

Running Head: QUALITATIVE REPORTS OF PROSTATE CANCER

The Context of Adjustment: Qualitative Reports from Australian Men Being Treated
for Non-Localised Prostate Cancer

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Abstract

Studies using standardised group measures can mask individual factors that patients consider important to understanding their adjustment. In this study, clinical psychologists categorised verbal and written comments from 77 Australian men before and during treatment for non-localised prostate cancer. Emergent themes included appraisals, health beliefs, coping resources, coping strategies, attributions about medication, and feelings about participating in research. Results demonstrated substantial individual differences in adjustment to prostate cancer. Themes raised by participants suggest potential avenues for clinical interventions and future studies in this patient group.

The Context of Adjustment: Qualitative Reports from Australian Men Being Treated
for Non-Localised Prostate Cancer

A health issue that concerns many older men is prostate cancer. In the United States and Australia, prostate cancer is the most frequently diagnosed internal malignancy in men and the second most frequent cause of male cancer deaths (Greenlee, Hill-Harmon, Murray, & Thun, 2001; Jain, 1994). Onset is strongly linked with advancing age. Most new diagnoses occur in those aged 60 years or older and onset before 50 years is uncommon (Karr & Yamanaka, 1992; Landis, Murray, Bolden, & Wingo, 1998).

In all areas of health, including oncology, there is growing interest in subjective aspects of adjustment to illness. A dominant paradigm in the chronic illness field used to account for individual differences in adjustment is the Lazarus and Folkman (1984) stress and coping model. According to stress and coping theory, outcomes that occur in response to a stressor are mediated by the individual's appraisal of the stressor and his or her coping resources and strategies. Data have supported applicability of this model in a number of illnesses including prostate cancer (Bjorck, Hopp, & Jones, 1999; Krongrad et al., 1997).

The subjective nature of adjustment (Bowling, 1991) makes qualitative analysis of patient concerns useful, to complement and provide context for quantitative findings. Patients' beliefs predict important patterns of behaviour, such as demand for medical services (Ware, 1984). Health care practice is also moving towards clinical approaches that incorporate both consumer input and scientific evidence.

Previous qualitative studies for men with prostate cancer have focused on concerns or stressors reported by men with this tumour. Concerns identified by men with metastatic prostate cancer included feeling less masculine, sexual problems, change in physical appearance, spouse affection, spouse worry about their cancer, others not wanting to talk about their cancer, and worry about dying soon (Clark et al., 1997). Men with prostate cancer and their wives, interviewed retrospectively about treatment decisions, identified difficult aspects of the treatment decision as coping with the diagnosis, obtaining information, "who decides", learning about treatment options, and reviewing the treatment decision (O'Rourke & Germino, 1998). Whitrod (1996) interviewed 20 Australian men with prostate cancer who took part in discussion groups. He categorised principal sources of stress for men with prostate cancer as difficulty making decisions in conditions of uncertainty, a small repertoire of coping options, and isolation. For 112 men who had remained disease free 1-6 years after undergoing radical

prostatectomy, the most common life problem was impotence, followed by “concern about cancer” and “bladder problems” (Heathcote et al., 1998).

Coping with diagnosis, a need for information, uncertainty about the future, and others avoiding the person with cancer have been identified as stressors in a number of studies of people with different types of cancer (Burman & Weinert, 1997; Clark et al., 1997; Fridfinnsdottir, 1997; Silveira & Winstead-Fry, 1997; Webb & Koch, 1997; Whitrod, 1996). Stressors more specific to prostate cancer include deciding between treatment options and difficulties with sexuality and body image.

This study extended previous research by examining all contextual information that participants provided during a clinical study. Consistent with recent updates of the stress and coping model, this approach allowed for the possibility of positive and neutral as well as negative experiences of cancer (Folkman & Greer, 2000). Participants were taking part in research investigating how different management strategies for non-localised prostate cancer affected their cognitive function and quality of life. These results are reported elsewhere (Green, Pakenham, Headley, & Gardiner, 2002; Green, Pakenham, Headley, Yaxley et al., 2002). The current study focused on additional contextual information that participants chose to provide over a 12 month period of treatment.

Method

Participants

Participants were 77 men with non-localised prostate cancer for whom palliative treatment by hormonal manipulation was considered to be optional. Exclusion criteria were previous hormonal therapy, current psychiatric impairment, severe lower tract symptoms (International Prostate Symptom Score > 7), or abnormal serum testosterone. Patients were recruited through 19 urologists and 1 radiologist in public or private practice in South-East Queensland. They had a mean age of 73.9 years ($SD = 6.9$; range = 56-92 years) and a mean number of 9.0 years of education ($SD = 2.4$; range = 3-15 years). As part of a study comparing different management strategies for non-localised prostate cancer, participants were randomised to receive either an androgen-suppressing medication (leuprorelin, goserelin, or cyproterone acetate) or close monitoring by their specialists.

Procedure

Participants were assessed at pre-treatment baseline, then after 6 and 12 months of their assigned treatment. At these times, they undertook clinical interviews and neuropsychological assessments and completed self-report questionnaires. The data analysed in this study are all the verbal

comments from participants that the assessor wrote down during sessions and all written comments that participants added to self-report questionnaires. The clinical psychologist who had conducted assessments read the comments and devised a coding scheme to summarise the emergent themes. Themes were derived from the comments until no new themes emerged and were finalised in consultation with another clinical health psychologist. The coding scheme is shown in Table 1. Observations from a random sample of 30% of the participants were coded by two additional raters (postgraduate students in clinical psychology). Of 93 items, classifications among the 13 themes were unanimous for 69% of items and agreed by two or more raters for 96% of items.

Comments were analysed by frequencies, expressed as a proportion of all patients ($N = 77$). Attributions about medication were expressed as a proportion of patients on active androgen suppressing treatment ($N = 50$). If a comment was repeated by the same participant, it was tabulated only once, when the comment first occurred. Relationships of comments with several quantitative variables described in a previous publication (Green, Pakenham, Headley, & Gardiner, 2002) were examined using correlations and analyses of variance.

Results

Participants made between 0-11 comments ($M = 2.4$, $SD = 2.2$). The frequencies of responses are shown in Table 1, for pre-treatment (Time 1) and on-treatment (Times 2 and 3 combined) verbal and written comments.

Appraisal and Health Beliefs

The most frequent observation was participants commenting on how serious a problem prostate cancer was for them personally. These comments were evenly split between men who viewed it as high ($n = 10$, 13.0%) and low (14.3%) in personal severity. Two participants mentioned both high and low seriousness. One participant was initially distressed that his cancer was “incurable”, but wrote on the coping questionnaire that “I have no problems”. Another participant whose father had died of prostate cancer feared the pain and suffering his father had experienced but said that right now he had little burden from his illness.

Four participants (5.2%) mentioned personal beliefs about prostate cancer. One participant said that he talked to his cancer in bed at night, saying “I’m going to beat you”. Another was trying to sort out personal affairs because he believed that he would need to be hospitalised soon with his cancer. A third man said that he did not “believe” that he had prostate cancer, in the context of saying that

mental attitude is very important to health. The fourth participant wrote, “So far only a very small trace of cancer showed up and the blood tests indicate that it may have been cleared up”.

Coping Resources

A number of participants commented on aspects of their circumstances that were not directly related to their current treatment. Most frequently, they referred to health problems other than prostate cancer ($n = 18$, 23.4%). Three participants (3.9%) specifically mentioned that the other health complaint affected them more than prostate cancer, whereas no participant described other conditions as less severe than prostate cancer. The conditions that participants said affected them more than prostate cancer were diabetes, thrombosis, hernia and a bowel operation; emphysema and arthritis; and heart problems.

During neuropsychological assessment, many participants commented on their previous level of cognitive functioning. Nine men (11.7%) mentioned poor cognitive function previously, 3 (3.9%) good function, and 5 (6.5%) a mixture of good and bad features of their previous cognitive function.

Nine participants (11.7%) commented on the positive support of other people, such as their spouse, children, or doctor. Three participants (3.9%) reported negative support from significant others, such as having a partner who was “depressed” about the man’s cancer and thought he would die within 6 months. Eight men (10.4%) said that their sexual function was already diminished or absent before the study began.

Four men (5.2%) discussed work or retirement issues. Five men (6.5%) alluded to non-work responsibilities, such as caring for a spouse with Alzheimer’s disease. There were several comments about previous function in non-cognitive and non-sexual domains. These were from one participant who said he was moody since giving up smoking, one who mentioned that he had Parkinson’s disease that had been stable for the past 11 years, and one who said he was jittery and impatient since serving in the airforce.

Coping Strategies

Nine participants (11.7%) commented on their coping strategies. These were acceptance ($n = 3$), humour ($n = 2$), fighting spirit ($n = 1$), denial ($n = 1$), seeking information from the urologist ($n = 1$), and exercise ($n = 1$).

Attributions About Medication

The 50 participants on active medication reported a number of changes in behaviour or symptoms that they attributed to their prostate cancer medication. In descending order of frequency,

these were cognitive decline ($n = 7$, 14%), sleep disturbance (12%), hot flushes (12%), fatigue (10%), weight gain (8%), decreased strength (6%), mood swings (4%), relying on others for cognitive assistance (4%), muscle loss (4%), depression (4%), pain (4%), rage (2%), decreased appetite (2%), increased appetite (2%), breast swelling (2%), and “strange thoughts” (2%). Six men (12%) specifically mentioned that their cognitive function had not changed while on medication. For comparison, similar changes since baseline reported by men assigned to close monitoring were sleep disturbance ($n = 2$, 13.3%), cognitive deterioration (6.7%), and mood swings (6.7%). One man (6.7%) on close monitoring stated that his cognitive function had not changed since baseline.

Feelings About Participating in Research

Comments on feelings about participating in research were frequent. Ten participants (13%) mentioned positive feelings only, such as wanting to help others in the future with this condition, or enjoying the challenge of the tests. Five participants (6.5%) mentioned negative feelings only, such as finding the tasks boring. Four participants (5.2%) gave a mixture of positive and negative comments, such as a man who commented that he was apprehensive about the first session but had appreciated being visited at home to complete the session.

Relationships With Demographic and Quantitative Variables

To better understand comments, several relationships with other variables were investigated. Using an alpha level of .05, the number of comments showed a negative correlation with age ($r = -.26$, $p = .022$) and a positive correlation with distress at Times 2 ($r = .24$, $p = .033$) and 3 ($r = .37$, $p = .001$). The number of comments was not related to distress at Time 1, intelligence quotient, or years of education. T-tests comparing those who made ($n = 63$) or did not make ($n = 14$) comments showed no differences in age, education, intelligence quotient, or distress at the three time points. Treatment groups did not differ in the number of comments made, $F < 1$, or in perceived severity, social support, or feelings about research.

Perceived severity was investigated further for relationships with emotional distress and standardised measures of appraisal and coping (Carver, Scheier, & Weintraub, 1989; Green, Pakenham, Headley, & Gardiner, 2002; Lovibond & Lovibond, 1995). Excluding the two participants who reported both high and low aspects of severity, participants were grouped into those who made no comment, reported low severity, or reported high severity. With time as a repeated measures variable, Group x Time ANOVAs were conducted for each of the dependent variables. Distress showed a main effect of time, $F(2, 144) = 8.10$, $p < .001$, and a trend to a Group x Time interaction, $F(4, 144) = 2.44$,

$p = .067$, whereby there was a greater increase in distress in those rating high severity of prostate cancer than in those rating low severity or making no comment (Figure 1a). There were trends to Group main effects for threat appraisal, $F = 2.64$, $p = .078$ (Figure 1b) and emotion-focused coping, $F = 2.88$, $p = .063$ (Figure 1c). There was no other main or interaction effect that approached significance and no relationship between severity grouping and problem-focused coping.

Discussion

Comments from patients provide important information about issues that men with prostate cancer consider pertinent for clinicians and researchers to know. Spontaneous comments from participants were grouped into themes. In keeping with a stress and coping model, themes were in turn classified under appraisal and health beliefs, coping resources, coping strategies, attributions about medications, and feelings about participating in research.

An even split between participants regarding their level of personal concern about prostate cancer highlights individual differences in appraisal and coping. This interpretation is supported by the relationships found between the “spontaneous” comments about severity and standardised measures of appraisal, distress, and emotion-focused coping completed by all participants. The association between appraisal of prostate cancer as non-threatening and lower distress was consistent with previous studies (Bjorck et al., 1999; Krongrad et al., 1997). Greater use of emotion-focused coping suggests higher coping effort in the group rating personal severity as high. The range of appraisals and health beliefs found emphasises the importance of tailoring health professionals’ communications for individuals: distress and concerns frequently correspond more closely to appraisal and coping than to medical variables such as stage of cancer (Gleason & Schulz, 1996).

Other health problems were frequently raised. Comorbidity is particularly relevant for older patients, who often have complex regimes of multiple medications (Nair, 1999). Several men specifically mentioned that other health problems were more distressing than prostate cancer, whereas no patient said that prostate cancer was worse than other illnesses. This may be partly due to patient selection, in that most participants had known for some time that they had cancer, and potential participants were excluded if they had symptoms that indicated immediate hormonal treatment.

A number of men mentioned that their cognitive or sexual function was diminished before this study. Such comments emphasise the ethical importance of helping research participants to feel as comfortable as possible in completing assessments of potentially sensitive domains. Participants also

discussed positive and negative social support, responsibilities and work issues, and their functioning before the study in non-cognitive and non-sexual domains. These reports provide potential avenues to include as standard assessment areas for this patient group.

The most frequent spontaneously reported coping strategy was acceptance. Acceptance has been associated with better mental health outcomes in women with breast cancer (Parle & Maguire, 1995). While acceptance, denial, and information seeking were all included in the COPE questionnaire that participants completed (Carver et al., 1989; Green, Pakenham, Headley, & Gardiner, 2002), humour, fighting spirit, and exercise were additional to the standardised coping items. With the exception of information seeking, the strategies reported were emotion-focused. A previous qualitative study also found that married men with prostate cancer reported emotion-focused coping strategies more frequently than problem-focused strategies (Lavery & Clarke, 1999). The coping strategies reported by at least 50% of participants in the Lavery and Clarke study were diversionary activities, keeping positive attitudes, openly discussing problems, and stoic acceptance.

Attributions about medication were largely consistent with previous reports of symptoms associated with androgen suppressing medications. Hot flushes, fatigue, weight gain, decreased strength, muscle loss, depression, changes in appetite, and breast swelling have all been reported previously in association with these treatments (Cassileth et al., 1992; da Silva et al., 1996; Herr & O'Sullivan, 2000; Rosenblatt & Mellow, 1995; van Andel, Kurth, & de Haes, 1997). A number of men reported cognitive effects, which have not featured in previous reports from men with prostate cancer. Of course, the participants' knowledge that cognitive function was being tested would have sensitised them to the possibility of cognitive effects. Nevertheless, it was noteworthy that cognitive decline was the most frequent change that participants attributed to their hormonal medication. Seven men reported a subjective decline in cognitive function on medication, two men reported a change in behaviour such that they now relied on family members for assistance in finding their way around, and one man said that he had had two episodes of "strange thoughts" at night-time involving perceptual disturbances. In women treated with luteinising hormone releasing hormone analogues such as leuprorelin, subjective cognitive problems have been reported by 6-56% of patients (Friedman, Juneau-Norcross, & Rein, 1993; Kortepeter, Macmillan, & Ferrell, 1992; Newton, Slota, Yuzpe, & Tummon, 1996).

Although several participants attributed sleep disturbance or mood swings to their medication, the finding that similar proportions of men assigned to close monitoring reported the same changes over this time period suggested that these effects were not specific to medication. Two men attributed

increased pain to their medication, but this could also have been associated with symptoms from metastases. One 65 year-old man who had a long history of aggressive behaviour, including criminal charges of assault, had a rage episode 4 months after beginning leuprorelin treatment and sought help from a psychiatrist. In addition to rage, the patient was depressed and linked the timing of the rage and depression to immediately after his latest leuprorelin injection. It would be helpful to ascertain if other patients report these more unusual effects of sleep disturbance, mood swings, pain, and rage. These effects could have been coincidental with medication use, but may provide indicators for further research.

Comments about research are helpful in designing future studies. The predominance of positive over negative comments provides evidence for the internal validity of the project results, in that these conditions make it more likely that participants would have given their best cognitive performance and responded accurately to questionnaires. Research participation appeared to benefit some patients by giving them a sense of meaning and empowerment. Previous researchers have reported that attainment of meaning is associated with positive health and mental health status whereas meaninglessness is associated with pathological outcomes (Folkman, 1997; O'Connor & Chamberlain, 1996). Negative comments, such as participants finding the tasks boring, emphasise the importance of using minimally sufficient test batteries and selecting tasks that are engaging as well as providing necessary data.

Several trends were observed regarding the format of information. There was a general tendency to elaborate verbally rather than with written comments, but this pattern was reversed for some themes. Comments on sexual function were added only to a questionnaire about sexual function. This demonstrates that questionnaires can be a useful clinical tool for initiating or elaborating discussions of sexual matters with this patient group. Comments about positive and negative social support were more often written than verbal, and were often added to questionnaires concerning relationship satisfaction. Ratings of prostate cancer as having low personal severity were also more likely to be written than verbal, again probably in response to questionnaire content. For example, one participant wrote, "It would appear that a lot of the questions are being directed at some one more affected by prostate than myself" (sic).

No major shifts in content occurred on-treatment compared with pre-treatment, except for addition of comments about treatment experiences. However, the frequency of comments about other health conditions and about low severity of prostate cancer was increased on-treatment, possibly

indicating that, as patients adjusted to their treatment, concerns other than prostate cancer became more prominent. Another timing trend was that preparedness to give negative and mixed feelings about research participation increased later in the study.

The association between a higher number of comments and higher distress at Times 2 and 3 suggests that the provision of comments was associated with psychological processes such as attempts to solve problems or reduce distress. When required, comments were followed up by referrals to appropriate services. Older people made fewer comments, although age was not itself related to distress. Other studies have tended to find the same or better adjustment in older compared with younger people with cancer (Osowiecki & Compas, 1998; Oxman & Silberfarb, 1987).

Limitations of the study are noted. Comments were not entirely “spontaneous”, but occurred in the context of neuropsychological assessment and questionnaires (Green, Pakenham, Headley, & Gardiner, 2002; Green, Pakenham, Headley, Yaxley et al., 2002). In a different study context, patients may have given different “spontaneous” observations. Although the format of data collection allowed maximum participant selection of themes, it also limited the data available for analysis. Some prompting of participants, such as encouragement to provide open-ended verbal or written comments, would have retained participant selection of themes while increasing the amount of data. Future studies could consider using the themes from this study as prompts for patient comments. Another limitation was that participants were told at study entry and reminded during the study that they were not meant to disclose their treatment to the assessor. This would have limited reporting of treatment effects. Nevertheless, the variety of comments given by these men with similar prognoses invites further study of factors that promote adjustment to prostate cancer.

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Figure Caption

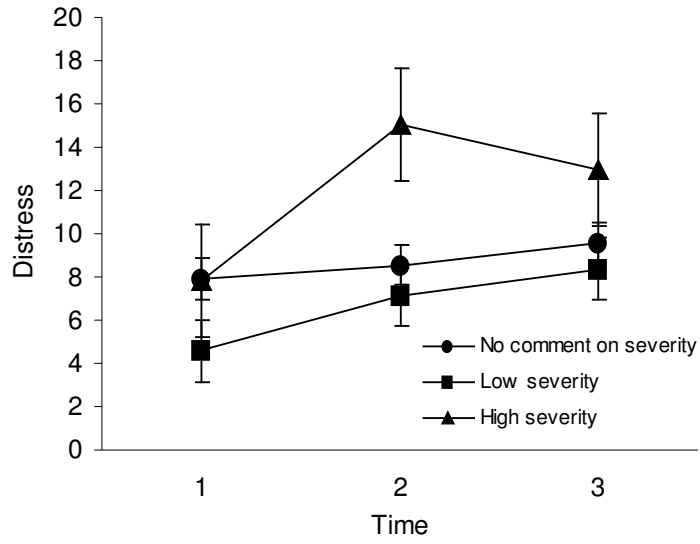
Means and standard errors for participants on (a) distress, (b) appraisal and (c) emotion-focused coping, grouped by whether they commented on prostate cancer being personally of high severity or low severity, or did not comment on its severity. Possible scores ranged from 0-63 for distress, 1-5 for appraisal, and 4-16 for coping.

Table 1
Classifications and Frequencies of Participants' Comments

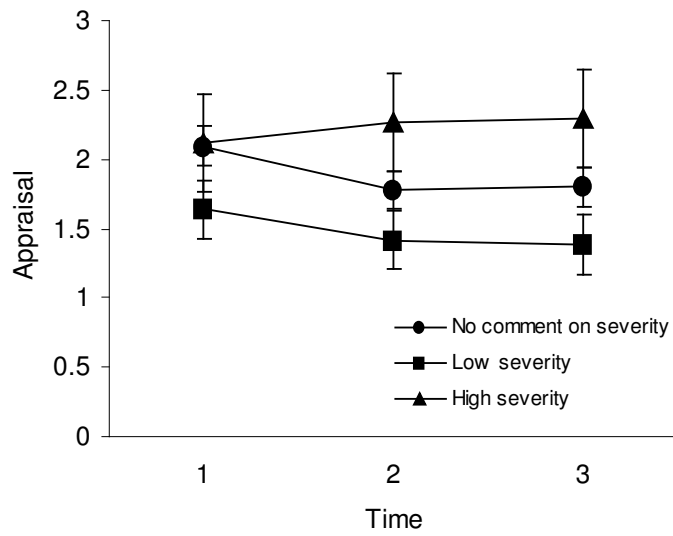
| Category | Number Who Commented ^a | | | | |
|---|-----------------------------------|----|----|----|-------|
| | PV | PW | OV | OW | Total |
| Appraisal and Health Beliefs | | | | | |
| Perceived personal severity of prostate cancer | 7 | 4 | 5 | 7 | 23 |
| (High | 4 | 3 | 2 | 1 |) |
| (Low | 2 | 1 | 2 | 6 |) |
| (Mixed | 1 | 0 | 1 | 0 |) |
| Belief/personal idea about prostate cancer | 2 | 0 | 1 | 1 | 4 |
| Coping Resources | | | | | |
| Health problems other than prostate cancer | 3 | 3 | 11 | 1 | 18 |
| Pre-existing cognitive function | 16 | 0 | 1 | 0 | 17 |
| Other people who provide +ve/-ve support | 4 | 3 | 0 | 5 | 12 |
| (Positive | 1 | 3 | 0 | 5 |) |
| (Negative | 3 | 0 | 0 | 0 |) |
| Pre-existing loss/decrease in sexual function | 0 | 8 | 0 | 0 | 8 |
| Responsibilities (non-paid, e.g. dependants) | 3 | 0 | 2 | 0 | 5 |
| Work (current or recent work or retirement) | 1 | 0 | 3 | 0 | 4 |
| Pre-existing function – non-cognitive, non-sexual | 1 | 0 | 2 | 0 | 3 |
| Coping Strategies | 3 | 2 | 2 | 2 | 9 |
| Attributions About Medication | | | | | |
| Changes in behaviour/symptoms after commencing medication | - | - | 21 | 1 | 22 |
| Absence of cognitive change on medication | - | - | 6 | 0 | 6 |
| Feelings About Participating in Research | | | | | |
| (Positive | 6 | 0 | 4 | 0 |) |
| (Negative | 0 | 1 | 4 | 0 |) |
| (Mixed | 1 | 0 | 3 | 0 |) |

^a PV = Pre-treatment verbal, PW = Pre-treatment written, OV = On-treatment verbal, OW = On-treatment written.

(a)



(b)



(c)

