

An investigation of the support needs of men and partners throughout the prostate cancer journey

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Abstract

Objective: Prostate cancer is one of the mostly commonly diagnosed cancers in men. Unfortunately, the treatment for this cancer can have a number of negative side effects, both for the man himself and his partner. This study investigated the support needs of both men and partners throughout the prostate cancer journey and how this journey may be optimally managed.

Methods: Thirty-one men who had undergone prostate cancer treatment within the last 6 years and 31 partners answered a questionnaire, which explored support care issues as identified in the literature and from focus groups.

Results: Men and partners were moderately satisfied with information given regarding diagnosis, treatment and side effects, but partners were more satisfied with information relating to the particular chosen treatment. Men's understanding of their chosen treatment's potential side effects was significantly different from their understanding of diagnosis, cancer outcome, treatment options and selected treatment. Timing of information delivery was preferred by men at diagnosis, whereas partners preferred after the diagnosis. Men wanted more time to think about the diagnosis and treatment, whereas partners wanted an opportunity to discuss the diagnosis. The management of common side effects such as emotional changes, incontinence and erectile dysfunction was rated as 'somewhat' satisfactory.

Conclusion: Men and partners may have different educational and supportive needs throughout the prostate cancer journey that require attention and tailored management.

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Background

Prostate cancer is the most commonly diagnosed cancer among men living in upper-middle to high income countries [1]. However, because of improvements in cancer screening, treatment and access to care within these countries, a significant proportion of patients are achieving longer survival [1]. This improved survival rate raises the important issue of the quality of life of men post cancer treatments, especially in light of research that has demonstrated that for many men, there can be significant, ongoing and unwelcome treatment sequelae, both of a physical and psychosocial nature.

Common physical problems experienced by men post treatment can include bowel and urinary incontinence [2,3] and sexual dysfunction [4,5], in addition to significant hormone disruption—commonly known as 'andropause' (for those undergoing hormone therapy) [6,7]. Examples of psychosocial problems that may be encountered include depression and anxiety [8,9], decreased quality of life [10] and a decline in partner communication and marital satisfaction [11,12].

These negative outcomes are not only limited to the man who is undertaking the prostate cancer journey but also impacts the partner who accompanies and supports him on that journey. There is a growing body of literature that demonstrates that partners also suffer sexual difficulties [13], psychological and marital distress [14,15] in addition to exhaustion [16], loneliness [17] and changes in partner communication and marital satisfaction [18,19]. These observations highlight the importance of focussing on and providing care for the couple rather than merely the patient himself, at diagnosis, during treatment and subsequent follow-up. However, such support services remain somewhat variable, with research demonstrating unmet needs in the sexual and psychological domains [15,20,21] and basic information provision [20].

Aim

The aim of this study was to explore the support needs of men and partners who had undertaken the prostate cancer journey to identify how the management of this journey could be optimised.

Methods

Participants

Men who had undergone prostate cancer treatment (prostatectomy, radiotherapy, brachytherapy, hormone therapy and/or chemotherapy) within the last 6 years and who had a partner who was also willing to participate in the study were eligible. Partners could be of either gender and were defined as a person that the man had been co-habiting with for at least 1 year at the time of his prostate cancer diagnosis and treatment. Participants were required to be mentally competent to consent to taking part in the study.

Procedure

This study was given ethics approval by the Southern Adelaide Clinical Human Research and Royal Adelaide Ethics Committees.

Men who had undergone prostate cancer treatment and their partners were recruited to the study via advertisements in metropolitan hospital outpatient departments, local prostate support groups, newspapers and radio. Men and their partners who expressed interest in the study were screened for their eligibility to participate and then sent a questionnaire with a return envelope, one for the man who had undergone prostate cancer treatment and one for the partner. The completion and return of the questionnaires was considered as 'opting in' and consenting to study participation.

The questionnaire incorporated semi-structured questions that were based upon issues identified via a literature review and themes identified from focus groups undertaken by the researchers preceding the questionnaire development. Important issues identified from the literature review included the type and quality of information provided to patients in relation to prostate cancer treatment and side effects [20,22]; the impact and management of treatment side effects such as incontinence [23], emotional changes [24] and erectile dysfunction [5,11]; and the adverse effect of prostate cancer treatment on both the man and the partner in terms of quality of life [25–28] and partner/marital relationships [13,19,27].

Focus groups involved men who had undergone prostate cancer and (separately) their partner (outcomes to be reported elsewhere). Based upon the identified issues from the literature review and themes from the focus groups, the developed questionnaire was divided into three sections, including 'Information Delivery and Understanding', 'Prostate Cancer Treatment and Outcomes' and 'Health Professionals and Support Services'.

Participants were instructed to answer the questionnaire by thinking back to the time of being diagnosed with the prostate cancer and their experiences during and after treatment. The majority of the responses were in the form

of 5-point Likert scales [29], with only the results from the Likert scale questions being reported here.

Once the questionnaire was developed and before it was sent out to participants, it was piloted with five men who had undergone the prostate cancer journey and their partners to test face validity, with all participants reporting a high level of face validity for the questionnaire items.

Analysis

All data were analysed using SPSS v19[®] (IBM, USA) using descriptive, chi-square and student *t*-test analysis.

Results

Overall, 100 questionnaires were sent to men who had undergone prostate cancer treatment ($n=50$) and their partners ($n=50$), with 62 being returned (31 from each group) for an overall return rate of 62%.

Profile

Men and their partners were similar in age (64.6 ± 7.6 and 61.7 ± 9.5 years, respectively), educational level (predominantly tertiary educated) and employment status, with the majority being retired. All partners who participated in this study were female. The mean time since prostate cancer diagnosis for the men was 32 months (± 19.2), with the majority having undergone prostatectomy (67.7%) followed by external radiotherapy (38.7%; Table 1).

Information delivery and understanding

In terms of satisfaction with quality and consistency of information received, both the men and partners reported, on average, that they were 'moderately' satisfied when it came to information related to prostate cancer diagnosis, treatment options, likely treatment outcomes, treatment side effects and who to contact if problems arose. However, a major discrepancy was identified between men and partners in terms of the quality of information regarding the man's particular chosen treatment, with partners being more satisfied with this information in comparison with the men (4.4 vs 3.7, $p=0.014$; Table 2).

Both men and partners identified the urologist as the person who predominantly delivered information regarding prostate cancer and the treatment. When given the preference for delivery of this information, men and partners consistently rated the urologist as the preferred information source, followed closely by the general practitioner and written material (Table 3).

Diagnosis was identified by the men and partners as the time that information about prostate cancer and treatment were routinely given. However, when given the preference for when prostate cancer and treatment information is given, men preferred at the time of diagnosis, whereas

Table 1. Sample profile

	Men	Partners	p-value
Age (years)			
Mean (+SD)	64.6 (±7.6)	61.7 (±9.5)	0.191 ^a
Range	49–80	42–86	
Educational level			
Primary school	3 (9.7%)	3 (9.7%)	
High school	3 (9.7%)	8 (25.8%)	
Tertiary	18 (58.1%)	12 (38.7%)	
Trade	7 (22.6%)	8 (25.8%)	0.316 ^b
Employment profile			
Full-time	7 (22.6%)	5 (16.1%)	
Part-time	2 (6.5%)	5 (16.1%)	
Casual	2 (6.5%)	2 (6.5%)	
Unemployed	—	1 (3.2%)	0.605 ^b
Retired	20 (64.5%)	18 (58.1%)	
Time since diagnosis (months)			
Mean (+SD)	32 (±19.2)		
Range	4–66		
Cancer treatment			
Prostatectomy	21 (67.7%)		
External radiotherapy	12 (38.7%)		
Hormone therapy	9 (29.0%)		
Brachytherapy	1 (3.2%)		
Chemotherapy	1 (3.2%)		
Hospital cover			
Public	7 (23%)		
Private	24 (77%)		

SD, standard deviation.

^at-test.^bChi-square.

partners preferred after the diagnosis but before treatment commencement ($p = 0.009$; Table 2).

Men and partners reported a 'moderate' understanding of the prostate cancer diagnosis, prognosis and treatments. In contrast, men rated their understanding of their chosen treatment's potential side effects as only 'somewhat' clear, which significantly differed from their understanding of their diagnosis ($p = 0.001$), cancer outcome ($p = 0.031$), treatment options ($p = 0.000$) and selected treatment ($p = 0.000$; Table 3).

Prostate cancer treatment and outcomes

When it came to mental preparedness, on average, both men and partners felt 'moderately' prepared for the

treatment process. A marked difference was seen when investigating how this preparedness could be improved, with men wanting more time to think about the diagnosis and treatment ($p = 0.039$), whereas partners wanted an opportunity to discuss the diagnosis with peers and health professionals ($p = 0.039$; Table 4).

The most commonly reported side effect following prostate cancer treatment was urinary incontinence (average 40%), followed by emotional changes (average 26%) and then erectile dysfunction (average 18%). Interestingly, partners reported a higher occurrence of urinary incontinence and emotional changes in the men in comparison with the men themselves, with the opposite being true for erectile dysfunction. Overall, men and partners rated the management of the aforementioned side effects as 'somewhat' satisfactory.

Encouragingly, men and partners consistently rated their ability to discuss the treatment side effects with each other as high, which may explain why counselling services were only offered and/or taken up in 23–35% of cases. However, despite this open dialogue, the prostate cancer treatment and outcomes had a significantly different effect on self-image, with the men rating their self-image as better after treatment in comparison with the partners (2.9 vs 2.0, $p = 0.013$, Table 4).

Health professionals and support services

Partners consistently rated their satisfaction with the time spent discussing issues with health professionals such as general practitioners, urologists and nurses as lower in comparison with the men. This was most noticeable with the rated satisfaction of the time spent with the urologist (3.4 vs 4.2, $p = 0.039$). Both men and partners felt that it would be 'moderately' beneficial to have the same health professional throughout the cancer journey, with the majority (men 81% and partners 65%) indicating that a specialised nurse would be the preferred health professional to undertake such a role (Table 5).

Although there are a number of physical and emotional support services available to men who have undergone prostate cancer treatment and their partner, the awareness of such services was highly variable. Most prominent were

Table 2. Satisfaction with the quality and consistency of information received

Item	Quality			Consistency		
	Men mean (SD)	Partner mean (SD)	p-value	Men mean (SD)	Partner mean (SD)	p-value
Prostate cancer diagnosis	4.2 (±1.1)	4.0 (±1.3)	0.597	4.0 (±1.2)	4.1 (±1.2)	0.917
Treatment options	4.2 (±1.1)	4.0 (±1.2)	0.574	4.3 (±1.0)	4.1 (±1.2)	0.543
Likely treatment outcome(s)	4.2 (±1.0)	3.8 (±1.2)	0.175	3.7 (±1.3)	3.8 (±1.3)	0.767
Chosen treatment(s)	3.7 (±1.3)	4.4 (±1.0)	<i>0.014</i>	4.4 (±1.0)	4.4 (±0.8)	1.000
Treatment side effects	3.9 (±1.2)	3.5 (±1.4)	0.189	3.5 (±1.5)	3.5 (±1.4)	0.998
Who to contact with problems	3.5 (±1.5)	3.5 (±1.5)	0.965	3.8 (±1.6)	3.5 (±1.5)	0.479

1, little satisfaction; 5, complete satisfaction.

Italics denotes statistical significance.

Table 3. Delivery and understanding of prostate cancer information

Item	Men	Partner	p-value
Information source(s)	n (%)	n (%)	
Urology specialist (verbally)	30 (97%)	27 (87%)	0.162
General practitioner (verbally)	3 (10%)	2 (6%)	0.641
Written material	15 (48%)	10 (32%)	0.150
DVD/CD-ROM	4 (13%)	5 (16%)	0.718
Internet	11 (35%)	7 (23%)	0.263
Phone (i.e. support group or cancer help line)	2 (6%)	2 (6%)	1.000
Other people (i.e. family or friends)	4 (13%)	6 (19%)	0.490
Preferred information source(s) for diagnosis	Mean (SD)	Mean (SD)	
Specialist (verbally)	1.1 (±0.3)	1.1 (±0.4)	0.943
General practitioner (verbally)	2.4 (±1.0)	2.5 (±0.9)	0.764
Written material	2.8 (±1.4)	3.3 (±1.4)	0.251
DVD/CD-ROM	3.7 (±1.8)	4.5 (±1.8)	0.208
Internet	4.5 (±1.7)	5.2 (±1.6)	0.350
Phone	4.8 (±1.4)	5.7 (±1.6)	0.146
Other	3.4 (±1.4)	3.0 (±1.1)	0.443
Preferred information source(s) for treatment	Mean (SD)	Mean (SD)	
Specialist (verbally)	1.0 (±0.3)	1.1 (±0.4)	0.480
General practitioner (verbally)	2.6 (±1.2)	2.4 (±0.9)	0.612
Written material	2.8 (±1.1)	3.3 (±1.5)	0.230
DVD/CD-ROM	3.6 (±1.5)	3.3 (±1.5)	0.572
Internet	4.5 (±1.8)	4.9 (±1.7)	0.497
Phone	4.9 (±1.6)	5.8 (±1.5)	0.158
Other	3.5 (±1.5)	3.6 (±1.7)	0.936
When information was delivered	n (%)	n (%)	
At diagnosis	19 (62%)	16 (52%)	0.422
After diagnosis but before treatment	14 (45%)	11 (35%)	0.437
During treatment	3 (10%)	—	0.076
At diagnosis and during treatment	2 (6%)	3 (10%)	0.641
Preferred timing of information delivery	n (%)	n (%)	
At diagnosis	24 (77%)	14 (45%)	0.009
After diagnosis but before treatment	11 (35%)	12 (39%)	0.793
During treatment	—	—	—
At diagnosis and during treatment	2 (6%)	6 (19%)	0.117
Clear understanding of	Mean (SD)	Mean (SD)	
Diagnosis of prostate cancer	4.2 (±0.9)	4.3 (±0.8)	0.672
Likely outcome of the cancer	3.9 (±1.0)	4.0 (±1.0)	0.612
Treatment options for the cancer	4.2 (±1.0)	4.1 (±1.1)	0.539
Treatment(s) selected for the cancer	4.4 (±0.9)	4.2 (±0.8)	0.475
Side effects of selected treatment(s)*	3.5 (±1.2)	3.9 (±1.1)	0.229

1, little preference or understanding; 5, complete preference or understanding.

*Men's understanding of Tx side effects was significantly less in comparison with the understanding of diagnosis ($p = 0.001$), cancer outcome ($p = 0.031$), treatment options ($p = 0.000$) and selected treatment ($p = 0.000$).

Italics denotes statistical significance.

local support groups (58% and 55%, respectively) followed by continence nurse advisors (45% and 55%, respectively), whereas other potentially helpful organisations such as men specific helplines and continence information services were less recognised. There was also an overall lack of awareness of services that could be accessed through the public hospital system and in the private sector (Table 5).

Discussion

This study identified the urologist as the professional who most commonly delivered information on prostate cancer and treatment and as the most preferred source of information. However, this was closely followed by the general practitioner

and written material, indicating perhaps that different information delivered by different sources is required to fully comprehend both the diagnosis and treatment of prostate cancer [30].

The significant discrepancy in the men's rating of the quality of information received and their understanding of their chosen treatment and potential side effects indicates that improvements are required in this area. This is supported by a study by Snow *et al.* (2007), which also identified variability in the type and quality of information given to prostate cancer patients [31]. The identified differences between men and partners in the timing of information delivery (men preferring at time of diagnosis, whereas partners prefer after) and opportunity to discuss the diagnosis (partners wanted the opportunity to do this,

Table 4. Prostate cancer treatment and outcomes

Item	Men	Partners	p-value
Mental preparedness	Mean (SD) 4.3 (±0.9)	Mean (SD) 4.4 (±0.8)	0.552
How preparedness could be improved:	<i>n</i> (%)	<i>n</i> (%)	
More information on disease, treatment and side effects	6 (19%)	6 (19%)	1.000
More time to think about the diagnosis and treatment	4 (13%)	—	0.039
Opportunity to discuss the diagnosis	—	4 (13%)	0.039
More support from health professionals	3 (7%)	3 (7%)	1.000
Treatment decision-making	Mean (SD)	Mean (SD)	
Actual involvement in decisions	4.6 (±0.8)	4.2 (±1.4)	0.094
Preferred involvement in decisions	3.3 (±0.7)	3.4 (±0.7)	0.617
Reported treatment side effects	<i>n</i> (%)	<i>n</i> (%)	
Emotional changes	8 (26%)	9 (29%)	0.776
Urinary incontinence	11 (35%)	14 (45%)	0.437
Erectile dysfunction	7 (23%)	4 (13%)	0.319
Satisfaction with	Mean (SD)	Mean (SD)	
Health care management of emotional changes	2.9 (±1.6)	3.2 (±1.5)	0.677
Discussion about emotional changes with partner	4.6 (±0.7)	4.7 (±0.7)	0.573
Health care management of urinary incontinence	3.8 (±1.3)	3.9 (±1.2)	0.855
Discussion about urinary incontinence with partner	4.7 (±0.7)	4.8 (±0.7)	0.807
Health care management of erectile dysfunction	3.0 (±1.2)	3.2 (±1.5)	0.560
Discussion about erectile dysfunction with partner	4.3 (±1.0)	4.3 (±1.1)	0.966
Self-image since prostate cancer treatment	Mean (SD) 2.9 (±1.5)	Mean (SD) 2.0 (±1.2)	0.013
Received counselling regarding:	<i>n</i> (%)	<i>n</i> (%)	
Prostate cancer	10 (32%)	7 (23%)	0.390
Impact of treatment on quality of life	11 (35%)	10 (32%)	0.543
Impact of treatment on sexuality/relationship	11 (35%)	9 (29%)	0.593

1, little involvement or satisfaction; 5, complete involvement or satisfaction.
Italics denotes statistical significance.

Table 5. Health professionals and support services

Item	Men	Partners	p-value
Satisfaction with time spend discussing issues/concerns with	Mean (SD)	Mean (SD)	
General practitioner	4.2 (±1.2)	3.6 (±1.6)	0.145
Urologist	4.2 (±1.2)	3.4 (±1.6)	0.039
Nurse	3.9 (±1.3)	3.0 (±1.7)	0.056
Benefit of having same health professional throughout diagnosis and treatment	Mean (SD) 4.1 (±1.2)	Mean (SD) 4.0 (±1.3)	0.603
The most appropriate health professional to undertake this role:	<i>n</i> (%)	<i>n</i> (%)	
General practitioner	2 (6%)	3 (10%)	0.641
Urologist	3 (10%)	6 (19%)	0.279
Nurse	25 (81%)	20 (65%)	0.155
Awareness of support services:	<i>n</i> (%)	<i>n</i> (%)	
Local prostate cancer support group	18 (58%)	17 (55%)	0.798
Support organisations	10 (32%)	7 (23%)	0.398
Continence nurse advisors	14 (45%)	11 (35%)	0.437
Hospital based psychologists	1 (3%)	2 (6%)	0.554
Hospital based urology nurses	6 (19%)	6 (19%)	1.000
Hospital based physiotherapist	3 (10%)	2 (6%)	0.641
Private physiotherapist	10 (32%)	10 (32%)	1.000
Private psychologist	6 (19%)	5 (16%)	0.741
Relationship counsellors	5 (16%)	4 (13%)	0.718

1, little satisfaction; 5, complete satisfaction.
Italics denotes statistical significance.

whereas men generally did not) also suggest that men and partners may need to be approached and cared for differently. This is also supported by the fact that the partners'

perception of themselves was worse in comparison with the men after treatment, indicating that perhaps the partners need additional support during this time.

The common treatment side effects of urinary incontinence, emotional changes and erectile dysfunction found in previous studies [32,33] were also identified in this study. However, despite the established frequency of such side effects in men who have undergone prostate cancer treatment, both men and partners in this study rated the professional management of these as only 'somewhat' satisfactory. This reveals an inconsistency in the type of care received and perhaps that specific support needs were not satisfactorily met. This is also mirrored in a study by Ream *et al.* (2008), who found specific and significant unmet supportive care needs in 741 men surveyed post prostate cancer treatment [34].

The variability in the quality of information and care received identified in this study leads to the question of how the management of the prostate cancer journey can be optimised for both the man and his partner. The data strongly suggest that having tailored and consistent health care management and support throughout the prostate cancer journey is certainly warranted. This type of management is considered a way of providing support that is harmonious with the patient's needs [35] and to be the ultimate goal in prostate cancer care [36]. It is also strongly supported by other studies, which have found that tailoring information, communication and support to men and their partners can enhance shared decision-making and outcomes [37] and improve quality of life parameters [38]. It is proposed that this management would encompass assessing and managing the needs of both the man and his partner, from prostate cancer diagnosis, during treatment through to post treatment care and follow-up.

Conclusions

Health professionals who care for men diagnosed with and/or treated for prostate cancer need to be aware of and recognise that men and partners will often have different needs throughout the journey. For men, this includes the provision of quality information at the time of diagnosis on their chosen treatment option and possible side effects, in addition to the provision of time to think about both the diagnosis and treatment option. For partners,

the delivery of information is preferred after the initial diagnosis, with opportunity to discuss this with peers and health professionals. Most importantly, partners need additional support post cancer treatment, in terms of their own self-image. The fact that the management of the commonly reported treatment side effects of incontinence, emotional changes and erectile dysfunction were rated as only 'somewhat' satisfactory by both men and partners highlights that there needs to be a renewed and consistent focus on these side effects both during treatment and subsequent follow-up.

As there is now a growing body of evidence in relation to the support needs of men and their partners, future research needs to ideally focus on how tailored health care management, which encompasses timely information delivery, time for reflection and consultation and consistent support for self-image and common treatment side effects, can be best implemented in to practice.

Limitations

Although this study involved a small convenience sample and is potentially susceptible to recall bias, it has explored and identified the support needs of both the man and the partner undergoing the prostate cancer journey. In addition, both the identified issues and variability in the information and care received are congruent with the findings from other larger studies, which have explored these issues, adding to the overall body of evidence that the supportive care of men and partners undergoing the prostate cancer journey needs to be improved.

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Conflict of interest

The authors declare no conflicts of interest.

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