Living with prostate cancer
Voerman, Albert Elias

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... je merkt alleen dat het feit dat je over zulke dingen praat, dat je aanvankelijk meer contact heb gekregen met vrienden en bekenden die vroegen: hoe gaat het met je? En omgekeerd, omdat je ook van hun wat meer hoort, dat je ook naar hun toe gaat en vraagt: goh, hoe gaat het nu met jullie?
(Respondent 619)
Chapter 9

Introduction

The aim of this thesis is to study the psychosocial problems of men with prostate cancer, their psychosocial support needs and their evaluation of the supportive care provided.

The main research questions studied were:

1. What are the most important psychosocial problems in men with prostate cancer and what is their quality of life?

2. What are the supportive care needs in men with prostate cancer and what are the determinants of the use of psychosocial support?

3. How did the participating men evaluate the supportive care provided?

In the first three sections the answers to these three research questions will be summarized and discussed in relation to other studies. The fourth section outlines some general methodological issues. Finally, the last section describes some implications for clinical practice.
General discussion and conclusion

What are the most important psychosocial problems in men with prostate cancer and what is their quality of life?

To address this research question, the following topics will be discussed in succession: anxiety, depression and the health-related quality of life of prostate cancer patients. In addition, communication with physicians will be addressed as an important psychosocial factor in prostate cancer.

Anxiety

The literature study in chapter two showed that anxiety was present at all stages of the disease, with the highest level being found in the diagnostic phase. We found that more than three years after diagnosis, 30% of men with prostate cancer reported PTSD symptoms related to prostate cancer, which lead to the experience of fear or anxiety. Interestingly, our study showed that this was independent of the disease stage or treatment regime, whereas other studies found differences in anxiety levels at different disease stages or treatment, as shown for example in the review by Dale et al. (2005). At time of diagnosis, 5.2% to 13% anxiety was found for localized prostate cancer (Love et al. 2008; Nordin et al. 2001). Of recently diagnosed patients with advanced disease, 5.5% to 18% reported anxiety (Love et al. 2008; Nordin et al. 2001). After treatment for localized prostate cancer, anxiety was found for 9% of patients with radical prostatectomy (RP) (Kohler et al. 2014), 12% for radiotherapy (RT) (Sharpley & Christie 2007) and 17% for watchful waiting (WW) (Van den Bergh et al. 2009). In the longer term, studies found 6% anxiety after RP, 12% after RT and 10% during WW. Of men on ongoing hormonal treatment, 5.2% were found to have anxiety (Chipperfield et al. 2013).

Studies using the IES as an anxiety measure yielded higher anxiety scores. Among men with early-stage localized prostate cancer, Bisson found that 14% of their sample were above the cut-off score for case-ness (Bisson et al. 2002). Whitaker et al. found that 23% of their sample of prostate cancer patients suffered from intrusive thoughts at three years post-diagnosis (Whitaker et al. 2008). This is still lower than our finding of 30% above the cut-off score.

The use of the IES as the anxiety measure can explain the independence of the level of anxiety from the disease stage or treatment in our study. The IES measures PTSD symptoms rather than momentary arousal. PTSD symptoms can last for months or years and will therefore not vary very much during different disease stages (Kornblith et al. 1994; Kangas et al. 2002). The higher IES score we found compared to other studies can be explained by our sample: a substantial proportion of our sample were members of the prostate cancer foundation. We found that members have a higher IES score than non-members (see Chapter 6).

The clinical relevance of the anxiety found by many studies, including ours, can be questioned. Firstly, anxiety is only problematic if it interferes with daily life or causes significant suffering. Secondly, anxiety disorders cannot be diagnosed reliably by a questionnaire alone.

Interestingly, whereas we found 30% severe PTSD reactions, reflecting incomplete emotional adjustment to prostate cancer according to Lepore (2001), and although the need for supportive care was relatively high in these patients (Chapter 5), it was accompanied by low distress scores (Chapter 6) and high HRQOL scores (Chapter 4). Despite the cognitive/emotional symptoms measured by the IES, most men function well. We hypothesize that these men do not negatively appraise these symptoms and therefore have no burden (Whitaker et al. 2009).
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Depression

Depression was not found to be more prevalent in men with localized prostate cancer than in the general population of older men (about 5% for men aged 65 or older; see Chapter 2).

There is a considerable variation in the findings concerning depression in the literature. One study of prostate cancer patients found no depression at all (Bisson et al. 2002), but others studies found 48% of their sample to be depressed (Schag et al. 1994). Information was usually missing about the period of the depression described, which is important for actually diagnosing depression (American Psychiatric Association 1994).

Based on the stress coping paradigm (Lazarus & Folkman 1984), the factors which influence depression can be divided into internal and external factors. Internal factors increasing the risk of depression are threat or loss appraisal or hopelessness at having prostate cancer (Bjorck et al. 1999) and pain (Heim & Oei 1993). External factors are the availability of social support: lack of social support is related to intrusive recollections and increased feelings of depression (Helgason et al. 2001). We found a higher Profile of Mood States score, which includes depression, in prostate cancer foundation members (Chapter 6). Becoming a member might reflect an attempt to improve the external factor ‘social support’.

In sum, the different measures of depression used in the studies discussed make it difficult to compare results; however, most studies, including ours, did not find rates of clinical depression or depression to be higher than in the general population of older men. Risk factors for depression were having advanced cancer, threat or loss appraisal or hopelessness, suffering from fatigue and pain, fear of death, persistent treatment-related symptoms, and a history of depression. Protective factors were being older, being married, being more optimistic and having greater social support. These correlates of depression in men with prostate cancer are consistent with the results of studies in the general population (Sharpley et al. 2009).

Health-related quality of life

We found that the level of health-related quality of life was high in men with prostate cancer. It was related to the treatment regime: men on androgen withdrawal treatment had a lower generic HRQOL and a lower score in the physical and role functioning domains. More than three years after treatment, we found no difference between radical prostatectomy and radiotherapy on any of the HRQOL dimensions. The HRQOL we found (81 on a scale from 0-100) was higher compared to an international sample of men with prostate cancer, who scored 67 on this measure (Fayers et al. 1999). The treatment status in the international sample was not clearly described, HRQOL could be measured in patients shortly after treatment, who therefore have a lower HRQOL.

Further, in a secondary analysis of our data, Van Harten et al. (2013) transformed the HRQOL in a non-disease specific measure of quality of life, the EURO-QoL (The EuroQol Group 1990). Comparing this EURO-Qol scores with a healthy reference group (Szende & Williams, 2004), Van Harten et al. found that men with prostate cancer have higher scores on the general quality of life. This confirms our finding that on the longer term most prostate cancer survivors function very well.
Studies found a decline in HRQOL after treatment for localized prostate cancer, but in the longer term, the HRQOL almost reached pre-treatment levels, although there can be disease-specific problems including urinary incontinence or erectile dysfunction (Fransson et al. 2009; Miller et al. 2005). We found contrasting results, however. Comparing HRQOL in men who had started treatment less than twelve months previously with men treated more than twelve month previously found no difference in HRQOL scores for radical prostatectomy or radiotherapy. This result could be explained by the fact that only a small proportion of our sample (14%) had been diagnosed less than one year previously. Only men on hormonal treatment showed a decline in cognitive functioning and a greater burden of urological problems after one year. After more than three years, patients receiving hormonal treatment reported the lowest HRQOL: they experienced more pain, more fatigue and more sexual problems and had lower general HRQOL (Voerman et al. 2006).

The relationship between medical factors and a generic HRQOL measure was examined by Korfage et al. They found the SF-36 HRQOL measure to be insensitive for sexual, bowel and urinary function (Korfage et al. 2006). Further research needs to be conducted to determine if HRQOL measures are possibly insensitive to specific psychological or emotional symptoms also. This is also important because HRQOL has become an important outcome measure in medical research (Singh et al. 2010).

In our study we were further able to establish that men with localized prostate cancer have a good HRQOL after one to three years post-diagnosis. Progressive decline was found in men on hormonal treatment, however, though HRQOL was still rated high. We cannot rule out that response-shift played a role in these high scores (Korfage et al. 2006).

**Communication with the physicians**

Communication with the physicians is an important psychosocial domain and can be problematic because a complex decision about the treatment has to be made. After the treatment, the physicians are an important resource in dealing with the aftermath. We found that patients were satisfied with the way the decision what treatment regime to commence came about (Fischer et al. 2006). Another finding was that the majority of men were dissatisfied after treatment about the information provided about prostate cancer, the treatment aftermath and the options for further support (Fischer et al. 2005).

Concerning the treatment decision consultation, according to a study by Cohen and Britten, patients often perceive these consultations as physician-led. Patients were at first content with such one-sided decision-making. However, once patients were able to reflect on the complexity of their condition, acceptance of the decision-making decreased over time. (Cohen & Britten 2003).

These findings accord with ours. Differences in satisfaction with the physician can result from patient characteristics. Orom et al. found that men with prostate cancer and with low optimism can be at greater risk of treatment-related decision-making difficulties and dissatisfaction with the treatment-related decision-making process (Orom et al. 2009).
Dissatisfaction about the communication with the physicians after treatment was found in other studies as well. For instance Cegala et al. found that in retrospect, about one third of their sample of prostate cancer patients was less than satisfied with their communication with the physician (Cegala et al. 2008).

The conclusion is that satisfaction with the decision-making process depends on a match between patient needs and preferences on the one hand and the role the physician assumes to meet these needs and preferences on the other. However, once the medical process has begun, satisfaction with the communication with the physician declines. In the context of the healthcare system, physicians and nurses are probably unable to meet the prostate cancer patients’ information and support needs. To meet these information and support needs, active referral to patient organizations or supportive care programs is recommended. This is appropriate for patients with difficulties with dealing with medical/practical problems as well as emotional problems.

What are the supportive care needs in men with prostate cancer and what are the determinants of the use of psychosocial support?

We found a positive relationship between supportive care needs and the level of PTSD symptoms. Men who became members of the prostate cancer patients foundation report a need to talk about prostate cancer related problems. The needs expressed by the men in our supportive care groups were the need for contact with fellow patients, the need to learn about the disease and the need to find out how to cope with the disease.

Furthermore, our (unpublished) data showed that more than half (56%) of the sample had actually been searching for a form of supportive care from the moment of the diagnosis of prostate cancer. The need for supportive care expressed concerned educational meetings (a need expressed by 39% of the patients), a support group (a need expressed by 18%), telephone counseling (a need expressed by 12%) and individual support (a need expressed by 12%).

In concordance with our findings, supportive care needs were found by many other studies. Needs concern various areas such as the need for information (Visser et al. 1997; Steginga et al. 2001a; Boberg et al. 2003; Lintz et al. 2003; Ruesch et al. 2014), the need for support on sexual issues (Visser et al. 1996; Steginga et al. 2001a; Smith et al. 2007; Carter et al. 2011) or the need for support on how to deal with the emotions of loved ones (Steginga et al. 2001b; Lintz et al. 2003; Hart et al. 2008). Moreover, patients expressed the need for support in learning how to deal with practical daily life issues such as micturation problems or fatigue (Carter et al. 2011; Ream et al. 2008; Lintz et al. 2003; Steginga et al. 2001a; Visser et al. 1996; Voogt et al. 2001).

Despite the supportive care needs of men with prostate cancer, these men are often reluctant to actually seek and use supportive care. As shown in our study, only a very small percentage (about 1%) of all Dutch men with prostate cancer sought support by becoming members of the prostate cancer foundation at the time of this study. Moreover, in this research project it was found that only 6% of the men with prostate cancer approached involved themselves in a supportive care group. This is remarkable, since we found that 30% had prominent PTSD reactions, which is related to supportive care needs. The low participation rate in supportive care programs for men with prostate cancer was also found by other studies (Weber et al. 2000; Krizek et al. 1999; Manii & Ammerman 2008).
To investigate factors related to the intention to get supportive care and actually use it, we applied the theory of planned behavior (Ajzen 1991). Factors we found positively related to the intention to participate in a supportive care group were lower age, higher socioeconomic status, lack of social support, a more positive attitude towards group participation, and higher perceived control. Factors predicting actual participation among patients with the intention to participate are the number of prostate-specific problems (for instance, sexuality or incontinence issues) and perceived control (physical distance from the group facility).

In a different analysis we also found a higher intention to get supportive care among men who were more dissatisfied with the information provided by the hospital. This was not found for dissatisfaction with the emotional support provided by the hospital (Fischer et al. 2005).

The literature showed comparable results. Katz et al. found a higher level of education and annual income in support group participants (Katz et al. 2002). Poole et al. and Krizek et al. found a relationship between wanting to learn from other patients and group participation (Poole et al. 2001; Krizek et al. 1999).

Another study of determinants of the intention to get social support among Dutch prostate cancer patients by Deater et al. (2013) yielded different results. They found psychological needs, physical needs and depressive feelings to be the main determinants of the intention to seek supportive care. However, Deater et al. used a smaller sample and could not include data of support group participants, which likely affect the results. They also did not give an explanation for the low actual participation rate.

Since we found that attitude is an important determinant of the intention to seek supportive care, we hypothesize that men have a more negative attitude towards participation in supportive care settings, despite their needs. There are several possible explanations for this negative attitude. One is male socialization (being tough) (Krizek et al. 1999; Thaxton et al. 2005). Another explanation is that ‘men don’t like to talk about their problems’ or prefer to resolve their issues by themselves or perhaps with their spouse (Manii & Ammerman 2008).

It is notable that in the determinants of intention as well as in the actual participation, PTSD symptoms or psychological distress (as measured by the POMS) are rejected in the statistical model. Dissatisfaction with the emotional support provided at hospital was also unrelated to the intention to get supportive care. In Chapter 5 we reported that PTSD symptoms were related to the intention to seek psychosocial support; however, PTSD symptoms were ruled out as a factor by age, lack of social support, attitude and distance from the support facility. The number of prostate cancer-related problems was, however, related to actual participation. Most of these reported problems were of a practical or medical nature.

This leads to the following conclusion. Men seem to participate in supportive care groups for reasons other than having psychological distress or anxiety issues. To complicate things further, the majority of men we interviewed about their reasons for participation in supportive care groups hoped to discuss their feelings about the disease. This is contrary to the notion that men wish to share information rather than feelings, as stated by Kiss and Meryn (2001).
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It can be argued that the reasons for participation could be symptom-oriented or process-oriented. Men with symptom-oriented reasons are trying to find ways to handle symptoms such as erectile dysfunction or urinary complaints better. Symptom-oriented reasons also entail seeking information. Process-oriented reasons for participation could be a lack of social support or desire to exchange (emotional) experiences with other patients: in short, the men want to involve themselves in a psychological adjustment process concerning their prostate cancer.

In conclusion, many men experience a degree of psychosocial problems that warrants seeking help, but most do not seek help. The main requirement for considering support group participation is a positive attitude towards participation. If men actually participate, they do so mainly for symptom-oriented reasons in the form of informational help. Attendance at a support group also facilitates the emotional processing of the prostate cancer when that is the reason for participation.

How did the participating men evaluate the supportive care they were provided?

The prostate cancer patients in our sample who participated in supportive care groups (see Chapter 8) evaluated the whole supportive care program positively, with an average score of 7.5 on a scale from 1 to 10. The social support group for men only was awarded the highest score of 8.2, against 7.1 for the couples group and 7.3 for the existentially oriented group.

The topics discussed in the groups which were evaluated as beneficial by the patients were: relationships, sexuality, incontinence, treatment, contact with physicians, emotions, experiences, and coping with prostate cancer. The satisfaction thus refers to a broad range of the subjects discussed in the groups.

Nearly three quarters of the participants in at our groups (72%) indicated that most or nearly all previously formulated supportive care needs were fulfilled. In most cases, the patients’ original needs or wishes were met by the group format provided and how it was presented by the group facilitators. Moreover, 94.5% of the participants would recommend this kind of support to others.

The contacts with the fellow patients were valued very highly: this was an important reason for participation in one of the groups for 91% of the patients. An explanation for this can be found in the composition of our sample: most of the men attending the groups were members of the prostate cancer patients association and therefore had already expressed the intention to meet other patients. Other studies also found that contact with other patients was highly valued (Steginga et al. 2005; Thaxton et al. 2005).

Men with the need to learn how to better cope with the disease were less satisfied compared to men with other needs. This could be explained by considering that new (emotional) coping skills are not easily or quickly learned, meaning that men with this need possibly set their expectations too high.

Contentment with supportive care is found in many other studies of psychosocial interventions for men with prostate cancer. Men are reluctant to participate in support groups and traditionally the participation rate is low; however, once involved in a support group, most men are very content and satisfied (Gray et al. 1997; Steginga et al. 2005).
When exploring the dissatisfactory aspects at the group meetings, patients bring forth that they missed discussing topics such as sexuality, nutrition, alternative treatments and medical information. They also felt that the exchange lacked a depth of contact. In addition, the facilitators’ contribution in terms of giving structure was felt to be insufficient by almost half the men at these sessions. This was particularly true at the existentially-oriented support group. Sharing personal problem situations, talking excessively and the exercises given by the facilitators were considered the least useful elements of these sessions.

The results of the evaluation are contradictory when set in a broader context. While most supportive care needs were found to have been met, almost half the men felt the sessions lacked structure, which was rated as very important. Also the depth of the contact was considered too shallow, on the other hand, most men joined the support group in order to share information rather than emotion. We hypothesize that men with symptom-oriented reasons for participation value structured, educational sessions in which information-sharing is most helpful. Men with process-oriented reasons for participation place greater value on the depth of the contact with fellow patients obtained and the exchange of emotional experiences. More research needs to be done on the kinds of group dynamic which work best with the different kinds of patients in terms of their reason for joining support groups.

Our final conclusions concerning the evaluation of the support offered are that men who participate in a supportive care program consider contact with the fellow patients as very important and value the support provided highly. However, the level of satisfaction is related to the degree of structure brought into the sessions. Sessions seem to be most satisfactory when they have a more educational format with a clear structure. There should, however, be room for sharing personal experiences and emotions. How much room depends on the patient’s underlying reasons for participation.

**General methodological issues**

A strength of our study is that it is the first to provide a comprehensive outline of the psychosocial problems of men with prostate cancer, their need for psychosocial support and how they evaluate the support provided. A study of this breadth has not been performed in the Netherlands before and, even more than ten years after the start of the study, it is still the only study of such extent and to adopt this approach. Another strength is that most of the measurement instruments we used were translated, validated and standardized questionnaires with a good reliability, making this study comparable with international studies in the field. Moreover, we found no prominent differences between our Dutch results and studies in other Western countries on the topics of psychosocial problems, health-related quality of life, supportive care needs and the use of and evaluation of supportive care.

There also are some limitations. The sample is heterogeneous and selective and might therefore be biased in a few points. More than half of the participants were members of the prostate cancer patients foundation and therefore have different characteristics on some variables compared to men who are not members, as presented in Chapter 6 (Voerman et al. 2005). This especially concerns the wish to talk about prostate cancer and the level of distress, both of which were higher among members. However, this characteristic of the membership group was controlled for in statistical analysis when prostate cancer patients foundation membership was identified as confounder. This variable was then introduced as a covariate in the analysis.
We would also like to stress that the assumptions of parametric statistics were violated for some statistical tests due to skewedness, kurtosis or small sub-sample sizes. To resolve these problems, analyses were also performed non-parametrically, mostly yielding the same results. Multiple testing problems were compensated by very conservative testing (Games-Howel) with low alphas or Bonferroni corrections. This approach, however, could cause type II errors, meaning that there may be effects or results rejected by the statistics.

Despite the noted methodological limitations, this study provides valuable knowledge for the Dutch situation for optimizing the care for prostate cancer patients.
Implications for clinical practice

Some clinical implications can be derived from the study presented in this thesis. A first implication concerns the decision making process about the preferred treatment. Younger men and men with higher socioeconomic status prefer collaborative decision-making. Older men and men with lower socioeconomic status prefer their physician to decide about the treatment (Chapter 3). In the first case, the physicians should discuss multiple treatment options and take the role of adviser or sparring partner in the decision. In the second case, the physician can also point to different treatment options, but clearly make an expert statement of his or her preferred treatment for the particular patient. In either case, the physicians should explain the medical story in plain, easily comprehensible language and be sensitive to the patients decisional preferences.

A second implication is that the physicians should be alert to their patients’ levels of anxiety. At the time of diagnosis most patients have a considerable level of distress, which influences the decision-making process on the treatment. If medically justified, patients should have some time to mentally process the message of having cancer until the anxiety level lowers before deciding what treatment to commence (Chapter 2).

A third implication: the effects on the health related quality of life should be taken into account when considering the different treatment options. Although we found no difference in health related quality of life in the longer term, physicians should still encourage patients to consider what is important in their lives concerning sexuality and how they think they are going to handle being incontinent and/or impotent (Chapter 4). The use of a decision aid could be encouraged.

A fourth implication is that an anxiety disorder can be prevalent for longer periods after the initial treatment. Checking on anxiety or other problems could be considered during PSA check-up by administering a questionnaire such as the Distress Thermometer, which was developed to screen for distress and the desire for referral (Tuinman et al. 2008).

A fifth implication from the literature is that physicians and nurses should be alert to the presence or absence of a good quality social network. The absence of a good social network can slow down processing, possibly leading to psychological morbidity. In such cases, referral to supportive care facilities should be considered and discussed with the patient (Chapter 2).

The sixth implication is that men should be firmly encouraged to join a patient organization or find other help: many men express a need for support in one or more areas, but only few of them take action. Supportive care should have an educational character, with structured sessions involving a physician in one or more sessions is recommended (Chapters 7 and 8).

Finally, dealing with a man with prostate cancer is a major burden for the spouse, and the spouse is very important to the patient in coping with the disease (Chapter 2).

Therefore, the physician or urology nurse should pay extra attention to the spouse’s wellbeing.
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References


General discussion and conclusion


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General discussion and conclusion


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