid results on the subscales physical, psychological and social well-being but not spiritual well-being as compared to the earlier US validation reports [3, 5]. Also, it is possible that response bias among those who were willing to participate twice might have confounded the results, as second time responders were diagnosed more often with stage II disease and more often underwent prostatectomy. However, additional analyses revealed that test–retest results were high for different stage and treatment subgroups of patients.

In conclusion, the quality of life in Dutch long-term prostate cancer survivors was adequately measured by the physical, psychological and social well-being subscale and can be used in order to measure the specific aspects of quality of life important to cancer survivors. However, as the subscale spiritual well-being showed a low internal consistency, which could be related to cultural background, it seems to be appropriate to evaluate the validity and reliability of the QOL-CS in other cultural settings.

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