

Watching how cancer patients interact online could help clinicians provide better services

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Men who visited a major online support group after being diagnosed with prostate cancer were most likely to seek advice on therapy and treatment, together with emotional support, according to research in the May issue of the urology journal *BJUI*. But, surprisingly, they went to great lengths to avoid using the word "cancer".

Researchers studied 501 threads posted during a 32-month period on Germany's largest [prostate cancer](#) forum, run by an umbrella group of organisations covering the disease. They analysed 1,630 posts on 82 threads started by [men](#) who had just been diagnosed and needed help to make decisions. Off-topic threads and posts written by people seeking advice on behalf of others were excluded.

"Social support plays a major role for most patients with prostate cancer, because of the intimate nature of the disease and the fact that there are such a wide range of treatment choices available for men with localised disease" explains lead author Dr Johannes Huber from the University of Heidelberg, Germany.

"Online support groups enable us to understand how patients communicate with each other when it comes to making [medical decisions](#) and this knowledge increases our understanding of our patients' needs and concerns."

Key findings of the study included:

- Specific questions were posed in 79% of the threads, with the other 21% covering more general areas.
- Two-thirds of the questions (66%) were about therapy recommendations, 46% were about treatment, including side effects, and 46% of the men explicitly sought emotional support.
- The other topics to make the top five were diagnostic matters (39%) and physicians and institutions (28%).
- Over a third of the threads (35%) included comments on specific treatment options, 24% offered emotional support and 21% relayed the responder's first-hand experiences.
- Posters were less likely to recommend surgical options, with 67% suggesting [radical prostatectomy](#) and 82% advocating radiotherapy.
- Direct contact was rarely offered in email (7%) or by telephone (7%) and never in person. Men seeking advice were more likely to be advised to keep calm (21%) than act faster (15%) in a given situation.
- Emotional support was given regardless of whether the men requested it. However, men who did request emotional support were more grateful and more likely to explain their personal treatment decisions in detail.
- Just over half of the threads (51%) suggested that the men seek a second opinion and additional imaging was recommended in 40% of the threads. However, only 20% of these recommendations were medically sound, according to recent guidelines.

- More than half of the threads (57%) included recommendations for a particular physician and 36% advised men to go to a university hospital.

"One thing that did surprise us about the forum was the tentative language used by the posters and the fact that they went to great lengths to avoid using the word cancer" says Dr Huber. "It was almost as if the word was taboo. We were also surprised that they avoided using other common language, preferring medical phrases like 'prostate carcinoma' and 'positive biopsy findings', which were extraordinarily common."

The authors feel that virtual peer-to-peer interaction could provide similar positive benefits to those offered by conventional support groups.

"Without the necessity of direct personal contact, patients readily receive information, advice and emotional support" says Dr Huber. "Emotional issues are covered whether or not they are requested and the contact is much wider than focusing on facts and figures.

"In short, social interaction on the internet is successful and appears to be a regular part of coping with prostate cancer as well as the decision-making process. And monitoring this interaction is a good way for clinicians to develop a greater understand of their patients' needs and worries."

More information: Decision-making in localized prostate cancer: lessons learned from an online support group. Huber et al. BJUI. 107, pp1570-1575. (May 2011). [DOI:10.1111/j.1464-410X.2010.09859.x](https://doi.org/10.1111/j.1464-410X.2010.09859.x)

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