Brief Correspondence

Leveraging Social Media as a Thermometer to Gauge Patient and Caregiver Concerns: COVID-19 and Prostate Cancer

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Abstract

The COVID-19 pandemic dramatically impacted society and health care on a global scale. To capture the lived experience of patients with prostate cancer and family members/caregivers during the COVID-19 pandemic, we performed a mixed-methods study of posts to two online networks. We compared all 6187 posts to the Inspire Us TOO Prostate Cancer online support and discussion community from December 2019 to April 2020, to 6926 posts from the same interval in 2019, applying a linguistic ethnography method. A similar analysis was performed using data from the Reddit discussion website (246 posts from 2019 and 260 posts from 2020). Manual qualitative analysis was performed for all 207 posts that mentioned COVID, COVID-19, or coronavirus. The computational linguistic ethnography analysis revealed a more collective tone in 2020, with increased concern about death. Our qualitative analysis showed that patients with prostate cancer and caregivers have concern about a variety of COVID-19–related impacts on care, including delays in testing and treatment. There was also substantial concern about the impact of having cancer on COVID-19 risk and access to COVID-19 care. Misinformation was present in 7% of COVID-19–related posts. In conclusion, online networks provide a useful source of real-world data from patients and their families, and analysis of these data highlighted a substantial impact of COVID-19 on prostate cancer care.

Patient summary: We performed a study of online posts by patients with prostate cancer and their families on their perspectives about COVID-19. Concerns about the impact of COVID-19 included worry about delays in testing and treatment. Our research also revealed misinformation in COVID-19–related posts.

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The COVID-19 pandemic dramatically impacted health care on a global scale. Recent studies have examined the impact of COVID-19 on prostate cancer (PCa) care from the perspective of health care providers. For example, a worldwide survey of urologists reported significant cutbacks in prostate biopsy and PCa surgery [1]. Less is known about the impact of COVID-19 on PCa care from the perspectives of patients and their families.
To capture the lived experience of PCa patients and caregivers, we performed a mixed-methods study of posts to two different online social networks: (1) the Inspire Us TOO Prostate Cancer online support and discussion community, and (2) Reddit. Inspire is a leading health care social media platform connecting >2 million patients and caregivers via >250 online support communities focused on specific health conditions and diseases. The PCa community has >25 000 members, including patients with PCa and family members/caregivers. Through a data use agreement, we obtained the text from anonymized, publicly available comments posted to this community from December 2019 through April 2020. Data were also obtained from Reddit, a social platform with user-generated posts organized by subject into boards.

From December 2019 to April 2020, there were 6187 posts to the Inspire Us TOO Prostate Cancer online support and discussion community and 260 posts from Reddit discussions about PCAs. These were compared with 6926 and 246 posts to these respective platforms from the same time frame in 2019.

Posts were analyzed by applying a computational linguistic ethnography method [2], specifically using the Linguistic Inquiry Word Count (LIWC) psycholinguistic lexicon and WordNet Affect [3,4]. This analysis was used to determine the top word categories used during the COVID-19 period (2020) compared to 2019. A comparative analysis was performed on the language used in posts written in both communities from January to April 2020 to posts written during 2019.

Manual qualitative analysis was performed for all posts to the Inspire Us TOO Prostate Cancer online support and discussion community and Reddit that mentioned COVID, COVID-19, or coronavirus. Posts were coded independently by four trained coders using a codebook created and refined by the study team. The codebook categorized the characteristics of individuals generating posts (eg, patient, partners/family member, other), PCa characteristics (eg, any staging or treatment data presented), topic of the post (eg, COVID-19 itself, impact of COVID-19 on cancer treatment, impact of COVID-19 on clinical trials, etc.), and the presence of misinformation. The study protocol was approved by the New York University institutional review board.

The computational linguistic ethnography analysis revealed clear differences in the language used in 2020 versus 2019, suggesting a distinct behavior shift. Supplemental Figure 1 shows the word categories with the largest differences observed. In 2020, both communities used a more collective tone (with word categories such as we, affiliation, friends), as well as increased concern for health and death. Interestingly, the COVID era has seen less focus on the past or the future, as well as less concern with self (I), money, or religion. An analysis of the differences in emotion words for both Inspire and Reddit revealed that 2020 had significantly fewer mentions of emotions than 2019.

A total of 191 posts to the Inspire PCa community and 16 posts from Reddit were specifically related to COVID-19, including posts from both patients with PCa and partners/family members (Table 1). For posts from the Inspire Us TOO community with geographic data, approximately 75% were from the USA (29 unique states), 18% were from Canada, and the remainder were from outside North America. Among posts with staging information, a higher proportion in both communities were from patients with localized versus advanced disease. Common topics included the impact of COVID-19 on cancer care. There was also discussion about COVID-19 itself, and misinformation was present in 14 posts (7%). Topics of misinformation included inaccurate compar-

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**Table 1 – Contributor characteristics and content type for posts to the Inspire Us TOO Prostate Cancer online support and discussion community and to Reddit related to COVID-19**

| Parameter                                 | Result  |
|-------------------------------------------|---------|
| Median age, yr (range)*                   | 66 (40–80) |
| Gender, n (%)                             | Male 107 (52) |
|                                           | Female 48 (23) |
|                                           | Not specified 52 (25) |
| Geography, n (%)                          | USA 143 (69) |
|                                           | Canada 35 (17) |
|                                           | Other 13 (6) |
| Relationship to patient, n (%)            | Self 72 (35) |
|                                           | Partner/family member 19 (9) |
|                                           | Other 20 (10) |
|                                           | Not stated/unclear 96 (46) |
| Stage of disease, n (%)                   | Localized 35 (17) |
|                                           | Advanced 13 (6) |
|                                           | Not stated/unclear 159 (77) |
| Treatments received, n (%)                | Surgery (± radiation, hormones) 12 (6) |
|                                           | Radiation (± hormones) 11 (5) |
|                                           | Hormones (eg, Lupron, Casodex) 5 (2) |
|                                           | Other advanced treatment (eg, abiraterone, enzalutamide, chemotherapy) 4 (2) |
|                                           | Multiple lines of advanced treatment 2 (1) |
|                                           | Active surveillance/watchful waiting 11 (5) |
|                                           | Other/unknown/NA 162 (78) |
| Treatments planned, n (%)                 | Surgery (± radiation, hormones) 7 (3) |
|                                           | Radiation (± hormones) 21 (10) |
|                                           | Hormones (eg, Lupron, Casodex) 5 (2) |
|                                           | Other advanced treatment (eg, abiraterone, enzalutamide, chemotherapy) 9 (4) |
|                                           | Multiple lines of advanced treatment 1 (<1) |
|                                           | Active surveillance/watchful waiting 7 (3) |
|                                           | Other/unknown/NA 157 (76) |
| Main topic of post, n (%)                 | COVID-19 itself 77 (37) |
|                                           | COVID-19 testing 3 (1) |
|                                           | Shelter in place 6 (3) |
|                                           | Impact on cancer care 53 (26) |
|                                           | Impact on clinical trials 12 (6) |
|                                           | Financial hardship 1 (<1) |
|                                           | Fear of going to hospital/care settings 7 (3) |
|                                           | Other impact of COVID-19 15 (7) |
|                                           | Other, NA 33 (16) |
| Clinical research, n (%)                  | Yes 25 (12) |
|                                           | No 182 (88) |

NA = not applicable.

* Age and geography data were only available for posts to the Inspire Us TOO community.
isons between COVID-19 and influenza, false claims about public health strategies (eg, masks and stay-at-home orders), and misinformation about vaccines and treatments for COVID-19 (eg, hydroxychloroquine, remdesivir).

Figure 1 shows themes from COVID-19–related posts and Supplementary Table 1 provides representative quotes. These online communities were used as a place for patients and their families to share perspectives, research studies, and unanswered questions about COVID-19 itself. They were also used for discussion about a variety of impacts of COVID-19 on cancer care, including delays in testing and treatment. Conversely, there was discussion about the impact of having cancer on the risk of COVID-19 and access to COVID-19 care.

The study revealed that the impact of COVID-19 on cancer care and research is a major concern among patients with PCa and their caregivers. In addition, there was significant concern about whether their cancer would affect their prognosis or prioritization for emergency care if diagnosed with COVID-19.

Our study is the first to leverage online data sources to provide unique insights into the lived experiences of patients with PCa and their families during the pandemic. We also identified themes of misinformation that were circulating in online networks, which is important to inform public health messaging.

A limitation of the study is that data from individuals who actively participate in online networks may not be generalizable to all PCa patients and caregivers. Although social media use is more common among younger than older adults, it is notable that the median age of 66 yr among members who posted to the online Inspire community is the same as the median age at diagnosis of PCa in the USA. That notwithstanding, many posts to both networks lacked additional detail on demographics, cancer stage, and treatment to better contextualize the study population.

Strengths of the study include the use of real-world data from a geographically diverse group of patients and caregivers highlighting their lived experience. In addition, we used both qualitative and computational methods to provide a more comprehensive evaluation, and obtained data from two distinct social networks to provide more robust results.

In conclusion, the impact of COVID-19 on PCa patients and their families are vast and include delays in testing, treatment, and research. The posts evaluated in this study also demonstrate a clear shift in tone, with greater collective concern. Social media platforms are a useful thermometer for gauging PCa patient and caregiver concerns at a time of global crisis.

**Author contributions:** Stacy Loeb had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study concept and design:** Loeb, Borno.

**Acquisition of data:** Loeb, Mihalcea, Perez-Rosas, Ness.

**Analysis and interpretation of data:** All authors.

**Drafting of the manuscript:** Loeb, Mihalcea, Perez-Rosas, Borno.
Critical revision of the manuscript for important intellectual content: All authors.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.euros.2020.12.008.

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