

10 Benefits of an Online Community

By Kalli Spencer

Researchers have identified that those diagnosed with prostate cancer have several unmet needs¹. While some patients require specialised support from healthcare workers to deal with treatment side effects and psychological distress, others may prefer peer support as a means to manage these supportive care needs.

Very few prostate cancer survivors seek help for their psychological distress. A survey of Australian's who had been treated for localised prostate cancer determined that 20% of men with unmet supportive care needs sought help within 6 months, increasing to just 33% seeking help within a year². Prostate cancer treatment side effects, reluctance to talk to others, perception of withdrawal from others, and a lack of immediately available social support leave many men feeling isolated, lonely and embarrassed³.

While face-to-face peer support groups are a useful solution, certain barriers may prevent patients from accessing them: social stigma, attempt to adhere to masculine norms, living remotely, or having extensive work, travel, or family commitments.

With the growing popularity of social media platforms (e.g., Twitter and Facebook), cancer survivors increasingly rely on the Internet for peer support. Online cancer communities enable survivors to meet their peers online and give and receive social support specifically related to their disease⁴. Although low socioeconomic status or digital literacy may pose barriers to participating online, these platforms offer free 24/7 access to peer support at a convenient time and place⁴. Online cancer communities offer anonymity (by limiting disclosure of personal information), allowing members to share experiences and express emotions without fear of social conflict or judgement.

Online prostate cancer communities (OPCaCs) have received little research attention. In King et al. 's research study, only 1 of the 10 peer support studies explored online peer support¹. An Australian research group published a scoping review article in 2021 to ascertain what information is available in the medical literature regarding online cancer communities, with a specific emphasis on prostate cancer⁵. The review focused on 21 research articles from around the world and identified key commonalities across all studies:

Platform

Several terms have been used to describe the online platforms (e.g., websites; discussion boards or services; social networks or online support groups; online resources and mailing lists). Some services welcomed international participants, whereas others were country specific. Two platforms were governed by a professional body and two weren't. Of those, one platform was patient-led.

Design

OPCaCs had open (i.e., freely accessible to read, post, and respond to comments) or closed (i.e., account login required) levels of security. Some were both open and closed, with all participants being able to browse and read posts, but participants wishing to post and respond to comments needed to create an account. Some of the country-specific OPCaCs may only be in a language related to that country, limiting its use. While the main line of communication was through exchange of electronic messages, some platforms added features (e.g., sharing online 'hugs'), or allowed members to communicate privately and plan offline events. Three studies researched the Prostate Problems Mailing List which is a listserv (i.e., electronic mailing list software application) that allows members to

read and send unmoderated emails to fellow members.

Members

Three studies of the same online community in Germany demonstrated an increasing number of prostate cancer survivors turning to the Internet for support with the number of registered users steadily increasing with 1439 in 2010,²³ 3357 in 2017,²⁴ and 4400 in 2018. Survivors were the most prevalent posters, followed by spouses, immediate family or friends, and finally nurses, doctors, researchers, or administrators. It is interesting to note that prostate cancer support groups hosted on Facebook comprise of the majority of members, with 31 263 members identified across 99 prostate cancer-specific online peer support groups⁶.

Content

Most posts focused on medical information related to prostate cancer, its treatment, and side effects. "While one would expect the quantity of posts in Germany's OPCaC to increase over the 8-year period researched, it is interesting to note that despite increasing numbers of participants, only 5% of the most active members wrote 70% of all posts suggesting a high proportion of participants are silent readers, referred to as 'lurkers' in the online support group literature."⁵

10 Benefits of OPCaCs as noted from the research findings can be summarised as:

- 1) Cost effective and easily accessible any time (compared to a face-to-face support groups)
- 2) Ability to connect with peers and develop relationships and camaraderie with those on a similar journey.
- 3) The welcoming of new people into a community creates a sense of belonging, acceptance, value, esteem, and unity among members.
- 4) Offers members a sense of control and empowerment over their condition.
- 5) Sharing experiences validates the member's experience, making them feel understood, reducing their sense of isolation, fostering a positive attitude towards treatment outcomes, and providing hope for the future.
- 6) Anonymity is optional and may be advantageous because: one can 'open up' and talk more frankly about more sensitive aspects of their disease, share feelings, weaknesses, anxieties, and vulnerabilities, and bypass stigmas.
- 7) One can silently read messages without feeling obliged to post messages. This is useful for those who are shy and less computer savvy, allowing them to feel safe whilst still benefitting from receiving information, by having their questions answered through other members.
- 8) Helps members better understand their disease and offers support with diagnoses
- 9) An opportunity to understand treatment possibilities and their related side- effects.
- 10) Helps facilitate discussions and negotiations with medical practitioners and to make treatment decisions.

Support groups and online communities are not beneficial to everyone. Some members were noted to report higher levels of stigma and perceived stress. Possible explanations for this according to the research team "included the stigmatised men (a) feeling that the posts lacked the resources needed to help them cope, (b) being exposed to concerns of other men (e.g., long-term erectile dysfunction) that they had not considered themselves or had been explained to them as a possibility by their doctor; and/or c) reading other men vent (i.e., emotion-focused coping) making the collective experience more stressful."

In another study, "21% of participants report that all of their needs had been met. This is despite 75% of participants rating the quality of services provided by the OPCaC as being good or excellent, and 89% of participants reporting that they generally or definitely received the kind of services they

wanted".⁷

There are some limitations to this scoping review as most research has relied on self-report data and so it is not possible to determine OPCaC efficacy nor identify causal links between OPCaC participation and outcomes. There are also no longitudinal randomised control trials, beyond 8 weeks, so it is difficult to determine whether positive outcomes are gained and sustained in the long-term. It is also uncertain whether participants are meeting their needs by participating in OPCaCs or simply by accessing the Internet for support.

Future research should identify the demographics of OPCaCs users as well as disease status and psychological well-being. Characteristics, such as digital literacy and socio-economic status, and their influence on use should be explored to see whether they hinder accessibility. There should also be a focus on the platforms, designs, and content of OPCaCs to help with features and enhancements that make them more user friendly and effective. Exploring how men talk about themselves and other prostate cancer survivors in these forums may lead to identifying language that is supportive for men post diagnosis and treatment. Information gained from this research may help to inform recruitment strategies and the training practices of administrators, moderators, and online peer support group leaders to ensure that discussions are conducive to participants achieving positive outcomes.

The outcomes of this research will ultimately help to improve the physical and mental well-being of prostate cancer survivors and assist them to overcome barriers that minimise help seeking behavior.

References

1. King AJL, Evans M, Moore THM, et al. Prostate cancer and supportive care: a systematic review and qualitative synthesis of men's experiences and unmet needs. *Eur J Cancer Care*. 2015;24(5): 618-634.
2. Goodwin BC, Ralph N, Ireland MJ, et al. The role of masculinities in psychological and emotional help seeking by men with prostate cancer. *Psycho-Oncology*. 2020;29:356-363.
3. Chambers SK, Hyde MK, Smith DP, et al. New challenges in psycho-oncology research III: a systematic review of psychological interventions for prostate cancer survivors and their partners: clinical research implications. *Psycho-Oncology*. 2017;26(7):873-913.
4. Van Eenbergen MC, van de Poll-Franse LV, Heine P, Mols F. The impact of participation in online cancer communities on patient reported outcomes: systematic review. *JMIR Cancer*. 2017;3(2):e15.
5. Pyle D, Perry A, Lamont-Mills A, Tehan G, Chambers SK. A scoping review of the characteristics and benefits of online prostate cancer communities. *Psycho-Oncology*. 2021;30:659–668.
6. Struck JP, Siegel F, Kramer MW, et al. Substantial utilization of Facebook, Twitter, YouTube, and Instagram in the prostate cancer community. *World J Urology*. 2018;36(8):1241-1246.
7. Osei DK, Lee JW, Modest NN, Pothier PKT. Effects of an online support group for prostate cancer survivors: a randomized trial. *Urol Nurs*. 2013;33(3):123-133.



About the Author

Kalli Spencer
MBBCh, FC Urol (SA), MMed (Urol), Dip.Couns (AIPC)

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 public health 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.