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Development of a scale to assess patient misperceptions about treatment choices for localized prostate cancer

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Abstract

Objectives—To develop a questionnaire to assess a patient's knowledge of his cancer, understanding of treatment choices, and judgement of his survival (KUJ) with and without treatment, as treatment for localized prostate cancer (LPC) can lead to urinary, sexual and bowel side-effects and might not improve survival in 75% of patients

Patients and methods—Although > 90% of patients in the USA are diagnosed with LPC, ≈ 94% of them choose treatment, such that newly diagnosed patients need individualized counselling to address misperceptions about the management LPC. The internal consistency of an 18-item KUJ scale was evaluated among 184 patients recently diagnosed with LPC at a major urology practice. Principal-component analyses were applied for computing a KUJ index. Logistic regression modelling was used to identify predictors of the KUJ index.

Results—Cronbach's α for the KUJ scale was 0.76. Nearly half of the patients provided incorrect answers to most KUJ items. Of the patients, 68% had an income of > US\$50 000 and 90% had at least high (or secondary) school literacy level. Quality-of-life measures suggested that most patients were physically, mentally and socially healthy. Higher education, income and functional capacity were associated with worse KUJ.

Conclusion—The KUJ scale is internally consistent and clinicians can use it to identify the educational needs of patients with LPC before treatment selection. Overall, patients who were socioeconomically disadvantaged and those with physical ailments were better informed about the diagnosis, treatment options and prognosis of prostate cancer.

Keywords

prostate cancer; diagnosis; treatment; prognosis; patient education; quality of life

Introduction

Prostate cancer is the most commonly diagnosed nondermatological malignancy and the second leading cancer-related cause of death among men in the USA. Although a sixth of men in the USA will be diagnosed with prostate cancer during a lifetime, only one in 35 will die as a result of the disease [1]. With the widespread use of PSA screening, > 90% of diagnoses are of localized prostate cancer (LPC) [2]. In patients with no high-grade cancer, the cancer-specific survival without treatment was 99.2% after 8 years of follow-up in a Canadian study of 299 patients with LPC [3] and 100% after 10 years of follow-up in a multicentre European study of 616 patients with LPC [4]. Men who are diagnosed with LPC often die as a result of unrelated and competing health conditions, and treatments for LPC commonly lead to reduced health-related quality-of-life (HRQL) due to urinary, bowel and sexual side-effects. However, 94% of men in the USA diagnosed with LPC opt for surgical or radiological treatments, and few select observation [2]. The HRQL outcomes of different treatments have only marginal differences and the numerical probabilities of the frequency, severity and duration of treatment side-effects are not readily available. Previous studies have estimated that: 70–90% of patients with LPC chose a treatment option after one visit to a urologist [5]; 98% of patients who chose surgery thought it was a guaranteed cure [6]; after counselling, 75% of patients chose a lower radiation dose for better HRQL as a substitute for higher projected survival [7]. However, patients are often at risk of overlooking the fact that most treatments for LPC have no proven survival benefit.

Healthcare providers who counsel newly diagnosed patients need to evaluate their patients' level of awareness, risk-aversion and desired control in decision-making. Research over the last decade has consistently shown that patients have widely heterogeneous informational needs [8]. Patient perceptions of how comorbidities can affect their baseline life-expectancy can also vary [9]. Thus, educational efforts by the healthcare provider could be more effective if they can be tailored to the patient's level of awareness about diagnosis, treatment options and prognosis. Accordingly, we developed and characterized an 18-item Knowledge, Understanding and Judgement (KUJ) scale in a clinical sample of patients newly diagnosed with LPC. The KUJ scale was designed to assess a patient's knowledge of his cancer, understanding of treatment choices, and judgement of his survival with and without treatment.

Patients and methods

A cross-sectional survey was conducted among patients who had been newly diagnosed with LPC, had met with their urologist after the diagnosis, were scheduled to get treatment or had chosen observation, and had not yet been treated. All patients were recruited from a private urology practice in Norfolk, Virginia, USA. Staff at this practice systematically contacted patients newly diagnosed with LPC between March 2005 and October 2007 about their interest in completing a self-administered mailed questionnaire. Questionnaires were mailed to patients immediately after the initial visit to the urologist. Patients who did not return surveys were further contacted by telephone. In addition to the KUJ scale, survey items included scales that assessed generic, symptom-specific and domain-specific HRQL measures. Socio-demographic and clinical data were obtained from patient charts. Field procedures were approved by an Institutional Review Board.

Extensive literature searches yielded no instruments that were specifically devised for assessing the level of awareness of patients newly diagnosed with LPC. Accordingly, the KUJ scale was developed after consulting with experts in the field. Face validity and cultural relevance were checked for all items in group discussions with physician colleagues. The KUJ scale includes 18 items divided into three sections: the patient's *Knowledge* about

cancer diagnosis, *Understanding* of the pros and cons of various treatment options, and *Judgement* of his own life expectancy with and without treatment. Questions were developed after reviewing studies that had assessed perceived informational needs of patients and their families [8]. Similarly, questions were designed to sample a patient's KUI in key areas that could influence treatment selection, while assessing the full range of a patient's KUI regarding treatment options.

The *Knowledge* section had three open-ended questions, i.e. self-reported stage, Gleason grade and last PSA test result. Correct answers to these questions were obtained from the patient's chart. One point was given for each correct answer. In the *Understanding* section, three questions asked patients to identify the most frequent complication of surgery, radiotherapy and observation, and seven 'True' or 'False' statements were focused on treatment side-effects. 'True' statements presented probabilities of side-effect occurrences that were within the reported range, and 'False' statements presented probabilities of side-effect occurrences that were outside the reported range. Estimates of true ranges were obtained from patient education websites such as those of the American Cancer Society, the National Comprehensive Cancer Network, the AUA, and review articles in medical journals [10,11]. The *Judgement* section included five questions on the effect of treatment or observation on survival. Three of these questions were in a 'True' or 'False' format similar to those in the Understanding section, and two questions were in an ordinal-scale format that asked patients to estimate their life-expectancy if they chose observation (Q1) vs if they chose treatment (Q2). Also, the patient's baseline health-adjusted life-expectancy without factoring the newly diagnosed cancer was estimated based on patient age and his Charlson Comorbidity Index score. Using Q1 and Q2 responses and the health-adjusted life-expectancy, we calculated the patients' perceived decrease in longevity with choice of observation and perceived increase in longevity with the choice of treatment by a method we had described earlier [12] (Table 1).

A total KUI score was computed by summing the responses to each of the 18 items, after coding correct responses as '1' and incorrect responses as '0'. To assess internal consistency, Cronbach's α was estimated for the 18-item KUI scale and its three sections. Cronbach's α assesses whether several questions that propose to measure the same general construct produce similar scores, and is based on the correlations between different items on the same test [13]. In addition, a KUI index was created through data reduction using principal-component analysis (PCA) with varimax rotation [14]. Six factors identified as having eigenvalue ≥ 1 were used to estimate the KUI index for each patient. Specifically, each factor was weighted with its percentage variance explained, as shown in the equation below [14]. The six factors that form the KUI index were described by examining the conceptual relatedness of KUI questions with factor loadings of ≥ 0.5 .

$$\text{KUI index} = [(\% \text{ var exp factor 1}) \times \text{factor 1} + \dots + (\% \text{ var exp factor 6}) \times \text{factor 6}] \div 10$$

The role of sociodemographic and HRQL measurements as independent predictors of the KUI index was examined in multivariate regression analyses. Sociodemographic variables included: age, defined as continuous and categorical (< 60, 60–70, > 70 years) variables; race (Caucasian, African-American); education (less than high school, high school, college) and family income (< US\$50 000, $\geq$ \$50 000). Three HRQL measures were used to define physical functioning [15], anxiety/depression [16] and social support [17]. The 12-item Duke Activity Status Index (DASI) is a brief, validated, self-administered questionnaire that correlates well with peak oxygen uptake, while measuring functional capacity and various aspects of HRQL. Specifically, DASI measures activities of daily living for which each item is weighted by its known metabolic cost, and weights of positive terms are summed to form the DASI score expressed in metabolic equivalents (METs). DASI scores were analysed as

a continuous variable and categorized as ‘mild activities (< 3 METS)’, ‘moderate activities (3–6 METS)’ and ‘vigorous activities ($\geq$ 6 METS)’. The Hospital Anxiety and Depression (HAD) scale is a validated 14-item scale that includes two subscales, each consisting of seven Likert-type items for anxiety and depression, respectively. For each subscale, the total score is 0–21. Anxiety and depression subscales were analysed as continuous and categorical (0–7, none; 8–10, mild; 11–14, moderate; and 15–21, clinical) variables. The Medical Outcomes Study Social Support Survey (MOS-SSS) is a validated 19-item scale covering four domains, i.e. ‘Emotional or Informational Support’ (eight items); ‘Tangible support’ (four items); ‘Affectionate support’ (three items); ‘Positive social interaction’ (three items) and one additional item. A total MOS-SSS score is computed by taking the score average for the 18 items included in the first four subscales and the score for the additional item. Scale scores were transformed to a 0–100 scale, and categorized as < 50, 50– < 75 and 75–100. Health literacy was evaluated through telephone interview using a brief version of the Rapid Adult Assessment of Literacy in Medicine scale [18].

Descriptive statistics included proportions for categorical variables and the mean ($_{SD}$) for continuous variables. Pearson's correlation coefficients were used to evaluate bivariate relationships among continuous variables. Cronbach's α was used to estimate internal consistency of the KUI scale and its three sections. PCAs were used for data reduction through computation of a KUI index. Ordinal logistic modelling was applied for identifying socio-demographic and HRQL variables that can independently predict the KUI index, defined in quartiles. Stepwise selection was applied for constructing a parsimonious model for the KUI index.

Results

Surveys were mailed to 430 patients newly diagnosed with LPC, but in 69 the treatment had already been started by the time the patients received the surveys, three never received the surveys and two were found to be ineligible to participate as the cancer was not localized. Of the 356 remaining patients, 104 did not return the survey because they were ‘not interested’ in participating and 68 who did not return the surveys did not give a reason for not participating or could not be contacted. Furthermore, 184 of 356 patients (survey response rate of 52%) completed and returned the first pretreatment survey. As shown in Table 2, the mean ($_{SD}$) patient age was 61.5 (7.9) years, and most reported being Caucasian, college-educated and having a family income of $\geq$ \$50 000. As previously reported, > 90% of these patients had at least a ninth grade literary level [12]. HRQL measures suggested that most patients in the study sample were physically, mentally and socially healthy. While nearly 89% of patients were capable of vigorous activity (DASI scale), most scored low on the HAD scale and high on the MOS-SSS scale.

Table 3 shows the KUI scale as a whole and each KUI section separately. On average, over half of patients were accurate about knowledge and judgement questions, while fewer than half were accurate about understanding questions. Over 70% of patients provided the wrong answer for questions related to LPC treatment complications and prognosis in the absence of treatment. Cronbach's α for the KUI scale and each of the Knowledge, Understanding and Judgement sections were 0.76, 0.65, 0.55 and 0.52, respectively, suggesting adequate internal consistency. PCAs indicated a different pattern for factor loadings. Whereas factors 1 and 2 loaded on a mixture of items from the different sections of the KUI scale, factors 3–6 loaded on items from one section of the KUI scale. In particular, factor 3 loaded heavily on questions related to ‘impotence’, while factor 4 loaded heavily on questions of ‘survivorship’ with and without treatment (data not shown). The KUI index computed using the six factors and their variance explained had a mean ($_{SD}$, range) of 0 (0.48, – 1.07 to 0.93). When defined as a continuous variable, the KUI index was positively correlated with the

percentage of correct answers on the KUI scale (Pearson's $r = 0.95$), as was the Knowledge ($r = 0.71$), Understanding ($r = 0.84$) and Judgement ($r = 0.74$) sections of the KUI scale. Therefore, the KUI index simultaneously reflects the patient's knowledge about his cancer diagnosis, understanding of the pros and cons of treatment choices, and judgement of his life-expectancy with and without treatment. Because the KUI index was not normally distributed (Shapiro-Wilk test; $P < 0.001$), we created a categorized form defined according to quartiles, i.e. < -0.25 (46 men), $-0.25 < 0$ (35 men), $0 < 0.33$ (57 men) and ≥ 0.33 (46 men).

Sociodemographic and HRQL measures were evaluated as potential predictors of the categorized KUI index through ordinal logistic regression analyses. Stepwise variable selection was applied with probabilities for entry and remaining in the model both set at 0.35. Of 184 survey participants, 173 (94%) were kept in the multivariate model (Table 4). The model included education, income, functional capacity (DASI) and anxiety score (HAD). Whereas higher education and better functional capacity predicted lower KUI index scores, lower family income predicted a higher KUI index. There was no clear relationship between anxiety score and KUI index. Overall, men who were socioeconomically disadvantaged and those with physical ailments appeared to be better informed about the diagnosis, treatment options and prognosis of LPC. By contrast, age, race, depression and social support were not independent predictors of KUI index.

Discussion

In this study we developed a KUI questionnaire that can be self-administered to patients with LPC and used by their healthcare providers to evaluate their level of awareness at the time of diagnosis. To our knowledge, no studies thus far have examined the psychometric properties of a KUI-type instrument targeting patients who have been diagnosed with LPC, have met with their urologists, but have not yet received a treatment. We also tested this KUI questionnaire in a clinical sample of patients newly diagnosed with LPC. Although these patients had already selected a treatment plan at the time of survey administration, most provided incorrect answers on the KUI questions, implying a wide range of educational needs that encompass the diagnosis, treatment and prognosis of LPC. Our results also suggested that misperceptions about LPC were more prominent in patients who had better socioeconomic and health profiles.

In previous qualitative studies conducted after a treatment had been implemented, patients with LPC and their families recalled that they had several unmet informational needs when selecting a treatment option [19]. Patients frequently consulted the Internet [20], made their decisions based on incomplete data [21], and used anecdotes of family and friends in selecting a treatment option [22]. Furthermore, patients had different levels of desire to participate in decision-making [23], different informational needs [8], and their healthcare providers were frequently unaware of their individual preferences [24]. On the other hand, counselling of these patients by their healthcare providers is a difficult task due to the uncertainties surrounding the management of LPC. Although few clinical situations rival the need for patient counselling in decision-making for LPC, we could find no previously published KUI-type questionnaires that can be used either to tailor counselling to a patient's informational needs or to assess the usefulness of a decision aid. In a PUBMED search using the keywords 'prostate cancer knowledge questionnaire', 133 articles were identified; however, the vast majority of these articles reported a knowledge assessment for patients presenting for PSA testing. We excluded these articles because knowledge of treatment options is considerably more salient for patients diagnosed with prostate cancer than for those considering PSA testing. We also excluded articles describing questionnaires that were designed to characterize the knowledge 'needs' of patients with LPC. As a result, we found

only three studies that had used any kind of questionnaire to assess the KUI of patients who had been diagnosed with LPC or had been treated for LPC.

Deibert *et al.* [25] used a 14-item 'True' or 'False' questionnaire in patients who had already been treated for LPC. Four questionnaire items asked about which factors increase the risk of developing LPC, and only one question about surgery and one about radiation asked *if* these treatments 'can cause urinary or sexual problems'. These two questions might be too simple, given that treatment decision-making often considers the frequency, severity and duration of side-effects. By contrast, our KUI scale asked about numerical probabilities when addressing treatment side-effects. For survival expectations, Diebert *et al.* [25] asked only *if* surgery or radiation 'can cure prostate cancer in its early stage'. By contrast, our KUI scale asked patients to estimate the degree of longevity with and without treatment for LPC.

Holmes-Rovner *et al.* [26] also asked questions that appear over-simplified. Their questionnaire asked if surgery or radiation was 'associated with' sexual, urinary, or bowel side-effects, in a 'True' or 'False' format; however, a strength of their questionnaire was that it tested patient knowledge of Gleason grade, cancer stage and PSA level. We adapted these three questions to form the Knowledge section of our KUI scale.

Kim *et al.* [27] tested a 23-item Prostate Cancer Knowledge Questionnaire on 30 patients with LPC. This questionnaire had been developed by Rees *et al.* [28] using a sample of 28 patients with prostate cancer and 132 without. Rees *et al.* [28] discussed that the only questionnaire they could find that focuses on such patients was that of Conlisk *et al.* [29]. However, that 20-item questionnaire had been developed by Demark-Wahnefried *et al.* [30] in the context of PSA testing. The 23-item questionnaire developed by Rees *et al.* [28] was also initially developed for screening patients with prostate cancer. Eleven of its 23 questions are about prostate anatomy, the risk of cancer, and cancer diagnosis. For treatment, it only asks to check which of six methods could be potential treatments for prostate cancer, and which of six health conditions could be potential side-effects of the treatment. Unlike the KUI scale, no question was asked about the frequency or severity of treatment side-effects or about expectations of survival with and without treatment for LPC.

Our study findings indicated that patients fared best on the Knowledge section of the KUI scale. Whereas 85% of patients knew that their cancer was localized and about two-thirds correctly estimated their PSA levels, most did not know their cancer grade. The latter question described cancer grade qualitatively as 'very slow growing', 'slow growing', etc.; more patients might have answered this question correctly had we provided them with the more objective Gleason grade categories ('2-4', '5-6', '7', '8-10') as response options. In the Understanding section, 60-70% of patients answered questions incorrectly. Although reported rates of treatment side-effects vary widely, there is some consensus that the most common complication reported after surgery or radiotherapy is erectile dysfunction and that observation is not associated with any complication. However, > 70% of patients provided incorrect answers to these questions. In addition, > 70% believed that without treatment more than half of patients will develop urinary or sexual side-effects. On the Judgement section, the most common misperception was that without treatment one in three patients will die 10 years after diagnosis. Of note, 21 of 23 African-American patients shared this misperception. As a whole, the Understanding section's lower internal consistency is expected, as it attempts to elicit many concepts with too few items. The relatively low internal consistency observed for the Judgement section might be due to variations in item format.

Overall, the proposed KUI scale is internally consistent and can be completed by patients with LPC in clinical settings, to simultaneously assess their knowledge of cancer diagnosis,

understanding of treatment pros and cons, and judgement of life-expectancy with and without treatment. Survey findings indicate that such patients might need counselling, especially with issues related to treatment complications and prognosis of observation. Interestingly, it appears that socioeconomically disadvantaged patients and those with physical ailments were better informed about the diagnosis, treatment options and prognosis of LPC. Patients with more resources might be less aware of their personal risks because LPC is generally perceived as affecting low socioeconomic groups. It is also plausible that patients with low functional capacity have more frequent contact with their healthcare providers and more opportunities for discussion of health issues. However, such results need to be confirmed in larger studies.

The interpretation of study findings should take into account several limitations. First, the survey response rate was relatively low, with an increased chance of self-selection bias; the burden of the survey on eligible patients was considerable, potentially affecting the level of participation. Second, the survey was conducted at a single urological practice in Virginia, precluding direct generalization of study findings to other geographical regions; given the sociodemographic and health characteristics of survey respondents, we can only generalize our findings to higher income and healthy men in the USA. Third, the few African-Americans completing the survey precluded the conduct of stratified analyses or a formal evaluation of ethnic disparities; although the study sample does not reflect the local population in terms of ethnic distribution (African-Americans represent > 40% of the population of Norfolk, Virginia), it is reflective of the ethnic distribution of patients attending the urology practice. Fourth, correct responses on the KUI scale were frequently determined based on evidence from national and international organizations; a better option would have been to base the correctness of a response on data derived from the urology practice being surveyed. Nevertheless, our study should be extended to larger and broader population groups. Fifth, other psychometric properties of the KUI scale, including test-retest reliability and criterion validity, could not be evaluated in a single survey. In conclusion, clinicians can use the KUI scale to identify educational needs of patients with LPC before treatment selection. Further research is needed to comprehensively assess the psychometric properties of the KUI scale. Ultimately, we would like to identify meaningful threshold levels that can signal the need for an educational intervention for a diverse population of patients with LPC.

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Abbreviations

LPC	localised prostate cancer
HRQL	health-related quality-of-life
PCA	principal-component analysis
METS	metabolic equivalents
KUJ	Knowledge, Understanding, Judgement
DASI	Duke Activity Status Index
HAD	Hospital Anxiety and Depression
MOS-SSS	Medical Outcomes Study Social Support Survey

Table 1**KUJ items and valid item responses**

KUJ item	Responses
The stage of your cancer is:	Stage 1 (very early); Stage 2 (still early, spread within prostate); Stage 3 (spread outside the prostate); Stage 4 (spread in the body)
The grade, or aggressiveness, of your cancer is:	Very slow growing; Slow growing; Medium; Fast growing; Very fast growing
Your most recent PSA level is:	< 5; 5–10; 10–50; > 50
After surgery, the most common complication is:	No complication; Pain on urination; Urine leakage; Diarrhoea; Impotence
After radiotherapy, the most common complication is:	No complication; Pain on urination; Urine leakage; Diarrhoea; Impotence
After no treatment, the most common complication is:	No complication; Pain on urination; Urine leakage; Diarrhoea; Impotence
Without treatment, more than half of patients will have sexual or urinary symptoms in 5 years.	True; False
One of three patients who has surgery will have some problem with control of urine after surgery.	True; False
One of three patients who has surgery will need diapers due to very poor control of urine after surgery.	True; False
One of 10 patients who has surgery will need diapers due to very poor control of urine after surgery.	True; False
Three of four patients who have surgery will have penile erections firm enough to have sexual intercourse after surgery.	True; False
Four of five patients who get radiation rays (not seeds) are able to have erections firm enough to have intercourse after radiation.	True; False
Four of five patients who get radiation seeds are able to have erections firm enough to have intercourse after radiation seeds.	True; False
Without treatment, one out of three patients will die within 10 years due to prostate cancer.	True; False
You should make your decision about which kind of treatment within 6 months, or the cancer can spread beyond cure.	True; False
Without treatment, cancer will spread in one of three patients within 10 years.	True; False
Keeping in mind your age and health at present, how long do you expect you will live without any treatment for prostate cancer?	< 5 years; < 10 years; < 20 years; > 20 years
Keeping in mind your age and health at present, how long do you expect you will live after the treatment of your choice for prostate cancer?	< 5 years; < 10 years; < 20 years; > 20 years

Table 2

The basic characteristics of patients with LPC in the study sample (184 men)

Sociodemographic variables (N)	Mean (SD) or n (%)
Age, years (184)	61.5 (7.9)
<60	71 (38.6)
60–70	91 (49.5)
> 70	22 (11.9)
Race (184)	
African-American	26 (14.1)
Caucasian	158 (85.9)
Education (180)	
Less than High School	7 (3.9)
High School	65 (36.1)
College	108 (60.0)
Health literacy (173)	
< 6th grade	1 (0.6)
6–9th grade	16 (9.3)
> 9th grade	156 (90.2)
Family income, US\$ (179)	
Low < 50 000	57 (31.8)
High ≥ 50 000	122 (68.2)
HRQL variables	
Physical functioning (184)	
Mild activities (< 3 METS)	1 (0.5)
Moderate activities (3–6 METS)	20 (10.9)
Vigorous activities (6 + METS)	163 (88.6)
Score	6.7 (0.6)
Anxiety score (183)	5.1 (3.5)
None (normal, 0–7)	145 (79.2)
Mild anxiety (8–10)	23 (12.6)
Moderate anxiety (11–14)	12 (6.6)
Clinical (15–21)	3 (1.6)
Depression score (178)	1.7 (2.3)
None (normal, 0–7)	172 (96.6)
Mild depression (8–10)	4 (2.3)
Moderate (11–14)	1 (0.6)
Clinical (15–21)	1 (0.6)
Social support score (183)	2.7 (0.5)
< 50	7 (3.8)
50–75	33 (18.0)
75–100	143 (78.1)

Table 3

A description of the KUJ questionnaire items and scores for 184 men

Items	Correct answer	Mean (sd) % correct
Knowledge		
Q1. What is your cancer stage?	Known stage after biopsy	82.6 (38.0)
Q2. What is your cancer grade?	Known grade after biopsy	42.9 (49.6)
Q3. What is your PSA level?	Known last PSA	66.8 (47.2)
Knowledge subscale score	Total K score/3	64.1 (34.8)
Cronbach's $\alpha = 0.65$		
Understanding		
Q4. After surgery, the most common complication is	Impotence	26.6 (44.3)
Q5. After radiotherapy, the most common complication is	Impotence	27.7 (44.9)
Q6. After watchful waiting, the most common complication is	None	29.9 (45.9)
Q7. Without treatment, more than half of patients will have sexual or urinary symptoms in 5 years.	False	27.2 (44.6)
Q8. 1 of 3 patients who gets surgery will have some problem with control of urine after surgery.	True	39.1 (48.9)
Q9. 1 of 3 patients who gets surgery will need diapers due to very poor control of urine after surgery.	False	53.8 (49.9)
Q10. 1 of 10 patients who gets surgery will need diapers due to very poor control of urine after surgery	True	43.5 (49.7)
Q11. 3 of 4 patients who get surgery will have penile erections firm enough to have sexual intercourse after surgery.	False	44.0 (49.8)
Q12. 4 of 5 patients who get radiation rays (not seeds) are able to have erections firm enough to have intercourse after radiation.	False	41.8 (49.5)
Q13. 4 of 5 patients who gets radiation seeds are able to have erections firm enough to have intercourse after radiation seeds	True	47.8 (50.1)
Understanding subscale score	Total U score/10	38.2 (21.3)
Cronbach's $\alpha = 0.55$		
Judgement		
Q14. Without treatment, one of three patients will die within 10 years due to prostate cancer.	False	28.8 (45.4)
Q15. You should make your decision about which kind of treatment within 6 months, or the cancer can spread beyond cure.	False	47.8 (50.1)
Q16. Without treatment, cancer will spread in out of three patients within 10 years.	True	71.7 (45.1)
Q17. PDLO	See Methods	47.3 (50.1)
Q18. PILT	See Methods	57.1 (49.6)
Judgement subscale score	Total U score/5	50.6 (28.1)
Cronbach's $\alpha = 0.52$		
Total KUJ score	Total KUJ score/18	50.5 (28.3)
Cronbach's $\alpha = 0.76$		

PDLO, perceived decrease in longevity with choice of observation; PILT, perceived increase in longevity with the choice of treatment

Table 4

Ordinal logistic regression model for predictors of KUJ index

Variable	Adjusted odds ratio (95% CI)
Education	
Less than High School	1.00 (–)
High School	0.58 (0.12–2.73)
College	0.38 (0.08–1.79)
Family income, US\$	
Low, < 50 000	1.59 (0.87–2.92)
High, ≥ 50 000	1.00 (–)
Physical functioning	0.54 (0.32–0.89)
Anxiety score	0.95 (0.88–1.03)