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Living with a prostate cancer diagnosis: a qualitative 2-year follow-up

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Abstract

Aim. Previous research has identified how newly diagnosed prostate cancer affects men's daily lives, including daily activities and existential issues. The aim of this qualitative study was to provide information if and how prostate cancer affects men's daily lives 2 years after the diagnosis.

Methods. A second follow-up interview with men who were diagnosed with localized or advanced prostate cancer approximately 18–24 months earlier. Twenty-two men aged 50–85 years participated, data were analyzed by hermeneutical interpretation with Gadamer's approach.

Results. The men feel healthy, but prostate cancer affects their daily lives. They experience every day fatigue associated with several changes in life due to age. Three equivalent fusions which influenced the men are: 'Age is claiming its due', 'Living with uncertainty', and 'Strengthen self-esteem'. The unifying fusion is identified as 'Balancing a changed life situation.'

Conclusions. There is need for knowledge and guidance for men with prostate cancer on how to adapt to new life situation decreasing uncertainty and increasing welfare. Men found a sense of pride, despite physical changes, in appreciating independence and close relationships. Value of life was readjusted. The findings indicate harmony in living, enjoying being frank as well as rating the 'little' things.

Keywords: Prostate, cancer, oncology, fatigue, affected life situation, hermeneutic, longitudinal study

Introduction

Prostate cancer is the third most common cancer worldwide in men after lung and stomach cancer, with 543,000 new cases and with 200,000 deaths annually [1,2]. In Europe, 345,900 new cases of prostate cancer were diagnosed in 2006 [3]. In Sweden, a country with approximately 10 million inhabitants in 2006, a total of 9263 cases of prostate cancer were diagnosed; 1050 of them were diagnosed as having an advanced disease, i.e. either metastatic disease or a serum Prostate-Specific Antigen (PSA) of >100 ng/ml [4], which indicates that, today, most newly diagnosed cases of prostate cancer are in an early (localized) stage of the disease. In 2007, 8870 new cases were diagnosed. The mortality rate for prostate cancer has been approximately 2500 deaths per year, 2470 deaths in 2007 [5,6]. Treatment of prostate cancer is depending on the stage of the disease. Men with localized disease may be offered treatment with curative intent (surgery, radiation) or expectancy with delayed intervention. Treatments directed against

localized disease are associated with local side effects as erectile dysfunction, incontinence, bladder, and rectal disturbances. In contrary, patients with advanced disease cannot be offered the possibility of cure but are offered palliative treatment. This usually means some form of hormonal manipulation (anti-androgens or medical/surgical castration) with the aim to block serum testosterone from reaching the tumor. Castration therapy is not only associated with loss of *libido*, decreased sexual function and hot flushes/sweating but also long-term effects on bone mineralization, lowering of serum hemoglobin and a decreased cognitive function [7,8]. Most cases of prostate cancer are diagnosed in elder men. The risk of falling ill with a cancer increases with age [8,9]. This means that the disease affects men in different life situations, partly based on their age such as biological changes: normal loss of function capability.

Most of the research in prostate cancer and its effect in life domains have performed by using different kind of standardized QOL (Quality of Life) questionnaires [10]. Voerman et al. [11] measuring with EORTC-

QLQ-C30 and EORTC-QLQ-PR25 found that men with prostate cancer treated with hormonal therapy are functioning worse compared with other treatments according to physical functioning, role functioning, fatigue, pain, and sexual functioning. No differences have yet been found between radical prostatectomy and radiation therapy. Men treated with hormonal therapy who were diagnosed for prostate cancer for more than 2 years ago experienced a poorer cognitive function and also problems from urinary track. Arrington [12] found out that the value of health among prostate cancer survivors take precedence over the desire for making love among those who experienced erectile dysfunction. According to literature, the most frequently registered symptom of patients with cancer is fatigue. It is the most worrying symptoms connected with cancer and treatments since it largely bothers patients' QOL and capacity to act maximal in their normal lives [11].

In order to better understand the life situation of men diagnosed with or treated for prostate cancer, qualitative studies may provide new information not obtainable by QOL questionnaires. Men with prostate cancer do not experience fatigue dewing to conceivable cancer diagnosis [13] and it is reported upon how getting the diagnosis of prostate cancer, whether localized [14] or advanced [15] may affect men's daily lives. However, there were various affects and effects identified; awareness of body's vulnerability and mortality, loss of control, the way of dying, loss of intimacy because of physical changes as well as gratefulness to get back normal life again.

The aim of this qualitative study was to provide information about if and how prostate cancer affects men's daily lives 2 years after the diagnosis.

Method

With intent to achieve a good understanding of men with about 2 years' experiences of living with a prostate cancer diagnosis, interviews with a qualitative approach was used, followed by hermeneutical interpretation. Hermeneutics is relevant as a qualitative approach because it contributes to our understanding of human beings [16,17]. The analytical process is systematic and based on an understanding in addition to the facts. The present interpretation is the most valid and reliable at this moment, for this phenomenon [16]. In present study, authors' pre-understanding consists of personal experiences from primary care, cancer care and urology, from authors' specialists as carers and researches.

The present study was approved by the Committee on Research Ethics.

Sample

The target for the present study, a second follow-up interview, was men who were diagnosed with loca-

lized or advanced prostate cancer approximately 18–24 months ago. During the May 2005 and November 2006, men were interviewed by the first author (AJ). Criteria for the sample were: (a) all men who were alive since the first interview; (b) able to communicate; (c) willingness to participate in this qualitative interview study. These criteria gave a representative sample. Twenty-six men were approached for an interview. Four of the men had passed away, the remaining 22 men, with a median age of 68 (50–85) years accepted to participate in the interviews, and were contacted by the first author by telephone in order to schedule an interview at a convenient time. At the time of second interview, 20 of 22 men had been actively treated for cancer with different therapies as hormone therapy, operation, radiation, or seed implants.

Interview

The general interview guide added with issues from the fist interview texts was used, consisting of four to five research questions following the research topics [18]. Qualitative interview is like a conversation, even if interviewers have a list of issues about particular topics that they want to deal with [19,20]. The interview questions were broad, open-ended, and designed to avoid influencing the patient. The following topics were focused on during the interview: (1) Does cancer influence your life situation to-day? (2) Can you describe your life situation? (3) Have you experienced fatigue? (4) If so, how does it influence you? The participant or the interviewer often raised topics related to the interview guide, spontaneously.

The interviews, lasting 25–45 min, were, with the participant's permission, tape-recorded and transcribed verbatim by the fist author (AJ). The patients were assigned pseudonyms/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. Thus, the total time per interview varied between 50 and 60 min.

Analysis

The first and the third authors (AJ and CB, respectively) read the transcriptions and discussed researcher perceptions according to the interview situations and the outcome data throughout the process. For reliability, comparisons were made between the analysis made by AJ and CB and any discrepancies were elucidated through discussion. The text from the interviews has been analyzed using the principles of Gadamer's hermeneutics [16,21]. Principle one: The transcripts were read several times. The first analytic assignment is to build up a sense of the whole.

Principle two: Interpretation is not a subjective action. The validity of the interpretations of data in this study is represented by the basis that they are the outcome of a systematic approach with the focus on prostate cancer's effect on men and fatigue after about 2 years getting the diagnosis.

Principle three: Interpretations comprise two factors: A descriptive stage that progresses from the horizon of meaning of the texts, and the stage in which the text is interpreted and analyzed from the interpreter's horizons of meaning. Analysis was performed on both horizons in the hermeneutic circle, giving an adequate description of the complete text and then identifying different type of clusters as a whole.

Principle four: Interpretation includes the fusion of the horizons of the interpreter and the participants. Each phrase and sentence from the transcribed interviews was reconsidered to analyze and interpret the data. The basic idea was to find and sort out utterances describing whether or not men experienced if prostate cancer had an impact on men and if they experienced fatigue after about 2 years. The whole study has proceeded as a hermeneutic circle, from the part to the whole and back again.

Results

The men stated that they are living with a sense of feeling healthy. However, living with a diagnosis of a prostate cancer for about 2 years, both cancer stadium and age have an influence on them one way or the other. All the men experience every day fatigue and express that it depends on, for example, age, other diseases, or medication. The men have a very clear picture about what fatigue is and how it feels. Those who tell that they feel fatigue sometimes expressed that this feeling is not caused by prostate cancer. There have been several changes in life during these 2 years so it is not obvious that fatigue is due to their cancer diagnosis or its treatment.

Three equivalent fusions which influenced all men are interpreted in the interviews; 'Age is claiming its due', 'Living with uncertainty', and 'Strengthen self-esteem'. Conclusively, the unifying fusion is identified as 'Balancing a changed life situation'.

Age is claiming its due

The men describe different limitations that they regard as caused by aging. They talk about frailty. They realize the fact according to impairment of physical function owing to biological changes caused by aging but at the same time they deny to confess it officially. Using aids caused by reduced ability to use one's legs or dizziness affect their pride. They mean that they have not become that old yet. Some men express that there are diseases, which have been discovered at aging, such as heart failure and side effects of its' treatment which have impact on their

ability. Several men utter social and psychosocial limitations, which form a sense of sadness even if that is regarded as a necessity and has 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 are also social adjustment due to age.

'Well I'm so old, so I should die ... that's a fact ... //I walk a lot, if not strolls I'm walking in the forest with a clearing saw ... yes even with the power saw. Hew 10 seed-pines a day. I go home when I am tired (laugh) or is it age. You are getting older ... and you become more tired. You want to sit longer. I want to lie down longer. It is nice to rest. // There are lot of our friends that have passed away and that makes us lonely. And that is of course a disadvantage. Our common circle of friends it is to 75 % gone. There will not be a lot of people at my funeral (laugh).'

'... so this change of tasks, if one has been foreman and chief ... how shall I say about 40 years on on increasing scale ... heavier and heavier standings (positions) and you so all at once so so you leave the scene as a chief.// You are sitting there as an old, experienced man who must be at present and combine to solutions. But I am not collaborating with the responsibility for some particular sector any more. And it is has been a little bit hard you know. And then I will then at the same time take care of contacts with politicians and everything.// I can feel little bit tired sometimes. I can feel worn and tired. I feel that I need to rest a while.'

'Eh and it is with this staggering walk and I do not have (used walk pole) but I aim to do it. I see that there are people in all ages that walk with them, yes. No, no ... they (walking frame) are for the older ones. It is one stadium left before I am there. No, heaven! //Yes, yes, it makes that even the life becomes a little bit sad (age) ... But factually you, it began become harder to go down to the sea (summer house) ... but it is a fact and on the other side it is clear that it was a difficult divorce actually ... since 1948 and to last year (laugh).'

Men in the present study encourage and accept that their healthiness is changing as they become older; that is a natural human progress. They do not allow disease or its' omen influence on ordinary health behavior.

Living with uncertainty

Having a prostate cancer means to live with a life-threatening disease and not knowing how long life

will be. Men struggle with unpredictability of prostate cancer, what is going on and what could happen. Living with uncertainty is ambiguous. On one side, men express being in doubt about the information they get from the physician; can you trust on him, lack of information according to diagnosis and how serious cancer is at present as well as ambiguity of the site of cancer. On the other side, the men feel very confident with the physician and trust in his competence. Several men perceive still uncertainty of the primary nature of prostate cancer, its' primary cause, how and if they could have prevented it and if the choice of the treatment is most effective.

'Ah the soul is going a little up and down if you say so. Sometimes you are thinking about this and hope that shit hopefully it has not spread over as you say, you know.//That I think that the physician must take bigger responsibility ... to advice little more. //You know, I said the whole time that you can cut it off so I hope that it will go away you know ... cancer. // And then I do not know what more you ... they give quite a good information, you know. X was there at that time. He took vast time when he was informing. You were staying there, you know, you do not know what you should take ...'

'When you are a little wingshoten we say so ... yes if you are a little eh uncertain how it looks like and you become if you are walking and wondering if you ... how the life, how long it will be left to live if you get something ...'

'And I do not have pain anywhere or so ... I do not have pain in the skeleton ... than I think that it must be hidden somewhere in skeleton.. some kind of tumour ...'

The men express need to obtain knowledge of prostate cancers. This knowledge of cancer and even health is essential to decrease uncertainty and increase welfare and so giving reliable confidence between men and health care professionals.

Strengthen self-esteem

To live with a prostate cancer diagnosis for about 2 years affect the men's point of view. They discover the amenities of life and confidence is growing when they realize that they are still alive. Independence is important for the men and they find out that it is possible to maintain this freedom and integrity. Daily life is managed and they grow as well as increase as individuals. They begin to engage themselves in missions such as spreading the information about prostate cancer. The men point out that the intimacy, closeness, kindness, and friendships as well as straightforwardness are considered crucial in their

relationships. However, interactions are allowed to take place on men's own conditions. They do not have time to waste to worthless relations or duties. A man's identity, manliness, is deeply associated with his ability to sexual activity, but now there is a loss of both/either capacity to sexual act and/or desire to it. No matter the age; this feeling/experience is the same. However, the men point out that this issue is not strikingly important. Because of dwelling on, and reflecting on the situation the men become open-minded, attitudes are altered and self esteem could be strengthened.

'I joined this ProLiv (prostate cancer club) and this too. And really it shouldn't have been me working full time. Yes, I tried exposing myself a little bit to the media. And now, with the election coming up, we were thinking we will contact politicians, politicians in county council// I get perhaps a couple of calls every week from people who have had been stricken with (prostate cancer) then and are wondering which treatment to choose. // But it's just that you do not have any desire ... that's the worst, I guess. Then you can always fix it and that, too, he spoke to me about // When that question/matter comes upp, well, it's that feeling of not being a 100 percent.'

'However so you realize when something like this happens that people you thought were friends in reality were not so good friends at all. // I am a member of a brotherhood and there are a few who have stepped up. Just let me know if you need help with anything and I will fix it for you. Or help you with it. It has been people that one hardly has spoken with. And there have been others, too. It, it feels thoughtful.'

Several men express that they survived cancer, which was the reason why they initiated forum inspiring and giving courage to other men by speaking in public and have an impact on society and government by dialog with politicians. Physical closeness is a manifestation 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, and other values came forth.

Balancing a changed life situation

Living with a prostate cancer diagnosis affects men's life situation. Cancer causes some uncertainty and sense of being unsafe, which on diverse ways affect aging male-related normal life with gratitude knowing that cancer is conquered, at least a while. The men find their way; they balance their uncertainty with self-esteem and also use their life experiences due to age in this balancing a changed life situation. The whole approach to life is changed and this

makes a basis to a satisfying living and gratitude to the life itself: balancing the changed life situation. They value and recognize life as a unity; physically, mentally, and emotionally. If there is harmony, there is balance. The men manage to handle their physical limitations, to think positively and use their feelings to express themselves. The men also express having an economical security which make it easier to do what they want, which facilitate their balancing. Even though, at the same time they express that the material things are of less importance. Spirituality is essential forming stability for the men. It implies things as thoughts of God, aesthetic experience, sensation of nature and music; some are thoroughly enjoying traveling and discovering the world close or far away.

‘Yes, it has been amazing. Yes, we have been sailing many weeks in July. We usually do. //No, I look forward with positive approach.// Now at least I have the answer that I have apparently lived for 1.5 years and still feel normal. //Yes I know I have a diagnosis. But I still, as always, feel as healthy as I was before.’

‘Better, all of it. So it is, it’s more “on” as usual again, I could say. // That’s what you know; it (death) will come. (laughter) Sooner or later. Can’t avoid it. One has to be happy as long as one can stay up at least. When one has to lay down, then one isn’t very well off. //Eh, I don’t know what to say. I have gotten the best care I could imagine. And something beyond that.’

The men find a kind of inner power to live more intensely; at this moment, live day by day delighting in just the present day. They point out that it is important to be honest with themselves as well as be straight forward in their communication with others. The men revalue ‘little’ things; it is just those ‘little’ things men are enjoying in, in spite of running in the treadmill, as they did before this cancer experience. The choice, how to live the rest of their lives, short or long, is on the men themselves.

Discussion

To our knowledge the present study is the first to highlight men’s experiences living with a prostate cancer diagnosis, localized and advanced, by using qualitative 2-year follow-up interviews. The men in the current study were heterogeneous; men in different ages, being in different cancer stages and undergoing various prostate cancer treatments. The men presented their experiences, which were quite similar no matter their differences.

All through the analysis by a hermeneutic interpretation, the focus was on expressions that would illuminate how prostate cancer affects men’s daily lives during these 2 years. Confirmability was

reached by posing for explanations and illumination. Credibility of the present study has been confirmed by using direct quotations relating what the men said in their own words [18]. Findings in qualitative studies cannot be generalized, although a clear illustration can be visualized, so transferability of the findings should be estimated with consideration for the biographical and disease characteristics of the sample [21].

A surprising finding in the present study was that men regarded themselves as healthy persons in spite of prostate cancer diagnosis having some undesirable incidents as with sexuality, bowel, and the urinary tract. This might be explained by the fact that the men did not associate incidents with cancer but had accepted or adapted their cancer diagnosis and consequently today’s changed life was considered as normal. Oliffe [22] supports our findings that usually cited men’s health behaviors involve men’s denial of symptoms or illness and underutilization of health-care services. Through cancer experience men regained their health, which contributed to personal growth getting back a sense of control appreciating overall health and life itself.

All the men did experience every day fatigue [13] but they did not perceive fatigue caused by prostate cancer. They gave examples of situations when they felt fatigue and according to them it was a natural thing. Previous studies among men with new diagnosed localized and advanced prostate cancer [14,15] sustain present finding. The present finding does not support the researchers Morrow et al. [23], who in their review found that fatigue is among the most common symptoms of patients with cancer, all forms of cancer. Perhaps, in our study the men’s view of symptoms such as fatigue was not the same, as that of the healthcare professionals. It could be so that patients talk about every day fatigue but the staff and some inquiries were regarding that as unhealthy fatigue.

The men were aware of the changes which had slipped into them and referred them as typical aging. The key point was how the men reacted to the circumstances; they could change everything when they responded in a skilled approach and choose that alterations were normal due to aging. The findings show that the men modify their social adjustments. Charles and Carstensen [24] propose that age variations in how people control their emotions and action in response to negative social exchanges occur directly at the time of the provoking events and that older adults are adept at employing cognitive appraisal strategies during demanding circumstances.

The men, about 2 years after cancer diagnosis and chosen treatment, contented with powerlessness to foresee the probable pattern and response to any therapy recommended. This is similar to Oliffe et al. [25] who established that men experience prostate-specific and general health needs through the whole illness trajectory.

The men expressed need to more understanding and knowledge about prostate cancer even if they were treated 'Wait and see'-therapy, to get sense of control. Boyland and Davis [26] support this finding in their study about patients with carcinoma dealing with uncertainty. Physicians asked the men to decide on treatments but misjudged often the level of men's knowledge of prostate cancer. Several men wished to leave decision-making to their clinician, after all there are no perfect solutions, the right preferences or right decisions to treat men with prostate cancer. Oliffe and Thorne [27] point out that the science of prostate cancer is uniquely vague, which is important in the context of patient-physician communication, since logical ways of thinking and problem solving aligned to leading ideals of masculinity and medicine, were constantly interrupted.

The men's attitude in the present study was to see possibilities in their lives and value their current life situation when they managed to do daily activities by themselves getting back independency and a kind of control. The sense of male identity was changed because of bodily and emotional changes but found increased self-esteem as cancer survivors and made use of this experience, for example debating in political, public health, and clinical forums. The study by Bjorck et al. [28] about prostate cancer and emotional functioning found that the men reported normative levels of depression and anxiety as well as relatively high self-esteem.

Impotence and moderately small sexual desire had diminished interest in having sex. Even Arrington et al. [29] describe frustration of losing a healthy sexual life. In the present study, men talked about their sexuality; common expressions of affection were bodily closeness and non-sexual touch. There are several possibilities to sexual activity that most men in the present study did not appreciate. The similar experience was found by Mishel et al. [30], due to the artificiality of penile self-injection and vacuum devices, men and their spouses described that they found methods unpleasant.

The men in the present study became aware of the facts they hardly previously reflected over issues such as growing old, health, identity, independence, and masculinity. The study supports some findings of Arrington [12] who describes in his study about sexuality among prostate cancer survivors.

The men are balancing a changed life with a new life perspective which is now their normal living [15] and had found a more stable basis to stand on. The men had adapted themselves to new circumstances in their lives with balance, harmony and construction, forming a new person with awareness of prostate cancer and new focus and priority in daily life. Some men perceived prostate cancer experience as permission to live life more fully still being firm, dignified and somehow even brave accepting unavoidable death in the future.

Developing flexible approach to living is not only instrumental in helping to manage everyday problems but it also becomes the cornerstone for a key element of a happy life: balance.

Our findings about balancing a changed life is in agreement with Antonovsky [31] who confirmed concepts sense of coherence and general resistance resources. He meant that an impact of life is influenced by persons' life orientation. The men in our study were balancing a changed life situation, which was the main finding, whereas the men had found a harmony in living, enjoying being frank with themselves, and with others as well as rating other issues as important. The men tried to get balance between the unknown and uncertain by using their experiences and well-known skills to sustain some parts of ordinary life where roles, relationships, and identity are necessary. Both present and future rely on men themselves; they are creating their future taking control over their lives and daily activities with carefulness and compassion. They look forward to focus on the encouraging thoughts in everyday life.

Strength of the current study is that the men with their own words expressed how prostate cancer influenced on their every day lives and the study is a longitudinal study. The limitation of the study could be, in spite of the fact that it was the intentional criterion, the lack of comparison with sample characteristics, cancer states or different treatments, but qualitative studies are not aiming for comparison.

In conclusion, our findings emphasized the need for more research to explain cancer-related fatigue as well as psychological, social, spiritual, and physical effects of prostate cancer on men systematically evaluating and analyzing changes over time, age and cancer state. More research is also needed to face men's uncertainty, divergent desires and expectations, as well as need of information when communicating with health care personal analyzing for example by Barrows Theory of Problematic Integration [32] which focuses on situation where interaction of probabilistic and evaluative orientations are demanding.

The findings indicate that it is important that the health care professional should be aware of the changes that occur along the whole cancer trajectory. Life situations will change men's everyday life so health care professionals ought to inform about treatments, options, potential side effects, and potential social, psychological, and spiritual adjustments.

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