

# Link between the King's Health Questionnaire and the International Classification of Functioning, Disability and Health, for the evaluation of patients with urinary incontinence after gynecological oncology surgery

## *Ligação do King's Health Questionário com a Classificação Internacional de Funcionalidade, Incapacidade e Saúde, para avaliação de pacientes com incontinência urinária pós cirurgia oncológica ginecológica*

Luciana Castaneda<sup>1</sup>, Tiago Plácido<sup>2</sup>

### ABSTRACT

Uterine cervix tumors are the second most common type of tumor among women in the world. In Brazil, 18,680 new cases were estimated for 2008. The treatment of choice for this type of cancer involves surgery, chemotherapy, and radiotherapy that encourage healing but, on the down side, impairments develop such as urinary incontinence. This incontinence appears as an early and common complication of the surgical treatment and involves deterioration in the quality of life, generating levels of morbidity, affecting psychological, occupational, domestic, physical, and sexual areas. To assess the quality of life in patients with incontinence there are several questionnaires in the scientific literature. Among them, the King's Health Questionnaire (KHQ) is the most widely used as a research tool. In addition to assessing quality of life, the World Health Organization is advocating the use of the International Classification

of Functioning, Disability and Health (ICF) as a tool for statistics, research, clinical and social policies, to provide a common language for the conditions related to health. The objective of this study is to establish a correlation between the KHQ and the ICF. The KHQ was correlated by two separate professionals, and followed by a discussion and conclusion of the coded domains. Twelve categories were found for body functions (b), 22 for activities and participation (d), and 4 for environmental factors (e), however, 7 significant concepts of the questionnaire could not be linked to the ICF. The KHQ has focused predominantly on issues related to activity and participation. This is a pilot study that needs more evidence to conclude its findings.

**Key-words:** Urinary Incontinence, Quality of Life, International Classification of Functioning, Disability, and Health

### RESUMO

O tumor de colo uterino é o segundo mais incidente entre as mulheres no mundo e no Brasil estimam-se para 2008, 18.680 casos novos. O tratamento de escolha para esta neoplasia envolve procedimentos cirúrgicos, quimioterápicos e radioterápicos, que possibilitam a cura, mas que de forma negativa permitem o surgimento de seqüelas, como incontinência urinária. A incontinência apresenta-se como uma complicação precoce e comum ao tratamento cirúrgico destas pacientes e envolve deterioração da qualidade de vida, gerando níveis de morbidade, afetando domínios psicológicos, ocupacionais, domésticos, físicos e sexuais. Para a avaliação de qualidade de vida em pacientes portadoras de incontinência existem vários questionários que são divulgados na literatura científica mundial, dentre estes, o King's Health questionário (KHQ) é o mais utilizado como instrumento de pesquisa. Além dos questionários de qualidade (QV), a OMS vem preconizando a utilização da Classificação Internacional de

Funcionalidade, Incapacidade e Saúde (CIF), como ferramenta de estatística, pesquisa, clínica e política social, para proporcionar uma linguagem comum das condições relacionadas à saúde. O presente trabalho teve como objetivo estabelecer a ligação entre o KHQ e a CIF. O KHQ foi relacionado através de dois profissionais (individualmente), seguido de discussão e conclusão dos domínios codificados. Foram encontrados 12 categorias de funções corporais (b), 22 para atividades e participação (d) e 4 para fatores ambientais (e), no entanto, 7 conceitos significativos do questionário não puderam ser ligados com a CIF. O KHQ tem enfoque predominante nas questões referentes à atividade e participação. Trata-se de um estudo piloto que necessita de mais evidências para conclusão dos achados.

**Palavras-chave:** Incontinência Urinária, Qualidade de Vida, Classificação Internacional de Funcionalidade, Incapacidade e Saúde

<sup>1</sup> Physiotherapist at the City University Center in Rio de Janeiro / RJ

<sup>2</sup> Physiotherapist at the National Cancer Institute in Rio de Janeiro /RJ

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### MAILING ADDRESS

Luciana Castaneda • Av. Presidente Vargas, 2700 • Rio de Janeiro / RJ • Cep 20730-080  
E-mail: lucianacastaneda@yahoo.com.br

## INTRODUCTION

Uterine tumors are the second most common type of tumor in the world; in Brazil there are 18,680 new cases estimated for 2008 with a 5-year survival rate of approximately 49%.<sup>1</sup> The therapeutic tools currently available for treatment of uterine cancer are surgical procedures, chemotherapy, and radiation therapy, which frequently lead to urinary incontinence, an early and common complication.<sup>2</sup>

The International Continence Society defines urinary incontinence as any involuntary loss of urine associated with the most diverse causes, constituting a hygienic and social problem.<sup>3</sup> The presence of symptoms of urinary loss is associated with a negative impact on the quality of life of the sufferers of this comorbidity; it has large repercussions on social relations, and causes embarrassments and insecurity.<sup>4</sup>

To evaluate the quality of life among those who suffer from incontinence there are various questionnaires published among world scientific literature. Among these is the King's Health questionnaire, which looks to be a instrument reliable in its psychometric properties, having been translated into the Portuguese language and validated.<sup>5</sup>

The questionnaire is composed of 29 questions which are divided into eight domains: general perception of health; impact of urinary incontinence; limitations to daily activities; physical limitations; social limitations; personal relationships; emotions; sleep / mood. The ICF classifies the KHQ as highly recommendable for use in clinical research.<sup>6</sup>

Aside from questionnaires on quality of life, the WHO praises the use of the International Classification of Functionality, Incapacity, and Health (ICF) in various health fields

such as a tool in epidemiology, research, clinical use, and social politics to provide a common language for health-related conditions.<sup>7</sup> This instrument distributes the data in two main sections: the first refers to the functions and structures of the body, represented respectively by the lower case letters b and s, and data concerning activity and participation represented by the lower case letter d. The second section refers to contextual factors encompassing environmental factors and represented by the lower case letter e, aside from personal factors which cannot be classified.<sup>8</sup>

The concepts presented in the classification introduce a new paradigm for thinking and working with disability and handicap, not only perceived as a consequence of the conditions of binomial health/sickness,<sup>9</sup> but, determined also by the context of the physical and social environment, by the distinct cultural and postural perceptions related to disability, by the availability of services and legislation.<sup>10</sup>

In order to adapt this tool, forms named Core Sets<sup>11</sup> were developed where items that are pertinent to each prevalent, widespread pathology and are summarized grouped all into one document where access to the data becomes easier and more practical in the face of the long list of categories in the complete document.<sup>12</sup>

The methods used to develop the Core Sets involved a process of decision and formal consensus that had the following steps for each health condition: Delphi exercise, systematic review, and collection of empirical data via the checklist. Based on these preliminary studies, relevant categories were identified that represent the starting point for the final decision made at three conferences of differing consenses.<sup>13</sup>

Cieza et al,<sup>14</sup> proposed 8 rules for connecting between measurements of results (clinical measurements, of the state of health, and techniques) with the ICF. The specific rules determine that all significant concepts must be considered before making the connection with ICF categories and that the response options be included when they contain relevant concepts. If the concept of some item contains examples, these must also be connected. These rules were developed based on the accumulated experience during the connection process of hundreds of clinical measurements and state of health documents realized. It is worth pointing out that this type of study is only one of the steps necessary for developing the Core Sets.

In relation to the pathologies and the comorbidities stemming from oncologic pathologies, there is a Core Set for breast cancer<sup>15</sup> as well as for head and neck cancer,<sup>16</sup> but nothing for urinary incontinence.

## OBJECTIVE

The goal of the present work is to establish a connection between the King's Health Questionnaire and the International Functionality Classification, to verify which components of the questionnaire have a possibility of greater coverage: if, in the biological functions represented by the functions (b) and the structures (s), if in the activities of daily life and social life represented by the domains of activity and participation (d), or if in the aspects of the environment where the individual is inserted represented by the environmental factors (e).

## METHOD

Each item in the questionnaire was correlated by two professionals working separately. After finding each one, the correlated categories were re-evaluated and discussed. The methodology followed the guidelines drawn by Cieza et al.<sup>14</sup>

## RESULTS

The process of connecting the KHQ and the ICF leads to 12 categories of bodily functions (b), none for body structures (s), 22 for activities and participation (d), and 4 for environmental factors (e), totaling in all 38 connected categories. Seven significant concepts from the questionnaire could not be connected to the ICF: two were not definable – general health; two not definable – mental health; one not definable – activity and participation; one personal factor; and one not covered by the classification. Results are shown in Table 1.

## DISCUSSION

The women with UI point out limitations on a physical level and hindrances in social, occupational, and domestic activities. All of this influences their emotional state and sex life in addition to their social and hygienic discomforts for fear of urinary loss and smell, which necessitates the use of protectors and a more frequent change of clothes.<sup>17</sup> The symptoms of nocturia can frequently disturb sleeping and bring on bouts of fatigue, depression, and social isolation.<sup>18</sup>

The impact that incontinence can have on one's social life brings restrictions as to going out in public, traveling, sleeping away from home, and visiting friends, for example. Relat-

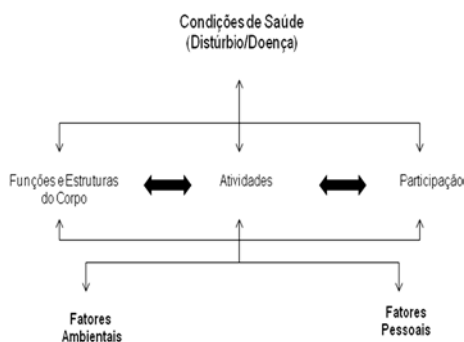


Figure 1 – Interaction between ICF components. Source: WHO 2003.

Table 1 – Connection between KHQ and ICF.

KHQ question	Significant content	ICF Category
1 - How would evaluate your health today?	health	nd-gh
2 - How much do you think your bladder problem hampers your life?	bladder problems, hampering your life	b620 - urinary functions, nd-gh
3 - Frequency: do you go the bathroom too often?	frequency going to the bathroom	d5300 - regulating urination
4 - Nocturia: do you get up at night to urinate?	nocturia, getting up	b620 - urinary functions, d4101 - getting up
5 - Urgency: do you feel urgency to urinate and have difficulty controlling it?	urinary urgency	b6202 - urinary continence
6 - Hyperactive bladder: do you lose urine when you feel urgency to urinate?	hyperactive bladder	b620 - urinary functions
7 - Urinary incontinence by exertion: do you lose urine during physical activities?	urinary incontinence, physical activities	b6202 - urinary continence, nd-A&P
8 - Nocturnal enuresis: do you wet your bed at night?	nocturnal enuresis	b620 - urinary functions
9 - Incontinence during sexual intercourse: do you lose urine during sexual intercourse?	incontinence during sexual intercourse	d7702 - sexual intercourses
10 - Frequent infections: do you have many urinary infections?	urinary infections	b435 - immunological system functions
11 - Pain in the bladder: do you feel pain in the bladder?	pain in the bladder	b2801 - localized pain
12 - Do you have any other problem related to your bladder?	problem related to your bladder	b620 - urinary functions, b2 - pain and other sensations
13 - How intensely do your bladder problems hinder your house chores? (cleaning, washing, cooking etc.)	house chores (cleaning, washing, cooking etc.)	d640 - performing house chores (d6401 - cleaning and cooking utensils, d6402 - cleaning the house; d6400 - washing and drying clothes; d630 - preparation of meals)
14 - How intensely do your bladder problems hinder your work or your daily activities outside the house? (shopping, taking children to school etc.)	work, daily activities outside the house (shopping, taking children to school etc)	d850 - paid work / d855 - non-paid work, nd-A&P (d6200 - shopping, d6601 - helping others to move)
15 - Do your bladder problems hinder your physical activities? (walking, running or any other sport?)	physical activities (walking, running or any other sport)	d570 - caring for your own health (d450 - walking, d4552 - running, d9201 - practicing sports)
16 - Do your bladder problems hinder you when you want to travel?	travelling	d920 - recreation and leisure
17 - Do your bladder problems hinder you when go to the church, a meeting, a party?	church, meeting, party	d9300 - organized religion, d9205 - socialization, d920 - recreation and leisure
18 - Do you avoid visiting friends because of your bladder problems?	visiting friends	d9205 - socialization
19 - Do your bladder problems hinder your sexual life?	sex life	d7702 - sexual intercourses
20 - Do your bladder problems hinder your life with your partner/husband?	partner/husband	d770 - intimate relations
21 - Do your bladder problems disturb your family members?	disturbing family members	e310 - immediate family / e315 - extended family
22 - Do you feel depressed with your bladder problems?	depression	b152 - emotional functions
23 - Do you feel anxious or nervous with your bladder problems?	anxious, nervous	b152 - emotional functions, nd-mh
24 - Do you feel bad about yourself because of your bladder problems?	feeling bad about yourself	nd-mh
25 - Do your bladder problem hinder your sleep?	sleep	b134 - sleeping functions
26 - Do you use any kind of hygienic protection such as diapers, pads, or lining to keep yourself dry?	hygienic protection	e1150 - products and general technology for personal care and daily life
27 - Do you control the amount of liquids you drink?	controlling the amount of liquids, drinking	nc, d560 - drinking
28 - Do you need to change your underwear (panties) when you get wet?	changing underwear	d530 - care related to excretion processes
29 - Do you worry about smelling like urine?	smelling of urine	d120 - other intentional sensory perceptions

ed to this is the shame women feel in relation to their condition and the fear of smelling of urine, of not finding an adequate place to urinate and do their personal hygiene, in cases of nocturia, urgency, or incontinent urge.<sup>19</sup>

The International Continence Society suggests using questionnaires to evaluate the quality of life because the methods generally used in clinical practice treat strictly the bio-medical parameters and do not include the impact that such a condition has on the daily life of these women. The King's Health Questionnaire evaluates the presence of UI symptoms as much as their relative impact, furnishing bases for the results of therapeutic interventions, serving as a guide for objectives, and focusing the dialog with patients.<sup>20</sup>

According to Cieza et al,<sup>14</sup> when the information from the document to be connected is not sufficient to make a decision as to the most appropriate ICF category, one must mark it with the expression nd (not definable) and beside that the concept domain, in our case it was general health (gh), mental health (mh), and not definable for activity and participation (a & d), aside from other significant concepts such as 'nc' (not covered) and 'pf' (personal factor).

Other codes may be relevant to evaluate these patients such as: d2401 (dealing with stress), e1100 (foods), e1101 (medicines), e430 (individual attitudes of people in authority positions), and e580 (services, systems, and health policies).

The questionnaire shows the majority of the concepts referring to activity and participation that refer to the limitations experienced in daily activities, and restrictions to social participation. However, the importance given to environmental factors that are extremely relevant to the social circles of patients with UI is minimal.

Considering all the many repercussions to the daily life and social participation of urinary incontinence, the ICF can be considered an ideal tool for measuring and classifying the diverse functional manifestations.<sup>21</sup> This classification allows the professional to have in one single document, not only the patient's traditional bio-medical findings, but also the findings and information concerning their daily life activities, social participation, and environmental factors,<sup>22</sup> which have extreme relevance to the consequences of urinary incontinence.

## CONCLUSION

Of the 29 questions present in the questionnaire, seven were not able to be linked to the ICF categories. The questionnaire is predomi-

nantly focused on questions referring to activity and participation. This is a study-pilot that needs more evidence to produce a conclusion about its findings.

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