Living with prostate cancer
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Chapter 1
General introduction

Dat was al in 1994, toen kreeg ik plasproblemen, ik wist niet wat er aan de hand was alleen ik kreeg er wat problemen mee. Ik ben er mee naar de dokter gegaan en die deed toen een onderzoek. Die heeft mijn bloed gecontroleerd, PSA dus, en dat is gedaan, toen moest ik terugkomen en bleek mijn PSA 40 te zijn. Dus dat was niet goed.

(Respondent 58)
Chapter 1

Introduction

This thesis analyses the psychosocial problems, the need for specialized psycho-oncological care, and the evaluation of this supportive care in men with prostate cancer. It is estimated that worldwide the incidence of prostate cancer is 536,279 new cases in 2000 (WHO 2000). In 2012 over 11,000 new cases have been diagnosed in the Netherlands and each year the incidence is still increasing (Dutch Cancer Registry 2014). An important reason of this study is the fact that, although prostate cancer is the most frequently occurring cancer among men, it does not get so much attention in the psychosocial approach of cancer compared to breast cancer.

Although there is an increasing amount of research on the psychosocial impact of prostate cancer, most knowledge in psycho-oncology is still based on research on younger women with breast cancer (see Figure 1 and Figure 2). In many breast cancer patients, anxiety and feelings of uncertainty about the future are expressed as well as feelings of guilt (Fallowfield et al. 1990; Dunkel-Schetter et al. 1992; Van ’t Spijker et al. 1997; Massie & Popkin 1998), depression and posttraumatic stress disorder (Passik & Grummon 2003; Schleife et al. 2014; Meisel et al. 2012). Further, the variety of supportive interventions for women with breast cancer show to be useful and effective in improving emotional well being (Antoni et al. 2006; Sherman et al. 2010; Tacon 2011). However, it is still rather unclear whether or not these results also apply for men with prostate cancer.

Unique aspects of prostate cancer

Prostate cancer is unique for several reasons. It affects only men and more specifically almost solely older men. Before the age of 40, prostate cancer is rare, the incidence rises with age with a peak around the age of 70 (Visser et al. 2002; Dutch Cancer Registry 2014). Contrary to other types of cancer, prostate cancer is often growing slowly and thus gives the patients time to carefully educate themselves and consider what treatment option is preferable. Different treatment options and their side effects are described in Box 1.

Although there is a growing attention in the media, cancer is still a disease with a taboo. Prostate cancer can bear an extra stigma since it manifests itself in the sexual, urination and defecating areas, which are shameful to most people. For instance, a substantial portion (26%) of men experience shame during digital rectal examination (Naccarato et al. 2011) or would not undergo a digital rectal examination at all because of shame (Romero et al. 2008). So prostate cancer has unique characteristics concerning age, treatment choices and treatment side effects compared to breast cancer patients. This warrants studying the psychosocial aspects in this specific group of cancer patients.
General introduction

Box 1. Prostate cancer and its treatment

The prostate gland is about the size and shape of a chestnut and it is located directly below the bladder. The urethra passes through the prostate gland. The function of the prostate gland is to produce the fluid that mixes with the semen, together forming the ejaculation.

Prostate cancer is usually asymptomatic in the first stages. It is often detected when men consult their doctor for micturation problems. The physician can perform a digital rectal examination (feeling the prostate gland with a finger through the anus) and determine the blood PSA (prostate specific antigen) level; both are (unreliable) indicators of a possible prostate cancer. To get a final diagnosis, several biopsies are taken from the prostate gland and viewed under the microscope. Prostate cancer can occur in several stages called the TNM (tumor, node, and metastasis) classification. T1 to T4 refer to the extent of the tumor growth, N0 to N1 indicate whether or not metastasis are found in the local lymph nodes and M0 to M1 refer to the occurrence of distant metastasis, for instance in the bones. The Gleason score is an indicator of the aggressiveness of the cancer cells.

There are several treatment modalities. These options depend on the stage of the disease. For local disease, radical prostatectomy (surgical removal of the entire prostate gland) or radiation therapy (external or interstitial) are most widely used as a curative treatment. New, experimental treatments currently under research are HIFU (high-intensity focused ultrasound and cryosurgery) (Bozzini et al. 2013). Both of these treatments are about equal in survival rate (75-90% after 10 years in the group with a low risk Gleason score) (IKNL 2014). In case of locally advanced disease or distant metastases, there is no curative treatment available at this moment. Hormonal therapy is then mostly used to slow down the growth of prostate tissue, including the malignant type. Depending on the medical condition, combinations of treatment options are possibly given. For any stage of the disease, watchful waiting can be a reasonable ‘treatment’ option (Aus et al. 2001; Carter 2011).

The treatment modalities often cause serious side effects. Kyrdalen et al. 2013 give an overview of studies concerning side effects of treatment options for localized prostate cancer. After radical prostatectomy in any form (retro pubic, laparoscopic or robotic), urinary incontinence frequently occurs immediately postoperative but this improves as time goes by.

Early after surgery erectile dysfunction is common and it does not show much improvement over time. Micturation problems can occur early after the surgery and these increase over time. Radiation therapy may also lead to irreversible erectile dysfunction. Other common side effects of radiation are rectal bleeding diarrhea, and rectal urgency, due to damage of the rectum. Hormonal treatment leads in most cases to loss of libido resulting in not being able to have sexual intercourse and experiencing a loss of sex drive (Fowler, Jr. et al. 2002). It also may cause hot flushes, breast forming and fatigue (Catalona 1994; Casey et al. 2012). Watchful waiting can cause anxiety by having cancer without receiving any treatment (Hedestig et al. 2003).
Chapter 1

Quality of life, psychosocial problems, and supportive care interventions

At the start of this study in 2002 there were relatively few research projects on the psychosocial aspects of prostate cancer. Over the last twelve years the number of studies has grown rapidly. Within the field of studies on psycho-oncology, a distinction can be made between three lines or domains of research: studies on quality of life, psychosocial problems, and supportive care. To put this study in perspective, we compared breast cancer and prostate cancer in the Netherlands. In 1989 (earliest year of cancer registration) the incidence of prostate cancer was 4200 rising to nearly 11,000 new cases in 2012. The incidence of breast cancer was 7709 in 1989 and in 2013 it rose to 14,326 new cases.

Figure 1 shows the number of studies on quality of life in women with breast cancer and men with prostate cancer found in the Pubmed database when entering the search terms ‘breast cancer or prostate cancer’ combined with ‘quality of life’ for the years of 1984 until 2014.

Figure 2 shows the numbers of studies for psychosocial problems and supportive care when entering breast cancer or prostate cancer combined with ‘depression or anxiety’ (representing psychosocial problems), and ‘psychosocial support’ for the years of 1984 until 2014.
Figure 1 shows a rapid growth of the number of quality of life studies over the last three decades for both breast cancer and prostate cancer, where as the number of studies are lower in men with prostate cancer. One of the reasons for this growth is that in many medical studies measurement of the concept of quality of life is included. The number of studies on psychosocial problems and psychosocial interventions (Figure 2), however, is still relatively small and compared to the number of studies on women with breast cancer far behind. It obviously has been recognized that prostate cancer has been a neglected area in psycho-oncology for decades (Visser & Van Andel 2000; Visser & Van Andel 2003; Christie et al. 2009). Where the incidence of breast cancer is about 1.3 higher then the incidence of prostate cancer, about five times more studies on breast cancer have been conducted.

A brief description of the different domains of research is given below.

Quality of life

The first domain of studies is on health-related quality of life (HRQOL). Numerous studies have appeared in the urological scientific journals and in other scientific journals (Van Andel 2003; Korfage 2005). HRQOL entails several domains. Most researchers acknowledge the following dimensions should be included: 1) physical health, referring to bodily functions and symptoms such as pain, gastrointestinal problems, problems with urinating and defecating etc; 2) functional health, including mobility, self care and role activities; 3) psychological health, which entails cognitive functioning, mood and psychiatric morbidity, and finally 4) social health, referring to social activities and interpersonal relationships (Macdonagh 1996; Van Andel 2003; Kaplan & Ries 2007). The content of HRQOL is described in detail in many studies on prostate cancer patients groups receiving different types of treatments (Kornblith et al. 1994; Eton et al. 2001; Van Andel 2003; Van Andel et al. 2004; Roeloffszen et al. 2010; Berge et al. 2011). Health-related quality of life outcomes are important in the decision what kind of treatment to apply, since for localized prostate cancer the main treatment options radical prostatectomy or radiation (both external beam or interstitial give similar results in terms of survival (60% to 90%) it is not established which treatment is the most optimal (surgery or radiation) (Denberg et al. 2006).
Chapter 1

Psychosocial problems

The second domain of research concerns psychosocial problems in men with prostate cancer. Where as the con-
cept of HRQOL consists of broad concepts like ‘mental health’, the research domain of psychosocial problems
delves much more into detail in psychosocial morbidity using specialized questionnaires for concepts as depres-
sion, anxiety, ways of coping and adaptation or relational problems and many others. Many studies within this
domain focus on depression or anxiety (Bisson et al. 2002; Pirl et al. 2002; Pirl et al. 2008; Whitaker et al. 2008;
Nelson et al. 2009). The importance of these studies lies in gaining knowledge on psychological problems related
to the prostate cancer. This knowledge is helpful in preventing psychosocial morbidity and in developing strategies
to facilitate adaptation to the disease.

Supportive care needs and interventions

This third research domain entails studies on supportive care needs (including informational needs), psychosocial
interventions and the effect of psychosocial interventions. In many studies the supportive care needs are identified
using questionnaires as the Supportive Care Needs Survey (SCNF) (Bonevski et al. 2000; Lintz et al. 2003). Other
studies use focus groups (Gray et al. 1997; Butler et al. 2001). Studies concerning psychosocial interventions often
apply a pre-designed intervention program and determine the effect on different outcome measures like depression
(Carmack Taylor et al. 2006), knowledge on prostate cancer (Lepore et al. 2003), self-efficacy (Weber et al. 2004)
or other outcomes (Davison et al. 2000; Poole et al. 2001; Steginga et al. 2005). The importance of these studies
is to establish evidence-based interventions for different patient groups with different psychosocial problems.

Scope of the study

Most of the studies on men with prostate cancer are conducted in the United States, Canada and Australia. How-
ever, several studies found cultural or racial differences in the way patients cope with a serious illness like prostate
cancer. African Americans turn more to religion and future temporal orientation compared to European American
men (Halbert et al. 2007).

Surbone summarizes three studies as follows: ‘There are cultural variations in patient’s health beliefs, values,
preferences, and behaviors affect the recognition of symptoms, the threshold for seeking care, the willingness
and ability to communicate and explain symptoms, the understanding of standard information about diagnosis,
prognosis and treatment options, the trust in different professionals, and the adherence to prescribed treatments’
(Surbone 2006). This shows that results of international studies might be partly representative for the Dutch situa-
tion. Therefore, an extensive study in the Netherlands seems appropriate to gain knowledge on the psychosocial
problems and the appropriate interventions specifically for Dutch men with prostate cancer.

In this study, the three domains of research are addressed in one sample. Quality of life is measured, psychosocial
problems are assessed and a seven sessions professionally lead intervention program is conducted and evalu-
eted. The data gave the opportunity to study the relations between psychosocial problems, supportive care needs,
the actual use of supportive care and the satisfaction with the received support.
Aim of the thesis

Preliminary studies have indicated that among Dutch prostate cancer patients there is a substantial need for psychosocial support in different forms (Visser et al. 1997; Ketelaar 1998; Riemens et al. 2000). These were, however, studies with small sample sizes, focusing on a limited number of themes and variables. The limited number of international studies on psychosocial problems in men with prostate cancer and the possibly different cultural aspects in the experience and adaptation lead to conduct a large Dutch study to answer the following questions:

I. What are the most important psychosocial problems of men with prostate cancer and what is their health related quality of life. This question will be addressed in chapters 2, 3, 4, 5.

II. What is the need for supportive care in men with prostate cancer and what are the determinants of the use of psychosocial support? This question will be addressed in chapters 5, 6, 7, 8.

III. How do men evaluate the supportive care they receive? This question will be addressed in chapter 8.
Chapter 1

Design of the study

The project entailed the recruitment of prostate cancer patients in any stage of the disease in order to describe a broad spectrum of the patients and their psychosocial problems involved. Potential participants in the study were offered to participate in cost-free professionally led supportive care groups. They were asked to participate in such a group and to fill out questionnaires. If they declined participation in a group, they were still invited to fill out the questionnaire. For the recruitment of the patients, leaflets with a response card were used, providing information about the study, also including the offer to attend one of the professionally led support groups for free. Urologists in five hospitals handed out these leaflets in their outpatient clinics during the consultation of all their patients, and during educational meetings on prostate cancer organized by two other hospitals. The leaflets were also mailed to all members of the Dutch Prostate Cancer patients’ foundation (PKS). When an affirmative response card was received, a questionnaire was mailed to the patients. If a patient chose to participate in a support group, an intake interview was scheduled. After completion of the group sessions (about after three month) there was a second measurement for all men participating in the study.

The inclusion of the final 238 participants in the study is depicted in the flowchart in Figure 3.

Outline of the thesis

Chapter two presents a survey of published reviews (1984 to 2012) about psychosocial problems associated with men with prostate cancer. The objective of this literature study was to provide an overview of the psychosocial problems of the prostate cancer patients.

Chapter three describes the preferences of men with prostate cancer concerning their treatment in relation to socio-demographic and medical variables. The importance of this topic lies in the fact that different treatments may cause different side effects.

Chapter four. The health-related quality of life in Dutch prostate cancer patients is studied in relation to different treatment modalities and time since diagnosis. This is relevant since treatments provide a good survival rate but also adverse side effects which may seriously impact the quality of life.

Chapter five focuses on the specific problem area of traumatic stress. Cancer may elicit symptoms of posttraumatic stress disorder such as intrusive recollections or avoidance behavior. This study discusses the extent to which this is a problem in Dutch men with prostate cancer. The social-cognitive processing model of emotional adjustment to cancer (Lepore 2001) is applied to relate the traumatic stress symptoms to the need for psychosocial support.

The need for supportive care introduced in chapter five, is further explored in the next three chapters. Our approach was to design the study partly demand driven by assessing men’s needs and then attempt to meet these needs with our intervention program. Since participation in supportive care is low in men with prostate cancer, we were also interested in the prostate cancer patients foundation as a form of support seeking and in determinants of support seeking.
Chapter six. The characteristics of members of a prostate cancer patients’ association are examined. These characteristics concern background variables, psychosocial variables like social support or distress and medical variables such as treatment and time since diagnosis. Although there are many reasons why an individual becomes member of a patient’s organization, membership of a patient’s organization can be regarded as a form of seeking support by meeting fellow patients. The kind of support can range from just wanting to have company to seeking medical information and other practical information from ‘experts by experience’ to seeking help for social emotional problems. All the above might be provided by the prostate cancer patients’ association.

Chapter seven applies the theory of planned behavior (Ajzen 1991) to the intention to participate in a support group by men with prostate cancer. According to this model, the intention to participate in a support group is a function of the attitudes about supportive care, the subjective norms of the patient and perceived control. Other factors that might play a role in the choice to participate in a support group are socio-demographic and medical background characteristics and psychosocial conditions.

Chapter eight. In this chapter it is evaluated how men who did participate in support groups perceived these group. This is mainly based on qualitative research focused on the experience of men who participated. It is discussed what aspects were seen as helpful, what aspects were least helpful, referring to content of the program but also referring to sharing of experiences and emotions.

Chapter nine finally gives a general overview of the conclusions and discussion about the results, together with a set of recommendations concerning how to deal with different groups of men with prostate cancer in order to minimize the psychological morbidity.
Chapter 1

Figure 3. Flow chart of the inclusion of the participants in the study

784 leaflets handed out
63 non-affirmative response cards received

303 affirmative response cards received

237 men wanting to participate in the study but not interested in support groups
66 wanting to participate in the study and interested in group participation

66 men approached to schedule an intake interview for group participation

18 men dropped out

237 questionnaires sent

25 non-response

48 questionnaires administered prior to enrolment in a support group

212 questionnaires received

192 questionnaires valid

1 meeting exclusion criteria

191 questionnaires non-group participants in database

47 questionnaires group participants in database

238 men total in database

20 missing values

192 questionnaires valid

1 missing values
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Chapter 1


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Chapter 1


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