

Emotional Isolation: Prevalence and the Effect on Well-being among 50–80-Year-Old Prostate Cancer Patients

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Objective: To investigate to what extent prostate cancer patients confide their emotional concerns, and whether having no one to confide in affects well-being.

Material and methods: A population-based study using epidemiological methods. A questionnaire was mailed to all 431 living prostate cancer patients aged 50–80 at the time of selection, diagnosed 1.5–2 years previously in Stockholm County, and 435 randomly selected men in the same age group. The questionnaire was completed anonymously. The main outcome measures included questions assessing the extent to which the men could share emotionally taxing feelings with their partner or others and questions assessing well-being.

Results: The questionnaire was returned by 79% of the patients and by 73% of the randomly selected men. Approximately one in five patients had no one to confide in. Of patients living with a partner, only one in 10 confided in someone other than their partner. Three out of 10 patients living in a relationship could not confide in their partner. Men having no one to confide in were less content with their life and reported poorer psychological and overall well-being compared with other men. The prostate cancer patients were not more likely to have someone to confide in than men in general.

Conclusions: The results indicate that a lack of emotional support may be a problem for many prostate cancer patients and that the traditional psychosocial support offered to most cancer patients in Sweden may not reach male patients. There may be a need for a gender-adapted approach to emotional support.

Key words: elderly men, emotional isolation, prostate cancer, well-being.

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Few would dispute that having close friends and good emotional relations with a partner (or other relatives) are essential for a good life. This is especially true in situations involving emotional strain. Being diagnosed with cancer can be a traumatic experience for many men (1) and has been reported to result in major depression in up to 25% of patients (2–4). For men diagnosed with prostate cancer the side effects of the available treatments also lead to distress in the majority of patients (5–7, 11–18). It is not known to what extent middle-aged and elderly men share their emotional concerns, nor whether this proportion changes after the men have been diagnosed with prostate cancer due to efforts by healthcare personnel or others to offer emotional support. It is also unclear if sharing emotional concerns affects well-being in this age group of men.

Sweden has good prerequisites for epidemiological investigations in large unselected populations. We have collected data on several quality-of-life aspects

from prostate cancer patients aged 50–80 years and an age-matched cohort of randomly selected men (5–8).

Here we report to what extent the patients share their emotional concerns with their partner or somebody else. We have also investigated whether those who do not confide their emotional concerns in somebody report a different sense of well-being to those who do.

MATERIAL AND METHODS

In October 1993, we identified all 431 men who were alive and had been diagnosed with prostate cancer in 1992 in the Stockholm area and who were 50–80 years of age at the time of selection. To obtain reference data we randomly selected 435 Swedish-born men aged 50–80 from the Stockholm county population registry. After an introductory letter, all 866 men received a questionnaire by mail assessing emotional relationships with their partner and/or others and questions

Table I. Questions used to assess emotional relationships^a

Q1 Can you share your emotional concerns, such as fears, anxieties and feelings of hopelessness, with your partner?
(1) I share all my emotional concerns with my partner
(2) I share most of my emotional concerns with my partner
(3) I share some of my emotional concerns with my partner
(4) I share few of my emotional concerns with my partner
(5) I share virtually none of my emotional concerns with my partner
(6) I share none of my emotional concerns with my partner
(0) Not relevant, do not have a partner
Q2 Can you share your emotional concerns, such as fears, anxieties and feelings of hopelessness, with someone other than your partner?
(1) I share all my emotional concerns with someone else
(2) I share most of my emotional concerns with someone else
(3) I share some of my emotional concerns with someone else
(4) I share few of my emotional concerns with someone else
(5) I share virtually none of my emotional concerns with someone else
(6) I share none of my emotional concerns with someone else

^a Men defined as “having no one to confide in” are those answering 4, 5, 6 or 0 to Q1 and 4, 5 or 6 to Q2.

assessing several aspects of well-being. The completed questionnaires were returned anonymously.

We asked if the men had someone to confide in using two different questions (Table I). In the analyses we combined the categories “I share all emotional concerns” and “I share most emotional concerns”. The categories “I share few emotional concerns”, “I share virtually no emotional concerns” and “I share no emotional concerns” were also combined in the analysis. Men defined as “having no one to confide in” were those who had a partner but shared few or none of their emotional concerns with their partner or someone else, and those who had no partner and shared few or none of their emotional concerns with someone else (Table I).

Psychological and overall well-being were determined using four different questions assessing average well-being during the previous week and the past year, using a seven-category analogue ordinal scale ranging from “very poor” to “excellent”. The question asked was: How has your “psychological”/“overall” well-being been on average during the past 12 months/7 days? High-level well-being was defined as the two highest categories on the scale (6 and 7).

Nine questions assessed the prevalence of different emotions or aspects of well-being. The men were asked

how often, during the previous year, they had felt “alert and strong”, “calm”, “energetic”, “happy”, “extremely nervous”, “extremely depressed”, “sad”, “worn out” and “tired”. The six possible responses were: “all of the time”, “most of the time” and “a great deal of the time” (defined as a high prevalence of these feelings), and “some of the time”, “a small portion of the time” and “not at all” (defined as a low prevalence).

The present method for assessing well-being is based on an evolving tradition in quality-of-life assessment that has been used in several studies to evaluate symptoms, symptom-related distress and its impact on quality of life in patients with prostate and cervical cancer and in population-based reference groups (5–9).

To measure associations, a ratio of proportions was calculated with 95% confidence intervals based on the Mantel and Haenzel method (10), adjusting for age as a three-category variable (50–59, 60–67 and 70–80 years).

RESULTS

The questionnaire was returned by 661 (76%) men, 551 of whom (83%) reported that they were living with a partner (Table II). Of all available men answering both

Table II. Characteristics of the study population

Characteristic	Prostate cancer patients	Randomly selected men
Response rate	342/431 (79%)	319/435 (73%)
Median age (years)	72	68
Age range (years)	51–80	50–80
Ever treated for depression?	14/342 (4%)	9/319 (3%)
Ever treated for other psychiatric disorders?	12/342 (4%)	11/319 (3%)
Living with a partner	275/342 (80%)	276/319 (87%)
No one to confide in ^a	76/322 (24%)	67/311 (22%)

^a See definition in Table I.

Table III. Proportion of men sharing emotional concerns with somebody^a

	Prostate cancer patients		Randomly selected men	
	With a partner	Without a partner	With a partner	Without a partner
Sharing emotional concerns with the partner				
Sharing all or most concerns	196/275 (71%)	N/A	188/276 (68%)	N/A
Sharing some concerns	33/275 (12%)	N/A	39/276 (14%)	N/A
Sharing few or no concerns	46/275 (17%)	N/A	49/276 (18%)	N/A
Sharing emotional concerns with someone other than a partner				
Sharing all or most concerns	21/262 (8%)	10/39 (26%)	27/274 (10%)	7/34 (21%)
Sharing some concerns	27/262 (10%)	3/39 (8%)	23/274 (8%)	4/34 (12%)
Sharing few or no concerns	214/262 (82%)	26/39 (67%)	224/274 (82%)	23/34 (68%)

^a Percentages may not add up to 100% due to rounding.

relevant questions (Table I), 143/633 (23%) had no one to confide in (Table II). The prevalence of having no one to confide in increased with age, being 16% for men aged 50–59, 22% for those aged 60–69 and 25% for those aged 70–80 (results not shown). Among men living with a partner, ≈70% stated that they were able to confide in their partner but only one in 10 confided in someone else. Among the men not living with a partner, ≈70% could not share taxing emotional

feelings with anyone (Table III). There was an insignificant difference between the randomly-selected men and the prostate cancer patients in terms of the extent and quality of available emotional support (Table III).

Men having no one to confide in were less likely to feel alert and strong, calm, energetic and happy. On the contrary, they were more likely to feel depressed, sad, tired and worn out (Table IV). They were also less

Table IV. Relative risk of certain aspects of well-being in relation to having someone to confide in

	Someone to confide in	No one to confide in
Presenting the risk of reporting a “low” prevalence of different feelings ^a		
Alert and strong	384/483 (80%)	83/137 (61%) 1.4 (1.0–1.9) ^b
Calm	353/479 (74%)	83/138 (60%) 1.5 (1.1–1.9)
Full of energy	340/480 (71%)	85/137 (62%) 1.3 (1.1–1.7)
Happy	353/478 (74%)	74/136 (54%) 1.7 (1.3–2.2)
Presenting the risk of reporting a “high” prevalence of different feelings ^a		
Very nervous	39/477 (8%)	13/136 (10%) 1.2 (0.7–2.2)
Very depressed	32/477 (7%)	14/139 (10%) 1.5 (0.8–2.7)
Sad	41/480 (9%)	17/138 (12%) 1.5 (0.9–2.6)
Worn out	54/481 (11%)	22/137 (16%) 1.5 (1.0–2.5)
Tired	98/478 (21%)	42/139 (31%) 1.5 (1.1–2.0)
Presenting the risk of not reporting a “high” well-being ^a		
High “psychological” well-being: past year	69/137 (50%)	214/480 (45%) 1.1 (1.0–1.4)
High “psychological” well-being: past week	63/138 (46%)	173/479 (36%) 1.3 (1.0–1.6)
High “overall” well-being: past year	81/139 (58%)	243/482 (50%) 1.2 (1.0–1.4)
High “overall” well-being: past week	77/139 (55%)	209/482 (43%) 1.3 (1.0–1.5)

^a See text for definition of “high” and “low”. Denominators vary due to missing information.

^b Age-adjusted relative risk with 95% confidence interval.

likely to report good psychological and overall well-being compared with other men (Table IV).

DISCUSSION

More than one in five Swedish prostate cancer patients aged 50–80 years confided few or none of their emotional concerns in someone. Among patients living with a partner, the spouse was the only source of support for nine out of 10 men. Approximately eight out of ten patients not living with a partner had no one to confide in. Men who confided their emotional concerns reported better well-being in all aspects assessed.

In men with prostate cancer, the emotional strain of the disease is often compounded by the side effects of treatment, which have been reported to cause distress in the majority of the patients (5–7, 11–18). In this taxing situation, one would hope that the proportion of men who can confide in others would be higher than that amongst the general male population owing to efforts by social contacts and healthcare personnel to offer emotional support and counselling. However, the patients studied were not more likely than men in general to have someone to confide in outside the partner relationship. These findings should be a matter of concern to all who are responsible for the treatment of middle-aged and elderly men. A special effort may be needed to break through the emotional barriers and to offer those who need emotional support some alternative.

At the present time, there are scarce population-based data in the literature where the prevalence of emotional isolation and its impact on well-being has been assessed in middle-aged and elderly men. Findings reported from Finland indicated that a poor emotional relationship with one's wife predicted depression within 5 years among initially non-depressed men (19). Poor emotional relations have also been reported to be associated with an increased risk of attempted suicide (20).

In the present study we abstained from using psychometric quality-of-life scales and concentrated instead on individual aspects of well-being using single questions. This alternative approach to quality-of-life assessment has received growing acceptance and several papers based on the method have been published in peer-reviewed journals (6, 9, 21). The same approach was used to assess emotional relations. The men were simply asked to what extent they shared intimate emotional concerns with their partners and others. An alternative method would be to calculate an "emotional relation index" based on the psychometric tradition. However, no such instruments are presently available for elderly men. Also, it is questionable

whether such scales are more valid than the more direct present approach.

The present results are based on a Swedish population, and we do not know to what extent they apply to men in general. It is also possible that the healthcare system in some countries may be better equipped to meet the emotional needs of men in this age group, which may result in a lower proportion of emotionally isolated prostate cancer patients in those countries.

Our findings reveal that most Swedish prostate cancer patients are solely dependent on their spouse for emotional support. The results indicate that the psychosocial support offered to most cancer patients in Sweden may not reach male patients and that there may be a need for a gender-adapted approach to emotional support for cancer patients.

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REFERENCES

1. Alter CL, Pelcovitz D, Axelrod A, Goldenberg B, Harris H, Meyers B, et al. Identification of PTSD in cancer survivors. *Psychosomatics* 1996; 37: 137–43.
2. Henriksson MM, Isometsa ET, Hietanen PS, Aro HM, Lonnqvist JK. Mental disorders in cancer suicides. *J Affect Disord* 1995; 36: 11–20.
3. Massie MJ, Holland JC. The cancer patients with pain: psychiatric complications and their management. *Med Clin N Am* 1987; 71: 243–58.
4. Lynch ME. The assessment and prevalence of affective disorders in advanced cancer. *J Palliat Care* 1995; 11: 10–18.
5. Helgason ÁR, Adolfsson J, Steineck G. Disease specific quality of life in men with prostate cancer—A three level epidemiological approach. *J Epidemiol Biostat* 1997; 4: 213–8.
6. Helgason ÁR, Adolfsson J, Dickman P, Fredrikson M, Arver S, Steineck G. Waning sexual function—the most important disease-specific distress for patients with prostate cancer. *Br J Cancer* 1996; 73: 1417–21.
7. Helgason ÁR, Adolfsson J, Dickman P, Fredrikson M, Steineck G. Distress due to unwanted side-effects of prostate cancer treatment is related to impaired well-being (quality of life). *Prostate Cancer Prostate Dis* 1998; 1: 128–33.
8. Helgason AR, Adolfsson J, Dickman P, Arver S, Fredrikson M, Göthberg M, et al. Sexual desire, erection, orgasm and ejaculatory functions and their importance to elderly Swedish men: A population-based study. *Age Ageing* 1996; 25: 285–91.
9. Bergmark K, Ávall-Lundqvist E, Dickman P, Henningsohn L, Steineck G. Vaginal changes and sexuality in women who had cervical cancer. *N Engl J Med* 1999; 340: 1383–9.
10. Rothman KJ. *Modern epidemiology*. Boston, MA: Little, Brown and Company, 1986.

11. Brasilis KG, Stanta-Cruz C, Brickman AL, Soloway MS. Quality of life 12 months after radical prostatectomy. *Br J Urol* 1995; 75: 48–53.
12. Litwin MS, Hays RD, Fink A, Ganz PA, Leake B, Leach GE, et al. Quality-of-life outcomes in men treated for localized prostate cancer. *JAMA* 1995; 2: 129–35.
13. Lim AJ, Brandon AH, Fiedler J, Brickman AL, Boyer CI, Raub Jr WA, et al. Quality of life: Radical prostatectomy versus radiation therapy for prostate cancer. *J Urol* 1995; 154: 1420–5.
14. Jönler M, Messing EM, Rhodes PR, Bruskewitz RC. Sequelae of radical prostatectomy. *Br J Urol* 1994; 74: 352–8.
15. Jönler M, Ritter MA, Brinkmann R, Messing EM, Rhodes PR, Bruskewitz RC. Sequelae of definitive radiation therapy for prostate cancer localized to the pelvis. *Urology* 1994; 44: 876–82.
16. Schover LR. Sexual rehabilitation after treatment for prostate cancer. *Cancer* 1993; 71: 1024–30.
17. Pedersen KV, Carlsson P, Rahmqvist M, Varenhorst E. Quality of life after radical prostatectomy for carcinoma of the prostate. *Eur Urol* 1993; 24: 7–11.
18. Bergman B, Damber J-E, Littbrand B, Sjögren K, Tomic R. Sexual function in prostatic cancer patients treated with radiotherapy, orchiectomy or oestrogens. *Br J Urol* 1984; 56: 64–69.
19. Kivela SL. Depression and physical and social functioning in old age. *Acta Psychi Scandi (Supplementum)* 1994; 377: 73–76.
20. Magne-Ingvar U, Ojehagen A, Traskman-Bendz L. The social network of people who attempt suicide. *Acta Psychiatr Scand* 1992; 86: 153–8.
21. Rådestad I, Steineck G, Nordin C, Sjögren B. Psychic complications after stillbirth in relation to memories and immediate management. *Br Med J* 1996; 312: 1505–8.