

Short report: What do men with prostate cancer want to know?

S. Gulavita, MD, FRCPC, FRCR(UK) C. Sinnott, RN, OCN, CONC A.E. Setliff, MA S.M. Sellick, PHD, CPSYCH

Prostate cancer is the most common malignancy and the second leading cause of cancer-related mortality among men in the United States and Canada.^{1,2} Because medical management of prostate cancer is complex, prostate patients are often faced with difficult treatment decisions. Therefore, it is essential that these men receive the information necessary for making informed decisions.³

In addition to enabling patients to become more active in decision making, provision of adequate information might have a positive effect on their lives and on their satisfaction with care.^{3,4} Despite these potential benefits, few data are available on the type and amount of information prostate patients require.⁵

To investigate what information men with prostate cancer need and when they need it, we collaborated with a patient representative to design a survey. Results of this survey were intended to assist in development of an information package for prostate cancer patients when they first present to the Northwestern Ontario Regional Cancer Centre (NWORCC) in Thunder Bay, Ont.

METHOD

The survey asked about 11 categories of information related to prostate cancer. The 11 categories were selected based on a literature review, the researchers' clinical experience, and input from a patient representative with prostate cancer. Respondents were instructed to think back and indicate when they would

Drs Gulavita and Sellick, and Ms Sinnott practise at the Northwestern Ontario Regional Cancer Centre in Thunder Bay, Ont. Ms Setliff is on staff in the Supportive Cancer Care Research Unit.

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have liked to receive each category of information: never, first day at the NWORCC, before treatment, during treatment, or after treatment. They were then asked to indicate how much information they wanted in each category using a Likert-type scale (1—none, 2—a little, 3—some, 4—a lot). Several questions were also included to obtain demographic data and information on treatment and diagnosis.

Following approval by the NWORCC's Patient Education Committee, the survey was mailed to all living patients (N = 142) who had been diagnosed with prostate cancer, were no

Table 1. Demographic and treatment characteristics

PATIENT CHARACTERISTICS	PERCENTAGE WITH CHARACTERISTIC
AGE (Y)	
50-59	8.0
60-69	36.8
70-79	55.2
LENGTH OF TIME SINCE DIAGNOSIS (Y)	
<1	35.6
1-2	26.4
2-5	31.0
>5	6.9
TREATMENT RECEIVED	
Radiation	50.0
Radiation and hormones	14.9
Surgery	11.5
Surgery and radiation	8.0
Hormones	5.7
Other (eg, watchful waiting)	9.9

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older than 80 years, were seen at the NWORCC between 1995 and 1998, and had completed treatment. Eligible patients lived in Thunder Bay (population 117 000) and outlying communities (populations from 1000 to 10 000). A letter accompanying the survey explained the purpose and goals of the project and that the survey was completely anonymous. Respondents were instructed to return the completed survey in the self-addressed stamped envelope provided.

RESULTS

Of 142 surveys mailed, three were returned undeliverable. Of the 139 surveys we assumed reached their intended destinations, 87 were returned for a response rate of 62.6%. Demographic and treatment characteristics of respondents are summarized in **Table 1**. Most respondents were between the ages of 70 and 79 years and had been diagnosed less than a

year before. Radiation therapy was the most frequent treatment received.

Patients' responses to the survey are summarized in **Table 2**. Most respondents indicated that they would have liked to receive information either on their first day at the NWORCC or before treatment began and that they would have preferred to receive "a lot" of information in 10 of the 11 categories. Slightly less interest was indicated in the category "support services," although 48% still requested a lot of information on that topic.

Kruskal-Wallis tests, a nonparametric alternative to analysis of variance (ANOVA), indicated that there were no significant differences between when information was desired or how much information was desired and age ($H [2] = 1.84$, $H [2] = 2.29$, respectively; P not significant for both) or treatment group ($H [8] = 9.09$, $H [8] = 7.37$, respectively; P not significant for both).

Table 2. **Timing and amount of information requested by respondents:**
Percentage of positive responses to each item

INFORMATION CATEGORIES	WHEN PATIENTS WANTED INFORMATION					AMOUNT OF INFORMATION WANTED		
	NEVER	FIRST DAY	BEFORE TREATMENT	DURING TREATMENT	AFTER TREATMENT	NONE	LITTLE/SOME*	LOTS
What prostate cancer is	4.6	59.8	33.3	0	0	0	21.8	74.7
Stages of prostate cancer	1.1	58.6	34.5	2.3	1.1	0	24.1	74.7
Conventional treatments	1.1	55.2	36.8	3.4	0	0	18.3	79.3
Alternative treatments	1.1	50.6	39.1	1.1	3.4	1.1	27.5	70.1
Screening for prostate cancer	3.4	57.5	34.5	0	1.1	0	31.0	64.4
Prevention of prostate cancer	8.0	51.7	25.3	1.1	8.0	4.6	20.6	72.4
Research on prostate cancer	1.1	48.3	28.7	10.3	9.2	0	35.6	63.2
Support services	4.6	46.0	23.0	12.6	10.3	2.3	45.9	48.3
Short-term side effects of treatment	1.1	43.7	46.0	3.4	2.3	0	19.5	77.0
Long-term side effects of treatment	2.3	44.8	36.8	4.6	8.0	1.1	16.0	79.3
Management of side effects	1.1	41.4	35.6	10.3	6.9	1.1	17.2	78.2

*Response categories "a little" and "some" were combined for reporting results.

DISCUSSION

Consistent with other research, this study found that men with prostate cancer wanted maximum amounts of information at an early stage.^{3,6-8} In fact, the proportion of respondents "never" wanting to receive information was consistently below 5%, except in the area of prostate cancer prevention in which 8% indicated no interest. "A little" or "some" information was wanted by 16% to 36% of respondents. This is consistent with a study by Cassileth et al,⁶ which found that 15% to 29% of cancer patients wanted only limited information.

Findings on the influence of age on information needs vary. For example, Cassileth et al⁶ found that age was the only sociodemographic predictor of desire for information, while Foltz and Sullivan⁷ found no effect of age on cancer patients' preferences for information. Our study found that age did not affect how much information respondents wanted or when they wanted to receive it. More studies are needed to explore the relationship between patient characteristics and information needs and preferences.

Limitations

The response rate of 62.6%, while certainly adequate, does not allow us to know if respondents were entirely representative of the whole sample. Because not all patients diagnosed with prostate cancer in northwestern Ontario are referred to the NWORCC, our sample might not be representative of the entire population of patients. Investigating the information needs of prostate patients who are not referred to a cancer centre would be an interesting and worthwhile endeavour. Finally, because of the retrospective nature of the study, responses could contain biases.

Conclusion

Most men in this study indicated that they would have preferred receiving lots of information at an early stage in their care. Their age and treatment they had received did not affect their preferences. Health care providers should be aware of how much information prostate cancer patients want and when they want it because provision of appropriate information might enable men to feel more confident and assume a more active role in decisions about treatment.³ ♦

Correspondence to: Dr S. Gulavita, Northwestern Ontario Regional Cancer Centre, 290 Munro St, Thunder Bay, ON P7A 7T1; telephone (807) 343-1610; fax (807) 343-1548, e-mail Sunil.Gulavita@cancercare.on.ca

Key points

- Most men with prostate cancer want a lot of information as soon as they are diagnosed with the condition.
- In this study, age and treatment received did not affect preferences regarding information.
- Health professionals should be prepared to provide men with information about prostate cancer early in their care.

Points de repère

- La majorité des hommes souffrant de cancer de la prostate veulent beaucoup d'information aussitôt que ce diagnostic est posé.
- Dans cette étude, l'âge et le traitement administré n'influençaient pas les préférences quant à l'information souhaitée.
- Les professionnels de la santé devraient être disposés à fournir aux hommes les renseignements concernant le cancer de la prostate dès le début de leur traitement.

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