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ORIGINAL ARTICLE

Living after radical prostatectomy for localized prostate cancer: A qualitative analysis of patient narratives*

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Abstract

The purpose of this study was to illuminate the experience of living after radical prostatectomy (RP) for localized prostate cancer (LPC). Ten men were interviewed after RP. The interview text was qualitatively analyzed using the content analysis. The men suffered from worry, anxiety, and distress, and longed for life as they had lived it before the diagnosis. Changes in bodily functions after RP include urine incontinence (UI) and/or erectile dysfunction (ED) making the patient feel like a changed man with a lost sex life, with changes in his intimate relations with his wife, and with lowered self-esteem. Most men choose to cope on their own. Coping strategies in our study population included finding new areas of interest and a new focus in the present. In the present study, living after RP meant striving to gain control over, and become reconciled with, the new life situation as a changed man living with an altered self.

Prostate cancer (PC) is the predominantly malignant tumor among older men in the Swedish population [1]. The cancer diagnosis often comes as a major shock for the patient. The illness may have a negative impact on the patient's life, often resulting in distress and a range of difficulties, including anxiety and worries about disease progression [2,3], as well as physical problems associated with treatment side effects [4]. This distress may be greater than most men will admit. Keller and Henrich [3] found that male cancer patients report physical and psychosomatic symptoms less frequently than female cancer patients, and they also report lower illness-related distress.

One effect of cancer diagnosis many patients suffer from is the psychosocial effect. For instance, cancer patients often report that people treat them differently after the diagnosis, at times avoiding them, at other times being overly solicitous. In a study group of untreated PC patients, most patients avoided disclosure of their illness, and tried to live a normal life without sharing the news of their cancer diagnosis [5,6].

Men with early-stage localized prostate cancer (LPC) can choose between curative treatment and conservative management (i.e., watchful waiting). The decision-making process used by men with LPC for choosing curative treatment has been described by Steginga and colleagues [7]. These authors found that in general, men do not comprehensively or systematically use information about medical treatments when making decisions, often basing their decisions on their beliefs about cancer and health instead. In our interview study of radiotherapy (RT) treatment for LPC [4], the patients' choice of treatment was based on discussions with other men treated for LPC as well as their expectations of a certain treatment. They also related their experience of being alone in their choice of treatment. Davison and colleagues [8] showed that the majority of men with PC wanted the physician to make the final treatment decision. Men in our previous study living with untreated LPC (i.e., watchful waiting) described their choice of treatment as "our choice" (i.e., their and the physician's choice). For these men the meaning of life was a "life [lived] under a shadow" [6].

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Radical prostatectomy (RP) and external-beam radiotherapy (EBRT) are two major therapeutic options for the treatment of clinically localized PC. A systematic overview of radiation therapy effects in prostate cancer [9] shows that the outcome of EBRT and brachytherapy (BT) is similar to those of RP. There are no randomized studies that compare the outcome of surgery with that or RT treatments for patients with LPC [9]. External-beam radiotherapy, however, is known to have side effects, affecting urinary, bowel, and sexual function. Urinary incontinence (UI) occurs in a range up to 53% [10] of RP patients. Erectile dysfunction (ED) following treatment is of particular concern, and occurs in up to 80% of patients treated by RP [11]. An important predictor of preservation of erectile function is preexisting erectile function before the surgical treatment (since in the sixth to eight decades of life, some level of ED may be present in more than 50% of men) [12], and the possibility to perform nerve sparing RP [11].

Hillner and colleagues [13] report that the rates of direct postoperative and late complications are significantly reduced if the treatment is received in a high-volume hospital and if the patient is operated by a surgeon who performs a high number of such operations. In Incrocci et al. [14] all men diagnosed with LPC while awaiting treatment reported a negative impact on sexual function in areas such as sexual interest, performance, and pleasure. Men who are sexually active prior to surgery usually express major distress at the possibility of impotence after treatment [15].

There is a lack of studies aimed to increase our understanding of what it is like to be a man living after treatment for LPC. Therefore, the aim of present study, using narrative interviews, is to illuminate the experience of living after radical prostatectomy for localized prostate cancer.

Material and methods

Subjects

Ten patients with RP-treated LPC participated in the study. The participants were 61–69 years old. All were married (one was a widower), retired and lived in their own homes (Table I). The group represented blue-collar as well as white-collar workers. They were selected from a database containing registration details of PC patients in northern Sweden.

The following inclusion criteria were used: subjects had to be 60–69 years of age and to have been diagnosed with LPC; they had to have a prostate-specific antigen (PSA) level ≤10 ng/ml at diagnosis, live in the county of Västerbotten in northern Sweden, speak Swedish, and have no other chronic disease that could affect their daily life. The patients had to have had RP more than six months but not more than tree years, previously. Exclusion criteria were being related to, or personally acquainted with, the interviewer. Thirteen patients met the inclusion criteria and ten were willing to participate. The same criteria for inclusion and exclusion had been used in our previous studies among men with LPC treated with watchful waiting [6] or EBRT [4].

Interviews

A tape-recorded narrative interview [cf.16, p.52–65] lasting 35–60 minutes was conducted in the men's home. The interviewer (OH) encouraged the patient to talk as freely as possible about his feelings and thoughts about life as experienced after RP. Two

Table I. Patient characteristics at the time of diagnosis and interviews.

Time of the diagnosis			Time of the interviews					
Tumor stage[1]	Grade	PSA (ng/ml)	PSA (ng/ml)	Time since treatment (months)	Time since diagnosis (months)	Age (years)	Occupation	Marital status
T 1c	1	6	<0.1	26	29	69	retired	married
T 1c	1	9	<0.1	26	29	69	retired	married
T 2	1	10	<0.1	22	24	63	retired	married
T 2	1	8	<0.1	34	36	69	retired	widower
T 2	1	2	<0.1	32	36	69	retired	married
T 2	1	10	<0.1	33	36	65	retired	married
T 1c	1	10	<0.1	26	29	67	retired	married
T 1c	06*	5	<0.1	18	20	64	retired	married
T 1c	08*	6	0.2	12	16	63	retired	married
T 1c	05*	3.7	0.2	32	35	64	retired	married

[1] Tumor stage according to UICC/ (International Union Against Cancer), 1992.

*Graded using the Gleason score.

PSA = prostate-specific antigen.

main questions were asked, namely, "What did it mean for you to receive the PC diagnosis?" and "What is your experience of having been operated for PC?" Additional questions were asked to develop the narratives, such as "What do you mean?", "What did you do?" or "Tell me more about your thoughts and feelings." After each interview, the interviewer entered his thoughts and feelings regarding the interview, in a reflective diary. This was done so as to record the sense of the interview and remind the interviewer of his impressions of the interview situation. This record also allows the interviewer to validate the interview data [cf.audit trail, 7, p.363] during the process of analyzing the material. The interviews were transcribed into text, and episodes of silence, and emotional expressions such as laughter and sighs were also included to the text. The transcribed text was validated against the audio tapes to ensure that the transcriptions were correct.

The study was approved by the Ethics Committee of the Faculty of Medicine at the University of Umeå, Umeå, Sweden (§85/00, Dnr 00-056).

Analysis

Interview data were analyzed using qualitative content analysis [17,18]. Both the manifest and the latent message of the text were searched for. The interview texts were analyzed in several steps. In the first step, the interview texts were read through while listening to the tapes, to validate the transcripts, and to gain a first impression of the content of the interviews. After one and each interview was read through the reflective diaries were also read. Parts of the text that were unrelated to the focus of the study, e.g., stories about areas of interest in the men's stories about their jobs, were excluded from the analysis. In a second step, the text was sorted with regard to its content. Three different areas related to content were identified such as; experience of side effects after surgery; being a cancer patient; and ways of coping with the new situation. In a third step, open coding was performed within each of these areas. In other words, meaning units were identified, condensed, and labeled. A meaning unit could be a sentence or a longer passage in the text expressing a similar meaning. Codes with similar content were sorted into categories [18,19]. A category answers the question "What" and can be identified as a thread of the manifest message through the codes [20]. Four different categories emerged, which were: "experiences of a changed body", "consequences for the daily life", "coping strategies", and "experiences of safety". With the aim of illuminating the experience of being a man treated for LPC with RP, each category was reflected on to find a latent message. In the final step, four themes were formulated to illuminate the experience of living after RP for LPC. A theme answers the question "how", and is a thread of an underlying (latent) message running through the codes and category, at an interpretative level [18].

Results

In the men's descriptions of how they experienced life after operation for LPC, the following themes emerged: "becoming a changed man"; "striving to gain a sense of control in a new life situation"; "managing a new life situation"; and "striving to become reconciled to the new life situation".

Becoming a changed man

The experience of becoming a changed man was understood as a consequence of side effects of treatment, such as UI and ED. This experience was described from three perspectives: changed bodily functions; a modified way of living; and an altered self-esteem.

Living after RP for LPC means longing for life as experienced before the diagnosis. Life after RP often brings feelings of being a mutilated man. The men in this study, who said that they had known about the side effects of RP before the operation, understood the new life situation to be a logical result of RP. The most important thing for them was their overall wellbeing.

Losing their erectile function, however, radically changed their sex life, which gave them a sense of grief. Seven of the men wrestled emotionally with the negative effect the operation had had on their sex life. One said he sometimes dreamt about a normal erection as he used to have before the operation. However, as one man philosophically said "To teach oneself to accept this situation, even if life is not as one had imagined – that is the art of being human".

The waning ability to attain erection and, consequently, a changed sex life were expressed as detracting from the patients' manliness. Most of the men said they did not feel like "a whole man". Other expressions the men used were, "half human", "a weak man", "cut down", and "mutilated". The "mutilation" was described as having changed the men's self-esteem, bringing a sense of not being a complete man when comparing current experiences with life before treatment. One man said, "I feel, well, [like] a man who is mutilated. I'm only a half human because the desire and the ability for sexual activity is lost".

In our study population, UI had often resulted in a need to wear absorbent pads on a daily basis as a precaution against urine leakage. Some men had to change their clothes several times a day despite the pads. They described living a normal social life as something that was almost impossible to do. One man said he had not been informed about ED or UI before the RP and he related his experience as follows: “I am cut down. A large part of my life has disappeared, and I also have to wear absorbent pads and change my clothes often every day”.

Men who suffered from UI said that the leakage of urine was usually related to physical activities, such as lifting heavy objects, shoveling snow, exercising, and rising from a chair, as well as coughing and sneezing. Cold weather, full bladder, high consumption of liquids, and distress were other factors worsening the incontinence.

Wellbeing for the men in this study meant maintaining physical strength. Waning physical strength was seen as a loss and was experienced with grief. One man said, “I am not as I used to be. I can‘t go at it as before”.

Striving to gain a sense of control in a new life situation

Striving for control in a new life situation was described from two perspectives, namely, control of the waning body; and the progression of the disease. Life after the treatment often meant striving to gain a sense of control of the declining body. The interviewees had tried erection aids but had found them to be a hindrance to arousal and sexual performance.

To maintain control over the leakage of urine, the men focused on the consumption of drinks, the frequency of lavatory visits, how they were dressed when going outside in cold weather, and how to avoid situations of stress and activities which they would worsen their incontinence. When visiting friends for example, or a shopping center or a conference, they knew that to avoid urine penetration they had to make sure they wore good absorbent pads. They were also worried about the odor from their wet pads and that people around them would be able to smell the urine.

To gain a sense of control over their physical strength, the men tested their ability to do hard physical work. Especially those men who had regular urine leakage or leakage related to easy physical activity experienced hard physical work as difficult.

The men expressed a need to communicate with other PC patients in order to compare experiences and find out about other PC patients′ way of living. The focus of their conversations with other PC patients was side effects, such as urine leakage, and the exercise techniques for reducing this problem. They also wanted to share their experiences of treatment and PSA levels. One man said, “From my brother (he had been operated for PC before me), I got a lot of information before my own surgical treatment. I am grateful to him. I have also spoken to a friend who has been surgically treated. It’s important to have someone to compare my own situation with”.

Surgical treatment for LPC also means regular follow-up visits. Most of the interviewees said the doctor’s checkup gave them a sense of security, and a sense of control over the progression of the disease, provided that the checkups were regular. Between the checkups, some men had questions they wanted to ask the professionals, but they often had difficulties contacting the professionals or getting answers out of them. Two men described feelings of frustration and irritation that the follow-ups had not been scheduled according to plan. Most interviewees said they wanted checkups to be 6 months apart. One man said, “My first follow-up was after 3 months; after that, they came with 6-month intervals. These 6 months become 7 and I felt that that wasn’t good for me, because I need to feel secure. The regularity for me means security”.

The PSA test was described as an important part of a regular follow-up, providing patients with a sense of security because an unchanged level of PSA gives a PC patient some feeling of control over the progression of the illness. Knowledge of one’s own PSA levels also provides an opportunity to compare one’s PSA values with those of other PC patients. In case their PSA level ever increased, most men said they would want to consult the doctor as soon as possible for a discussion and a new examination. Two of the men did not understand why the PSA value was important since their prostate gland had been removed.

For several men, life after RP was fraught with the question of why it had to be them. Why did they have to have PC? Several men believed that heredity had a large role to play. Others, however, did not ponder the cause of their PC.

Managing a new life situation

Living after RP and managing the new life situation was described from three perspectives. Firstly, the patients said that disclosing their new circumstances to others was an important part of managing. Secondly, they had to look forward and plan for the future; and thirdly, they had to learn to cope with, and manage, their own worry and anxiety.

As a first step in managing, the men expressed it as important to inform their family and friends about their illness. One man said, “Once I’d had this big operation and managed it, it was a pleasure to inform others about what had happened”.

Life after the operation often meant pondering about their present life situation and the future. For most men, thoughts about the future were associated with a growing worry, anxiety, or sadness. As one man put it, "The future is behind me." At the same time, most men expressed the desire and hopes for a cancer-free life. One man said, "I know my situation and I'm adapting to it. The illness is a reality and I can't change anything about that, but I distance myself from it. I take each day as it comes".

Another man said, "I am still a cancer patient and thinking about the future, and so on, and this makes me sad and I feel that everything is not as fun as it was before".

Most of the men kept their innermost thoughts to themselves, as a self-chosen strategy for managing. The innermost thoughts included thoughts about the future, the prognosis, and death, as well as feelings about being a mutilated man, their changed sex life, and their waning physical strength. One man said that his family sometimes asked him about his innermost feelings, but added that he did not want to reveal his thoughts to them. Seven men said they did not think upon their illness often, but added that they told their wives about their physical problems. Most men experienced a great amount of support from their family. One man said, "Even though I have a family, I will keep some thoughts to myself; that's my own private space".

Sometimes life after RP brought experiences of worry and anxiety. The men's strategy for coping with this situation was to find activities with a new focus in the present. Examples of such activities were being in nature, listening to, or making music, working with something, starting a new hobby, and socializing. Spending time alone and not thinking about the illness was another strategy for managing anxiety. Whereas one man said that he needed company when experiencing worry and anxiety, other men said they preferred to be alone. One man said, "Walking in the forest is music for my soul. When I was told that I had cancer I went to the sea to go ice-fishing. That diverts one's thoughts. Walking quietly in the forest ...then there will be order in my mind ... a relaxation".

Striving to become reconciled in a new life situation

Part of living after operation was described as a process of striving to become reconciled to the new life situation. This could be understood as a way of reaching next step in the new life. In the narrations, three strategies were identified. The first was striving to live in the present; the second was reminding oneself that the operation means being cured; and the third was to prioritize things which would enhance the quality of life (QoL).

To become reconciled with a new situation involves an attempt to live in the present. As one man said, "To live in the present and take care of my own life is very important to me".

In the process of becoming reconciled with the new circumstances, the men made themselves believe that they had been cured from the cancer. Reminding themselves that the physician had recommended RP and the tumor had been removed gave them a greater sense of security.

Striving to become reconciled to the situation also involved a striving for a sense of security when visiting the hospital for checkups. It was important to see the same physician as on earlier visits. To most men, seeing the same physician meant increased confidence, since the contact was more satisfactory, being less superficial, and consequently gave them a sense of enhanced safety. As one man said, "It's always better to be able to speak with a person who has been involved in my treatment all the time. When I meet a new physician I never know perhaps he's coming with new ideas. No, I have more confidence if I see the same physician. I am better known by him and it's easier for me to speak".

All men in the study said that they had reevaluated their life with regard to what is important and valuable. One man said, "After the operation I don't take life for granted. To be able to stand on my own legs and go out, for example, is important. Playing golf has taught me a lot about life. Life isn't always smooth, and it happens differently from what we want as humans".

Discussion

The experience of living after RP for LPC could be understood as a striving to reach a sense of being in control and become reconciled with a new life situation. The men described themselves as being a changed man living in a life-threatening situation, and sometimes experiencing worry, anxiety, and distress. The worry and distress were diminished when they felt in control. This need for control may be understood as a consequence of the waning body and the threat to life that cancer poses.

The experience of being a changed man brings the frustration of not being a complete man, of a change in the self-esteem with regard to their masculinity, and a felling of shame at not having control of the body. Charmaz [21] argues that illness and treatment side effects can reduce a man's status in terms of masculine hierarchy, causing a shift of his power relations with a woman, and raise his self-doubts about masculinity. Bokhour and colleagues [22] report that sexuality is a substantial part of what defines an individual man with PC. Sexual function, potency, and physical appearance are all aspects of self-esteem [23].

Not all men in this study were aware about the treatment side effects before the surgery. We do not know whether this was due to a real lack of information or to the well-known phenomenon of denial or disavowal following cancer diagnosis. Lack of information about the disease and treatment options and side effects has been reported elsewhere. In a qualitative study among eleven PC men, Jakobsson and colleagues [24] found lack of information about the consequences of PC treatment for their sexual life. In another study [10], 39% of RP men reported that they had not received enough information to prepare them for UI after the treatment.

Physical strength and the ability to work are perceived as important aspects of masculinity [25], but have also been described as a way of handling worry and anxiety in men with LPC [4,6]. Engagement in hobbies and at work has been narrated as a way to distract thinking about the illness and the new life situation. The present study suggests that men with UI after RP have fewer possibilities to use physical activity as a distraction, as exerting oneself could cause urine leakage.

Being a changed man and having one's self-esteem undermined presents a form of suffering. Jakobsson et al. [26] likewise found suffering and loneliness in a study of PC patients reviewing their situation after treatment. Charmaz [21] proposes that suffering emerges as an existential experience when a "loss of self" is being experienced. Rondorf-Klym and Colling [27], studying men after RP, found that social support and self-esteem were significant predictors of QoL. In this context, Eriksson [28] has described three categories of suffering, namely, suffering of life, which is suffering experienced in life itself; suffering of illness, which is suffering caused by illness and treatment; and suffering of caring, which is related to the care situation. In the present study, the men's experience of being affected by PC and, consequently, living in a life-threatening situation, could be understood as a form of "suffering of life", while one example of "suffering of illness" is the men's experience of having their manhood mutilated, as a result of treatment side effects. The men's waning physical strength could also be seen as a "suffering of illness". The experience of not having been well informed about side effects could be interpreted as "suffering of caring".

Strategies for managing a new life situation could be understood as the platform for a possible process of becoming reconciled with the new life situation. Forsberg and colleagues [29], who studied patients with colorectal and gastric cancer, found that in their patients, wellbeing was related to the ability to cope. Cancer patients who were living alone had lower wellbeing than patients living with relatives. In the present study, the men's attempt to reconcile themselves with their new circumstances could also be understood as a way to reduce life suffering, the suffering of illness, and the suffering of caring, and find meaning in the new life situation.

The treatment choice in the men we studied had been recommended by their physician; however, the sense and meaning of the treatment and its side effects at an individual level often only became a reality weeks and even months after the operation. Having a sense of control over the illness progression could be understood as a way of mentally adjusting to the threatening situation [30]. The men saw their situation as threatening based on a sense of being alone. Elsewhere, this has been described as a sense of powerlessness in the new situation [26,31].

This study shows that the emotional strain experienced by several of the interviewees was often managed by the men themselves, without involvement of professionals. However, when the need to discuss problems and raise questions becomes pressing, and when the anxiety and worry become unbearable, it is important for such men to have easy access to professionals, to share their thoughts and problems with, and receive information from, persons they know. The importance of a caring organization, which offers easily accessible, individual information and support, cannot be overemphasized. It is well known that social support has a bearing on how people cope with cancer [31–33]. Meeting this need is a challenge for a PC care organization in the future.

The method of data collection and analysis was chosen as a way to reach a deeper understanding of what it is like to be a patient operated for LPC. With a qualitative study design, the evaluation of the research results is based on the trustworthiness and transferability of the results.

In the present study, which aims to illuminate the meaning of lived experience, themes were formulated based on the latent message in the transcripts. In the presentation of the results, we have given some quotes from the narratives to confirm the relevance of the themes. The themes show the experiences of study population, but do not give a view of each man's individual experience. One man's experience cannot become another man's experience. What can be transferred from one man to another is not the experience as experienced, but its meaning. The experience as lived, remains private, but its sense and meaning can become public [34].

The findings in this study can not be generalized and applied to other populations of men with LPC. Future research and clinical experiences may show whether the findings are transferable to men in other context. The method used in this study implies that the results should be seen as a contribution to an ongoing discourse about the meaning of being treated with radical surgery for LPC. One "test" of credibility of any study is whether its findings are viewed as trustworthy, i.e., whether they can be applied and recognized by other men radically operated for PC, as well as by researchers and clinicians in the field.

The interviewer in the present study is a male oncology nurse, lecturer, and researcher, with more than 41 years' of experiences working with men and woman with different kind of cancer. In this context, we might ask the question: What difference does it make, with regard to the content of the narratives and the findings, whether the interviewer is a man or a woman? In a previous study among men living after EBRT for LPC [4] some of the men reported feeling exposed when they spoke about intimate matters, especially about sexual dysfunction, to a female physician or nurse. These men preferred to speak to a male physician or nurse because they found it easier to relate their sexual experiences and problems to a professional of the same sex. They also said they thought it was more difficult for a woman to understand what a male problem such as ED means to a man. For some men in a caring situation, it may therefore be easier to disclose intimate matters related to masculinity to a person of same sex.

Conclusion

In conclusion, the experience of living after radical operation for LPC could be understood as striving to gain a sense of having control and to become reconciled with a new life situation. The new situation after radical surgery is that of a life as a changed man living with an altered self.

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