Digital ethnographic analysis of prostate cancer discussions on social media

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1 | INTRODUCTION

Men struggling with prostate cancer report significant decision-related distress surrounding cancer surveillance and treatment.1,2 Typically, prostate cancer shared decision making (SDM) involves three main parties: the patient, patient’s loved one(s), and physician. However, individuals now increasingly turn to online resources to inform these decisions,3 though this has been less extensively studied.

Online discussion boards offer discussants anonymity that facilitates conversations without potential embarrassment. Similarly, patients have the option of speaking directly with others who may be further along in their cancer treatment, allowing for unfiltered feedback related to personal experiences and struggles. Previously published studies exploring online discussion boards about similarly sensitive topics, such as erectile dysfunction, have revealed valuable insights into the concerns and anxieties of discussants.4 Here, we employ a mixed-method approach to understand online prostate cancer discussions and how they may impact patient’s decision making. In leveraging both quantitative natural language processing (NLP)-based approaches alongside manual post-annotation, we reveal the important role of social media in prostate cancer decision making and concerns of patients at different points along the treatment spectrum.

We selected four publicly available online discussion boards with the greatest number of prostate cancer posts from January through December 2019 using the search criteria “prostate cancer discussion board” and “prostate cancer forum” in an incognito Google Chrome browser without geographic or language restrictions: CancerResearchUK.org (249 posts), CSN.Cancer.org/Forum (158), HealthBoards.com (72), and CancerCompass.com/Message-Board.htm (27). All posts including the term “prostate” were extracted. Posts were defined as the initial discussant’s body of text in a discussion thread. Response posts that were part of the same thread were excluded.

We performed a NLP analytic technique called the Meaning Extraction Method with principal component analysis (MEM/PCA)5 on all extracted posts (step-by-step explanation in Jiang et al6). Once word clusters were grouped, a common descriptive theme was manually assigned to each cluster by mutual agreement of the first and senior author. We further interrogated a subset of 145 posts for quantitative data on whether relevant topics of discussion were mentioned, including quality of life (QOL) concerns (eg, erectile dysfunction, bowel or bladder incontinence), longevity discussions (eg, prognosis, therapeutic modalities (eg, prostatectomy, radiation therapy), and active surveillance. We also collected information on the author of each post (patient vs family/caregiver) and whether a post was authored prior to or after any therapeutic intervention.

Chi-squared and Fisher exact tests were used to compare categorical variables, and negative binomial regression was used to compare count variables. Multivariate logistic regression was used to identify predictors of discussions of QOL or longevity. RStudio 1.1.463 was used for statistical analysis, with p<0.05 considered statistically significant.

We extracted a total of 506 posts from the online discussion boards. MEM/PCA on all posts revealed word clusters that organized into the following themes: Diagnostics, Treatment Decisions, Quality of Life Considerations, Treatment Planning, Biopsy Results, and Patient-Physician Interaction. Words and their respective factor
Multivariate comparisons revealed that posts were more likely to feature discussions of QOL factors if they were authored by the patient (OR: 2.10, $P = 0.049$) and if they were written after...
data points that would assist in contextualizing our findings. Posts
ent information related to age, cancer risk stratification or other
the vast amount information readily available online.7,8
Additionally, patients may also have trouble finding and evaluating
pecially related to urological conditions, including prostate cancer.
that, unfortunately, inaccurate information proliferates online, es-
ing option within the context of treatment decision making. These
S2). Posts that featured discussions surrounding life expectancy
P
initiating a therapeutic intervention (OR: 2.56, P = 0.027) (Table
S2). Posts that featured discussions surrounding life expectancy
and prognosis were more likely to mention more than two ther-
apeutic interventions (OR: 4.41, P = 0.020) and less likely to have
that post authored by the patient himself (OR: 0.39, P = 0.012) (Table
S3).
With the recent growth of readily available cancer-related in-
formation online, discussions that occur outside of the clinic play
an increasingly valuable role in decision making. Our results re-
veal that many patients struggle with a different facet of decision
making during each aspect of their clinical course including diag-
nosis, treatment, and posttreatment care. Using NLP and multivar-
iate analysis, we sought to better characterize when QOL factors
and life expectancy may be pertinent concerns to a patient in his
prostate cancer care and how these are integrated into the deci-
sion-making process.
Results from our thematic analysis highlight the substantial anx-
xiety that comes with a diagnosis of prostate cancer. Our data sug-
gest that anxiety surrounding decision making may be a key driver
for this distress, as many discussants expressed extreme discomfort
in deciding between a therapeutic intervention and active surveil-
ance, or between weighing QOL factors and cancer cure in deciding
on a therapeutic intervention. It is important to underscore, though,
that the act of sharing these concerns online may be therapeutic.
These patients may, as a result, be more likely to make decisions
related to prostate cancer treatment that more closely align with
their goals.
Patients were more likely than partners or family members to
emphasize QOL factors, though these discussions were often fea-
tured after a therapeutic intervention had already been initiated.
Online discussion boards also create a space for caregivers of pa-
tients with prostate cancer to discuss their collective experiences
and unique challenges. Our data reveal that patients were more
likely than their partners or caregivers to emphasize QOL issues
online. In contrast, patients’ caregivers were primarily concerned
with life expectancy as it related to selection of treatment modal-
ities. This is consistent with data from Reamer et al., who showed
that patients with prostate cancer who consult with their support
network were over 11 times more likely to choose a treatment
based on life expectancy and cure rather than treatment-related
QOL effects.5
Several posts highlighted complementary medicine as an appeal-
ing option within the context of treatment decision making. These
alternative interventions were often framed as having efficacy
without any negative impact on QOL. Previous work has reported
that, unfortunately, inaccurate information proliferates online, es-
specially related to urological conditions, including prostate cancer.
Additionally, patients may also have trouble finding and evaluating
the vast amount information readily available online.7,8
Our study is not without limitations. We were unable to pres-
ent information related to age, cancer risk stratification or other
data points that would assist in contextualizing our findings. Posts
represent a snapshot in time, limiting long-term follow-up decisions
or a standardized measure of concerns between discussion posts. In
identifying discussion forums for analysis, we used the search engine
Google; factors such as geography and search engine optimization
may have impacted forum selection. Nearly 50% of the analyzed
posts were from a United Kingdom-based online discussion board;
these discussions may not reflect the SDM process of patients from
other countries as therapeutic options available in those countries
may differ. Additionally, individuals who seek information online
through discussion boards may be different with respect to informa-
tion preferences compared to those who do not turn to the internet
for similar concerns.
Online discussion boards represent an important space where
patients and caregivers can discuss shared experiences surround-
ing all aspects of their prostate cancer experience. By analyzing
unfiltered social media data, we have the opportunity to truly
listen to our patients; our findings can be used to better inform
decision aid development, as best practices often recommend
developing such tools by initially querying patients. This study
also suggests a potential role for physicians on social media to
engage directly with patients online and connect them to accurate
resources.

COMPETING INTEREST
Sriram Eleswarapu is a consultant for Metuchen Pharmaceuticals.
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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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