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Original Research Article

A qualitative study on the perceptions of patients with urethral stricture

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ABSTRACT

Background: Urethral stricture means narrowing of the urethra and is caused due to injury, instrumentation, infection etc. In as much as urethral stricture is a highly disabling condition and is common in our places, it definitely plays an important role in a sufferer daily life. In our project, we have ventured a qualitative study of perceptions and actual impositions on the life of patients suffering from chronic urethral stricture.
Methods: The study was one of qualitative descriptive type involving in depth interviews (IDI) of 18 male patients of Urethral stricture who were diagnosed and treated at IPGMER.
Results: The results showed that the IDIs could be divided into several categories each of which is further divided into several codes. The categories are given here with codes in parenthesis. Catheter related problems (leakage, block, physical problems, change, availability, health personnel, dress change, smell of urine, water drinking), disturbance of sleep (initiation, awakening, disturbance of bed partner, sleepless night), Role of family members (care giving, attitude, negligence), financial condition (jobless, help from friends, support, reversal of role, family crisis), social life (activity, enjoyment, getting hurt), mental health (loneliness, helplessness, sadness, getting hope) and sexual life (urge, erection, coital pain , discomfort).
Conclusions: The major findings were that most of the patients had very good co-operation and care from the family; financial assistance was also obtained from family and friends. Majority of the patients were hopeful that they would be totally cured in near future.

Keywords: Category and code, Qualitative study, Urethral stricture

INTRODUCTION

Urethral stricture may be defined as a narrowing of the urethra caused by injury, instrumentation, infection and certain non-infectious forms of urethritis.[1] Injury, urethral instrumentation, infection, and non-infectious inflammatory conditions of the urethra are the common causes of urethral stricture, as also in cases after previous hypospadias surgery. Less common causes include malignancy of the urethra which leads to urethral fibrosis and stricture and congenital urethral strictures. Urethral strictures after blunt trauma can generally be divided into two sub-types. Pelvic fracture-associated urethral disruption occurs in as many as 15% of severe pelvic fractures.[2] These injuries are typically managed with suprapubic tube placement and delayed urethroplasty 3 months later. Early endoscopic realignment may be used in select cases instead of a suprapubic tube, but these patients should be monitored closely as vast majority of them will require urethroplasty.[3]

Blunt trauma to the perineum compresses the bulbar urethra against the pubic symphysis, causing a "crush" injury. These patients are typically treated with suprapubic tube and delayed urethroplasty. Other specific causes of urethral stricture include, instrumentation (e.g., after transurethral resection of prostate, transurethral resection of bladder tumor, or endoscopic kidney surgery), infection (typically with Gonorrhea), Lichen sclerosis.[4] Surgery to address hypospadias can result in a delayed urethral stricture, even decades after the original surgery. A weak urinary flow is the main symptom of urethral stricture. Other symptoms include:

- Urinary stream flowing as a splay
- Increased frequency of urination
- Urge incontinence of urine
- Necessity of straining for complete urination
- Dysuria (due to pain during urination)
- Urinary tract infection
- Prostatitis
- Retention of residual urine after bladder evacuation.

Some patients with severe urethral strictures are completely unable to urinate. This is referred to as acute urinary retention, and is a medical emergency. Hydronephrosis and renal failure may also occur. The common complications of urethral stricture include

- Urinary retention
- Prostatitis
- Bladder dysfunction
- Urethral diverticulum
- Peri-urethral abscess
- Fournier's gangrene
- Urethral fistula
- Bilateral hydronephrosis
- Urinary infections
- Urinary calculus.

The two principal investigations used for diagnosis of urethral stricture are: cystoscopy and urethrography. The treatment of urethral stricture includes: Dilation and other endoscopic approaches. Urethral dilation and other endoscopic approaches such as direct vision internal urethrotomy (DVIU), laser urethrotomy, and self-intermittent dilation are the most commonly used treatments for urethral stricture. However, these approaches are associated with low success rates and may worsen the stricture, making future attempts to surgically repair the urethra more difficult.[5,6] A Cochrane review found that performing intermittent self-dilatation may confer a reduced risk of recurrent urethral stricture after endoscopic treatment, but the evidence is weak.[7]

Urethroplasty

Urethroplasty refers to any open reconstruction of the urethra. Success rates range from 85% to 95% and depend on a variety of clinical factors, such as stricture as the cause, length, location, and caliber.[8-11]

Urethroplasty can be performed safely on men of all ages.[12] In the (posterior urethra, anastomotic urethroplasty (with or without preservation of bulbar arteries) is typically performed after removing scar tissue. In the bulbar urethra, the most common types of urethroplasty are anastomotic (with or without preservation of corpus spongiosum and bulbar arteries) and substitution with buccal mucosa graft, full-thickness skin graft, or split thickness skin graft. These are nearly always done in a single setting (or stage).[8-10]

In the penile urethra, anastomotic urethroplasties are rare because they can lead to chordee (penile curvature due to a shortened urethra). Instead, most penile urethroplasties are substitution procedures utilizing buccal mucosa graft, full-thickness skin graft, or split thickness skin graft. These can be done in one or more setting, depending on stricture location, severity, cause and patient or surgeon preference.

Urethral stent

A permanent urethral stent was approved for use in men with bulbar urethral strictures in 1996, but was recently removed from the market. A temporary thermo expandable urethral stent (Memotherm) is available in Europe, but is not currently approved for use in the United States.

Emergency treatment

When in acute urinary retention, treatment of the urethral stricture or diversion is an emergency. Options include: urethral dilatation and catheter placement. This can be performed in the Emergency Department, a practitioner's office or an operating room. The advantage of this approach is that the urethra may remain patent for a period of time after the dilation, though long-term success rates are low.

Insertion of a suprapubic catheter with catheter drainage system. This procedure is performed in an Operating Room, Emergency Department or practitioner's office. The advantage of this approach is that it does not disrupt the scar or interfere with future definitive surgery.

Following urethroplasty, patients should be monitored for a minimum of 1 year, since the vast majority of recurrences occur within 1 year. Because of the high rate of recurrence following dilation and other endoscopic approaches, the provider must maintain a high index of suspicion for recurrence when the patient presents with obstructive voiding symptoms or urinary tract infection.

The future of treatment of urethral stricture includes: The use of bioengineered urethral tissue which is promising, but still in the early stages. The Wake Forest Institute of

Regenerative Medicine has pioneered the first bioengineered human urethra, and in 2006 implanted urethral tissue grown on bio absorbable scaffolding (approximating the size and shape of the affected areas) in five young (human) males who suffered from congenital defects, physical trauma, or an unspecified disorder necessitating urethral reconstruction. Recent informations suggest that all five recipients report the transplants are functioning well.[13]

In as much as urethral stricture is a highly disabling condition and is not so uncommon in our places, it definitely plays an important role in a sufferer's daily life. Unless we come to know the actual problems related to these sufferers it would be unwise to think of measures to be taken to solve the problems of these patients.

On this stand point, in our project, we have ventured to a qualitative study of various aspects of perceptions and actual impositions on the life of patients suffering from chronic urethral stricture, particularly in people residing I eastern Indian states like Bihar and West Bengal, with the expectations that it would reveal the feelings of urethral stricture patients in this geographical area.

METHODS

The study was conducted in the Urology department of Institute of Post Graduate Medical Education and Research (IPGMER), Kolkata, West Bengal. The study was one of qualitative descriptive type involving in depth interviews (IDI) of 18 male patients of Urethral stricture who were diagnosed and treated at IPGMER. All the interviews with the Urethral stricture patients were conducted after taking consent by the first author guided by the second author.

The first author was trained about the interview methods by third and fourth author who were trained in "Qualitative methods in health research. Before beginning of the study an interview guide was prepared by the authors after through literature review. All the patients were approached face to face and permission was taken from the patients for audio recording of the interview.

Qualitative data was obtained by the in-depth face to face interviews of 18 patients that lasted for 10 to 17minutes. All the interviews were conducted in Bengali language which is the native language of the participants. Non-participants were not allowed to remain while conducting the interview.

Handwritten notes were taken during the interview. The interviews were first translated and typed into English. The transcript analyses were performed manually by the third and fourth author. Descriptive 'codes' of the text information were done. Then 'Categories' were formed by merging similar codes together. The consolidated criteria for reporting qualitative research guidelines were followed. All the questions used during the interview were open ended.

Before beginning of the study formal approval was taken from the Institutional Ethical Committee (IEC) of the institution. The script was written by the third and fourth author and reviewed and revised by the other authors. Finally the scripts were prepared for publication.

RESULTS

In total, 18 male patients with urethral stricture were included in the study. Of this one patient was 19 years old. Three patients were in the age group of 21 to 30 years. Five patients were in the age group of 31 to 40 years. Four patients were in the age group of 41 to 50 years. Four patients were in the age group of 51 to 60 years and one patient was 63 years old.

The results showed that the IDIs could be divided into seven categories each of which is further divided into several codes. The categories are given here with codes in parenthesis.

Catheter related problems (leakage, block, physical problems, change, availability, health personnel, dress change, smell of urine, water drinking), disturbance of sleep (initiation, awakening, disturbance of bed partner, sleepless night), Role of family members (care giving, attitude, negligence), financial condition (jobless, help from friends, support, reversal of role, family crisis), social life (activity, enjoyment, getting hurt), mental health (loneliness, helplessness, sadness, getting hope) and sexual life (urge, erection, coital pain , discomfort).

DISCUSSION

During qualitative data collection, our studies showed that the data related to urethral stricture, could be classified into seven categories, vig., catheter related problems, disturbances of sleep, role of family members, financial condition, social life, mental health and sexual life.

The category "catheter related problems" could be further classified into nine codes, viz., worries related to catheter leakage, catheter block, physical problems (sometimes there is pain and burning sensation during micturition or there is a dragging pain in the penis), catheter change (who will change and where, going to the hospital, spending a huge time, getting all accompaniment for the whole process, travel problems and monetary affairs), availability of catheter (sometimes it is not available and not even in the nearly shops), lack of proper health personals, dress change (difficulties during dress change if wearing trousers and so some patients prefer to wear lungies), smell of urine (which produces shame feeling), and worries regarding water drinking qualities.

Table 1: Qualitative data analysis.

Category	Code	Comment
Catheter related problems	Catheter leakage	I am always worried about leakage of catheter. Catheter leakage create more hazards, I am very much anxious about it.
	Catheter block	Blockage of catheter causes much distress and pain, I am always afraid of this condition. I have to change the catheter for blockage, so I am always worried about the condition.
	Physical problems	Sometimes there is pain, burning sensation during voiding. I am feeling dragging pain in the penis.
	Catheter change	Most of the time there is problem regarding change of the catheter due to lack of privacy and suitable place. I get more pain during change of the catheter.
	Availability of catheter	Catheter is not available in the medicine shops of remote places. We have to go to town for buying catheter.
	Health personnel	There is non-availability of trained health personnel in rural areas. We feel difficulties regarding any problems
	Dress change	I feel difficulties during the time of dress change. I have changed my habit of wearing pants, now I used to wear Lungies.
	Smell of urine	Sometimes there is smell of urine from the body and I am ashamed of this condition.
	Water drinking	I am always worried about amount of drinking water.
Disturbance of sleep	Initiation of sleep	I feel worry about initiation of my sleep at night. Sleep initiation is difficult most of the nights.
	Awakening	I am worried about emptying of the urinary bag, so I have to awake during the sleep.
	Disturbance of bed-partner	My wife changes the uro-bag full of urine, so her sleep is disturbed, and I feel guilty.
	Sleep-less night	I have to spend sleepless night occasionally.
Role of family members	Caregiving	My wife acts as caregiver. My mother acts as caregiver. My family members given me a lot of care.
	Attitude of family members	My family members helped me all the time. Except my parents' other family members do not help me.
	Negligence	Nobody neglected me in my family. A few of my family members neglected me.
Financial condition	Jobless	I am now jobless. I am not able to continue my jobs at present.
	Help from friends	I have got much help from my friends. I have got help from neighbours.
	Support of others	I have got mental support from family members. My friends supported me all the time.
	Reversal of role	As I am jobless, my wife now works and earns for the family. My son is now continuing our family business.
	Family crisis	I am feeling unsecured during family crisis.
Social life	Activity	I do not take part in social activities due to my illness. I try to avoid social activities.
	Enjoyment	I can't enjoy social gathering. Most of the members asked me about my disease, I feel ashamed. I try to avoid tour and travel.
	Getting hurt	Few people throw bad comments regarding my catheter which hurts me.
Mental health	Loneliness	I feel lonely, so I spend most of the time alone in the garden. Everybody is doing their work, I am sitting in the home alone without any work.
	Helplessness	I am feeling helpless, what will happen in future in the absence of my parents. Who will take care of me in the absence of my wife. How I will continue my family expenses.
	Sadness	I am feeling sad, why I am suffering from this disease.
	Getting hope	I am getting hope of cure. My family and friends giving me hope that I will be fully cured. My doctors and nurses giving me hope about total cure of the ailment.
Sexual life	Sexual urge	I have no sexual desire at present. My sexual desire reduced to some extent. My sexual urge is not reduced.
	Penile erection	My penile erection is not as before of my disease. I have no erectile problem at present.
	Coital pain	I used to feel pain during intercourse at present for my disease.
	Discomfort	The catheter produces mechanical discomfort. Catheter is an obstacle of my sexual act.

The category "disturbances of sleep" can include four codes, viz., initiation of sleep (which is very difficult in most patients most of the time), awakening (if there is a break in the sleep, one has to evacuate the bag), disturbances of bed partner (wife evacuates the urobag in

the middle of her sleep, gets disturbed, patient feels quality), and sleep-less nights which the patient has to undergo sometimes. The category "role of family members" has always of been a positive one and noteworthy in our findings which include the codes "caregiving" (nicely and loving given by wife, mother and others), "attitude of family members" (mostly helpful), and "negligence" is few and far between.

The category "financial condition" includes five codes, viz, joblessness (highly depressing), help from friends (they do help), support of others (get good physical and mental support from family members), reversal of role (often the wife becomes bread earner in the family in lieu of the husbands, i.e. patient who is now jobless), and family crisis (feels in secured during any family crisis). The category "social life" consists of three codes, viz, activity (mentally moroseness due to non-taking of any part in social activities), enjoyment (cannot enjoy in social gathering, rather feeling ashamed to be there) and getting hurt (sometimes in the socially some people throw unwanted comments which hurt).

The next category is "Mental health" consisting of four categories, viz., loneliness, helplessness, sadness and getting hope (then is a positive mental feeling whereby patient feels the joy of locally being cured in very near future). The last in the category section is "sexual life" consisting of four categories, viz., sexual urge (which is often not up to the mark, coital pain (often the patient feel pain in the penis during intercourse) and discomfort (mostly due to the catheter which is a big hindrance to sexual act). In a review by Mina Razzak it is stated that the patient-reported outcome measure (PROM) for men treated for urethral stricture have shown that the quality of life (QOL) and symptom control benefits of urethroplasty are sustained 2 years after the operation.[14] It is only the patients' overall benefits that are recorded and not the detailed ones.

In a study by Whybrow et al semi-structured interviews were conducted with a sample of 19 men seeking treatment for urethral structure.[15] The finding reveals how men tend to develop routines and tactics to adapt to their symptoms and hide them from others rather than seek help. It is argued that this concealment becomes an inseparable part of how the disease is managed and is an additional hidden practical and emotional burden for these men. Weese et al found that anterior urethral stricture disease negatively impacts the quality of life of family members.[16] The authors quantified the QOL distress experienced by immediate family members of patients with urethral structure. It was found that the disease urethral structure had a profound impact on the family members of those affected even after decades. The problems include sleep disturbance, decreased social interactions, emotional stress and impaired sexual intimacy. Whybrow et al performed a study on the effects of qualitative researchers in recurrent bulbar urethral stricture.[17] It was found that there was between patient's expectations and actual outcome relative to treatment of urethral stricture. Qualitative studies may optimize these in the target population.

CONCLUSION

In conclusion, it can be said that the present study is quite novel one in both its approach, methodology and outcome. The major findings were that most of the patients had very good co-operation and care from the family; financial assistance was also obtained from family and friends. Often, there was a reversal of role like the wife become the bread earner instead of the ailing husband. Other physical and mental problems were as expected which included effects on sexual life also. A lot of problems were catheter-centric. Majority of the patients were hopeful that they would be totally cured in near future.

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