

Bladder Cancer Diary: A Necessary Clinical Tool for Management of Bladder Cancer Patients

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ABSTRACT

Background: Bladder Cancer is one of the most common urological malignancies. It carries a high risk of disease progression and recurrence, due to which extensive follow-up and surveillance are suggested, which may extend up to years. Efficient record-keeping over the years is of critical importance in management. Maintaining a bladder tumor diary can be an efficient and critical clinical tool that can help both the patient and the treating Urologist in planning and devising treatment plans for bladder cancer patients.

Objective: To formulate and validate a bladder Cancer diary for patients with bladder cancer.

Material and Method: By reviewing existing literature and “The European Association of Urology Guidelines” on bladder cancer, we have formulated a bladder tumor diary that contains the patient’s Clinical record. The draft of the diary was then sent to a panel of experts, including consultant Urologists in different teaching hospitals of the province via emails and in person. Based upon their recommendations and validations a 2nd final draft of the bladder cancer diary was created on which the Pilot project was run and the significance of the Bladder Cancer diary was analyzed.

Conclusion: Bladder Cancer treatment requires extensive follow-up spanning over years. Use of bladder Cancer diary is an effective clinical tool that can be used by patients and treating urologists for record keeping and planning the management of bladder cancer. This will reduce the chances of error and probability of “lost to follow up” by a considerable margin, as it contains valid patient information being collected at a single place in the form of a tumor diary.

Keywords: Bladder Cancer; Bladder Tumor; Tumor Diary; Record Keeping; Electronic Record Keeping

Introduction

Bladder cancer is one of the most common Urological cancers. Bladder carcinoma is most frequently seen above the age of 55 years and is significantly more common in men, than in women [1]. Several risk factors are associated with bladder carcinoma namely smoking, occupational exposure to aromatic hydrocarbons and amines seen in paint, petroleum factory workers, chronic bladder inflammation

including schistosomiasis, and others [2]. Bladder cancer owing to its multifocality carries a great risk of recurrence and progression, requiring extensive surveillance and follow-up extending over years or maybe even a lifetime, depending upon the risk group stratification [3,4]. Such a prolonged follow-up also causes a significant cost burden on health systems globally [5]. Additionally, there is a great variation and discrepancy among health systems across the world in

the implementation of follow-up for patients with bladder cancer [6]. A significant portion of patients are either lost to follow-up over these years or succumb to errors in follow-up made by treating Urologists as “complete patient information” including initial presentation, initial histopathological biopsy, operative records, staging radiological investigations, follow-up cystoscopies and adjuvant treatments conducted and data on recurrences are not available at a single place. The problem is less frequently encountered in established healthcare setups like National Health Services (NHS) UK, but significant in health systems where electronic patient records are not available nationally.

Even in established healthcare setups, it takes a lot of time to retrieve all the patient clinical letters and data in outpatient clinics were patients normally present for follow-up of bladder cancer. The rationale of using and formulating a “Bladder Cancer diary”, is to create a diary having all the patient clinical information from the time of initial presentation to date, available at a single glance. Although the bladder cancer guidelines already exist, there is a huge discrepancy in implementation, leading to unnecessary interventions on the one hand and an increased risk of progression and recurrences, due to incomplete follow-up on the other hand. This diary will also serve the purpose of the patient’s right to information, which is of pinnacle importance in modern-day medicine [7]. The purpose of this study is to use a Bladder cancer diary as a clinical tool, which can be conveniently used to provide critical clinical information required for the management and follow-up of bladder cancer available at a single glance.

Material and Method

Our research is a descriptive type of study, conducted at Services Hospital Lahore on new and follow-up cases of Bladder Cancer between June 2023 to August 2023. By reviewing existing literature and “The European Association of Urology Guidelines” on bladder cancer, we have formulated a bladder cancer diary that contains the patient’s clinical record. This bladder cancer diary can be filled by the treating urologist, nurse, MDT coordinator, and others and is to be kept with the patient for record keeping and planning further interventions, at a single glance. This diary is to be kept with patients serving the purpose of patient right to information as well, where they can bring it to their clinical appointments and present it to the treating urologist who can then both review the previous clinical information as well as add clinical notes at the end of the session for future reference.

- **Inclusion Criteria:**

- 1) Both Males and Females
- 2) Age 40 – 80 years
- 3) All New and Follow-up cases of Bladder Cancer
- 4) Patients who consent to participate

- **Exclusion Criteria:**

- 1) Patients with refused to participate

Validation of Bladder Cancer Diary

The draft of the diary after formulation was sent to a panel of experts, including Consultant Urologists and Radiologists from different teaching hospitals via emails and in person. Based upon their recommendations, a 2nd final draft of the bladder cancer diary was created.

Pilot

After Validation, a pilot project of 30 patients was run, in which a bladder cancer diary was filled and completed and deficiencies in follow-up were noted to interpret and analyze the importance of a bladder Cancer diary.

Results

The proposed changes after validation from the expert panel in 2nd draft included:

1. Addition of MRI for local staging, in addition to CT scan in preoperative radiology.
2. Addition of Previous Biopsy details in the recurrence section.
3. Addition of stoma care section after Cystectomy and Diversion.
4. Addition of History of tuberculosis in the History section.

Results of Pilot After Validation

This was followed by a Running Pilot project of twenty Patients, for which bladder Cancer diary Performa’s were filled and results were interpreted and analyzed. The mean age of the patients was 64.3 years \pm 8.97. Among 30 patients included there were 21 male and 9 female patients. Following commonly occurring deficiencies were seen regarding management and follow-up of bladder Cancer patients (Table 1).

Table 1: Commonly Observed Deficiencies in Patients of Bladder Cancer during Pilot Project.

Sr #	Commonly Observed Deficiency in Management	Number of Patients with said deficiency in the Pilot Program	Percentage of Patients with said deficiency
1	Lost to Follow-up and Later Presentation with Hematuria and Recurrence	13 / 30	43.3 %
2	Loss of Initial Biopsy Report	09 / 30	36.6 %
3	Loss of Operative Record (TURBT notes) / Discharge Slip	12 / 30	40 %
4	Loss of Staging CT / Radiology Workup	17 / 30	56.6 %
5	Failure to Check Cystoscopies according to Risk Group Stratification	21 / 30	70 %
6	Failure to Follow up and later presentation with incurable disease	2/ 30	6.6 %

Table 2.

The proposed final tumor diary after formulation and validation is presented as follows: Bladder Cancer Diary:
Patient Bio-Data:
Name: _____ Age: _____ Gender: _____ Medical Registration Number: _____ Address: _____ Contact Number: Email: _____ Next of Kin, Contact details: _____ Patient weight / BMI: _____ History: _____ Principal diagnosis: _____ Date of Initial diagnosis: _____ Presenting Complaints at the time of initial diagnosis: _____
Co-morbidities:
DM _____ HTN _____ IHD _____ Viral Markers: _____ History of cardiac intervention: History of Antiplatelet Treatment: Risk factors for bladder malignancy: Smoking: Number of cigarettes per day / No. of pack years: _____ Smoking cessation if and when initiated:
History of Naswar / Pan/ Hukka Use:
History of Occupational hazard and number of years in said occupation:
Family History of Bladder Cancer / Other Malignancies: Use of Hair Dyes: _____ History of Ionizing Radiations / Drugs Abuse/ History of Tuberculosis: History of travel (Schistosomiasis Endemic countries): History of previous surgery / Bladder resections:

Previous Biopsy report: Previous Clinical /Pathological staging: Dietary habits:
Pre-operative Radiology: Ultrasound Findings: _____ CT scans Findings / MRI for staging: Staging Radiology / CT findings: Additional Comments by Radiologist / Workup Suggested: Tumor Markers / Urine Cytology / Other Special Work if conducted: Flexible / Diagnostic Cystoscopy Findings (If Conducted Separately): Other hematuria screening / Nephrology Input:
Operative Record: Procedure: Date of procedure: _____
Principal Surgeon: Hospital: _____
Per operative findings: _____ Number of tumors: _____ Location of tumor / Size of tumor: Resection Complete / Incomplete: _____ The reason for Incomplete Resection is: Involvement of Ureteric Orifices: Deep Muscle biopsy taken/ not: _____ Bimanual Examination: _ Associated suspected CIS / Suspected area biopsy: Associated Upper tract TCC / Biopsy: Other Comments (Surgeon):
Bladder Diagram: Complication /Suspected Complication during surgery: Intravesical therapy / Mitomycin treatment (Postoperative): Post Operative stay / Secondary Intervention in the same stay: MDT Decision: Date of MDT: MDT coordinator: Email of MDT coordinator: Next Appointment following MDT Decision: Further MDT if needed (Date and Specialty):
Post Operative Follow Up: Biopsy Report: Clinical staging: Pathological Staging: EORTC Score:

<p>Risk Group Stratification:</p> <p>Low risk / Intermediate Risk / High Risk / Highest risk:</p> <p>MIBC:</p> <p>Local Invasion:</p> <p>Metastasis:</p>
<p>Plan:</p>
<p>BCG treatment (Lamm's Regime) :</p>
<p>Date Started:</p> <p>Gap after initial Resection:</p> <p>1st Dose Date:</p> <p>Dose given:</p> <p>1st Course:</p> <p>Week 1 _____</p> <p>Week 2 _____</p> <p>Week 3 _____</p> <p>Week 4 _____</p> <p>Week 5 _____</p> <p>Week 6 _____</p> <p>At 3 months Course:</p> <p>Week 1 _____</p> <p>Week 2 _____</p>
<p>Week 3 _____</p> <p>At 6 Months Course:</p> <p>Week 1 _____</p> <p>Week 2 _____</p> <p>Week 3 _____</p> <p>Further Courses details:</p> <p>Yearly treatment Date:</p> <p>Year 1 _____</p> <p>Year 2 _____</p> <p>Year 3 _____</p> <p>Treatment Stoppage:</p> <p>Reason for stoppage:</p> <p>Complications with BCG treatment:</p> <p>Intervention /Modification due to Complication:</p>
<p>Check Cystoscopies:</p> <p>Three-Month Cystoscopy:</p>
<p>Date of Procedure:</p>
<p>Initial Biopsy:</p> <p>Cystoscopic Findings:</p>
<p>Recurrences:</p> <p>Plan in Case of Recurrences:</p> <p>Plan:</p>

Next, Check Cystoscopy Appointment: Check Cystoscopy: (10 Pages) Date: Initial Biopsy: Latest Biopsy (In case of recurrence)
Cystoscopic findings:
Recurrences: Plan in Case of Recurrences: Plan:
Next, Check Cystoscopy Appointment: Recurrence Details :(1 to 5 pages) Secondary TURBT / Procedure for recurrence:
Date of Procedure: _____ Previous Biopsy / Stage: _____ Per op findings:
Bladder Diagram: Previous Surgery/ TURBT/Recurrences:
Biopsy: Comparison with Initial Biopsy: Plan after recurrence Biopsy:
If to continue check cystoscopy / Date of Next Check cystoscopy Appointment:
Cystectomy and Diversion: Date of Procedure:
Hospital: Per operative findings:
Lymph Node status / Number Removed:
Type of Diversion: _____ Complication / Suspected Complication:
Specimen Biopsy:
Lymph Node biopsy:
Plan:
Follow up: MDT Decision: Date of Decision: MDT coordinator:
MDT coordinator email:
Date of next appointment after MDT:
Complications of Diversion if and when seen: Stoma Care: (1 to 2 pages) Stoma Care provider: Stoma Nurse: Stoma Complication:

Intervention: _____
Date of Next Stoma Change:
Chemo- Radiation:
Type of treatment Opted:
Chemotherapeutic Agents Used:
Radiation Dose per session:
Total Radiation Dose (On Completion):
Hospital:
Date of Start of Treatment:
End date of treatment / Expected Date of Completion:
Number of Cycles with Dates and Comments:
Complications Seen:
Treatment Stop:
Reason for Stoppage:
Oncologist Comment:
Plan:
Date of Discharge from treatment / Referral Back to surgeon:
Additional Comments from Oncologist:

- 1) A large majority of patients did not have follow-up check cystoscopies beyond a year, until recurrence of symptoms like painless hematuria.
- 2) Few Patients lost their Radiology and biopsy reports in follow-up, with no previous record available.
- 3) Few patients did not have any follow-up at all after First TURBT until the recurrence of bladder cancer causing life-threatening and incurable disease burden.

In almost all patients except a few, there was a significant lack of implementation of follow-up for Bladder Cancer patients causing unnecessary interventions on one hand and complete or partial lack of follow including check cystoscopies on another hand, necessitating the use of record keeping in form of Bladder Cancer diary (Table 2).

Discussion

Clinical Record keeping is an essential part of good clinical care, patient safety, clinical audit, and clinical governance [8,9]. Record keeping helps doctors liaise with other doctors, their patients, support staff, community-based services, and regulatory bodies. It is essential for continuity of care in health services [10]. Poor record keeping also comes with the risk of medicolegal errors, errors in patient management, and unnecessary repetition of investigations and interventions [11]. Therefore, it is vital and critical. Bladder Cancer due to the natural history of the disease requires follow-up stretching over years. There also exists a great discrepancy in the follow-up of patients with bladder cancer. In healthcare systems where electronic record keeping is not available or not synchronized nationally, there

exists a lack of implementation of bladder cancer follow-up guidelines, leading to a greater risk of progression of disease, recurrences, and even later on presentation with incurable metastatic disease. Any clinical tool that presents the option of cataloging, collection, and reproducibility of clinical data for bladder cancer patients carries a significant appeal for its use in clinical practice. The bladder tumor diary that we have suggested and formulated in our study is one of the prime examples of a necessary clinical tool in the management of patients with Bladder Cancer.

Worldwide greater importance and stress are now being laid by regulatory bodies for record keeping of patients. In Urology, the collection of clinical information does exist in the case of the management of overactive bladder and urinary incontinence in the form of a bladder diary [12], but no such valid attempts are seen in clinical practices for the sake of bladder cancer management. Bladder cancer diary is a quite fresh concept with few previous efforts seen in the same domain across different healthcare systems globally for bladder cancer patients. In an era of clinical governance and essential record keeping, our study has presented a fresh yet valid clinical tool for the management of bladder cancer patients in the form of a bladder tumor diary that also comes up with the benefit of the patient’s right to clinical information. Limitations of our study, however, include a lack of similar efforts in literature, bladder tumor diary being a fresh concept that still has to pass the test of time and practical implementation in clinical practice, and expert opinions on the matter, but still

is an introductory effort that can form the basis of similar and better efforts in future to help in standardization and implementation of good clinical care for bladder cancer patients.

Conclusion

It is concluded that a bladder tumor diary is a critical clinical tool that can be used conveniently in the management of bladder cancer patients. The use of a bladder Cancer diary will not only reduce the errors in implementation of follow-up of bladder cancer patients but will also minimize the time taken in clinical appointments to gather, retrieve, and tabulate previous clinical records of patients. This is of particular importance in healthcare systems where electronic patient records are either not available or not synchronized nationally. Bladder tumor also carries a universal appeal, where this can lead to standardization of patient care with far fewer chances of discrepancies in follow-up of bladder cancer.

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