

“The Worst Thing Was...”: Prostate Cancer Patients’ Evaluations of Their Diagnosis and Treatment Experiences

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Christopher F Sharpley¹, Vicki Bitsika², and David R. H. Christie³

Abstract

The objective of the current study was to identify the patient-perceived “worst aspects” of their diagnostic and treatment processes for prostate cancer (PCa) so as to inform targeted interventions aimed at reducing patient anxiety and depression. Two hundred and fifty-two patients who had received their diagnoses less than 8 years ago answered a postal survey about (a) background information, (b) their own descriptions of the worst aspects of their diagnosis and treatment, and (c) their ratings of 13 aspects of that process for (i) how these aspects made them feel stressed, anxious, and depressed and (ii) how they affected their relationships with significant others. They also answered standardized scales of anxiety and depression. The worst aspects reported by patients were receiving the initial diagnosis of PCa, plus the unknown outcome of that diagnosis, because of the possibility of death, loss of quality of life and/or partner, and the shock of the diagnosis. The most common coping strategy was to “just deal with it,” but participants also thought that more information would help. Principal contributors to feeling stressed, anxious, and depressed were also the diagnosis itself, followed by surgery treatment effects. The aspects that most affected relationships were receiving the diagnosis and the side effects of hormone therapy. The identification of these specific worst aspects of the PCa experience provides a set of potential treatment and prevention “targets” for psychosocial care in PCa patients.

Keywords

Prostate cancer, oncology/cancer, depression, mental health, treatment

A recent meta-analysis of 27 studies across eight nations with 4,494 prostate cancer (PCa) patients reported that the prevalence of depression in these men was 18.44% following treatment (95% confidence interval [CI] [15.1, 22.22]), which is several times higher than for their non-PCa peers (Watts et al., 2014). There are also other data reporting elevated anxiety in PCa patients (Linden, Vodermaier, MacKenzie, & Greig, 2012). These two disorders can add to the overall disease burden carried by PCa patients, and may also impede their recovery from treatment (Jayadevappa, Malkowicz, Chhatre, Johnson, & Gallo, 2011). High levels of anxiety can precede low-level illness (Cosci, Fava, & Sonino, 2015; Fries, Hesse, Hellhammer, & Hellhammer, 2005; Niles et al., 2015) that may compound PCa. Depressed PCa patients have more frequent emergency room visits, hospitalization, outpatient visits, and mortality, as well as increased inpatient pharmacy, laboratory, physiotherapy, and medical and surgical costs (Jayadevappa et al., 2011). The continued search for possible correlates of this elevated

prevalence of anxiety and depression among PCa patients remains a key priority in psychosocial oncology research. Recent suggestions regarding effective treatment for anxiety and depression have emphasized individualized treatment models based upon patients’ specific experiences and symptomatology (Insel, 2013). Investigation of PCa *patients’ experiences* of their diagnosis and treatment might, therefore, provide one pathway toward greater individuation of treatments for their anxiety and depression.

¹Brain-Behaviour Research Group, University of New England, Armidale, Australia

²Centre for Autism Spectrum Disorders, Bond University, Gold Coast, Australia

³Genesiscare, Tugun, Queensland & Brain-Behaviour Research Group, University of New England, Armidale, Australia

Corresponding Author:

Christopher F Sharpley, Brain-Behaviour Research Group, University of New England, PO Box 378, Coolangatta, QLD 4225, Australia.
Email: csharp13@une.edu.au



A previous study of this issue reported that about half of one sample of PCa patients had fears about cancer spreading, concerns about the worries of people close to them, and worries about their own sexuality (Lintz et al., 2003). Another study reported that many of these men experienced significant and distressing reductions in sexual performance, interest in sex, memory ability and sleeping (Sharpley, Bitsika, & Christie, 2009). Although these (and other) studies have reported valuable data on the issue of what makes these men anxious and/or depressed, such studies usually focus on the *consequences* of PCa diagnosis and treatment events rather than the *specific aspects* of their diagnosis and treatment which are particularly stressful for these men.

Two recent studies have measured the effect of specific aspects of receiving a diagnosis of PCa upon patient well-being. Lehto et al. (2015) surveyed 1,239 Finnish PCa patients regarding aspects of the diagnosis and treatment process that were chosen by the researchers. Results indicated that hearing about their diagnosis in an impersonal way, receiving insufficient information about their PCa, and not being permitted to take a friend or family to the consultation with their doctor, predicted poorer general patient well-being. In addition, fear of being disabled by their PCa and poorer partner relationships were associated with generally poorer psychological well-being. There were confounding effects from the type of treatment received, with hormonal therapy patients reporting poorest well-being and brachytherapy patients reporting greatest well-being. Another study of 2,426 Swedish PCa patients undergoing robot laparoscopic prostatectomy reported that the level of emotional shock experienced by PCa patients when they received their diagnosis was predictive of their psychological well-being at 3, 12, and 24 months after prostatectomy (Kollberg et al., 2017).

These data suggest that there may be some identifiable aspects of the PCa diagnosis and treatment experience that are key factors in the development of poorer psychological well-being, but that the generalizability of data collected in these studies was limited by the national source of patient recruitment (Sweden, Finland), treatment type (i.e., restricted to robot prostatectomy in one study), and based upon either self-reports of "shock" at diagnosis (Kollberg et al., 2017) or general lists of psychological symptoms that do not necessarily represent the most common clinical definitions of anxiety or depression (APA, 2013). Most importantly, the specific aspects of the PCa diagnosis and treatment process selected for investigation were chosen *a priori* by the researchers, rather than being based upon patients' own perceptions of their experiences. While the observations and understanding of experienced clinicians who have observed many PCa patients are a valuable source of information about the diagnosis and treatment experiences of PCa

patients, the validity of patients' own identification of what troubled them most is also a potential contributor to a more complete list of the distressing aspects of PCa diagnosis and treatment.

Therefore, this study aimed to extend the previous literature by using (a) patients' own nominations of the "worst aspect" of their PCa diagnosis and treatment experience, and (b) a structured questionnaire of 13 common aversive events that PCa patients usually experience as identified by a team of experienced oncologists. In addition, standardized scales for anxiety and depression were also included so as to test for the relationship between the patients' "worst aspects" and their psychological health as defined by their anxiety and depression status.

Methods

Participants

A random sample of 500 consecutive PCa patients from GenesisCancerCare treatment centers in South East Queensland, Australia, during the period 2008–2015, was posted an invitation to participate in a study "about how you feel." All participants had PCa limited to the primary site and regional draining lymph nodes using conventional staging investigations. Treatments included radiotherapy and/or surgery and hormone therapy when required. Other inclusion criteria were: (a) the diagnosis of prostate cancer was proven histologically, and (b) all of the treatment options were considered by patients via discussion with their GP, a radiation oncologist, and a urologist (as per patient reports). Unwillingness to participate in the study was the only exclusion criterion

Measures

Background questionnaire: age (in years), relationship status (married/de facto, widowed, separated/divorced, never married), month and year of first diagnosis, past treatments and current treatments (radiotherapy, surgery, hormone therapy, none), present status (cancer still present and undergoing initial treatment, no obvious sign of cancer [in remission], cancer re-occurring after previous treatment).

"Worst aspect" questionnaire: Patients were asked to state in their own words: what was the worst aspect of their diagnosis and treatment; why this was the worst aspect for them; how they attempted to cope with this worst aspect; and how they thought that worst aspect could be alleviated. Second, participants were asked to provide a 1 to 5 point rating for a list of 13 aspects or events in their diagnostic and treatment procedure that had been generated by a panel of three oncologists familiar with PCa to cover the major events in the sequence

that occurred during the diagnostic and treatment procedures for PCa. This list is hereto referred to as “the oncologist-generated list.” The ratings were “Not at all” (scored as 1), “A bit” (2), “Moderately” (3), “A lot” (4) and “Extremely” (5), and were given for the two areas of “how stressed, anxious, or depressed they made you feel,” and “how much they affected your relationships with others (wife/partner, children, family, and friends).” Psychometric data for this author-developed scale are reported under Results.

Anxiety was measured by the Zung Self-Rating Anxiety Scale (SAS; Zung, 1971, 1980). The SAS is a 20-item self-report instrument based on the current *Diagnostic and Statistical Manual (DSM-5; APA, 2013)* definitions of generalized anxiety disorder (GAD; Zung, 1971). Responses are given as: “None or a little of the time” (scored as 1), “Some of the time” (2), “Most of the time” (3), or “All of the time” (4). Total raw scores range from 20 to 80, with higher scores indicative of greater anxiety, and a cutoff score of 36 or more indicative of clinically significant anxiety. The SAS correlates .75 with the Hamilton Anxiety Scale (Zung, 1971) and significantly discriminates between normal adults and patients with anxiety disorders (Zung, 1971). Reliability data are .71 (split half; Zung, 1971) and .77 (coefficient alpha) in a previous sample of Australian PCa patients ($n = 195$; Sharpley & Christie, 2007).

Depression was measured by the Zung Self-Rating Depression Scale (SDS; Zung, 1965), which is a 20-item standardized paper and pencil test of depression. The SDS includes items for all of the current *DSM-5 (APA, 2013)* criteria for major depressive disorder (MDD), and has 20 items with responses answered on the same scale as the SAS. Raw scores range from 20 to 80, with higher scores being indicative of more severe depression; scores of 40 or more indicate clinically significant depression. The SDS has demonstrated split-half reliability of .81 (Zung, 1965), .79 (DeJonge & Baneke, 1989), and .94 (Gabrys & Peters, 1985). Internal consistency (alpha) has been reported as .88 for depressed patients and .93 for non-depressed patients (Schaefer et al., 1985) and as .84 for a previous Australian PCa sample (Sharpley & Christie, 2007).

Procedure

The questionnaire package, plus explanatory material and a consent form, were posted to participants and they were asked to return the completed questionnaire package to hospital administration in a stamped and addressed envelope. Participants were instructed to complete the SAS and SDS for how they “felt during the last two weeks” (as per the original instructions for these scales).

Table 1. Background Data for Sample ($n = 252$).

Variable	Mean	SD	Range
Age	72.2 yr	6.6 yr	47–85 yr
Time since diagnosis	55.8 mo	14.3 mo	2–96 mo
SAS total score	25.18	6.05	20–50
SDS total score	27.02	7.46	20–63
Relationship status		<i>n</i>	%
	Married/de facto	222	87.6
	Widowed	15	5.8
	Separated/divorced	11	4.7
	Never married	4	1.9
Past treatment			
	Radiotherapy	2	0.9
	Surgery	106	42.1
	Hormone therapy	38	14.9
	Combinations	13	5.3
	None	93	36.8
Current treatment			
	Radiotherapy	184	72.8
	Surgery	2	0.8
	Hormone therapy	0	0.0
	Combinations	62	24.8
	None	4	1.6
Present status			
	Initial treatment	17	6.7
	Remission	203	80.7
	Re-occurring	3	12.6

Statistical Analysis

SPSS 23 was used to analyze these data, with frequencies providing distributions of the background and scale data, and tests for normality. Pearson correlations and ANOVA were used to test for the association between variables, and linear regression identified the most powerful contributors to SAS and SDS scores from among the “worst aspect” item data.

Ethical Approval

The study was approved by the Uniting Health Care Human Research Ethics Committee, Brisbane approval no. 20065.

Results

Data

A total of 252 responses was received to the postal survey, a return rate of 50.4%. Table 1 reports the background information and SAS and SDS data for the sample. The internal consistency (Cronbach’s α) for the

Table 2. Three Most Common Worst Aspects of Diagnosis and Treatment, Reason, Coping Mechanism.

Worst Aspects	% Reporting	Reasons Why	% Reporting	Coping Mechanisms	% Reporting	Ways to Improve Worst Aspect	% Reporting
Receiving a diagnosis of PCa	25.3	Possibility of death Shock of the diagnosis	41.1 30.4	Dealt with it Family/friends support	31.5 16.7	More explanations from health professionals	44.2
Unknown outcome	17.6	Possibility of death Loss of quality of life	44.7 18.4	Dealt with it Thought positive	25.0 20.0	More explanations from health professionals	33.3
Disruption to sex life	7.7	Loss of marriage/partner Loss of quality of life	58.8 17.6	Dealt with it Family/friends support	41.2 23.5	More explanations from health professionals	26.7

13-item oncologist-generated list was .959; for the SAS, .858; and for the SDS, .883. SAS and SDS scores were significantly correlated ($r = .854, p < .001$) and did not need transformation due to non-normality. Using the recommended cutoff scores (see Methods), 7.5% ($n = 19$) of the sample had clinically significant anxiety, and 5.9% ($n = 15$) had clinically significant depression.

There were no significant associations between SAS or SDS scores with any of the background variables, nor between any of the background variables and participants' responses to the oncologist-generated list or other questions regarding the most stressful, anxiety-provoking, or depressing aspects of their diagnosis or treatment, or for the aspects that most affected their relationships.

The Worst Aspect of Diagnosis and Treatment

Responses to the questions about the worst aspect of their treatment are reported in Table 2, including the three aspects that were named most frequently by patients, and the percent of patients who named that aspect as worst. Those patients who named a particular aspect were identified and their responses to the remaining questions are presented in each row of Table 2 so that those responses in columns 3 to 8 are specific to the particular worst aspect that is shown in column 1.

The most frequent rating was for the experience of receiving the diagnosis of PCa, which was described as a shock and raised the possibility of death. The uncertainty of the outcome of diagnosis was next most-frequently nominated, followed by the effects that PCa had upon the sex lives of these men. When asked why these were the worst aspects of their diagnosis and treatment, the loss of relationships, quality of life, and the possibility of death

figured most prominently. Coping mechanisms were stoical, with the most common strategy to just "deal with it," although some participants sought support from their family and friends. The sample was fairly consistent in its suggestions for improving the worst aspect by more information from the various health professionals that they encountered.

Effects of Specific Aspects of Diagnosis and Treatment on Patient Stress, Anxiety, and Depression

Participants rated each of 13 aspects listed on the oncologist-generated list for "how stressed, anxious, or depressed these made you feel" (see Methods). The five most highly rated aspects are reported in Table 3 (a), plus the mean rating given for each of those five aspects, and the number of men who identified each particular aspect. Those men who rated a particular aspect as making them feel stressed, anxious, or depressed "A lot" or "Extremely" were selected and their reasons for their rating are tabulated. The number and percent of participants who identified these reasons are shown.

The aspects that caused these men most stress, anxiety, or depression were spread across diagnostic and treatment events, although the most stressful event was receiving the diagnosis of PCa from their urologist, followed by the side effects of surgery. The reasons given for all five most stressful aspects were uniformly the fear of what might happen to them and the shock of receiving a diagnosis of PCa, suggesting that the aspects of PCa diagnosis and treatment that caused most stress, anxiety, and depression to these patients occurred quite early in the process of receiving that diagnosis (i.e., hearing from their GP that they might have PCa) and continued through to the after-effects of surgery.

Table 3(a). Five Aspects of Diagnosis and Treatment, plus Patient Ratings.

Aspect of Diagnosis and Treatment	Mean/5 Rating, <i>n</i>	Reason Why Aspect Made Patients Stressed, Anxious, or Depressed	Percent, <i>n</i> Who Gave Each Reason
Receiving the diagnosis of PCa from the urologist	3.16, 95	Fear of the unknown Diagnostic shock	22.7, 57 22.7, 57
Treatment effects from surgery	2.84, 38	Fear of the unknown Diagnostic shock	24.4, 61 20.0, 50
Biopsy	2.80, 57	Fear of the unknown Diagnostic shock	27.1, 68 15.7, 39
Your GP telling you that you might have prostate cancer	2.74, 52	Fear of the unknown Diagnostic shock	28.3, 71 25.0, 63
Waiting to see the urologist to find out the results of your tests	2.67, 55	Fear of the unknown Diagnostic shock	29.7, 79 18.8, 47

Table 3(b). Five Aspects of Diagnosis and Treatment, plus Patient Ratings.

Aspect of Diagnosis and Treatment	Mean/5 Rating, <i>n</i>	Reason Why Aspect Made Patients Stressed, Anxious, or Depressed	Percent, <i>n</i> Who Gave Each Reason
Receiving the diagnosis of PCa from the urologist	2.46, 47	Friends and family anxious, worrying Incontinence & impotence	48.2, 121 14.3, 36
Treatment effects from hormone therapy	2.32, 20	Incontinence & impotence Friends and family anxious, worrying	25.0, 63 20.8, 52
Treatment effects from surgery	2.24, 19	Friends and family anxious, worrying Incontinence & impotence	40.9, 103 27.3, 69
Biopsy	2.18, 30	Friends and family anxious, worrying Incontinence & impotence	37.1, 93 17.1, 43
Treatment effects from radiation therapy	2.14, 20	Friends and family anxious, worrying Incontinence & impotence	29.2, 74 25.0, 63

Note. PCa = prostate cancer.

Effects of Specific Aspects of Diagnosis and Treatment on Patient Relationships

The same 13 aspects of the oncologist-generated list were surveyed for the effects that these had upon patients’ relationships with wife/partner, children, family, and friends, and results are reported in Table 3 (b). Again, receiving the diagnosis of PCa from their urologist was the most frequently cited aspect of diagnosis and treatment. Treatment effects from hormone therapy, surgery, and radiation therapies were also among the five most powerful effects on relationships, as was the biopsy process, and there were aspects from the diagnosis, the procedures to obtain a diagnosis (i.e., the biopsy), and from the treatments themselves in this list of the five worst aspects for relationships. The reasons why the five most frequently cited events affected patients’ relationships were almost uniform, that is, about the worry that the events caused to friends and family, plus the threat of impotence and incontinence to the patients themselves.

Relationships Between Aspects of Diagnosis and Treatment With Current Anxiety and Depression

Four linear regressions were run to identify which of the five aspects that most affected patients’ stress, anxiety, and depression were significant contributors to SAS and SDS scores, and which of the five aspects that affected patients’ relationships were also contributors to their SAS and SDS scores. All four regression equations were significant at the *p* < .001 level, and Table 4 presents the standardized beta and the *t* values for each of the five aspects shown in Table 3 (a) and (b).

For those five aspects which were rated most frequently for their effects on patients’ stress, anxiety, and depression, the strongest beta value for their association with SAS scores was for the treatment effects from surgery, followed by the experience of having their GP tell them that they might have PCa, and then actually receiving their PCa

Table 4. Results of Linear Regressions of PCa Diagnosis and Treatment Aspects on Current SAS and SDS Scores.

Effects on stress, anxiety, depression	SAS		SDS	
	Beta	t	Beta	t
Receiving the diagnosis of PCa from the urologist	.296	2.034*	.320	2.263*
Treatment effects from surgery	.259	2.476*	.286	2.819**
Biopsy	.158	1.324	.189	1.702
Your GP telling you that you might have PCa	.233	2.385*	.288	3.014**
Waiting to see the urologist to find out the results of your tests	.089	.601	.126	.876

Effects on relationships	SAS		SDS	
	Beta	t	Beta	t
Receiving the diagnosis of PCa from the urologist	.488	2.055*	.471	2.073*
Treatment effects from hormone therapy	.249	1.694	.293	2.077*
Treatment effects from surgery	.303	1.171	.475	1.912
Biopsy	.134	.756	.110	.647
Treatment effects from radiation therapy	.375	1.329	.202	.747

Note. PCa = prostate cancer.

* $p < .05$; ** $p < .01$.

diagnosis from their urologist. These three aspects also significantly predicted patients' SDS scores, but in the order of the GP experience first, followed by surgery effects and the diagnosis from their urologist. It is clear that these three aspects of their PCa diagnosis and treatment were most powerfully associated with their clinical anxiety and depression, again indicating that the anxiety and depression effects of the PCa diagnosis and treatment experience commenced at the beginning of the process (in their GP's office) and continued until after surgery. When rated for their effects on patients' relationships, receiving the formal PCa diagnosis from their urologist was the most powerful predictor of SAS and SDS; hormone therapy effects also contributed to patients' SDS scores.

Discussion

These data provide an insight into the perspective of PCa patients and the ways that they experience the various procedures that they undergo from the first suggestion that they may have PCa to the post-treatment phase. Background variables did not significantly predict SAS or SDS scores, or the type or rating of the worst aspects nominated by participants.

Participants clearly found the actual moment when they received their diagnosis from their urologist as worst. It appears from these data that PCa patients experienced elevated stress, anxiety, and depression well before they underwent treatment, starting as early as when their GP alerted them to the possibility that they may have PCa. This finding argues for the provision of psychosocial support services well before treatment begins for PCa.

Aspects that adversely influenced personal relationships were also dominated by the experience of receiving their formal PCa diagnosis from their urologist, followed by treatment effects, plus the biopsy itself, suggesting that relationship-based psychosocial therapies might also be best targeted to commence from the time of a formal diagnosis. The confound between family and friends being a source of patients' coping (Table 2) but also being an additional source of stress when they become anxious themselves (Table 3), reflects the dynamic nature of the relationship factor for PCa patients. That is, because family and friends are the closest available source of support for these patients, they may also become fatigued as their own fears emerge regarding the patient's well-being.

Study Limitations

Limitations of this study include the geographical, cultural, and chronological constraints of the sample, and the use of self-reports of anxiety and depression. In addition, these data are cross-sectional, and longitudinal data would extend these current findings. These measures would benefit from a series of such assessments from the time of the GP interview to several years after treatment. No attempt is made to suggest that the 13 events chosen by the three oncologists represent the total of such events. Finally, the response rate of just over 50% is good for this population but nearly half of the targeted sample did not respond, thus limiting the data's generalizability.

Clinical Implications

In conclusion, the two sets of data obtained from the self-identified and oncologist-identified worst aspects of PCa argue for two different timing models for psychosocial support services to PCa patients. One, focused upon patients' stress, anxiety, and depression, might commence at the time of the GP's first suggestion that PCa might be present, and then accompany the patient through the diagnostic process and afterwards if they elect for surgery. The second, concerned with patients' personal relationships, might most profitably begin at the time of the formal PCa diagnosis from the urologist (in Australia, this is probably between 2 and 4 weeks after the GP consultation). The data presented in Table 4 highlight the specific topics that might be addressed in these psychosocial

support service models, although the effect of what are two diagnostic steps (i.e., with the GP and then later with the urologist) may dictate that these topics could vary over the period between GP and urologist visits. These findings provide some evidence for a rethink about the kind of, and timing for, psychosocial support services to PCa patients, at least in the nation where this research was conducted. Because of subtle differences across health-care systems in different countries, the generalizability of these suggestions for clinical treatment may be limited.

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