

Original article

Measuring health-related quality of life in men with prostate cancer: A systematic review of the most used questionnaires and their validity

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Abstract

Objectives: To identify and study the psychometric properties of the most used health-related quality-of-life (HRQoL) instruments in men with prostate cancer.

Methods: We performed a literature search using PubMed and EMBASE to identify all studies on prostate cancer using a HRQoL instrument. The most often used HRQoL instruments were investigated in detail by 2 independent reviewers. Data were extracted regarding the characteristics and psychometric values of the instruments, i.e., content validity, internal consistency, criterion validity, construct validity, reproducibility, responsiveness, floor and ceiling effects, and interpretability. Good psychometric outcomes indicate a high methodological quality of the instrument.

Results: Our systematic search revealed 13,812 potential relevant articles, of which 2,258 appeared relevant after screening the titles and reading the abstracts. We studied the psychometric properties of the 20 most often used HRQoL instruments, the first 3 of which were the Expanded Prostate Index Composite, University of California—Los Angeles Prostate Cancer Index, and Short Form-36 (SF-36). Content validity, internal consistency ($\alpha > 0.70$), criterion validity, construct validity, and reproducibility were good in 60%, 90%, 10%, 35%, and 65% of the 20 instruments, respectively. Responsiveness was not reported for 12 of 20 instruments (60%). Floor and ceiling effects and the interpretability of the questionnaires were only reported in 3 (15%) and 6 (30%) instruments.

Conclusions: Considering the psychometric properties, we advise to use the SF-12 as a generic instrument, the Cancer Rehabilitation Evaluation System-SF or the Functional Assessment of Cancer Therapy—General as cancer-specific HRQoL instruments, and the University of California—Los Angeles Prostate Cancer Index, the QUFW94, or the Functional Assessment of Cancer Therapy—Prostate as prostate cancer-specific instruments. © 2014 Elsevier Inc. All rights reserved.

Keywords: Prostatic neoplasma; Health-related quality of life; Instrument; Characteristics

1. Introduction

Prostate cancer is the most common noncutaneous malignancy in men, with an estimated incidence of 241,740 new cases in the United States in 2012 [1]. Prostate cancer treatments such as radical prostatectomy, radiation therapy, and hormonal treatment, have well-known side effects including incontinence, impotence, and hot flashes. These side effects can greatly influence the quality of life. With an ageing population and increased prostate cancer

screening, the worldwide incidence of prostate cancer has doubled in the past 10 years [2,3]. Despite this increased detection, the relative 5-year survival rate of all patients with prostate cancer increased from 68.3% to 99.9% during the past 25 years [1]. With increased survival and advancing treatment techniques (e.g., laparoscopic surgery and internal radiation therapy), functional results have become almost as important as oncological outcomes.

The subjectively perceived quality of life in patients with prostate cancer is often evaluated using health-related quality-of-life (HRQoL) questionnaires. Over time, different disease-specific HRQoL instruments have been developed to measure prostate cancer burden, e.g., the Expanded

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Prostate Index Composite (EPIC), European Organization for Research and Treatment of Cancer Quality of Life Questionnaires (QLQs), and the University of California—Los Angeles Prostate Cancer Index (UCLA-PCI) [4–6]. These questionnaires are commonly used in clinical practice, particularly to discriminate between patient groups. They are also increasingly used as an outcome measure in clinical trials. The number of available health status questionnaires has increased tremendously over the past decades, thus the choice of a suitable questionnaire is becoming a major difficulty for many urologists and researchers in the field. Practical principles and algorithms have been developed to guide researchers through the process of selecting an instrument [7]. A part of the selection process is the appraisal of the psychometric properties of the different instruments.

Few review articles regarding measuring HRQoL in patients with prostate cancer have been published [8,9]. A very recently published review by Rnic et al. [10] also reported on measuring the effect of prostate cancer treatments. Contrary to their article that focused on prostate cancer symptom scales, our study focuses on HRQoL instruments. Furthermore, we investigated other and additional psychometric properties in comparison with earlier studies. Finally, none of these studies investigated the frequency of use of these instruments in the literature. Therefore, we performed a systematic review regarding the most often used HRQoL instruments in prostate cancer and subsequently studied 8 psychometric properties of these instruments, which will help to identify which instruments should be used in future studies.

2. Materials and methods

2.1. Search strategy

The biographical databases of PubMed and EMBASE were searched using the terms prostate cancer, treatment, quality of life, and synonyms, in the title or abstract. Refer to [Appendix](#) for the complete search strategy. The language was restricted to English, there were no restrictions regarding publication date and a reference and related article search was performed. The last search was performed on May 15, 2013. We imported all citations identified with the Medline and EMBASE search strategies into the bibliographic database of EndNote, version X5 (Thomas Reuters, New York City, NY).

2.2. Study selection

After retrieving all records, the duplicates were removed. Subsequently, 2 reviewers (E.H.J.H. and E.S.) independently screened all identified titles for eligibility without blinding to authorship or journal. Any uncertainties were discussed and resolved by consensus. Afterward, abstracts

of relevant titles were read for further inclusion and the full text of an article was retrieved if needed. Our inclusion criteria were (1) patients with prostate cancer, (2) use of a questionnaire to measure HRQoL, and (3) presentation of original study data. After study selection, an overview was made of all questionnaires used in these studies. Subsequently, instruments were included for further analysis if (1) an article regarding the validity of the instrument could also be retrieved, (2) the instrument consisted of multidimensional HRQoL measurements, (3) the instrument was patient assessed, and (4) it was used by more than 1 study group in the retrieved articles. We excluded preference-based instruments and symptom scales. A flow diagram of the search strategy is shown in the [Fig](#).

2.3. Data extraction and analysis

From the articles describing the psychometric characteristics, we extracted the following psychometric information: number of items, scaling, range of scale, number of domains, content validity, internal consistency, criterion validity, construct validity, reproducibility, responsiveness, floor and ceiling effects, and interpretability according to the quality criteria given by Terwee et al. [11]. For this research, we only used studies that were validation studies of particular questionnaires. If present, we also included later validation studies of the same instrument. If more than 1 validation study was used for the assessment of the psychometric properties, each study was examined separately and the best outcomes were reported. In [Table 1](#), the used quality criteria are displayed. If no validation article could be retrieved, the original authors were contacted to provide additional information.

The psychometric properties of the instruments were independently assessed by 2 readers (E.H.J.H. and M.D.R.). Any uncertainties were discussed and resolved by consensus.

To give an advice regarding the best instrument to use, we designed a scoring model. Each positive-rated psychometric property yielded 1 point, each doubtful property 0 points, and each negative property –1 point. If no information was reported on a specific property, no points were assigned. With the use of this scoring model, an overall score was calculated.

3. Results

We identified 13,812 unique hits with the search terms “prostate cancer,” “treatment,” and “quality of life,” and their synonyms. After screening titles and abstracts, 2,258 studies using 298 different questionnaires remained. After applying our inclusion criteria, 20 health-related quality-of-life questionnaires could be included ([Fig](#)). We asked authors of 2 instruments for more information regarding the validation of their instruments, and both replied to this

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