

HEALTH AND QUALITY OF LIFE IN UROLOGY: ISSUES IN GENERAL UROLOGY AND UROLOGICAL ONCOLOGY

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Summary.- OBJECTIVES: Frequently, the term "quality of life" has been used to justify personal and professional decisions in all fields of medicine. Nowadays, quality of life studies are based on development and validation of sensitive measures of patient outcomes, incorporating functional status and perceived health status. Thus, quality of life has become an outcome as important as survival and effectiveness.

METHODS: A systematic review using Pubmed and Medline was performed, searching for papers concerning health related quality of life and urology. The most relevant articles where questionnaires and interviews were described and validated were listed.

RESULTS: Based on psychometric proprieties, a search between 1970 and 2007 identified a total of 25 recommendable articles with generic inventories and specific modules that have been developed, validated and used in clinical practice or research. Historical aspects, quality of life concepts, validation of questionnaires and structured interviews, and most used instruments in generic health-related quality of life, general urology and urological oncology have been discussed.

CONCLUSIONS: A brief review of historic background of health related quality of life and urology was performed.

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Resumen.- OBJETIVO: Con frecuencia, el término "calidad de vida" había sido utilizado para justificar decisiones personales y profesionales en todos los campos de la medicina. Hoy en día, el estudio de la calidad de vida se basa en el desarrollo y la validación de mediciones sensibles de los resultados de los pacientes incorporando el estado funcional con la percepción del

estado de salud. Así, la calidad de vida (CV) se ha convertido en un resultado tan importante como la supervivencia y la eficacia.

MÉTODOS: Una revisión sistemática usando Pubmed y Medline fue realizada, buscando artículos referentes a calidad de vida relacionados con la salud y la urología. Los artículos más relevantes donde los cuestionarios y las entrevistas fueron descritos y validados han sido listados y revisados.

RESULTADOS: Una búsqueda entre 1970 y 2007 identificó un total de 25 artículos relacionados recomendables. De acuerdo con propiedades de la psicometría, los cuestionarios genéricos y los módulos específicos que se han desarrollado, validado y utilizado en la práctica e investigación clínica. Los aspectos históricos, definiciones relacionadas con la calidad de vida, validación de cuestionarios y estructuración de entrevistas, han sido utilizados en instrumentos que relacionan la calidad de vida a la salud general, urología general y la oncología urológica.

CONCLUSIONES: Se realizó una revisión bibliográfica acerca de los aspectos históricos sobre calidad de vida y el estado de salud y como se interrelacionan en el área de la urología, verificándose su importancia actual en la práctica médica.

Palabras clave: Calidad de vida. Cuestionarios. Urología. Neoplasmas urológicos.

INTRODUCTION

For a long period of time, medical treatment based on survival was the main concern in medical profession. Nowadays, a tendency exists of noticing disease condition in a much wider way, emphasizing not only to treat patients in order "to join years in their life", but also to improve physical, emotional, and social aspects, that is, "to join life to those years."

The measure of quality of life (QoL) has become an important outcome in clinical research and practice. A search using PubMed (National Library of Medicine) employing "quality of life" as a keyword, reveals the growing interest in QoL related publications (1). Considering urologic disease such as benign prostatic hyperplasia and neurogenic dysfunctions, is evident that even "benign" conditions can have a significant negative impact in quality of life.

Habitually, QoL is evaluated by patient-report questionnaires or structured interviews, whose reliability and validity were previously tested, highlighting patient opinion in medical decisions.

DEFINITION

Different definitions of QoL have been proposed aiming include all its aspects. The term "quality of life" include several positive and negative dimensions, convictions and individual perceptions, being really an abstract, subjective and changeable concept. Social, physical, financial, cultural and emotional factors interact modulating individual QoL. Transform a subjective concept in an objective one is an arduous task, mainly because the variability of different environments, cultures, even different moments regarding individual life (2-4). Specifically in medicine, the QoL concept focuses health related aspects, diseases and proposed treatments, labeled as health-related quality of life (HRQoL). Although there is no clear and consensual concept, in 1948, the World Health Organization (WHO) defined health as "a state of complete physical, mental, and social well-being."; and quality of life as "individuals' perception of their position in life in the context of the cultural and value systems in which they live and in relation to their goals, expectations, standards and concerns" (5). In 1977, the term "Quality of life" was firstly used in Medical Subject Headings (MeSH) and defined as: "a generic concept reflecting concern with the modification and enhancement of life attributes, e.g., physical, political, moral and social environment; the overall condition of a human life" (1).

Health-related quality of life (HRQoL)

Kaplan proposed the term Health-related quality of life aiming to represent a variety of topics, such as: general health, physical symptoms, functionality, emotional health, cognitive subjects, social paper, spiritual sexual and financial matters, job satisfaction and life conditions. The literature demonstrates that patients' self-reports differ of the health professionals evaluations, who tends to underestimate the severity of symptoms (6). Besides, interviews should be accomplished by a third person, avoiding that form a bias, also because patients tend to please their doctors. The best "judge" of QoL is the own patient, and the most appropriate form of measure it, is his self-report. Emphasizing that carry a disease is different of feeling sick. In a recent trial, two radiation protocols for treatment of localized prostate cancer were offered to properly inform patients (70Gy or 74Gy). The majority of patients (75%) chose a smaller radiation dose, opting for a better QoL related the less toxicity instead survival or cure (7). Indeed, QoL has been studied also as prognostic factor, predicting morbidity, costs and collateral effects, allowing a better understanding of different therapies impact in an individual life, correlating, for instance, poor survival with the increase of fatigue, reported in questionnaires.

Using multivariable analysis and patient-reported outcomes (PRO) questionnaires validated by European Organization of Research and Treatment of Cancer (EORTC), Langendijk and cols, could not linked poor performance status with overall survival in small cells lung cancer patients, however, the authors demonstrated that pre-treatment QoL was the most accurate prognostic factor for survival (8).

Different treatment modalities impact QoL in varied levels. Even considering same modality, such as radiotherapy (RT), late sequels and morbidity vary according with the technique employed. One of the most common symptoms related to radiation is fatigue. However, only 50% of the patients discussed it with their physician and only 25% received treatment for it, proving how bad communication between health professional and patient can be (9-12). Probably, QoL measures should be reserved to trials where results will be really useful, such as studies proposing comparison among therapies or quantification of effectiveness and toxicity, otherwise these questionnaires can become unpleasant to patients and doctors (13).

QUESTIONNAIRES AND STRUCTURED INTERVIEWS

Using psychometrics theory is possible to express qualitative phenomena in quantitative (14.) More than 800 HRQoL questionnaires are available.

Validation protocols and psychometric tests

Initially, QoL questionnaires should be submitted to a translation process and rigorous cultural adaptation in order to compare results from different countries. The inventories should be capable to differentiate what supposed to discriminate. An inventory choice should be based on population profile, treatments investigated, local culture and study design. Preference should be given to instruments previously validated on standard methods of psychometric testing. However, if no specific questionnaire is available, a pilot-test should be the initial step to develop a questionnaire, revealing possible comprehension problems (15). The following step is evaluated psychometrics properties, fundamentally based on three criteria: reliability, validity and responsiveness (16).

Reliability

Distractions, fatigue, error and wrong interpretations can product inconsistencies when a person is answering questions. Reliability is the consistency

of a set of measurements. Reliability is important to measure score consistency, but it doesn't guarantee the validation of a questionnaire.

The reliability can be accessed using the following tests: test-retest reliability, involves repeated tests in different moments to the same group of patients. Test-retest confirms questions' stability over time; intra-observer reliability, same patient answering the same items in two different moments; inter-observer or inter-rater reliability, compares answers of two or more individuals regarding the same problem or two independent interviewer, this is considered as the best way of testing reliability; alternate-form or parallel-form reliability, two different structured questions asking about the same topic, measuring a specific variable. Split half reliability, compare the relationship among half of the items with the other half (15).

The internal consistency is a reliability test that measures homogeneity of different reply. It is accessed by Cronbach's alpha coefficient (based on inter-item correlations). The alpha coefficient should be superior to 0.70 in order to be considered reliable (0.90 = excellent, 0.80 = good, 0.70 = moderate) 16.

Validity

Validity reflects the questionnaire precision in measuring what intends to be measure.

Types of validity

Face validity, a casual revision determine if one item seem to measure what is intended, this is the most superficial type; *Content validity*, is similar to face validity, although based on formal experts review, used in initial phases of questionnaires development; *Criterion validity* (includes predictive and concurrent) measures test' accuracy using comparison. *Predictive validity* refers to compare the test to another event, predicting a specific outcome, (ex: urinary incontinence scale and its capability to predict number of pads used). *Concurrent validity* is based on comparison to other measures, possible the gold-standard test, (e.g.: compare a new urinary incontinence questionnaire score to urodynamics findings). *Construct validity* is the most important type of validity, intent to measure if an inventory is clinical significant in daily practice. *Construct validity* is a long and complex process, usually taking several years to be concluded. Indeed, construct validity is divided in two distinct subtypes: *Convergent validity*, important to know if the test presents results similar to other tests that intend to measure the same or a related event. *Discriminant validity*, evaluated how capable is a sca-

TABLE I. GENERIC QUESTIONNAIRES OF LIFE QUALITY.

| | Questionnaires | Items and Domains | Comments | Psychometrics properties | Cutoff points |
|------------------------|---|---|--|---|---------------|
| WHOQV-100 ⁵ | WHOQoL | 100 items, 6 domains: physical, psychological, independence, social relationships, environment and spirituality, religion and personal faiths | Long. Global use. | $\alpha^* = 0,93$ $r \dagger = 0,27-0,8$ | |
| WHOQV-26 ⁵ | WHOQoL-bref | 26 items 4 domains: Physical, psychological, social relationship, environment | Brief. Good reliability | $\alpha = 0,90$ $r = 0,7-0,9$ | |
| SF-36 ¹⁹ | Medical Outcomes Study 36-item Short-Form Health Survey | 36 items, 8 domains: physical function, physical health problems, bodily pain, general health perception, emotional well-being, emotional problems, energy/fatigue, social function | Brief. Global use Can be used in clinical setting as well in research as a questionnaire or interview http://www.sf36.com | $\alpha = 0,77-0,93$ $r = 0,55-0,81$ | |
| QLQ-C30 ⁸ | European Organization for Research and Treatment Cancer | 30 items, 7 scales: Global health status 5 functional scales: physical, role, emotional, cognitive, social. 9 symptoms scales | Brief. Commonly used in oncology http://www.eortc.be/home/QoL | $\alpha > 0,7$ | 0-100 |
| FACT-G ²¹ | Functional Assessment of Cancer Therapy-General | 27 items, 4 domains: Physical wellbeing, social/family wellbeing, emotional wellbeing, functional wellbeing. | Global use Cancer, symptoms and chronic disease-specific modules http://www.facit.org | Excelentes $\alpha e r$ | 0-108 |
| SIP ¹⁸ | Sickness Impact Profile | 136 items, 2 domains: Physical, psychosocial 12 scales: sleep, appetite, work, hobby, mobility, corporal care, social interaction, behavior and communication. | Long. Used as interview or solemnity-applicable | $\alpha = 0,94$ $r = 0,92$ | |

* Cronbach' alpha, † reliability test-retest

le to discriminate what should be measure and what should not correlated with it (15).

Responsiveness

Responsiveness is the property to demonstrate significant clinical change overtime, for instance: be able to differentiate groups of patients treated and not treated, demonstrating clinical significance. The Student' t test is commonly employed for measure responsiveness.

METHODS

A structured review of literature was performed in the PubMed/MEDLINE electronic database to retrieve references on quality of life and urology, mainly general urology and urologic oncology. The period was limited to 1970-2007. The MEDLINE searches were conducted by applying singularly or combining the following terms: questionnaires, interviews, instruments, quality of life, urology, urinary symptoms, urogenital neoplasm. Subsequently, the

TABLE II. SELF REPORTED QUESTIONNAIRES ON UROLOGIC ONCOLOGY.

| | Questionnaires | Items and Domains | Comments | Psychometrics properties | Use with |
|----------------------------|--|---|--|---|---------------------------|
| UCLA-PCI ³¹ | University of California – Los Angeles Prostate Cancer Index | 20 items, 6 domains: urinary, bowel and sexual function: urinary, bowel and sexual bother | Used in CaPSURE. Commonly used 18 additional items of identification and clinical conditions | $\alpha = 0,65-0,93$ $r = 0,66-0,93$ | RAND SF-36 v2 36 itens |
| UCLA-PCI SF ³² | UCLA-PCI Short Form | 15 itens | 85% of detected information on UCLA-PCI long-form | | RAND SF-12v2 12 itens |
| EPIC ³⁴ | The Expanded Prostate Cancer Index Composite | 57 items, 4 domains: urinary, bowel, sexual and hormonal | Based on UCLA-PCI. Androgen deprivation effects cover | $\alpha >0.82$ $r >0.80$ | RAND SF-12v2 12 itens |
| FACT-P ³⁵ | FACIT 12-item Prostate cancer subscale | 12 itens | | $\alpha = 0,65-0,69$ | FACT-G |
| QLQ PR-25 ³⁷ | QLQ-prostate specific 25-item | 25 itens urinary, bowel and sexual symptoms and functioning, side-effects of hormonal treatment | Genito-urinary EORTC group | NA | QLQ-C30 |
| FACT-BI ³⁶ | FACIT Bladder cancer subscale | 13 itens | | | FACT-G |
| QLQ-BLS24 ³⁸ | EORTC superficial bladder cancer | 24 itens | Approved for clinical trials. In phase 3 development by EORTC | NA | QLQ-C30 |
| QLQ-BSM 30 ³⁹ | EORTC muscle invasive bladder cancer | 30 itens | Approved for clinical trials. In phase 3 development by EORTC. | NA | QLQ-C30 |
| FACT FKSI-15 ⁵⁷ | | 15 itens | Also available in a 10 itens short version (FKSI-10) | | FACT-G |

TABLE III. GENERAL UROLOGY QUESTIONNAIRES.

| | Questionnaires | Items and Domains | Comments | Psychometrics properties | Cutoff points |
|-------------------------------------|--|---|--|---|---|
| I-PSS ³⁹ | International Prostate Symptom Score | 8 items LUTS: 7 items QoL: 1 item | American Urological Association (AUA) symptom index + 1 QoL item | $\alpha = 0,86$ $r = 0,92$ | < 7 mild 8-19 moderate 20-35 severe |
| ICIQ-MLUTS (ICS male) ⁴¹ | ICIQ-Male Lower Urinary Tract Symptoms ou ICS male questionnaire | 23 items (long-form) 13 items (short-form) | Brief 4-5 minutes to complete Subscales are not added to the final score. Short-form available | - | Long-form 1-84 (none to severe symptoms) |
| ICIQ-FLUTS ⁴² | ICIQ-Female Lower Urinary Tract Symptoms ou Bristol Female Lower Urinary Tract Symptoms questionnaire ⁵¹ | 18 items (long-form) 12 items (short-form) | 10-15 minutes (long-form) 4-5 minutes (short-form) | - | (high values=severe) Subscales 0-15 filling symptoms 0-12 voiding symptoms 0-20 incontinence symptoms |
| NIH-CPSI ⁴⁵ | National Institute of Health - Chronic Prostatitis Symptom Index | 13 items, 3 domains: pain urinary symptoms QoL impact | Chronic prostatitis | $\alpha = 0,86-0,91$ $r = 0,83-0,93$ | |
| OAB-q ⁴⁶ | Overactive Bladder symptom and health-related quality of life questionnaire | 33 items, 4 domains: coping, concern, sleep, social interaction, 8 items | Evaluation of both continent and incontinent symptoms of OAB and HR-QoL impact. Also called as ICIQ for OAB (ICIQ-OABQoL). 10 minutes to complete. | $\alpha = 0,86-0,94$ $r > 0,7$ | |
| OAB-q SF ⁴⁷ | OAB-q short form | 13 items 6 bother symptoms | http://www.oabq.com | $\alpha = 0,91-0,95$ | |
| OAB-V8 ⁴⁷ | OAB Awareness Tool | first 8 items of the OAB-q. | Screening and awareness tool | | Positive awareness in 95,7% |
| POSQ ⁴⁷ | Primary OAB Symptom Questionnaire ²² | 5 items | Also known as OAB Bother Rating Scale. | $\alpha > 0,86$ | |
| USS ⁴⁸ | Urinary Sensation Scale | 5 points scale: Urge-incontinence extreme urgency, discomfort, can't hold urine, wetting accident before bathroom | | | |

TABLE III Continue

abstracts were pooled and the authors identified the inventories recently used in urological clinical trials applying this as a limit. Each of the select questionnaires were distinguished according to psychometric tests methodology (validity, reliability and responsi-

veness). The extracted data were reviewed and discussed and the authors suggested recommendations for use in clinical practice and research base on test' standardization and coefficient results. No language limits were used.

(CONTINUE) TABLE III. GENERAL UROLOGY QUESTIONNAIRES.

| | Questionnaires | Items and Domains | Comments | Psychometrics properties | Cutoff points |
|-------------------------------------|---|--|--|--|---------------|
| Urge-IIQ and Urge-UDI ⁴⁹ | Urge-Incontinence Impact Questionnaire Urge-Urinary Distress Inventory | 30 items, 6 domains: Travel, activities, feelings, physical activities, relationships, sexual function, short version: 9 items, 1 domain | Only for women | $\alpha = 0,740,95$ $r = 0,73-0,89$ | |
| ESRD-SCL-TM ⁵³ | End-Stage Renal Disease Symptom Checklist-Transplantation Module | 43 items, 6 domains: Limited physical capacity, limited cognitive capacity, renal and heart dysfunction, side effects of corticoesteroids, increase growth of gum and hair, transplantaation associated psychological distress | Focused in immunossupression adverse effects | $\alpha = 0,76-0,85$ | |
| KTQ ⁵⁰ | Kidney Transplant Questionnaire | 35 items, 5 domains: physical symptoms depression, fatigue social relationship, frustration | | $\alpha = 0,69-0,93$ | |
| KDQV ⁵² | Kidney Disease-Quality of Life and KDQV-SF (short-form) | 42 items, 10 domains: Symptoms and problems effects of renal disease. bourden of renal disease, cognitive function, work status, sexual function, social interaction, sleep, social support, dialysis' staff encouragement | Applicable with SF-36. Long original version: 134 items. Only for patients in dialysis | $\alpha = 0,7$ $r = 0,49-0,93$ | 0-100 |

RESULTS

Between 1970-75, the MEDLINE search identified only 126 articles using "quality of life" as a keyword. During the last decades, the rising interest in QoL was evident by the exponential scale rising number of articles/studies published. More than 36,400 articles were identified published in these last 5 years and 87,350 in total (1). All the self-report questionnaires and structured interviews identified were listed below in the tables.

Regarding HRQoL generic core questionnaires, the authors interpreted that the questionnaires' development merges with changes in QoL concept by health professionals and health promotion politics, during the 80's and 90's. The generic PRO questionnaires were synthesized in Table I.

Table II summarizes urologic oncology inventories selected. Detailed psychometrics results, comments and recommendations for use are covered. Indeed, when compare uro-oncology related modules' structure to formerly approval generic questionnaire, it is evident that construction has developed. Those new modules are now faster and easy to completed, pooling no more than 30 items contrasting with the 30 to 136 questions pooled in the generic instruments.

Questionnaires recommended for use in general urology are showed in Table III. They intent to cover QoL related to urinary symptoms, bladder dysfunctions and chronic renal disease.

DISCUSSION

HRQoL generic questionnaires (Table I)

The questionnaires are divided in generic and disease-specific. Generic inventories focus general issues of individual's QoL. Initially, they were long, containing more than one hundred questions, such as: World Health Organization QoL long-form questionnaire (WHOQoL). WHOQoL is broken in 6 domains: physical, psychological, independence, social relationships, environment and spirituality, religion and personal faiths (17). Developed later in the 70's, Sickness Impact Profile is a 136 items questionnaire of 136 items that evaluates two global domains (physical and psychosocial) and 12 categories: sleep, appetite, work, pastimes, corporal care, social interaction, behavior, and communication. It is particularly useful when changes on patient's behavior should be accessed (18).

In 1993, SF-36 (RAND Medical Outcomes Study 36-item Short-Form Health Survey) was propo-

sed by Ware (19). SF-36 is shorter than the predecessors, clear and easy to comprehend. Nowadays, the second version of SF-36 has been widely studied and validated, covering 8 domains of QoL: functional capacity, physical aspects, pain, health condition, vitality, social aspects, emotional aspects and mental health (20). Others widely used generic instruments are the Functional Assessment of Cancer Therapy-General (FACT-G) and the EORTC QLQ-C30. Both can be completed with disease-specific developed modules. Nowadays, the FACT-G version 4.0 is available in more than 40 languages (21). FACT-G is a 27-items questionnaire that covers physical, social, emotional and functional wellbeing aspects. Each question can be graded from 0 to 4, (5 points Likert scale) and the final score varies from 0 to 108. Several cancer-specific modules have been validated. Two decades ago, European Organization for Research and Treatment of Cancer (EORTC) created the QoL Group. The EORTC QoL group was established aiming to develop a standardization approach for QoL clinical trials, in Europe. Their questionnaires and manuals have dictated a standard translation methodology and the way that these instruments should be used. EORTC QLQ-C30 (version 3.0) is a copyright instrument translated and validated in more than 60 languages, used in more than 3,000 trials globally. The disease-specific modules should always be used together with the QLQ-C30 (22,23). Several other questionnaires were developed and validated, such as: Rotterdam Symptom Check List (RSCL) containing 90 items (24), Symptom Distress Scale developed by McCorkle (25) with 13 items, Functional Living Index-Cancer with 22 items (26), Cancer Rehabilitation Evaluation System with 59 items (27), and the QoL Index, a 14-items visual scale (28).

There is no consensus if statistical threshold ($p < 0.05$) is enough to elucidate QoL differences among groups. Several methods were developed to interpret QoL data. In a recent review, Wyrwich and Clinical Significance Consensus Meeting Group discussed which method is the best for interpreting the QoL data (29).

Uro-oncology trials (Table II)

QoL outcomes have been considered indispensable in oncology research. Specifically concerning urologic oncology, cancer-specific modules have been developed, focusing topics as sexual and urinary dysfunction and intestinal bother. Using patient's report is possible to standardize functional results objectively, such as: erectile dysfunction (ED) and urinary incontinence (UI). These inventories minimize variability of descriptions and concepts and make possible comparison between different Institutions.

In the nineties, Litwin et al, developed the University of California Los Angeles - Prostate Cancer Index (UCLA-PCI). The UCLAPCI was the first validated instrument for measure QoL outcomes in prostate cancer (PCa) patients (30-32). The PCI has been used in international trials, and is now considered the gold-standard for prostate cancer and covers important topics in prostate cancer management that are not directly focused in the generic core questionnaire used together (RAND SF-36v2). The topics are addressed local treatment' benefits and complication: urinary, sexual and intestinal function and bother domains. Widely used in multicentre trials, the UCLA-PCI is used by Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE), where are registered more than 10,000 PCa patients (33).

In 2000, Wei et al, created The Expanded Prostate Cancer Index Composite (EPIC). EPIC questionnaire was based on UCLA-PCI, searching deeper the previous domains and add hormonal function items, in a total of 50 items (34).

FACIT developed a prostate cancer-specific module, the FACT-P and for bladder cancer, the FACT-BI (35,36).

Recently, a PCa-specific module was validated by EORTC (37). The EORTC QLQ PR-25 embraces important functional aspects and is used together with the main instrument, QLQ-C30. The topics are addressed to functional outcomes impacted by local treatment and hormonal deprivation (sexual, urinary and intestinal domains).

Regarding bladder cancer, new specific modules still are in phase 3. A 24-items questionnaire focus superficial disease (EORTC QLQ-BLS24) and a 30-items inventory inquires muscle invasive bladder cancer (EORTC QLQ-BLM30) (38).

General Urology and urinary symptoms (Table III)

Probably, one of the most used QoL questionnaire is the International Prostate Symptom Score (IPSS). The IPSS is a combination of the previously validated American Urological Association (AUA) 7-item symptom index plus a eighth question that measure urinary symptoms related QoL (39). The final score is graded as no symptoms, mild, moderate and severe (40). Nowadays, Benign prostatic hyperplasia' (BPH) prevalence varies according to clinical definition adopted. The BPH prevalence is mainly based on the patient self-report (IPSS>7) associated with objective measures, such as: urinary flow and prostatic volume. As any other chronic disease, BPH have a negative impact on wives and family. Usually, they reported

sleeping problems, social life privation and surgery and PCa fear.

In 1998, The 1st ICI Scientific Committee established by The International Continence Society and The International Consultation on Urological Diseases recognized that new globally urinary symptoms related QoL questionnaires should be developed, in order to be widely used in international trials. These questionnaires are available in <http://www.iciq.net>. (41-44):

National Institute of Diabetes and Digestive and Kidney Diseases created The Chronic Prostatitis Collaborative Research Network. They aimed to define chronic prostatitis concepts and standardization clinical practice and future prostatitis research. Nowadays, symptoms are the main criterion to define chronic prostatitis, and the NIH-Chronic Prostatitis Symptom Index (NIH-CPSI) was developed to be an internationally accepted outcome parameter for prostatitis (45).

Some instruments were specifically developed for Overactive Bladder (OAB) evaluation. Coyne et al reported a recommended tool to assess OAB outcomes in continent and incontinent patients (OAB-q) (46). Indeed, a short-form (OAB-q SF) has been developed as well (47). Both forms have been accepted by ICS as The International Consultation on Incontinence Questionnaire for OAB (ICIQ-OABQoL). The Urinary Sensation Scale (USS) is other recommended self-report questionnaire to assess OAB QoL outcomes (48). Originally validated to assess stress urinary incontinence, the IIQ (Incontinence Impact Questionnaire) and the UDI (Urogenital Distress Inventory) have been more recently modified and adapted to discriminate OAB and urge-incontinence in women (Urge-IIQ and Urge-UDI respectively) (49).

An assessment of chronic renal disease and renal transplantation QoL outcomes can be obtained by the validated Kidney Transplant Questionnaire (KTQ) (50,51), Kidney Disease-Quality of Life (KDQoL) (52) and by The End Renal Stage Disease Symptom Checklist Transplantation Module (ESRDSC-TM) (53). KDQoL is a self-report questionnaire specifically designed to be used by dialysis patients (54). ESRDSC-TM is aimed to detect and follow-up immunosuppressive QoL impact.

CONCLUSIONS

Using psychometric methodology, it was possible to transform the QoL subjective concept in an objective score. QoL outcomes measurements have

became an important endpoint in urology. They have allowed urologists to understand better how each disease is different in different individuals. Disease-specific modules have been reported and new ones are being in development process. Nowadays, the use of these instruments in clinical practice and research are recommended. In the clinical settings, major urology society guidelines have made recommendations based on self-report questionnaires, such as the I-PSS in BPH. Societies such as: CaPSURE registry and EORTC QoL Group developed specific instruments for urological malignancies. BPH and urinary incontinence are benign diseases, not threatening conditions, but can have a huge negative impact in QoL.

COLLABORATORS

FL Heldwein, R Sanchez-Salas, PE Teloken and C Teloken worked in the conception and study design methodology, analysis and data interpretation and composition of the article. A critical revision was accomplished by RE Sanchez-Salas. and C Teloken. The final version was approved by RE Sanchez-Salas, O Castilho and G Vallancien.

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