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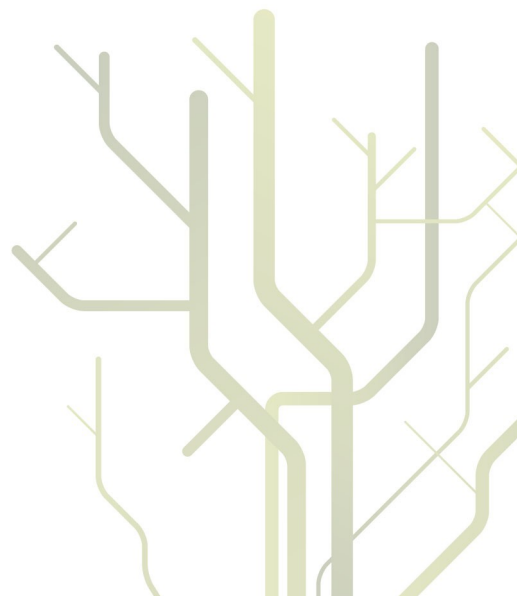
# Everyday life with prostate cancer:

## A qualitative study of men's and spouses' experiences



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## ***Words over the gate***

You move toward my innermost gate  
And I go towards yours, too.  
Inside, each of us is lonely,  
and shall always be that way.

Never push yourself too far,  
was the law that mattered to us.  
Whether we met often or seldom,  
the meeting was trust and peace.

If you aren't standing there one day when I come,  
it will be easy for me to turn  
when I have stood awhile and looked toward your house  
and thought about you living there.

As long as I know you will come now and then,  
like now, over crunchy gravel  
and smile when you see me standing here,  
I will have a home in my house.

Halldis Moren Vesaas 1955

(In Selected Poems, translated by Wakefield R and Thompson O. 1989)

## ***Ord over grind***

Du går fram til mi inste grind,  
og eg går òg fram til di.  
Innanfor den er kvar av oss einsam,  
og det skal vi alltid bli.

Aldri trenge seg lenger fram,  
var lova som gjalt oss to.  
Anten vi møttest tidt eller sjeldan  
Var møtet tillit og ro.

Står du der ikkje ein dag eg kjem  
felle det meg lett å snu  
når eg har stått litt og sett mot huset  
og tenkt på at der bor du.

Så lenge eg veit at du vil koma i blant  
Som no over knastande grus  
og smile glad når du ser meg stå her,  
skal eg ha ein heim i mitt hus.

Halldis Moren Vesaas 1955

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## **Preface**

Patients' experiences of everyday life after being diagnosed with cancer have been an area of interest for me for many years. During more than 20 years of work as a specialist nurse in cancer care, on in-patient wards, in postgraduate study in cancer nursing (teaching) and now in palliative care, my focus has shifted from specialized treatment at hospitals toward life at home for patients and their families. This change towards everyday life is based on following patients and their families through often long-lasting treatment in hospital. After finishing treatment I often used the words: "now you can go back home to live your normal life".

However, after obtaining more experience as a cancer nurse these words became a bit hollow, and I was inspired to gain more knowledge from the patients' perspective about life at home after a cancer diagnosis. Therefore my master degree from 2002 was an interview study of women with breast cancer which focused on the experiences of living with breast cancer from an everyday life perspective. The results showed that the illness had great impact on the women's everyday life emotionally and practically. Existential issues, bodily alterations and relation to spouses and close ones were especially important for the women.

Working in the field of palliative care for the last 12 years has offered me a new insight into the challenges patients and their close families are facing living with a potentially fatal illness for month, weeks and years. Results from studies conducted internationally and in Norway, encompassing different types of cancer, point at a variety of problems and needs for patients in everyday life after a cancer diagnosis. The results indicate a need for a more systematic follow-up, especially regarding psycho-social aspects, information and guidance. While the experience of living with breast cancer has been an area for multiple studies, men's and spouses' experiences of living with prostate cancer have been less studied. Furthermore, men's experiences of serious illness are poorly documented internationally and in Norway. Therefore the focus in the thesis is men's experiences of living with prostate cancer. As prostate cancer has a great impact on spouses' daily life as well, the study includes the experiences of spouses of men with prostate cancer.

The study sample consists of men with localized or local advanced prostate cancer receiving endocrine therapy or under active surveillance (not potentially curative treatment) (Studies 1 and 2) and spouses of men with prostate cancer receiving potentially curative treatment as

surgery or radiation therapy (not married to the men in Studies 1 and 2) (Study 3). With short stays in hospital for initial treatment, patients and their spouses face practical and existential challenges after discharge. Thus a greater focus on follow-up regimes and rehabilitation is important. The aim of this project is to gain knowledge of the experiences of everyday life from the perspective of prostate cancer patients and their spouses in order to improve treatment and care in hospitals and the organization of follow-up and rehabilitation in a way that meets the needs of patients and their family members.



## Acknowledgements

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Thanks to friends and family for being interested in my work and especially to my mother, nearly 97 years old but still interested and really looking forward to seeing her daughter finish “school”. Last but not least I want to thank Knut for always, always being there for me, and Martin and Lars for supporting their mother and encouraging me to write in English.

## **Abstract**

Prostate cancer is the most common cancer among men in Norway. Cancer is a frightening illness, still associated with suffering and death. Furthermore, the main treatment options for prostate cancer, surgery, radiation and endocrine therapy, cause substantial side effects, where impotence, lack of sexual desire and urine leakage are the most common. Cancer in one family member affects the whole family. Previous studies have shown that prostate cancer in men has impact also on spouses` every day life and spouses provide the best support for men with prostate cancer. For most men hospital stays at the time of diagnosis and treatment are limited, and therefore many questions about the illness arise after coming home.

The main aim of this study was to illuminate men`s experiences of living with prostate cancer and the impact of prostate cancer on the everyday life of men and their spouses. The study was conducted via qualitative interviews of 13 men and 9 spouses, using a phenomenological hermeneutical approach.

The results showed that prostate cancer was experienced as a frightening illness and a threat to everyday life for men and spouses. Cancer as a potential life threatening illness, and uncertainty about the prognosis for the individual patients cast a shadow throughout the course of the illness, and new aspects of the cancer were often experienced as an existential threat in everyday life. Physical side effects of treatment were of significance for men`s experience of masculinity and the sexual/marital relationship. Different bodily alterations were a source of uncertainty in daily life and brought forth reflections on the experience of being well or ill on an existential level.

Prostate cancer in men had significant impact on spouses` every day life practically and emotionally. The couples were considerate of each other`s experiences. The men tried to reduce the strain of the illness on the spouses, and the spouses underlined the importance of not compromising their partners in intimate matters. Spouses tried to achieve a balance between managing their own emotional, bodily, and relational needs and meeting their husband`s needs for support and care over the course of the illness. Those spouses who had lived in such a situation for years expressed a feeling of exhaustion and a need for focusing on their own needs as well. Information, a sense of community, encouragement, a sense of humour and an optimistic outlook (life courage) were significant factors for dealing with

prostate cancer in everyday life for both men and spouses. In general, men and spouses dealt with the prostate cancer experience without letting the illness dominate their day-to-day lives. However a new thoughtfulness and readiness for new changes had now emerged in their life.

Challenges for health care services include taking account of the existential experiences of men with prostate cancer during brief clinical encounters, meeting the spouses' need for information (if allowed by husbands) and support, and providing follow-up support for the men.

## Sammendrag

Prostatakreft er den hyppigste kreftformen hos menn i Norge. Å få en kreftdiagnose er i seg selv en skremmende opplevelse, og kreft blir fortsatt assosiert med lidelse og død. De vanligste behandlingsformene ved prostatakreft, kirurgi, stråle- hormonbehandling, medfører i tillegg betydelige bivirkninger. Impotens, mangel på seksuell lyst og urinlekkasje er de hyppigste følgene av behandling.

Kreft er en sykdom som berører hele familien. Tidligere forskning har vist at prostatakreft hos menn har stor betydning for ektefellers hverdagsliv, og at menn med prostatakreft opplever ektefeller/partnere som sin beste støtte gjennom sykdommen. Korte opphold i sykehus og poliklinikker ved diagnostisering og behandling medfører også at mange spørsmål knyttet til sykdommen blir aktualisert først etter hjemkomst.

Hensikten med studien var å belyse menns erfaringer med prostatakreft, og hvilken betydning sykdommen har for menns og ektefellers hverdagsliv. Studien har en fenomenologisk hermeneutisk tilnærming, og er gjennomført ved hjelp av kvalitative intervju av 13 menn med prostatakreft og 9 ektefeller til menn med prostatakreft..

Resultatene viste at prostatakreft opplevdes som skremmende sykdom og en trussel for hverdagslivet for både menn og ektefeller. Usikkerhet knyttet til kreft som en livstruende sykdom og usikkerhet i forhold til prognose for den enkelte lå som et bakteppe gjennom hele sykdomsforløpet, og nye sider/følger av sykdommen opplevdes som en eksistensiell trussel i hverdagen. Bivirkninger av behandlingen hadde stor betydning for mennenes opplevelse av maskulinitet og for forholdet mellom ektefellene. Sykdommen medførte også en ny oppmerksomhet på kropp og fysiske symptomer. Kroppslige endringer ble en kilde til usikkerhet og ledet til refleksjoner knyttet til opplevelsen av å være frisk eller å være syk.

Kreftsykdommen hadde stor innvirkning også på kvinnenes hverdagsliv praktisk og følelsesmessig. Begge parter viste stor omsorg for hverandre, og mennene ønsket å skåne ektefellene for de belastningene sykdommen brakte med seg. Kvinnene var spesielt opptatte av å unngå å utlevere sine ektefeller og forhold av intim art overfor andre. Ektefellene prøvde å finne en balanse mellom å mestre egne følelsesmessige, kroppslige og relasjonelle behov og møte mennenes behov for støtte. Kvinnene med lengst erfaring som pårørende uttrykte

slitenhet og et ønske om også å ta vare på egne behov. Informasjon, fellesskap, oppmuntring, humor og livsmot var sentrale elementer i mestring av hverdagen for begge parter. I all hovedsak opplevde menn og ektefeller å ha funnet måter å leve med sykdommen som gjorde at sykdommen ikke dominerte hverdagslivet. Samtidig var en ny ettertenksomhet og varhet kommet inn i livet, noe som medførte at de levde i en type beredskap for endringer relatert til sykdommen i det daglige.

Det synes å være en utfordring for helsevesenet i å inkludere den eksistensiell dimensjonen ved prostatakraft i korte møter mellom helsepersonell og pasient og pårørende. En annen utfordring er å inkludere ektefellers behov for informasjon (om menn tillater) og støtte, og videre forbedre oppfølging av menn med prostatakraft.

## **Original articles**

Ervik, B, Nordøy, T, Asplund K. (2010). Hit by Waves - Living With Local Advanced or Localized Prostate Cancer Treated With Endocrine Therapy or Under Active Surveillance. *Cancer Nursing*, 33 (5), 382-389.

Ervik, B, Asplund, K. (2012). Dealing with a troublesome body: A qualitative interview study of men's experiences living with prostate cancer treated with endocrine therapy. *European Journal of Oncology Nursing*, 16 (2), 103-108.

Ervik, B., Nordøy, T, Asplund K. (2012). In the Middle and on the Sideline: The Experience of Spouses of Men With Prostate Cancer. Published ahead of print in *Cancer Nursing* Aug. 2012. <http://cancernursingonline.com> DOI:10.1097/NCCobO13e31824fe1ef

## 1.0 Introduction

Cancer is a frequent diagnosis and a frightening illness. In Norway 27 520 people were diagnosed with cancer in 2009, and approximately 200 000 people were living with one or more cancer diagnoses (Cancer Registry of Norway, 2011). In 2009, 9 834 persons died of cancer, which is thus the second largest cause of death in Norway after cardiovascular diseases (Sund and Hansen, 2011). Initial symptoms, treatment options and prognosis vary between the different types of cancer. Some forms of cancer present symptoms at an early stage while others can have spread significantly before detection. An early start to treatment is of great importance for the prognosis and thus for the outcome of the disease. If the cancer is disseminated at time of diagnosis curative treatment may not be an option, and the disease will lead to death (Kåresen and Wist, 2000). From 1999 to 2009 there has been an increase in the survival rate for the main cancers in Norway, breast, prostate, lung, colon and rectum cancer. Increasing attention to cancer by both health care providers and the general public has been suggested as an explanation for the increase in the survival rate, together with screening programmes and improvements in treatment (Cancer Registry of Norway, 2011).

Cancer is still associated with suffering and death and is thus a frightening diagnosis (Kelly and White, 2011). Being struck by cancer is described as a shock that turns daily life upside down for both patient and family, giving rise to anxiety and uncertainty regarding treatment, prognosis and the future. Distressing symptoms from the cancer and treatment side effects may cause severe physical problems. Thus patients often experience physical challenges and practical problems, combined with significant emotional and existential strain (Kelly, 2009; Sekse et al., 2010) and for some patients these problems can persist for years after treatment is ended.

In Norway improvement in diagnostic procedures and treatment options have led to a shift towards more day and outpatient treatment for cancer patients, and average inpatient hospital stays have fallen from 7.5 days in 1989 to 4.5 days in 2009 (Statistic Norway, 2010). Being at home is considered a better alternative for patients than busy hospital wards, and from an economic perspective outpatient treatment is less expensive than inpatient stays in hospitals. Questions regarding one's future with cancer have been shown to arise after coming home (Kåresen and Langmark, 2000), and patients seem to lack information about where to get help when needing assistance (Sægrov and Halding, 2004). Gaining knowledge about the experiences

of living with cancer, from the perspective of those affected, is therefore central to create good patient pathways and provide care and support for the patients and their close ones through the course of the illness.

Prostate cancer is the most common cancer among men. The large number of prostate cancer patients needing treatment and follow-up creates huge pressure on the health care services at the specialist level, and the “Norwegian plan of action for treatment and follow up of prostate cancer” (Johannesen et al., 2009) recommends more follow-up actions handed over from the specialist health care services to (primary care settings and) general practitioners. “The Coordination Reform” (Ministry of Health and Care Services, 2009) implemented in 2012 indicate greater responsibility for primary health care for prevention and rehabilitation. These changes can be said to have brought about a new situation for patients in the organisation of follow-up after the diagnosis. As men with prostate cancer are shown to rely heavily on their spouses for practical and emotional support (Fergus et al., 2002) these changes have the potential to lead to a more prominent role for spouses in the rehabilitation process (Adams et al., 2009).

The study was conducted in northern Norway. Follow up for men with prostate cancer complies with the guidelines laid down in the national plan of action mentioned above (Johannesen et al., 2009). There are few rehabilitation centres for cancer patients in Norway, and in northern Norway only two centres offer rehabilitation courses for patients with cancer. Additionally three-day courses are held twice a year at learning and coping centres in two hospitals. The Norwegian Cancer Society provides shorter courses and seminars for patients with cancer and their families.



## 2.0 Background

### 2.1 Prostate cancer

Prostate cancer is the most common cancer among men in Norway. In 2009, 4 299 men were diagnosed with prostate cancer, 1 048 men died of the disease, and about 27 500 men were alive after being diagnosed with prostate cancer (Cancer Registry of Norway, 2011).

The incidence of prostate cancer is increasing in Norway and in the rest of the Western world (Hernes et al., 2010), probably due to screening programmes and an ageing population.

Prostate cancer is often referred to as an “old man’s disease”, and approximately 90% of the new cases occur in men over 60 years of age. However, in recent decades we have seen an increase in prostate cancer in younger men. With localized prostate cancer the 5 year relative survival rate is 97.3%. With local advanced prostate cancer the relative survival rate is 83.3%, however if the cancer is disseminated the relative survival rate is only 31.0% (Cancer Registry of Norway, 2011).

Prostate cancer is diagnosed in biopsies of the prostate gland. Gleason score<sup>1</sup>, prostate specific antigen (PSA) score<sup>2</sup> and TNM<sup>3</sup> are important prognostic factors in prostate cancer. These factors in combination with the patient’s age, general health condition and co-morbidity are important parameters in deciding on treatment (Johannesen et al., 2009; Jonsson et al., 2010). However, even when using the best prognostic factors there is significant heterogeneity in clinical outcome, with some patients having a dramatic and aggressive disease with short life expectancy, while in others tumour growth can be slower and treatment can be postponed for years (active surveillance<sup>4</sup>) (Ploussard et al., 2011).

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<sup>1</sup> Gleason score. Histopathological gradation of prostate tissue that reports primary (1-5) and secondary (1-5) grade of the dominating growth pattern in the tumour. The scores are summarised. Gleason score is a powerful prognostic factor for predicting the development of the cancer (Johannesen et al., 2009; Kuroiwa K et al., 2011).

<sup>2</sup> Serum PSA is increased in both benign and malign diseases involving cells from prostate epithelium and therefore not specific for prostate cancer (Eide and Angelsen, 2000).

<sup>3</sup> TNM; classification of stage of disease, size of tumour, affection of lymphatic nodes and metastasis (Johannesen et al., 2009).

<sup>4</sup> Active surveillance: Control of PSA every third month for 2 years, then every sixth month with new biopsies after 1, 4, and 7 years (Johannesen et al., 2009).

### **2.1.1. Treatment options and physical side effects from treatment**

The following chapter presents a short overview of treatment options of relevance for patients in this study.

For men with localized prostate cancer and a life expectancy more than 10 years (Paper 3), surgery (radical prostatectomy) and/or external radiation therapy are the main treatment options provided with a curative intention. Radical prostatectomy involves up to 5 days in hospital, while external radiation therapy is given as outpatient treatment over 7-8 weeks (Johannesen et al., 2009). For men with low risk prostate cancer active surveillance is the preferred option, either to avoid radical treatment with undesired side effects, or to postpone radical treatment until the cancer shows signs of progression. This alternative is provided on the basis of certain criteria in the Norwegian guidelines for treatment of prostate cancer (Johannesen et al., 2009).

Endocrine therapy alone is the main treatment option for men with localized or local advanced prostate cancer without dissemination and a life expectancy less than 10 years (where curative treatment is not an option). In Norway endocrine therapy is provided for the men either as luteinizing hormone-releasing hormone (LHRH) analogue (castration), administered by syringes every third month, or as anti-androgens (bicalutamine) in tablet form (Papers 1 and 2). The main treatment goals of endocrine therapy are to keep the disease at bay and relieve troublesome symptoms (Engstrom, 2008; Schulman et al., 2010).

The main treatment options, surgery, radiation and endocrine therapy, all have significant physical side effects (Auclerc et al., 2000; Hofmann and Schulman, 2009; Johannesen et al., 2009), impairment in urination and erectile dysfunction being the most common. With radical prostatectomy the main long-term side effects are incontinence and erectile dysfunction (Johannesen et al., 2009); however, the extent of impairment in urination and erectile dysfunction is reduced in later years due to better surgery techniques and especially nerve saving surgery. In addition, programmes for post-operative pelvic training, established in larger urological centres in Norway, have contributed to a decrease in problems with urine leakage (Overgård et al., 2008). However, a large group of men will live with problems related to incontinence (20-40%) and erectile dysfunction (70-80 %) for the rest of their lives (Parker et al., 2011; Talcott et al., 2003). The main long-term side effects of radiation therapy are proctitis (up

to 20%) and erectile dysfunction (30-45 %). Erectile dysfunction may develop years after treatment is terminated (Johannesen et al., 2009). Castration by a LHRH analogue causes substantial adverse effects of which hot flushes, osteoporosis, fatigue and impotence are the most common (Norwegian Medicines Agency, 2004; Stone et al., 2000). These side effects are less evident with anti-androgen treatment. However, anti- androgens may cause gynaecomasty, itching and symptoms of flushing (Auclerc et al., 2000; Hofmann and Schulman, 2009).

## **2.2 Living with prostate cancer – the experiences of men and spouses**

Previous studies regarding men's experiences of prostate cancer in an everyday life perspective are mainly about side effects of treatment and their impact on masculinity, embodiment and the sexual/marital relationship. There have also been many studies on quality of life and psychosocial aspects of prostate cancer, such as anxiety and depression. We also see an increase in studies encompassing spouses' experiences of living with men with prostate cancer.

Although e.g. bodily alterations and experiences of sexuality are closely intertwined with our being in the world, and are thus existential experiences, we have attempted to distinguish between studies dealing with a) prostate cancer as an existential threat (spouses' experiences are presented in 2.2.3), b) bodily alterations related to side effects from treatment, c) the impact of prostate cancer on the sexual/marital relationship, and d) spouses' experiences of living with a man with prostate cancer. In the following presentation the articles are limited to those dealing with the aim and research questions of our study. The literature review includes studies conducted within different theoretical and methodological frameworks.

### **2.2.1 Prostate cancer as an existential threat**

Cancer is associated with suffering and death; this gives rise to anxiety and uncertainty about the future (Andreassen et al., 2007; Sægrov and Halding, 2004). In a review article about the anxiety level in men with prostate cancer, Dale et al. (2005) showed that the anxiety level appeared to *“vary plausibly over the clinical timeline in response to stress and uncertainty”* (p. 475). The highest anxiety level was reported by those awaiting results from biopsy to confirm or rule out

the diagnosis (Dale et al., 2005). It has also been shown that fear of recurrence or dissemination of the cancer play an important role for the patient's anxiety level (Grimsbø et al., 2011). Fear of recurrence was found to have a significant impact on men's health-related quality of life (HRQoL); however, Dale et al. (2005) found no studies reporting a rise in anxiety over time.

In many studies the anxiety level is compared between various treatments but with contradictory results. In a study by Burnet et al. (2007) active surveillance was not associated with greater distress than more immediate treatment for prostate cancer, while Dale et al. (2005) described higher anxiety in men under active surveillance compared with men who had undergone surgery. Getting rid of the cancer was suggested as a reason for lower anxiety in the surgery group (Dale et al., 2005). In a study of depression, anxiety and post traumatic stress disorder in prostate cancer patients, Menhert et al. (2010) found that men treated with prostatectomy reported no higher degree of depression and anxiety than the general population. Cherrier et al. (2009) found that patients receiving endocrine therapy had an increase in anxiety and depression from baseline during treatment, and in a study of men under active surveillance by Burnet et al. (2007) patients reported most depression later in the illness trajectory.

The possibility of a shortened life is an ever-present factor for many patients under active surveillance, and the unpredictable dimension of cancer is shown to contribute to uncertainty about the future (Hedestig et al., 2003; Wallace, 2003). Mehnert et al. (2010) showed in their study that 23.9% of patients treated with radical prostatectomy experienced their cancer diagnosis as "somewhat", "quite a bit" or "very" threatening, while 76.1% evaluated the disease as "not" or "a little" threatening. However, 83.4% had experienced distressing periods or events. The threat was rated highest by men younger than 65 years, by men with advanced disease, lack of positive support and those who had experiences of detrimental interactions (e.g. overprotection, pessimism). Kelly (2009) found that the existential threat of prostate cancer resulted in men questioning their priorities in life and focusing on the future with new insight and hopes.

## **2.2.2 Side effects of treatment and masculinity**

Most studies regarding prostate cancer as a bodily experience are about the side effects of treatment. Multiple studies have shown that physical side effects from treatment have significant impact on men's sexual health (Messaoudi et al., 2011; Oliffe, 2006) and thus quality of life for patients and their partners (Chapter 2.2.3) (Wassersug, 2009). Erectile dysfunction, problems with orgasm and reduced intercourse frequency are significant problems related to surgery and endocrine therapy (Gannon et al., 2010; Levinson et al., 2011). Inability to perform and lack of lust have been shown to undermine the foundations and legitimacy of masculinity (Donovan and Flynn, 2007). Although sexuality is shown to be an area of concern (unmet needs) for cancer survivors across tumour groups (Kelly and White K., 2011), sexual problems may be of particular significance in patients with prostate cancer.

In his article about mastering emancipation from endocrine therapy, Wassersug (2009) asserted that health care services often focus merely on erections and penetration and the use of different devices (technical and medicaments), and he views this one-sided focus on erection as problematic. Because many men will not regain their previous erectile ability after radical prostatectomy, lack of success in getting an erection may cause low self-esteem (Levinson et al., 2011; Wassersug, 2009). As shown in a study by Messaoudi et al. (2011) those men who were most motivated to return to their previous ability experienced greater distress from erectile dysfunction than those less motivated.

Fatigue following endocrine therapy causes a change in energy level in men, and contributes to a situation where men experience the inability to fulfil their male role (Cecil et al., 2010). Additionally hot flashes and breast growth following endocrine therapy have been found to contribute to a feminisation of the body and difficulties in preserving masculinity (Navon and Morag, 2003 a). However, in a study by Gray et al. (2005) men receiving endocrine therapy rejected liminality and claimed to be neither less masculine nor more feminine because of treatment.

The physical side effects makes many men experience their body as essentially different (Auclerc et al., 2000; Hofmann and Schulman, 2009), yet there are not many studies on other bodily themes than sexuality and masculinity. In his study of the embodied impact of prostate

cancer, Kelly (2009) highlighted men's experiences of embodiment through the illness trajectory, and he emphasized the sequential dimension of the cancer experience; the awareness of the cancer at time of diagnosis, the experience of side effects from treatment and the men's attempt to return the body to an optimal functional level. Kelly (2009) and Lilleaas (2006) underlined men's experience of vulnerability when the body is not functioning as before, and Kelly (2009) found that men tried to strengthen their body to preserve or restore aspects of their previous selves. A newly published review article by Baumann et al. (2012) suggests that clinical exercise may have a positive effect on e.g. quality of life, fatigue and body constitution in men with prostate cancer.

### **2.2.3 Marital and sexual relationship and spouses' experiences**

With regard to the impact of prostate cancer on spouses' marital and sexual relationship, it is primarily the affect of treatment side effects on couples' intimate and everyday lives that has been investigated (Badr and Carmack Taylor, 2009; Gray et al., 2000 a; Wassersug, 2009). Navon and Morag (2003 b) found that perceived changes in identity from erectile dysfunction created an emotional and/or physical distance in the spousal relationship for some men while other men found that these struggles enhanced the emotional aspects of their relationships. For some couples the experience of prostate cancer resulted in a closer relationship (Harden et al., 2002).

Talking about cancer and sexual problems is a source for distress for both men and spouses (Badr and Carmack Taylor, 2009; Northouse et al., 2007) and the degree of openness about the illness and whom one can talk to are important issues. Gray et al. (2000 a, b) found that most men with prostate cancer avoided discussing their illness unless it was absolutely necessary, and many men only confide in their spouses. The results from Hedestig et al. (2003) support the findings in Gray et al. (2000 a, b), and in their study the reluctance to tell anybody about the illness was explained by wanting to prevent others from needing to feel pity for them. In a study by Manii and Ammerman (2008) many men indicated that they would have liked to talk to someone about their concerns during the process of diagnosis and treatment, but only a small fraction of men actually participated in e.g. group therapy.

Spouses have been shown to provide the best support through the course of the illness (Harden et al., 2002; Helgason et al., 2001; Northouse et al., 2007), and many men rely heavily on their spouses for practical, emotional and medical support (Fergus et al., 2002). However, spouses also experience anxiety and uncertainty about the future (Galbraith et al., 2005; Galbraith et al., 2008; Harden et al., 2002). A study by Couper et al. (2006 a) showed that partners reported greater psychological distress than the patients themselves at the time of diagnosis. The patient distress increased after 6 months, whereas it decreased for the partners.

Spouses have been shown to play an active role in e.g. encouraging men to seek treatment, and many spouses act as a mediator between the health care services and their husband (Harden et al., 2002). Thus spouses need much information, often more so than their husbands (Echlin and Rees, 2002; Gray et al., 2000 a). In a review article about the information needs of the partners and family of cancer patients, Adams et al. (2009) found that partners and family members had a wide range of information needs, and they underlined the importance of acknowledging that information needs may differ between patients and partners. The review revealed that most studies are conducted within the first year after diagnosis and we therefore lack knowledge about information needs in later stages of the illness trajectory.

Men with prostate cancer are aware of the strain the illness places on their partners, and they try to ease their spouses' burden (Fergus et al., 2002). The need to protect and spare the partner from anxiety also applies to the spouse, and Gray et al. (2000 a) showed that women minimized their own talk about cancer in order to support their husbands. Spouses found ways to provide support without appearing to do so to avoid letting their men feel in need of support. Other studies show that partners need to balance worrying about their husband's illness against considering the implications for their own well-being (Fergus et al., 2002; Hawes et al., 2006). In a study of couples' experiences with prostate cancer performed with three focus groups (in dyads, caregiver-only and patient-only groups), Harden et al. (2002) showed that emerging themes were similar across the groups, but the caregiver-only groups (and patient-only groups) seemed to speak more freely without their partners present.

## Rationale

As shown in the above literature review, studies of men's experiences of prostate cancer cover various areas of importance for men and spouses. The impact of prostate cancer and the physical side effects from treatment on masculinity and sexuality are well documented. In this study we broaden the perspective to also include bodily alterations in men through the course of the illness. Previous studies have provided important insight into psychosocial aspects of prostate cancer, such as health related quality of life, anxiety and depression. These studies were mainly conducted using different standard measurement tools, and often by comparing different (potentially curative) treatment options. In this study we focus on men's experiences of everyday life with prostate cancer when potentially curative treatments are not an option at time of diagnosis. Information needs, the effect of exercising and humour are examples of issues investigated in studies of quality of life. By using a qualitative design we wish to add to the existing knowledge base by focusing on men's and spouses' narratives about their experiences of what has been important to them in how they have coped with the illness in everyday life.

Previous studies have shown that spouses are considered to be the best support for men with prostate cancer, and there is increasing attention to the experiences of spouses in research. Studies of patients' and spouses' experiences are often conducted within a psychosocial framework, and by comparing the responses of the men and spouses in the same study. These studies have provided insight into areas of concern for both men and spouses, especially regarding sexuality and quality of life. The current study is designed to investigate only the spouses' experiences (not married to the men in studies 1 and 2), since we presuppose that spouses will narrate their stories more freely without their husbands included in the study. A phenomenological hermeneutic approach provides a first person perspective into the many-faceted experience of prostate cancer. This may offer a broader picture of the impact of prostate cancer on everyday life for men and spouses and add important knowledge to the already existing knowledge base.



### **3. Aims**

The present study was designed to illuminate the experiences of men and spouses of everyday life with prostate cancer, especially the impact of the illness on daily activities, bodily alterations and the marital relationship.

Research question:

How do men with prostate cancer experience the illness and how does prostate cancer influence the everyday life of men and their spouses?

The study comprises three papers with the following specific aims:

Paper 1:

An illumination of men's experiences of living with prostate cancer when potentially curative treatment is not an option at time of diagnosis (Basis for Studies 2 and 3).

Paper 2:

An illumination of how men treated with hormones for prostate cancer experience their bodily alterations through the course of the illness.

Paper 3:

An illumination of the impact of prostate cancer on the everyday life and marital relationship of spouses.

## **4.0 Theoretical framework**

The study was guided by a phenomenological hermeneutic philosophy and the work of central philosophers such as Husserl, Heidegger, Merleau-Ponty, Gadamer, Schutz, Ricoeur, Løgstrup and Pahuus (Gadamer, 1989; Heidegger, 1996; Husserl, 1995; Løgstrup, 1988; Løgstrup, 1999; Merleau-Ponty, 1994; Pahuus, 1995; Ricoeur, 1976; Ricoeur, 1992; Schutz, 2005). A phenomenological hermeneutic perspective implies studying the experiences of a phenomenon from an individual, first person perspective in order to understand the lived experience of the phenomenon (Bengtsson, 2006).

### ***4.1 Phenomenological hermeneutics***

Phenomenology is described as a movement that originated from Husserl's transcendental philosophy. Husserl's philosophy was later developed in an existential direction represented by Heidegger, Sartre, and Merleau-Ponty (Bengtsson, 2006). Modern hermeneutic phenomenology is mainly based on existential phenomenology, and Ricoeur (1975) stated that phenomenology was a presumption of hermeneutics and vice versa. Existential phenomenology is concerned with the lived experiences of a phenomenon – its ontology, that something is, but also what something is (Bengtsson, 2006; Heidegger, 1996). This ontological perspective in hermeneutics involves questions concerning what characterizes the basic conditions of human beings living in the world.

In a phenomenological hermeneutic perspective, being in the world and relating to other people is fundamental to our existence as human beings (Heidegger, 1996). As human beings (subjects) we participate in a social fellowship (intersubjectivity) and constitute a part of our relationships with other persons and things (Gadamer, 1989; Gulddal and Møller, 1999). Intentionality is a core concept in phenomenology, and refers to the inseparable connectedness of human beings to the world. In our being in the world, a meaningful world, we are already and always in a process of understanding (Gadamer, 1989). Because we already are understanding and interpretative within our own history and reality, each experience is associated with a particular meaning for us as human beings (Gadamer, 1989; Heidegger, 1996). All human actions and experiences therefore involve an aspect of

interpretation, and thus consciousness about things is consciousness about things as something, not things in themselves (Bengtsson, 2006).

Schutz (2005) developed phenomenology in a social direction and placed intersubjectivity into a larger context. For Schutz intersubjectivity is about socialisation, praxis (activities) and interaction. Both Merleau-Ponty (1994) and Schutz (2005) emphasized the social dimension of experiences and maintained that human beings are accessible for each other through interaction, embodiment and language, and Merleau-Ponty (2002) asserted that “*Truth does not “inhibit” only the “inner man” or more accurately, there is no “inner man”, man is in the world, and only in the world does he know himself*” (p. xi). For Merleau-Ponty (1994) our being in the world is an embodied existence, and the current of a person’s intentional existence in the world is experienced through the body, thus the body is a condition for our experiences and not an object in the world. Merleau-Ponty (1994) emphasizes that we approach the world through sensing as “bodily” beings, and that sensing belongs together with our ability to move and to orientate in time and space in a world already meaningful for us (Råheim, 1997).

Lifeworld<sup>5</sup> is a central concept in phenomenology and refers to the lived relationship between an experiencing and acting (body) subject and the world – a shared experience and a lived experience (Merleau-Ponty, 1994; Råheim, 2006). Everyday life consists of some common structures and characteristics that can be described and thus enable us to talk about everyday life; time, space and social structures (Schutz, 2005). These common structures refer to the fact that as human beings we are aware of our mortality and that history will survive us. We also realize that we are placed in the world in a historic time, place and tradition. This “biographic situation” constitutes the starting point for our orientation in the world (Gadamer, 1989; Schutz, 2005) and creates a foundation for our experiences. This shared store of knowledge makes it possible for humans to understand each other in spite of distinct individual experiences (e.g. of being ill). In addition the lifeworld consists of knowledge built up through our own and others’ experiences in life (Schutz, 2005). In everyday life this bank of knowledge is not made into an object for discussion but creates a basis for our understanding. This makes it possible to manoeuvre in the world in an unproblematic way without reflecting on our being and activities (Bengtsson, 2006).

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<sup>5</sup> In his later work Schutz uses everyday life as synonymous with lifeworld (Bengtsson, 2006; Bengtsson, 2001; Schutz, 2005).

Therefore “everything happening” in daily life is experienced on the basis of something unproblematic or taken for granted (Bengtsson, 2006) and many experiences are thus perceived as unproblematic and dealt with within the person’s repertoire of action. Other experiences stand out from what we expect and affect us. These experiences require interpretation and contribute to the knowledge base in the person’s lifeworld. According to Gadamer (1989) the latter type of experiences - “experiences” in the genuine sense - are always negative (p. 347) and change both the understanding of the phenomenon experienced and the experiencing person (Gadamer, 1989).

Hermeneutics is not limited to science but is an approach to the understanding and interpretation of different aspects of life expression, such as art, texts and social interactions. Gadamer (1989) saw the task of hermeneutics to be a way of clarifying the conditions in which understanding takes place but not a procedure of understanding. He criticized Husserl for emphasizing consciousness as having direct access to things in the world, and stated that because our access to things in the world is confined we will never gain a pure understanding. In this perspective there is no objective truth about a situation or the interpretation of a text. As humans we are always in a situation (historically placed in the world and in a tradition), and the situation limits or marks the horizon for understanding. Understanding may come into being in a dialogue between e.g. the reader and the text, and may result in a “common” understanding and fusion of horizons. However, “horizon” is not a fixed pattern, but our understanding is a movement as we incorporate new experiences into the lifeworld (Gadamer, 1989). Understanding is an ongoing process, and as humans we are always in a circle (or spiral) of being and understanding, and in this process we understand the whole from its parts and the parts from the whole (Schleiermacher, 1999). Reflexivity, openness, curiosity and sensitivity are all central for encouraging an open-minded process of understanding and for being prepared to confront our attitudes and our understanding - to place our presuppositions “at risk” (Dahlberg et al., 2001; Gadamer, 1989; Johnson, 2000; Moules, 2002).

Consciousness of our presuppositions, or to use Gadamer’s (1989) concept prejudices, is important but challenging as they may be hidden from us in daily life. We become aware of our consciousness through provocation or by challenging what we take for granted in everyday life. Our prejudices allow us to be aware of things we might otherwise have ignored

(Moules, 2002). In the process of understanding Gadamer (1989) distinguished between true prejudices, which enable us to understand, and false prejudices, which may lead to misunderstanding. Gadamer (1989) stated that we cannot step back over our shadows (Moules, 2002). *“In fact history does not belong to us; we belong to it. Long before we understand ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society, and state in which we live.”* (p. 278) (Gadamer 1989).

As stated above, human beings' (subjects') existence in the world, a meaningful world, is already and always in a process of understanding (Gadamer, 1989). Illness is an example of an experience that in a fundamental way changes life conditions, and enforces a new interpretation of everyday life on the sick person (and the family members) (Svenaeus, 2005). *“Illness may be understood as a particular way of being in the world – a way of being that exhibits certain typical characteristics. Such characteristics must be recognized if one is to grasp what illness means to patients”* (p. xvi) (Toombs, 1993). In her study of patients' and physicians' understanding of chronic illness, Toombs (1993) emphasized the importance of everyday life in a more practical sense. She claimed that ill persons do not see their illness primarily as a disease process but *“Rather one experiences it essentially in terms of its effect upon everyday life”* p.11., and further that *“the categories that they (patients) use to define illness are primarily concerned with everyday life and function”* (p.12) (Toombs, 1993). In this study everyday life comprises all the varied activities that individuals conduct and participate in (Borg, 2003). Illness and disease are understood in accordance with Elsaas (1993), cited in Delmar (2006).

*““Disease” is the professional’s view of the patient’s condition, and is often understood in physiological changes and expressed in biomedical terms. “Illness” is the layperson’s experiences of his condition. And these are often very concrete experiences connected to how illness intervenes in individual’s life, with all that this entails in terms of anxiety, pain, doubt and hope”* (p. 237).

## 5.0 Methodology and method

The philosophy underpinning the study is presented in Chapter 4.0. A phenomenological hermeneutic approach in research seeks to understand a phenomenon in the way it appears, or stands out, within the structures of meaning in the lifeworld (Gadamer, 1989). This approach is well suited for obtaining rich descriptions from participants in order to provide access to the meanings people attribute to their experiences and the social worlds (Olsen, 2003), and to enable researchers to gain access to issues overlooked by other methods (Grimen and Ingstad, 2006). However, the transition from philosophy and perspective to method in a particular research project is not straightforward. According to Ricoeur (1976) phenomenology and hermeneutics presuppose each other, and observation and description are not enough if one wants to be faithful to the studied phenomenon. Further, van Manen (1997) states that phenomenology should not only explain what something is, but rather explore possible ways to understand a phenomenon, through language. The danger that methods in phenomenology will function reductively and not open up and give access to the phenomenon in all its variation and multiplicity is asserted by Bengtsson (2006).

Studies conducted within a phenomenological hermeneutic framework show some variation, especially regarding methods for analysis. In the present study, the analysis is inspired by Ricoeur's philosophy of interpretation, emphasizing the analysis of texts as a movement between understanding and explanation, a hermeneutic arch to bring forth a broader comprehensive understanding (Gonzalez, 2006; Lindseth and Norberg, 2004), and Gadamer's philosophy which emphasizes understanding and interpretation through a dialogue with the text (Fleming et al., 2003; Gadamer, 1989).

## 5.1 The study

An overview of the studies and papers comprising this thesis is shown in Table 1.

Table 1. Overview of Studies 1-3 and Papers 1-3

| Study | Participants                                                                                                                              | Data collection        | Data analysis                         | Focus of the paper                                                                                           |
|-------|-------------------------------------------------------------------------------------------------------------------------------------------|------------------------|---------------------------------------|--------------------------------------------------------------------------------------------------------------|
| 1     | Men with localized or local advanced prostate cancer (10), endocrine therapy (7) active surveillance (3)                                  | Qualitative interviews | Phenomenological hermeneutic approach | The existential dimension of living with prostate cancer (when not receiving potentially curative treatment) |
| 2     | Men with localized or local advanced prostate cancer treated with endocrine therapy (10), seven men from Study 1 and three additional men | Qualitative interviews | Phenomenological hermeneutic approach | The experience of bodily alterations through the course of the illness when treated with endocrine therapy   |
| 3     | Spouses of men with prostate cancer treated with surgery or radiation therapy (9)                                                         | Qualitative interviews | Phenomenological hermeneutic approach | The experiences of spouses of men with prostate cancer                                                       |

### 5.1.1 Participants and recruitment

The study enrolled 13 men with prostate cancer (Papers 1 and 2) and 9 spouses of men with prostate cancer (Paper 3). The sample size was decided on the basis of the aim of the study and the method.

Studies 1 and 2 included men with localized or local advanced prostate cancer when potentially curative treatment such as surgery or radiotherapy was not an option at time of diagnosis. Study 2 included 7 men receiving endocrine therapy from Study 1 and 3 additional men receiving endocrine therapy. As further requirements patients had to be diagnosed within the previous 3 years in Study 1 and 4 years in Study 2, and be able to speak and understand Norwegian.

Table 2. Descriptions of participants, Studies 1 and 2.

|                   | Age (y)            | Treatment (n)                                | Working status (n)                    | Civil status                                 |
|-------------------|--------------------|----------------------------------------------|---------------------------------------|----------------------------------------------|
| Study 1<br>n = 10 | 58-83<br>Mean 71   | Endocrine therapy 7<br>Active surveillance 3 | Retired 8<br>Working 2                | Married/female friend 10                     |
| Study 2<br>n = 10 | 56-83<br>Mean 68.6 | Endocrine therapy 10                         | Retired 8<br>Working full/part time 2 | Married/female friend 9<br>Divorced/single 1 |

Study 3 comprised spouses of men with prostate cancer, not married to the men in studies 1 and 2. As a requirement for inclusion spouses/partners had to a) be married or in a steady relationship with a man diagnosed with prostate cancer within the previous four years and treated with surgery, radiation therapy or endocrine therapy, and b) be able to speak and understand Norwegian. A total of 78 spouses were invited, only spouses of men receiving potentially curative treatments, i.e. radical prostatectomy and radiation therapy, responded to the invitation.

Table 3. Description of participants, Study 3.

|                  | Age (y)            | Time of interview after diagnosis (mo) | Working status of spouses (n)                        | Duration of marriage (y) |
|------------------|--------------------|----------------------------------------|------------------------------------------------------|--------------------------|
| Study 3<br>n = 9 | 52-68<br>Mean = 59 | 2-48<br>2-4 4<br>24-36 4<br>48 1       | Working full/part time 5<br>Retired 3<br>Housewife 1 | 23-48 8<br>Under 5 1     |

In Studies 1 and 2 men with prostate cancer were obtained from the register of the outpatient service in the Departments of Endocrinology and Urology at the University Hospital of North Norway (UNN). Spouses in Study 3 were recruited through their husbands (see ethical considerations) from the outpatient services in the Departments of Endocrinology and Urology and from seminars organized by the Learning and Coping Centre at the University Hospital of North Norway. Due to problems with recruitment of spouses, information about the study was provided at a meeting for men with prostate cancer arranged by the local branch of PROFO (a nationwide organization for men with prostate cancer in Norway).



Nurses at the outpatient services and at the Learning and Coping Centre distributed an envelope to men who met the eligibility criteria, containing an information letter that broadly explained the aim and the methods of the study and the level of commitment required to participate. Men attending the PROFO meeting were asked to hand over the envelope to their spouses/partners, and those spouses/partners who agreed to participate were asked to return a reply letter to the first author.

### **5.1.2 Data collection**

Data were collected through in-depth interviews (Kvale, 1997) based on an interview guide designed with three main themes. Each interview started with an open introductory question to explore the men's and spouses' experiences of prostate cancer in everyday life. Follow-up questions were asked regarding their experiences (and symptoms) at time of diagnosis, treatment and side effects, follow-up by health care professionals, and the impact of the illness and treatment on everyday life and their relationship (Papers 1, 2 and 3). For Study 3 follow-up questions also included spouses' ways of supporting their husbands, their own need for support and if relevant their experiences of encounters with the health care services. The first author conducted all the interviews and repeated the aim of the study before starting them.

A phenomenological hermeneutic approach implies obtaining rich narratives that bring out the phenomenon explored in its full breadth, with as many nuances as possible. Thus short anecdotes and details are important for the whole picture of the lived experiences (Lindseth and Norberg, 2004). Some participants narrated their experiences in a way that covered the themes in the interview guide and the guide was used as a control. Others wanted to be led through the interview by definite questions, and when not interrupted many told important and detailed stories about their experiences (Thagaard, 2002).

The interviews concluded when the participants felt they had narrated their stories, and all themes in the interview guide were covered (Norlyk and Harder, 2010; Thagaard, 2002). As the interviews were about sensitive issues (Liamputtong, 2007), each interview was rounded

off by asking the informants about what they felt about participating and about the themes discussed. This way of closing the interview situation allowed the participants to reflect on the interview situation, and possible problems emerging during the interviews could be expressed. None of the participants felt the interview to be too distressing despite much thoughtfulness and many tears shed by some spouses. All participants expressed gratitude for the possibility to talk about their experiences, and some emphasized being able to help others was an important reason for participating in the study.

The interviews were carried out respectively at the participant's home (n =17; 9 men and 8 spouses), at the participant's workplace (n= 2; 2 men), and at the hospital (n = 3; 2 men and 1 spouse). Each interview was tape-recorded and transcribed verbatim within 2 weeks after it had taken place. The 10 first interviews were transcribed by the first author. Due to illness of the first author the last 12 interviews were transcribed by a secretary from the hospital (with obligation to maintain secrecy). The written transcriptions were validated by the first author by comparing with the interview tapes.

### **5.1.3 Analysis and interpretation**

The method of interpretation used in Paper 1 has been developed and described by Lindseth and Norberg (2004) and inspired by Ricoeur's philosophy (Ricoeur, 1976). Each interview was seen as frozen dialogue (text) and as a subject for interpretation. Ricoeur emphasizes that in understanding a text the text is set free from the real situation and the author is not in the forefront in the analysis. The method of analysing consisted of 3 phases: naive reading, structural analysis, and comprehensive understanding. This process is not a strict stepwise procedure, but requires movement back and forth between the phases in a dialectic process, moving from understanding to explanation and from explanation to comprehension (Persson and Hallberg, 2004; Ricoeur, 1976).

Ricoeur's interpretation theory implies a "hermeneutic arch" where the analysis starts with an immediate understanding. This first naïve reading provides an initial grasp or surface interpretation of the text as a whole, and what it says about the informant's experiences. "*In the beginning, understanding is a guess*" (p.74) (Ricoeur, 1976). In the first step one is supposed to set previous understanding aside in order to be open to the phenomenon under

investigation. Because it is not possible to fully set earlier knowledge aside, Ricoeur also includes presuppositions as a perspective in this method of analysing and understanding. The structural analysis is an explanation of what the text expresses or refers to. Comprehensive understanding comprises understanding and explanation and is enlarged with literature (theories and previous studies) to bring forth a new understanding. The overall goal of interpretation for Ricoeur (1976) is self-knowledge, and in hermeneutic research to gain knowledge that brings changes or new actions. This procedure is presented in Paper 1.

The analysis in Papers 2 and 3 was inspired by Gadamer's philosophy of understanding. (Gadamer, 1989) (Chapter 4.1). Although Gadamer (1989) did not see his philosophy as a method, Fleming et al. (2003) have developed a stepwise method for research based on his philosophy (Gadamer, 1989), which has been used in various studies (Sutherland N., 2009). Gadamer (1989) sees a text as one phase of the accomplishment of an event of understanding. Interpretation of a text is a matter of asking questions to the text while remaining open for the text to disclose its meaning. Our approach to the text in the analysis was through questions experienced as not answered by the text, wholly or partly. This approach may be deliberate or unconscious and may lead to new questions and answers in a hermeneutic circle (Gadamer, 2003). This method is presented in Papers 2 and 3.

## ***5.2 Ethical considerations***

The Regional Committee for Research Ethics (P REK NORD 130/2006 /200605404-5/MRO/400) and the Norwegian Social Science Data Services (15880) approved the project. The study was conducted according to the Declaration of Helsinki (World Medical Association, 2008).

Ethical reflections are of great importance in all parts of the research process (Kvale, 1997). As the topic of the study is sensitive (Frank, 1995), ethical reflections were required about the necessity of carrying out the project. The implementation of the study was justified in the belief that the study could contribute new insight of importance to the existing knowledge base about men's and spouses' experiences of prostate cancer.

Illness is considered to be a particularly vulnerable experience that requires a special awareness in the research process, especially in the interview situation (Liamputtong, 2007). In analysing the data a particular effort was made not to “over-interpret” the results. There was particular awareness of ensuring the anonymity of the participants in the presentation of results and especially in the quotations.

Spouses were invited to participate through their husbands/partners in order to avoid disclosure of the men’s illness and experiences – information about a third person - without their knowledge.

## 6.0 Results

Table 4. Overview of the main themes from Studies 1, 2 and 3

|   | Study                                                                                                                                                                  | Themes                                                                                                                                                                          |
|---|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | Men's experiences of getting prostate cancer, and living with localised or local advanced prostate cancer treated with endocrine therapy or under active surveillance. | Getting cancer<br>Being hit in "the strength"<br>Being on one's own<br>Not being worthy of treatment<br>A "silent" health care service<br>The best support                      |
| 2 | The experiences of bodily alterations through the illness trajectory of men with prostate cancer treated with endocrine therapy.                                       | Something is "wrong"<br>When the body becomes troublesome<br>To be well or to be ill<br>Dealing with the alterations<br>To talk about cancer and the intimate details           |
| 3 | Spouses' experiences of living with men with prostate cancer.                                                                                                          | Strong and optimistic vs. vulnerable and overstrained<br>Maintaining partners' sense of manhood<br>Being on the sideline<br>Need for relationships outside the immediate family |

### 6.1 Main results in Papers 1, 2 and 3

The overall aim of the study was to illuminate men's and spouses' experiences of prostate cancer in everyday life. The studies are presented chronologically as they were carried out and published.

#### Paper 1

Being diagnosed with cancer was a shocking and overwhelming experience for the men. The position of "cancers" in society, and personal experiences from family and friends suffering from cancer at the end of life were of great importance for the men's own experience of having cancer.

Worries about treatment and the future caused anxiety and uncertainty, especially the fact that the tumour was not removed, and the physicians were unable to predict exactly the progression of the cancer for them as individuals. Some scepticism or wondering were expressed by older men regarding the reason for them not receiving potentially curative treatment, i.e. life expectancy less than 10 years and age and treatment costs.

New aspects of the illness revealed themselves gradually and were comprehended in relation to the first shock and the cancer “label”. Troublesome side effects from treatment such as urine leakage, erectile dysfunction, hot flashes and fatigue were experienced as a threat to the patients’ functioning in daily life and their male identity. Apart from information about potency medication, patients found that their doctors showed little interest in problems related to side effects.

Some men felt left alone when coming home. Lack of knowledge about prostate cancer in general, and especially what to expect regarding side effects and progression of the illness caused uncertainty about when to contact health care providers. Some men doubted the general practitioners’ knowledge of prostate cancer. A good relationship with their general practitioner prior to prostate cancer was of importance for daily life after the prostate cancer diagnosis. Doctors showing interest in the men’s experiences and worries about the future were appreciated.

Spouses provided the best support in everyday life, but the men were aware of the possibility of putting too much strain on their spouses. Encounters with peers were of importance for informal discussion and information about prostate cancer.

Living with prostate cancer without receiving potentially curative treatment meant living with uncertainty about the future. Although the men tried and wanted to live as normally as possible, each new bodily alteration (erectile dysfunction, pain) caused worries and new uncertainty emerged. Overall their experience with prostate cancer can be described as living in a state of readiness for new things to happen regarding the illness.

## Paper 2

The men became aware of bodily alterations through a vague feeling of something “wrong” regarding the urination function. Actually having cancer without other significant symptoms was a shocking and frightening experience. The men also lacked knowledge of prostate cancer in general and especially of endocrine therapy.

The illness became evident through physical side effects of treatment, where erectile dysfunction and impotence were considered to be the worst. Erectile dysfunction was experienced as a threat to masculine values, but it also brought forth reflections on what it meant to be a man, and some felt having sexual problems was an acceptable price to pay for a prolonged life. Other physical side effects had an impact on the ability to participate in leisure activities, e.g. fishing and skiing.

Although the men adapted to the new situation after some time, a new awareness of physical signs from the body had occurred. Incomprehensible pain caused fear of progression of the cancer and influenced the men's experiences of their everyday life - "feeling well" or "feeling ill". Being able to continue with daily activities was related to feeling well. There were individual differences in the ways of dealing with the illness, and the need of support varied through the course of the illness. Initially information about biomedical issues provided some control in a new and chaotic situation, but later on bodily alterations from treatment caused worries. Some men reflected on gender, whether men had more difficulties than women in talking about feelings. When they were open about their experiences, men preferred talking with spouses and health care providers or others with a good knowledge of cancer. A sense of humour, used with sensitivity, and a positive attitude were regarded as important in successfully dealing with a taboo illness. Humour and a positive attitude were also associated with sparing their spouses in what was a difficult situation for them too and easing difficult encounters with e.g. health care providers.

Their embodied experience of prostate cancer treated with endocrine therapy can be understood as a journey from a having a "hidden" body previous to diagnosis to the body becoming "visible" through treatment. The journey included struggling to live with the different bodily alterations in daily life. Thus their experiences of bodily alterations may be understood as a challenge to their identity on an existential level.

### Paper 3

The spouses were strongly involved in their husbands' illness process, and thus the illness had a significant impact on the spouses' everyday lives in both practical and emotional terms. All spouses described a "we-shared" journey, especially in the first phase of the illness trajectory. Despite the strong focus on "we", the results showed that their husbands' needs were in the foreground, and the

spouses had to suppress their own anxiety in order to provide care and be in control of their feelings in a difficult and threatening situation for them as well.

Erectile dysfunction in men had a great impact on spouses' sexual life and the marital relationship. Some spouses experienced difficulty with their husband's lack of sexual desire and being unable to perform intercourse, while other spouses had accepted a life without intercourse. The spouses described their responsibility in maintaining the men's experience of dignity and worth regarding sexual issues. Thus they avoided exposing their husband's problems in encounters with others. Some spouses described themselves as very active in their support.

Although the spouses played an active role in providing care, they placed themselves on the sideline in focusing on their husband's needs. At the same time they were relegated to the sideline by health care providers, family and friends as the attention was on their husbands. After a while many spouses sought someone other than close family and friends to talk to about their own anxiety and fear. Professional health care providers with expertise in prostate cancer and peers were preferred. The study offer insight into how spouses have to balance between managing their own emotional, bodily and relational needs and meeting their husbands' needs for support and care through the course of the illness, and the results indicate a change in focus over time from focusing on the husbands' needs to a broader perspective that also includes the spouses' own needs.



## **7.0 Discussion**

The present study was designed to illuminate men's and spouses' experiences of prostate cancer in everyday life. A phenomenological hermeneutic approach was chosen to obtain a first person perspective and gain insight into the many-faceted everyday experiences of prostate cancer.

In Paper 1 we made use of a wave metaphor in illuminating men's experiences of living with prostate cancer when potential curative treatments were no option. In our opinion the wave metaphor is applicable for the thesis as a whole. The cancer diagnosis can be described as a large wave rolling in, hitting men and spouses as a shock, leaving them feeling uncertainty about the future. Initially, getting cancer was experienced as an existential threat; a threat to life itself – and to their being in the world. After the first shock, the water calmed down and gave time for reflection. Then new waves appeared and in different ways stirred up the water again, e.g. treatment side effects, problems with sexuality, a new awareness of the physical body, a feeling of being left alone, practical and physical obstacles to living “normally”, distress in the marital relationship, and encounters with friends and health care providers. These new experiences, and the manner of relating to them, must be understood in light of the individual and the first large frightening cancer wave.

The discussion is divided into three chapters: 7.1 “Losing security (and destination) in life”, 7.2 “Dealing with bodily sensations and alterations” and 7.3 “As a male cancer patient one needs humour, courage and a wife that constantly presses one forward”. Although the existential dimension of cancer is evident throughout the course of the illness, the discussion is presented sequentially, starting with the existential dimension of cancer as a life threatening illness, followed by the impact of prostate cancer on embodiment, while the last chapter discusses important aspects of dealing with the illness in everyday life and its impact on relationships. Some aspects of spouses' experiences are discussed separately in Chapter 7.3.1 in order to illuminate special challenges in their everyday lives.

### ***7.1 Losing security (and destination) in life***

In the first phase of the illness both men and spouses felt overwhelmed, feeling anxiety and uncertainty about the future. The men faced the possibility of losing their lives and spouses

described fear of being alone if their husband did not survive the cancer. Despite a 67 % five-year relative survival rate for cancer (all types) (Cancer Registry of Norway, 2011), the disease is still associated with death and suffering (Kelly and White, 2011). The results from our study support previous studies regarding the perception of “cancer” as causing uncertainty about the future (Dale et al., 2005; Grimsbø et al., 2011; Mehnert et al., 2010) with an impact on the patient’s unreflective way of being in the world. It was especially incomprehensible and frightening to have cancer in such an advanced stage with only minor urination problems. Life became more unpredictable and a new awareness towards bodily changes emerged. The results in this study showed that the cancer “label” cast a shadow over all activities and experiences (practical issues, embodiment, follow-up), and cancer was often referred to as something special which stood out from other illnesses. In the study by Mehnert et al. (2010) men younger than 65 reported a higher degree of perceived threat from prostate cancer. In our study men in all age groups expressed uncertainty for the future. However, with an increase in the incidence of prostate cancer in younger men (Cancer Registry of Norway, 2011), potentially more men will be living with cancer for many years.

Our being in the world is a central issue in Heidegger’s phenomenological philosophy (Heidegger, 1996). As human beings living in the world we are already and always attuned. It is through attunement we primarily discover and understand ourselves, the world and our fellow men. Attunement is not a conscious attribute of human beings, and we are not always aware of the attunement in our daily life. The concept is more the name of a being than a knowing (Heidegger, 1996; Svenaeus, 2000). In a phenomenological perspective we are always in a situation, and as human beings we are attuned by the world before we start to reflect on it (Bengtsson, 2006). The past and the future are connected in the present and how we are attuned constitutes our pivotal point for experiencing things in life. Experiences are therefore individual experiences in a historical time. Both men’s and spouses’ narratives revealed reflections about life and death. The men rarely expressed their thoughts in a definite way in the interviews, but rather in a subtle manner; by wondering how long the endocrine treatment would work and the meaning of different bodily alterations. Spouses expressed their fear of being alone and losing their husband.

Living against death is also a central theme in Heidegger’s philosophy. He asserts that human beings know and understand death as the most fundamental meaning-giving possibility in life

(Heidegger, 2007; Johnson, 2000). However, despite all of us being affected by death in different ways in society, the consciousness of our own death is blurred, or need not be present in everyday life (Heidegger, 1996). We are often more concerned with doing than being, and thus live inauthentically, as claimed by Heidegger. The awareness of one's own death entails the opportunity to choose to live in accordance with one's limited possibilities, to live authentically. In Heidegger's perspective living authentically is not a totally new way of living, or a better way of living, but an adjustment to living inauthentically (Heidegger, 1996; Jacobsen et al., 1998; Jacobsen, 2000).

The initial shock and the men's reflections on existential issues may be understood as a "tsunami wave" across the unreflective way of being in the world on an ontological level. With a potential threat of early death one would be inclined to believe that patients with cancer totally changed their way of living. However, in our study the men's everyday activities generally continued with some adjustments (discussed in 7.2.1 and 7.2.2), and the men also wanted to live as normally as possible.

In a study of the embodied impact of prostate cancer, Kelly (2009) showed that the existential threat of cancer resulted in men questioning their priorities in life, and focusing on the future with new insight and hopes (discussed in 7.3). In *The Wounded Storyteller*, Frank (1995) uses the expression "*loss of the destination and map*" (p.1) when describing the experience of serious illness and the need for thinking differently for those affected. In our study both men's and spouses' reflections on life and death in our opinion revealed a more authentic way of being in the world. Spouses described the importance of appreciating every single day and expressed gratitude for having their husbands alive. Some men reflected on physical side effects as something bearable if it was the price to be paid for a longer life. The main alterations revealed in the men's and spouses' stories were related to changes in attunement towards a more wistful and thoughtful mood.

Svenaesus (2000) describes illness as a break in the continuity in life and a loss of security, and Holm (1986) in Busch (2001) states that when one becomes incurably ill "*the understanding of whom you are and consequently, the fundamental principles of your life are destroyed or cannot be maintained*" (p. 3). Prostate cancer certainly caused a break in continuity in life for the men

and spouses in this study, and the possibility of death became more evident in their everyday life. As attunement in Heidegger's (Svenaesus, 2000) perspective implies understanding and discourse always working together, opening for a gradual change in the way of being in the world. This is a change that leads to new hopes and expectations, as described by Kelly (2009), or "a new map" using Frank's metaphor (Frank, 1995).

The anxiety level in men is shown to vary "*plausibly over the clinical timeline in response to stress and uncertainty*" (Dale et al., 2005). Life at home immediately after the cancer diagnosis seemed to be a particularly distressing period with much uncertainty. The men felt left alone without knowing when or how to contact the health care services regarding physical alterations. A feeling of being alone was also found in a study by Grimsbø et al. (2011) about cancer patients' experiences at home reported through E-mail communication with oncology nurses. The huge change the men had gone through in a short period of time may contribute to an understanding of the uncertainty and the feeling of being left alone after coming home. There seems to be a contrast between patients' expectation of follow-up when having cancer and the routines of the health care services, with some men expecting the services to play a more active role. Spouses described their husbands as more dependent on them after discharge, practically but also emotionally. Emphasizing the importance of a "we-shared journey" shows the way spouses took much responsibility in the rehabilitation process by e.g. encouraging their husbands to take part in their lives again.

## **7.2 Dealing with bodily sensations and alterations**

Studies of men's experiences of bodily alterations from prostate cancer have mainly focused on the impact of the physical side effects of treatment on masculinity, men's sexual health and sexual relationships (Messaoudi et al., 2011; Oliffe, 2006). Sexuality and masculinity with prostate cancer were also central issues in our study (discussed in 7.2.1), but other areas of importance regarding embodiment were revealed in addition. Men's descriptions of unrest and uncertainty at the time of diagnosis were significant. Another important issue was the relation between physical changes and identity on an existential level, especially appearing in men's reflections on feeling well or feeling ill (discussed in 7.2.2).

Symptoms of illness are reported by patients to be an experience of alien body sensations (Toombs, 1993). As human (bodily) beings we approach the world through sensing and according to Merleau-Ponty (2002) sensation and understanding are tightly interwoven. As our understanding of bodily sensation is based on previous experiences, not all bodily sensations are experienced as alien or unusual; one may have become accustomed to them (Toombs, 1993). Impairment in urination, and a general feeling of something being wrong, caused enough worries for the men in this study to visit the general practitioner. Through bodily sensations at time of diagnosis the men's bodies became "visible" (Kelly, 2009; Leder, 1990). However the men's lack of knowledge about prostate cancer and the function of the prostate gland complicated their situation considerably. By means of the concept of the "recessive body", Leder (1990) includes the inner body in the theory of embodiment. The visceral organs and digestion are used as examples of areas withdrawn from our consciousness and attention on a daily basis. When functioning well the prostate gland is hidden in the body, and only becomes "visible" through e.g. problems with urination or infections.

In a phenomenological perspective embodiment and language are central aspects in human interaction (Merleau-Ponty, 1994; Schutz, 2005). Antonovsky (1987) states that patients may tend to use a medical language in encounters with physicians. He warns about the danger of patients losing themselves and their lived body by taking a biomedical perspective on illness. By offering insight into processes in the body, biomedical explanations were of great importance in the first phase of the illness for men in this study. PSA results, X-rays and information about the stage of the illness, treatment options and prognosis provided help for the men in gaining some sort of control. However a biomedical explanation and language alone allow for the possibility of an alienation of the body through objectification (Merleau-Ponty, 1994). In a study of the diagnostic process, Tishelman and Sacks (1998) showed that the process of becoming a (cancer) patient involved a constant negotiation between different worlds and modes of explanation (medical and lay explanations). Tishelman and Sacks interpreted this negotiation as an effort to normalize the situation and avoid chaos. By focusing on medical explanations alone one may overlook patients' intuitive awareness that their symptoms and different bodily disturbances are a part of a larger picture and "*point to, or signify, a more complex entity of which they are simply one phase or facet*" (p. 35) (Toombs, 1993).

Most men in our study had no experience of serious illness themselves before getting prostate cancer, thus their previous encounters with health care providers were few. Overall their knowledge of prostate cancer was limited, and came from experiencing family members and other persons in their environment living with cancer, especially in a late stage of the illness. It has been shown that (Norwegian) men visit the health care services to a lesser degree than women (Lilleaas, 2006; Manii and Ammerman, 2008; Stortingsmelding 8, 2008). Additionally, statistics from Norway show that men over 45 years of age living in a relationship visit the primary health care services more often than men living alone (Stortingsmelding (Proposition to the Storting) 8, 2008). The results in this study provide no clear “evidence” that the spouses actually made the men contact the doctor in the first place. However, our data indicated that spouses played an important role in encouraging men to contact the general practitioner or health care services at time of diagnosis and after coming home. The active spouses attempted to get their husbands to be more involved in their illness by taking physical signs from the body seriously and contacting the health care service when feeling uncertain.

### **7.2.1 Being “hit in one’s strength”**

Problems associated with physical side effects from treatment were an important issue for men and spouses in this study. Most men described erectile dysfunction, loss of libido and impotency to be the worst treatment side effects. The men were especially concerned about the impact of erectile dysfunction on their wives’ quality of life, and many expressed sadness about the situation they felt they had inflicted upon their wives. Masculinity and the sexual relationship were also central in the spouses’ narratives. This finding is in accordance with previous studies showing that physical side effects from treatment have a significant impact on men’s sexual health (Messaoudi et al., 2011; Oliffe, 2006), and quality of life for patients and their partners (Wassersug, 2009). Independently of age differences, sexuality was an issue for all men in our study, but was most striking in the narratives of men around 60 years of age and those receiving endocrine therapy.

In this study endocrine therapy caused side effects associated with a weaker body; fatigue, tiredness, hot flashes, limpness and decreased muscle strength (Murphy, 1990; Oliffe, 2006). These side effects are associated with feminisation (Wassersug, 2009), and this includes the men in this study. However most references to masculinity were about erectile dysfunction,

and metaphors such as “dried-up manhood”, “not being a first lover any more” and feeling like a eunuch were used. Additionally spouses emphasized their efforts to maintain their husband’s sense of manhood after surgery or radiation therapy. Spouses also described their relief when managing to perform sexual intercourse, which indicated a close connection between masculinity and sexual intercourse for most participants in this study.

Erectile dysfunction, inability to accomplish intercourse, and lack of lust are found to undermine the foundations and legitimacy of masculinity (Donovan and Flynn, 2007; Messaoudi et al., 2011; Oliffe, 2006). Traditionally masculinity has been referred to as *the* masculinity (Gray et al., 2002). This one-dimensional understanding of masculinity is criticized by Connell (1987), who argued for the possibility of different masculinities. Thus, what previously was described as *the* masculinity is now commonly referred to as hegemonic masculinity. Hegemonic masculinity is a central concept in a social-constructionist gendered framework (Oliffe, 2006; Watson, 2000) and refers to those masculine ideals most commonly subscribed to in a society (Oliffe, 2006). Masculinity is thus a cluster of ideas that changes over time (history) and place (cultures) rather than a static entity (Tjelle, 2011).

As human beings we are placed in the world in a certain time and place, culture and tradition (Gadamer, 1989; Schutz, 2005) and we are attuned by the world (Heidegger, 1996). The men’s and spouses’ experiences and ways of dealing with erectile dysfunction must be understood in relation to a Norwegian or Western context. In this context “real masculinity” currently is associated with the physical body and the way men behave. The body is a way to demonstrate masculinity, with the ideal being a muscular, athletic, strong physique (Oliffe, 2006; Watson, 2000). However, this study also revealed a more reflective attitude among men regarding what it meant to be a man and the close relationship between masculinity and sexual performance. Oliffe et al. (2006) found that men reformulated many ideals about hegemonic masculinity in response to functional body changes, and they argued for a plurality of hegemonic masculinities, e.g. differences between young and older men. This may indicate that the male identity is mobile and that the erectile dysfunction contributed to changes in the understanding of masculinity. According to Heidegger (1996) time is not understood as separated into past, present and future. Time or temporality is rather “*the horizon from which meaning of an entity is understandable in its meaning*” (p. 138) (Johnson, 2000), not as a particular point on a time line. As humans we are always becoming and we are constituted by the possibilities of what we could become, here what the male identity may hold for the men.

Even though prostate cancer is a common illness and sexual issues are often discussed in newspapers and magazines, this form of cancer and the side effects from its treatment still tend to be a taboo subject in the general public. As shown in this study cancer causes silence, and must be hushed up; and most men were reluctant to talk about the illness with others than the close family. Compared with articles about breast cancer in women's magazines, prostate cancer is a rare topic in men's magazines in Norway. Some men used the lack of public information as a reason for being open about their illness history, thus encouraging men to have their prostate checked in order to prevent cancer. In *Stigma*, Goffman (1972) refers to stigma as an unwanted quality or feature that differs from what is expected in society and thus socially constructed. Goffman argued that society requires a considerable level of body control from people, and e.g. erectile dysfunction and impairment in urination could therefore be understood as stigmatizing and a reason for men to keep quiet about the illness. Goffman also claimed that stigmatization is embarrassing not only for the person stigmatized but for those around. The results in this study showed that spouses were concerned about their husband's dignity as men and tried to spare them by avoiding talking about their intimate life in encounters with others. Spouses also used humour in an attempt to ease the burden for the men (7.3).

Many men in the current study found it difficult to talk with health care providers about sexual problems in the relationship. Maybe the one-sided focus from physicians on remedies and medication for erections indicates that sexuality is a difficult issue for health care providers as well. It may therefore be easier to focus on "repairing" the impotence than discussing challenges regarding the impact of the side effects on life and the marital relationship for the men. According to Watzlawick et al. (1968) all actions are a kind of communication, and he asserts that "one cannot not communicate". By avoiding giving the men the opportunity to talk about their sexual problems health care providers indicate that they find these problems to be of minor importance for the men's everyday lives. It may also be that physicians supposed that men primarily wanted help with getting erection. In an article about mastering emasculation, (Wassersug, 2009) points to the contradictions often found in information brochures about prostate cancer. Initially it is stated that men may feel "less of a man" when treated with hormones but later it is emphasized that there is little reason for them to feel that way. Wassersug (2010) therefore argues for more openness in society about



castration, erectile dysfunction and impotence to make it easier for men to be open about the subject and avoid ambiguous communication.

The present study showed that impairment in urination with urine leakage was another sensitive area for both men and spouses. Wearing nappies is associated with children or menstruating women, and may therefore contribute to reducing the feeling of masculinity. Although it is possible to hide urination problem in encounters with others, this is not the case in intimate marital relationships (Nilsson A.E. et al., 2011). The impact of incontinence in daily life has been less studied than sexual issues. Newer surgical techniques have reduced the extent of the problem, but it is important not to minimize problems related to incontinence because of the significance for those affected.

Despite men in general being “the norm” in research into medical conditions and treatment (Ministry of Health and Care Services, 1999), men’s experiences of illness, embodiment and health have not received much attention in Norway (Lilleaas, 2006; Stortingsmelding 8 (Proposition to the Storting), 2008). When the illness is not life threatening or acute, men’s suffering is less exposed and according to Simonsen (2006) men withdraw and “suffer in silence”. Emotional self-control associated with the male gendered role (“men don’t cry”) is suggested as one reason for this reluctance (Broom, 2005; Chapple and Ziebland, 2002; Lilleaas, 2006). The results from our study lend some support to this understanding. Another reason for reluctance may be the desire not to distress spouses or others in their environment (Hedestig, 2006). Our findings also suggest that given the right circumstances many men talk with openness about their situation.

### **7.2.2 “Well or ill” - bodily sensations and limitations**

The study revealed a new awareness of the physical body appearing in the men after living with prostate cancer over time. In a study of bodily problems in patients with advanced prostate cancer, Lindquist et al. (2006) found that different bodily issues had different meanings for the patients. Pain (a new type of pain) was experienced as loss of existential control whereas fatigue was experienced as temporarily hindering patients in living normal lives. In our study pain that may have been present before was now associated with cancer and the spread of the illness. Minor physical alterations recreated the uncertainty and anxiety

from the first period of the illness causing “dark thoughts”. Merleau-Ponty (2002) stated that serious illness and injury is a complete form of existence (Råheim, 2006). Our being in the world springs out from the sensing body, and our understanding of phenomena in the world is perceived from a certain perspective (Merleau-Ponty, 2002). Thus having the experience of being diagnosed with cancer resulted in an association between bodily sensations and (recurrence of) cancer. The unpredictable dimensions associated with cancer (Grimsbø et al., 2011; Hedestig et al., 2003; Hedestig et al., 2005; Wallace, 2003) also contributed to fear of recurrence or dissemination of the illness.

Fatigue that hinders men in living normal lives with prostate cancer may be an area overlooked (Lindqvist et al., 2006). The men showed a great ability to adjust to the situation regarding practical and leisure activities e.g. picking blueberries instead of long skiing trips when the body felt weak. From our results it is important to recognize that in addition to hindering men in daily activities fatigue may also influence the experience of being a man on an existential level. Fatigue may be a threat to the male role of a man of action, strong and sexually active and therefore a threat to their identity as a man (Hedestig et al., 2005; Hughes, 2000; Watson, 2000). With reference to Heidegger, Svenaeus (2000) emphasizes the close relationship between concrete actions, the immediateness in situations and experiences, and the existential dimensions of the illness experience. Embodied consciousness is primarily related to “I can” (Toombs, 1993). For the men in our study the limitations caused by the illness became evident in particular situations that had not previously been the object of reflection.

Our results confirm the findings from Lindquist et al. (2006) regarding patients being reluctant to define themselves as ill. They used expressions like “not very ill” and “feeling well”. Being ill often means focusing on possible (new) limitations in daily life. The men in this study wished to live as before, or as normally as possible, despite significant physical side effects. Being physically active with some adjustments was important for their experience of well-being. This is in accordance with findings from a study of patients with lung cancer (Berterø et al., 2008). Heidegger emphasizes the importance of understanding oneself through other ways of doing things and other ways of relating to and understanding the body (Svenaeus, 2000). In an existential perspective being active and adjusting activities to the actual limitations of prostate cancer may be understood as presenting their “changed bodies”

to the world (Kelly, 2009), with new access points to the world and the basis upon which their existence was experienced.

Our results underline the findings from Lindquist et al. (2006) about the cyclic movement between experiencing wellness and experiencing illness. When the illness (side effects from treatment or dark thoughts) was in the background the men felt well and vice versa when the illness was in the foreground they felt ill. However, the “short way” between feeling well or ill may indicate another way of being in the world (Toombs, 1993). There is thus a place between the biomedical concepts of ill or well that could be interpreted as living with afflictions (Grøholdt, 2010) or as concluded in Paper 1 as being in “a state of readiness” for something to happen.

### ***7.3 “ ... as a male cancer patient one needs humour, courage and a wife that constantly presses one forward”***

Illness cannot be repaired, it has to be lived (Heidegger, 1996; Svenaeus, 2000). The heading of this chapter, uttered by one of the men, covers some important issues revealed in men’s (and spouses’) narratives about dealing with prostate cancer in everyday life. However it is important to keep in mind that illness is experienced and dealt with individually.

The present study revealed that humour was present in intimate situations between men and spouses, among peers and in encounters with health care providers that had lasted for a while. In the context of cancer humour can be said to have different purposes. According to George and Fleming (2004) “*humour is a strategy to dilute embarrassment or divert attention away from sensitive issues*”. Humour may therefore also be a way to escape difficult encounters or conflicts (O’Bannon, 2008) and Oliffe et al. (2009) warn about using humour as a defence against anxiety and a way to e.g. avoid important issues.

The spouse’s use of humour when talking about nappies was interpreted as a way to lighten the situation as shown in other studies (Nanton et al., 2009). It may also be understood as a way to say “I see you” and “I understand that this may be an embarrassing situation for you”. In their study of humour in the context of cancer, Chapple and Ziebland (2004) found that nearly all humour was applied to the situation rather than “pure” humour (telling jokes). Our study indicates that humour functioned at its best and thus helped to reduce anxiety, when the

men were the initiators and in control over the circumstances. Our findings confirm the results from a study of communication between male prostate cancer patients and male physicians by Oliffe and Thorne (2007) regarding the importance of a trusting relationship between patients and health care providers on the subject of humour.

Both men and spouses underlined the value of having a positive attitude and trying to remain positive, especially in the relation between them as a couple. Staying positive enabled spouses to support their husbands and not be overwhelmed by their own feelings. On the other hand the men tried to have a positive attitude to make their spouses endure the situation with them being ill. We found that both men and spouses in different ways balanced or oscillated between e.g. anxiety and hope for the future, feeling left alone and feeling secure and trusting and finding support in spouses and from health care providers (Busch, 2001; Delmar et al., 2005).

Prostate cancer means living with practical and existential challenges; it is a demanding situation that requires courage, or life courage. Anxiety, hope, trust and life courage are all central life phenomena in the Danish life philosophy tradition (Løgstrup, 1988; Løgstrup, 1999; Pahuus, 1995), utilized in nursing by e.g. Delmar (2005, 2006). The Danish life philosophy is about life as experienced by human beings and about how persons (best) live their lives (Pahuus, 1995). Life phenomena are “*to be understood as a generalized label for the various ethical and existential phenomena which are given with life*” (p. 238) (Delmar et al., 2005). Løgstrup (1998, 1999) focused on ethical life phenomena (or expressions of life) in his philosophy, such as trust, empathy/sympathy, vulnerability and shame. These ethical life phenomena are primarily pre- cultural according to Løgstrup, yet all life phenomena are individually expressed in a social context and therefore also influenced by social contexts. Pahuus (1995) supplemented Løgstrup’s life philosophy by focusing on existential life phenomena of importance for how the individual life can be shaped. Pahuus (1995) distinguished between life happiness as an attitude and openness to what is given, and spirit of life/ life courage as vitality and an active drive to “carry on life”. In this perspective it is the union of life happiness and life courage which produces the whole person – a meaningful life (Delmar, 2006; Pahuus, 1995).

Existential life phenomena can be divided into *life-limiting* life phenomena such as loneliness, being alone, “homelessness”, despair, anxiety etc. and *life-facilitating* life phenomena such as

life courage, life happiness, hope, longing etc. (Delmar, 2006; Pahuus, 1995). However, this categorisation between different life phenomena is not entirely strict and depends on circumstances and the actual situation where the life phenomena are expressed (Delmar, 2006).

Both life-limiting and life-facilitating phenomena were revealed in men's (and spouses') narratives. Men and spouses described life-limiting life phenomena such as vulnerability, a feeling of being left alone and a loss of previous sexual life. Men expressed suspicion related to possible age discrimination, lack of trust in health care services and their body. The study also showed life-facilitating life phenomena of great importance in daily life, e.g. encounters with health care providers encouraging hope and the longing for normality, adjustments, being together with family, ability to stay active, trust in health care providers. According to Løgstrup (1999) life phenomena become "visible" in times of life crisis and illness, and often it is the most basic life phenomena we notice last. Løgstrup uses trust as an example and claims that when having trust in each other we are not aware of the phenomenon. Not until distrust occurs do we become aware of trust.

According to Pahuus (1995) life courage and life happiness are basic expressions of life, and hope and life courage are central aspects in the process of adapting to a new situation and finding harmony in life. Life courage is also stronger or more basic than anxiety. In a study of the experience of living with cancer, Jacobsen et al. (1998) found that for half of the patients the illness had not had any influence on their life courage, whereas for the other half there had been an increase in life courage.

In the process of finding ways to live with prostate cancer it may be said that life courage is rooted in the individual but is expressed in social interaction with others (Pahuus, 1995). As shown in our study relations and positive interaction with health care providers, spouses and peers played an important role for men's experience of encouragement and hope for the future. In the present study an understanding attitude from a doctor in a consultation or a telephone call from a nurse contributed to a trusting relationship between men and health care providers. By contrast, encounters that limited communication caused uncertainty and frustration. As asserted by both Merleau-Ponty (1994) and Schutz (2005), human beings are accessible for each other through interaction, embodiment and language. We found that the choice of words or themes was important for experiencing an encounter as life facilitating or

life limiting; some words were experienced as aggressive or sensitive, or there could be excessive talk about e.g. PSA. The philosopher Schmidt (1997) focuses on what he calls a crack in communication between the biomedical (professional) and the ordinary (existential) horizon. The professional emphasizes certainty, what is reliable knowledge, while the everyday attitude is related to security, i.e. what knowledge is important in maintaining a feeling of security. Because it varies between individuals what information each person is able to live with and still feel secure, the capacity to individualize information is one of the most challenging tasks for health care providers in encounters with cancer patients. Furthermore, as shown in our study, the need for information changes through the illness trajectory.

Men are said to have difficulty in talking about their feelings (Manii and Ammerman, 2008), and many cancer patients prefer not to talk about difficult emotions (Kvåle, 2007). Gray et al. (2000 b) found that men avoided discussing their illness unless it was absolutely necessary. The results from our study indicate that men do talk about their experiences, but maybe not their inner feelings. If they experienced the environment to be understanding, based on professional knowledge or peer experiences, the encounters were felt to be what we interpret as life facilitating and encouraging. Frank (1995) emphasizes the importance of telling stories about one's own cancer. In his opinion telling stories is as a part of the healing process and contributes to giving a voice to cancer as a lived experience rather than a disease. In Norway the Norwegian Cancer Society has established two rehabilitation centre (Vardesenter), where peers can meet and share experiences. However, overall our results showed that the men limited the people they talked to, and many confided only in their spouses. The results from our study are in line with results from other studies about spouses' important role in supporting their husbands with (prostate) cancer (Helgason et al., 2001; Northouse et al., 2007).

### **7.3.1 Spouses' experiences**

With reference to Heidegger (1996), spouses are thrown into a new life situation when their husband is diagnosed with cancer and their experience of distress and anxiety at the time of diagnosis supports the findings from previous studies (Couper et al., 2006 a,b). The emphasis on a "we-shared" journey in the current study is also found in other studies (Gray et al., 2000 a;

Nanton et al., 2010) as well as the underlining that supporting their husbands practically and emotionally is what partners normally do as a part of a couple (Nanton et al., 2009).

The strong we-feeling might be understood as a way to assure each other about their capacity to manage to endure the situation together (Gray et al., 2000 a). In a life philosophical perspective (Pahuus, 1995) the close relation between men and their wives might be seen as a life facilitating phenomenon giving hope for the future and preventing the men and spouses from feeling alone. However, the relation between men and their wives is complex. As shown in psychological studies, partners` reactions influence each other and on the quality of life for both parties (Segrin et al., 2012). Berg et al. (2011) found that when spouses experienced a negative effect of the cancer, so did their husbands. According to Nanton et al. (2010) a strong involvement in their husbands` way of dealing with the illness may contribute to more distress for the spouses, as exemplified by the active spouses in the current study. Additionally, the spouses` careful approach to sexual issues has two dimensions. It may prevent the spouses from talking about their own feelings, and they may thus experience distress connected to things being unsaid. At the same time in an ethical (life phenomenon) perspective a prudent approach may imply preventing spouses from compromising their husbands - taking care of their husbands` vulnerability - and thus maintain trust or confidence in the relationship (Løgstrup, 1999).

There is a growing body of studies about spouses` and couple`s experiences of prostate cancer and their ways of dealing with the new situation, and a “we-shared” outlook in partners is associated with optimal adaptation for couples (Fergus, 2011). The results in the current study support these findings in the sense that some spouses felt the illness brought them closer together as a couple. However the study also indicated fatigue and a change in focus for spouses who had lived in the situation for many years, from the husbands` needs and the emphasis on a “we-shared journey” to a broader perspective that also included their own needs. We found a change in attunement in the spouses` feelings and way of being in the world; from fear, anxiety and uncertainty being the dominating feelings in the first phase to a more wistful mood later on. Attunement is something deeper than feelings, which can be transitory, but both feelings and attunement are about our being in the world on an existential level (Fløistad, 1993).

Being in a situation where men's prostate cancer defined everyday life was distressing, and especially being under strong pressure for years to have to suppress one's own feelings brought forth a quiet thoughtfulness and for some exhaustion (Lilleaas, 2005).

Providing information to spouses at time of diagnosis and follow-ups was of great importance for reducing the feeling of being on the sideline. However, as shown in Adams (2009), we do not know how spouses' needs for information change over time. Another important question to ask is if there is a place for spouses to grieve and find new ways to be in the world with the illness experience with an emphasis on actions to deal with the illness and being supportive (Frank, 2002).

#### ***7.4 Methodological considerations***

The first author's protracted illness and a lack of funding led to a time gap between the interviews that constituted the data in Paper 2. Additionally the interviews with spouses were carried out over a long period due to problems with recruitment. To ensure similarity the interviews were consistently conducted by the same interviewer using the same introductory question and the same interview guide (Denzin, 2005; Drageset and Ellingsen, 2010; Fog, 1998). Furthermore, there were no changes in the treatment or organisation of care between the interviews that would influence the outcomes from the studies.

The low response rate among spouses may have been caused by the recruitment procedures and the sensitivity of the topics covered in the interviews (Neese et al., 2003). We are also unaware of the number of men who actually gave the letters to their spouses.

The spouses were a heterogeneous group with regard to age and location, and their experiences covered different phases of the illness trajectory. This contributed to ensuring the broadness of the phenomenon but the sample size only allowed us to indicate differences between groups in the dataset (Guest et al., 2006). Only spouses of men receiving potentially curative treatment agreed to participate in the study. The results might have been different with spouses of men where curative treatments were no option.

By interviewing other spouses than those married to the men in the study, spouses were given an opportunity to talk about sensitive issues without exposing their husbands. All spouses talked frankly about their experiences. However, this approach made it impossible to compare



the experiences of men and spouses in a couple. Interviewing both members of a couple may provided insight into other areas of importance (Harden et al., 2002).

The quality of the interviews increased with experience, and by listening carefully to the first interviews. As data collection and interpretation are parallel processes, the time gap between interviews may therefore also have strengthened the quality of the interviews.

In preparing for the study, talking with men and spouses about sensitive issues such as erectile dysfunction and masculinity was expected to be difficult. However, when questions about side effects were introduced as a way into the interviews, men and spouses talked with frankness about their experiences. In addition, the fact that the interviewer was around 50 years of age, married and with long experience in cancer care, may have contributed to this openness.

The second author read two interviews with men receiving endocrine therapy and three interviews with spouses. Through discussion an agreement was reached about emerging themes in the study. During the research process preliminary results were presented to fellow doctoral students and men with prostate cancer and their spouses at seminars in the Learning and Coping Centre.

The results from this study indicate areas of importance for men with prostate cancer and their spouses. The results may also be transferable to patient experiences with other types of cancers or life threatening illnesses, and to spouses of men with other serious illnesses. The study was conducted in Norway, however the existential dimension of the illness revealed in this study may make the results relevant in other cultures as well. (Interestingly the wave metaphor used in Paper 1 has aroused attention from as far from Norway as Hawaii).

## **8.0 Concluding remarks and possible implications for practice and research**

The main goal in the thesis has been to illuminate men's experiences of prostate cancer and the impact of the illness on men's and spouses' everyday life.

The results showed that prostate cancer was experienced as an existential threat, not only at time of diagnosis, but throughout the course of the illness. Living with prostate cancer over time meant experiencing different problems which revealed themselves gradually, with society's ever-present cancer label casting its shadow. Their emphasis on cancer as an illness which stood out from other illnesses was more evident than expected, in view of the fact that the men experienced significant physical side effects from treatment. Having prostate cancer without receiving potentially curative treatment may contribute to explaining the existential threat experienced through the course of the illness.

In accordance with our presuppositions we found that erectile dysfunction was experienced as the most common and challenging side effect from treatment for both men and spouses, and thus for their mutual relationship. In spite of leading to some reflections on what it meant to be a man, erectile dysfunction was generally experienced as a threat to men's feeling of masculinity on an existential level - their way of being in the world as men. It was similarly a threat to spouses' experiences of being attractive as women. Problems regarding sexuality were an especially sensitive subject and a source for distress in the relationship, but also brought some couples closer together. By focusing solely on technical remedies for erection the health care services may be said to provide poor help for men and spouses as individuals and as couples.

The men's new awareness of the body was striking. From living in an "unreflective" way, where the body was taken for granted, bodily sensations became an area for uncertainty and experiences of an existential threat after the cancer diagnosis. Lack of knowledge about prostate cancer and treatment were evident, and may reflect the silence which surrounds prostate cancer in Western society, especially compared to breast cancer in women. Lack of knowledge about the body had particular significance immediately after coming home, and the men felt left alone without knowing whom to contact when experiencing physical

alterations. The men's previous limited encounters with health care services may contribute to understanding these findings.

The impact of prostate cancer manifested itself in various practical ways in everyday life, e.g. in finding ways to limit the problem of urine leakage, in needing practical help with urine catheters, in deciding on the level of disclosure about the illness in encounters with others and in being prevented by fatigue from leisure activities carried out before the cancer. These areas were also important in the spouses' narratives. Such practical problems changed men's and spouses' ways of being in the world and are areas of importance for understanding the impact of prostate cancer in an everyday perspective. Although these practical issues contribute to defining men's and spouses' everyday life, they seem to be less studied than e.g. sexuality and are therefore an area needing more research. Spouses were experienced as the best support by the men. Although strongly involved in their husband's illness, spouses had to achieve a balance between managing their own emotional, bodily and relational needs and meeting their husbands' need for support and care.

Although the cancer caused various obstacles in daily life, the men wanted to live as normally as possible without worrying too much about the illness. A sense of humour and a positive attitude were considered very important for enduring life with prostate cancer, yet humour seemed to be more readily accepted if the men were the initiators. Danish life philosophy (Løgstrup, 1988; Løgstrup, 1999; Pahuus, 1995) offered insight into life-limiting and life-facilitating life phenomena of significance for both men and spouses, and life courage seemed to be of great significance for managing the situation and adjusting to prostate cancer in everyday life.

Overall we found that after the first big "cancer wave" life became calmer for both men and spouses. The results indicated a change in attunement (Heidegger, 1996) over time towards a more thoughtful mood for the men and those spouses who had provided support over years. However, the anxiety and uncertainty from the initial phase of the illness trajectory could easily be reawakened. For the men this new way of being in the world could be interpreted as being in a state of readiness for something to happen regarding the illness. As for the spouses' experiences, trying to suppress their own feelings and thoughts over time may explain the need for reflection and focusing on their own needs after living with men with prostate cancer for years.

The results from the study indicate some implications for practice. The uncertainty and the existential threat connected to prostate cancer need to be recognized in encounters between patients (spouses) and health care providers. The results also indicate that men should be given the opportunity to talk about their experiences. As the quotation from one man shows, some important questions may be hidden under the surface by men, “...*as men, we can appear calm on the surface, but you will find some undulations inside*”. In addition, sexuality seems to be an area needing a broader approach than solely information about technical remedies and medication for erection. The need for information and support changes over the period following diagnosis. The first phase after being diagnosed with cancer appears to be an especially vulnerable time for the men, and an area for improvement in terms of follow-up. Recent years have seen an increasing interest in the use of the Internet and Internet-based tools in providing individual information and self-support for (prostate) cancer patients at home (Bjørnes et al., 2011; Ruland et al., 2012). This may be an area for further development. As more follow-up actions are handed over from the specialist health care services to primary care settings, and given the fact that prostate cancer is the most common cancer among men, a greater focus on prostate cancer by general practitioners seems necessary. Awareness of life-facilitating life phenomena may help the health care service in supporting patients’ and spouses’ efforts in dealing with the illness. Spouses are already heavily involved in their husband’s illness and provide important support. The results indicate that the spouses’ need for information and support should be recognized and better included in follow-up work (if allowed by patients). Including spouses in rehabilitation courses and addressing their needs in courses seems appropriate.

The study opens for reflections into areas of importance for further research. Spouses’ experiences of prostate cancer, especially their long-term experiences, seem to be an important area for further investigation.

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## **Papers I-III**

Ervik, B., Nordøy T., Asplund K.

Hit by Waves – Living With Local Advanced or Localized Prostate Cancer Treated With Endocrine Therapy or Under Active Surveillance. *Cancer Nursing* 2010; 33 (5): 382-389.





## **Paper II**

Ervik B., Asplund K.

Dealing with a troublesome body: A qualitative interview study of men's experiences living with prostate cancer treated with endocrine therapy. *European Journal of Oncology Nursing* 2012; 16 (2): 103-108.



## Paper III

Ervik, B., Nordøy T., Asplund K.

In the Middle and on the Sideline: The Experiences of Spouses of Men With Prostate Cancer

Published ahead of print in *Cancer Nursing* Aug. 2012. <http://cancernursingonline.com>



## **Appendix I**

Documentation of approval

Bente Ervik  
Avdeling for sykepleie og helsefag  
IKM, Med. fak  
UiTø  
9037 TROMSØ

Deres ref.:

Vår ref: 200605404-5/MRO/400

Dato 27.11.2006

**P REK NORD 130/2006 HVERDAGSLIV MED PROSTATAKREFT - EN STUDIE AV  
OPPLEVELSEN/ERFARINGEN HOS MENN MED PROSTATAKREFT OG DERES  
EKTEFELLER/SAMBOERE - SLUTTIVURDERING - KOMITEEN HAR INGEN  
INNVENDINGER MOT AT PROSJEKTET GJENNOMFØRES**

Vi viser til prosjektleders brev av 13.11.2006 med vedlegg.

Prosjektleders tilbakemelding på komiteens merknader til prosjektet i møte 05.10.2006 tas til etterretning.

*Regional komité for medisinsk forskningsetikk, Nord-Norge (REK Nord) har ingen innvendinger mot at prosjektet gjennomføres.*

Det forutsettes at prosjektet er godkjent av aktuelle formelle instanser før det settes i gang.

Det forutsettes at prosjektet forelegges komiteen på nytt, dersom det under gjennomføringen skjer komplikasjoner eller endringer i de forutsetninger som komiteen har basert sin avgjørelse på.

Komiteen ber om å få melding dersom prosjektet ikke blir slutført.

Vennlig hilsen



May Britt Rossvoll  
førstekonsulent

**REGIONAL KOMITÉ FOR MEDISINSK FORSKNINGSETIKK, NORD-NORGE**

Regional komité for medisinsk forskningsetikk, Nord  
Universitetet i Tromsø, No-9037 Tromsø, tlf 77 64 40 00, e-post postmottak@uit.no, http://uit.no  
førstekonsulent May Britt Rossvoll, tlf 77 64 48 76, faks , e-post May.Rossvoll@fagmed.uit.no

Tone Nordøy  
Kreftavdelingen  
Boks 13, UNN

9038 TROMSØ

Deres ref.: 10.05.2002

Vår ref.: 200104857-5/IA Y/400

Dato: 29.05.2002

**P-REK V - 62/2001 "PROSTATAKREFT - OPPFØLGING FRA HELSEVESENET  
GJENNOM SYKDOMSFORLØP" — SLUTTAVURDERING - KOMITEEN HAR  
INGEN INNVENDINGER MOT AT PROSJEKTET GJENNOMFØRES**

Vi viser til prosjektleders brev av 10.05.2002 vedlagt revidert forespørsel om deltakelse i forskningsprosjektet, samt endelig intervjuguide.

Saken er forelagt leder for Regional komité for medisinsk forskningsetikk, Nord-Norge 29.05.2002.

Prosjektleders tilbakemelding på komiteens merknader til prosjektet i møte 11.10.2001 tas til etterretning.


*Regional komité for medisinsk forskningsetikk, Nord-Norge har ingen innvendinger mot at prosjektet gjennomføres.*

Det forutsettes at prosjektet er godkjent av aktuelle formelle instanser før det settes i gang.

Det forutsettes at prosjektet forelegges komiteen på nytt, dersom det under gjennomføringen skjer komplikasjoner eller endringer i de forutsetninger som komiteen har basert sin avgjørelse på.

Komiteen ber om å få melding dersom prosjektet ikke blir slutført.

Vennlig hilsen



Ingunn Ytrehus  
førstekonsulent

**REGIONAL KOMITÉ FOR MEDISINSK FORSKNINGSETIKK, HELSEREGION NORD-NORGE  
REK V**

Universitetet i Tromsø, N-9037 Tromsø, telefon 77 64 40 00, telefaks 77 64 53 00  
Ingunn Ytrehus, førstekonsulent, direkte innvalg 77 64 48 76, e-post rek-5@fagmed.uit.no  
<http://www.etikkom.no/NEM/REK/rek.htm>





Bente Ervik  
Avdeling for sykepleie og helsefag  
Institutt for klinisk medisin  
Universitetet i Tromsø  
Breivika  
9037 TROMSØ

Vår dato: 08.01.2007

Vår ref: 15880/JE

Deres dato:

Deres ref:

## TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 01.12.2006. Meldingen gjelder prosjektet:

15880 *Hverdagsliv med prostatakreft - en studie av opplevelsen/erfaringen hos menn med prostatakreft og deres ektefeller/samboere*  
Behandlingsansvarlig *Universitetet i Tromsø, ved institusjonens øverste leder*  
Daglig ansvarlig *Bente Ervik*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

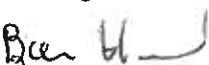
Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

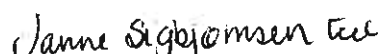
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/endrings skjema>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/register/>

Personvernombudet vil ved prosjektets avslutning, 31.12.2010 rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Bjørn Henrichsen

  
Janne Sigbjørnsen Eie

Kontaktperson: Janne Sigbjørnsen Eie tlf: 55 58 31 52

Vedlegg: Prosjektvurdering



Personvernombudet har vurdert prosjektet og finner at behandlingen kan hjemles i personopplysningsloven (§§ 8 første ledd og 9 a).

Reviderte informasjonsskriv per 5. januar finnes tilfredsstillende.

Prosjektet består av tre deler med forskjellige utvalg. I del 1 består utvalget av pasienter med prostatakraft. Data samles inn ved intervju og gjennomgang av medisinsk journal (ved onkolog). I del 2 består utvalget av ektefeller/samboere til menn med prostatakraft. Disse skal også intervjues. I prosjektets del 3 skal prosjektleder observere menn ved prostatakraft på legekonsultasjoner. Observasjonene følges opp med intervju av et utvalg menn og ektefeller/samboere. Det innhentes skriftlig samtykke fra deltakere i alle prosjektets deler, også helsepersonell i del 3.

Ved intervju av ektefeller/samboere i del 2 vil det forekomme opplysninger om partneren, som da er tredjeperson. Prosjektleder opplyser at tredjeperson vil informeres muntlig av sin partner, jf. telefonsamtale 4. januar 2007.

I prosjektets del 1 hentes det anonyme data fra studien 9309 "Prostatakraft - oppfølging fra helsevesenet gjennom sykdomsforløpet". Det inkluderes også nye informanter.

Det registreres sensitive opplysninger om helse, jf. personopplysningsloven § 2 punkt 8 c).

Ved prosjektslutt 31.12.2010 skal datamaterialet anonymiseres. Anonymisering innebærer at direkte og indirekte personidentifiserende opplysninger slettes eller omkodes (grovkategoriseres), lydopptak og koblingsnøkkel destrueres.

Prosjektet er tilrådd av Regional komité for medisinsk forskningsetikk.

## **Appendix II**

Information to men and spouses

Til:

**FORESPØRSEL OM Å DELTA I FORSKNINGSPROSJEKT**

*Til deg som blir behandlet/har blitt behandlet med hormoner for prostatakrefte ved Universitetssykehuset Nord-Norge (UNN)*

Prostatakrefte er den vanligste kreftformen blant menn i Norge, og for mange som rammes medfører sykdommen endringer i hverdagen. For å kunne gi et best mulig behandlings- og omsorgstilbud til pasienter med prostatakrefte, og deres pårørende, er det viktig for helsevesenet å få kunnskap om menns opplevelser og erfaringer med sykdommen. Da du går til kontroller ved UNN ber vi om å få intervju deg om dine erfaringer med å få og leve med prostatakrefte. Prosjektet er en del av et doktorgradsprosjekt ved Avd. for sykepleie og helsefag (ASH), Universitetet i Tromsø for undertegnede, kreftsykepleier/cand. polit. Bente Ervik. Kenneth Asplund, professor 11, ASH, Universitetet i Tromsø er hovedveileder for doktorgradsstudien, og overlege Tone Nordøy, Kreftavdelingen UNN, er veileder og medarbeider i denne delen av prosjektet.

Doktorgradsprosjektets tittel er: *"Hverdagsliv med prostatakrefte – en studie av opplevelsen/-erfaringen hos menn med prostatakrefte og deres ektefeller/samboere"*

Denne delen av prosjektet har tittelen *"Prostatakrefte - oppfølging fra helsevesenet gjennom sykdomsforløpet"* og har som hensikt å få innsikt i 1) hvordan det oppleves å få og leve med prostatakrefte for dem som får hormonbehandling og videre 2) hvordan møtene og oppfølgingen fra helsevesenet oppleves.

Intervjuet gjennomføres som en samtale og vil vare i ca. 1-1 ½ time. Samtalen kan gjennomføres på ditt hjemsted eller i Tromsø. Intervjuet taes opp på lydbånd som oppbevares nedlåst i prosjektperioden. Alle opplysninger vil bli behandlet konfidensielt og opplysningene vil bli oppbevart avidentifisert i prosjektperioden. Alle personidentifiserbare opplysninger, også lydbåndopptak, slettes ved prosjektets avslutning 31.12.2010.

Som ledd i prosjektet ønsker vi også informasjon fra journal, og dersom du samtykker til å være med i prosjektet samtykker du også til at overlege Tone Nordøy får tilgang til journalopplysninger om diagnose og oppfølging av sykdommen. Resultatene i prosjektet vil ikke ha noen direkte konsekvenser for deg som deltaker i prosjektet, men vil kunne ha betydning for andre kreftsyke i framtiden.

Denne forespørselen er sendt ut via Urologisk og endokrin poliklinikk ved UNN, og prosjektansvarlige er ikke kjent med de forespurtes identitet på forhånd. Ved bruk av vedlagte svarkonvolutt vil *kun* prosjektleder og prosjektmedarbeider ha kjennskap til personidentifiserbare data/opplysninger. Det er aktuelt å benytte direkte sitat fra intervjuene i presentasjon av prosjektet. Alle personidentifiserbare opplysninger vil da være fjernet slik at det ikke skal være mulig å føre noe tilbake til den enkelte.

Deltakelse i prosjektet er frivillig. Samtykke kan trekkes tilbake på et hvilket som helst tidspunkt uten at du må oppgi noen grunn og uten at det vil ha noen konsekvenser for deg. Innsamlete data som lydbåndopptak vil da bli slettet umiddelbart. Om du ikke ønsker å delta i studien trenger du heller ikke begrunne det, og det vil ikke ha noen betydning for ditt forhold til behandlere eller andre.

Ansvarlig for prosjektet er Bente Ervik, adr.: Avdeling for sykepleie og helsefag, Institutt for klinisk medisin, Universitetet i Tromsø, 9037 Tromsø. Jeg kan kontaktes på overstående adresse eller tlf. 776 45463 (evt. Kreftavdelingen 776 26074). Prosjektet er tilrådd av Regional komitè for medisinsk forskningsetikk Nord-Norge og er meldt inn for Personvernombudet for forskning, Norsk samfunnsvitenskapelige datatjeneste.

Dersom du ønsker å delta i prosjektet bes du underskrive samtykkeerklæringen. Denne returneres i vedlagt svarkonvolutt og du beholder et eksemplar selv.

Med vennlig hilsen

Bente Ervik  
Kreftsykepleier/cand. polit.  
ASH, Universitetet i Tromsø  
og Kreftavdelingen UNN  
Prosjektleder

Tone Nordøy  
Overlege  
Kreftavdelingen  
Prosjektmedarbeider

Dag Lein  
Seksjonsoverlege  
Urologisk og endokrin poliklinikk

\*\*\*\*\*

#### SAMTYKKE-ERKLÆRING

Jeg har mottatt skriftlig (og muntlig) informasjon og er villig til å delta i studien.

Navn: .....og jeg kan kontaktes på

tlf. ....

.....den .....

Signatur .....

Til

**FORESPØRSEL OM Å DELTA I FORSKNINGSPROSJEKT I REGIAV  
"REGIONALT KOMPETANSESENTER FOR LINDRENDE BEHANDLING I  
HELSEREGION NORD"**

*Til deg som blir behandlet for prostatakraft ved Universitetssykehuset Nord-Norge*

"Regionalt kompetansesenter for lindrende behandling" har blant annet som oppgave å bidra til å bedre behandlings- og omsorgstilbudet for kreftsyke, og være med på utvikle gode samarbeidsrutiner mellom sykehus og primærhelsestjenesten. I dette prosjektet ønsker vi å fokusere på det å leve med prostatakraft, og spesielt knytte dette til møter med helsevesenet ved diagnostisering og oppfølging av sykdommen. Da du fortsatt går til polikliniske kontroller ved Universitetssykehuset i Nord-Norge (UNN) ber vi om å få intervju deg som en del av prosjektet.

*Prosjektets formål er 1) å få innsikt i hvordan det oppleves å få og leve med prostatakraft og hvordan møte og oppfølgingen fra helsevesenet fungerer 2) å utvikle kunnskap om hvordan helsevesenet best mulig kan følge opp og ivareta menn med prostatakraft og de evt. problemstillingene som sykdommen medfører i hverdagen.*

Forespørsel om deltakelse er sendt ut via Kirurgisk poliklinikk, og de prosjektansvarlige er ikke kjent med de forespurtes identitet på forhånd. Ved bruk av vedlagte svarkonvolutt vil *kun* prosjektansvarlig og prosjektmedarbeider ha kjennskap til deltakernes identitet.

Intervjuet vil foregå som en samtale og er beregnet til å ta ca. 1 – 1 ½ time. Det kan gjennomføres i forbindelse med kontroll ved Kirurgisk poliklinikk i Tromsø eller på eget hjemsted. Intervjuet vil bli tatt opp på lydbånd. Båndene oppbevares nedlåst. Alle opplysningene vil bli behandlet konfidensielt og alle personidentifiserbare opplysninger slettes ved prosjektets avslutning, senest 2 år etter prosjektstart, november 2004. Det kan være aktuelt å benytte direkte sitat fra intervjuene i presentasjon av prosjektet, og da vil alle personopplysninger være fjernet slik at det ikke skal være mulig å føre noe tilbake til den enkelte.

Som ledd i prosjektet ønskes også informasjon fra journal, og dersom du samtykker til å være med i prosjektet samtykker du også til at overlege Tone Nordøy får tilgang til journalopplysninger om diagnose og oppfølging av sykdommen.

Deltakelse i prosjektet er frivillig, og det trengs ingen begrunnelse for ikke å delta. Du kan også trekke deg fra deltakelse i prosjektet på et hvilket som helst tidspunkt uten begrunnelse, og uten at det har konsekvenser for deg. Innsamlete data, som lyd-båndopptak, vil da bli slettet umiddelbart. Resultatene av prosjektet vil ikke ha noen direkte konsekvenser for deltakerne i prosjektet, men vil kunne ha betydning for framtidige kreftpasienter.

Om du ønsker flere opplysninger eller har spørsmål kan du kontakte overlege ved Kreftavdelingen Tone Nordøy på telefon 77669145, eller kreftsykepleier Bente Ervik 77626074 / 77669144.

Dersom du ønsker å delta i prosjektet bes du underskrive samtykke-erklæringen. Denne legges i vedlagt svarkonvolutt. Du beholder et eksemplar selv.

Med vennlig hilsen

Tone Nordøy  
Overlege Kreftavdelingen  
Prosjektansvarlig

Bente Ervik  
Kreftsykepleier  
Prosjektmedarbeider

Dag Lein  
Avdelingsoverlege  
Kirurgisk poliklinikk

.....  
**SAMTYKKE-ERKLÆRING**

Angående forskningsprosjekt "*Prostatakreft – oppfølging fra helsevesenet gjennom sykdomsforløpet*" i regi av Kompetansesenter for lindrende behandling i Helseregion nord. Jeg har gjort meg kjent med ovenstående informasjon og sier meg villig til å delta i prosjektet.

Navn: .....og jeg kan kontaktes på

tlf. ....

Jeg har selv tatt vare på et eksemplar av informasjonsbrevet/samtykke-erklæringen

.....den .....

Signatur .....

*Til deg som har en ektefelle/samboer som blir behandlet for prostatakraft ved Universitets-sykehuset Nord-Norge*

***FORESPØRSEL OM Å DELTA I FORSKNINGSPROSJEKT OM EKTEFELLER/-SAMBOERE TIL MENN MED PROSTATAKRAFT SINE ERFARINGER SOM PÅRØRENDE***

Prostatakraft er den vanligste kreftformen blant menn i Norge i dag. Sykdommen kan medføre store endringer i hverdagen for den som rammes og deres ektefeller/samboere. For å kunne gi et best mulig behandlings- og omsorgstilbud til pasienter med prostatakraft, og deres pårørende, er det viktig for helsevesenet å få kunnskap om menn og deres partners erfaringer med sykdommen. I prosjektet ønsker vi å intervjuere ektefeller/samboere til menn med prostatakraft om deres opplevelser og erfaringer som pårørende, og i den sammenheng ber vi om å få intervjuere deg om dine erfaringer. I intervjuet kan det også være aktuelt å komme inn på din ektefelle/samboers diagnose. Prosjektet er en del av et doktorgradsprosjekt ved Avd. for sykepleie og helsefag (ASH) ved Universitetet i Tromsø for undertegnede, kreftsykepleier/-cand. polit. Bente Ervik. Kenneth Asplund, professor II ved ASH, Universitetet i Tromsø er hovedveileder for doktorgradsprosjektet.

Doktorgradsprosjektets tittel er: *"Hverdagsliv med prostatakraft – en studie av opplevelsen/erfaringen hos menn med prostatakraft og deres ektefeller/samboere"*

I denne delen av studien ønsker vi 1) innsikt i hvordan ektefeller/samboeres opplever at kreftsykdommen påvirker hverdagen og samlivet og videre 2) innsikt i behov for informasjon og støtte fra helsevesenet for ektefeller/samboere.

Intervjuet gjennomføres som en samtale og vil vare i ca. 1-1 ½ time. Samtalen kan gjennomføres på ditt hjemsted eller i Tromsø. Intervjuet taes opp på lydbånd som oppbevares nedlåst i prosjektperioden. Alle opplysninger vil bli behandlet konfidensielt og opplysningene vil bli oppbevart avidentifisert i prosjektperioden. Alle personidentifiserbare opplysninger, også lydbåndopptak, slettes ved prosjektets avslutning 31.12. 2010.

Det kan være aktuelt å benytte direkte sitat fra intervjuene i presentasjon av prosjektet og da



vil alle personidentifiserbare opplysninger være fjernet slik at det ikke skal være mulig å føre noe tilbake til den enkelte. Det er kun prosjektleder som har tilgang til personidentifiserbare data.

Resultatene i prosjektet vil ikke ha noen direkte konsekvenser for deg som deltaker i prosjektet, men vil kunne ha betydning for framtidige kreftpasienter og deres pårørende. Deltakelse i prosjektet er frivillig. Samtykke kan trekkes tilbake på et hvilket som helst tidspunkt, uten at du må oppgi noen grunn, og uten at det vil ha noen konsekvenser for deg eller din ektefelle/samboer. Alle innsamlete data også lydbåndopptak vil da bli slettet umiddelbart. Om du ikke ønsker å delta i studien trenger du heller ikke begrunne det, og det vil ikke ha noen betydning for ditt eller din ektefelle/samboers forhold til behandlere eller andre.

Prosjektet er tilrådd av Regional komitè for medisinsk forskningsetikk i Nord-Norge og er meldt inn for Personvernombudet for forskning, Norsk samfunnsvitenskapelige datatjeneste. Ansvarlig for prosjektet er Bente Ervik adr.: Avdeling for sykepleie og helsefag, Institutt for klinisk medisin, Universitetet i Tromsø, 9037 Tromsø. Jeg kan kontaktes på ovenstående adresse eller tlf.776 45463 (evt. Kreftavdelingen 776 26074).

Dersom du ønsker å delta i prosjektet bes du underskrive samtykkeerklæringen. Denne returneres i vedlagt svarkonvolutt og du beholder et eksemplar selv.

Med vennlig hilsen

Bente Ervik  
Kreftsykepleier/cand. polit.  
ASH, Universitetet i Tromsø  
og Kreftavdelingen, UNN.  
Prosjektleder

\*\*\*\*\*

SAMTYKKE-ERKLÆRING – ektefeller/samboere

Jeg har mottatt skriftlig (og muntlig) informasjon og er villig til å delta i studien.

Navn: .....og jeg kan kontaktes på

tlf. ....

.....den .....

Signatur .....

## **Appendix III**

Interview guides

## Intervjuguide

### Tema 1 Opplevelse av egen livssituasjon

- å få kreftdiagnosen
- behov for informasjon og emosjonell/psykisk støtte
- sykdommens betydning i hverdagen
- evt. problemer i forhold til sykdommen i hverdagen
- behov for hjelp og støtte
- hvem er til hjelp

### Tema 2 Oppfølging

- hvilken oppfølging fåes fra helsevesenet - hvordan oppleves den
- behov for støtte – informasjon
- dekkes dette behovet?
- udekkede behov?
- trygghet

### Tema 3 Egne tanker om forbedringer i tilbudet fra helsevesenet

- ved diagnosen
- senere
- primærlegen- primærhelsetjenesten
- andre tilbud
- annen organisering
- grupper

Prosjekt : P- REK V nr. ... "Hverdagsliv med prostatakreft – en studie av opplevelsen/erfaringen hos menn og deres ektefeller/samboere".

## Intervjuguide ektefeller/samboere

### Innledning

Informasjon om bakgrunn for studie

Alder

Familie - og arbeidsforhold

Ektefelle/samboer:

- når fikk diagnose
- behandlingsform
- organisering av oppfølging

### Tema 1 Opplevelse av egen livssituasjon

- tiden rundt avklaring om kreftdiagnosen
- behov for informasjon, emosjonell/psykisk støtte ved diagnosen
  
- sykdommens betydning i hverdagen i dag for deg
- samlivet
- behov for hjelp og støtte
- hvem/hva er/var til hjelp
- nærmiljøet
- egen mestring/egne ressurser

### Tema 2 Møte med / oppfølging fra helsevesen

- behov for støtte – informasjon
- opplevelsen av inkludering av partnere i oppfølging
- oppleves av oppfølging fra helsevesenet - positivt/ negativt
- trygghet
- organisering

### Tema 3 Andre sider som har betydning for hverdagslivet nå

- primærlege - primærhelsetjenesten
- avstand til sykehus
- andre tilbud – relevante/benytte seg av – (PROFO, Montebello, Kreftforeningen, Lærings- og mestringssenter)
- annet som ikke er berørt i intervjuet





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