

A Qualitative Study on the Perceptions of Bladder Cancer Patients

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Abstract

Background: Bladder cancer is a serious and dreadful disease. In our region in India, it is fairly common and in most cases treated with TURBT followed by BCG immunotherapy. Since practically no qualitative research has been done in India or abroad in such patients to know their perceptions regarding the disease, the form of treatment and their quality of life, this study has been ventured.

Methods: This study was conducted in the department of Urosurgery, SSKM Hospital (IPGMER), Kolkata, West Bengal. The research method was a qualitative approach using in-depth interviews on 15 male patients aged 40-70 years who were confirmed bladder cancer patients and underwent TURBT followed by BCG immunotherapy. The audio recordings of the interviews were converted into English transcripts which were then analyzed to find out suitable codes and categories.

Results and Discussion: From the transcripts, we found out five categories, viz., initial clue of the disease, initial reaction of patients, reaction of family members, feeling of patients after operation, and effects on personal life. The results were very encouraging as it showed patients themselves, postoperatively, were active with good self-care and were having very positive and empathetic attitude from family members, friends, doctors, and relatives.

Conclusion: It can be concluded from the study that the early diagnosed post TURBT patients undergoing BCG immunotherapy have a highly appreciable and satisfactory quality of life including good attitude of themselves and those around them.

Keywords: Bladder cancer, Qualitative research, In-depth interview

INTRODUCTION

The epithelial lining of the urinary bladder, commonly known as urothelium, is not infrequently a seat of several types of cancer. Rarely, non-epithelial cell cancers like lymphoma or sarcoma also do occur inside the bladder. Strictly speaking, any cancer involving the urinary bladder is called "bladder cancer," though more colloquially the term is restricted to only carcinomas of the urinary bladder.

Like other cancers, it is also a socially dreadful disease and even in the United States the 5 years survival rate is 77%;¹ globally, it is the 9th leading cause of cancer with an occurrence of 430,000 new cases and 165,000 deaths in 2012 alone.²

In 80-90% of patients, the earliest symptom is hematuria, though often it is asymptomatic and revealed only during an incidental checkup like ultrasonography.

There are some notable carcinogens which specifically cause bladder cancer and these include benzidine, 2 naphthylamine which are present in cigarette smoke, and thus globally cigarette smoking is the most common cause of bladder cancer.³ These carcinogens are also present in other smokes and therefore bus drivers, motor mechanics, blacksmiths and factory workers are commonly victims of bladder cancer as also hairdressers because hair dye too contains the carcinogen.⁴ In West

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www.surgeryijss.com

Month of Submission : 02-2017
Month of Peer Review: 03-2017
Month of Acceptance : 04-2017
Month of Publishing : 05-2017

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Bengal and in some other parts of India particularly along the gangetic belts, high arsenic in drinking water leads to bladder cancer also.⁵

In early diagnosed bladder cancer, without metastases, TURBT is the treatment of choice followed by intraurethral injection of BCG vaccine to induce immunotherapy. The 5 year survival rate is 98%. But in advanced cases, radical cystectomy (RC) followed by urinary diversion and chemotherapy is the treatment of choice and the 5 year survival rate is 15%. There are other novel methods of treatment also. The gravity of the disease begets detailed and variegated studies on the issue.

One approach to confront a medical issue in recent years has been a qualitative research. Quite a few qualitative research articles have been published on bladder cancer but mostly in developed countries including Japan and China.⁶ Huang *et al.* from China studied the health-related quality of life in bladder cancer patients after RC followed by either Ileal conduit (IC) or orthotic ileal neobladder (OIN). There are other studies also like those of Sullivan *et al.*⁷ and Hautmann⁸ who actually compared the functional and psychological advantages of the different modes of urinary diversion after RC in their qualitative studies.

Gilbert *et al.* made an effort to measure health-related quality of life in bladder cancer patients using a novel tool named bladder cancer index (BCI).⁹ Later (2010) development and validation of BCI were also done in patients with localized bladder cancer. Multiple other studies applying qualitative modes of research were also performed mostly using probes other than BCI like Functional Assessment of Cancer Therapy in General (FACT-G), in Bladder Cancer (FACT-BL), in relation to questionnaire to create Vanderbilt Cystectomy Index (FACT-VCI). In the questionnaire BCI had 36 items, FACT-BL and FACT-VCI each had 45 items.¹⁰

The European organization for Research and Treatment of Cancer Quality of Life in early years developed a 30 item questionnaire for all cancer patients in general, and later two 45 item tools were developed on Bladder Cancer and Bladder Cancer Management (EORTC-QOL-BLM) also.

Our study has been unique in several aspects

1. It is probably the first such study in India or from any developing country for that matter.
2. It has a very homogeneous population, *viz.*, all males with stages 0-2 bladder cancer and treated by TURBT followed by BCG immunotherapy.
3. We are the first not to use a rigid questionnaire but used only open-ended questions through in-depth interview (IDI).

MATERIALS AND METHODS

Study Area

The study was conducted in the Department of Urology of SSKM Hospital IPGIMER in Kolkata, West Bengal.

Study Setting

Being a super specialty leading Government Postgraduate Medical College and Hospital, the catchment area includes the entire population of West Bengal and the neighboring states such as Bihar, Jharkhand, Northeast states and even neighboring countries such as Bangladesh, Nepal, Bhutan, and so on.

Study Design

The study was one of the qualitative descriptive patterns involving IDI of 15 patients who underwent cystoscopy removal of bladder tumor followed by intravesical BCG vaccine therapy.

All the IDIs were conducted by the first author only under guidance and strict supervision of the third author. Before beginning of the study, the interviewer who summoned the patients individually and privately performed all the IDIs taking audio recording of all was trained thoroughly about the interview methods the background and purpose of the qualitative study by the World Health Organization and Reulen *et al.* He was also from time to time monitored and guided by the other authors. The transcript and analysis of the data were performed mainly by the second and fourth author. They also prepared the final script of the paper which was shown to all other authors concerned and finalized before being sent for publication.

In total 15, IDIs were taken by the first author. Translation and transcription of the recorded interviews were done by the second and fourth authors who also typed the interviews in English language. The descriptive content analysis was performed manually. At first, descriptive coding of the text information was done, and categories were formed by merging similar codes together. The consolidated criteria for reporting qualitative research guidelines were followed in this study. The questions in the interview were all open ended. Some ideas were however taken from FACT-BL (version 4).¹⁰

Ethical Issues

Before the beginning of the study, formal approval was taken from the Institutional Ethical Committee of the relevant institutes.

RESULTS AND ANALYSIS

All the 15 patients included in the qualitative IDI were male. They were in the age group of 46-70 years. They are from different places of West Bengal with diverse of

occupations such as van-puller, political worker, laborer, and retired employee. The results of our study, in tabular form are given in Table 1.

DISCUSSION

The results of our study show that from the 15 interviews done on post T U R B T patients of bladder cancer undergoing BCG immunotherapy; we could find five definitive categories from the transcripts. These categories included (a) initial clue of the disease, (b) the initial reaction of the patient, (c) reaction of the family members, (d) the feeling of patients after operation, and (e) effects on personal life. There were 4-5 codes belonging to each category. The codes belonging to each category were quite as expected and mostly commonplace excepting a few significant points, i.e. a very positive approach from most of them, in the category of feelings of the patients after operation like “I feel I have no disease,” “I feel I am getting fully cured.” This is an expression of sense of well-being even after the dreadful disease which is however detected early and treated properly. Again on the personal life no weight loss rather mild weight gains after treatment in case of most of the participants. Also no urinary problem, doing daily activities, performing routine works, feeling physically well, having good appetite, sleep, and energy - these are all very encouraging signs for the patients, relatives, doctors, paramedics and the whole society at large if we consider an early diagnosis and a prompt TURBT, followed by intra-vesicle BCG vaccine immunotherapy.

From the societal point of view also patients are highly encouraged and reassured as they get hope about cure, spending more effective time, cooperation from family members, relatives, and friends. This proves that social stigma and lack of awareness have to a great extent been removed in recent years which could be due to a persistent and effective counseling by doctors, nurses, social workers, and so on. Reports also tell about considerable monetary supports from the near and dear in this disease.

Gilbert *et al.*⁹ measured HRQoL outcomes and later Mohamed *et al.*¹¹ also did the same using body image scale (BIS).¹² In those studies, all the questionnaire forms were filled out by patients personally and completed by them perioperatively and after 6 months of surgery.

One study¹² for assessing body image changes in patients with cancer is generally accepted as a brief patient self-report measure in conjunction with the EORTC-QOL^{13,14} study group. It contains 10 items including affective, behavioral and cognitive aspects. Each item is scored on a 0-3 scale, and the overall summary scores range from 0 to 30 with higher scores representing the progression

of the symptoms. The BCI initially created by Gilbert *et al.* consists of 34 items within three primary domains accessing urinary, bowel and sexual functions. All these items are responded through the five-point Likert scale. Each primary domain contained two parts (function and bother) and standardized to the 0-100 scale with higher scores representing a better outcome.

Most of the above-mentioned studies deal with the controversies over whether OIN was the most preferred form of urinary diversion in advanced bladder cancer patients undergoing RC followed by urinary diversion and chemotherapy. Other than OIN, IC is another form of urinary diversion. In many of the studies, simply a comparison between OIN and IC is done after RC reviewing in their qualitative researches the HRQoL of those particular patients. Among those studies,¹⁵⁻¹⁷ some reported better HRQoL scores in OIN, compared to IC, whereas some other studies¹⁸⁻²⁰ reported that HRQoL scores were better in IC than OIN groups. Huang *et al.*⁶ did a match pain analysis in which based on the baseline characteristics; they evaluated the HRQoL from two aspects at regular intervals postoperatively using both BCI and BIS questionnaires. They also found some differences in unmet need at each time point of the illness trajectory.

In a polish study,²¹ quality of life was evaluated based on a specific questionnaire completed by 20 patients. The quality of life was similar in all groups of urinary diversion, but some differences in general health status were revealed. Patients with Bricker's IC rated their present health status worse than the other groups. Patients with continent urinary diversion presented the best emotional status and lowest rate of disturbances in self-care, professional, social and leisure activities. Surprisingly high quality of life in patients with simple urinary diversion suggests a good adaptation to this so-called difficult situation.

In another study from Riyadh, UAE,²² it is revealed that although primary squamous cell carcinoma of the urinary bladder is very rare in Western countries (1-7%); it is the most common in UAE (20%), probably because of endemic schistosomiasis in the country. Again almost all squamous cell carcinoma are already advanced and muscle infiltrative at the time of diagnosis. Therefore, the treatment of choice there is mostly RC after a course of chemotherapy and or radiotherapy followed by urinary diversion.

However, in this study, we have found that most cases of bladder cancer are non-invasive, non-infiltrative and non-metastatic in this region of the globe and a TURBT followed by BCG immunotherapy has been the treatment of choice. That said mode of the treatment is highly satisfactory and provides a good outcome has been consistently proved in this qualitative study of ours.

Table 1: Results of qualitative IDI data analysis

Categories	Codes	Statements
1. Initial clue of the disease	a. Hematuria	Passing of blood in urine, red color urine
	b. Painful voiding	Feeling pain and burning sensation while passing urine, feeling pain after passing urine
	c. Mass in abdomen	A mass felt in the lower part of abdomen
	d. Weakness	Physical weakness and loss of energy, apathy to work
2. Initial reaction of patients	a. Anxiety	Worries about the future, anxious of treatment, worries for the family
	b. Helplessness	Feeling of helplessness, loneliness, frustration
	c. Fear	Fear about death, fear about operation
	d. Anguish	Feeling of mental pain and anguish
	e. Sorrow	Feeling of sadness "why I am the victim," not able to complete the desired work
3. Reaction of family members	a. Depression	Initially sad and gloomy, hopeless and afraid
	b. Mental support	Give me hope about cure, spend more time with me, discuss about the treatment
	c. Cooperation	They cooperate with me, stay beside me, no avoidance from family members and friends
	d. Financial help	Monetary support from relatives, friends and neighbors
4. Feeling of patients after operation	a. Disease -free	I am feeling cured, no feelings of disease
	b. Feel well	I am feeling well, no features of the disease
	c. Weakness	feeling mild weakness, like to lie down, not Getting more energy to work
	d. Pain	Feeling pain and burning sensation during voiding urine
5. Effects on personal life	a. Daily activities	Doing daily activities, performing routine works
	b. Physical strength	Feeling physically well, good appetite and sleep, good energy
	c. Weight	Slight weight loss, no loss of weight, mild weight gain after treatment
	d. Urinary incontinence	No urinary incontinence, slight incontinence occasionally

IDI: In-depth interview

CONCLUSION

Our study has been on the perceptions of bladder cancer patients following TURBT and subsequent BCG vaccine immunotherapy. The approach of this study is a qualitative research performed through in-depth interviews. The results of the study have been very encouraging revealing in clear terms that if early diagnoses before advancement of bladder cancer is possible, then TURBT followed by BCG immunotherapy is a highly effective mode of therapy, in which most of the patients report of having a highly acceptable and commendable quality of life. The patients can continue good self-care activities and positive knowledge and attitude from family members, friends, and relatives.

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How to cite this article: Gupta NK, Paul UK, Pal DK, Bandyopadhyay A. A Qualitative Study on the Perceptions of Bladder Cancer Patients. *IJSS Journal of Surgery* 2017;3(3):40-44.

Source of Support: Nil, **Conflict of Interest:** None declared.