



Online support groups and online communities for prostate cancer.

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Diagnosis with prostate cancer leads to a wide range of emotions such as fear, anxiety and helplessness. Men with prostate cancer increasingly turn to online groups for support. Online support groups and online communities are sources of information, shared experiences and empowerment for people affected by cancer. A new Australian study has analysed publicly-available conversations from online support groups to track discussions of emotional distress.

Online support groups for cancer

Online support for people affected by cancer is becoming increasingly popular. Two common forms of online support are members' groups and open forums. Members' groups, such as Facebook groups, require a joining process. These are often closed to public viewing until membership is granted. Open forums can usually be seen by the public and may or may not require a sign-up process for interactions. Both types of online support follow a similar process; a conversation is started by one person who posts a comment or question, then others can reply.

Online support groups offer a number of unique features: the potential to interact with people globally and across cultural divides, anonymity and 24-hour access to information and support. We can add another timely advantage to this list: access is available during pandemics when people are asked to restrict their social contacts.

Peer support for emotional distress

Peer support for men with prostate cancer can help with issues such as distress. Many men join face-to-face groups for emotional support from the sharing of experiences with others. But a face-to-face support group is not ideal for everyone. Some men wish for more immediate help or to remain anonymous. Men who hesitate to share their experiences face-to-face may find it easier to do this online. Online support groups are also sought out by partners and family members of men with prostate cancer.

An important question here is: do these online support groups actually reduce distress?

Australian study of online support groups

A new Australian study has used artificial intelligence to track emotional responses in online support groups for prostate cancer. Their [results are now published](#) in the open access journal PLoS One. The senior author of the study is urologist Prof Damien Bolton of the University of Melbourne and Olivia Newton-John Cancer Centre.

The Australian team analysed conversations from ten publicly available online support groups for prostate cancer (shown in the table below).

Online support groups	URL	n (% in total)
Healingwell	www.healingwell.com/community	2 520 (39.0)
Cancer forums	www.cancerforums.net	873 (13.5)
Cancer Survivors Network	csn.cancer.org/forum	810 (12.5)
Healthboards	www.healthboards.com/boards	429 (6.6)
Prostate cancer info link	prostatecancerinfolink.ning.com/forum	396 (6.1)
Cancer compass	www.cancercompass.com	356 (5.5)
Prostate cancer UK	community.prostatecanceruk.org	308 (4.8)
Patient info	patient.info/forums	299 (4.6)
Us too	www.inspire.com/groups/us-too-prostate-cancer	236 (3.7)
Macmillan UK	community.macmillan.org.uk	230 (3.6)

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Table 1 from Adikari 2020, showing the names and websites for 10 online support groups for prostate cancer or cancer in general.

The study focussed on the men with prostate cancer, rather than their partners, family or caregivers. An artificial intelligence was used to analyse 277,805 total conversation threads from 18,496 men diagnosed with prostate cancer.

Results from this study showed:

- The majority of people joined the group at 4 key times: after diagnosis, when choosing treatments, dealing with side effects and when the cancer returns.
- 62% joined to seek information on treatments.
- The most frequently discussed emotions were “open”, “interested”, “afraid” and “hurt”.
- Men seeking information on side effects were more likely to say they were “sad” or “hurt” than others.



- Over 12 months, expressions of negative emotions occurred less often.
- Patients who joined the group after their treatment expressed more negative emotions than those who joined before their treatment – but both groups improved over time, expressing fewer negative emotions 12 months later.

Conclusions from this study

This Australian study has provided insights into the emotional distress experienced by men joining online prostate cancer support groups. Results showed an improvement in expressions of negative emotions over a 12 month period. They also showed less negative emotions expressed by men joining before their prostate cancer treatment, compared to afterwards. These findings hint at help for emotional distress provided by online support groups and communities.

It's tempting to conclude that joining online support groups has improved the emotional distress felt by these men. However, we need to keep in mind that these men are receiving care and support from other sources at the same time. A trial using a control group for comparison will be needed to directly test whether this online support reduces emotional distress.

PCFA's Online Community has over 5000 members. It hosts a community forum where people affected by prostate cancer can connect with others, share stories and useful tips. They support each other through difficult testing or treatment decisions, and during life after treatment. PCFA's online community is free and easy to join via this [link](#).