

Sharing experiences in a support group: Men's talk during the radiotherapy period for prostate cancer

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ABSTRACT

Objective: Prostate cancer, one of the most common cancers in men, is often treated with radiotherapy, which strains both physical and mental health. This study aimed to describe the experiences of men living with prostate cancer shared within conversational support groups during a course of radiotherapy.

Method: Nine men participated in one of two groups that met six or seven times, led by a professional nurse. Qualitative content analysis was used to identify themes and subthemes in the recorded group conversations.

Results: The analysis resulted in six themes: living with a changing body, being in the hands of others, learning to live with the disease, the importance of knowledge, everyday life support, and meeting in the support group. The men discussed a wide variety of bodily experiences and described support from healthcare professionals, relatives, friends, and the support group as crucial to their recovery.

Significance of results: Meeting men in a similar situation, sharing experiences of living with the disease, and feeling allied to each other were important to the men in our study. The conversational support group provided the patient with prostate cancer a forum where sharing was made possible.

KEYWORDS: Prostate cancer, Experience, Qualitative content analysis, Support group

INTRODUCTION

In Sweden, ~9500 men are diagnosed with prostate cancer each year, most of whom are >70 years of age (Swedish National Board of Health and Welfare, 2009). Worldwide, it is the second most common cancer among men, with ~900,000 new cases per year, and causing ~260,000 deaths per year (GLOBOCAN 2008, 2012).

In a study by Steginga et al. (2001) with 206 participating men with prostate cancer at different stages, sexuality, relationships, and masculinity were important issues. The men wanted information from the healthcare service about side effects, managing self-care at home, and access to local support groups. They also wanted to have a contact person in the healthcare system and to be treated as individuals, not as “cases.” The men were worried about recurrence and about how to handle anxiety among family and people close to them. The men also described lacking energy and feeling exhausted. In another study the men were reluctant to talk about their emotions. Instead they talked about the disease,

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their prognosis, and their future, and these conversations revealed their emotional experiences and their struggles for control during the development of the disease, the course of the radiotherapy treatment, and control in daily life. The men talked about how physical activities could change their thoughts and help them focus on the present moment and put their worries aside. Talking with other men in a similar situation has been described as a tool for coming to terms with their situation (Hedestig, 2006).

Conversational group support can help men to realize that it is normal to experience mixed emotions including sadness, anger, or despair over losses caused by the disease, and such interventions have shown improvements in anxiety, depression, men's abilities to cope with the situation, and their quality of life. Effective leadership is crucial for group stability (Oliffe et al., 2008) and the group should have a professional facilitator and meetings should focus on sharing experiences (Swedish National Board of Health and Welfare, 2007). Participants of conversational support groups had significantly better illness-related knowledge than did a control group (Noeres et al., 2011). Women with breast cancer benefited psychologically from conversational support groups; they experienced friendship, safety, understanding, and a strong feeling of belonging. The discussions in the group led to new perspectives and increased their knowledge of the disease (Edwards et al., 2008; Stang & Mittelmark, 2010).

Few studies have been conducted on men with prostate cancer sharing experiences while participating in conversational support groups, and their results have been contradictory. In one study, men in support groups distanced themselves from each other and stated that the disease was the only thing they had in common (Oliffe et al., 2010).

The aim of this study was to describe the shared experiences in a conversational support group of men with prostate cancer during a course of radiotherapy.

METHOD

Participants and Sampling Procedure

Thirty men with prostate cancer were asked on their first visit to the Department of Radiotherapy at Cancer Centrum, Umeå University Hospital, if they wished to participate in a conversational support group during the 8 weeks of radiotherapy sessions. The selection criteria were that the participant had been referred to the clinic for curative radiotherapy after newly diagnosed prostate cancer, had agreed to participate, could speak Swedish, and did not

have a physical or psychological disease that hindered active participation.

Intervention

Three to six patients were consecutively selected to one of six conversational support groups at the start of the radiotherapy session. The group meetings were held once a week, 90 minutes per session for 7 or 8 weeks in a room at the Department of Cancer Centrum. A male nurse (author OH), with a specialization in oncology care and long-term work experience, led the group meetings. The participants were informed that they themselves were responsible for the content of the conversations and that the group leader would facilitate and organize the meetings and act as a resource person. The participants were also informed that the group meetings would be recorded for analysis.

Analysis

Two groups were randomly selected for analysis; one group with six participants and one with three participants. The total recorded material for analysis from the two groups comprised 19.5 hours. The texts were read through several times in order to get an overview of the whole. Qualitative content analysis (Graneheim & Lundman, 2004), which focuses on similarities and differences in a material, was chosen for the analysis. The texts were read through again and individual meaning units in the text were marked. These were condensed and coded separately by each of two of the authors (MJ, NK). The condensed meaning units and the codes were discussed among all of the authors until agreement was reached. The codes were then arrayed to enable the construction of subthemes and themes. The authors finally agreed on 27 subthemes combined in 6 themes that ran like threads of meaning (Graneheim & Lundman, 2004) through the text in response to the question of how men experienced the disease, the treatment, and the support group intervention.

Ethical Approval

The study was approved by the Umeå University Ethical Committee at the Medical Faculty (archive number 07-120M).

RESULTS

The analysis resulted in 6 themes and 27 subthemes (see Table 1). Within the support groups the men discussed a range of altered physical experiences, changes in their relationships, and how their own

Table 1. Overview of themes (at top) and subthemes

Living with altered body experiences	Being in the hands of others	Being empowered to live with the disease	Having important knowledge	Having support in everyday life	Meeting in the conversational support group
Urinary function and continence	Being examined	Experiencing weakness	Lacking knowledge	No support	Gaining strength from the group
Bowel function and continence	Getting the diagnosis	Accepting weakness	Getting information	Support from health care personnel	Feeling part of a community
Sleep and insomnia	Getting treatment	Experiencing one's own strength	Making the decision	Support from relatives	Gaining insight through the conversations
Sexual function and impotence	Waiting	Being open	Owning knowledge	Support from other patients	
Hormonal changes		Discovering other perspectives			
Discomfort		Believing in the future			

strengths were supported by the group, by their families, and by healthcare personnel.

Living with Altered Body Experiences

The changed body experiences concerned mainly the time during radiotherapy and had a continuous impact on the men's daily lives. The experiences mirrored the men's self-images, and their different ways to live with a damaged body and cope with new situations.

Urinary Function and Continence

The majority of the men talked about needing to urinate more often than before, even during the night, and sometimes as often as once an hour. They described having a weaker flow and difficulty emptying the bladder, despite feelings of urgency that were sometimes exacerbated by body position. These troubles were worst in the week following radiotherapy, but could then diminish. Some men reported better pressure and ability to empty the bladder when there was a break in the radiotherapy treatment.

... I get out of bed to wee, but not much comes out, and I hardly get back to bed and put my head on the pillow before I feel the need to wee again, and then I get out of bed and it flows directly.

The men described bladder contractions as very troublesome, and they dealt with them in various ways, including relaxation. Sometimes they said they felt the urge to urinate, but could not. That could be painful, but taking a walk or thinking about something else could help them to relax enough to let the urine flow. "... You can sit on the toilet and brush your teeth, because then you can relax, and then it functions, but it takes time." Using a catheter for empty-

ing the bladder demanded planning, but when urinating was easy, it was described as a heavenly experience and they felt lucky.

One man described how he had once had a stronger ability to hold his urine when a toilet was not available. The men talked about having to plan their whole day to accommodate frequent pressing urges to urinate, and this restricted their leisure activities as they had to check whether toilets would be available before they went anywhere. One man needed to practice contracting his muscles to be able to hold the urine.

Bowel Function and Continence

Many men described a changed pattern of bowel movements, including episodes of diarrhea, more frequent movements, and difficulty holding their bowels. This could result in having to sit on the toilet instead of standing up to urinate, not being able to eat all kinds of foods, and needing always to know where a toilet was located.

The bowel movement is a bit soft. Sometimes it comes on frequently, like an attack ... it feels urgent, but it can pass quickly when you are on your way to the toilet. When you walk a bit, it's over and then it comes on again.

Sleep and Insomnia

A disturbed night's sleep was a recurrent problem. The men did not get continuous sleep because of urgent nocturnal visits to the toilet to urinate, although visits to the toilet to urinate or taking painkillers were also strategies to improve sleep. Racing thoughts also kept the men awake. One man used a catheter to be able to sleep all night. "You have hardly gone to bed, and it takes a while before you fall

asleep, and then you have to visit the bathroom. So you get only about half an hour's sleep first."

Sexual Function and Impotence

Sexual function was changed for the worse among several of the men, and some of them accepted it as partly related to their advancing age. Reduced sexual function was related both to loss of desire and to impaired potency. Some of the men had the desire for sex but no capacity, while some had lost desire and wished to regain it. "... The hard thing is having no sex, that's what I suffer most from ... there is no connection." When the men discussed potency aids, some described not being helped by them and one man did not try them because he did not trust them. One man described an erection so painful that it disappeared completely, while another man decided to test his potency and discovered that it actually functioned.

Hormonal Changes

Hot flashes and perspiration were described as troublesome and sleep disturbing. The men related recurrent onsets of perspiration both to the hormone treatment and to smoking and drinking coffee. Enlarged breasts and aching toes and fingers were related to the hormone treatment. "... I think that they [breasts] have got bigger, but not so that it is disturbing." One man was grateful for the slower growth of his beard as he didn't need to shave as often as before.

Discomfort

Recurrent discomfort or pressure in the abdomen was described and some men talked about having discomfort or pain with urination. Men also felt general discomfort or ill-being that they did not relate to anything specific. "It feels like a kind of a pressure in here. But it doesn't hurt ... it is an unpleasant feeling ... it is not an ache ..."

Being in the Hands of Others

This theme contains experiences about not being in control of one's own life, feeling coerced, and being at someone else's mercy.

Being Examined

Two men described the examination with biopsy of the prostate gland as an unpleasant experience and one of them compared the experience to a rape: "... and they took that prostate and fired eight shots at me. Oh, oh, that was not good, I think." "[It was like] ... rape."

Getting the Diagnosis

The delivery of the cancer diagnosis was described as hard, brusque, and information laden. One man said it was "terrible" and another man experienced the information from the physician as a judgement. All the men described the information as distressing. Sometimes the diagnosis came as an unexpected shock. One man described feeling that the diagnosis was "the end, good night." Another man also said that he was frightened and thought about how near he was to the end of life. "It was bloody hard when I was told I had this."

Getting Treatment

Treatment experiences included feeling unsafe during radiotherapy, not trusting the radiation equipment, feeling excluded from the process, being embarrassed during examinations before radiotherapy, and feeling drained of energy by the treatments. One man said he felt "grilled." Positive experiences, however, were also expressed in stories, for example, about the staff's reducing their embarrassment in the examinations through calming talk, about their experiences of recovery, or their feelings of being lucky or being happy about the benefits of treatment even though a long journey was required.

The first time when I was lying there I felt excluded [from knowing what was happening] ... preferably you would like to see it [the radiation equipment], pick it to pieces, oh ... that would alleviate the pressure of that feeling of not knowing.

Waiting

Waiting was described by all men as a difficult period of uncertainty, particularly in the beginning of treatment, but these feelings could return after the treatment was over. Some men experienced the uncertainty of the waiting period as the worst experience of all.

... the worst thing during this whole time was having this "buddy," uncertainty. He was the worst buddy you could have... When I finally got the letter... I wondered whether to open it or not, and then I threw it away... because I waited too long.

Being Empowered to Live with the Disease

The men described how the disease and treatments led to lost energy. They also talked about how they handled their weaknesses and gained new strengths.

Experiencing Weakness

Several men described feeling a weakness that manifested itself as psychological imbalance with emotional instability; they were easily moved to tears

and prone to feeling sorry for themselves. Negative thoughts led to a bad mood, and one man described having had depression and thoughts about death. "Tiredness" was described as a feeling of faintness and such fatigue that the man just had to lie down. One man was ashamed of his need to rest during the day. Another man worried that he may have hurt someone through his unguarded words, and he had nightmares about being punished. The men also expressed anxiety about some of their symptoms and worry that the cancer may have metastasized; two men also experienced feeling sexually inadequate despite their wives' expressed understanding.

... I have experienced that I have become so temperamental. My mood changes so quickly. I can lose my temper ... inside myself ... and then it can go the other way and I get sad. I get enormously sad, so sad that I cry sometimes; that's what I have felt, and then I think a lot about the disease.

Accepting Weakness

Some men talked about being able to accept their disease, their weaknesses, and their situation. One participant said that it was hard for him to accept that his body did not function as before and that he made demands on himself: "... I'm trying to accept ... you have to, otherwise you will have an unbearable life."

Experiencing One's Own Strength

Some of the men experienced the weeks with treatment as an ordinary Monday to Friday job. Several men talked about their hope of recovery. Some men described trusting the healthcare personnel and therefore feeling able to leave the responsibility for the treatment to them. As time passed, the men felt less anxiety, and some men said that there was nothing that they had to worry about. One man said that he had landed in the situation; another man said that he took each day as it came. Physical exertion, such as fetching firewood home from the forest or shoveling the snow away, was described as a positive expression of strength. Trying to improve one's own sleep was a way to exercise some control over improving one's quality of life. One man talked about how he tried to kill the cancer cells with the help of his thoughts: "... and then I say too, as I am lying there, that now, now, you [the cancer cells] are burning in hell."

Being Open

Many men talked about the importance of being open about their disease when meeting neighbors and friends. They said that openness promoted friendship and being open from the beginning facilitated

their relationships with others. The men felt that it was necessary to talk, and as time passed it became easier and easier to talk about sensitive matters. One man described talking openly about his impotence with one neighbor: "It's easier for all of my buddies in the hunting team to talk with me now. Because I have told them all now, and [it's easier to talk] when you know you don't need to try to conceal something."

Discovering Other Perspectives

Unexpected events that the men experienced such as the illness of a relative or death of a friend, gave the men new perspectives. Even something as simple as a parking fine could be seen in a new light. The men explained that unexpected events made them think about things other than their own disease or side effects from treatments: "... but if I say it like this I haven't had so much time to think about myself because my boy ... is operated on Monday so my thoughts have been more on him than on myself."

Believing in the Future

Going from darkness to looking forward to a better future was described in the group conversations. Positive thoughts and wanting to work, go on trips, and spend time with family and grandchildren were themes especially in the last conversations: "You stop thinking about it after a while. I don't think about it anymore. Now you just want to start working again and earning money."

The Importance of Knowledge

Lack of knowledge was an acknowledged problem. Getting information or having knowledge was crucial to being able to make decisions.

Lacking Knowledge

The men talked about their deficient knowledge about the disease and treatments, and they said they needed information to be able to choose treatment. One man who had never been ill before and knew too little about the situation said: "... it was good at the beginning, but the nearer I came to treatment time, I know now that I knew too little ..."

Getting Information

Information on a proper level was claimed as important. The men said that they had got information but then did not remember what was said. A combination of verbal and written information was easier to integrate than only a verbal. The men appreciated the information that they had gotten and felt that they needed it. "When you are at that stage, at first you

can have had so much information and then you walk out, saying, ‘What the hell did he say?’”

Making the Decision

To be able to make a decision about treatments, the men were offered needed information. One man decided on radiotherapy instead of an operation in the hope of avoiding impotence as a side effect. Another man wanted treatment to go quickly, but still chose radiotherapy. He was a pensioner and had time to accept the treatment he thought would be most effective. Some men were satisfied with their decision to have radiotherapy and said that they had made the right decision. Some had also involved their wives in their decision making. “What we talked about then, I think it was a difficult time . . . it is you as a human being and as a patient who determine how you are going to be treated.”

Owning Knowledge

Knowledge was valuable and made the men understand better. The information was described by one man as “sovereign” and another man said that his “question marks were straightened out.” “I asked, I read, and that made me accept things in a better way.”

Having Support in Everyday Life

The men talked about lacking support from people outside their family and said that support from relatives, friends and healthcare personnel was very important.

No Support

Several of the men said that although some of their friends knew that they had cancer, they did not want to risk talking to them. Some men also lacked support from their physicians when choosing treatment options, and one man said that he had wanted his physician to advise him after an assessment. Another man said that he had struggled to be allowed to take a prostate-specific antigen (PSA) test at the healthcare center and it was thanks to that that his increased levels had been discovered: “. . . they know that I have cancer . . . but they go around and around and deflect instead of saying, ‘Well, how do you feel?’”

Support from Healthcare Personnel

The healthcare personnel at the radiotherapy unit were described as positive, nice, sensitive, obliging, and very socially adept. The men were calmed after having had a conversation with the physicians, who were experienced as sensitive to the men’s worries and to their needs for information. The men felt confident in, and well cared for by, the healthcare per-

sonnel, who they said were unique and professional. “I think that they are perfect, the health care personnel. I have never before experienced better care in my whole life. They are incredibly nice.”

Support from Relatives

The men’s wives and the friends constituted important support. The men felt important to their wives, who were described as understanding their men’s limited capacities. One man had a welcome surprise when his wife visited him at the outpatient lodging. Another man talked about how his wife, who worked at the hospital, had helped him to get an early diagnosis through being obstinate and demanding a blood test for him.

You look at the woman and think what if? But there is no longer any funny feeling . . . yes, and so it continues, and I say that, ‘this is life, you are life; that you are with me, that’s what is important.’

Support from Other Patients

The time between treatments in the outpatient lodging was described as a time of building community spirit. The patients met at lunch and sat together, and the atmosphere was good. One man said that he felt free to talk about even taboo subjects and another man said that without the other patients it would have been dull. Several men met in the carpentry workshop and talked about how it functioned as a safety valve and made the time pass quickly. Some men thought that it was a pity that more men who seemed lonely did not go to the joinery: “. . . Ah, it would be rather dull without our buddies.”

Meeting in the Conversational Support Group

The conversational support group was very meaningful as a place where the men met and shared experiences.

Gaining Strength Through the Group

It was very important to participate in the group; the discussions were described as fruitful and the good atmosphere as positive. One man said that his psychological well-being had improved in part because of the group. There was room for open-hearted discussions and there was consideration among the men. It was important to be able to speak openly about one’s own feelings in the group. Humor, described as making the situation bearable, was often present in the sessions, and the men could laugh together to jointly face their difficulties. The men were consoled by the fact that all of them were in the same boat, and nothing they shared was strange.

“To be able to live with this, humour is a great help, and we joke about this and that. I think that makes it bearable.”

Feeling Part of a Community

Only positive experiences from participating in the group were described during the conversations. Fellowship, getting on well together, meeting, talking, and forgetting about oneself were examples of such positive experiences. In the group the men could also air subjects commonly held to be taboo. Being together and not feeling alone in the situation was described as incredibly valuable, as was the opportunity to talk about things that the men did not usually talk about with their wives: “... this fellowship ... it is incredibly valuable.”

Gaining Insight Through the Conversations

The conversational support group gave the men the opportunity for fruitful talks, which in turn brought them greater understanding and insight. Several men described the discussions as interesting and important to their ability to come to terms with their feelings. The men looked forward to the group meetings and the opportunity to listen to and learn from each other, to give and take, and to learn from each other's experiences. “I actually long for, I actually miss these Wednesdays when we are here, and we can listen to each other, and give and take, and I have learned so much, I think...”

DISCUSSION

Living with altered bodily experiences because of prostate cancer was a major subject in the group talks. Similar results were shown in another study in which men discussed their loss of potency, enlarged breasts, and increased perspiration. It was difficult for them to accept that they had lost some bodily functions, but they discovered ways to handle the changes (Cecil et al., 2010; Oliver Hedestig (2006) describes two sides of men's experiences in terms of nakedness: showing their naked bodies and baring their feelings in telling female doctors and nurses about their erectile difficulties. The loss of erectile ability was described in that study as a mutilation.

Some men in our study described feeling physically weak, off balance, and unwell. The participants stressed that it was important for them to accept weakness. Several men felt that they lacked knowledge about the disease and available treatments. Sometimes they found it difficult to make decisions about treatment options, and they pointed out a lack of support from the beginning. Being treated kindly and professionally by the staff was important

to the men and made them trustful. Information and psychological support are greatly important in interactions with people with cancer (Hiramanek & McAvoy, 2005; Chen et al., 2009). Men with prostate cancer have expressed a need for support when fears about metastasis arise, or when they have worries about their family or changed sexuality (Lintz et al., 2003). Several of the men in our study expressed support and understanding from their partner and family. Support from friends was greatly appreciated, but was sometimes experienced as insufficient. Partners of men with prostate cancer can also need more information and feel unsure about the future (Carter et al., 2010). Families who share their stories of the illness can gain better understanding into the consequences of the disease (Wright & Bell, 2009; Bell, 2011). When a family's strengths are supported, they can develop strategies for coping with the new situation (Bohn et al., 2003; Houger Limacher & Wright, 2003; Benzein et al., 2008).

Consistent with Cesil et al. (2010), some men in our study reported that some friends had distanced themselves, but that their families offered emotional support. Most of the men had confidence in the staff at the oncology clinic and saw the staff as an important support. Our results show an evident need for information and psychological support from the beginning of the investigation, including information about the diagnosis, treatment decision, and common side effects. This was confirmed in another study that showed the men's need for knowledge about treatments, common side effects, and the path to recovery (Boberg et al., 2003).

Meeting other men in the conversational support group alleviated feelings of being alone. Some of the men said that they were able to talk in the group about difficult and embarrassing experiences with men with similar experiences, and the conversations often included laughter. We noticed during the analysis of the group meetings that humor seemed to play an important role for the men and it helped them to talk about their difficulties. They told stories to the group and joked about their own problems. Humor is described in similar studies as a way to cope with disease, reduce anxiety, and promote a good spirit in the group (Ahlberg & Nordner, 2006; Oliffe et al., 2009).

The men described only positive opinions and no negative experiences of participating in the conversational support group. Some men said that they longed for the group meetings, that they gained strength in the group, and that the atmosphere was good. It can, however, be difficult to express criticism when the group leader is present, as it may be perceived as ingratitude rather than an attempt to share and grow. This uniformly positive result in the men contrasted with that in a group of women with breast

cancer who participated in a parallel case–control study of similar support groups and described their experiences in private diaries. In that study both positive and negative feelings were described (Emilsson et al., 2012a). Participation in a support group increased levels of coping resources assessed with the Coping Resources Inventory (CRI). Results of the CRI showed a significant difference between the study group and the control group in the social domain at the end of radiotherapy and in the emotional domain at 6 months after the radiotherapy sessions (Emilsson et al., 2012b).

The participating men in our study seldom talked about their feelings during the group meetings. They often focused on the technical aspects of the radiotherapy and described episodes that they had experienced, but not how they felt about them. Researchers have observed socially and culturally constructed differences between men and women when they talk about their illness or supporting a partner with a cancer diagnosis. Men often talk about doing what is necessary. They talk about concrete actions rather than feelings. Women on the other hand describe both their own feelings and those of their partner (Seymour-Smith & Wetherell, 2006).

The focus in this study was on the men's own experiences. Our analysis generated many and varied themes, which, according to Graneheim et al. (2004), strengthen the validity. Although the division into themes and subthemes was done with high precision, and similarities and differences were paid attention to, other interpretations are possible.

Our results show that the conversational support group can serve an important purpose for men with prostate cancer. Meeting men in a similar situation, sharing experiences, and feeling allied to each other were important to the men in our study. The conversational support group provides patients with prostate cancer with supportive tools to cope better with their life situations and experience a better quality of life. There are still few studies about men with prostate cancer in support groups, and more research is needed.

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