Social Media: A Force for Good in the COVID-19 Era?

By Kalli Spencer

With many parts of the country back in lockdown, medical care and support for cancer patients has reverted to the online space. This includes telehealth consultations, virtual support groups and the use of social media for peer-based support.

Despite the availability of this technology some of the emotional and mental well-being needs of these patients remain underexplored and underreported. Many have tried to address the void by seeking information and emotional support on diverse social media platforms, with Twitter being the most widely used followed by online cancer support groups (OCSG).

Urology Professor Damien Bolton and his team from the Olivia Newton-John Cancer Centre, University of Melbourne used a validated artificial intelligence framework to conduct a comprehensive real-time analysis of two data sets of 2,469,822 tweets (from Twitter) and 21,800 OCSG discussions by patients with all types of cancer during this pandemic[1]. Most concerns expressed were regarding missed treatments, delayed diagnosis, weakened immunity and cancellations. All patients expressed significant negative sentiment, with fear being the predominant emotion.

The research team applied the Patient-Reported Information Multidimensional Exploration (PRIME) framework on both data sets. It has been effectively used for the extraction, analysis, and synthesis of patient-reported information on mental and physical well-being, such as real-life experiences, mental health issues, emotional burden, symptoms, treatment decisions and side effects of patients with cancer, survivors, and caregivers.

They found a threefold increase in the volume of tweets on March 11, 2020, when the World Health Organization declared a global pandemic. Most of these tweets focused on the dissemination of guidelines issued by health care providers, such as the importance of social distancing for patients with cancer and the anticipated delays in access to medical care.

In applying the PRIME framework on the OCSG data set, they analysed the emotional burden of the pandemic on patients with cancer, based on more substantial discussions, which were "semantically rich and context-aware in comparison with tweets". They used a combination of machine learning algorithms to extract two sentiments (negative and positive) and eight emotions (anger, fear, anticipation, trust, surprise, sadness, joy, and disgust). The overall positive sentiment gradually decreased from February 1 to April 30. The most prominent emotions were "fear" and "joy," with "fear" being consistently expressed during this period, whereas "joy" underwent a significant drop soon after the pandemic was declared, followed by a gradual decline with occasional peaks of positivity that were influenced by media releases on the development of treatments for COVID-19.

Tweets mainly focused on treatment delays, diagnosis delays, and weakened immunity. Cancellation of consultations, missed scans, and risks of undergoing chemotherapy were the main focus in OCSG discussions. Going beyond these medical concerns, both data sets contained a significant volume of concerns expressed on mental health, adjusting to the "new normal," and daily physical activity.

They formulated these findings of patient needs in terms of key themes and corresponding topics as illustrated in the sunburst diagram below:
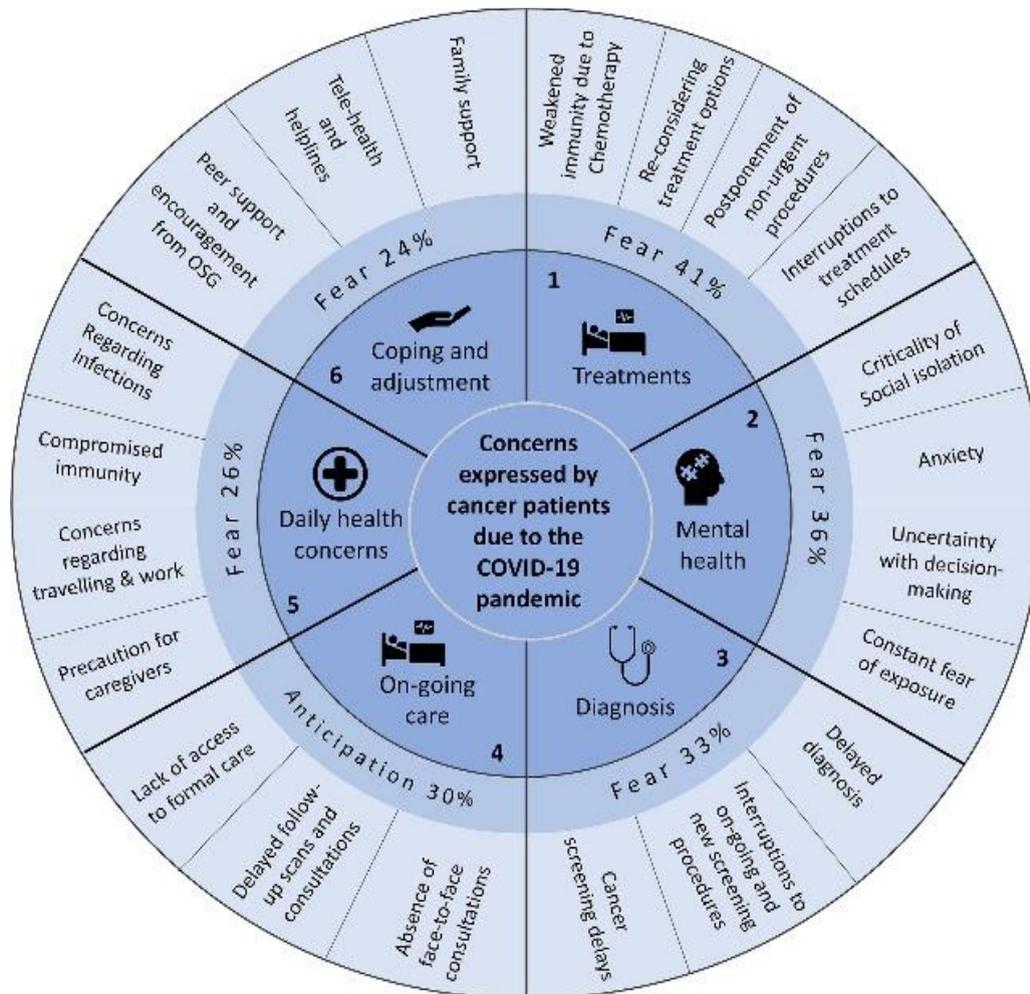
The circle in the centre represents the themes, the intermediate circle represents the emotions for each theme, and the outer circle denotes the topics of concern for each theme. The themes are numbered 1 to 6, in descending order from most to least significant. The emotion which stands out the most across all themes is "fear, with the exception of "ongoing care," which is positive with "anticipation" at a level of 30% intensity.

The findings of this research are of particular importance, as they formalise the health care value of online patient-reported information during a period when clinical resources are overburdened and formal care is imperilled. The correlation between the sustained threefold increase in social media participation and the steady decline in positive emotions is a weighty concern for the effective management of cancer care for as long as the pandemic persists. Urologist Stacey Loeb and her team from New York University reported similar findings when reviewing posts from the American "Inspire Us TOO" Prostate Cancer (PCa) online support and Reddit discussion groups.

The repercussions of COVID-19 on prostate cancer patients and their families are widespread and include delays in testing, treatment, and research. Those posts evaluated in the study also indicated a manifest shift in tone, with greater collective concern.

In 2020, both communities utilised a more collective tone (with word categories such as "*friends", "affiliation", "we"*), as well as heightened concern for concepts such as *health* and *death*. Notably, the COVID era has seen a reduced focus on the past or the future, as well as diminished concern with self (I), *money*, or *religion.* An analysis of the variances in emotion words for both Inspire and Reddit revealed that 2020 had markedly fewer mentions of emotions than the year prior. Common topics included the impact of COVID-19 on cancer care.

There was also discussion regarding the pandemic itself, and misrepresentation and falsehoods were present in 14 posts (7%). Topics of misinformation included misleading comparisons between coronavirus and influenza, duplicitous claims about public health strategies (eg, masks and stay-at-home orders), and fabrications regarding treatments and vaccines for the virus.

The study showed that the impact of COVID-19 on cancer care and research is a major concern among patients with PCa and their caregivers. Moreover, there was substantial concern about prioritization for emergency care if diagnosed with COVID-19, as well as whether their cancer would influence their prognosis.

Social media platforms are a useful barometer for gauging the concerns of PCa patients and caregivers at a time of universal crisis. The Melbourne team have attested to how PRIME can be used to detect emotions with a degree of precision in real time, including sensitive emotional fluctuations as a result of media announcements on COVID-19 treatment development. This means that telemedicine and remote health care technologies can be utilised to dispense responses to patients with cancer in distress and actively rank patients who require urgent support in order of priority. The pandemic is not over yet, and it is imperative for formal health care systems to incorporate the findings of this research for the real time identification and delivery of effective care for oncology patients.

Even when some lockdown measures are relaxed, it remains critical that patients with cancer are engaged using social media platforms for the provision of both emotional and informational support.

References:

1. Moraliyage H, De Silva D, Ranasinghe W, Adikari A, Alahakoon D, Prasad R, Lawrentschuk N, Bolton D. Cancer in Lockdown: Impact of the COVID-19 pandemic on patients with cancer. *The Oncologist* 2021. 26(2) e342-344.

2. Stacy Loeb et al. Leveraging social media as a thermometer to gauge patient and caregiver concerns: COVID-19 and prostate cancer. *Eur Urol Open Sci* 2021. 25: 1-4.

About the Author

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Kalli is an internationally renowned Urological Surgeon, specialising in oncology and robotic surgery. He trained and worked in South Africa, before relocating to Australia where he has worked at Macquarie University Hospital and Westmead Hospital. His passion for what he does extends beyond the operating room, through publichealth advocacy, education and community awareness of men's health, cancer and sexuality.

Kalli has been involved with the Prostate Cancer Foundation of Australia for many years, advocating for improved cancer care and facilitating community prostate cancer support groups.