

Living with Urostomy: Patient's Perspective

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Abstract

The diagnosis of bladder cancer and necessity of urostomy is profoundly life changing. This qualitative study was conducted in order to assess lived experiences of patients who had received urostomy due to bladder cancer or any other urinary pathology. The sample included 30 patients with urostomy admitted in the Urology ward, AIIMS, New Delhi. Purposive sampling was used and data was collected using semi structured interviews. Narrative data was analysed using Colaizzi's steps of analysis for qualitative data. Ten themes emerged from the analyses which were further categorized into sub themes. The theoretical framework of the themes and subthemes defined the phenomenon of living with urostomy in entirety.

Key words: *Qualitative research, Lived Experience, Bladder cancer, Urostomy, Colaizzi's Steps of Qualitative Analysis*

Introduction

Urostomy is a procedure that reroutes the flow of the urine out of the body.¹ Urostomy surgery may be required for many reasons, the most frequent indication being bladder cancer, which is the second most common urologic malignancy.² Of all bladder cancers, 10-20 percent is the muscle invasive type which is classically treated with cystectomy and urostomy.³

Creation of a urostomy significantly alters elimination pattern and can have both physical and psychological effects. The most common physical complications with urostomy are infectious, gastrointestinal, wound related and genitourinary. The physiologic complications involve changes of the stoma and peri-stomal skin including dermatitis, pain, bleeding, necrosis, prolapse, stenosis, herniation, infection and retraction of the stoma.^{4,5}

Many urostomy patients have emotional, social and sexual problems. Urostomy patients are concerned

about the effect of the stoma on their ability to carry out activities of daily living. Ostomy surgery is a life-enhancing procedure that restores a vital bodily function, but it's not easy to accept.⁶

Nurses involved in the care of patients with a stoma should have an understanding of the reasons for stoma creation, and the types of stoma and appliances available. Issues related to diet, sexual relationships and self-image should also be discussed with patients.^{7,8}

There have been significant advances in stoma appliances and an increase in nurses specialising in stoma care. Despite this, a large proportion reportedly up to 75% of patients continue to experience adjustment problems, which suggest that improvements in stoma management are by themselves not enough to enhance functioning.⁷ This inspired the examination of problems of urostomy patients in this study.

Objective: To explore the lived experiences of the patients living with urostomy.

Materials and Methods

Research Design and Sampling:

A phenomenological qualitative research design was used. Sample size was limited to 30 when data saturation

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occurred. Purposive sampling was used to select patients who had undergone radical cystectomy and ileal conduit surgery. Patients after 5 days of the surgery, above 18 years of age and willing to participate in the study were enrolled.

Research Tools

1. Demographic Profile Sheet:-

The demographic profile sheet was used to collect socio-demographic data of patients. Content validity was obtained from the experts.

2. Semi-Structured Interview Guide:-

An interview schedule was developed which listed the open ended questions to explore the experiences of the urostomy patients. It was validated by experts.

Data Collection

The study was conducted from January 2018 to July 2018. The willing participants were explained about the study and informed consent was signed. Anonymity, confidentiality and privacy of patients were maintained. Face to face interview was conducted by the researcher with a fairly open framework. An interview session lasted 10-30 minutes and was audio taped with the consent of the patient. Field notes were maintained. The place for interview was a private room in the urology ward. Active attention was given to the body language, posture, facial expressions and voice intonation of the participants. Short pauses and silences were dealt with patience as they helped the patient to understand their feelings and put them into words. Emotional support was extended when patient got distraught and cried during the interview.

Data Analysis

The demographic data was analysed using descriptive statistics in SPSS. Statistical tests used to describe the data were frequency distribution, mean and standard deviation.

Qualitative analysis was done simultaneously with data collection. Recorded interviews were transcribed verbatim and translated into English by the researcher and rechecked by translator. Colaizzi's steps of qualitative analysis were used for analysis. The data

was read and re-read numerous times to identify the significant responses. A total of 623 significant responses were extracted from the interviews. Meanings were formulated for these significant responses. In total 808 meanings were identified and grouped under 10 themes as some of the responses were not exclusive but were interrelated and overlapping. Formulated meanings were coded in a MS Excel sheet to extract common themes which were further categorized into sub- themes. The derived theoretical framework integrated participants description to achieve comprehension of the experience of living with urostomy.

Results

Demographic description of sample

The sample composed of primarily male participants 90% (n=27) with average age of 57±11.61 years. Urinary bladder cancer was the primary disease in 28 patients, with only two female patients having urinary bladder metastasis. Majority of the patients had radical cystectomy and ileal conduit with or without nephroureterectomy, prosectomy and lymph node dissection. The mean weight of the participants was 62±9.97 kgs and mean height was 173.2±9.6cms. Most of the patients were not employed 53.3% (n=16). A large proportion of the patients 36.6% (n=11) belonged to lower income group. A striking number of patients 60% (n=18) have smoked or chewed tobacco before diagnosis.

Qualitative Analysis

Ten themes emerged from the lived experiences of the urostomy patients which were further divided into sub themes. [Number] in brackets is the number of significant responses for the particular theme and sub theme. *Italicised sentences* are the expressions of the participants. Following themes were identified.

1. Knowledge regarding urostomy

Most of the patients confirmed lack of knowledge regarding urostomy [36].

...*"I don't know how to wear or change bag and also how to manage if a leakage occurs."* Patient 6

Due to lack of knowledge, patients experienced dependence on the health care staff for changing

urostomy bag [14]. Some patients expressed readiness to learn urostomy care [19].

...*“I want to know about the diet, how to change the urostomy bag and what is the frequency of bag changes and also can I lay in prone position?”* Patient 20

2. Physical problems

Patients experienced numerous physical problems related to their disease, treatment and urostomy. Weakness [20] and fatigue [25] was present in most of the patients

...*“I feel very much physically weak. I face difficulty in daily activities.”* Patient 1

Skin problems around urostomy were fairly common [9]. Most of the patients had pain and oozing at surgical site [15] thus increasing the risk of infection. [4] Urine leakage from the urostomy was a difficulty faced by almost all the patients [23]. Continuous lying down in bed also caused discomfort [5].

... *“Because of constant lying down on the bed, I have developed bed sores on my back.”* Patient 13

Patients had difficulty in maintaining hygiene due to surgical incision and urostomy [6]. Surgical creation of ileal conduit requires resection of ileal segment causing digestive problems in the patient postoperatively like abdominal bloating [18], stomach ache [15], nausea, vomiting [1], and loss of appetite [23], constipation [4] and diarrhoea [1].

...*“I was distressed by stomach ache and gas for which they gave medicine and now it's better.”* Patient 25

3. Psychological Problems

Mental tension [15] and depression [17] were evident followed by feelings of hopelessness [4], helplessness [24] and dependency [12].

...*“It feels as if half of my life has slipped out of my hands.”* Patient 1

...*“Yes, mental tension is there. It is better to die than to suffer from this.”* Patient 3

Most of the patients were middle aged males and sole earner for the family. They were highly stressed due

to the failure to meet family role [22].

...*“We are helpless for my son's education. Even if I sell my land, then where will we go? I dreamt of making him a doctor (Pause).”* Patient 23

Patients had fear of urine leakage from urostomy [7] and were anxious [6] and embarrassed because of the urostomy [16].

...*“I feel sometimes, that why has this happened in front of my children. Now, they will have to even tie my pyjama. I feel ashamed because of that.”* Patient 20

Some patients also expressed anger [11].

... *“Everyone has to die one day, but it should not be so early in my case.”* Patient 27

Feelings ranged from disbelief, confusion and ambivalence towards urostomy [14]. Some patients vehemently denied mental stress [12] to avoid stressful disclosure with the researcher, while some were unwilling to communicate on certain questions [3]. Conversely, some patients talked optimistically about urostomy and were hopeful of the future [43]. Positivity was also noted by in terms of readiness to change to a healthy lifestyle [16].

... *“This operation saved my life otherwise I would have died. So, whatever has happened is for good.”* Patient 28

...*“Isn't there is something which can be fitted inside the body. It would be better, if it is not visible outside.”* Patient 22

4. Impact on daily activities

Patients reported difficulty in performing their daily activities [9]. Sleeping was disturbed in some of the patients [5].

...*“Yes, the sleep is stressful, I worry that it may leak and spoil the bed.”* Patient 27

Doubts related to diet were common [16]. Travelling was deeply impacted because of urostomy [21]. Patients were concerned about bag leakage [10] and practical difficulties in driving [8]. Dressing was also a matter of concern for most of the patients like ability to wear undergarments and their regular clothes [23].

... *"If I wear pants below the stoma, it is not very comfortable, so, I try to wear it above the stoma. The pants have to be stitched according to the stoma."* Patient 27

5. Social Problems

Many of the patients restricted their social activities. They were concerned about extra preparations needed for urostomy [26].

...*"If there is a function somewhere, I won't be able to attend as I will have to keep supplies with me."* Patient 23

Most of the patients felt social stigmatization because of the urostomy and recognized the lack of social support system [22].

...*"People will wonder that what disgusting problem I am suffering from. My neck will be hung in shame."* Patient 11

6. Family Problems

Family functioning was greatly disturbed. Most of the patients perceived anxiety and stress in the family members [7] and were aware of the caregiver's burden on their attendants [5].

...*"Everybody has been caring for me from last 1 year. There has been lot of tension in the family."* Patient 10

Most of the patient were male and were experiencing sexual difficulties but they were not comfortable enough to discuss it with the researcher except few [5].

...*"I have very much problems. I can't talk about sex right now. Please ask about it later."* Patient 23

...*"I am not able to maintain sexual relations with my wife (nonverbally messages not to talk about sexual problems),"* Patient 26

7. Occupational Problems

Patients were anxious about their inability to do heavy work [21] and were uncertain of whether occupation can be continued. Financial consequences of incapability to work were a cause of turmoil.

... *"I am sitting idle for about 3 years now. My work is done partly by my children, so I am able to live. What can I do?"* Patient 2

8. Financial Problems

Majority of the patients with few exceptions had strained finances [14] and was worried about additional expense of urostomy [23].

...*"The main problem is monetary expenses. The supplies are very costly."* Patient 26

Few patients were unable to procure supplies for urostomy and struggling for daily needs [5].

...*"Sometimes, the bag bursts. If by chance we don't have money to buy bag that day, then my clothes are drenched in urine whole day."* Patient 3

9. Religious and Spiritual Problems

Some patients quoted the need to change to spiritual lifestyle considering they have got a second chance at life because of urostomy [5]. In contrast, urostomy was considered causing impurity of body because of bodily contact with urine by some [14]. Patients were emotionally stressed because they couldn't offer prayers [2].

...*"In our religion, even if a drop of urine touches the body then prayers are not offered. We have to be totally pure to pray. (Eyes well up with tears)." Patient 16*

10. Health Care Issues

The patients from remote areas were stressed because of the inaccessibility of health care near their home [7]. Some patients experienced distress due to delayed care because of limited health care staff and resources [6].

... *"Staff is very less here."* Patient 23

Most of the patients had faith in capability of health care team [3].

...*"They have done really good for me. Whatever happened with me has been good so far."* Patient 24

The detailed description of the themes and sub

themes facilitate vision of the overall experience of living with urostomy. Researcher observed that the experiences of different patients were as varied as their personalities, demographics and social circumstances, but were unified by their common struggle of living with urostomy.

Discussion

In the last 30 years, much has been done to improve the quality of life for patients with stoma. In spite of these, however, even today it is a very difficult to live with urostomy. Literature describes the numerous problems of urostomy patients. The present study also confirmed these issues.

The findings of the present study are consistent with other researchers who have discussed physical problems of urostomy patients.⁸ In the present study some of the physical problems were problems due to location of urostomy. Skin problems and urine leakage was a major issue. Patients also described lots of digestive problems.

Around one-quarter of stoma patients experience clinically significant psychological symptoms postoperatively.⁹ In this study, mental tension and depressive feelings were present in most of the patients. Patients had fear of urine leakage and were embarrassed of the urostomy and declared it as retribution for their bad conduct. Socially, urostomy patients found themselves vulnerable to other's reaction to the urostomy, thus restricting their social activities.¹⁰ In general, family and friends can be an immense source of support which was also narrated by most of the patients in the study.¹¹ Ostomy surgery may affect the patients' sexual relationship with their intimate partner which was also the case in present study.¹²

Most of the participants belonged to lower economic group with few exceptions. It was difficult for them to bear the burden of disease and urostomy. Another important finding relates to religious issues. As with many religions, it is important to be clean, especially when praying. This was regarded as the worst effect of the urostomy by some patients. Study participants expressed faith in the health care professionals although they were aware of the shortage of the health care staff and resources.

In this qualitative study, researcher was able to establish a trusting relationship with most of the patients. Interview offered the patients an opportunity to express their thoughts, feelings and beliefs without being judged. Patients acknowledged the interview to be therapeutic. The findings of this study cannot be extrapolated to wider populations because qualitative research results cannot be tested for statistical significance.¹³ However, the findings are useful for health care providers when creating a supportive environment to improve quality of life of urostomy patients.

Conclusion

Living with a urostomy takes significant adjustment in daily living. A detailed knowledge can facilitate health care personnel to understand the problems of these particular patients and design the health care accordingly. Motivation of the patient to take independent care of their urostomy will lead to better self care efficacy and psychosocial adjustment.

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