

An exploratory study on the information needs of prostate cancer patients and their partners

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Abstract

The aim of this study is to explore the information needs of men with prostate cancer and their partners retrospectively at various points in the treatment process. An online questionnaire was used to collect information from men with prostate cancer and their partners about information needs, and when these developed. Readers of a Prostate Care Cookbook and members of a Prostate Cancer Charity were invited to participate: 73 men with prostate cancer and 25 partners completed the questionnaire. Responses showed that participants develop their information needs close to diagnosis. Less educated men with prostate cancer and partners developed their needs closer to the time after diagnosis than those with higher education. Partners develop an interest on information related to treatment and interaction earlier than patients. Patients prioritised treatment and disease-specific information. Patients and partners differ in how their information needs develop. Medical information is prioritized by patients as

opposed to practical information by partners. Health care provision can be tailored to meet the different needs of prostate cancer patients and their partners at different times in the treatment process.

Introduction

Information provision is an important component of interventions, aiming to support patients after diagnosis with a serious health condition (Rees, Ford, & Sheard, 2003; Sebregts, Falger, & Bär, 2000). However, in order for information to be useful, there is a need to understand the nature of information that patients and their partners require. Information-seeking behaviour may provide increased certainty in finding meaning to cancer patients' experiences (Rees *et al.*, 2003). A theoretical framework has been proposed (McCaughan, & McKenna, 2007) which proposes patients pass through several stages on their journey of making sense of their condition: from *taking in* and experiencing the stressful event of the diagnosis, through *taking hold* of the experience and engaging in information-seeking behaviour, to *taking on* where cancer is considered as a life-changing experience. Attempts to *take control* succeed a period of *blocking response* after diagnosis and this can be the period when cancer patients develop an information-seeking behavior (Wallace & Storms, 2007).

Recent findings from a 1-year longitudinal study with 34 prostate cancer patients undergoing surgery and their partners show that the need for information is associated with coping with prostate cancer diagnosis after elevated stress as a result of diagnosis (Gray, Fitch, Phillips, Labrecque, & Klotz, 1999). Other research also suggests that the information needs of patients are not satisfied (McPherson, Higginson, & Hearn, 2001; Sinfield, Baker, Agarwal, & Tarrant, 2008). Needs related to support, knowledge of recurrence and side effects of the illness are the most commonly unmet (Boberg *et al.*, 2003). Moreover, the three main interests that cancer patients have after being diagnosed are related to treatment, their body's response and possible side effects (Lee, Francis, Walker, & Lee, 2004).

Multiple questions about their illness sends patients in search of available information, and the way they process information impacts decisions. A recent study (Noh *et al.*, 2009) explored the means by which cervical cancer patients search for information, suggesting that information acquisition needs are higher closer to the time of diagnosis and when patients' educational level is higher. On the other hand, there is also evidence that at the time of diagnosis patients are not receptive to information due to anxiety, stress and their inability to think clearly (Friis, Elverdam, & Schmidt, 2003).

Improved treatment and survival means the number of men living with prostate cancer is growing. Significant others play an important role in the men's coping process and, as a consequence, often experience adverse psychological, physical and social effects (Karademas, & Giannousi, 2013). The interests and concerns of partners are largely similar to those of patients (Lemon, Zapka, & Clemow, 2004), although

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it has been suggested that the partners of prostate cancer patients are more concerned with treatment-related worry (pain and physical symptoms) whereas patients themselves are more concerned about sexual functioning (Cliff, & MacDonagh, 2000). Some evidence suggests that partners have higher levels of psychological distress than patients (Couper *et al.*, 2006; Kornblith, Herr, Ofman, Scher, & Holland, 1994), though other research does not confirm this (Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003).

This cross-sectional descriptive study explore prostate cancer patients' retrospective patterns of information seeking post diagnosis. Its specific aims are to: i) explore the relationship between participants' educational level and expressed need for information, and ii) compare the information needs of prostate cancer patients with that of partners of prostate cancer patients. No hypotheses were made as this is a hypothesis generating study and findings can inform the design of a future longitudinal study rather than reporting causal relationships.

Materials and Methods

Research design

An exploratory cross-sectional research design was used. The study received a favourable ethical opinion from the University of Surrey Ethics Committee. Participants completed an online questionnaire through which they were screened to ensure they met the inclusion criteria: i) to have been diagnosed with prostate cancer or to have been a partner of a person diagnosed with prostate cancer, and ii) to be able to complete the online questionnaire. Participants were recruited in the UK through an invitation placed in the Prostate Care Cook Book (Rayman, Gibbons, & Dille, 2009) and a link to the questionnaire on the Prostate Cancer Charity's website and monthly bulletin *Voices*.

Measures

Demographic and medical information

All participants were asked to provide details on their age, gender, marital status, level of education and employment status (see Table 1 for details of the scales used). Prostate cancer patients were also asked to provide information on their treatment status and time since diagnosis information.

Information needs

The items related to information needs were derived from those identified in a systematic review (Rutten, Arora, Bakos, Aziz, & Rowland, 2005), which identified a typology of cancer patients' information needs. More specifically the review identified ten types of information needs identified in the literature from which we used one item for each type or created a new item based on the type of information (Table 1). One extra item was added: *diet and nutrition* in order to account for information which we perceive as underrepresented in health care information provision, thus resulting in eleven items. For each of the eleven needs, participants were asked *To what extent were you interested in getting information in relation to the following after being diagnosed* and the partners were asked *...after the person you are significantly linked with was diagnosed* on a 5-point Likert Scale ranging from *not interested at all* to *extremely interested*.

Time of information need development

Participants were asked to respond on how soon after diagnosis (or after their partner was diagnosed) they developed an interest in each of the eleven items. Possible responses were *immediately, less than 1 month, 1-3 months, 4-6 months* and *more than 6 months*.

Data analysis

Descriptive statistics and percentages were used to see when patients developed their information needs based on the 5 points of the Likert Scale (immediately, less than 1 month, 1-3 months, 4-6 months and more than 6 months). Normality of distribution was not confirmed for all variables therefore non-parametric tests were used. To investigate the role of educational level on information needs at various points in the treatment process, and compare the needs of patients and significant others, a series of Jonckheere's tests was used: i) one for comparing between different levels of education and iii) one for comparing between patients and significant others. Three education categories were combined: *no formal education, less than primary* and *primary education completed*. Mann-Whitney tests were used to follow up these findings. A Bonferroni correction was applied so all effects are reported at $P=0.016$ level of significance. Mean Ranks of the participants' responses are reported with a higher mean rank indicating higher agreement with the need for obtaining an information need and longer time of development since diagnosis in the case of the time of information need development questions.

Table 1. Typology of information needs used in the study.

Information need	Type of information	Comments
Available treatments/options	Treatment-related	Item's name same with source
More information about prostate cancer	Cancer-specific	Item's name not in the source as a separate need but used a name that captures the type of information
Likely progress of disease	Prognosis	Item's name not in the source as a separate need but used a name that captures the type of information
Self-care issues or home care during recovery	Rehabilitation	Item's name same with source
Effect on family, friends or caregivers	Interpersonal/social	Item's name same with source
Emotional reactions, emotional support, coping with cancer	Coping	Item's name same with source
Interaction issues with health care providers	Medical system	Item's name same with source
Sexuality	Body image/sexuality	Item's name same with source
Cost of treatment, insurance coverage, or other financial issues	Financial/legal	Item's name same with source
Maintaining psychological health	Surveillance and health	Item's name same with source
Diet and nutrition	None	New item

All information needs were included in Rutten *et al.*'s (2005) review except "Diet and nutrition".

Results

Participants

In total 98 people participated in the study, 73 of which were diagnosed with prostate cancer and 25 were a partner to someone diagnosed with prostate cancer (not the patients participating in this study). The participants' ages ranged from 23 to 81 for those diagnosed with prostate cancer and 23 to 70 for the partners (Table 2).

The majority of the respondents were married or living as married ($n=87$) while fewer were single/living alone ($n=11$). Regarding the participants' educational level, most had received education from secondary school or gained a job-related qualification and higher ($n=59$) and fewer had only a primary education or no schooling ($n=39$).

Participants accessing the online questionnaire through the Prostate Cancer Charity reported having completed significantly more education than participants accessing the online questionnaire through the Prostate Care Cook Book $\chi^2(1, N=98)=4.58, P<0.05$. No significant differences were found between the two recruitment sources and marital status, $\chi^2(1, N=98)=1.19, P>0.05$, nor their age, $t(98)=0.95, P=0.34$.

Table 2. Characteristics of respondents (N=98).

	Prostate cancer patients				Partners			
	N	%	M	SE	N	%	M	SE
Age	73		50.9	2	25		47.2	3.2
Age of diagnosis	73		58.3	2.5				
Gender								
Male	73	100						
Female	0	0			25	100		
Relationship with patient								
Member of family					14	56		
Relative					2	8		
Friend					5	20		
Other					4	16		
Marital status								
Married/living as married	54	74			16	64		
Living with another adult(s)	10	13.7			7	28		
Single/living alone	9	12.3			2	8		
Education								
No formal education	14	19.2			11	44		
Less than primary school	3	4.1			1	4		
Primary school completed	3	4.1			0	0		
Secondary school/job-related qualifications	14	19.2			3	12		
Tertiary education	26	35.6			6	24		
Postgraduate degree	13	17.8			4	16		
Employment status								
Full-time paid work	45	61.6			12	48		
Part-time paid work	7	9.5			4	16		
Retired/not working	21	18.9			9	36		
Treatment status								
Under treatment	21	60						
In complete remission	3	8.6						
Recurrent	6	17.1						
Not reported	5	14.3						
Treatment type								
Surgery	14	19.2						
Radiation therapy	16	21.9						
Chemotherapy	1	1.4						
Other/unspecified	42	57.5						

The time of developing information needs

In general, men developed their information needs closer after diagnosis than later, with 56.8% developing their information needs immediately and 15.8% during the first month after diagnosis as opposed to 3.8% and 6.8% who developed their needs during the first to third month and fourth to sixth month after diagnosis respectively. When it comes to significant others a higher proportion (73%) developed their information needs immediately and a lower proportion developed their needs later (Figure 1).

The role of educational level on information needs

Comparing the need for information by educational level

Both patient and partners' responses were used for these analyses. In general, the Jonckheere's tests showed that the less educated participants were less in need of all the types of information after their diagnosis or the diagnosis of their partner. Mann-Whitney post-hoc tests confirmed these findings with participants with education ranging from *no education* to *primary school* being less in need of information than the other 3 groups (Table 3). The effect size was large for all information needs. Higher educated patients were more in need of information on *sexuality* while less educated significant others were more in need of information on the *cost of treatment, insurance coverage and other financial issues*.



Comparing the information needs at various time points by educational level

Results revealed that the educational level of the participants was significantly associated with the time of information need development regarding all types of information needs. Jonckheere's tests for all types of information needs revealed that the less educated participants were, the more they were in need of information closer to diagnosis. Post-hoc tests confirmed these findings (Table 4). The effect of education was higher when the difference on the level of education was larger. For example, participants with education ranging from *no education* to *primary school* significantly differed from participants with a *secondary education* only as regards information on *cost of treatment, insurance coverage and other financial issues* ($U=166, r=-0.42$) but with participants with *no formal* to *primary education* significantly more in need of all types of information closer to diagnosis than patients with *postgraduate education*. Also, between *no education* to *primary school* and *secondary education* three types of information had a higher effect size and significance level than others: *self-care issues or home care during recovery* ($U=253, r=0.45$), *sexuality* ($U=36, r=0.49$) and *cost of treatment, insurance coverage and other financial issues* ($U=210, r=0.55$).

Comparing the information needs of patients and partners

Patients and partners did not significantly differ on the type of information need they developed. However, partners were found to develop the need for particular types of information earlier than patients, namely for *available treatments/treatment options* ($U=729, r=-0.15$), *more information about prostate cancer* ($U=734.5, r=-0.18$), *self-care issues or home care during recovery* ($U=681.5, r=-0.12$), *interaction issues with health care providers* ($U=571.5, r=-0.09$) and *maintaining psychological health* ($U=709, r=-0.15$). All of the effect sizes were small.

Discussion

In general, less educated patients and less educated partners were less in need of information after diagnosis but developed their needs closer to diagnosis compared to higher educated patients and partners who developed their information needs later. Among participants in this study the types of information needs that partners develop earlier than patients are available treatments/treatment options, more information about prostate cancer, self-care issues, interaction issues with health care providers and maintaining psychological health.

Based on the percentages of participants' self-reports in this study, it is not clear why patients' interest in having information increased following the 3rd month after diagnosis (Figure 1). However, these results provide an indication of the trajectory of interest in information, which could be, explored further using a longitudinal research design. It may be that once the *blocking response* period is over

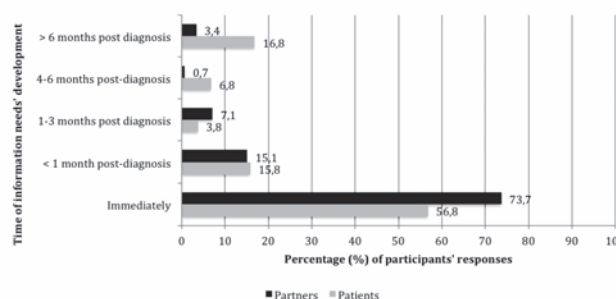


Figure 1. The patient and partners' time of information needs' development.

Table 3. Differences between different levels of education and time of information needs' development (N=98).

Information need	No education- primary (n=32)	Secondary (n= 17)	U	r	No education- primary (n=32)	Tertiary (n=32)	U	r	No education- primary (n=32)	Post-graduate (n= 7)	U	r
Available treatments/ options	24.5	25.9	256	0.07	29.2	33.8	407	0.18	21.9	30.9	171*	-0.4
More information about prostate cancer	24.6	25.8	259	0.05	30.5	32.5	449	0.07	21.6	31.5	162*	-0.4
Likely progress of disease	24.6	25.9	257.5	0.06	28.8	34.4	394	0.19	21.8	31.1	168*	-0.38
Self-care issues or home care during recovery	23	28.8	207	0.25	24.4	39.1	253**	0.45	18.9	36.4	78**	-0.66
Effect on family, friends or caregivers	23.5	27.8	224	0.19	25.6	37.7	293*	0.39	19.9	34.6	109**	-0.56
Emotional reactions, emotional support, coping with cancer	22.9	28.9	205.5	0.26	26.3	37	314*	0.35	19.3	35.8	88**	-0.64
Interaction issues with health care providers	22.9	28.9	206	0.25	25.5	37.9	288*	0.39	18.9	36.4	78**	-0.66
Sexuality	23.9	27.1	236	0.15	23.9	39.6	236**	0.49	20.4	33.6	126**	-0.52
Cost of treatment, insurance coverage, or other financial issues	21.7	31.2	166*	0.42	23.1	40.5	210**	0.55	17.9	38.3	46**	-0.78
Maintaining psychological health	23.4	28	221	0.2	36.8	36.8	322*	0.33	19.8	34.9	104**	-0.58
Diet and nutrition	22.6	29.6	194	0.31	26.9	36.5	331*	0.33	19.1	36.2	81**	-0.66

*P<0.01, **P<0.001. Mann-Whitney U Test, Mean Ranks are reported: the highest the Mean Rank the later the participant indicates to the 5-point Likert Scale that they developed a need for the information.

(McCaughan, & McKenna, 2007), patients seem to want to receive information. It may also be that stress levels are lower after the third month so more patients are in need of information. The study's findings are contrary to some other studies (Friis, Elverdam, & Schmidt, 2003; McCaughan, & McKenna, 2007; Salminen, Bishop, Poussa, Drummond, & Salminen, 2004), which suggested that patients' interest in acquiring information about cancer linearly increases from the time of diagnosis. However, the measures used in this study are more nuanced than previous ones. There is a point after cancer diagnosis where the *teachable moment* is lost (Stead, Caswell, Craigie, Eadie, & Anderson, 2012). Other studies have explained a period of blocking information suggesting that the shock from a cancer diagnosis can be associated with information avoidance (McCaffery *et al.*, 2001; Miles, Voorwinden, Chapman, & Wardle, 2008). Moreover patients may at that time have experienced and evaluated the symptoms and consequences of cancer during the first months and will then seek information for coping purposes.

Previous findings (Hathaway, 1986; Hervouet *et al.*, 2005; Lee-Jones, Humphris, Dixon & Bebbington Hatcher, 1997; Sanson-Fisher *et al.*, 2000; Steginga, Occhipinti, McCaffery & Dunn, 2001; Suls & Wan, 1989) provide indications on the development of information needs in the trajectory of cancer. Before treatment and after diagnosis, patients were found to need treatment-related information (Hathaway, 1986; Suls & Wan, 1989). While during and immediately after treatment, they need side-effects-related information (Hervouet *et al.*, 2005; Sanson-Fisher *et al.*, 2000), emotional health-related and interaction-related information at the same time they are focusing on coping with new roles (Steginga *et al.*, 2001). After treatment they need relapse-related information (Lee-Jones *et al.*, 1997).

Previous studies have shown that cancer patients have a range of unmet needs post-diagnosis, which can explain the great need for information in the immediate period post-diagnosis found in this study (Boberg *et al.*, 2003; McPherson *et al.*, 2001; Sanson-Fisher *et al.*, 2000; Steginga *et al.*, 2001). Their coping process can also be associated with reassurance seeking, which has been found to cause health anxiety (Stark *et al.*, 2004) and is developed gradually after diagnosis where the patient seeks medical consultations, asks friends and family about symptoms and reads about the illness.

This study confirmed the findings of other studies that also showed a desire for information to increase together with patients' educational level (Noh *et al.*, 2009; Salminen *et al.*, 2004). Information needs like *treatment-related information, likely progress of the disease and available treatments and options* were not as significantly different between education groups as other types of information. This information is

seen as vital because they may be conceptualized as *life and death* issues, which are crucial for coping with cancer. On the other hand practical information like self-care issues are considered more important and are developed much earlier for less educated patients and partners. Furthermore, the more educated patients usually have the resources to seek information from various sources and to gain second opinions from health-care professionals.

The interest of partners in obtaining information on decision-making and problem-solving activities related to the cancer is higher than that of patients (Lavery, & Clarke, 1999) and so are more in need for information immediately after diagnosis compared to the later. In this study, although partners did not differ in how much they were interested in information, they were more in need of acquiring information about treatment and interaction issues earlier than the patients. This can be interpreted in the context of the partner's role. While a patient can be in denial or experience the shock of diagnosis, the significant other can strive for information in order to support the patient and prompting them to understand the disease so as to they can be part of the patients' coping process.

Furthermore, the differences between patients and partners on specific needs can be seen in the context of the partner's needs. Partners have been shown to experience higher levels of stress (Murray *et al.*, 2010; Persson & Sundin, 2008) and lower levels of quality of life compared to patients. They are found to develop a need earlier for information early on that will provide them with reassurance and practical information (treatment-related) to help them deal with the changes to their lives. Findings are also supporting a systematic review (Adams, Boulton & Watson, 2009) which found partners and significant others of cancer patients to have unmet needs related to supportive care rather than medical information.

There are other issues to consider. The study's research design limits the accuracy of its findings because a retrospective self-report is used and the period after diagnosis is not examined in a longitudinal design. However, this study's purpose is not to draw cause-effect relationships but rather to explore the needs of patients and partners providing evidence for designing further longitudinal research. Perceptions, behaviours and needs when assessed using self-report measures are prone to self-report bias. The participants' age at diagnosis and the time since diagnosis differed so the coping stage they were at the time of recruitment was not homogeneous. Also, the participants' varying cultural backgrounds may have affected the study's results. Finally one issue to consider is whether participants in this study are representative of the general prostate cancer population since they were readers of a cookbook, sufficiently interested to

Table 4. Differences between patients and partners on time of information needs' development (N=98).

Information need	Patients (n=73)	Partners (n=25)	U	r
Available treatments/ options	50.7	42.1	729	-0.15*
More information about prostate cancer	50.7	42.4	734.5	-0.18*
Likely progress of disease	50.2	43.6	764.5	-0.16
Self-care issues or home care during recovery	51.4	40.3	681.5	-0.12*
Effect on family, friends or caregivers	50.7	42.3	731.5	-0.19
Emotional reactions, emotional support, coping with cancer	49.9	44.4	785.5	-0.14
Interaction issues with health care providers	53	35.9	571.5	-0.09**
Sexuality	49.3	46.3	833	-0.29
Cost of treatment, insurance coverage, or other financial issues	50	44.3	782.5	-0.05
Maintaining psychological health	51	41.4	709	-0.15*
Diet and nutrition	50.7	42.3	731.5	-0.09

*P<0.05; ** P<0.01. Mann-Whitney U Test, Mean Ranks are reported; the highest the Mean Rank the later the participant indicates to the 5-point Likert Scale that they developed a need for the information.



respond and have access to the web. However, assuming generalizability of findings is not the purpose of this study but rather to explore relationships to inform future research and generate hypotheses.

Conclusions

Expanding upon previous work, we can argue that there is an indication that the closer the time to diagnosis, the greater the need for prostate cancer-related information. Finally patients may be more in need for treatment and medical information and there are increased reports of need for information after the third month post-diagnosis whereas partners are more in need for practical information and earlier. These findings require further investigation.

The findings are indicative of further researching the trajectory of patient and partners' information needs. It is similar to the importance of establishing the patients' stage of change (Palmeira *et al.*, 2007; Prochaska & Velicer, 1997) to enable healthcare professionals to implement stage-specific interventions. Identifying the most opportune time to provide advice after cancer diagnosis is essential (Pinto & Trunzo, 2005). Findings from this study add to the understanding of the stages through which patients pass after diagnosis. Also, identifying patients' information needs can benefit treatment-related choices. Finally, family interventions can benefit both patients and their partners whereas partners seem to constitute a well-defined population for healthcare providers to focus on delivering appropriate family and systemic therapies as well as psycho-education, which may benefit patients and their families.

Future research needs to follow the journey of patients and partners after diagnosis, taking into account the different stages of coping with prostate cancer diagnosis and the psychological processes which diagnosis triggers. Educational interventions may be effective if they take into account the point after which a patient is discharged from cancer follow-up back to their health professional. The perception of healthcare providers can also be compared with patients' actual information needs.

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