



# Inferring bladder cancer research prioritization from patient-generated online content

Matthew Mossanen<sup>1,2</sup> · Alice Chu<sup>3</sup> · Angela B. Smith<sup>4</sup> · John L. Gore<sup>3</sup>

Received: 27 April 2018 / Accepted: 5 September 2018 / Published online: 10 September 2018  
© Springer-Verlag GmbH Germany, part of Springer Nature 2018

## Abstract

**Purpose** Patients and their families utilize online resources when dealing with a diagnosis of bladder cancer. Many patients have questions regarding clinical management options. Online research forums may help researchers and providers identify research areas of interest. Our objective was to review online forums and identify research questions that are important to patients and families impacted by bladder cancer diagnosis.

**Methods** We reviewed 1 month of online content from the Bladder Cancer Advocacy Network Inspire online community (<https://www.inspire.com/groups/bladder-cancer-advocacy-network>). Using affinity diagramming, we categorized the submitted content from patient users into themes stratified by the cancer severity of the patient user (non-muscle-invasive bladder cancer, muscle-invasive bladder cancer, metastatic bladder cancer). We categorized the content by the audience of forum posts (i.e., inwardly directed, those seeking support, vs. outwardly directed, those sharing personal experiences) and constructed comparative effectiveness research questions from the submitted content.

**Results** From 14 July 2014 to 14 August 2014, a total of 394 forum posts were collected, of which 3 were excluded from analysis due to non-relevant content, leaving 391 comments for final analysis. Almost 38% of posts involved muscle-invasive bladder cancer and 25% of posts were from people other than the patient. Inwardly and outwardly directed posts were commonly related to clinical treatment concerns.

**Conclusions** Review of online patient-generated content may offer insight into comparative effectiveness research topics of importance to bladder cancer patients. A more formalized process may better represent research priorities among bladder cancer patients.

**Keywords** Bladder cancer · Online forums · Patients · Caregivers · Communication

✉ Matthew Mossanen  
mmossanen@bwh.harvard.edu

Alice Chu  
achu3@uw.edu

Angela B. Smith  
angela\_smith@med.unc.edu

John L. Gore  
jlgore@uw.edu

<sup>1</sup> Division of Urology, Department of Surgery, Brigham and Women's Hospital, Harvard Medical School, 75 Francis St, Boston, MA 02115, USA

<sup>2</sup> Dana Farber Cancer Institute, 450 Brookline Avenue, Boston, MA 02215, USA

<sup>3</sup> Department of Urology, University of Washington, 1959 NE Pacific St, Seattle, WA 98195, USA

<sup>4</sup> Department of Urology, Lineberger Comprehensive Cancer Center, The University of North Carolina at Chapel Hill, 450 West Dr, Chapel Hill, NC 27599, USA

## Introduction

Bladder cancer care can be complex and costly [1]. Patients and families facing a bladder cancer diagnosis may use online chat rooms as a resource to obtain information from other individuals with bladder cancer or caregivers. According to the Center for Disease Control and Prevention, as many as 61% of all US adults have used the internet to search for medical information, and 49% have used a website for a specific medical condition [2]. Clearly, the internet has become an important component of the patient's cancer experience.

Online chat rooms are a dynamic forum for thought expression and interaction between patients and families. Reviewing online chat room posts may facilitate a better understanding of the concerns of patients and families facing a diagnosis of bladder cancer, thereby contributing to

patient-centered care and patient engagement. Patient-centered care has been linked to improved health care outcomes, patient satisfaction, and quality of life [3]. Promoting patient engagement may also result in economic advantages as more engaged patients have also been shown to incur fewer health-care costs [4]. Thus, identifying opportunities to provide more patient-centered care through the identification of topics of interests to bladder cancer patients has potential to improve bladder cancer health outcomes. In this work, we review an online chat room over a discrete time period to identify research questions that are important to patients and families impacted by a bladder cancer diagnosis.

## Methods

We compiled all new forum posts, excluding comments, from the Bladder Cancer Advocacy Network online support group and discussion forum (<https://www.inspire.com/group/s/bladder-cancer-advocacy-network/>) over a 1-month period from July 14, 2014 to August 14, 2014. Included posts displayed content that focused on the experiences of bladder cancer patients, their family and friends before, during, or after a diagnosis of bladder cancer. We excluded posts with technical chat room questions and posts requesting medical information unrelated to the bladder cancer diagnosis or its treatment. Multiple posts by an individual user were included if each post's content was unique.

We categorized chat room users according to the user's status as patients, caregivers (either family or friends), and those we were unable to determine. As users did not always specify their bladder cancer stage explicitly, we inferred their stage of bladder cancer from the content of the post as pre-diagnosis (e.g., patients with hematuria), non-muscle-invasive bladder cancer, muscle-invasive bladder cancer, metastatic bladder cancer, upper-urinary tract urothelial cancer, or not specified or available. For example, we categorized patients contributing content about radical cystectomy care or external beam radiation therapy as muscle-invasive bladder cancer unless they otherwise stated their disease stage.

We used affinity diagramming to develop content-based themes and to organize online data into groups based on natural relationships. Themes reflected the users' clinical situation (e.g., questions related to radical cystectomy care preoperatively vs. questions reflective of postoperative concerns) and the target audience of the users' posts. For all online posts, we constructed a research question that represented a researcher-directed synopsis of the user's content. For example, for a user post that asks the forum for guidance in selecting a urinary diversion after radical cystectomy based on quality of life and complications, we constructed the research question, "What is the comparative

effectiveness of different urinary diversions with respect to quality of life and complications?"

We classified the content of forum posts into four categories: (1) clinical treatment concerns (i.e., content regarding experiences with bladder cancer treatment or surgery); (2) clinical decision-making (i.e., content comparing treatment options for bladder cancer); (3) social support (i.e., content primarily focused on non-medical support from the online community); and (4) spiritual support. For each post, we classified the target audience of forum posts as inwardly directed (i.e., those seeking support or action from the online community), and outwardly directed (i.e., those sharing personal experiences, or testimonials without asking for reciprocal action). Lastly, two researchers independently reviewed and sorted user posts into the user's bladder cancer stage, content category, and directed audience. The derived research questions were constructed through consensus between these researchers in a combined meeting. A third researcher resolved disagreements in categorizations and derived research questions. We utilized descriptive statistics to present proportions of categorized user posts. This project was IRB exempt as all comments were analyzed in an anonymous fashion and no identifiable patient information was used.

## Results

From 14 July 2014 to 14 August 2014 a total of 394 forum posts were collected, 3 of which did not meet inclusion criteria. A total of 391 posts were ultimately analyzed. Agreement between independent raters was 93%. Most online bladder cancer forum users were bladder cancer patients (65%); 26% of the users were friends or family of a bladder cancer patient. We were unable to categorize 9% of users. Of the diagnoses discussed, 37% of the posts were written about a patient with muscle-invasive bladder cancer, 28% of the posts were written about a patient with non-muscle-invasive bladder cancer, and the remaining posts were related to metastatic bladder cancer (9%), pre-diagnoses (3%), and upper-urinary tract urothelial cancer (1%). We were unable to assign bladder cancer stage for 21% of the posts. Also, we found that the majority of forum posts were inwardly directed (Table 1), most of which expressed clinical treatment concerns. Among posts that were outwardly directed, the most common topics were regarding clinical treatment and social support. There were also several posts in which users shared daily-life experiences with their bladder cancer diagnoses.

Table 2 displays synthesized research questions derived from user content and organized into themes. Prominent themes were related to caregiver support, postoperative, and survivorship care concerns. Caregivers frequently

**Table 1** Content categories and directed audience of bladder cancer online forum posts

Category	Inwardly directed	Outwardly directed	Total
Total	293	98	391
Clinical treatment concerns	194 (66.4%)	45 (45.4%)	239 (61.1%)
Clinical decision-making	38 (13.2%)	3 (3.1%)	41 (10.5%)
Social support	50 (16.6%)	48 (49.5%)	98 (25.1%)
Spiritual support	11 (3.8%)	2 (2.1%)	13 (3.3%)

questioned how they may best contribute to the bladder cancer and non-bladder cancer health outcomes of their loved ones. Patient and caregiver users identified several aspects of bladder cancer care where more information is needed to guide bladder cancer care, from a patient's perspective, including reduction of symptom burden related to intravesical therapy, selection for neoadjuvant and adjuvant chemotherapy, and selection of urinary diversion.

## Discussion

In this study, we reviewed the user content contributed to an online bladder cancer forum to gain insights into research topics of interest for patients and families impacted by a diagnosis of bladder cancer. Reviewing and categorizing individual patient and caregiver comments may be valuable for several reasons. Studying readily available online content can be a useful method to infer clinical issues that are important to patients. In turn, this content can be organized to direct patient-centered research and allow more deliberate allocation of resources. By studying patient-generated comments, there is a unique opportunity to inform novel research ideas beyond those generated by researchers. By aligning new research efforts with questions generated from patient content, we would be able to answer clinically responsive and patient-centered research questions. Thus, these data can help set priorities for research that may inform funders, and also identify issues with clinical equipoise and relevance.

Many topics identified in our review of online content overlap with recognized gaps in the literature for bladder cancer. In this regard, questions posed by patients may direct clinical trials, pragmatic comparative effectiveness research studies, or quality-improvement projects. For example, patients with non-muscle-invasive bladder cancer undergoing treatment are interested in learning if there are methods for alleviating discomfort during intravesical therapy. For patients undergoing radical cystectomy, decision-making in the selection of urinary diversion can be difficult.

The majority of inwardly and outwardly directed posts were treatment-related. For example, patients may have difficulty grasping the implications of their diagnosis when trying to comprehend their pathology and understand their treatment options. Pathology reports are written beyond the

health literacy of most patients [5]. A systematic review revealed the limited resources available to patients attempting to understand their cancer diagnosis with specific attention to the pathology report [6]. Although not included in our post review, we have identified a recurring post on INSPIRE where a pathologist has created a Frequently Asked Questions-document to guide INSPIRE users trying to disentangle their pathology report, given the prevalence of this concern in the online community. For patients with bladder cancer, providing patient-centered pathology reports can improve knowledge regarding a cancer diagnosis [7]. Tools and resources to promote patient engagement in bladder-cancer care are limited and many are unaware of support and education resources such as those available through advocacy organizations like BCAN.

Although most user posts were from bladder cancer patients, a substantial proportion of users were caregivers—either family or friends—of loved ones with bladder cancer. The prominent role of the caregiver underscores the importance of caregiver engagement in consideration of the clinical care of bladder cancer patients and derivation of patient-centered outcomes for bladder cancer treatments. Bladder cancer is a disease that predominantly affects older individuals, and patients may rely on partners, family, or friends to help navigate their treatment options and survivorship care. Also, many patients with bladder cancer face social, economic, and contextual barriers that impact diagnosis and treatment, and these factors can similarly impact caregivers [8]. Promoting caregiver engagement in bladder cancer research may be an additional avenue for optimizing the health outcomes of bladder cancer survivors.

Based on bladder cancer forum posts, it is possible to identify patient-centered research needs. Regular reviews of online forums provide real-time feedback to researchers that can drive future research efforts and promote interaction between patients and providers or researchers. However, reviewing these posts is onerous, labor-intensive, and time-consuming. Manually abstracting data as diagnosis and treatment paradigms change may be infeasible and yield delays between content generation and derivation of research priorities, which can affect the contemporary relevance of the exercise.

In the future, leveraging advancements in technology may expedite our capacity to extract information from

**Table 2** Themes from users of a bladder cancer online forum and associated comparative effectiveness research questions

Category	N (%)	Comparative effectiveness research question	Exemplary user quote
Complementary and alternative medicine	8 (2%)	What is the comparative effectiveness of complementary and alternative medicines for adjunctive treatment?	“Has anyone tried any holistic or natural medicines for bladder cancer? Any pros or cons (to drinking alkaline water) as it relates to use during bladder cancer treatments?”
		What is the comparative effectiveness of dietary changes for adjunctive treatment?	“I have been eating mostly organic. I take turmeric organic tablets every day, vitamin D, 1/2 an aspirin”
		What is the comparative effectiveness of caregiver support for mental health outcomes among bladder cancer patients?	“I’m scared for (my husband’s) pain and discomfort. He is so quiet and depressed. Any advice on getting through this would be so greatly appreciated. What can I do to help him? What can I do to stop this feeling of fear?”
Cost	7 (2%)	What is in the incidence of financial toxicity in patients with bladder cancer and what strategies may be helpful to patients facing financial hardships?	“I have called many different organizations and churches none of which had any answers for me...but is there any type of funding or assistance for the costs of treatments for cancer?”
Treatment decision-making	53 (14%)	What is the comparative effectiveness of bladder-sparing therapies versus radical cystectomy?	“Outcomes are no worse and may actually be better for selected patients undergoing partial rather than radical cystectomy for muscle-invasive bladder cancer. Not sure how robust the research is”
Cytology/pathology	7 (2%)	What is the comparative effectiveness of adjuvant chemotherapy in patients that have positive lymph nodes after neoadjuvant chemotherapy?	“After being diagnosed with T3 invasive, high grade BC, I went through 4 rounds of Gem/Cis chemo, then had RC 6 weeks ago. My doctor told me (...) that, of 7 lymph nodes removed for pathology, 3 tested positive. (...) My oncologist recommended not having any more chemo, since she says there’s no data to indicate it would do any good”
		What is the comparative specificity of biomarkers for detecting recurrent bladder cancer?	“Is my urologist right (...) in feeling positive FISH results is an indication of bladder cancer in my near future? Does anyone have more recent info on positive FISH results in determining future bladder cancer?”
Preparation for treatment	3 (1%)	How can pathology reports be easier to interpret?	“The path report from our local hospital was very confusing. I have been through a lot of information (...) and I have never seen a tumor that is grade 2–3 labeled as low grade”
		What is the comparative effectiveness of adjunctive treatments to make intravesical therapy more tolerable?	“Starting my 6 weeks of BCG next Wednesday. Any tips for making these treatments go smoothly?”
Postoperative and survivorship care	90 (23%)	What is the comparative effectiveness of prehabilitation strategies before chemotherapy?	“Is there anything I can be doing before the start of chemotherapy to “prepare” my body, so it doesn’t totally wipe me out?”
		What is the comparative effectiveness of exercise in improving postoperative recovery?	“Here’s my question: does anyone have any experience with weight training after (radical cystectomy)? (...) I’m very interested in hearing what other people’s experience is after they’ve recovered from the procedure, what their medical team has advised, etc”
		What is the comparative effectiveness of prophylactic antimicrobial prophylaxis in preventing complications after orthotopic neobladder?	“I have a neobladder (...) but have been on antibiotics since the start. I always knew when I had a bladder infection but am not feeling a hundred percent (and) I am not having any of the previous (signs of) infection. Just wondering if you can have an infection with no symptoms”

**Table 2** (continued)

Category	N (%)	Comparative effectiveness research question	Exemplary user quote
		What is the comparative effectiveness of urinary sphincters to manage postoperative incontinence after orthotopic neobladder?	“I have had severe incontinence ever since surgery. It was confirmed by a urodynamics test. The (doctor) recommends a surgery to put in an artificial sphincter. (Has) anyone successfully dealt with this condition in another way?”
Provider interactions	17 (4%)	What is the impact of bladder surgery and intravesical therapy on urinary symptoms?	“Has anyone noticed after having a few turbits over the years (along with BCG and MMC) that you urinate more often?”
Related health outcomes	9 (2%)	What is the role of physician assistants in the management of bladder cancer surveillance?	“My (doctor) came into room and told me his Physician Assistant would be doing the procedure with his supervision”
		What is the risk for other cancers among bladder cancer patients?	“Any of you who have had bladder cancer should be aware that you are at a higher risk for almost all cancers having had that diagnosis (including) skin cancer, colon cancer, breast cancer, etc”
Urinary diversion	22 (6%)	What is the comparative effectiveness of different urinary diversions with respect to quality of life and complications?	“(Can) anyone could shed some light and give me some feedback to which is a “better” diversion. I know it's your own choice, but I would like to inform my father of the safest diversion with the least likelihood of issues down the road”
		What is the optimal strategy for improving return of continence after orthotopic neobladder?	“(I recently received a neobladder and I) am just starting the whole continence training process. So, wondering what others have found that worked early on in the process?”
Testimonial	83 (21%)	What are ways to optimize patient awareness of and access to clinical trials?	“They did scans that showed the cancer metastasized to bone and (because of) that they (recommended) we start a clinical trial”
Other/not classified	8 (2%)	What health-related information should bladder cancer patients keep with them at all times?	“Is it a good idea to wear a bracelet after you've had a radical cystectomy with neobladder?”

online forums. Natural language processing may allow for the processing of large amounts of data in a cost-effective and efficient way [9]. By harnessing biomedical informatics techniques to promote data extraction from online content, the results may be operationalized closer to “real-time”. Directed inquiry via the BCAN Patient Survey Network removes the inference from the research prioritization exercise and may formalize the patient-centered research prioritization process [10]. The existence of the Patient Survey Network does not obviate the relevance of online forum content. Rather, this content may inform new research questions to add to the Patient Survey Network for broad input. Therefore, application of innovative approaches to automate data mining may allow efficient operationalization of online that may compliment efforts like the Patient Survey Network to inject the patient voice into bladder cancer research prioritization.

This study is subject to a number of limitations. First, our review of posts is limited to 1 month from a single online forum, albeit the largest online forum dedicated to bladder cancer in the US. The content extracted may represent bladder cancer topics that received particular attention during that time period. Second, we realize online posts may not be generalizable to the concerns of all bladder cancer patients, and different strategies are needed to extract clinical concerns and research priorities from a diverse group of patients with respect to age, gender, race, ethnicity, health literacy, and geography. Third, these themes may not represent those of individuals without computer access. Fourth, review of online content is subject to human error; however, all posts were reviewed by two investigators with classification discrepancies resolved by an investigator ombudsman. Fifth, due to the nature of online posts, at times we had to infer the stage of diagnosis for patients. Lastly, we lacked demographic information about patients or families who posted to the BCAN online forum.

Despite these limitations, we demonstrate that review of posts on a website can identify patient-centered, clinically relevant research topics which could drive future research efforts. To more readily identify topics of interests to patients, the BCAN Patient Survey Network has been developed as a powerful tool to query large groups of bladder cancer patients according to their stage of disease. Applying novel text extraction tools like natural language processing may mitigate the burden of analyzing patient-generated content and augment the Patient Survey Network by informing new research questions for formal prioritization.

**Acknowledgements** This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

**Author contributions** M Mossanen: protocol/project development, data collection or management, data analysis, and manuscript writing/editing. A Chu: data collection or management, data analysis, and manuscript writing/editing. A Smith: manuscript writing/editing. J Gore: protocol/project development, data collection or management, data analysis, and manuscript writing/editing.

## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Research involving human participants and/or animals** This article does not contain any studies with human participants or animals performed by any of the authors.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

## References

1. Mossanen M, Gore JL (2014) The burden of bladder cancer care: direct and indirect costs. *Curr Opin Urol* 24:487–491
2. Cohen RA AP. National Center for Health Statistics 2011. Use of the Internet for health information: United States, 2009. <http://www.pewinternet.org/2009/06/11/61-of-american-adults-look-online-for-health-information/> Accessed 18 Apr 2018
3. Epstein RM, Fiscella K, Lesser CS, Stange KC (2010) Why the nation needs a policy push on patient-centered health care. *Health Aff* 29:1489–1495
4. Hibbard JH, Greene J (2013) What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff* 32:207–214
5. Mossanen M, Calvert JK, Wright JL, True LD, Lin DW, Gore JL (2014) Readability of urologic pathology reports: the need for patient-centered approaches. *Urol Oncol* 32:1091–1094
6. Mossanen M, True LD, Wright JL, Vakar-Lopez F, Lavalley D, Gore JL (2014) Surgical pathology and the patient: a systematic review evaluating the primary audience of pathology reports. *Hum Pathol* 45:2192–2201
7. Mossanen M, Macleod LC, Chu A, Wright JL, Dalkin B, Lin DW et al (2016) Comparative effectiveness of a patient centered pathology report for bladder cancer care. *J Urol* 196:1383–1389
8. Jacobs BL, Montgomery JS, Zhang Y, Skolarus TA, Weizer AZ, Hollenbeck BK (2012) Disparities in bladder cancer. *Urol Oncol* 30:81–88
9. Yim WW, Yetisgen M, Harris WP, Kwan SW (2016) Natural Language Processing in oncology: a review. *JAMA Oncol*. 2:797–804
10. Smith AB, Chisolm S, Deal A, Spangler A, Quale DZ, Bangs R et al (2018) Patient-centered prioritization of bladder cancer research. *Cancer* 124(15):3136–3144