Responses and experiences after radical prostatectomy: perceptions of married couples in Switzerland

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Abstract

The purpose of this qualitative study was to explore the responses and experiences of a sample of Swiss men after radical prostatectomy and their intimate partners. Interviews were conducted with 10 couples and analyzed using constant comparative method. Getting a grip on it was the core process that was developed. Men focused on regaining control over their lives, urinary and erectile function while wives efforts focused on being there. The results revealed that current clinical practice of follow up at 3 months may not address the serious deficits in the patient’s ability to “get a grip” on incontinence and other complications of surgery.

Keywords: Prostate cancer; Incontinence; Erectile dysfunction; Nursing care; Medical care

1. Background

Prostate cancer is the most commonly diagnosed cancer in Swiss men. In the years 1989–1993, there was a yearly average of 3217 newly diagnosed cases of prostate cancer in Switzerland. In the same period, an average of 1449 men died from prostate cancer per year (Levi et al., 1998). Four additional tendencies can be observed internationally. Over the last two decades: (1) the men are diagnosed at younger ages (Smith et al., 2000); (2) prostate cancer is diagnosed at an earlier stage (Noldus et al., 2000); (3) the mortality rate is decreasing (Tarone et al., 2000) and (4) there is an increase in curative approaches along with palliative care (Post et al., 1999).

Radical prostatectomy is one of the common modalities to treat localized prostate cancer throughout the developing countries (Catalona, Ramos, & Carvalhal, 1999). The issues of bladder, bowel, and sexual dysfunction after surgery are addressed in practically every report on complications of radical prostatectomy. The majority of studies evaluating such complications are conducted in men up to 10 years after surgery (Fitch, Gray, Franssen, & Johnson, 2000; Potosky et al., 2000; Schapira, Lawrence, Katz, McAuliffe, & Nattining, 2001). Post-surgical data collection regarding complications typically begins at 3 months (e.g., Litwin and McGuigan, 1999). Little is known about the immediate, 12 week post-operative period. Men are typically discharged from the hospital with a urinary catheter and leg bag along with the patient teaching about catheter care (Held, Osborne, Volpe, & Waldman, 1994). Only two North American research studies have systematically studied the self-reported post-operative experiences of men in the first 2 months of post-prostatectomy.
(Moore and Estey, 1999; Phillips et al., 2000). These authors reported deficits in the self-care abilities to manage complications despite pre-operative teaching.

Urologists of the participating institutions have been concerned about the knowledge gap about patients needs in the time between discharge and the first follow up after 3 month.

Thus, the purpose of this study was twofold: (1) to describe the responses and experiences, expectations, and preferences perceived by a sample of Swiss men after radical prostatectomy and their intimate partners; (2) to provide baseline data for a multiphased research study including the development and testing of interventions for this specific population in Switzerland.

2. Methods

The cross-sectional qualitative study, using grounded theory method of analysis, was conducted in cooperation with two university-affiliated hospitals in Basel, Switzerland. A purposeful sample of men being treated for prostate cancer and their intimate female partners were recruited. The participants were informed by the surgeon that this study was taking place. A preliminary consent form was given to them. After a reflection period of at least one night they were again asked if they were willing to participate. If they agreed their name was given to the investigator, who was not a member of the treatment team. Couples were then contacted by phone and written individual consent was obtained from both men and their partners prior to data collection. The study was reviewed and approved by the Ethical Committee of the University Hospital, Basel, Switzerland.

2.1. Participants

Ten men and their female partners participated in the study. Nine were within 4–8 weeks after radical prostatectomy, 1 participant was within 12 weeks after the surgery. All participants were able to read, and speak Swiss–German. One participant, initially recruited, dropped out because of language difficulties. The mean age of the responding men was 64.6 years, 4 men were retired, 7 were still working. No demographic data have been collected from the wives.

2.2. Data collection

A home visit was scheduled to interview both the man and his partner. Private interviews with each couple were conducted, lasting between 45 and 90 min. Some interviews were conducted separately with each partner, some of them together, depending on the couple’s preferences. The interviews were audiotape recorded and transcribed verbatim. Data collection was halted after 10 interviews as pre-determined by available funding. Redundancies were found in all the categories after 8 interviews.

2.3. Data analysis

The constant comparative method of grounded theory data analysis described by Glaser and Strauss (1967) and Strauss and Corbin (1990) was applied to the interview data. The anonymous raw data were entered into a code-based data analysis package, WinMAXpro®. In the first step of analysis, participants’ experiences were identified and coded. Each incident or concept was compared to previously coded incidences for similarity or differences. Codes were grouped together to build categories. Relationships between the codes and the categories were explored with the analytic techniques available in WinMAXpro®. Finally, a core set of categories, which composed the core process, the major theme of the data, was identified.

Trustworthiness was established by consulting with other experts knowledgeable in grounded theory methodology and prostate cancer, the implementation of an audit trail of data and analysis utilizing on-screen coding and memoing in WinMAXpro; double coding of two of the transcripts by a co-investigator and the discussion of developed themes with those who recognized the content.

3. Findings

Getting a grip on it describes, in the participants’ own words, the core process developed through the inductive analysis of the experiences of the participants. The process described the efforts of both the men and their wives to deal with the diagnosis of prostate cancer, the subsequent surgery and its complications with the goal to “return to normal life”. The core categories that composed the core process were reclaiming control, on the part of the men and being there for the women.

3.1. Men: regaining control

Regaining control over their lives and their urinary and erectile functions was the main goal of the men’s efforts in dealing with the diagnosis of prostate cancer, surgery and its consequences. The amount of control regained was perceived as an indicator of the success of the recovery process.

3.1.1. Setting priorities

All men set priorities of what was important to them in managing the diagnosis and the complications of surgery. For most participants (n = 8) the diagnosis of
cancer elicited emotional responses of shock as the following statement exemplifies: “…and then the biopsy unfortunately showed cancer and of course that moment was a hammer” (#2). Others said; “they were prepared” (#4&5). Consequently, getting the cancer out became the highest priority for these men. All men chose to have a radical prostatectomy. They stated: “For me it was totally clear, there was no alternative given what I have seen; the stuff must be out” (#1) or “there was no discussion; surgery was the first priority, not the consequences” (#9). After surgery, dealing with incontinence became the first priority and erectile dysfunction was less important. “Yes, it is like priorities, at the moment incontinence is my priority, if that is o.k., then I’ll deal with the other (erectile function)” (#5).

3.1.2. Managing urinary incontinence

Six out of 10 participants were discharged with an indwelling urinary catheter and returned to the hospital for a one night to several days stay to have it removed. In some cases (n = 3) complications led to a prolonged period of living with the catheter. One participant was still wearing one at the time of interview. Despite irritations, pain and activity restrictions managing the catheter was not a problem for the participants. One participant reported that he was instructed by the hospital nurse how to manage the catheter. With removal of the catheter the men actively started to regain control over their incontinence. Most men, however, managed their incontinence by trial and error. Incontinence strategies were not taught systematically by the health care providers. Some men (n = 3) had systematic teaching and therapy about Kegel exercises: “I talked to my primary physician about it and he suggested Kegel exercise. I’m doing that now for a month…” (#5), whereas others received only information and/or short introductions: “I was informed by a physical therapist before surgery, but only very short, very short” (#6). Only four participants performed Kegel exercises on a regular basis. “I do it (Kegel exercise) very intensively, even during the night when I’m awake…” (#2).

Pads were handed to the man by nurses in most cases at discharge or after removal of the catheter, but usually they did not fit and the participants had to seek other options: “They gave us some, but they were much too big, so we went to get others” (#10). Men tried different suppliers, forms and sizes until they felt comfortable and safe as the following examples show: “I have to say, the X-ones are pretty good. I tried several types at the beginning. For example those Y-ones were not good because they were leaking when I was turning”, “I use X in addition; that lasts the whole day. Before that it happened that my pants became wet, but now it holds the whole day” (#1).

Being comfortable and safe including feeling dry, prepared and not fearing accidents facilitated men’s sense of control and success. This success was required in order for them to resume their social activities, such as going out, walking, hiking, and work. “When I know I am going out, like tonight, I anticipate that I will have a little alcohol and mineral water. So I know one pad will be enough. Or when I go to the city, I take one extra with me and after two hours I go to the toilette to change it. I can predict that” (#4).

3.1.3. Dealing with sexual activity

With progress in control over urinary function the men started to face the issue of sexual function. Some participants (n = 4) spoke openly and spontaneously about how they thought about and dealt with erectile dysfunction. Others (n = 6), responded to questions on the topic, often using the term “it” and displaying hesitancy to talk about this issue. At the time of the interviews, 4–8 weeks after surgery, none of the men within 4–8 weeks after surgery were able to achieve an erection. Although there was concern whether “it” will ever return, most of them thought it was too early to know for sure. “It is too early, I am already happy that everything else went well, that things are developing well, that is most important right now” (#10).

Men remained hopeful that the ability of erectile function will return naturally after several months, but fearing that it may be permanent, a burdensome uncertainty. “Well the impotence, I mean it is a kind of burden psychologically, I mean. That is a point where I hope that it will come back” (#9).

One participant had regained full erectile function within 8 weeks. Two participants, with preexisting erectile problems had already come to terms with the fact that erectile dysfunction was permanent. One approach to deal with erectile dysfunction was placing it in the context of age, health and relationship. Most of them thought that at their age it was not as “life sustaining” as in younger years and being healthy again was more important. “We are at a certain age, you look at it differently…” (#3) or “the first thing is that the surgery was successful, that’s for sure. Health of course stands on the first place, with the other we have to see” (#5). Some said that sex was not everything in life and that there are other ways of showing love and affection. “We have touched, caressed, and kissed each other; that is still the same and we can develop that further” (#1).

Most men believed that even permanent impotence would not have an impact on their relationships with their wives. “I don’t think that our relationship would suffer or my wife would cheat on me because of this” (#4). One participant even showed relief, since his sexual relationship with his wife had “fallen asleep anyway” and that he had now “one burden less” to deal with (#5). One of the men with already permanent erectile
dysfunction expressed uncertainty about the trajectory of his marital relationship over time. Despite the prevalent cautious optimism and the attempt to prepare for the worse that was present in most of the men, the possibility of permanent impotence caused uncertainty of what lies in the future and how to deal with it.

3.2. Wives: being there

Wives played a vital part in the couples’ efforts to reestablish normal life that was disrupted by the diagnosis of cancer, surgery and its complications. Being there meant to be physically present and actively support their husbands efforts of managing complications through care giving as well as being emotionally present and accessible while recovery was gradually progressing and life returned to normal.

3.2.1. Dealing with burdens

Hearing about cancer, the uncertainty of the trajectory and waiting for the outcome of the surgery were perceived as the main burdens by the women. Wives had not only to deal with their own anxiety but also that of their partners and families. As one woman stated: “Well, mothers are always the lightning conductor” (#4).

Family, friends and neighbors comprised an important resource for the women. Emotional and practical support was received and welcomed. “Our neighbor offered help any time, day and night, that was very sweet” (#3) or “Our daughters came and helped, clean and do the laundry” (#6). Strong family ties facilitated a positive burden management. “We have a very close relationship with our daughter. She was as much involved as we are. She got information for us and supported us emotionally, that gave us hope” (#2).

Nevertheless, some women felt left alone. Not only by friends and family focusing only on the patient, but also by physicians and health care providers, not providing systematic information from the health care providers’ women sought information, found different suppliers, and compared costs. “I got information from my sister and brother in law, they told me that I could go to one place, but then I found the one they had in the hospital at another place, so I went and bought them there.”(#5)

Women also provided important emotional support. They dealt with their husbands’ “irritability”, trying to lessen their frustration. They encouraged them “to be patient”, “to take their medication and do their exercises”. They “kept an eye on them” so that they “did not do too much”, or didn’t “carry heavy things because that was prohibited”.

Not surprisingly, women took on control of the social environment. Wives functioned as protectors, channeling visitors and calls, providing information and promoting understanding for their partners and others: “I had 40 calls last week, when he came home the “do not disturb service” was activated (#1).” “I informed our employees and asked them to be understanding” (#6).

In some cases, a self-owned business was involved, so the women took over their husbands’ work in addition to their own. In doing so women made an important contribution to create an environment that facilitated recovery.

3.2.2. Taking on

Wives took on a variety of tasks to support their husband’s efforts to recover. Overall men were very independent in managing their self-care and regaining control over urinary functions. In the early post-operative phase women supported them in the care of the catheter as well as in wound care. Finding solutions in how to diminish physical restraints became one task the women took on. “We tried every day a new method (different kind of underwear and fixations) and at the end of the week it was perfect” (#2). With removal of the catheter no active physical care was necessary. A main chore became to get supplies for managing incontinence, especially finding the appropriate pads. Lacking systematic information from the health care providers’

3.2.3. Placing erectile function into perspective

In the context of the diagnosis of cancer all the wives were thankful that surgery was successful and the cancer was removed. Most (n = 7) of them did not deny that being confronted with their husband’s possible impotence was initially difficult to deal with. One woman said: “At the first moment it was a shock to hear about the possible consequences, but then we talked…and we found an agreement.” For the others (n = 3), sexual life was already compromised before surgery, thus the husbands impotence didn’t “change much”. However, having their husbands back healthy and alive was
most important. With statements like “life is more important”... we are not 50 anymore,”, or “sex is not the most important thing” the women justified their perspective why impotence was less important. They did, nonetheless, recognize the worry of their husbands regarding impotence and felt that it was probably more difficult for them as they did acknowledge. One woman expressed great uncertainty about how her husband’s impotence would affect their relationship in the future, not knowing if she “still loves him in a year” (#7). The majority, however, reassured them, that whatever would happen it would not have a negative effect on their relationship. As one of them expressed it: “We’ve been together for 34 years, and we went through a lot. So, a prostate cannot shake that” (#1).

4. Discussion

“Getting a grip on it” illustrates the process couples engage in when confronted with the diagnosis of prostate cancer, surgery and its consequences. It describes a variety of approaches utilized by the participants to master the specific challenges of incontinence and erectile dysfunction as well as the overall challenge of living with a prostate cancer diagnosis. Overall, the presented results confirm the existing knowledge about the post-operative experiences of men with prostate cancer and their partners. However, this study provides an important contribution since it was conducted 4–8 weeks after treatment, a time period that is not well researched, yet.

While “getting a grip on it” describes the process couple engaged in with their own words, it resembles the concept of mastery, which is well described in the cancer literature (Skaff et al., 1996; Hagopian, 1993). Specifically, the presented results mirror and confirm those of Maliski et al. (2001). Conducting interviews with 20 couples 3 months after surgery, the authors found that regaining mastery was the work couples engaged in to regain control over their lives. As in the present study, the ability to manage incontinence and erectile dysfunctions were considered important steps in the overall recovery process and its success. One important strategy in regaining control is to determine what is important in the current situation. Setting priorities appears to be an important strategy of self-management. The least importance of erectile dysfunction in this early post-operative period has been documented (Phillips et al., 2000; Maliski et al., 2001). It is, however, important to recognize that the concerns regarding these issues are not underestimated. Despite the men’s hopeful attitude the deep underlying worry was present during all times of the conversation. The prospect of permanent erectile dysfunction clearly provides a great source of future distress in these men (Phillips et al., 2000).

In this study men needed little physical care and were very independent in their efforts to regain control over their lives, urinary incontinence and impotence, but their wives’ contributions were crucial to create an environment which facilitated recovery and control. By providing care supplies, taking care of the household and other work as well as focusing on problem solving, emotional support and protection wives enabled their partners to focus on managing complications in daily life. The important role wives play in the recovery process was underscored by Maliski et al. (2001). In another study of couples after a prostate cancer diagnosis, Harden and colleagues (2002), analyses focus group sessions including 10 men post-prostatectomy and their wives. The wives were reported to have drawn together and shifted roles with their husbands.

Informational support from health care providers was perceived as deficient. The participants received information about the nature of the complication, but systematic and consistent teaching strategies to manage complications were missing. Many participants felt that they had not been sufficiently informed and instructed by the health care providers. This was due partly because they could either not recollect information given to them prior to surgery, did not understand the consequences of the information on their daily life or information was not given at all. This finding is consistent with a report of a study similar in methods by Moore and Estey (1999) who documented the lack of guidance on how to buy and use incontinence supplies by men post-prostatectomy. Not knowing what was a normal post-operative recovery experience and when to contact the health care providers for an abnormal incident is consistently documented in this study and in other studies from the United States (Harden et al., 2002; Moore and Estey, 1999; Phillips et al., 2000). Maliski and colleagues (2001) reported that men receiving post-prostatectomy home visits from advanced practice nurses were prepared for the incontinence, adhering closely to Kegel exercise protocols and having incontinence supplies on hand before catheter removal. However, men in that study who did not receive home visits described dealing with incontinence by “trial and error” (p. 989).

5. Limitations of the study

The small sample size and the composition of the sample may produce diffuse results and restrict an application of the findings to a larger population. The prevalence of middle class couples with long marriages make findings less applicable to those of lower socioeconomic status and shorter marriages. The results may also be less relevant for single and gay men. Furthermore, the discussion of controversial issues may have
been compromised by predominantly interviewing the couples together. Finally, the purposeful sample and the fact that those who consent to participate are generally more open to share their experiences and admit physical and psychosocial problems may represent some selection bias.

6. Further research

Exploration of the post-operative experiences of men and their partners from underserved racial and economic groups is necessary and could illuminate different problems and coping strategies. Inductive methods would again provide the participants with the option to tell their own stories and not be hampered by forced choice questioning.

Clearly, improving both the retention of pre-operative information provided and the comprehensiveness of information is mandated by these findings. Randomized trials of various patient/partner education methods can be designed and implemented for the pre- and post-operative period surrounding radical prostatectomy. Nurse monitoring of patient/partner self-care abilities and resources plus interventions in the immediate post-operative 8 weeks could be tested for a set of improved patient outcomes.

7. Clinical implications

Systematic and written patient education information regarding treatment side effects, catheter care and incontinence supplies are needed to enhance the patient/spouse ability of self management. Information provided should be tailored and be repeated. Pre-surgery education could contain a general overview of treatment side effects, information that should be repeated after surgery. Post-surgical education includes handling and taking care of the catheter and its side effects. Men should be systematically trained in performing Kegel exercises; information about available incontinence supply and how it is used needs to be given. Nurses should have several types and sizes available for display and testing. Spouses should be included in these interventions. Telephone follow ups in the first weeks after surgery may assist patient/spouse with the management of the recovery process and upcoming questions as well as prevent unscheduled hospitalizations.

8. Conclusions

Recovering from a radical prostatectomy may be a more complicated task for men and their partners than previously realized. Current clinical practice of follow up at 3 months may not address the serious deficits in the patient’s ability to “get a grip” on incontinence and other complications of the surgery. Only the patients or partners who have the assertiveness to call in to the clinic or provider’s office will receive any intervention at all. Revising pre-operative teaching methods and follow up procedures is imperative to improve the patient’s and his partner’s experiences.

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