

Patients' Perceptions of Radical Prostatectomy for Localized Prostate Cancer: A Qualitative Study

Sophia Eilat-Tsanani MD^{1,4}, Hava Tabenkin MD^{1,4}, Joseph Shental MD², Irit Elmalah MD³ and Dov Steinmetz MD⁵

Departments of ¹Family Medicine, ²Urology and ³Pathology, HaEmek Medical Center, Afula, Israel

⁴Faculty of Medicine in the Galilee, Bar-Ilan University, Safed, Israel

⁵Department of Family Medicine, Sackler Faculty of Medicine, Tel Aviv University, Ramat Aviv, Israel

ABSTRACT: **Background:** Radical prostatectomy is one option for treating localized prostate cancer, but it can cause functional impairment of the urogenital system.

Objectives: To describe the outcomes of radical prostatectomy as perceived by the patients, and their ways of coping with them.

Methods: We conducted a qualitative study of 22 men with localized prostatic cancer 1 year after surgery. The key questions related to the effect of the disease and the surgery on their lives and their view on the value of the surgery.

Results: The surgery was perceived as a necessary solution for the diagnosed cancer. All the participants suffered from varying degrees of urinary incontinence and erectile dysfunction. Urinary incontinence caused severe suffering. The impaired sexual ability affected relations with partners and led to feelings of shame and guilt and a decreased sense of self-esteem. In retrospect, the participants still viewed the surgery as a life-saving procedure. Faith in the surgeon contributed to their affirmation of the decision to undergo surgery despite the difficulties.

Conclusions: Patients were prepared to suffer the inevitable physical and psychological sequelae of radical prostatectomy because they believed the surgery to be a definitive solution for cancer. Surgeons advising patients with localized prostatic cancer on treatment options should address these difficult issues and provide psychological support, either themselves or in collaboration with professionals.

IMAJ 2013; 15: 153–157

KEY WORDS: prostate cancer, radical prostatectomy, sexual dysfunction, urinary incontinence

For Editorial see page 00

Localized cancer of prostate can be treated either expectantly or by surgery, radiation therapy, or androgen deprivation [1]. All treatments have a negative impact on urogenital functioning [1], on general and mental health [2], and on quality of life [3–5].

Patients with prostate cancer who have undergone radical prostatectomy will have to cope on two fronts: living with the threat of cancer and living with the surgical outcomes. A

discrepancy has been found between patients' reports of the adverse effects of RP on the one hand, and high scores on generic quality-of-life measures on the other [6]. In another study, patients expressed confidence in the surgical treatment and a feeling of control over the cancer despite suffering from significant urogenital symptoms [7].

The present study was designed to describe the real-life experience of patients treated with RP. We sought to describe their view of the disease and their choice of treatment 1 year after RP. A year is the time period when the adverse effects of RP tend to stabilize or disappear [3].

We used qualitative methodology to enable the participants to express themselves freely while describing their view of the disease, the decision to undergo surgery, and different aspects of living with the surgical outcomes.

PATIENTS AND METHODS

The study population comprised men with localized prostate cancer who underwent surgery in the Department of Urology at HaEmek Medical Center. This is a medium-sized community hospital situated in northern Israel and serving a mixed population of Jews, Arabs, veterans and new immigrants living in rural villages, kibbutzim and small towns. Urological surgery and chemotherapy, but not radiotherapy, are available on site. The inclusion criteria were men with localized prostate cancer who underwent RP in the hospital and were alive 1 year after the conclusion of therapy, who spoke Hebrew and agreed to participate in the study. Ten patients were not included due to their generally deteriorated state of health. The diagnosis of localized prostate cancer was confirmed by records from the hospital's Pathology Institute.

We conducted a semi-structured interview in the patient's home using a questionnaire with open-ended questions. In-depth interviewing was chosen as the method of gathering the data [8]. Based on previous reports in the literature, the key questions were related to the effect of the disease and the surgery on everyday life: bodily functions, sexual activity, function at home and at work, and marital relations. The participants

RP = radical prostatectomy

were also asked specifically about their needs and their attitudes towards receiving psychological support.

All the interviews were performed by one research assistant who was trained by the authors (D.S. and S.E-T). The questions were read aloud to all participants to ensure that each question was asked in the same manner, verbally and non-verbally. A list of permissible prompts was designed and used.

The interviews were recorded on an audio-tape recorder and transcribed verbatim. Two pilot interviews were conducted to test the quality of the questions and to eliminate any problems or misunderstandings related to the questionnaire. A few questions were corrected as a result of this procedure.

Transcripts of the interviews were reviewed by two investigators (D.S, S.E-T) to create coding categories. Categories were developed to encompass all topics discussed. After creating the coding categories (the “code book”), the two investigators independently coded the transcripts and then met to review and assess inter-coder reliability. There were no disagreements regarding the application of the categories. Key words, phrases and concepts were determined. In some cases more codes were applied to a single unit of analysis by only one of the investigators. In these cases the additional codes were accepted. Evaluation of the codes continued until both investigators were satisfied. The coded segments were reviewed and summarized [8]. The Helsinki Committee (Institutional Review Board) of HaEmek Medical Center approved the study.

RESULTS

The interviews continued until no further issues or information were forthcoming. The study group included 22 men; their average age was 73 (range 60–81) and all were Jewish [Table 1]. Recurrent themes in the interviews were:

- The perception of the disease and its treatment
- The outcomes of surgery, and living with them
 - Coping with the physical effects
 - Implications for marital relations
- The high value set on the surgery
- The lack of need for psychological support
- The surgeon as a support

THE PERCEPTION OF THE DISEASE AND ITS TREATMENT

A recurrent motif in the interviews was the perception of cancer as a real threat to life: “I decided on surgery because it was cancer. Only for that reason. I chose what would be a better chance to stay alive” (patient #2).

Surgery was perceived as an act to eliminate the threat: “When I learned that I had cancer the first thing I said to the doctor was to take it out. They told me I could have radiation therapy. I said: nothing doing, just cut it out” (patient #7).

The diagnosis of cancer by laboratory or pathological tests was seen as a life-changing event: “The PSA level came back

Table 1. Participants’ sociodemographic characteristics

| Patient # | Age (yrs) | Country of birth (date of immigration) | Marital status | Occupation |
|-----------|-----------|--|----------------------|----------------|
| 1 | 66 | Israel | Married | Kibbutz member |
| 2 | 71 | Data not available | Married | Retired |
| 3 | 81 | Austria (1938) | Married | Agriculture |
| 4 | 76 | Germany (1935) | Divorced | Retired |
| 5 | 76 | Germany (1935) | Divorced | Kibbutz member |
| 6 | 80 | Russia (1990) | Lives with a partner | Retired |
| 7 | 79 | Israel | Married | Kibbutz member |
| 8 | 64 | Russia (1993) | Divorced | Unemployed |
| 9 | 78 | Morocco (1948) | Married | Retired |
| 10 | 79 | Russia (1975) | Married | Retired |
| 11 | 71 | Romania (1972) | Married | Retired |
| 12 | 80 | Russia (1990) | Married | Retired |
| 13 | 60 | Israel | Married | Unemployed |
| 14 | 74 | Brazil (1956) | Married | Kibbutz member |
| 15 | 75 | Israel | Married | Kibbutz member |
| 16 | 80 | Poland (1947) | Married | Kibbutz member |
| 17 | 75 | Russia (1980) | Married | Retired |
| 18 | 67 | Israel | Married | Agriculture |
| 19 | 68 | Israel | Divorced | Worker |
| 20 | 75 | Israel | Married | Retired |
| 21 | 64 | Israel | Divorced | Worker |
| 22 | 61 | Israel | Married | Worker |

high... A repeat test was the same – it went up by one decimal point, so they sent me for a biopsy where they found prostate cancer. Four or five of nine were affected. That was when everything got crazy” (patient #1).

THE OUTCOMES OF SURGERY: COPING WITH THE PHYSICAL EFFECTS

- **Urinary incontinence.** This was reported by all participants to one degree or another and was described as a very difficult complication. Loss of continence occurred in the context of stress or sleep, but was also spontaneous: “I use pads. Sometimes I wake up totally wet. This doesn’t happen every day, maybe once a week” (patient #3).

Some participants used a diaper or pad, which caused discomfort; some used Penrose drains, which caused mechanical problems, and some decided to forego any aids and dealt with the embarrassment of wetting themselves. “Since the surgery I need to go to the bathroom often and also wet myself” (patient #2). “I have to hold the pad because I can get into a situation where I really wet my clothes” (patient #1).

The loss of urinary control and the need for pads or diapers caused a feeling of impotence, shame and discomfort:

“Because of that I prefer not to go anywhere, because of the shame and the fear that I will wet myself” (patient #2). “I was very disturbed by the feeling of lack of control” (patient #1).

- **Sexual function.** All participants cited a reduction in or total loss of sexual function following surgery. They tried to cope by using medications, having sex without an erection, or giving up on sexual relations: “I maintain a romantic relationship with intimate contact even though I don’t have an erection, but somehow we’ve managed without it... there simply is no erection...” (patient #20). “I’m afraid to start up with new women because of the inability to have full sexual contact with penetration. I am concerned about it and stay away from it” (patient #13).

This loss of sexual function led to impaired self-esteem and a feeling of guilt because of the inability to function as a male. “This situation in which there is no sexual satisfaction and there is lack of full control of urination is enough to cause a normal person to feel angry at himself, at the environment, and at everyone” (patient #4).

The investigators noted a degree of rationalization in the participants’ attitudes to the issues that were raised. On the one hand there was a feeling of frustration and disappointment, while on the other a sense of consolation in the fact that some of the changes were natural and age-dependent: “...I took it relatively well because I had surgery at the age of 79, so I figure that my capacity is decreased because of my age as well” (patient #6).

The doctors played a role in the patients’ acceptance of the situation: “The doctors told me that the percentage of men who have sexual relations at this age is low, so if I succeed I am in relatively good shape” (#16).

- **Implications for marital relationships.** In describing their partners’ attitudes they mentioned an understanding based on years of good relations. “We have been together for over 50 years so things like that don’t matter today, and everything is as usual” (patient #6).

At the same time they described relationships that were affected negatively by the impaired sexual capacity. Despite ostensible understanding, they did not seem to be able to overcome negative personal feelings. “I can say that it affects me more than her, with the fact that I cause the lack I also feel the lack.” “I have very strong guilt feelings that I can’t give her satisfaction and feel satisfaction myself” (patient #4). “Although after surgery there was no erection at all and no relationships. Today it’s there a little but there is no ejaculation... my wife accepted this in part because of our age... there’s a lot of understanding between us perhaps because we understood what was happening...”, nonetheless “The physical distance has an effect on the depth of the relations between us.” (patient #9).

THE IMPORTANCE OF SURGERY

The participants felt that the surgery was essential despite the hardships. The feeling was that a price has to be paid for saving their lives: “As far as it depends on me I prefer to have surgery despite the hardships that it caused if it gave me more years to live. I prefer not to give cancer a chance and to have the surgery” (patient #20). “I’m happy that I solved the prostate cancer, and that gave me strength and optimism. As for the sexual function, I stayed alive and we expect a longer life, which is more important than sex” (patient #16).

The fear of cancer introduced a sense of urgency: “One of my fears in that period was that I might miss the boat” (patient #16).

Under the threat of cancer there was no time left for discussion or preparation: “I had thoughts about what might happen... we didn’t talk about it, perhaps I was afraid. I didn’t want to cause mental anguish... let things be. Today I might do otherwise and explain to her that surgery might affect my sexual capacity. But then when I learned that it was carcinoma I decided to have the surgery” (patient #11).

THE LACK OF NEED FOR PSYCHOLOGICAL SUPPORT

The participants were offered support or counseling. They declined the offer, stating that they did not need it.

There is a need for information, but not support: “I am a member of Hosen (a support group for cancer patients). I get material from them and I have the opportunity to go to meetings, but I don’t need to” (patient #3).

Although the patients declined the offer, the investigators had the impression that there was an unstated need for help. The patients said that everything was fine, but the investigators suspected the opposite: “I’m sad, you know, only because I can’t do things I could before... but I get the situation. ... I’m in worse shape and become more tired. There is nothing you can do about it I convince myself. When I see the others, there are younger people in a worse state than me. I ... I’m not depressed, I don’t suffer from depression” patient (#5).

A good relationship with the urologist is also a form of support: “No. I’m not interested in talking with anyone about this. Visiting the doctor is good enough for me. If something is wrong he will let me know. I feel healthy and good” (patient #12).

THE SURGEON AS A SUPPORT

To an overwhelming degree all the participants praised their surgeons and were very appreciative of them. Faith in the urologist contributed to their affirmation of their decision to undergo surgery: “Maybe you have to have faith in the doctor... that’s why you decide on treatment” (patient #3). “I have complete faith in the doctors and I hope I can live a little longer” (patient #17). “I have only praise for Dr. S. He won me over at the start of our first meeting. I had great faith in him...my dependence on him was great from the outset. He’s a good person. He explains things clearly so nothing is

hidden and everything is known in advance. For that reason I trusted him when he told me that if I want to get rid of this thing it's only through surgery, and we did it, and I'm glad we did it" (patient #20).

DISCUSSION

Previous work has shown that postoperative urogenital dysfunction, in addition to adverse physical effects, impacts negatively on sexual activity, physical exercise and the extent of activity outside the house [9]. The results of surgery affect both partners, though sexual satisfaction is related to the couple's level of function before the surgery [10]. The role played by the woman in the patient's ability to cope with the adverse effects of RP is also supported by previous research [10-12]. Women are aware of the emotional problems that their husbands face but they have their own difficulties in coping as well [12,13].

Previous research did not report any effect of RP on quality-of-life scores [14]. Patients who were operated showed improvement in generic QOL scores more than patients who were treated by radiation. At the same time functional scores (urinary and sexual) improved less [15]. The discrepancy between the development of urogenital symptoms and improved QOL scores after RP has been discussed [16]. Feelings of confidence in the choice of surgery were found to help in the acceptance of urogenital dysfunction [7,17]. As in our study, patients after RP for prostate cancer reported that the feeling of salvation from cancer overwhelmed the negative feelings related to the physical complaints due to the surgery [7,17]. The active nature of surgery produced a greater sense of control, security and confidence than other treatments [7,16]. Surgeons have been reported to actively encourage the choice of surgical rather than other treatments [17]. Analysis of the data from CaPSURE, a longitudinal database on morbidity, treatments and outcomes of prostate cancer, shows an increase in the rate of low risk prostate cancer due to early detection. At the same time the rate of active treatment is also rising [18].

Thus, the present in-depth qualitative study of patients' perspectives after RP complements earlier studies and highlights several well-established themes. On the negative side is the ubiquitous postoperative sexual dysfunction with all its attendant psychological problems, and problems with urine control that persisted for a year post-surgery. On the positive side, patients expressed confidence in the necessity for surgery to eradicate the cancer, even in hindsight. The participants described the seminal role of the urologists in supporting their decision to undergo RP as well as after surgery. As in our study, satisfaction with the relationship with the surgeon has been found to play a significant role in the participants' attitudes towards the disease and the treatment [19].

QOL = quality of life

Qualitative studies such as this do not provide statistical data on the prevalence of postoperative complications, or ranges of quality-of-life scores. Rather, they serve to identify and highlight themes that are perceived by the patients to be important. There is no control group, because the RP patients' perspective is valid in itself, irrespective of how patients on watchful waiting feel about their experience. Indeed, this study points the way to similar research on patients under watchful waiting.

As for the reliability of the results of qualitative research, the number of subjects is not determined by statistical power analysis because the data are not expressed in terms of statistical probabilities. Rather, data acquisition continues to saturation point, where further interviews stop yielding new insights. In our case, saturation was reached after the first 20 interviews, this small sample size proving adequate for the purposes of the study. The primary limitation of this study is that information based on recall a year after the event may not accurately reflect the decision-making process when the diagnosis was reached. In addition, only Hebrew speakers were included so the findings only represent this subpopulation of our hospital's patients. Finally, the family relationships cannot really be understood unless the wife is also interviewed, and the same applies to the attitudes towards the surgeons who were not interviewed either.

The main advantage of the study is that it portrays the dilemma of living with cancer or living with the outcomes of treatment. Our study brings an overarching description of the experience of the disease and the outcomes of the surgical treatment. The retrospective view helps us understand the judgment of the men regarding RP and the importance of their relationship with the surgeons. This information is particularly important in light of the uncertainty of the contribution of RP to survival in localized prostate cancer.

At the time of writing, a year after the RP, the participants in our study continue to suffer from its outcomes. Knowing that the treatment was to eradicate cancer helped them accept it and even express gratitude. Still, the interviews brought forth sounds of distress that might even increase over time.

The situation that was explored in our study is multifactorial and not simple. We cannot outline a model of care that would fit all patients with localized prostate cancer who opt for RP. From the interviews we conclude that the patients' needs are different and change with time. Care providers should be alert and sensitive to these changes. Surgeons have an important role in advising patients before surgery and supporting them during follow-up. That involves providing psychological support themselves or in collaboration with other health professionals.

Corresponding author:

Dr. S. Eilat-Tsanani

Amakim Regional Office, HaEmek Medical Center, Afula 18101, Israel

Phone: (972-4) 606-8800

Fax: (972-4) 606-8828

email: eilat@clalit.org.il

References

1. Catalona WJ, Han M. Definitive therapy for localized prostate cancer – an overview. In: Wein AJ, Kavoussi LR, Novick AC, Partin AW, Peters CA, eds. *Campbell-Walsh Urology*. 9th edn. Philadelphia: Saunders-Elsevier, 2007: 2932-46.
2. Treiyer A, Anheuster P, Bütow Z, Steffens J. A single center prospective study: prediction of postoperative general quality of life, potency and continence after radical retropubic prostatectomy. *J Urol* 2011; 185: 1681-5.
3. Litwin MS, Pasta DJ, Yu J, Stoddard ML, Flanders SC. Urinary function and bother after radical prostatectomy or radiation for prostate cancer: a longitudinal, multivariate quality of life analysis from the Cancer of the Prostate Strategic Urologic Research Endeavor. *J Urol* 2000; 164: 1973-7.
4. Suárez JF, Guedea F, Fernández P, et al. Multicentric Spanish Group of Clinically Localized Prostate Cancer. Health-related quality of life 2 years after treatment with radical prostatectomy, prostate brachytherapy, or external beam radiotherapy in patients with clinically localized prostate cancer. *Int J Radiat Oncol Biol Phys* 2008; 72: 421-32.
5. Litwin MS, Hays RD, Fink A, et al. Quality-of-life outcomes in men treated for localized prostate cancer. *JAMA* 1995; 273: 129-35.
6. Schapira MM, Lawrence WF, Katz DA, McAuliffe TL, Nattinger AB. Effect of treatment on quality of life among men with clinically localized prostate cancer. *Med Care* 2001; 39: 243-53.
7. Clark JA, Inui TS, Silliman RA, Bokhour BG, et al. Patients' perceptions of quality of life after treatment for early prostate cancer. *J Clin Oncol* 2003; 21: 3777-84.
8. Miller WL, Crabtree BF. Depth interview. In: Miller WL, Crabtree BF, eds. *Doing qualitative research*. 2nd edn. Thousand Oaks, CA: Sage Publication, Inc, 1999: 89-108.
9. Cayless S, Forbat L, Illingworth N, Hubbard G, Kearney N. Men with prostate cancer over the first year of illness: their experiences as biographical disruption. *Support Care Cancer* 2009; 18: 11-19.
10. Badr H, Taylor CL. Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psychooncology* 2009; 18: 735-46.
11. Harden J, Schafenacker A, Northouse L, et al. Couples' experiences with prostate cancer: focus group research. *Oncol Nurs Forum* 2002; 29: 701-9.
12. Hawes S, Malcarne V, Ko C, et al. Identifying problems faced by spouses and partners of patients with prostate cancer. *Oncol Nurs Forum* 2006; 33: 807-14.
13. O'Brien R, Rose P, Campbell Ch, et al. "I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Educ Couns* 2011; 84: 200-7.
14. Faithfull S, Cockle-Hearne J, Khoo V. Self-management after prostate cancer treatment: evaluating the feasibility of providing a cognitive and behavioural programme for lower urinary tract symptoms. *BJUI Br J Urol Int* 2010; 107: 783-90.
15. Jayadevappa R, Chhatre S, Whittington R, Bloom BS, Wein AJ, Malkovitz SB. Health-related quality of life and satisfaction with care among older men for prostate cancer with either radical prostatectomy or external beam radiation therapy. *BJUI Br J Urol Int* 2006; 97: 955-62.
16. Korfage IJ, Hak T, de Koning HJ, Essink-Bot ML. Patients' perceptions of the side effects of prostate cancer treatment – a qualitative interview study. *Soc Sci Med* 2006; 63: 911-19.
17. Ihrig A, Keller M, Hartmann M, et al. Treatment decision-making in localized prostate cancer: why patients chose either radical prostatectomy or external beam radiation therapy. *BJUI Br J Urol Int* 2011; 108 (8): 1274-8.
18. Porten SP, Cooperberg MR, Konety BR, Carroll PR. The example of CaPSURE: lesson learned from a national disease registry. *World J Urol* 2011; 29: 265-71.
19. Cegala DJ, Bahnson RR, Clinton SK, et al. Information seeking and satisfaction with physician-patient communication among prostate cancer survivors. *Health Commun* 2008; 23: 62-9.

Capsule

Ca2+ regulates T-cell receptor activation by modulating the charge property of lipids

Ionic protein-lipid interactions are critical for the structure and function of membrane receptors, ion channels, integrins and many other proteins. However, the regulatory mechanism of these interactions is largely unknown. Shi et al. show that Ca2+ can bind directly to anionic phospholipids and thus modulate membrane protein function. The activation of T cell antigen receptor-CD3 complex (TCR), a key membrane receptor for adaptive immunity, is regulated by ionic interactions between positively charged CD3ε/ζ cytoplasmic domains (CD3CD) and negatively charged phospholipids in the plasma membrane. Crucial tyrosines are buried in the membrane and are largely protected from phosphorylation in resting T cells. It is not clear how CD3CD dissociates from the membrane in antigen-stimulated T cells. The antigen engagement of even a single TCR triggers a Ca2+ influx and TCR-proximal Ca2+ concentration is higher than the average cytosolic Ca2+ concentration. Our biochemical, live-cell fluorescence resonance energy transfer and NMR experiments showed that an increase in Ca2+ concentration induced the dissociation of CD3CD from the membrane and

the solvent exposure of tyrosine residues. As a consequence, CD3 tyrosine phosphorylation was significantly enhanced by Ca2+ influx. Moreover, when compared with wild-type cells, Ca2+ channel-deficient T cells had substantially lower levels of CD3 phosphorylation after stimulation. The effect of Ca2+ on facilitating CD3 phosphorylation is primarily due to the charge of this ion, as demonstrated by the fact that replacing Ca2+ with the non-physiological ion Sr2+ resulted in the same feedback effect. Finally, 31P NMR spectroscopy showed that Ca2+ bound to the phosphate group in anionic phospholipids at physiological concentrations, thus neutralizing the negative charge of phospholipids. Rather than initiating CD3 phosphorylation, this regulatory pathway of Ca2+ has a positive feedback effect on amplifying and sustaining CD3 phosphorylation and should enhance T cell sensitivity to foreign antigens. This study thus provides a new regulatory mechanism of Ca2+ to T cell activation involving direct lipid manipulation.

Nature 2013; 493: 111
Eitan Israeli

“The best way to have a good idea is to have lots of ideas”

Linus Pauling (1901-1994), American chemist, biochemist, peace activist, author and educator. Among the most influential chemists in history, Pauling was one of the founders of the fields of quantum chemistry and molecular biology. He is the only person to be awarded two unshared Nobel Prizes, one of only four individuals to have won more than one