# Prostate Cancer and Its Influence on Men´s Daily Lives

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Front cover: “Man in the moon” by Edward Webb ©

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”I blomman, i Solen
Amanda jag ser.
Kring jorden, kring polen
Hon strålar, hon ler.
I rosornas anda,
I vårvindens pust,
I druvornas must
Jag känner Amanda.”

– Erik Johan Stagnelius -

# ABSTRACT


Prostate cancer has been a disease of older men but age at diagnosis is falling in Sweden. Fatigue has been regarded as a common symptom of cancer and may compromise quality of life in prostate cancer patients. The overall purpose of this thesis was to identify and describe fatigue and its influence on men's lives when undergoing examinations for suspected prostate cancer and diagnosed with prostate cancer. Further, the purpose was to understand if prostate cancer affects the men's daily lives. The data were collected consecutively at the outpatient clinics of two different hospitals in Sweden. Data from qualitative interviews using the same topics, with modification in paper IV, were analysed by Gadamer´s hermeneutics.

**Paper I:** Eleven men undergoing routine examination for prostate cancer (transrectal ultrasound and biopsy), but diagnosed as having benign disease were interviewed during the spring of 2002. At the time of the prostate cancer examination, the men did not feel fatigue, i.e. not because of the examination; they felt healthy.

**Paper II**: Sixteen men newly (within 2-4 weeks) diagnosed as having localized prostate cancer and with a prostate-specific antigen level of <10 ng/ml and untreated at the time of the interview participated between spring and autumn 2003. Most of the men did not experience fatigue due to the diagnosis but experienced every day fatigue and cancer influenced the men´s daily lives. The men felt healthy.

**Paper III:** Ten men newly (within 2-4 weeks) diagnosed as having advanced prostate cancer PSA of ≥ 100 ng/ml and treated for no more than 2 weeks at the time of the interview participated between autumn 2003 and December 2005. The men did not experience fatigue due to advanced prostate cancer but they experienced normal every day fatigue. The men felt healthy with some dysfunction influencing their daily lives.

**Paper IV**: All 22 men who were still alive since the first interview (in studies II and III) were followed up between May 2005 and November 2007. The men were living with a sense of feeling healthy, even when having lived with prostate cancer for approximately two years; both cancer stage and age had an influence on them. All the men experienced Every Day Fatigue.

**Conclusions:** Personality and anxiety contributed to fatigue when undergoing examination for suspected prostate cancer. Localized prostate cancer affected the men´s emotions and contacts giving them a new perspective on life. Advanced prostate cancer affects men´s lives: they are placed in a new life situation, against their will, and in this new situation, they form a new life perspective. The follow-up study confirmed the men´s view that age influences them, they live with uncertainty but with strengthened self-esteem, finding a balance in a changed life situation. According to the present studies the men felt healthy in spite of prostate cancer. Complementary findings were found about existential thoughts. Health professionals have a unique position to identify the different stages of the men´s adaptation to prostate cancer to guide them towards their individual needs at each stage of their adjustment.



**Key words**: Prostate cancer; fatigue; influence; aging man; health; existential thoughts; Hermeneutic; qualitative research; follow-up.

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# LIST OF PUBLICATIONS

This thesis is based on the following original papers, referred to in the text by their roman numerals:

I Jonsson A, Aus G & Berterö C. (2006). No Fatigue Related to Prostate Cancer Examination: A Qualitative Study. Austral-Asian Journal of Cancer, 5, 163-168. ISSN-0972-2556.

II Jonsson A, Aus G & Berterö C. (2007). Men´s perception of fatigue when newly diagnosed with localized prostate cancer. Scandinavian Journal of Urology and Nephrology, 41, 20-25. ISSN- 0036-5599. www.informaworld.com/suro .

III Jonsson A, Aus G & Berterö C. (2009). Men´s experience of their life situation when diagnosed with advanced prostate cancer. European Journal of Oncology Nursing, xx, 1-6. ISSN- In press. http://dx.doi.org/10.1016/j.ejon.2009.02.006 .

IV Jonsson A, Aus G & Berterö C. (2009). Living with a prostate cancer diagnosis; a qualitative two year follow-up. Submitted.

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# ABBREVIATIONS

| | |
|---|---|
| AS | Active Surveillance |
| BT | BrachyTherapy |
| CT | Computed Tomography |
| DRE | Digital Rectal Examination |
| EAU | The European Association of Urology |
| EORTEC | The European Organization for Research and Treatment of Cancer |
| HIFU | High Intensity Focused Ultrasound |
| MRI | Magnetic Resonance Imaging |
| NANDA | The North American Nursing Diagnosis Association |
| NCCN | The National Comprehensive Cancer Network |
| PSA | Prostate-Specific Antigen |
| RP | Retropubic Prostatectomy |
| RT | RadioTherapy |
| TNM | Tumour, Node, Metastasis |
| TRUS | TransRectal UltraSonography |
| UICC | Union Internationale Contre le Cancer<br>(The International Union against Cancer) |
| WW | Watchful Waiting |
| QOL | Quality of Life |

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# INTRODUCTION

New cases of prostate cancer are diagnosed among Swedish men (about 5 million men) at a rate equivalent to one every hour, every day of the year. This corresponds to nearly 9000 new cases each year and makes prostate cancer the most common cancer among males in Sweden. This is also true for many western countries, such as in Northern Europe and in the US. On average, the incidence of prostate cancer in Sweden has increased by 2.8 per cent per annum seen over the last 20 years, although it has diminished in the last two years. In 2007, 8870 new cases were diagnosed, which accounts for 34.2 per cent of all cases of cancer in men. The mortality rate for prostate cancer has been approximately 2500 deaths per year during the last decade, 2470 deaths in 2007 (1- 2). Early prostate cancers (stage T1 and T2) are increasing whereas local advanced (T3 or T4) or metastatic (prostate-specific antigen; PSA over 100 ng/ml) tumours are decreasing (3).

Several aspects of the disease are common for all men with prostate cancer, while others are widely different, determined by for example tumour state or the patients age. Even if men with prostate cancer have similar experiences, every man has his own inimitable troubles. The life expectancy of men has extended by more than 25 years during the last few decades, men´s life expectancy is still significantly shorter than that for women in most regions of the world (4). Cancer is a common disease of the elderly men and a consequent effect of aging is the simultaneous increase of prostate cancer in the older population (1, 5-7). More knowledge is needed regarding different treatments for older men but still with long and increasing life expectancy. It has been emphasized that biological age is weightier than chronological age (8) with regard to choices of cancer treatment. Better methods than age alone for estimation of life expectancy together with better understanding of the aging males' needs and wishes are needed if we should be able to offer tailored prostate cancer treatment to an aging population (9).

Fatigue has been regarded as a common and sometimes disabling symptom of cancer or its treatment. There is no universally accepted definition of fatigue, but there are a lot of definitions focusing on the specific setting of each piece of research. According Glaus (10) fatigue as a multidimensional experience has not only biochemical or pathophysiological but even emotional and psychological origins.

This thesis is about men with suspected prostate cancer, diagnosed prostate cancer and their experiences of fatigue, as well as how a cancer diagnosis affects their life situation.

# BACKGROUND

## Prostate cancer

All cancers initiate in cells, the body's fundamental unit of life. Cancer is an idiom used for diseases in which anomalous cells replicate uncontrolled and can occupy other tissues. Once prostate cancer spreads, it is commonly first discovered in nearby lymph nodes and the new tumour has similar anomalous cells having the same name (11).

Risk factors for developing localized prostate cancer are not well known. However there are some risk factors confirmed for example age: with increasing risk as a man gets older, as well as family history, whereas diet and race are still under debate (5-7, 11). With life expectancy increasing, the proportion of older men with prostate cancer has increased. Nearly 50% of all new prostate cancers are diagnosed in men over 70 years old. Developments in medical care have increased the possibility of many of these older men living for years with their prostate cancer (7).

In the earliest stages, the majority of prostate cancers do not cause any symptoms and when symptoms occur, the signs can be quite similar to non-malignant prostatic diseases (12, 13). Men with advanced prostate cancer may have local symptoms as poor stream, frequency and urgency as well as symptoms from metastases, such as bone pain or lymphoedema. Men with advanced prostate cancer may also often have systematic advanced cancer prostate symptoms, such as lethargy (due to anaemia, uraemia and non-specific effects), weight loss and cachexia (4).

The main diagnostic and staging examinations used for prostate cancer are digital rectal examination (DRE), elevation of prostate-specific antigen (PSA), transrectal ultrasonic sound (TRUS) and transrectal core biopsy taken at the same time as the ultrasound examination, supplementing with a bone scan, computed tomography (CT) or magnetic resonance imaging (MRI) and X-ray in specifics circumstances (6). To prepare treatment there is a need to know the stage of the prostate cancer. The Union International Contre Cancer (UICC) 2002 Tumour, Node, Metastasis (local extent of tumour = primary tumour/ metastases to regional lymph node status/ distant metastasis TNM) system is commonly used for the staging classification of the prostate cancer (9, 11).
The Gleason scoring system is usually used to grade adenocarcinoma of prostate cancer, and it is based on the growth pattern of the tumour as seen in the histopatological preparations of the biopsy cores or operative specimens. The score is the sum of two most frequent patterns (grades 1-5) of tumour growth found. The

sum of the two most common growth patterns (Gleason grades) is reported as the Gleason score. To be counted, a pattern (grade) must take more than 5% of the biopsy specimen. The higher the Gleason score the more aggressive the cancer is: grade 2 is thus the least aggressive and 10 the most aggressive. In other words do this grade differentiation describe how abnormal the cancer cells appear and how quickly the tumour is likely to grow and spread (6, 12, 13)

Knowledge of prostate cancer is quickly changing, where treatment of prostate cancer depends on stage and grade of the disease together with age and health status of the patient at the time of diagnosis. The European Association of Urology (EAU) has drawn up guidelines and summarized the most recent findings and put them into clinical practice (6). Men with a life expectancy of more than 10-15 years diagnosed with localized disease may either be offered observation with later curative therapy (so-called active monitoring) or directly treatment with curative intent. Curative treatment options includes surgery (radical prostatectomy) either by open or laparoscopic/robot assisted route or some of the various forms of radiation available (external-beam radiotherapy/RT, brachytherapy/BT) or both. Also minimal invasive therapies as cryotherapy or High Intensity Focused Ultrasound (HIFU) have been offered to certain patients with localized prostate cancer (14). Patients with a shorter life expectancy (< 10-15 years) are usually offered observation (watchful waiting WW) only with possible later hormonal therapy. Primary hormonal therapy is seldom used in patients with early stage prostate cancer. The most common side effects of treatment with curative effect is related to urinary problems (i.e. incontinence after surgery, frequency after RT), sexual dysfunction (mainly erectile dysfunction but also ejaculatory disorders) and bowel problems (after RT).

The success of treatment in early-stage prostate cancer thus involves balancing the disease aspects against the patient quality of life aspects and depends on the physician’s ability in responding to the desires and interests of the individual (14).

Men with locally advanced prostate cancer but without known metastases may be offered therapy with a combination of radiation therapy and hormonal therapy if they have a sufficient long life expectancy (15). Elderly patients are usually offered some form of hormonal therapy and here may treatment with anti-androgen monotherapy has a role.

Men with advanced disease are offered treatments which are palliative (non-curative). As prostate cancer mostly needs the male sex hormone, testosterone, for its growth is the first line therapy some form treatment aimed at lowing the serum-testosterone. This can be done by either medical or surgical castration (12). Castration therapy is associated with loss of libido, decreased sexual function, hot

flushes/sweating but also long-term effects on bone mineralization, lowering of serum haemoglobin and a decreased cognitive function (16).

The follow-up after treatment with curative intent in asymptomatic men are a disease-specific description and PSA supplemented with DRE recommended at 3, 6 and 12 months after treatment, after that every 6 months until 3 years and then once a year. The follow-up after hormonal treatment should be shaped individually according to symptoms, predictive aspects and given treatment. Men ought to be evaluated at three and six months after initiating treatment including PSA, DRE and valuation of symptoms to assess treatment control and side-effects of given treatment (6).

## Prostate cancer's entry in men's normal life

Davison et al. (17) identified and described that decision making influences on men who decide to manage their low-risk prostate cancer with active surveillance. The study shows that the urologist's explanation of prostate cancer is the most influential aspect on men selecting active surveillance and setting up coming active treatments. Most men relied on their urologist's recommendation and did not perceive the necessity for any extra therapy or support until the cancer needed active treatment. The chronological age of patients still has a significant role to play in treatment, rehabilitation, co-morbidity and non-compliance (18). As a result, WW has been as a logical alternative to therapy for men over 70 years with prostate cancer. Bailey et al. (7) found uncertainty, appraisal of risk and possibility confirmed by experience with WW.

Types of treatments for cancer have been pointed out having several consequences on patients. Sanda et al (19) found out that different prostate cancer treatments were associated with a distinct pattern of change in quality-of-life domains related to suboptimal urinary, sexual, bowel and hormonal function. These changes influenced satisfaction with treatment outcomes among patients and their partners.
Suboptimal urinary, bowel and/or sexual function are often a consequence of initial prostate cancer therapy but after treatment, high overall health quality of life was described. The men did not view these dysfunctions as aspects of health even if they were disturbances in life (20, 21). Men who had undergone radical retropubic prostatectomy (RP) or low-dose-rate BT had similar experiences of quality of life. Even these men perceived high quality of life about a year after treatment (22). The three topics men described most as influencing them after radical prostatectomy were reduced to health, family and relationship with a partner, further topics described were activity, autonomy, independency, hobby and financial security (21). Ten years after external beam RT or WW, the pattern of dysfunctions was similar even between these treatments. Treatment with RT had

minimum effects on health-related quality of life in relation to that of WW at 10 year-follow-up (23).

Prostate cancer is faced successively, starting when the men receive their diagnosis, turning attention to trouble of the usually “quiet” male body. The path of incidents brings out the importance of treatment side effects, embodied vulnerability, and the influence of the cancer on men’s “embodied” lives. Men meet existential risk together with bodily changes, resulting in a new view on life and priorities following cancer (24).

There is probably no other disease that demonstrates the social structure of masculine identity so clearly as prostate cancer, a disease including frequent symptoms and treatment side effects, leaving men with a diminished feeling of control over their bodies. This kind of loss of agency exposes the behaviour where society’s norms about correct masculine sexual behaviour and identity are social constructions not biological truths. Arrington (25) describes that there should be the possibility of redefining sexuality and masculinity among prostate cancer survivors. The study by Berterö (26) studying men with prostate cancer shows altered sexual patterns after treatment. This author found that the men made a choice of consequences, like between life and death, when they made treatment decisions. She also found that age, not necessarily prostate cancer, affects sexual life. The men had a hope to improve sexual function despite years of treatment even if they had accepted their new sexual pattern. The image of manliness shows that men tried to admit and handle their change in self-image. There were not only bodily changes but even the way the men felt about themselves as men and their personality in the context of their lives were different.

Existential topics like the meaning of everyday life are aroused, when life is threatened for example by a cancer diagnosis. Weisman et al. (27) studied the existential plight in cancer among one hundred and twenty newly diagnosed cancer patients significance of the fist 100 days after the definitive diagnosis. The main signs were the predominance of life/death concerns as well as worries about health and physical symptoms. Dwyer et al. (28) found in their interview study among the inhabitants of three nursing homes that a sense of meaning is created by a sense of: physical capability, cognitive capability, being needed, as well as belonging. Meaning was established throughout inner dialogue, communication and relationships with others. They described even that the experience of meaning is sometimes difficult to understand. Their findings illuminated how age can have an effect on one’s outlook of life. Westman et al. (29) studied among other things cancer patients (breast and prostate cancer) existential reflections on the cancer finding that they reported a need of existential support. Existential reflections can be aroused by life threatening disease and age. Consequently prostate cancer as life threatening illness as well as age could have an effect on one’s outlook on life.

# CONCEPTUAL FRAMEWORK

The choice of approach was Gadamer's hermeneutics. Hermeneutics is about the lived experience of individuals as a way in to the social, cultural, political or historical context. Focus is mostly on meaning and interpretation, how persons interpret their world within their given context (30-34). In order to give the reader a better understanding of the use of the concepts and the perspective guiding the qualitative studies of men diagnosed with prostate cancer presented in this thesis, a short presentation of the concepts of fatigue, health and existentialism is given below.

## Fatigue

Glaus (10) describes that there is not yet an across the world accepted definition of fatigue. Aaronson et alt. (35-36) pointed out that the clear definition of fatigue was difficult to derive from the literature because many disciplines such as medicine, nursing, physiology, psychology, and ergonomics had investigated this problem with as many different perspectives being identified.

The following definition is proposed for nursing usage: fatigue is a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals` ability to function to their normal capacity (37). The definition of fatigue according to The North American Nursing Diagnosis Association (NANDA) is "An overwhelming sustained sense of exhaustion and decreased capacity for physical and mental work at usual level" (38). Fatigue is "a subjective state of overwhelming, sustained exhaustion and decreased capacity for physical and mental work that is not relieved by rest" according to Cella et al. (39).

Everybody experiences fatigue sometimes, which is the body's way of indicating its need for rest and relaxation. Fatigue is a kind of a protective system, designed to sustain health and to prevent disease (10). Normal fatigue is not easy to separate from abnormal fatigue. One way is to allow the person's own judgement and to regard fatigue to be abnormal when a fatigued person starts to perceive him-/herself as sick (40). When fatigue becomes a permanent sense of tiredness or exhaustion more than normal tiredness, it can be a signal that something is wrong. The meaning of the term is both instinctively understandable, based on one's own experience, but also indefinable (41).

Little is known about fatigue in a healthy population. Aaronson et al. (35-36) offer a definition based on qualitative findings: "fatigue in generally healthy adults is an

acute, subjective, sometimes overwhelming, but temporary state (with physical, emotional, and behavioural manifestations) caused by stress and overwork in one's life roles, which disrupts activity and alerts the person to take restorative measures". Fatigue in healthy individuals lasted between 15 and 30 minutes and did not usually stir up hidden emotions (10).
According to Piper (42) acute fatigue is perceived as normal or expected tiredness, identifiably connected to a specific cause. It generally occurs in healthy individuals, it has a rapid start and a short duration. A healthy individual is usually brought back to a normal level of daily living and quality of life by rest, diet, and exercise and stress management.

Primary causes of fatigue in humans according to Glaus (10) are circulatory and metabolic adaptation failure, metabolic disorders, endocrine and hormonal disturbances, disruption of central nervous functions, chronic infections and humoral disorders, immunological and auto-immune processes and finally emotional distress associated with chronic disease. He means that anxiety is perceived as a correlate of fatigue.

Fatigue, a frequent symptom in primary care, pessimistically influences job functioning, family life, and social relationships. The differential diagnosis includes lifestyle issues, physical conditions, mental disorders and treatment side effects (43). Twenty per cent of family medicine cases perceive fatigue, and about 33 per cent of adolescents inform having fatigue at least four days a week. Patients with fatigue explain that they have the inability to finish some activities due to a lack of energy, while grief and depression are associated with a patient explanation that is more global, for instance being unable to do "anything" (43).

Chronic fatigue has an unknown function, mostly influencing ill clinical populations and having several, additive or unidentified reasons. Chronic fatigue is often experienced with no relation to activity. It is perceived as abnormal, unusual or immense, has an insidious start, is constant, lasting weeks, is not predicted to finish soon, is not generally relieved by usual restorative techniques and has a major effect on the individual's activities of daily living and quality of life (10, 42, 44).

Cancer-related fatigue is an almost worldwide disorder among cancer patients and has been identified as an essential problem by them (45). According to the National Comprehensive Cancer Network (NCCN) in the United States, the definition of cancer-related fatigue is: "A distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (46). Stone et al. (47) in their study describe that fatigue was reported to affect 56 percent of patients (n = 1370) and have a considerable impact on

quality of life; fatigue is a common and distressing symptom. Cancer-related fatigue is multidimensional, having many origins as does cancer itself, related to the side effects of practically each treatment, depression, and other bio-psychosocial factors. Fatigue can be suffered by patients as a very frustrating state of chronic energy reduction, leading to loss of production which may diminish self-esteem (39).

Few qualitative studies can be found focusing solely on people's own experiences or perspectives of fatigue.

## Health

The definition of health is fundamentally easy to understand but still does no universally accepted definition exist. According to a modern variant of the holistic-humanistic perspective of health, man is taken to be fundamentally a social agent, a complete human being acting in society. Health is characterised in equilibrium theory by Pörn (48), who described that general conditions must be fulfilled for an individual (as a whole) to be healthy. The combination of the ability with a set of environmental situations creates a capacity which is adequate for the realization of a goal of his indicating a harmony between his capacity and his goal, a kind of balance. This balance is crucial to the conception of health; the concept of ability is an obvious starting-point in order to form the key ingredients of this conception. Ability is a capacity making an action achievable. Generalized adaptedness belongs to health and can be considered as a relation between the ability, the environment and the goal profile. This multifaceted relation could be termed equilibrium. When generalized adaptedness is reached and equilibrium exists, the ability may be adequate with respect to the environment and the goal profile; secondly the environment may be appropriate in relation to the ability and the goal profile. Adequacy, appropriateness and realism are the three main aspects of generalized adaptedness (48).

A person has good health if and only if he has the ability which his generalized adaptedness requires; his health is less good, if and just if his ability is inadequate. Health is a dimensional expression the polarization of which should be described, as a sequence of life variations between perfect or good health and ill or extremely poor health. Health is a kind of wholeness and the health of a person is thus a kind of agreement between his capacities being an acting subject within the limits of his evolutionary development (48).

It is a human fact that people must always keep the future open as involving new possibilities. Health is a condition to be involved, to be in the world, to be together with friends, of active and rewarding engagement in one's everyday tasks. Health

can pictured as a state of equilibrium. It is a condition of experienced lightness, where different forces are balanced. Health manifests itself by virtue of escaping the awareness. Persons are not all the time aware of their health; it belongs to that capacity persons have to forget themselves. The harmony which is hidden is greater than the harmony which is shown. Health is an example of such a concealed harmony (49).

Nordenfelt's (50) idea is that the notion of illness when it comes to humans has its basis in the individual experience of a perceived problem, as Pörn (48) and Gadamer (49) consider. The equilibrium theory presents a bridge between the humanistic concepts and the scientific biological ones. Diseases affect the basis of a person's capabilities. They are states of an anatomical, physiological, or psychological kind, such as tend to restrict people's capabilities relative to their goals (48, 51). The person can have, on the molecular level, serious diseases which have not reduced his ability to realise vital goals. Cancer for instance is not a disease because it is in abnormal state; it is a disease because it tends to entail grave incapacity. It need not so far affect the person and he can live for a long time without noticing it. The person can be said to be perfectly healthy as long as he functioned well in his daily affairs and the disease does not have any effect. As a result, a disease, even a dangerous disease, may be present in a completely healthy person (51).

Every disturbance in health, is a sign that persons must do up what is correct, to regain the balance of equilibrium, which is constitutive of life itself. Nature tries to restore what is disturbed, and to do so that the art allows itself to disappear after the natural equilibrium of health has returned. The nature of health sustains its own balance and proportion. If health cannot be measured, a natural form of 'measure' because it is a form of harmony with oneself, it cannot be overridden by outer control. Healing is even about re - convalescence and care for health. The physical pain is recorded through the person feeling a disturbance in harmonious physical balance constituting health, not by measurement. Dialogues increase the relationship between doctor/health personnel and patient. The final goal is enabling patients to enjoy the role they had previously in everyday lives. Only when it is attained can one speak about a full 'recovery´, which extends beyond the sphere of the health care personnel sphere. The re-entry into everyday life can be problematical, even if persons have got back their physical health (49).

In the hidden character of health, is the mystery of our nature as living beings. All that touches on life also touches on death; this is the double aspect of our existence. The body is life which is alive, and the soul is what animates (49).

## Existentialism

There are some key themes that all existentialists appropriate in their own way rather describing a similarity than constituting a definition of ‘existentialist’. Existentialism can be put in the following way. Existence comes before essence; a person’s essence (what he is) is the consequence of one’s existence (his choices) rather than the contrary, i.e. it is not a destiny. Existentialism includes a philosophy of freedom and responsibility meaning that humans can stand by and reflect on what they have been doing. In this sense, all human beings are always ‘more’ than themselves being as responsible as being free (52). Frankl (53) thinks that ´logos´, meaning, do not appear from the human’s existence but are sooner something he has to confront with and that will be realized by him. He means that humans have the freedom to make choices between accepting and rejecting an offer i.e. realize the possibility of meaning or throw away it involves.
The essence of existence according to Frankl (53) involves the human as a responsible essence who has to realize the potential meaning of his own life. This is because the true meaning of life is rather to be found in the world than in the human himself and his own psyche (soul), as this would be a closed system. So the real purpose of life cannot be self-fulfilment because the human existence is fundamentally self-transcendence, not self-fulfilment. The meaning of life is changing all the time but never stops existing, so meaning is to be found by acting, experiencing value and through suffering. The only way to find the meaning of life is to experience something, for example nature or culture, and to have someone to show love to.
Every time a human confronts with an inevitable situation, such as inoperable cancer, he has his last chance to realize the highest value, to fulfil the deepest meaning, meaning of suffering. Frankl (53) means that suffering ceases to be suffering at the moment it gets a meaning through a change of attitude. Humans are ready to suffer under the condition that their suffering has a meaning.
It is not only suffering but even the death which seems to deprive humans of the meaning of life. Only really perishable aspects of life are possibilities. This perishability is the ground for the humans´ responsibility because everything depends on humans fulfilling their inner perishable possibilities. It is important that humans cannot do anything to change fate but they can, no doubt, change themselves. Perishability and death, increase humans´ responsibility because in facing they are responsible to use fleeting possibilities to bring potentialities to life, to realize values, whether they are creative, empirical, or intended attitudes. A human being has, through his chosen attitude, the possibility to find and fulfil meaning even in hopeless situations (53).

Heidegger’s philosophy could be described as the existentialist ontology. His ontology is about his thoughts of being human in the world so it is not possible to split doing and being emphasizing that one becomes through doing. He attempts to

explain what it means to be human and the specificity of being human because man and the world are one i.e. being-in-the-world independent of context. The existentialists are identifiable within different contexts within real humans' lives. Being-with is illustrated by a mood, by how a person finds himself in specific circumstances (54, 55).
People are basically social in nature; born into a cultural world where one's being-with corresponds to what 'anyone' does, developing a 'social´. This cultural world is called by Heidegger a tradition, received as part of a common heritage. This tradition assists the creation of humans as a people and he talks about 'destiny' in this context, not blind fate but the objective limits and chances which appear out of collective past. In the existentialist sense, these chances can give rise to the possibility of true or untrue alternatives (54). The understanding must occur within the framework of a context with professional self-understanding. A professional understanding has dimensions of understanding oneself and of understanding others. The unpacking of that pre-understanding, a person has previous inklings, makes his existentialist view important. Concepts like Angst (existential anguish) and ecstatic temporality have a central place in his early belief. So does even the idea of mortal temporality (being-unto-death), the realization and optimistic acceptance of which allow both concretization of one's limitation and to open humans to the meaning of being by meeting oneself with the chance of ending to be (52, 54).

Gadamer developed Heidegger's insight that as human beings, people are already in some form of interpretation, whether it is explicit or not. By focusing on the notion of 'pre-understanding' and how more improved understanding comes into sight; Gadamer brought forward a tradition which opens the discussion concerning the connection between 'reflexivity', 'method' and 'insight' (31). Gadamer means that understanding and interpretation are basics of being-in-the-world.
Gadamer talks about spirit which can be considered as an existence. Existentialism figures out questions of life, its source and its conditions anywhere meaning, freedom, loneliness and death turn out to be essential in a concept of "spiritual health". Spirit consists of the body and that which animates it, embodying the spirit of the particular shape of life. Humans are not equal with life which reproduces itself, each one as a human must die his own death. The 'soul' symbolizes an individual field amongst others and reflects the entire embodied human existence, being the living power of the body. The life is awoken to think, to question thoughts and questions away from all limits. To know anxiety and to be unable to grasp death is called the ´human birth cry´ that under no circumstances fully dies (49). The life of the body is as an endless movement between the loss of equilibrium and the search for a new stability. Minor changes in balance is nothing that humans slant until falling and next turn back equilibrium but whenever humans exit this point of balance, they enter into enduring problems. Gadamer calls this the essential model for physical existence as a human, exposing the rhythm of sleeping

and waking, the rhythm of disease and rescue, and the transformation into nothingness, the dying progress of life itself. These create temporal constructions adjusting the whole course of our lives (49).

# AIMS

The overall purpose of this thesis is to identify and describe fatigue and its influence on men's lives when diagnosed with prostate cancer. Further, the purpose is to contribute to our understanding of the influence of prostate cancer and its affect on men's daily lives; increasing knowledge in order to develop the care of men with prostate cancer.

## Specific aims

I To identify and describe what fatigue means to men undergoing a prostate cancer examination and determine whether the examination causes fatigue as regards of feelings of uncertainty.

II To identify whether fatigue is found in men with newly diagnosed localized prostate cancer (predominantly early stage/very low tumour burden/asymptomatic patients) and to gain a perception of whether fatigue has an influence on these men and to try to find out what the cause of this fatigue was.

III To improve knowledge and understanding of how an advanced diagnosis of prostate cancer affects the men and their life situation and causes fatigue.

IV To provide information about if and how prostate cancer affects men's daily lives two years after the diagnosis.

# METHOD

The choice of research approach was qualitative inductive research design because there was little known about the topic (33). The qualitative research approach includes interviews and subsequent analysis of the content in order to gain new knowledge on the subject studied.
The use of hermeneutic design is one way of deepening the understanding of multifaceted phenomena, such as that of human experience (30-32). Thus an understanding of the topic and the aims of this research necessitated the hermeneutic approach in order to be able to interpret the phenomena being studied. Hermeneutics is about the lived experience of individuals as way in to the social, cultural, political or historical context and leads to a better understanding of the experiences occurring. Focus is mostly on meaning and interpretation, how persons interpret their world within their given context (31, 34).

Qualitative interviews offered a better way to gain understanding of how a disease impacts on humans and their life situation, or whether they experience vaguely defined symptoms or not. The interviews offered the possibility for the patients to explain their perceptions of what a symptom or disease means to them personally. This information is hard to gain from questionnaires.

Gadamer´s philosophical hermeneutics proposes no new norm of interpretation or new methodological suggestions to restructure existing hermeneutical practice, but tries to describe what really happens in each experience of understanding. The subjective intent is an insufficient standard of interpretation, since it is non-dialectical, though understanding itself according to, is basically dialectical — new concretization of meaning starting from the interactions that are proceeding constantly between the past and the present. Each interpretation attempts to be visible to the text, in order that the meaning of the text is able to speak to ever new circumstances, eliminating and requiring the translation of what is transmitted (56). In a hermeneutic study, the interpretation and understanding of the data is based on the researcher's existing knowledge and experience of the topics i.e. pre-understanding −coming together with the men's experiences. Prejudices help to understand what and when the person understands (31, 57).

## Setting and sample

The data were collected at two different hospitals in Sweden. The aim was to recruit a consecutive sample of men fulfilling our entry criteria and managed at the Outpatient Urology Clinic of a County Hospital in the Southern part of Sweden. The number of men with presumed advanced prostate cancer (study III and study

IV) diagnosed in the outpatient setting was diminishing at that hospital and recruitment was thus expanded to the second hospital, a University Hospital in the South-Western part of Sweden, in order to achieve the planned sample size. Otherwise, there was no difference in entry criteria between hospitals and the interviews were performed by the same investigator in all cases.

Purposeful sampling was used, selecting men for participation based on the particular knowledge of a phenomenon for the purpose of sharing knowledge (57). A total of 37 men were interviewed (See Figure1). The intention in studies I, II and III was to recruit between ten and fifteen men with the specific inclusion criteria stated below. Characters of the men are described to give some information which is of interest according to men´s life situation after receiving their diagnosis from the physician, not to perform any comparative analyses or to generate explanations (57).

The primary inclusion criteria in all studies were:

(i) Men ≤ 80 years old because multiple diseases after that age are normal and could influence the findings.

(ii) Not having participated in any prostate cancer investigation within the previous five years

(iii) Able to communicate: ability to speak Swedish, ability to understand (not unclear or confused)

(iiii) Able to give informed consent and willingness to participate in this qualitative interview study

The specific inclusion criteria in the respective studies were:
Study I
Participants in study I were men undergoing routine examination for prostate cancer (transrectal ultrasound and biopsy) but diagnosed as having benign disease. Seven men refrained from participation due to personal reasons. From a total of eighteen men, eleven men aged 56 to 77 years (mean 65.8 years; median 68 years) participated in the study. Nine out of these 11 interviewees were retired; ten were married and had children, while one was single and living on his own.

Study II
Participants in study II were men newly (within 2-4 weeks) diagnosed as having prostate cancer and with PSA level of ≤10 ng/ml and who were untreated at the time of the interview. One man refrained from participation. From a total seventeen men, sixteen men aged 48 to 78 years (mean 63.5 years; median 64 years) participated in the interviews. Eight of these 16 interviewees were retired; 14 were married and two were divorced.

Study III

The participants in study III were men newly (within 2-4 weeks) diagnosed as having advanced prostate cancer; PSA of ≥ 100 ng/ml and had been treated for no longer than 2 weeks at the time of the interview. Age criterion was expanded to men up to 100 years old because of difficulties in recruiting men with PSA of ≥ 100 ng/ml. Five men refrained from participation due to personal reasons or upon medical advice. From a total fifteen men, ten men aged 54 to 88 years (mean 72.1 years; median 75.5 years) participated in the interviews. Five of the 10 participants were retired; four were married, two were divorced, three were widowers and one was unmarried.

Study IV

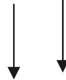
The participants in study IV comprised all men still alive following studies II and III. Four of the total of 26 men who took part in the interviews in studies II and III had passed away prior to study IV. All of the remaining 22 men, aged 50 to 85 (median 68 years), participated in the interviews in study IV. At the time of this second follow-up interview, 20 of the 22 men had been actively treated for cancer with different therapies, such as hormone therapy, surgery, radiation or seed implants.

# In total 37 participants/59 interviews

**Study I**
**Eleven men diagnosed with Benign Prostatic Hyperplasia (BPH)**
**Suspecting a Prostate cancer**
**Data: Qualitative interviews**
**Analysis: Gadamer´s Hermeneutics**

**Study II**
**Sixteen men diagnosed with newly diagnosed Localized Prostate Cancer, PSA ≤ 10 ng/ml**
**Data: Qualitative interviews**
**Analysis: Gadamer´s Hermeneutics**

**Study III**
**Ten men diagnosed with newly diagnosed Advanced Prostate Cancer, PSA ≥ 100 ng/ml**
**Data: Qualitative interviews**
**Analysis: Gadamer´s Hermeneutics**



**Study IV**
**A two-year follow-up**
**Twenty-two men; sixteen men from study II and six men from study III**
**Data: Qualitative interviews**
**Analysis: Gadamer´s Hermeneutics**

**Figure 1: Study design**

## Interview

A qualitative interview is like a conversation, even if interviewers have a list of issues focusing on the research topics (31, 58) that the participants want to deal with (58). The general interview guide approach was used in studies I, II and III, consisting of four to five broad and open-ended research questions, covering the area of the study (58-59) and designed to avoid influencing the patient. The participant or the interviewer often raised topics related to the interview guide, spontaneously. Interview style was open, which is crucial, concentrating on the power of attentive listening (31, 57-58). To get the men engaged in their own belief and bring in that was central for them about the topics, the interviewer waited quietly saying things like “I see”, “Can you tell me more about…”, “In what way” and so on (57). The general interview guide with issues added from the first interview texts was used in study IV. All participants were asked to present supplementary details to the interview if there were something they thought was important but was lacking.

## Data collection

During the spring of 2002 data were collected for study I. After the men gave their informed consent to the physicians, they were contacted by the researcher by telephone within two weeks of receiving their diagnoses and interviews were scheduled at a time and place suitable for them. Patients were mailed information immediately before the interview dates describing the study, its aim, structure and voluntary nature.
Data collection for study II was performed during the spring and autumn of 2003 and for study III from the autumn of 2003 until December 2005. An enquiry about participation in studies II and III was made by the physician or mailed after informed consent was given to the physician and telephone contact was taken by the researcher.
In the follow-up interview; study IV, the data were collected between May 2005 and November 2006, the men were contacted again 18-24 months after the first interview (studies II and III).

The interviews were conducted at places convenient to and chosen by the men, such as their homes, different consultation rooms at the hospital or in primary care, and in rooms for teamwork at different neutral places.
The interviews were tape–recorded with the interviewees’ permission and transcribed verbatim. The participants were assigned codenames to preserve their confidentiality. Before the interview, there was some small talk to create a relaxed relationship between interviewer and interviewee. After the interview, time was

given for reflection on the interview. The interviews lasted 25 – 45 minutes, with the total time per interview varying between 50 to 120 minutes.

The following topics were focused on during the interview:
Study I 1) How would you describe fatigue? 2) What does it mean to you? 3) Have you experienced fatigue today? 4) Do you remember what you were thinking about, when you were waiting for your planned prostate examination? 5) How did it influence you?

Study II 1) Are you experiencing fatigue today? 2) Have you experienced fatigue at some time in your life? 3) How did it influence you? 4) Does cancer influence your life situation to-day?

Study III 1) Does cancer influence your life situation today? 2) Can you describe your life situation? 3) Have you experienced fatigue? 4) If so, how does it influence you?

Study IV 1) Does cancer influence your life situation today? 2) Can you describe your life situation? 3) Have you experienced fatigue? 4) If so, how does it influence you?

## Data Analysis

In order to gain a deeper understanding, a hermeneutic analysis and interpretation guided by Gadamer (31) was used for this analysis, in order to explain and describe how a cancer diagnosis affects the men and their life situation. Co-operation with the research team consisted of reading the transcriptions and discussing any researcher perceptions related to the interview situations and the outcome data throughout the process of analysis. The text from the interviews has been analyzed using the principles of Gadamer´s hermeneutics (31, 57). The text from the interviews has been analyzed in four steps:

This first step can be understood as openness. The transcripts were read through several times. The first analytical task was to build a sense of the whole (31-32, 57). This step gave a general sense of the content of each interview and an insight into what was important in the context and gave an initial understanding − of affected life situation.

At this second step, an awareness of the power of tradition, understood as a personal history or effect is an important principle. The meaning of the text is the result of the fusion of the horizons of the text and its interpreter. The data interpretations are the result of a systematic approach whereby the researchers

began to have a dialogue with the text by focusing on the participant's present life situation in order to establish if they had changes in their life or if they felt that they experienced fatigue due to their cancer.

This third step consists of two elements: a descriptive phase that proceeds from the horizon of meaning of the text and another phase in which the text is interpreted and analyzed from the interpreter's horizon of meaning of the text. The interpretation consisted of the descriptive phase progressing from questions, posed by the text. A meaningful dialogue regarding the men's understanding horizons was conveyed through language. Questions were generated both by the text and by the researchers. Analysis was done on both horizons in the hermeneutic circle, giving a description of the whole text and then identifying different types of clusters as a whole (31, 57).

Understanding is carried by the fusions of horizons and refers to the integration of constructions given by the men, by our interpretation of situations explained in interviews, by our professional background and by selected literature.

The fourth step is based on interpretation that involves the fusion between the horizons of the interpreter and the text. Each phrase and sentence from the transcribed interviews was reconsidered in order to analyze and interpret the data; aiming toward interpretation and understanding from two different horizons of meaning (31, 57). The whole analysis has proceeded with as a hermeneutic circle; from the part to the whole and back again, man by man, sentence by sentence. The analytical process is systematic and based on an understanding of the text of the interviews in addition to the facts. The text must be understood as an answer to a real question (60). In the process of understanding a real fusion of horizons occurs and the researchers´ own meaning appears.

## Trustworthiness (Validity)

This whole thesis was planed and designed prospectively. In qualitative research, the concepts credibility, transferability, dependability and confirmability, are used to illustrate different aspects of trustworthiness (34, 57, 59). Although splitting the expressions of trustworthiness, they should be seen as interrelated. Lincoln and Cuba (59) mean that trustworthiness exists when the findings of a qualitative study give a picture of reality. Fleming et al. (61) present a way of acting with the trustworthiness of a qualitative research process, which are applicable to a Gadamerian research process.

The initial topic concerning credibility starts with a choice of the focus of the study, selection of context, participants and approach to data collection. Concepts need to

be clearly described relating to each other with no overlap. Choosing participants with diverse experiences enlarges the chance to illuminate the research issue from different aspects (57). The interviewees were of various ages, in different prostate cancer stages and in different phases in their lives, with various perspectives fulfilling the criteria.
In this thesis, co-operating with research teams during the whole research process; critical checks concerning the participants, reflecting researcher's own influence over the situation and involvement; open questions and assistance questions; follow-up on some un-clear points forward and back again between data gathering, analysis, quotations from the transcribed text and dialogue have been ways of achieving credibility. The value of dialogue among co-researchers has been highly important. Credibility distributes the research and refers to relying on how data and processes of analysis are confronted (34). Major trustworthiness is credibility and cannot be well established without access to the data sources themselves (59).

Trustworthiness includes even transferability referring to the area where the findings are transferable to other groups (34, 59). In the present thesis, to facilitate transferability, clear and individual descriptions of culture and context, selection and characteristics of participants, data collection and process of analysis is crucial. Even the findings together with appropriate quotations enhance transferability. Findings in qualitative studies cannot be generalised but can be applied in another context, such as for the disease characteristics of the sample (62).

Another aspect of trustworthiness is dependability/reliability. Dependability (34, 59) is about confirming the way for both instability and phenomenal or design induced changes, that is, the degree to which data change over time and alterations made in the researcher's decisions during the analysis process. There is a risk of inconsistency in data collection, when data are broad and the collection eventually expands. It is important to ask the same topics for every participant yet interviewing is a developing process when interviewers attain new insights subsequently influencing follow-up questions or narrowing the focus. In this thesis, dependability was gained by use of the interview guide, tape-recorder, describing data collection and methods for analyses; describing participants and context described and coding and reading by the research team. The consistent and accurate audit in the thesis examined the process results in dependability so the inquiry audit involved an analysis of data in the form of recorded materials, data reduction, data reconstruction as findings, relationships and interpretations, and process notes by the research team.

Lincoln and Cuba (59) mean that the steps of research process have to be identifiable by interested participants; the confirmability audit is a criterion of truth in qualitative research so the conclusions and interpretations emerge obviously from them. Objective understanding is only possible in the respect that it can be

achieved on the basis of common characteristics, such as language and culture, so understanding is not possible independent of them. Objectivity in hermeneutic research can be understood by faithfully representing the texts and even being an ideal and cannot be reached fully because the person who reads shall interpret findings from their own horizons. In this thesis confirmability (objectivity) was attained by asking for explanations and elucidations and by discussing summaries with the participants. Inquiry audit trail involved examining the data and reconstruction of results to achieve confirmability (by co-operating with research team, interview transcripts, data reduction and analysis, process notes, personal notes on intentions and data reconstructions process).

According to the truthfulness of the analysis, research in the Gadamerian tradition can be different from other qualitative methods. If the person, who is reading, is familiar with the situation, he is able to understand the truth of that situation Gadamer (61) nevertheless, explained there is no statement that is generally correct, since no statement can avoid the complexities of interpretation. For Gadamer (31), understanding can only be reached by harmony of the whole and the parts of a text. This presents a standard for trustworthiness related to the processes instead of simply to the conclusions of the research.
There is no single exact meaning or general application of findings, but the most probable meaning from a specific perspective. In qualitative research, trustworthiness of interpretations deals with establishing arguments for the most probable interpretations (61).

## Ethical considerations

The study protocols (Dnr 01-124 and Dnr 01-124 Addition) of studies I, II, III and IV were approved by the Research Ethics Committee at the University of Linköping, Sweden, and of studies III and IV by the Research Ethics Committee at the Sahlgrenska Academy, University of Gothenburg, Sweden. Swedish (63-65) and international guidelines for medical research (66) were underlined and that participation was voluntary, as well as the patients being able to withdraw, without any explanation, at any time they wished, without any negative consequences for their treatment. These guidelines served as a guide during the whole research process.

Ethical consequences of autonomy and risk of causing emotional harm through interviews were considered. The men were recruited to studies I, II and III during their medical visits. As soon as the urologist deemed it suitable, the men were given oral and written information about the research studies. They were briefed on their right to withdraw from the study at any time without any motivation. An informed, voluntary consent was an explicit agreement which was returned to the

researcher by the research participants. Before study IV, the researcher called the men to ask if and be sure that they were willing to participate in the interviews. At the same time, they were informed of their entitlement to refuse participation. The researcher tried to be as explicit as possible when making time limits for interviews and looking out for potential sidetracks according to researchers´ scientific responsibility, relations to the participants and independence.

Approach and process in research have to be fair and in accordance with the principle of justice (66, 67). In this thesis, the men had the right to fair and equitable treatment before, during and after their participation in the study as well as their right to privacy; to participate or not in the studies did not influence on the men´s care or treatment.

The probable risk of men´s involvement in the studies could have been of an emotional nature, as it could be stressful to discuss the circumstances of the disease. Ethical considerations were emphasized with regard to the interviews. The principles of beneficence, non-malefience, doing good and doing no harm were effected (66). In interviewing adult men with a suspicion/diagnosis of prostate cancer and asking them to relate their experiences, it is possible that discomfort and anxiety can be aroused. They could be reminded of feelings and memories which were hurting at the time, but could, on the other hand have a beneficial influence on the person. Speaking about their feelings always involves a risk of crossing the border which the people regard as their personal sphere. The researcher paid attention to the men’s desires to finish the interviews, either owing to emotional worry or an expression that the interview was over. After the interview, the interviewer recapitulated the main points from the interview, so that the men could comment on this feedback. They received even the chance to deal with issues they had been thinking or worrying during the interview. After the interviews, the participants could phone the researcher who, in turn, could refer to the social officer or psychologist as support if needed. Treating the participants with respect, caution and sensitivity was a central approach for the researcher.

Qualitative researchers study small samples, and there is a need to be conscious of the necessity of shielding the identities of the participants. All data were coded to guarantee confidentiality. In order to achieve confidentiality, the patients’ real names were not used on the tapes and transcriptions but code numbers/letters or pseudonyms were assigned instead. The list of codes that applied to the true patient identities, i.e. the ‘key’, was stored separately. Data were continuously gathered on discs stored in locked files, to which only the researcher had access as a further method on ensuring confidentiality. The men could, without any motivation, ask to see the recorded data. This management of data was one way of not harming the participants’ integrity.

# FINDINGS

## Summary of the four studies included in the thesis

## Study I; No Fatigue Related to Prostate Cancer Examination: A Qualitative Study

Eleven men undergoing prostate cancer examination on the basis of a clinical suspicion of prostate cancer but who actually had benign disease, participated in the interviews. The findings were called Everyday fatigue, Personality and Anxiety, they were all involved and integrated with one another.

### Everyday fatigue

Everyday fatigue is a part of normal life and was sometimes raised as a condition without any causes. In relation to aging and biological processes it was closely associated with frailty. Capacity was changed but was accepted or compensated for by persistence and cunningness. After effort, a sense of fatigue could occur as a nice, natural feeling for a moment. Other causes of fatigue were described as lack of sleep, mental and physical disturbances, such as after operations and medical treatments. Everyday fatigue is a natural temporary human reaction to make the person settle down.

### Personality

The men who experienced fatigue, expressed disharmony, mental instability, emotional strain, less worth and uncertainty which were not associated with the examination for suspected prostate cancer. They had had, even earlier than the examination for the suspicion of prostate cancer, for example depression and expressed a kind of sensitiveness to fatigue, because of future uncertainty.

### Anxiety

Anxiety contributed to and could cause fatigue. Fatigue was described as physical and mental resignation. Mental and physical fatigue goes together; the body is not able to manage the task, causing negative thoughts which lead consequently to apathy, and to mental resignation. The prostate cancer examination itself was not the reason for anxiety but the thoughts it made them conscious of were the real cause.

Around the time of prostate cancer examination and expecting the answer, the men did not feel fatigue because of the examination. All men expressed that they did experience normal every day fatigue. Personality, in the sense that those who were treated for some mental health problems, was a factor which influenced the men, causing fatigue. These men even expressed anxiety as contributing to fatigue.

## Study II; Men's perception of fatigue when newly diagnosed with localized prostate cancer

Sixteen men newly (within 2-4 weeks) diagnosed as having localized prostate cancer with PSA ≤10 ng/ml and who were untreated at the time of the interview participated. Findings consist of five stages and were elaborated, in succession. They are called Enclosing Intrapersonal Emotions, Enclosing Interpersonal Attachments, Re-opening Intrapersonal Emotions, Re-opening Interpersonal Attachments and Living with New Perspective.

### Enclosing Intrapersonal Emotions

Enclosing Intrapersonal Emotions was a kind of vacuum. The men's expectations regarding the diagnosis influenced their initial emotions. They experienced a sense of physical vulnerability and they felt uncertain knowing that they might have to confront possible tumor dissemination, loss of control. The first emotional reactions were similar to shock. Their feelings were, for example, anxiety; fear of maiming surgery, loneliness and restrictions to their manhood. The men appeared to be blocked and overwhelmed in emptiness created by them, without capacity for ”input”.

### Enclosing Interpersonal Attachments

Even Enclosing Interpersonal Attachments was a kind of vacuum. On the one hand, the men wished to receive practical advice and tips, someone to talk to offering empathic backing. On the other hand, they had difficulties in being open and discussing their cancer perceptions. Their relationship with the physician could be valuable, similar to friendship, or abrupt but distinct. For a while they did not manage to tackle “input” or “output”. The men did not wish to hear pity, but the supportive persons around were valued for their positive thoughts and thus providing an atmosphere encouraging action.

### Re-opening Intrapersonal Emotions

Re-opening Intrapersonal Emotions contributed to go-ahead spirit. After a mental block the men triggered off a rebellion allowing them to move forward. They had to accept a diagnosis of prostate cancer in spite of their disappointment. Adapting their emotional reactions, the men got the fighting spirit in order to live with dual perceptions, such as a sense of anxiety and hope; giving up and getting up in revolt; vacillating fait; acceptance and denial; liveliness and reflection. This was a way to gain control over the situation contributing to optimism and hope.

### Re-opening Interpersonal Attachments

Re-opening Interpersonal Attachments also triggered and contributed to go-ahead spirit. The men became again aware of those around and opened their minds to them. The people in their surroundings had their own processes of adapting to the

situation. Some men did not discuss their experiences of prostate cancer whereas some did. The talkative men felt that prostate problems are natural and first now had they found several others around them with prostate cancer. The men themselves must find their own individual way of going forward in their lives.

### Living with New Perspective

Living with New Perspective was obvious for the men. They had the need to solve the practical problem to get on with life, "get a foothold" and to stay in their changed world, where life continues whatever. The men tried to generate activities in different ways in order to gain control over the situation and their daily routines. They searched for information about prostate cancer and its treatment through the mass media and some valued informal networking-groups among friends. To live, to take care of their beloved ones was essential; carrying out meaningful activities, returning to their normal social network was the embracing wish.

Most of the men did not experience fatigue due to their diagnosis of localized prostate cancer. Findings in the study, in consecutive order, are detailed below, showing that prostate cancer did affect the men. Firstly, they got into an emotional vacuum with feeling of void immediately when receiving the diagnosis where "input" was useless; it was to ask for impossibilities. Soon after that a contact vacuum was a reality and no "input" or "output" was realistic but the men still wished for an inciting and optimistic environment. Next after that the men got back their emotional go-ahead spirit to control their lives again in spite of twofold emotions where "input" was possible. Quite soon they found even different approaches to face the people around them again and to meet the future. Finally the men stated that the cancer gave them a new perspective to their lives with new priorities.

## Study III; Men's experience of their life situation when diagnosed with advanced prostate cancer

Ten men newly (within 2-4 weeks) diagnosed as having advanced prostate cancer, or having a PSA of ≥100 ng/ml and treated for no more than 2 weeks at the time of the interview participated. Side-effects of treatments at the time of their interview were not manifested. The findings consist of The Awareness of Mortality, Influence on emotions, and Influence on normal life.

### The Awareness of Mortality

The Awareness of Mortality was obvious. The men were aware of their mortality and life's fragility causing initially a sense of sadness. The men turned into themselves wondering about and adapting to the received cancer information. The thoughts were about the risk to their lives, their physical integrity and wellbeing,

their self-concept and stability. Each person has his own unique social roles and activities, so they have to adapt to new social and physical situations.

Reflections about the future, and the need to plan for practical issues came up, even if the men's thoughts in reality were about mortality and were present constantly. Some men did withdraw from other people to reflect upon their new situation. Death itself did not frighten them as much as the way they would die. Everyone has to die, of-course, no matter how you think or what you do. This understanding caused spiritual thoughts like if a person becomes religious as they become older or thoughts about life's transitional aspects became obvious.

A kind of a driving force to live each day as if it were their last day, living more intensively was emphasized. A person has no power to lengthen his life even if he wants that. The cancer diagnosis, not aging, made the men conscious of, and reminded them of death. A death caused by aging did not make the men conscious of their mortality but the prostate cancer diagnosis, which more clearly defined their expected term of life, did. While trying to be their normal quite optimistic selves, in the backs of their minds there were many ominous thoughts.

### Influence on emotions

Influence on emotions was aroused by the diagnosis of advanced prostate cancer. Emotional consequences based on life being threatened; normal life is interrupted with changes in daily life. Those men, who withdrew themselves, did not know how to proceed, so they were living in a kind of vacuum, struggling with all their emotions and thoughts, by themselves. After a while, some men opened themselves up to those around them and talked about their cancer, mortality and death. Those men who did not talk about their cancer stated that the reason for not talking about it was their awareness of their own sorrow and that they themselves had hardly the strength to get through their situation.

Emotions were swinging between being rational and irrational, at the same time as laughing and a moment later crying, illustrating the confusion between hope and despair. Feelings of fear and nervousness reminded the men of their vulnerability. Cancer causes changes in daily life which changed the men's suppositions about self-value and control. All these emotions and reactions came as a kind of shock and the men needed to be comforted. They were influenced emotionally when the hopes of their nearest relations were shattered. They could achieve a sense of protection by avoiding talking about the issue and dissociating themselves from the problem. Their only wish was to close their eyes, withdraw and stabilise their emotions in order to continue as before.

The men have different personalities with individual strategies with regard to being close or open in relation to these emotions caused by their cancer diagnosis.

Somehow, they had a sense of being stronger and more alive than ever alternating with feeling weak.

### Influence on normal life

Influence on normal life and life pattern was result of a diagnos of possible terminal cancer. The wish to live as normal and to regain control as far as possible was crucial. All the men's attention was turned to incidents and disturbances related to everyday life, like having a catheter, making choices concerning therapy, the side effects of treatment, prognosis and the future.
The greatest issue besides all the decisions being taken was the risk of losing control over their lives and a wish to get back into their social life, to feel that they are alive with a respite of some more years to live. The wish for their cancer to be under control i.e. for two to three years and, after that, a new time period was like intermediate goals. The situation was not rational; on one side you feel healthy and on other side you have incurable cancer. To know the diagnosis gives the possibility of acting and, in some sense, of sustaining ordinary daily life.
The men planned to go back to work as soon as possible. Working gave them a feeling of control; they had concrete tasks to do and these represented a way of keeping thoughts away from the cancer and the resulting pressure. The men lived one day at time and, at the same time, they wished to live here and now.
The men with a catheter wanted to be rid of it; it was a reminder of their lost sexuality. The future inability to have sex and possible side effects from the hormone therapy were embarrassing. It was easier to talk about an enlarged prostate than prostate cancer. Differences between men and women were raised, like men cannot easily admit that they cannot function sexually. Prostate cancer put a definitive end to masculinity, one's sexual desire recedes. You can live without being sexual active, the most important thing is to control the cancer. The good thing is if you can talk about it with your partner and still remain a man, a partner.

The men did not experience fatigue due to advanced prostate cancer. They had experienced normal every day fatigue in their daily lives, for example after exerting effort, due to aging, other biological processes and due to other concomitant diseases. Mortality was present, even if it was in the background, which initially gave a sense of sorrow. The men were wondering about the different risks in their lives because of cancer, such as new social roles and need to adapt to new situations. Thoughts about the future and how to die were worrying, even if they realised that death was unavoidable. The men wanted to live more intensively. They felt emotional vacuum and, at the same time, they perceived themselves being both logical and illogical. They wanted to live as previously expressing that somehow they felt more alive and next moment weak. Bearing catheter influencing one's masculinity and the feeling that there is a risk of losing control were aspects which the men perceived disturbing. They were longing to work which give normality and other things than cancer upon which to reflect.

## Study IV; Living with a prostate cancer diagnosis; a qualitative two year follow-up

The follow-up interview was made with all the men, diagnosed with localized or advanced prostate cancer (studies II and III) approximately 18-24 months previously, who were still alive after the first interview was conducted (study IV). Four of the men who participated in studies II and III had passed away prior to study IV. Twenty out of 22 men had been actively treated for cancer with different therapies, such as hormone therapy, operation, radiation or seed implants. The findings consist of Age is claiming its due, Living with uncertainty, Strengthen self-esteem and the unifying fusion Balancing a changed life situation.

### Age is claiming its due

Age is claiming its due means that different limitations were caused by aging. The sense of frailty was apparent. Impairment of physical function, owing to biological changes caused by aging was realized but, at the same time, the men denied to confess it officially. Using aids caused by reduced ability to use ones legs or dizziness affected their pride; they had not become that old yet. There are diseases, which have been discovered to be related to aging, such as heart failure and the side effects of its treatment which have impact on one's ability. Social and psychosocial limitations form a sense of sadness even if these are regarded as inevitable and have to be accepted. Social adjustments consist of emptiness owing to becoming widowed and losing friends due to death, loss of social roles including obligations outside the home. Selling the house or the house in the country side and living in the apartment were also social adjustment due to age. Men encourage and accept that their healthiness is declining as a natural human progress as they become older. They do not allow disease or its omen influence their ordinary healthy behaviour.

### Living with uncertainty

Prostate cancer was perceived as unpredictability and living with uncertainty is ambiguous. Men express being in doubt about the information they received from the physician but despite that had confidence in the physician, trusting in his competence. Uncertainty was about the primary nature of prostate cancer, its primary cause, if and how they could have prevented it and whether the chosen treatment is most effective.

The need to obtain knowledge about prostate cancer was highlighted. Knowledge of cancer and even health are essential in order to decrease uncertainty and increase welfare and thus give reliable confidence between men and health care professionals.

### Strengthen self-esteem

Strengthen self-esteem in living with prostate cancer for about two years was identified. The amenities of life and confidence are growing aspects when the men

realize that they are still alive. Independence is important and the men find out that it is possible to maintain this freedom and integrity. Daily life is managed and they grow as individuals.
The men point out that kindness, friendships and straightforwardness are considered crucial in their relationships. However, interactions are allowed to take place on the men's own conditions and they do not have time to waste on worthless relations or duties. Physical closeness involves manifestations of love; hardly any one of the men wanted to improve sexual functioning by using different aids. It is uncomplicated to admit impotence and for some men sexual desire has practically disappeared, other values emerging instead.
Survival of cancer was the reason why some men initiated forum inspiring and giving courage to other men by speaking in public and having an impact on society and government through a dialogue with politicians.

## Balancing a changed life situation

The unifying fusion; Balancing a changed life situation, was identified. The men were back in life knowing that cancer is conquered, at least for a while. They balanced their uncertainty with self-esteem using their life experiences due to age in this balancing. The whole approach to life was changed, forming the basis of satisfying living and appreciation of life itself. They value and recognize life as a unity; physically, mentally and emotionally. The men manage to handle their physical limitations, to think positively and use their feelings to express themselves. They express having economic security, which makes it easier to do what they want facilitating their balancing, but at the same time the material things were of less importance.
The men found a kind of inner power to live more intensely; at this moment, live day by day delighting in just the present day. To be honest with themselves, as well as be straight forward in their communication with others was essential. The men revalue ´little´ things which they enjoy in, in spite of running on the treadmill.

Age as well as various diseases has an effect on the men´s ability. There are limitations due to social roles and circumstances, both at home and in society as a consequence of aging. Uncertainty around their prostate cancer created the necessity to obtain more facts and different aspects around these facts. The men expressed how they got increased confidence when they understood that they were still living. They found that they could sustain independency and integrity which were important regardless of cancer. Their relationships were considered to be valuable but they only chose to maintain those they considered worthy.

# COMPLEMENTARY FINDINGS

By an overall examination of the findings, additional findings about health appeared. In studies II, III and IV, the men expressed that they felt healthy. Seven men in study III explained spontaneously that they are healthy persons, not sick. In study IV, the men were living with a sense of feeling healthy, even when having lived with prostate cancer for about two years.

Through this examination of the findings, even findings about existential thoughts appeared. In studies I, II and III, the men expressed their thoughts, in different ways, about mortality, the fear of death (study I), uncertainty about the way of dying but they expressed that they were not afraid to face death itself. The men realized that the body is vulnerable, life is fragile and their own existence was threatened. Death is unavoidable, no matter how you think or what you do. This understanding created spiritual reflections for example about life's transitional aspects. In study IV, the men expressed living with a life-threatening disease is the same as not know how long life will be. Spirituality gave stability for the men, implying in different ways thoughts of God, aesthetic experience, sensation of nature and music; some were enjoying travelling and discovering the world. The cancer diagnosis reminded the men of death, clearly defining the expected period of life. Living could no longer be taken for granted and they meant that to live and take care of their beloved ones is important.

# GENERAL DISCUSSION

## Discussion of the Findings

### Fatigue

In the present studies the men use their individual meaning of fatigue built on their own thoughts and experiences when they talk about fatigue. The surprising finding in this thesis is that the men clearly express that they do not feel fatigue due to prostate cancer, no matter for what type of prostate disorder, or at which stage of prostate cancer the interviews were conducted. Cancer diagnosis influences men in the way which is described in the present studies, for example as changes in physical capacity and emotions. These feelings are described as being associated with cancer-related fatigue in other studies (68-73), which the men in the present studies do not define as fatigue but as being normal Every Day Fatigue. Given et al. (74) studied predictors of fatigue among elderly cancer patients (841 patients aged 65 or older newly diagnosed with breast, colon, lung or prostate cancer) and found that stage and more co morbidity were related to fatigue. The results of the present studies are in contrast with previous studies (68-73), conducted with self-report instruments, which show that fatigue is a common symptom owing to cancer and its treatments. All men in the studies (I and II) has either gone through examination of suspected prostate cancer or has been recently diagnosed with prostate cancer, i.e. before beginning therapy. Anxiety is a common reaction on being diagnosed with cancer (70) and thus suspected cancer could, through anxiety, be expected to contribute to fatigue, which study I does not show. The men has experienced normal Everyday Fatigue due to, for example age, concomitant diseases or medication, biological processes, exertion or lack of sleep. Fatigue is not perceived as an illness but rather as a normal incident. This kind of experience corresponds with other studies as well as Glaus´s and Piper's perception of reactions in healthy individuals (10, 14, 36, 42). Kim et al. (75) measured 282 symptoms of breast-cancer patients who were treated with chemotherapy or radiation therapy, at baseline and two follow-up points. They found that the psycho neurological cluster (depression, discouragement, fatigue, pain, insomnia and cognitive disturbances) had as the significant predictor age and physical status at baseline and at the last measuring even therapy effect. They support the present findings. Cooley et al. (76) through their study among lung cancer patients disagree and mean that the relationship between symptom intensity and age do not exist. These different findings can be reflected upon whether the patients and the health care personnel are really thinking about the same thing, or condition, when discussing or making inquiries about, for example fatigue. If this is the case then the gap between men and health care personnel needs to be bridged, in order to find a way breaking down misunderstanding and to reestablish communication to support the men as needed. One reflection pertaining to the studies in this thesis is

whether the questionnaire is constructed in such a way that it presumed that there is an agreement about what fatigue is. The men in study I answer regarding what they themselves associate with fatigue and how they would define fatigue, so the answer should be from the men's perspective, which is the aim of this thesis.

## Health

People in the western world are becoming older and are thus living with chronic disorders, which affect their everyday lives. Living is threatened because of prostate disease or prostate cancer, through the loss of equilibrium. According to Gadamer (49), this loss affects the whole person, including psychological balance. All men in the studies (I, II, III and IV) at the time of the interviews feel, however, healthy. Age and health status are topics when the men talk and regard themselves, they find themselves valuing health, the possibility to live longer and be physically in a better state. They consider that those troubles they experience are age-related rather than prostate cancer related.

According to Gadamer (49), health manifests itself when a person is not aware of health, it is hidden and you do not think about it, which was apparent because the men had not thought about health or disease before coming to the physician. The capacity to perform certain physical functions is changed or diminished, which is what make the men visit their physician. The men are thus aware of these changes but they believe them to be caused by aging rather than to a prostate disorder or prostate cancer. Even psychological disturbances and physical changes corresponding to relationships and emotions connected to normal aging can endanger self-image, which can be further jeopardized by a prostate cancer diagnosis. Diminished abilities are described by Gadamer (49), Pörn (48) and Nordenfelt (51) as disturbances in the balance of one's life, making the person regard his health as being less good. Some men pointed out that prostate cancer and health go together and perhaps you have to make choices because of that. Experiences of prostate cancer open the men to thoughts and understanding about health, aging, male identity and, at the same time, how it threatens their independence and their need for control. The men talk about understanding of prostate cancer and health back-ups driven by need and found through their own action. They point out functions when discussing the prostate cancer disturbances in their daily lives but these are not necessarily faced as a dilemma or as initiating suffering. The diagnosis require that they, at the same time, adjust to the changes due to cancer, as well as to other standard changes particular to their age group, in correspondence with other studies (77-80).

The men reflect over their health behaviour and feel that acting is like gaining control over their prostate cancer; they hope that PSA levels would be reduced and that the prostate cancer would shrink after treatment. They maintain their health through different physical activities, recovering their condition and life; they spend

time with their families and the friends they chose. No one talk spontaneously about having made life style changes when receiving their prostate cancer diagnosis in accordance with the study of Satia et al. (81). Imprecise feelings of aging, together with symptoms of prostate cancer could make the men consider their disturbances to be natural consequences of aging and therefore ignore symptoms of newly diagnosed prostate cancer. Harden et al. (77) explored by the literature review the relationship between developmental age and disease-specific issues that may affect a couple's QOL as they adapt to a prostate cancer. They mean that as couples they face developmental tasks specific to their age, examining stages of aging in three phases: 50-64 years/65-74 years/75 years and older. The men (50-64 years) perceived psychological issues and physical changes associated with aging can threaten self-image. Many men (65-74 years) continue to experience good health but are beginning to experience physical changes related to aging. The men (older than 75 years) expressed that at this point biological factors are predominant in the aging process. They found that few studies considered age as a relevant factor in the analysis of outcomes of treatment. Harden et al (77) are in harmony with the present studies according to changes associated with aging. From a health perspective, loss of that equilibrium is obvious because of those disturbances between physical ability, social relations and even goals the men has difficulty in fulfilling. The men in the present studies perceive a balance between abilities, social relations and goals, which, in turn, influence their perception of health. This corresponds with Pörn´s view (48) of health.

The all-embracing depiction is that the men has found a kind of balance in their lives approximately two years after their prostate cancer diagnosis. This process of balancing begins in some way already when they are informed about the prostate cancer diagnosis, so the vacuum, they go into can be regarded as the start of that balancing. The men has gone through a process of accepting the altered reality. They find it essential to re-establish equilibrium as soon as possible. After about two years, the men has made different adjustments in their living and has recovered equilibrium between emotions, relations and physical capacities or abilities as a whole person. Some men express biological changes like bowel problems, decreased mobility and troubles to do common activities but they would not admit it officially. Their ability is decreased because of other diseases and aging. Social, as well as psychosocial limitations, in their interactions are present and has awoken sadness but they know at the same time that they has to accept them. Harmony in balance between abilities, environment and goals find in these studies agree with the findings of Pörn, Gadamer and Nordenfeldt (48-51).

Health is changing as a natural process of aging, so the men in this thesis are aware that normal biological changes are prevalent in aging. A new situation physically, socially and mentally on the private front diminish social connections owing to death of friend which can lead to sense of loneliness. Social adjustments caused by

friends' mortality, one's own changed living and social roles influence some men in such a way that they feel unworthy. When a man becomes older, he needs time for adaption or revival expands. The men tend to be health optimists with better health insights than only neutral facts; this confirms the findings of Harden (77-78). Older people tend to use several points of reference in order to value their whole health and health-related satisfaction, which can be different when the person adapts to circumstances (78, 80). From a health perspective, the men has found equilibrium between their abilities, the environment and their new goals. They has made an adjustment to their altered health and accept it accordingly: they has recovered harmony, build on their perceived experiences during the last two years of living with prostate cancer. This feeling of balance or equilibrium corresponds with literature (48-49), which describes the perception of regaining health.

Some men has wished for information on changes in sexuality and relationships, on ambiguity about the future and worry about therapy results beyond control, as well as on bodily and daily living plus on being informed about examination outcomes once they were available. The studies in this thesis correspond with previous studies among men with prostate cancer (26, 82-84). In the study (85) about psychosocial barriers to active surveillance (AS) for the management of early prostate cancer, it was found that enhanced AS consists of improved instruction and communication, interventions to diminish anxiety and uncertainty, and the empowerment of patients by increasing of a feeling of control and meaning. Many thoughts occupy the men's minds: about methods of preventing prostate cancer, receiving back-up to achieve a positive attitude, the need for supportive informers providing advice about the best treatment and knowledge and about cancer and health in general. There is a need for information about follow-up routines and the men´s medical conditions. They trust in the urologists, who influence them when they make the decision about their treatment, since they perceive insecurity in not be able to predict cancer progress, spread of cancer and death. The same result has been shown in other studies (17), i.e. relating to the men´s trust in specialists´ decision making regarding choice of therapy. They expect that the physicians would call them for check ups of their prostate cancer and inform the men if the cancer progressed. The men are seeking the way to adjust their abilities in the form of increased knowledge to better understand and so develop a new, improved life condition. Health includes the whole human being, where even knowledge about one's function is important to make the best choice between the alternatives. As described by Pörn (48), adequacy, appropriateness and realism are the main aspects relating to generalized adaptedness called equilibrium.

Upcoming latent and even present physical limitations the men are thinking about, are for example impotence, incontinence, and dependency as possible incapacities because of possible body changes related to loss of physical function. Even if some men note impaired sexuality, they do not see it as the most important disorder. The

men perceive that the limitation of sexuality reduce somehow their social identity, too. Arrington (25) describes that social norms about male sexual behavior and identity are cultural consequences not biological answers. Kelly (24) means that “crisis” of prostate cancer has just been shown to confront basic expressions of masculine embodiment, like continence and sexuality. The men in the present studies do revalue sex and health. They mean, however, that if they have to choose between the cancer treatment and sexual inability, of-course they do not risk their health by avoiding treatment for the sake of sexuality.

There is a kind of disturbance in social relations because of the vacuum the men went into, which could be described as an imbalance in their environment. Even worries about the eventual reduce physical abilities contributed to this imbalance. The imbalance is found in their environment, affecting their social relations, when the men close out their friends and lock themselves in. Quite soon, however, the men start to struggle to adapt to a new situation, with positive attitude and new possibilities, which agrees with Pörn´s (48) way of regarding health, i.e. to keep the future open for new positive chances. The causes of imbalance in the men´s lives could be separated. It is observable in this thesis that, as mentioned before, cancer affects men´s capacities and, due to this, it tends to cause severe inability that can not be attributed to its abnormal status. Thoughts are present about the effects of prostate cancer, in the form of possible reduced mental and physical vulnerability and loneliness and these seem to cause imbalance, which the men has not reflected upon in the past. This is especially predominant in study III. The men learn to handle and to try to rebalance this increased imbalance in their environment. According to Pörn, Gadamer and Nordenfelt (48, 49, 51), social environment has to be considered with abilities and goal profile to reach generalized adaptedness, as in the present studies.

Health perspective is viewed by the changes in physical functions which influence the men, both emotionally and physically because of some disturbances. The men find a new perception and attitude to the life. They come back to their normal environmental social context; they adjust their goals to correct to realistic abilities to get back to their normal lives. They are triggering to regain equilibrium, harmony. From a health perspective, the men has found balance, harmony and found themselves with new perceptions about themselves, which enlarged them as “new” healthy persons. This can be seen to concorde with the explanation of Nordenfelt (50-51), that one can feel healthy if he functions satisfactorily in daily life and disease does not affect the ability to do so.

## Existentialism

Cancer influences the men´s thoughts about existence. Franklin (53, 86) points out that it is finding a relation between meaning and shock in individuals with advanced disorders that makes one aware of existence. A potential terminal

disorder could be regarded as a crisis - a matter of distress or hopelessness in itself performing an opportunity for growth and meaning, such as positive psychosocial changes with an enlarged feeling of meaning in life related with malignancy. In the present thesis, the men go into a vacuum and from there coming back to their lives. The men with both localized (study II) and advanced (study III) prostate cancer go into a vacuum when informed about their prostate cancer diagnosis. The men close out the outside world, which can be compared to the expression ´voluntary isolation´ used by Kelly (24). Getting the diagnosis put men into a vacuum, with different intensity and time-span which is described as a kind of shock in other studies (87-88). The findings of this thesis correspond with other studies (68, 70, 89) presented as a usual effect on being diagnosed with cancer. In the study by Franklin et al (90), participants described how the opinions of others influenced their inner strength, dignity of identity, self-image and could either support or disturb feelings of dignity of identity.

Gojmerac-Leiner (91) describes location of spirituality to be in the body, and all together for the authority of the spirit to go beyond the body once it is distressed. He points out that the human being can survive due to the shear strength of his spirit. The belief that humans´ spirituality is in his body can worry the patient. It is not pleasant that the form of body could be indicative of the form of his inner side, the spirit. It is not easy to admit the unattractiveness of a cancer in the body and more so in the spirit becoming sad. Humans use wishful thoughts instead of the actual ones, which become blocked and they lose the chance of explanation because of fear and love to life as they understand it (91).

In the present studies, emotional consciousness of potential future disturbances due to physical and mental vulnerability, fear of treatment and side-effects, restriction to manhood, a kind of apprehension and loneliness are new experiences which the men has not reflected upon in the past. According to Gadamer (49), in each threat to life and well-being the truth is hidden. This truth is a desire to live, the power of hope and liveliness which we all own as our most natural endowment. This desire coaches human beings to understand what is given and what limits. All examinations, diagnoses and treatments around the prostate and prostate cancer awaken different earlier hidden speculations about existence, not necessary positive or negative but only reflections. Some anxiety is found about cancer return, another cancer and symptoms the men had to face may be cancer. In other studies (85-92) about prostate cancer, emotions are aroused indicating that men with prostate cancer commonly have a minor level of psychological disorders compared to those with other forms of cancer, but psychosocial problems include anxiety due to lack of backing, uncertainty due to loss of control and lack of instruction and support at the time of initial therapy planning. In the present studies, the men feel loss of control in their social life and because of prostate cancer itself and even during its

treatment which is one of the most overwhelming discoveries for the men themselves.

Raem et al (93) found that a high level of psychological distress is reported among men with prostate cancer and that there was a greater unmet supportive care need of e.g. anxiety and depression. The present studies do not agree with their findings about high level of psychological distress, even if the men express some need after the visit. Linzt et al. (69) found that advanced disease and those diagnosed within a year are the subgroups whose quality of life are most negatively impacted, which could depend on for example high symptomology and impending death in metastatic patients. In that study of 249 prostate cancer patients, 210 men were approached during urological oncology clinics and asked to complete different questionnaires (Support Care Needs Survey SCNS, Support Care Preference Questionnaire, EORTEC QLQ-C30 version 3 Measure plus Prostate Module, the Hospital Anxiety and Depression Scale HADS) over a three-month period during their regular follow-up clinic visits. This result is contrary to the present studies, which show that the men are living with few symptoms and new perspectives.

Relationships with others become disturbed and for a while excluded in studies II and III. According to Frankl (53), fragile phases of life can, however, represent possibility. The men in the present studies feel unfamiliar with their ambiguity, on one hand wishing to obtain advice and, on the other, having difficulty in accepting that advice The men appreciate those who are optimistic and supportive, since this give them a sense of strength and further possibilities for the future. Bjorck et alt. (94) found that optimistic behavior is positively related to emotional functioning, meaning that programmes to encourage optimism and helpful assessments among men with prostate cancer should be developed. Present studies show that around the time of diagnosis, the men accept the situation with new emotional reactions with fighting spirit to gain control over the changed situation, to decrease apprehension and to see possibilities. Later on, the fighting spirit has more focus on physical health. Giddens (95) means that some ”life course crises” are important when individuals form functional rebuilding of the person. The men (studies II and III) find the way of reviving communication to encourage optimism and positive appraisal with those around, thus opening up to them and adapting even this connection and finding the individual approach forward in their lives. These findings are contradictory to Arrington et alt (96) who found that topics about emotional responses are avoided and little attention is paid to emotional issues, confirmation of feelings and consolation, for example death was a discussions topic only once during two years in prostate cancer support groups.

The men understand that another “foothold” is needed to live with new perspectives because you have to live, meet unknown challenges and solve practical difficulties due to prostate cancer. They begin to adapt to their new life, expressing and

emphasizing the value of taking care of their loved ones, to sort out meaningful activities and to come back to a normal social context. The men point out the value of continuing to live as usual. Even if the findings in studies II and study III are alike initially when receiving the prostate cancer diagnosis, the men in study III emphasize and spend most time discussing the current situation with new perspectives. They make new goals, which according to Frankl (53) help diminish the sorrow. The men in present studies focus on responsibility of their partners and children, find creativity in new interests and ascertain their values and priorities. Discussions and practical tasks help to reflect on various sides of life. The men build the new goals for a shorter period and select more discerningly among activities.

The men find that life cannot be taken for granted any more, they has survived but death is unavoidable but not frightening. This consciousness strengthens the wish to take care of their loved ones. Frankl (53, 86) wrote that love is the ultimate and the highest goal to which man can seek and he believed that love was crucial to a healthy existence. The men in the present thesis point out that the relationship and togetherness had grown, becoming an important element in their lives. Prostate cancer seems to be a chance for the men to change themselves and their lives. The men do not want to waste time any more on worthless relations or duties but appreciate communication on their own terms. They re-establish faithfulness to friends they selected. They value those who are straight forward and show kindness. Physical closeness is a manifestation of love but the men express that they have to accept impotence. The men find that other values are discovered in return like disseminating their knowledge and experiences to other men. Arrington (97) shows the same finding in his study among prostate cancer survivors. The men do not perceive living as threatening as it was two years earlier because they are still alive so survival time is longer than they first expected.

The central and obvious findings among these men are their capacity to settle in after the vacuum to physical integrity, improved self-confidence, eagerness toward stability in social roles and activities. Their wish to adapt to new social and physical situations as well as their reflections over the future occupy their minds almost constantly but even the wish to retreat from others was obvious. Adaptation involves an emotional reorientation that is made up of adjusting one's ambition stages, correcting goals to reliable ones that are suitable to abilities, restructuring priorities and a cognitive revaluation of life (79). A prostate cancer diagnosis give a sense of living more intensively, being more alive and confident every day, like a driving force leaving ominous but emphasizing happy thoughts. The men are influenced emotionally as are even their nearest and dearest ones. Some have a dilemma due to their loved one's shattered condition and sorrow owing to prostate cancer so the men feel a sense of loneliness trying to be strong in front of them, but they themselves have no one to talk to.

Franklin et al (90) described different ways of regarding dignity. Dignity of identity and self-image among men in the current studies is, due to catheters and disturbance in the lower urinary genitals, about the worth and self-respect the men ascribe to themselves and the worth and value ascribe by others as the men perceive it. Firstly a catheter is a kind of violation against the men´s integrity and dignity, which they have stoically accepted and later adopt actively. Not managing to control physical elimination and feeling frail because of that is a disturbing feeling. The use of a sanitary pad has an undesired influence, a kind of feminine touch with femininity characteristics impacting on the men´s integrity, being emasculated. The men try to overcome these embarrassing disturbances by joking. In the present studies, no one express anything specific about body image perceptions so findings do not agree with studies which found the opposite. Hedestig et al. (98) found that men express feelings of exposure and mutilation that is identified with diminishing erectile capacity and the self-perception which led to unwillingness to expose their bodies. At the end of life among elderly people dignity is often related to how they experience their own body and is described as unrecognizable body with fragility and dependency (90). Feelings of inability to have sex, diminished desire and an ending of masculinity are some obstacles the men in the present studies has to overcome or accept. The ability to let men get older pleasantly and sustain independent life, free from disabilities as long as possible is an important aspect in aging with dignity according the men and the findings correlate with statement from World Congress on the Aging Male (4). Franklin et alt (90) found that dependency and loss of control meaning reduce autonomy were issues, which even some men in present studies seem to be troubled about.

The men survive the interruption to their lives caused by prostate cancer and meet with a response to that which initially threaten to lead to death. They enjoy strengthened self-esteem finding it possible to maintain one’s own freedom, integrity, and independency when one can be in charge of one’s daily life and, due to that, have a sense of inner growth. They can accept their new lives and get ready for the future. Throughout, the men regard themselves as healthy from prostate cancer, abilities to function can be weakened because of individual treatment complications or aging. Some men inspire and guide others with prostate cancer by speaking publicly about prostate cancer and becoming engaged in prostate cancer associations. By doing so they provide effective health promotion by mixed health and cancer information. Like Frankl (53), the men in the present studies find meaning by acting in this way, thus experiencing something new. The cancer experience gives a new meaning and awareness of death awakens responsibility and creativeness toward other people finding their own ability to do something in new circumstances.

The men are balancing a changed life situation with the help of their experiences. The new approach to life is adapted including satisfying living, appreciation of

existence itself and valued whole living. The men find different individual ways to overcome physical limitations, which they experience as incomparable and complex, they adopt positive thinking and realize that material things are not essential. Gadamer (49) thinks that life is to think from the viewpoint of all limits. Important insight in study IV is discerned that humans want to live now and here being honest and straightforward, revaluing little things after cancer experience. As Frankl (53) means, humans choose the attitude and find a meaning in a hopeless situation, even realizing the value of love.

In a nursing context, spiritual care generally involves religion, common spirituality, existential aspects as described within existentialism by philosophers, being a crucial aspect in life. Spirituality, religion and existentialism constitute the theoretical basis. These concepts normally have powerful aspects and overlap partially, having a power so both religious and non-religious individuals can be included. The idea of spirituality is a lot wider than that of any world religion, giving a deep human dimension to all individuals, no matter what their religious beliefs are (99-100). This kind of spirituality is common in the present thesis.

In all studies (I, II, II and IV) existence is threatened when life's fragility become obvious. The men find that their bodies has changed leading to consciousness about existential threats and open the doubts about essential beliefs about manliness and life itself. In studies (III and IV), spiritual and existential reflection arise as different approaches. Some men talk alternately with humour and seriousness about God when considering the received prostate cancer diagnosis and the future including death. Bowie et al. (101) found that spirituality among survivors of prostate cancer, the effect of faith and religion is positive. They found that a place of worship, such as a place of social support and a place for spiritual renewal were valuable. Religion and spirituality were important aspects to overcome prostate cancer, having positive inherence. The present studies do not confirm that only religion is a central aspect of prostate cancer. In a nursing context, spiritual care generally involves religion, common spirituality, existential aspects as described within existentialism by philosophers. Spirituality, religion and existentialism constitute the theoretical basis. These concepts have powerful aspects normally and overlap partially, having a power so both religious and non-religious individuals can be included (99). Frankl (53) realised that not all people believe God, seeing meaning in life as acting with respect to the deepest and ultimate things and not about happiness and satisfaction. In the present thesis, experiences when sailing and walking in the countryside are described like spiritual experiences for some of the men, more significant than in the past. Other men find that music and art make a deeper and more intensive impression on them, even this is a kind of spiritual experience. Some men continue or begin to travel and discover the world which give them a spiritual know-how and, at the same time, they perceive everything as a part of the whole.

## Methodological Considerations

Could inquiries using questionnaires have been more appropriate? Previous research mostly involves quantitative instruments, such as measuring quality of life (QOL) with standardized QOL questionnaires (102), cancer-related fatigue with Multidimensional Fatigue Inventory (103), sexuality as well as side effects of different treatments with, for example, The European Organization for Research and Treatment of Cancer (EORTEC) developed questionnaires EORTEC-QLQ-C30 and EORTEC-QLQ-PR25 (104-106) or focusing on survival (23) as well as psychosocial consequences (38). Using questionnaires to assess fatigue, health or quality of life demands great agreement between respondents' and researchers' view of the researched area to be explored, i.e. do they have the same way of defining fatigue, health and quality of life? However, the use of quantitative instruments has severe limitations if one wants to get a deeper understanding of how a disease/condition may affect patients and their daily life. Hermeneutics is chosen in the present thesis due to aim to understand phenomena and actions seen each as the whole in relation to all around, to get better possibilities to understand maintain other persons and phenomena in the unique context. Context and the dynamic whole-part interrelations of a holistic perspective are crucial from the beginning of the thesis and hermeneutics, with the hermeneutic circle, gives a process for formally engaging in interpretation (31, 57, 62).

Existential hermeneutics seeks a so fair picture as possible of what the persons mean, experience and what their thoughts and intentions are. According Gadamer, the use of explaining theories is not an important controversial question because he manifests that a theoretical model is always created in that tradition where it has been shaped. Gadamer invites cautious use of theories so a central point to be observed during the whole study was to be aware of not making Gadamer´s approach into theory or method. Gadamer confirms existential perspective in hermeneutics with the purpose of contributing to increased understanding for the human being in the world. A true question has a "sense of direction" (31) which outlines how the study should be designed and performed, for example how to open an interview and expecting openness and flexibility during the interviews. The researcher was aware of risk involved in proposing interpretations during the interview but let the men narrate their own thoughts and feelings. The crucial aspect in interpreting an interview is the quality of the text from the interview situation.

The choice of research approach can always be questioned. As mentioned above, the focus in this thesis is on understanding and action in the men's own context. Could any other methodology been more appropriate? Depending on the focus for this thesis: aiming toward an understanding of these men's reality, there could indeed have been other qualitative methods used.

Another methodology using interpretation is Phenomenological Hermeneutics inspired by Ricoeur. The interpretation process has three to four steps; namely naive reading of the whole text, structure analyses to obtain explanations, distance avoiding subjectivity and finally sophisticated, critical understanding i.e. the interpreted whole. Ricoeur is for explaining and understanding- Gadamer is for fusion of horizons; Ricoeur has analysis method - Gadamer approach and openness; Ricoeur is for communication – Gadamer is for dialogue. Both methodologies are hermeneutics, and it is up to the researcher to decide which approach is most suitable and appropriate to use according to the aims of the study (31, 107-111).

Content Analysis is a procedure to analyze written or verbal communications in a systematic and objective method, characteristically with the ambition of quantitatively measuring variables by progressing base of explicitly formulated rules (34, 59) for description of the manifest content of a text. Content Analysis can be both quantitative and qualitative; working deductively or inductively, or combining those directions (112-113). In present thesis, prejudices and openness are essential, so that determining any kind of rules before analysis is not preferable.

The strength of Gadamer´s hermeneutics is openness to the otherness but at the same time there is a kind of difficultly leading to an unpractical puzzle because there is no method to use when analyzing data, just due to that openness to the text. The important aspect during the whole analysis process has been researchers' openness to the text, reminding each other of pre-understandings which turned out to be more complex than expected, so co-researchers opinion's are valuable to consider. Through discussion, the horizons from different perspective were confronted. The most trustworthy and plausible interpretation and understanding at that time are presented as findings (31).

Patton (57) identifies triangulation where more than one method is used to study one problem. Sources such as different data with the same method but different time points or comparing people from different view points, analyses using multiple observers or researchers and theory, using multiple theoretical perspectives to examine and interpret the data. A form of triangulation used in these studies is researcher triangulation; whereby several researchers with various perspectives analyzed and discussed the data and the findings.
Triangulation explains and attains understanding, it can predict and findings can be generalized, causal relation is to be found. In this thesis, there are no searches for that kind of causal relation. Triangulating tries to find when and why there are differences and comparisons (57) but the aim of this thesis was to catch perspective and illuminate context where human beings exist. Different data (qualitative vs. quantitative) may lead to different findings and the researcher tries to understand the reasons for that, which in the present thesis was not the aim of the analysis. A combination of qualitative and quantitative findings can assist to find balancing

aspects of the same experience (57). Thinking in these terms, triangulation and by combining methods, a methodology appropriate for further research could be mixed methods (111-112).

The primary inclusion criterion in all studies is men ≤ 80 years old because the multiple diseases after that are normal and could influence the findings. This age criterion is expanded to men up to 100 years old because of difficulties in recruiting men to study III. More than one additional year was required to recruit the participants according to this criterion and only two additional men were found as a result of it. Recruitment was expanded from the Urology Clinic at a County Hospital in the Southern part of Sweden to a University Hospital. The men who participated in all studies were out- patients. Difficulty in recruiting can depend partly on that some men with advanced prostate cancer are referred direct via outpatient surgery to hospital because of serious symptoms, other diseases or critical conditions, so these men are not identified for the study. The number of these unidentified cases is not known.

In study I and even later in study II and study III another way to recruit men could have been to ask consecutive men visiting the urologist's office for disturbances unrelated to fatigue or to give a questionnaire. Those who, if so, gave a positive answer could be then asked to participate in interviews. This way of progressing was given up because the meaning was not to steer men's experiences to the researchers' pre-understandings but rather to get an understanding of men's experiences and even a picture what the men meant with fatigue. The major barriers to recruitment were the physicians' busy working conditions, uninformed physicians and fewer newly diagnosed patients with such a high PSA.

The sample size is always discussed when considering qualitative studies. There are no definitely established criteria or rules for sample size in qualitative research. It is determined due to informational needs and methodology issues. With a homogenous sample, fewer than ten cases can be enough (34) and even single cases (N=1) can be selected purposefully and are sufficient. The purposeful sampling means studying information-rich cases in depth and detail to understand and illuminate the crucial findings (57). In the present thesis, sample size suffices for that.

Interviews could have been performed later, so that the men had got further in their adaptation to the new situation but the aim is to get an understanding of newly diagnosed men's experiences and perceptions of prostate cancer and fatigue. In study III, men are diagnosed as having advanced prostate cancer so it would have been ethically indefensible if the treatment is started first after the interview in two weeks. The treatment is initiated upon visiting the urologist and the interview is performed as soon as possible after that.

## Limitations

The limitations of all qualitative research approaches and their findings are that they cannot be generalised. They are generalizable (transferable) to those specific situations only or similar contexts and groups of samples.

In these studies, the purpose of consecutiveness is to get as similar contexts as possible, systematic drop-out of men represent threats to credibility and transferability.  It is important to recruit men using specific inclusion criteria to find the men with established phenomena of knowledge, having experience and who are willing to share this knowledge by narrating it. Clearly described selection, data collection and context make transferability possible to similar groups or contexts.

# CONCLUSIONS

An overall identified finding bringing these four studies together is that the men felt healthy in spite of prostate cancer. Regarding health concepts, the men are in equilibrium in their lives, which include changed attitudes to themselves and the world.

The men do not feel fatigue due to prostate cancer. All men have experiences of normal Everyday Fatigue due to exertion, age, biological processes, different treatments, and other diseases. Those feelings of fatigue are not caused by prostate cancer. Personality and anxiety contribute to fatigue in connection to examination on the basis of suspected prostate cancer. Several changes in life during and after two years of living with prostate cancer take place, so it is not obvious that those who later feel fatigue do so because of their cancer diagnosis or its treatment.

It is not possible to handle new and detailed information about prostate cancer at the first visit. There is a need for the men to get information so that they have the possibility of calling someone as needed and a new appointment should be offered within one to two weeks.

Both localized and advanced prostate cancer have influence on men´s daily lives. Receiving a cancer diagnosis affects the men´s emotions and their contacts close to them but they find new ways of living, living with new perspectives.  The men find a way to live in balance in their new changed life situation, with strengthened self-esteem and they realize that they manage to be alive in spite of uncertainty about future.

Prostate cancer raises existential thoughts and spirituality which grant strength for the men.  The cancer diagnosis highlights the fact that death is present for all living persons and to live is not a matter of course, so one has to live intensively as well as not being able to appreciate one’s loved ones too much. The understanding of existence createss spiritual reflections, for example about life’s transitional aspects. The cancer diagnosis reminds the men of death, clearly defining the expected period of life.

# IMPLICATIONS

Health care professionals:
Have to adopt a widespread approach when meeting and communicating with men who are going through examination for suspected prostate cancer, as well as with men with newly diagnosed prostate cancer, they must see the whole human being.

Must identify the men who are at different stages of adaptation to their prostate cancer diagnosis, in order to guide them according to their individual needs for each stage of their adjustment to prostate cancer and a new life situation.

Need to evaluate, perceive and furthermore understand the men´s apprehensions and expectations, on an individual basis.

Need to observe men´s preferences respectfully concerning the need for information, encouraging them toward use of the different cancer services suitable for each individual, therefore acting so as to promote integrity and dignity.

Need to improve understanding of how a prostate cancer diagnosis affect men´s appraisal of their situation, for example by education including aspects of health and spiritual thoughts.

# FURTHER RESEARCH

To:
Find out what kind of self-care abilities and actions there is within men diagnosed with prostate cancer.

Find out how a cancer diagnosis, perhaps in combination with age, affects men's normal/ordinary life and how they should act and react in order to maintain normal life.

Obtain better understanding of psychological, social, spiritual and physical aspects of prostate cancer by systematically evaluating and analyzing in relation to time, age and cancer state.

Find out and understand similarities and differences between cancer-related fatigue and Every Day Fatigue.

Evaluate by prospective studies physical and mental health abilities before treatment to consider changes in such abilities after treatment.

Break down prostate cancer survivors into age groups to find out if health, functioning and psychosocial differences are to be found between age groups.

# SWEDISH SUMMARY

## Sammanfattning på svenska

I genomsnitt får en svensk man diagnosen prostatacancer varje timme, året runt. Så har det varit de senaste åren där det diagnosticerats ca 9000 fall/år i Sverige. Detta kan ställas i proportion till att det föds cirka 45 000 män per år vilket innebär att nästan 1 av 5 män kommer att drabbas av prostatacancer under sin livstid. Ca 2500 män (ca 6 % av alla män som dör) avlider som en direkt följd av sin prostatacancersjukdom. Detta gör prostatacancer till den absolut vanligaste cancerformen bland män och också till den vanligaste dödsorsaken i malign sjukdom. Ingen annan cancersjukdom skördar så många mäns liv i Sverige.

Sett ur ett holistiskt perspektiv så drabbar en cancersjukdom sällan enbart en person. I den drabbades närhet finns familj och vänner som också påverkas, mer eller mindre, av att mannen ifråga fått prostatacancer. Såtillvida är prostatacancer en av de stora folksjukdomarna.

Behandlingen av prostatacancer är beroende av i vilket stadium sjukdomen är vid upptäckt d v s, om den är belägen inne i själva prostatakörteln, om den växer igenom själva kapseln eller om den har satt dottersvulster (metastaser) till andra organ, vanligen lymfkörtlar eller skelettet. Därtill fästes stor vikt vid mannens förväntade överlevnad (som ju i huvudsak är beroende av ålder och övriga samtidiga sjukdomar). Eftersom tidiga stadier av prostatacancer (de som är belägna inne i prostatakörteln) vanligtvis växer långsamt så kan behandling avstås om sjukdomen drabbar en man med förväntad överlevnad på mindre än 10 år – den kommer inte att hinna ge symptom under mannens livstid. Annars prövas botande behandling (antingen med operation eller strålbehandling) till dem med tidiga stadier av sjukdomen och de som har växt alldeles utanför kapseln. För de med spridning till andra organ kan inte bot erbjudas men väl lindrande och bromsande behandling, vanligen med någon form av hormonbehandling. Alla behandlingar kan ha biverkningar som påverkar bl.a. sexualfunktion, lust och vattenkastning.

Orkeslöshet ("eng. fatigue") är ett symptom som tidigare associerats med andra cancerformer. Tillståndet är i sig svårdefinierat men samtidigt självklart när människor talar om det. Det kan ha en stor inverkan på hur en människa upplever sin livskvalitet. Orsaken till att cancer är kopplad till orkeslöshet skulle kunna vara att cancern, och ibland behandlingen, helt enkel suger musten ur kroppen men också oro och ångest skulle ha kunna betydelse för symptomets uppkomst. Orkeslöshet har tidigare bara studerats sparsamt hos män med prostatacancer. Eftersom prostatacancer är en så pass vanlig sjukdom i Sverige var det viktigt att studera om och hur patienter med misstanke om eller med konstaterad prostatacancer (i olika stadier) upplevde/påverkades av symptomet orkeslöshet samt hur prostatacancern påverkade männens dagliga liv. I denna avhandling har

kvalitativa intervjuer använts, systematiskt analyserade med Gadamer´s hermeneutik, för att besvara ovanstående frågor. Männen som intervjuats var polikliniska patienter på två större sjukhus i Sverige och samma frågeställningar användes i samtliga fyra studier som ingår i avhandlingen.

I studie I intervjuades män som undersökts (med cellprovstagning) på misstanke om prostatacancer men där ingen cancer kunde hittas. Männen upplevde ingen orkeslöshet relaterad till undersökningen vid misstänkt prostatacancer. Alla män hade upplevt normal vardagsorkeslöshet, såsom orkeslöshet relaterad till ansträngning eller brist på sömn. Män som upplevde oro eller annan psykisk ohälsa sen tidigare upplevde mer orkeslöshet. Dessa män uttryckte även själva att oron var en bidragande orsak till orkeslöshet. Således verkar det inte som att oron för att få cancer kan förklara eventuell förekomst av orkeslöshet.
I studie II intervjuades män som nyss fått diagnosen lokaliserad prostatacancer. De flesta männen upplevde ingen orkeslöshet orsakad av lokaliserad prostatacancer, men att få diagnosen prostatacancer påverkade männens liv. Först hamnade männen i ett känslomässigt vakuum när de fick diagnosen och då var patienten inte nåbar för någon information. Även om de inte kunde ta emot information eller fatta beslut om t.ex. behandling under denna period av ”vakuum” så uppskattade de ändå en optimistisk omgivning. Efter en relativt kort period återfick männen sin känslomässiga stabilitet och önskade att återfå kontrollen över sina liv. Under denna period var behovet och sökandet efter kunskap stort. Ganska snart därefter hittade männen olika sätt att igen möta människorna runt omkring och även framtiden. Slutligen gav cancer männen ett nytt perspektiv i livet med delvis nya prioriteter.
I studie III intervjuades män som nyligen fått diagnosen avancerad, icke - botbar prostatacancer och i studie IV de av männen ifrån studie II and III som fortsatt var i livet två år senare. Männen upplevde inte orkeslöshet som de satte i relation till avancerad prostatacancer. Däremot upplevde de normal vardagsorkeslöshet. Männen funderade på olika risker som cancer kunde föra med sig som nya sociala roller och behovet av att anpassa sig till nya situationer. Tankar om framtiden och sättet att dö var oroande fastän de insåg att döden var oundviklig.
Männen önskade leva intensivare. De önskade leva som förr men de kunde känna sig mer levande i nuet för att nästa stund känna sig väldigt utsatta och svaga. Kateter påverkade männens manlighet och känslan av att det finns risk för att tappa den personliga kontrollen var aspekter som männen upplevde störande. De längtade tillbaka till arbetet vilket skulle normalisera livet och ge annat än cancer att tänka på.

Åldern har en effekt på männens förmåga. Det finns begränsningar gällande sociala roller och omständigheter både i hemmet och i samhället. Männen talade om hur de fick utökad tillit när de förstod att de fortfarande levde. De upptäckte att de kunde behålla självständigheten och integriteten trots cancer vilket var viktigt.

Relationerna var värdefulla men männen valde att behålla endast sådana relationer som de upplevde upplyftande. Fokus var på att hitta en bra balans i en förändrad livssituation. Männen hade fått en inre styrka och de uppskattade små händelser.

Vid ytterligare granskning av fynden, uppenbarade sig en upplevelse av hälsa. Männen upplevde sig friska, och även i studie IV levde männen med känslan av att vara friska trots att de hade levt med avancerad prostatacancer i ca två år. Även existentiella tankar kunde särskiljas. I studierna I, II och III, uttryckte männen sina tankar på olika sätt gällande dödlighet, en viss rädsla inför döden, osäkerhet om sättet att dö men de sade sig att de inte var rädda för att möta själva döden. Männen upptäckte att kroppen var sårbar, livet är skört och deras egen existens var hotad. Döden är oundviklig, oavsett hur man tänker eller vad man gör. Denna förståelse skapade andliga reflektioner t ex om tiden och övergången mellan livet och döden.

Andligheten gav stabilitet för männen innebärande förhållningssätt till Gud, estetiska upplevelser, upplevelsen av natur och musik medan andra njöt av att resa och upptäcka världen. Att ha fått diagnosen avancerad prostatacancer innebar att livet inte kunde tas för givet och männen menade att leva nu och att ta hand om de käraste var viktigt.

Resultatet av studierna är något förvånande då nästan ingen av männen uppgav orkeslöshet till följd av sin cancersjukdom, oavsett om den vara avancerad eller inte. Studien understryker det faktum att det inte är någon idé att ge information just efter att man meddelat diagnosen men att det finns ett stort informationsbehov redan efter någon vecka. Män som var oroliga och ängsliga i sin personlighet eller hade upplevt ohälsa sen tidigare hade en större upplevelse av alldaglig orkeslöshet och var mer benägna att tänka negativa tankar. En något förvånande, men glädjande, upptäckt var att männen upplevde att de hade god hälsa trots att de levt med avancerad prostatacancer och dess behandling under två års tid. De flesta satte de symptom de upplevde i relation till att man blev äldre, inte till cancersjukdomen.

Vårdpersonal har en unik position när det gäller att identifiera de män som behöver extra stöd samt se till att erbjuda information som männen efterfrågar när de är redo att ta emot den.
Behov av ytterligare forskning handlar om att ta reda på hur prostatacancer diagnosen kombinerad med ålder påverkar männens normala liv samt förstå psykologiska och sociala aspekter mellan ålder och prostatacancer. Framtida studier bör relatera utfallet till åldern och identifiera de existentiella aspekter som finns relaterat till ålder och livshotande sjukdom. Det behövs även fler studier för att utvärdera förändringar i den fysiska och mentala förmågan till följd av given behandling. ***Nyckelord:*** Prostate cancer; fatigue; influence; aging man; health; existential thoughts; Hermeneutic; qualitative research; follow-up.
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