

Meeting the support needs of patients with complex regional pain syndrome through innovative use of wiki technology: a mixed-methods study

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Plain English summary

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When people are living with a chronic health condition, the internet can be a valuable resource, providing information, descriptions of treatment options, and a source of support. Participating in an online forum (an internet site where individuals write messages to one another which can build into discussions) can help people to learn about their condition and connect them with people who are experiencing similar problems, thereby developing a 'shared identity'. The process of finding that their experiences are not unusual and that other people have faced similar situations can make them feel better about their own situation simply through the realisation that they are not alone.

In this study, we set up an online support forum for people with a chronic pain condition called complex regional pain syndrome. We also asked participants to take part in a joint writing task in which they wrote the content for an online information resource that explains their condition to friends, family, carers, employers and health-care professionals. We were interested to know how and what sort of support developed and evolved in a newly created online forum, and whether or not taking part in the writing task increased positive support outcomes compared with using only the forum. To answer these questions, we analysed the conversations taking place on the forum.

Members' first posts helped to establish a shared identity, and set up a positive supportive environment for several months. Few members of the forum explicitly requested social support, but many offered it (emotional support was the most prevalent). We also found that although a supportive community can quickly develop, it can also quickly erode. The study was unique in that by setting up our own forum, we were able to investigate these processes from the very beginning. We concluded that it is no longer feasible to study online supportive communities in isolation. Instead, researchers need to consider them in the context of participants' wider social media practices.

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