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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Declared competing interests of authors: none

Published July 2014
DOI: 10.3310/hsdr02240

Scientific summary

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Health Services and Delivery Research 2014; Vol. 2: No. 24
DOI: 10.3310/hsdr02240

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Background

Online discussion forums are increasingly used by patients as a source of information, advice and psychological support for health-related issues. While face-to-face support groups provide members with the opportunity to help each other, online forums provide similar opportunities, but also open up the possibility for discussing taboo topics and forms of self-expression that are often unavailable offline. There is growing evidence that forum participation can have a positive impact, for example reduced sense of isolation, increased self-efficacy and reduced anxiety. The development of a shared group identity and the validation of patients' thoughts, feelings and experiences are important factors in online support. Online social support may be particularly beneficial to people with complex regional pain syndrome (CRPS) who often become socially isolated and withdrawn, lack mobility and face threats to their sense of identity as a result of a reduced involvement in a variety of social roles. To date, research on online social support has been conducted retrospectively on pre-established message boards. No researchers have created a board from scratch and/or charted the development of support over time. Furthermore, the bulk of online support has been restricted to discursive online systems (such as online forums) and not made use of web technologies designed to encourage collaborative writing and joint accounts of feelings, experiences and other condition-relevant information.

Objectives

The first objective was to set up a peer support online forum in order to identify the nature of support provided and to explore its development over time. The second was to facilitate the development of social processes implicated in psychological support by incorporating a collaborative writing task involving the creation of a patient-generated information resource. There were three research questions: (1) What constitutes support in newly developed online interactions? (2) How does the process of giving and receiving support online evolve? (3) Can the combination of an online forum and a collaborative writing task increase support relative to an online forum alone?

Methods

We adopted a three-phase mixed-methods approach to this study. In phase 1, an online forum for people with CRPS was developed and all members of a static information-based online group for people with CRPS were invited to join, subject to agreeing to the moderation policy we developed in anticipation of this work. Phase 2 commenced after 3 months, when we introduced a collaborative writing task designed to run alongside the forum. In this task, forum members were invited to coconstruct a web page presenting CRPS in a way that they felt addressed the misconceptions around the condition. This was to be modelled on the Wikipedia page for the same condition, which had been written by experts and so lacked the voice of the person with CRPS. The intention behind the task, therefore, was to address this gap and ensure that the point of view of people with CRPS themselves was represented. In phase 3, the completed information resource was made available to forum members, their friends, family and carers, and written qualitative feedback was sought.

The forum members

After running for 6 months, there were 62 forum members, 29 threads and 217 topics on the forum. Twenty-six forum members were active forum participants. Their posts were analysed in the three phases of this study. The anonymous nature of the internet meant that demographic information about these

members was limited. It was possible to obtain some information about the 26 members by examining the self-disclosed content of postings. Sex was available for all active participants, comprising seven males (26.9%) and 19 females (73.1%). Age was available for nine participants, ranging from 20 to 54 years with a mean age of 35.6 years. Number of years since diagnosis was available for 14 participants, ranging from 5 months to 10 years with a mean duration of 3.9 years. However, the difficulties involved in diagnosing CRPS meant that some participants were diagnosed immediately while others reported suffering from symptoms for up to 12 years prior to diagnosis.

Data analysis

Support was investigated through qualitative analyses of the online forum and writing task interactions which were regularly archived throughout the life of the project. First, a thematic analysis was conducted on all 'introductory posts' (i.e. the first post by each active forum member) in the first 5 months of the forum's operation. The aim was to explore the role of first posts in the development of a supportive community, in terms of both forum content and tone. Second, a content analysis was conducted on all forum posts in the main body of the forum posted during the first 12 months of the forum's operation. This allowed us to explore whether or not elements of support were present and whether or not they changed over time. This analysis used a version of the Social Support Behavior Code modified for online support, which codes for five categories of social support (informational, emotional, esteem, network and tangible).

Survey data were collected at three points. Baseline data were collected at time 1 from new members as they registered for the forum. Time 2 data were sought from forum participants after 3 months of forum activity and time 3 data 3 months later. The survey was designed to measure their experience of CRPS and of the support available. It consisted of initial background questions on the use of the internet, experience in other off- and online support groups, and a number of other self-report questionnaires on psychosocial well-being and support. Completion of the survey was voluntary, and sampling issues prevented us from addressing fully the longitudinal aspects of forum use. Some of the survey items were free response and were thematically analysed as a supplement to the analysis of first posts.

Results

Five themes were identified in members' first posts. These established a 'common-identity' community via three types of information sharing evidenced in members' initial self-presentations. 'Journey to diagnosis', 'treatment', and 'contact with health care professionals' were a means of demonstrating to other members the posters' right to membership of the forum. These three themes established a common experience of the route to diagnosis, the types of treatment and the kinds of interactions with health-care professionals that they had experienced. Together, these themes contributed to a developing sense of social identification and enhanced the chance of being accepted by the community, thus fostering commitment and attraction among the group. The remaining two themes ('looking for the positive' and 'hobbies') were a means of establishing the tone of the forum. Although it was acceptable to write about negative experiences in a first post, and to note the struggles and obstacles that had been placed in one's way, there was an explicit attempt in the posts (through gentle humour or overt positive framing) to proactively look for the positive in their (difficult) situation. This latter set of themes was consistent with the establishment of a 'common-bond' community.

A content analysis was conducted on all forum posts on the two most active boards ('welcome' and 'your thoughts and experiences') over a period of 12 months. The data consisted of 79 messages (two threads) from the 'welcome' board and 157 messages (20 threads) from the 'your thoughts and experiences' board. Duplicate messages were removed, leaving an overall total of 232 messages for analysis. Messages were copied and pasted into a Microsoft Word document (Microsoft Corporation, Redmond, WA, USA),

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where the messages were converted into plain-text format. The majority of forum activity occurred within the first 6 months after launch, with 215 out of 232 messages (92.7%) being posted during this period. Only 17 messages (7.3%) were posted during the second 6 months from December 2012 to May 2013. At this stage, most activity on the forum was occurring in the 'raising awareness of CRPS' board. Posts were analysed for both requests for social support and for the type of support offered. Requests for social support occurred infrequently on the forum, occurring in only 15.5% of posts. Support was frequently offered, however, occurring in 88.8% of posts. Support requests were present in 36 out of 232 messages (15.5%). In the 'welcome' board, 13 out of 76 messages (17.1%) contained requests for support, while in the 'your thoughts and experiences' board, 23 out of 156 messages (14.7%) contained requests for support. The most frequent category was requests for informational support (8.6%), followed by request for network support (2.6%) and tangible aid (2.6%), with emotional (1.7%) and esteem support (1.3%) being the least frequently requested. Social support was present in a high proportion of forum postings. In the 'welcome' board, 75 out of 76 messages (98.7%) were found to contain some form of social support. In the 'your thoughts and experiences' board, 131 out of 156 messages (84.0%) contained social support. Group members most frequently offered emotional support (72.8%), followed by informational support (36.2%) and esteem support (30.2%), with network support and tangible aid (7.8%) less frequently offered (2.6%).

Conclusions

We were able to address the first two research questions in full.

1. What constitutes support in newly developed online interactions? Few members of the forum participants explicitly requested social support, but many offered it. Perhaps joining the forum was a request for support in and of itself. Indeed, nearly 90% of posts contained some form of social support. Support was constituted here in a number of ways: emotional support (in particular empathy and understanding) was the most prevalent. From the outset, there was evidence of both common-identity and common-bond community development on the forum, which was present in first posts as well as in the types of support offered in the first 12 months of forum activity.

   An advantage of online support compared with support offered face to face is that it facilitates the discussion of taboo topics. The forum analysed here did open up such discussions, providing a safe space to criticise the health profession without fear of jeopardising their treatment options. Belonging to a group of people with similar experiences gave permission to 'tell it how it really is.' Finally, the online environment created by members of this forum provided an opportunity for them to reach out and offer support to similar others, in effect helping them to re-engage with the wider world.

2. How does the process of giving and receiving support online evolve? One of the unique features of this study was that we were able to investigate the development of a supportive online community from its inception. That is, we were able to investigate this online community from the very first post. We have shown that during the early stages of the forum, the members set up a space that had an over-riding positive, open and supportive tone. These first posts also served to establish a common bond between users of the forum. Sharing the struggles and obstacles they faced served to emphasise the similarities in their respective offline situations, thereby creating a common connection. The elements of a common-bond and common-identity community, once established in initial posts, continued to shape forum interactions throughout the 12 months of forum activity.

3. Can the combination of an online forum and a collaborative writing task increase support as well as a sense of psychological and physical well-being relative to an online forum alone? For a variety of reasons we were unable to address this question fully. Because we were watching a forum grow organically, we made the decision not to assign participants to different groups. Instead, we gave all members the option of contributing to the collaborative writing task. We expected to be able to

compare those who accepted the invitation with those who did not. However, the response to our invitation was 'all or nothing': either they contributed to both the forum and the writing task or they stopped participating in the forum and did not contribute to the writing task. This did not allow us to compare across conditions. Moreover, within days of the writing task being launched, the forum was hacked by an unknown person or persons who created 40–50 fake user accounts. As a result, the forum was closed for 5 days to delete the fake accounts and tighten security. After this event, usage of the forum markedly dropped off. It was, therefore, not possible to compare support before and after the introduction of the writing task. Similarly, it was not possible to collect the quantitative data, further limiting our ability to compare across time and task.

Implications and future research

It is no longer feasible to think of an online community as existing in a single, bounded online space. Instead, it is necessary for future work to focus on 'networked communities', operating across several discrete but overlapping online settings. In terms of CRPS, the focus of much support centred on the frustration and anxiety experienced as a result of what is perceived to be a 'long journey to diagnosis'. This has implications for practitioners. In particular, forum posts indicated that forum users felt that their experiences were not heard by health-care professionals. This implies that health-care professionals who actively listen to patients' experiences, rather than medicalising the frustration, are more likely to foster a productive partnership.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

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Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

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The research reported in this issue of the journal was funded by the HS&DR programme or one of its proceeding programmes as project number 10/2000/40. The contractual start date was in January 2012. The final report began editorial review in October 2013 and was accepted for publication in April 2014. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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