

Distress due to unwanted side-effects of prostate cancer treatment is related to impaired well-being (quality of life)

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Based on traditional quality of life scales, it has been suggested that known side-effects of prostate cancer treatment do not influence the quality of life. The present authors have developed an alternative approach to quality of life assessment applying epidemiological methods.

Using a self administered questionnaire, we investigated 431 prostate cancer patients and an age stratified sample of 435 randomly selected men.

Patients reporting any level of distress due to waning sexual functions (66%) or urine or bowel symptoms (38%), reported a lower psychological well-being compared to patients not reporting these symptoms or patients not distressed by their symptoms.

Our results stress that an intact sexual and urinary and bowel functions are important for the quality of life among elderly men with or without prostate cancer.

Keywords: sexual function; urinary and bowel symptoms; distress; quality of life; well-being; prostate cancer

Introduction

We have previously confirmed a relatively high prevalence of sexual desire, intact erectile function and orgasms (with and without intercourse) among a representative sample of randomly selected 70–80 y old men.¹ Moreover, among men with an intact erectile function, 70% stated that a waning erection would distress them and a majority of the men reporting waning erection expressed distress due to this.¹ Among prostate cancer patients, waning erection capacity was the most common source of distress followed by distress due to diminished orgasm pleasure, waning sexual desire and reduced ejaculate volume.² Distress derived from urinary and bowel symp-

toms was more common in prostate cancer patients compared to men without prostate cancer but was less common than distress caused by waning sexual functions.²

It has been argued that side-effects of prostate cancer treatment including waning sexual function and urinary and bowel symptoms, do not affect the quality of life among prostate cancer patients in spite of reported distress due to these symptoms.^{3,4} Available data, however, are compromised by a large non-response and the use of psychometric scales that may be insensitive, leaving the issue open for debate. If quality of life after treatment is immediately affected in elderly men as a result of, for example waning sexual function, this must be balanced against possible long-term treatment benefits. For diseases where medical interventions have a moderate long-term efficacy, like for example, localized prostate cancer^{5–7} where there are many treatment options and where all treatments may result in impaired sexual function or urinary or bowel symptoms,^{2–4,8–11} this may be of

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central importance in clinical decision-making. The aim of the present study was to assess the impact that distress deriving from waning sexual function and urinary and bowel symptoms have on the physical, psychological and overall well-being in prostate cancer patients and men without the disease, applying epidemiological methods.

Materials and methods

In October 1993, 900 men aged 50–80 y were identified from the Stockholm area in Sweden. Half of the men were randomly selected from the Swedish Population Registry. The sample was stratified to have the same age distribution as that of men with newly detected prostate cancer. The other half included all men in this age group that had been diagnosed with prostate cancer in the area during 1992. Description of the prostate cancer population, including sub-groups of patients subjected to different treatment protocols and prevalence of symptoms in these groups, is published elsewhere.² The time from diagnosis to follow-up was 1.5–2 y for the prostate cancer population. All men not born in Sweden or dead at the time of the investigation were excluded, leaving 866 men. Details of the study can be found in earlier reports.^{1,2} The study was approved by the local ethics committee. After a letter of introduction, a questionnaire was sent by post to be answered anonymously.

The questionnaire included 'The Radiumhemmet Scale of Sexual Function', which assesses the frequency and/or intensity of sexual desire, erectile, orgasmic and ejaculatory functions and the extent to which a waning function causes distress. The present analysis is based on four questions combining the assessment of prevalence of intact function and to what extent waning function distresses the men. The aspects of sexual function assessed include sexual desire, erectile capacity, orgasm pleasure and ejaculate volume. The answer alternatives comprise seven verbal categories. The first two stating; 'the function 'x' has not decreased' and 'the function 'x' has increased' and the last five stating different levels of distress in case of waning function: (a) no distress; (b) almost no distress; (c) low distress; (d) moderate distresses; and (e) high distress. In the analysis the categories 'no distress' and 'almost no distress' are combined and called 'no distress.'

Erection stiffness was assessed using three separate questions assessing erection stiffness on an eight category ordinal scale during sexual activity, morning erections and spontaneous erections. 'Physiological potency' was defined as 'erection stiffness sufficient for intercourse most of the time' in one or more of the erection stiffness questions. A more detailed description of the erection stiffness scale is published elsewhere.¹

The prevalence and severity of urinary and bowel symptoms were assessed using a four category scale ranging from absence to a high frequency or severity of the symptom: (a) no symptom; (b) a little; (c) moderate; and (d) severe. The urinary symptoms assessed included hesitancy, leakage, urgency, dysuria and weak stream and the bowel symptoms comprised urgency, fecal leakage and constipation. For each symptom the prevalence/severity questions were followed by a question assessing the distress due to the symptom. The distress was assessed on a four category scale ranging from no distress

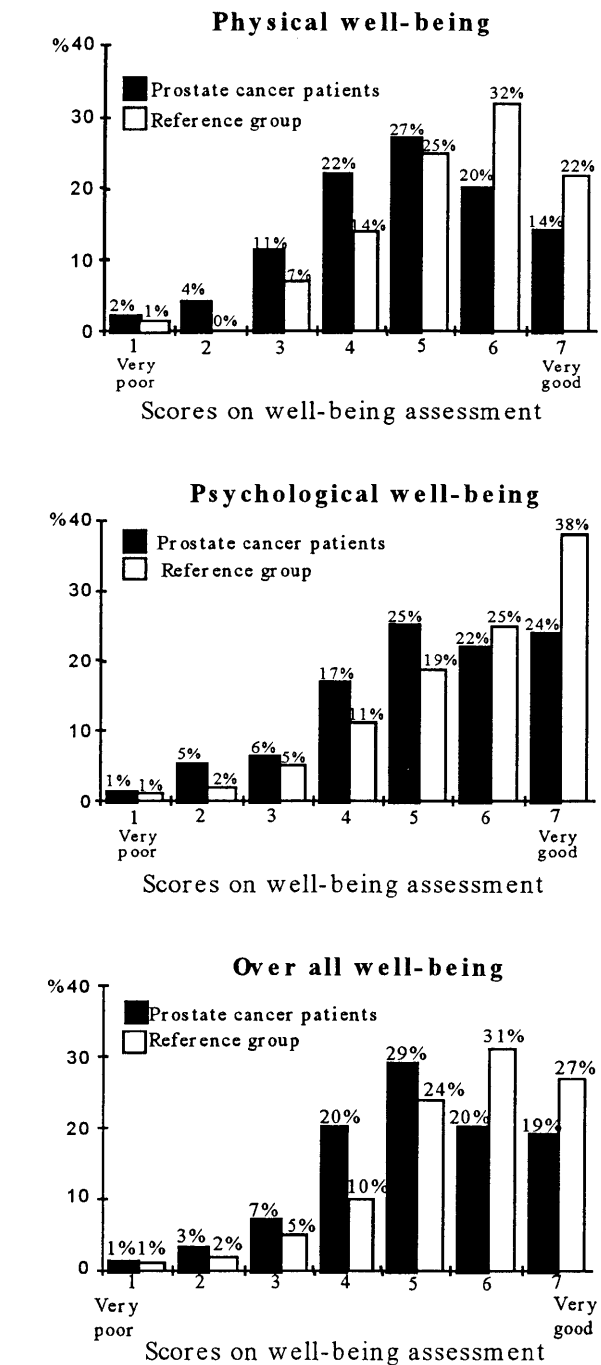


Figure 1 Percentage of prostate cancer patients and randomly selected men from the general population reporting different categories on a 7-category ordinal visual scale assessing the feeling of well-being.

to a high level of distress: (a) no; (b) little; (c) moderate; and (d) high.

The average physical, psychological and overall well-being during the past year was assessed using single-item seven-point visual ordinal scales ranging from a 'very poor' to a 'very good' feeling of well-being (Figure 1).

Mean scores on the well-being assessments were calculated with 95% confidence intervals and, when appropriate, a *P*-value was computed using a two-tailed *t*-test. Ratios of proportions (relative risk) with 95% confidence

intervals were calculated to compare the prevalence between groups, based on the method proposed by Mantel and Haenszel.¹² All analyses were adjusted for age using a three-category scale (50–59, 60–69 and 70–80 y).

Results

In the patient population and the randomly selected reference population, the response rate was 79% (319 men) and 73% (342 men), respectively. In the reference group, five men had previously been diagnosed with prostate cancer. They were not included in the subsequent analysis, leaving 314 randomly selected men.

The prevalence of 'physiological impotence' (erection stiffness usually not sufficient for intercourse during either sexually stimulated erections, morning erections or spontaneous erections) was more than twice as high in the prostate cancer population compared to the randomly selected population, 71% and 31%, respectively. There was no apparent difference between men with or without prostate cancer with respect to the level of distress experienced owing to 'impotence.' 48% of the 'impotent' prostate cancer patients and 47% of the 'impotent' randomly selected men reported the two highest distress categories in the question assessing distress due to waning erection stiffness. The prevalence of moderate and high distress (reporting the two highest distress categories on the five category distress scale) due to waning function in one or more aspects of sexuality was 52% (177 out of 342) in the prostate cancer group and 38% (120 out of 314) in the randomly selected group.

Urinary and bowel symptoms were relatively common with 76% of the prostate cancer patients and 59% of the randomly selected men reporting at least a 'little' symptom in one or more aspects of urine/bowel functions assessed. However, the prevalence of 'moderate' and 'severe' urinary or bowel symptoms was low (Table 1). The most frequent severe symptom was weak urine stream which was reported by 3% of the prostate cancer population and 1% of the randomly selected men. The prevalence of moderate or high distress (reporting the two highest distress category on a four category scale) due to one or more of the urinary or bowel symptoms

was 12% (42 out of 342) in the prostate cancer group and 4% (11 out of 314) in the randomly selected population.

Men with prostate cancer were less likely than the reference population to report the two highest categories (6 and 7) on the well-being scales (Figure 1). The prostate cancer patients were more likely to report all other categories of the scale, with the possible exception of the lowest category, which only approximately, 1–2% of all men reported. The mean scores on the physical well-being scale for the prostate cancer patients and for the reference population were 4.8 and 5.5, respectively, for psychological well-being they were 5.2 and 5.7 and for overall well-being 5.0 and 5.5, respectively. All mean differences were statistically significant ($P < 0.001$).

Prostate cancer patients not treated and those only subjected to external beam radiation therapy or prostatectomy, that is those probably having clinically localized tumors, were also less likely than the age-adjusted reference population to report the two highest categories on the well-being scales, with relative risks and 95% confidence intervals of 1.3 (1.1–1.6) for physical well-being, 1.4 (1.2–1.8) for psychological well-being and 1.3 (1.0–1.5) for overall well-being (not in the figures).

Men reporting waning sexual function in one or more aspects assessed, and men reporting one or more of the assessed urine or bowel symptoms scored lower on the well-being assessments compared to men with intact sexual function and no urine/bowel symptoms (Tables 2 and 3). Similarly, the level of distress due to waning sexual function and urine/bowel symptoms was negatively associated with the average scores in all three well-being categories (Tables 2 and 3). A graphic illustration of the relationship between distress due to waning sexual function and psychological well being is presented in Figure 2.

Irrespective of prostate cancer, impotent men who were highly distressed due to waning erection stiffness were significantly less likely to report the two highest categories on the psychological well-being assessment with a relatively risk, with a 95% confidence interval, of 1.5 (1.2–1.8) compared to potent men. Impotent men that were not distressed because of their impotence were, however, not less likely than potent men to report the

Table 1 Percentages of all men reporting moderate or severe^a urinary or bowel symptoms

	Prostate cancer patients (<i>n</i> = 342)		Men without prostate cancer (<i>n</i> = 314)	
	Moderate %	Severe %	Moderate %	Severe %
Hesitancy	5	1	2	0 ^c
Urine leakage	3	0 ^c	1	0 ^c
Urinary urgency	8	2	1	1
Dysuria	2	0 ^b	0 ^b	0 ^c
Weak urine stream	11	3	3	1
Fecal leakage	0 ^b	0 ^c	0 ^b	0 ^c
Bowel urgency	4	1	0 ^b	0 ^b
Constipation	4	1	1	1

^a Reporting the severity of the symptom on a four category scale: no symptom, little, moderate, severe.

^b Reported by one man.

^c Not reported.

Table 2 Presenting mean scores (with 95% confidence intervals) for psychological, physical and over all well-being for prostate cancer patients and randomly selected men reporting different levels of distress owing to waning function in one or more aspects of sexual function^a

	Prostate cancer patients (<i>n</i> = 342) ^b	Randomly selected men (<i>n</i> = 314) ^b
No decrease in sexual function	(<i>n</i> = 6)	(<i>n</i> = 23)
psychological well-being	6.3 (5.5–7.2)	6.2 (5.7–6.6)
physical well-being	6.0 (4.7–7.3)	6.0 (5.6–6.4)
over all well-being	6.5 (5.2–7.8)	6.0 (5.7–6.4)
Waning sexual function	(<i>n</i> = 320)	(<i>n</i> = 288)
No distress ^c	(<i>n</i> = 93)	(<i>n</i> = 90)
psychological well-being	5.8 (5.5–6.1)	6.0 (5.7–6.2)
physical well-being	5.4 (5.1–5.7)	5.9 (5.6–6.1)
over all well-being	5.6 (5.3–5.9)	5.9 (5.6–6.1)
Low distress ^d	(<i>n</i> = 50)	(<i>n</i> = 78)
psychological well-being	5.5 (5.1–5.8)	5.7 (5.4–6.0)
physical well-being	4.9 (4.6–5.3)	5.3 (5.1–5.6)
over all well-being	5.3 (5.0–5.6)	5.4 (5.1–6.0)
Moderate distress ^e	(<i>n</i> = 96)	(<i>n</i> = 78)
psychological well-being	5.0 (4.8–5.3)	5.8 (5.5–6.0)
physical well-being	4.7 (4.4–5.0)	5.1 (4.8–5.4)
over all well-being	4.9 (4.7–5.2)	5.4 (5.1–5.7)
High distress ^f	(<i>n</i> = 81)	(<i>n</i> = 42)
psychological well-being	4.6 (4.2–4.9)	4.9 (4.4–5.5)
physical well-being	4.2 (3.9–4.6)	5.2 (4.8–5.7)
over all well-being	4.4 (4.1–4.7)	5.1 (4.6–5.6)

^a Assessing erection capacity, orgasm pleasure, ejaculate volume and sexual desire.

^b Relevant information was missing from 16 prostate cancer patients and 3 randomly selected men without prostate cancer.

^c Men reporting waning function in one or more aspects of sexuality but ‘no’ or ‘almost no’ distress owing to this (the two lowest distress categories).

^d Men reporting waning function in one or more aspects of sexuality and low distress owing to this.

^e Men reporting waning function in one or more aspects of sexuality and moderate distress owing to this.

^f Men reporting waning function in one or more aspects of sexuality and high distress owing to this.

Table 3 Presenting mean scores (with 95% confidence intervals) for psychological, physical and over all well-being for prostate cancer patients and randomly selected men without prostate cancer, reporting different levels of distress owing to one or more urinary or bowel symptoms

	Prostate cancer patients (<i>n</i> = 342) ^a	Randomly selected men (<i>n</i> = 314) ^a
No urinary or bowel symptoms	(<i>n</i> = 71)	(<i>n</i> = 112)
psychological well-being	5.8 (5.5–6.1)	6.0 (5.7–6.2)
physical well-being	5.4 (5.0–5.7)	5.7 (5.5–6.0)
over all well-being	5.8 (5.5–6.1)	5.8 (5.6–6.1)
Urinary/bowel symptoms	(<i>n</i> = 260) ^b	(<i>n</i> = 184) ^b
No distress ^c	(<i>n</i> = 102)	(<i>n</i> = 105)
psychological well-being	5.5 (5.3–5.8)	5.7 (5.5–6.0)
physical well-being	5.1 (4.9–5.4)	5.5 (5.2–5.7)
over all well-being	5.3 (5.0–5.6)	5.5 (5.2–5.8)
Low distress ^d	(<i>n</i> = 87)	(<i>n</i> = 48)
psychological well-being	4.7 (4.4–5.0)	5.5 (5.2–5.9)
physical well-being	4.4 (4.1–4.7)	5.1 (4.7–5.4)
over all well-being	4.6 (4.3–4.9)	5.2 (4.8–5.6)
Moderate distress ^e	(<i>n</i> = 28)	(<i>n</i> = 5)
psychological well-being	4.8 (4.1–5.5)	5.2 (3.2–7.2)
physical well-being	4.5 (4.0–4.9)	5.4 (3.5–7.3)
over all well-being	4.7 (4.2–5.2)	5.4 (3.5–7.3)
High distress ^f	(<i>n</i> = 14)	(<i>n</i> = 6)
psychological well-being	4.2 (3.5–5.0)	4.2 (1.9–6.4)
physical well-being	3.6 (2.7–4.6)	4.2 (2.9–5.4)
over all well-being	4.0 (3.3–4.7)	4.2 (2.4–6.0)

^a Eleven prostate cancer patients and eighteen randomly selected men did not supply information on the prevalence of urine and bowel symptoms.

^b The difference between *n* and the sum of *n*s below is due to missing information.

^c Men reporting one or more urine/bowel symptoms but no distress owing to this.

^d Men reporting one or more urine/bowel symptoms and low distress owing to this.

^e Men reporting one or more urine/bowel symptoms and moderate distress owing to this.

^f Men reporting one or more urine/bowel symptoms and high distress owing to this.

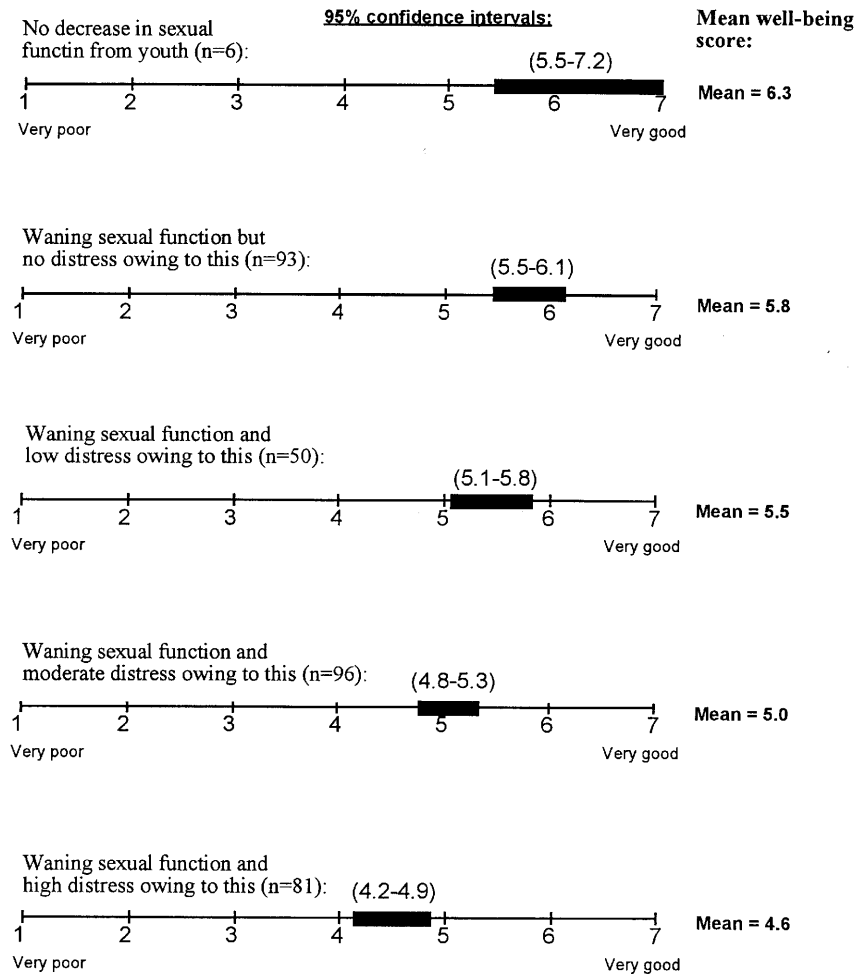


Figure 2 A graphic presentation of the relationship between psychological well-being and distress owing to waning sexual function in 326 prostate cancer patients, including all men diagnosed with prostate cancer in the Stockholm region two years before follow-up aged 50–80 y at the time of assessment.

two highest categories on the psychological well-being assessment, the relative risk being 1.0 (0.8–1.4).

In order to assess whether men with somatic disorders confounded the relationship between distress due to waning sexual function and declining psychological well-being, the analysis was restricted to include only men reporting the two highest categories on the physical well-being scale. The observed decline in psychological well-being remained significant. To assess if urinary and bowel symptoms confounded the relationship, men reporting distress owing to these symptoms were excluded from the analysis. This did not affect the observed significant decrease in psychological well-being. Owing to a lack of statistical power, we were not able to establish whether or not impaired well-being related to distress derived from urinary or bowel symptoms, was independent of waning sexual functions and physical well-being.

Discussion

The prostate cancer patients scored lower on all well-being scales compared to the randomly selected men and this was also true for patients likely to have clinically

localized tumors. Distress due to waning sexual function and urinary or bowel symptoms was associated with impaired well-being in all aspects assessed. There was no difference between 'impotent' prostate cancer patients and other 'impotent' men with respect to the level of distress experienced due to the loss of erectile capacity. Our results stress that an intact sexual and urinary and bowel functions are important for the quality of life among elderly men with or without prostate cancer.

Men with prostate cancer had a higher prevalence of urinary and bowel symptoms and sexual problems (in all aspects of sexuality) and their well-being was consequently decreased as compared to randomly selected population based controls. Our results disagree with recently published findings. Lucas *et al*⁴ found no relationship between distress experienced from loss of sexual function and 'quality of life ratings.' The authors themselves suggested this may be due to an insensitivity of the quality-of-life index used. Litwin *et al*³ reported distress due to waning sexual function in prostate cancer patients with presumably clinically localized tumors, but found no difference between the prostate cancer patients and a reference population with regard to 'health-related quality of life' and 'well-being.' They concluded that prostate

cancer treatment 'is unlikely to affect general health-related quality of life.' Several factors other than the possible insensitivity of the quality of life module may contribute to the contradiction between the present findings and those by Litwin *et al.* They included prostate cancer patients diagnosed up to 30 y before follow-up and the reference group comprised 'comparison patients' enrolled in a man aged care plan, but not men randomly selected from the general population as was the case in the present study. They also did not directly analyze the relationship between symptoms, distress and quality of life. Moreover, the authors point out that the response rate in the reference group was only 46% compromising the representatives of the comparison group.

The present results are based on a new evolving epidemiological approach in 'quality of life' assessment, abstaining from psychometric methods and 'quality of life indexes.' The feeling of well-being is a summary of different symptoms or situations distressing the patient. How distress due to each symptom is weighted into the subjective feeling of well-being is based on the individual and his own values. Therefore, it may be misleading to assume *a priori* that certain symptoms will necessarily have an equal effect on the patients feeling of well-being. This phenomenon may be a systematic source of error in quality of life assessments where *a priori* symptoms are assessed and the mean 'severity' score of these symptoms is an index for the assessed aspect of well-being. This may negatively affect the sensitivity of traditional quality of life scales in detecting the impact of isolated symptoms, like waning erection stiffness, on well-being.

Attempting to avoid the above potential source of error we first identify disease specific symptoms by assessing the prevalence of each symptom in the patient population compared to a randomly selected reference group. Thereafter we assess if, or to what extent, each symptom distresses the patient. Finally, the relationship between reported distress and general well-being was estimated. Our integrated measure of quality of life comprises single questions assessing well-being on seven-point visual ordinal scales. Four domains have been suggested for assessing the 'quality of life' of cancer patients: 'physical well-being', 'psychological well-being', 'social well-being' and 'spiritual well-being'¹³ and we included the first two domains and then added an overall assessment of well-being. Opposed to traditional quality of life measures using mean score indexes to describe changes in quality of life, the present approach applies verbal categories. This may facilitate the communication of the findings between patient and clinician in clinical decision-making.

One draw-back with a single question approach could be an instability of the assessment. However, the test-retest reliability of single-item assessments of well-being 'on the average' over a longer period of time, in an elderly population, has proved to be satisfactory.¹⁴ Moreover, a decreased reliability would dilute the observed differences between the groups. As we did find differences, the single-question assessment proved to be discriminative enough for detecting differences between the investigated groups. In the present study information was collected by means of a self-administered questionnaire. There is an evolving concept that subjective assessment of life quality aspects is more accurate when made by the patients themselves.

Conclusions

Waning sexual function and severe urinary and bowel symptoms affect quality of life in elderly men. Treatment decisions that may permanently impair sexual, urine or bowel functions are a trade-off between the likelihood of an immediate impairment of quality of life and the probability of a prolonged life expectancy. Litwin *et al.*³ state: 'Physicians interacting with prostate cancer patients should advise them that treatment is unlikely to affect general HRQOL' (health related quality of life). According to our data, this conclusion may be based on insensitive Quality of Life instruments.

All available treatment options for prostate cancer affect sexual and urinary and bowel functions in a substantial proportion of men,^{2-4,8-11} and this in turn is related to well-being.

Acknowledgements

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