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Experiences of Patients Who Developed Urinary Incontinence After Radical Prostatectomy: Focus Group Study

Radikal Prostatektomi Sonrası Üriner İnkontinans Gelişen Hastaların Deneyimleri: Odak Grup Çalışması

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Abstract:
Objective: The study was performed to determine the experiences of patients with urinary incontinence after radical prostatectomy.
Method: A qualitative research method was used in the study. Data were collected from 44 patients who developed and continued experiencing urinary incontinence after radical prostatectomy by using focus group interviews**.** Data were collected in a public hospital between April 2014 and March 2015 using a semi-structured interview form. Study data were examined using content and thematic analyses. Ethics committee approval was obtained to conduct the study.
Results: Of all the patients included in the study, 54.5% were aged 65 years or older, 86.4% were married. As a result of focus group discussions, four main themes and 12 sub-themes were determined. The four main themes; identified are unpleasant job, half-a man, social interactions, and surviving as a great prize.
Conclusions: Urinary incontinence, causes men to experience physical, psychological and social challenges during daily life. The patients reported that felt the need to receive information and support in coping with the difficulties they experienced postoperatively

Key Words: Prostate cancer; radical prostatectomy; urinary incontinence; patients; experience; focus group.

Özet:
Amaç: Çalışma, radikal prostatektomi sonrası üriner inkontinansı olan hastaların deneyimlerini belirlemek amacıyla yapıldı.
Yöntem: Araştırmada nitel araştırma yöntemi kullanılmıştır. Veriler, radikal prostatektomi sonrası üriner inkontinans gelişen ve devam eden 44 hasta ile odak grup görüşmesi yapılarak toplanmıştır. Veriler, bir kamu hastanesinde Nisan 2014 ile Mart 2015 tarihleri arasında yarı yapılandırılmış görüşme formu kullanılarak toplandı. Çalışma verileri içerik ve tematik analizler kullanılarak incelenmiştir. Araştırmanın yapılabilmesi için etik kurul onayı alındı.
Bulgular: Çalışmaya alınan tüm hastaların %54.5'i 65 yaş ve üzerinde, %86.4'ü evli idi. Odak grup görüşmeleri sonucunda dört ana tema ve 12 alt tema belirlenmiştir. Belirlenen dört ana tema; tatsız iş, yarım adam, sosyal etkileşimler ve büyük bir ödül olarak hayatta kalmaktır.
Sonuç: Üriner inkontinans, erkeklerin günlük yaşamda fiziksel, psikolojik ve sosyal yönden güçlükler yaşamalarına neden olmaktadır. Hastalar, ameliyat sonrası yaşadıkları zorluklarla baş etmede bilgi ve destek alma ihtiyacı hissettiklerini belirtmişlerdir.

Anahtar Kelimeler: Prostat kanseri; radikal prostatektomi; üriner inkontinans; hasta; deneyim; odak grup.

Introduction

Prostate cancer is one of the most common types of cancer and the second most frequent cause of death due to male cancer in worldwide.(1-4) Radical prostatectomy is a common treatment of localized prostate cancer.(1,4-7) Urinary incontinence after radical prostatectomy is a complication that significantly affect the quality of life of the patients.(1,6,8,9) Urinary incontinence is defined as involuntary loss of urine by the International Continence Society.(10,11) Currently, the prevalence of post-prostatectomy incontinence varies from 1% to 87%.(5) Urinary incontinence after prostatectomy adversely affects patients physically, psychologically and socially.(12,13) Urinary incontinence leads to the development of pressure ulcer, dermatitis, urinary tract infections, falls and fractures.(14-16) In addition, this situation causes of patients to experience fear, anger, depression, anxiety, decreased self-confidence, shame, unhappiness, loss of sense of control and stigma.(1,4,9,12,14-17) Urinary incontinence leads to social isolation and to restriction life styles.(18,19)

The patients need physiological and psychological support during the recovery period after radical prostatectomy. The health care team has important responsibilities for providing this support.(20) The lack of support about the disease and its treatment could make it difficult for the patients and their families to cope with the problems and negatively affect the postoperative recovery period. In addition, the lack of support causes the patients to feel insecure, hesitant, and lonely and to experience fear, anxiety, frustration, and stress.(7) These symptoms in the early and late postoperative periods cause difficulty in the patient's adaptation to the postoperative process. Therefore, it is important to understand the experiences of these patients. There are studies in the literature to determine the urinary incontinence experiences of patients after radical prostatectomy. There is not enough data on the urinary incontinence experiences of patients after radical prostatectomy in Turkey. The impact of incontinence after radical prostatectomy on the life experiences of men in Turkish society important to be fully understood. The purpose of this study to describe the urinary incontinence experiences of Turkish men post-radical prostatectomy process.

Methods

Study Design

Qualitative research method was used in the study.

Setting and participants

Patients who developed and continued experiencing urinary incontinence after radical prostatectomy were included in the study. Inclusion criteria were as follows: Being aged over

18 years, ability to speak Turkish, at least 15 days have elapsed since removal of the Foley catheter, and having no disorders that would hinder cognitive, sensory, or verbal communication.

The study population comprised of 58 patients and the sample 44 patients who underwent open radical prostatectomy in a state hospital between 24 May 2013 and 26 March 2015 and who continued experiencing urinary incontinence after surgery. Four patients were not included in the study because they were out of town during the interviews, 5 patients did not attend the interviews even though they said they could attend the interviews, and five patients said they could not attend the interviews due to health problems. In the study, data were collected in three periods as early (zero-three months), middle (over three months-six months) and late (over six months or longer) according to the time elapsed after surgery. Two separate focus group interviews were held for each of the three terms. In the literature, it is stated that the number of focus group between 3 and 5 are sufficient to reach saturation.(21,22) But also, it is stated that at least two focus group should be performed for each variable related to the subject.(23)

The focus group interview method allows working with a large sample and in-group interaction. Thus, by increasing group dynamism and creativity, it provides access to newer, deeper and richer information about the subject of the research.(24,25) It is emphasized that focus group interviews are more effective than individual interviews in examining sensitive issues.(25,26)

Data Collection

Data were collected at focus group interviews by using a patient identification form and a semi-structured interview guide. A semistructured interview form was prepared by the researchers in the light of the literatüre.(27-38) The questions were evaluated by 2 urology specialist physicians and 2 urology nurses to investigate their suitability. Patients were also queried on demographic characteristics age, educational level, and monthly income.

The interviews were conducted by experienced a female researcher with expertise on qualitative studies between April 2014 and March 2015. Within the permission of the hospital management, the phone numbers of the patients were obtained from the relevant unit. The patients fulfilling the inclusion criteria were phoned and informed about the aim and method of the study. Those who volunteered to participate in the study were invited for an interview and focus group interviews were conducted.

Throughout the focus group interviews, a moderator was responsible for guiding the interviews and collecting data while two people were responsible for audio and video recordings.

Interviews were held in the meeting room of the hospital, by the same moderator. The average length of an interview was 98 minutes, ranging from 65 to 148 minutes.

Ethical Considerations

This study was approved by the scientific ethics committee of a Ege University Nursing Faculty (Approval No. 2014-34, dated March 13, 2014). Written permission to perform the study was obtained from the institution in which the research was conducted. The patients were informed about the aim of the study by the researcher, their oral and written consent was obtained.

Data Analysis

By adopting Creswell’s method, variation in data was achieved since the participants had different ages, socio-economic and educational status, were experiencing different stages of the postoperative period. Data were analyzed with deductive content analysis.(25,39) The interviews, which were recorded using a voice recorder and video recorder, were manually transferred to a computer in their original form by the researchers on the same day. The researchers documented the interview recordings by listening them twice. The documented data were read repeatedly wo researchers and confirmed to be matching with the audio and video recordings. The smallest meaningful expressions obtained from the data were listed and then codes were generated. Codes were compared and classified according to their similarities and differences. When sufficient repetitions about patients experiences on UI were performed, data saturation occurred and thematic analysis commenced. The list of expressions obtained was collected under common semantic units (category and theme creation) in line with their proximity to each other. The codes were investigated by 2 experts external from to the the research team to ensure the internal consistency of the research. The consistency of data was determined between the identified themes, and the main themes and subthemes were created. Themes created from the resulting semantic units were confirmed by participant statements.(39)

Quantitative data (demographic characteristics) were analyzed by using the Statistical Package for the Social Sciences, version 15.0 (SPSS).

Rigor

In order to increase the validity and reliability of the research, the following were provided: (1) at the end of the interviews, patients confirmation was received; (2) the patientsts’ statements were quoted without any interpretation; (3) data analysis and results were described in detail; (4) data analysis was performed by two separate researchers, whereas another researcher listened to the data recordings and compared the codes/themes (analysis trilogy); (5) data collection tools, research data, coding made during analysis, observation notes and perceptions that form the basis of the report were stored to be submitted for confirmation, when necessary.(39)

The study design was carried out and reported in accordance with the criteria of Consolidated criteria for REporting Qualitative research (COREQ).(40)

Limitations

The results cannot be generalized to the entire population, as data were collected from a single hospital.

Results

Of all the patients included in the study, 54.5% were aged 65years or older, 86.4% were married, 40.9% were living in the province, 63.6% were primary school graduates, 84.1% were retired and 90.9% had health insurance (Table 1).

Table 1. Socio-Demographic Characteristics of Patients Who Developed Urinary Incontinence After Radical Prostatectomy (n=44)

Variable	n	(%)
Age		
65 Years and Over	24	54.5
64 Years and Under	20	45.5
Marital status		
Married	38	86.4
Unmarried	3	6.8
Widowed	3	6.8
Place of residence		
Province	18	40.9
District	15	34.1
Town- Village	11	25.0
Education		
None	1	2.3
Primary school	28	63.6
Secondary school	5	11.4
High school	1	2.3
University	9	20.4
Employment		
Retired	37	84.1
Employed	5	11.4
Unemployed	2	4.5
Social Security Status		
Yes	40	90.9
No	4	9.1
Total	44	100

As a result of focus group discussions, four main themes and 12 sub-themes were determined. Main Themes, Subthemes and Informant Data About the Effects of UI on Patient's of this study are presented in Table 2.

Table 2. Main Themes, Subthemes and Informant Data About the Effects of UI on Patient's

Theme	Subtheme	Informant Data
Unpleasant Job	Hard to achieve hygiene	"... I change my clothes four or five times a day. ... Different ... unpleasant job, I mean. It is nice to wash the hands and have a bath but ... you know … washing, cleaning, changing my"
	Coping with urinary incontinence	At first, it was leaking a lot… I would compress the dripping urine with a small rubber band…I mean, by strangulating. As if I was trying to"
	Information needs	"Before surgery…we were not fully informed…if we had been fully informed, we would get out of situation a little more easily…"
Half a Man	Unhappiness	"... the problem of urinary incontinence and erection ...this is the only cause of my"
	Communication with spouses	"…we are like strangers ..."
	Support	"... my psychology was greatly affected…I've seen a psychiatrist ... I've used a drug prescribed … I am very much relieved …"
	Seeking for a solution	"… I had to postpone having an implant since I had this urinary problem and until my urinary problem could be eliminated"
Social Interactions	Stigma	"... sometimes ... I leak too much. … Would people smell the odor of urine? Would they not? I feel depressed. …I'm obliged to put on perfume. So that people around me do not smell it and become uncomfortable.… And sometimes … I have to leave that community.
	Sharing the problem	"I've already told them that I leak urine … I share it, but I'm being mocked in return. …belittled…instead of feeling proud of a friend who openly shares it … they mock you …"
	Social life	"I continue to live as if I had had no surgery. … I don't have any problems. I don't feel it."
Surviving as a Great Prize	Continuing to live	"Now leaking urine decreases my morale a little. … After I talk to my doctor, I feel happier and more hopeful"
	Worrying about recurrences	"… I doubt that it may spread to another part of my body."

Theme 1: Unpleasant Job

Hard to achieve hygiene*:* Most of the patients said that they had a large amount of urinary incontinence after the foley catheters were removed, and that their daily lives were affected greatly:

"After the catheter was removed, the leakage never stopped. I felt so desperate." (K10, 66 years old, early stage).

"The urine issue affects me, I mean, it is disturbing. I don't go out or even when I go out, I wonder where the toilet is and how I can find the toilet if something happens suddenly? How can I change my diapers? At first, these would pose a problem and I wasn't able to go anywhere." (P6, 55 years old, late-stage).

Coping with urinary incontinence*:* Most of the patients said that they used pads, panties, adult diapers and some methods they developed for urinary incontinence.

“At first, it was leaking a lot. To prevent the ürine coming I would compress the dripping urine with a small rubber band ” (P6, 55 years old, late-stage).

Some patients said that they benefited from physiotherapy and Kegel exercises in gaining back continence:

“I am exercising. Previously, I used to use eight diapers a day. Now I have reduced it to 4” (P11, age 69, early stage).

Information needs*:* Some patients stated that being informed about the complications that may occur after the surgery may be effective in accepting the situation more easily:

“I would have accepted this situation if the necessity of prostate removal and the problems that may develop due to this surgery had been explained to me before the operation.” (P27, 69 years old, late-stage).

“My doctor gave me the necessary information in advance. You will have this much urinary incontinence; you might be wearing a diaper or using a pad. … Once you trust doctors who performed the surgery, you don’t have any psychological problems. You know that you will recover.” (P16, 61 years old, middle-stage).

Theme 2: Half a Man

One of the questions in our semi-structured interview guide was: "How did your complaint (urinary incontinence) affect your sex life?". Depending on this question, the experiences of patients about how surgery affects their sexual lives were also included in the findings.

Unhappiness*:* Patients reported they unhappy and their felt stressed because of urinary incontinence and erectile dysfunction:

“The problem of urinary incontinence and erection. These two cause of my distress. The doctor said that they would end in two months. It has been 13 months, but it's still not finished. I am stressed. ... I feel weak” (P1, 73 years old, late-stage).

"I get depressed because of my erection problem. But I cannot say anything to my wife … sometimes I feel as if I were useless, but there’s nothing to do … sometimes I tell myself that it can’t go on like this. (P42, 68 years old, early-stage).

“The urine leaks until I get to the bathroom. ... this, of course, disturbs me ... Worse than my condition before the surgery. I happened to think why I had surgery then, why I suffered all this pain” (P27, 69 years old, late-stage).

Communication with spouses*:* Some patients reported that their relationships with their partners were adversely affected due to post-operative erectile dysfunction:

“My communication with my wife has been greatly affected. My wife stays away from me. I regret having the surgery; I would rather die. My life has been turned upside down. My wife has the right to beat me, kill me, leave me.” (P7, 60 years old, late-stage).

“… I feel as if I was a failure in my wife’s eyes.” (P2, 69 years old, late-stage).

Some patients reported that erectile dysfunction did not affect their relationship with their spouses:

“If we were young, this situation could have affected our family life. We are aged now … our wives are also aged … I don’t think that my family life will be disrupted because of this issue.” (P11, 69 years old, early-stage).

Support*:* A Patient stated that his psychology was impaired due to urinary incontinence and he received psychiatric support.

“My psychology was greatly affected. I started to get angry suddenly. I started walking in small steps. I could not climb up the stairs. I’ve seen a psychiatrist. I’ve used a drug prescribed. I am very much relieved” (P27, 69 years old, late-stage).

Patients reported that they felt good psychologically and did not feel the need for psychiatric support:

“We are cancer patients ... We are struggling against it by ourselves. We are withstanding, actually … If we do our best to beat cancer there’s no need to see a psychologist in my opinion” (P11, 69 years old, early-stage).

Seeking for a solution: Most of the patients stated that they were looking for solutions to their sexual problems. They said that they were waiting for the the healing process to be completed and for continence to be established.

“My doctor said that penile prosthesis can be applied after one year at the earliest. … this will not be possible as long as my urinary incontinence problem persists. … Therefore, I will have to wait until the leak disappears” (P11, 69 years old, early stage).

Theme 3: Social Interactions

Most of the patients reported that they avoided joining social activities and experienced social isolation because of urinary incontinence in early postoperative period.

Stigma: Some patients admitted that they were hiding their experience of urinary incontinence and erectile dysfunction due to their fear of stigmatization:

"In our society, this problem cannot be shared with anyone because it is perceived as something embarrassing ... society has an unchangeable point of view ... They think I have had prostate surgery and my manhood is lost" (P20, 59 years old, middle-stage).

"Sometimes I leak ürine too much. I'm obliged to put on perfume so that people around me do not smell urine and become uncomfortable. Sometimes I have to leave that where I'am to avoid disturbing other people" (P12, 59 years old, early-stage).

Sharing the problem*:* A patient said he shared his problem of urinary incontinence with others freely, but that people mocked him:

"I've already told them that I leak urine. I share it, but I'm being mocked in return. Iinstead of feeling proud of a friend who openly shares it they mock you" (P42, 68 years old, early-stage).

Some patients commented that they could share their problems with other people easily and received their support on this matter:

"I share, and I always receive support and care from them. I didn't have any problems with these matters." (P11, 69 years old, early-stage).

Social life*:* Most of the patients said they could perform their daily activities and join social activities just as they did before:

"I continue to live as if I had had no surgery. I don't have any problems." (P5, 69 years old, late-stage).

The patients reported that urinary incontinence prevented them from praying:

"I can't go to the mosque for the Friday pray as it may stink and disturb people." (P4, 73 years old, late-stage).

Theme 4: Surviving as a Great Prize

Continuing to live: Some patients commented that they accepted the problems due to urinary incontinence and erectile dysfunction:

"Surviving is already a great prize for me ... I don't care about the rest. There's nothing that affects my life; I only leak urine" (P27, 69 years old, late-stage).

"Both my wife and I thought that I should get rid of this cancer. … I'm very pleased with my condition now. … Even if some things are lost, it doesn't matter anymore." (P42, 68 years old, early-stage).

"… But, just because there's such a thing … I'm not going to get weary of life. Why should I demoralize myself, distress myself? If I get obsessed with it, then my health will get worse. I try not to think about it." (P5, 69 years old, late-stage).

Worrying about recurrences*:* Some patients expressed their concern about the recurrence of prostate cancer:

"I was a bit uncertain at first as they said it was malignant. … but the professors said they removed it fully … still, I don't feel at ease … I doubt that it may spread to another part of my body" (P16, 61 years old, middle-stage).

Discussion

Following radical prostatectomy, patients have to cope with the physical, psychological and social problems in their lives caused by urinary incontinence. In addition, patients indicated that urinary incontinence crated challenges in the sexual function, religious lives, and it created restrictions in daily activities. In this study, the patients reduced their consumption of tea, coffee, acidic beverages and some fruits with diuretic effects,(36,38,41-44) they used pads, sanitary napkins, diapers, condom tubes or clamps (28,32,37,38,42) and they stated that they feel the need to find the toilet in the places they visited.(36,43) In the study, most of the patients stated that they did not receive training on pelvic floor muscle exercises (22,28,38,41) while some stated that they applied these exercises and received physiotherapy.(36,38,41,42,44,45)

In our study, most of the patients stated that they experienced social isolation in the early postoperative period, they were able to participate in social activities in the late period (6 months and above), and their social lives were not adversely affected, this is consistent with the literature.(46,48) This situation can be explained by the decrease in the amount of urinary incontinence of the patients in the late postoperative period and their adaptation to the situation. There are many studies patients reported that they have decreased social interactions and experience social isolation especially in the early postoperative period (0-3 months).(8,28,33,37,38,46,47) Hayder and Schnepp (2010), in their study stated that patients could not perform leisure activities at all or had to limit.(36)

In the literature, it is stated that the sources of information are physicians, health counselors, prostate support groups, internet, video, textbook, and family members.(29-31,36,42,44,48,49) In the present study, while the majority of patients showed doctors as a source of information, only a few showed the internet. Fernández-Sola et al. (2020) stated in their study that they tried to meet the information needs of the participants from their social environment due to the insufficient information received from health professionals.(50) The patients who were informed about the complications of surgery said that they accepted the situation more easily. Similar results were reported in two studies conducted in parallel with our study.(44,48) In the present study, patients stated that they were not adequately informed about the surgery-related sexual disfunction, and if they were informed enough, they would consider canceling surgery. Fernández-Sola et al. (2020) stated in their study that some participants are not sufficiently informed about the effect of prostatectomy on sexual function, and that they can make decisions that may lead to different results if they have more comprehensive information.(50) Our study, most of the patients reported that they were supported by their spouses in coping with urinary incontinence and thus felt better. There are many studies reported that they were supported by their spouses in coping with urinary incontinence and thus felt better.(28,31,41,46,50)

Some patients stated that they felt useless as a result of urinary incontinence and erectile dysfunction developing after surgery, which is also similar to another report in the literature.(33,37,48) This can be explained is caused by the stigmatization of the patients and the damage to their masculinity feelings. In the present study, patients reported that they consider urinary incontinence as the first problem and that its resolution is difficulty for them.(28,31,38,41,46,48) Our study, the majority of patients stated that erectile dysfunction is one of the most serious complications that cause them distress and negatively affects their lives. There are many studies the majority of patients stated that erectile dysfunction is one of the most serious complications after surgery.(27-29,32,33,37,42,47,51) In the present study, some patients stated that they felt guilty and experienced a sense of inadequacy due to erectile dysfunction, which negatively affected their communication. In the literature, there are studies stating that patients experience a sense of inadequacy and their relationships with their partners are affected due to post-operative erectile dysfunction.(27,37,44,46) Besides, it has been reported that if the problem was not resolved, patients would have to separate from their spouses, which is also similar to other reports in the literatüre.(37,46) Patients indicated that sexual function loss is an expected condition for their ages, and their spouses do not care about this loss.(27,28,34,42)

Most of the patients reported that they took the risks of surgery since they cared about getting rid of cancer and regaining their health, which is also similar to other reports in the literatüre.(27,29,32,33,41,44,46,48) Patients stated that they had a fighting spirit due to their cancer and they did not think that psychiatric support could be effective in coping with post-operative difficulties, which is consistent with the literatüre.(27)

Implications for Practice

To know the experiences of the patients due to urinary incontinence developing after surgery; It will be effective in providing the necessary information before and after the surgery and in providing the support they need to cope with the difficulties they experience.

Conclusion and Suggestions

It was found that patients experienced social isolation due to stigma anxiety and difficulty in preservation hygiene in the early postoperative period (0-3 months). At the same time, it was observed that almost all of the patients experienced erectile dysfunction and therefore felt inadequate and unhappy. It was reported that patients attach great importance to spouses' support in coping with urinary incontinence and erectile function and avoid sharing these problems with their environment. Also, it was shown that patients had anxiety about the recurrence of cancer. It was observed that patients who were informed about urinary incontinence and coping strategies by healthcare professionals and supported by the family in this process were less affected by this condition. Patients should be informed by health professionals about urinary incontinence and coping strategies and support mechanisms should be activated. Nurses should ensure effective communication with these patients and plan interventions to strengthen their coping methods.

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