

Patient Participation in Chronic Pain Management Through Social Media: A Clinical Study

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Abstract. Chronic pain places a significant burden on individuals as well as health services. Long wait lists to access public clinical pain management services can result, and health outcomes deteriorate. Innovative technologies, such as social media provide opportunities to support self-management within the participatory health framework. This paper aims to investigate patients' perceptions towards using social media while waiting for clinic access, with a particular focus on therapeutic affordances. Seventeen wait-listed patients underwent intervention using various social media resources as part of self-management. Thematic content analysis of semi-structured interviews examined patients' perceptions about social media use and participation. Three therapeutic affordances were most evident in the qualitative data: exploration, connection and narration. Barriers to participation were also identified, such as 'specificity of the resources'. Findings suggest social media are perceived positively. However, there is also the need to balance a desire to deliver evidence-based practice with patient-preferences in shared-decision making about social media use.

Keywords. Chronic Pain; Chronic Disease; Participatory Health; Patient-Reported Outcomes; Self-Management; Social Media; Thematic Content Analysis; Therapeutic Affordances

1. Introduction

Chronic pain is a serious burden for individuals and healthcare services [1, 2]. Patient-reported outcomes (PROs) may deteriorate as people wait (often up to 6 months in Australia) for access to specialized multidisciplinary pain management clinics [2, 3].

Innovations with web-based interventions to manage chronic pain have been described [1, 3, 8]. These include social media [9-11]. Social media can be distinguished from other types of web-based interventions by the use of tools to facilitate increased autonomy in user options, engagement in content creation, and interaction with other users, including peer to peer [12, 13]. These functionalities may contribute to patient self-efficacy and empowerment [1, 14-16]. They may give healthcare services the ability to individualize management, reach large diverse populations, and provide out-of-hours support [1, 17].

To date, very few studies have focused on patients' motivations and experiences in using different social media or actively involved patients in the design process [19]. Recent theoretical and empirical work [20-23] has shown clear therapeutic affordances of social media amongst PWCP. To establish a role for social media in self-

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management of chronic pain requires greater patient input within the participatory health paradigm, acknowledging that there are synergies between the functionalities of social media and the individualized needs of patients [24].

Therefore, the aim of this paper is to examine therapeutic affordances of social media that were described by patients within a clinical program of chronic pain management. The authors theorize that the different ways individuals choose to use social media will generate different health outcomes. Greater knowledge in this area may improve patients' and clinicians' decision-making about how to use social media in pain management.

2. Methods

A pilot study implemented a social media intervention for people with chronic pain on the waiting list for a specialized pain service. This paper reports on qualitative research conducted within the project. The Human Research Ethics Committees of Melbourne Health and the University of Melbourne approved this study (ID No. 2014.043).

2.1. Recruitment

Study setting was a large public hospital in Australia serving approximately 900-1100 outpatient referrals a year. There are usually 200-300 PWCP wait-listed, and wait times can be up to 6-8 months for the first appointment. Inclusion criteria included: competent in English, regular Internet access with competent usage abilities [25], medically stable, willing to register with Gmail and Facebook, and not currently undertaking an online intervention and/or using social media for pain management. Exclusion criteria included: change in priority status (i.e. intervention required immediately) or being discharged from the waiting list.

2.2. The Intervention

General chronic pain social media resources rather than resources specific to any one condition were used in this study. This was deliberate and followed an evidence-based practice approach to holistic chronic pain management, which focuses on a general multi-faceted approach to pain, rather than disease specific avenues [8]. Pre-existing social media resources were used in this study, including a large chronic pain support community on Facebook, various chronic pain blogs and YouTube pain management videos. Patients were requested to interact with the suggested pain based social media resources autonomously during the study period. All study investigators (including pain clinicians) reviewed and agreed upon the selection of resources. Participants received an email from the primary investigator, with links to the suggested social media resources and instructional information about how to get started and for using forms of social media that they might not be familiar with. The intervention ran for 12 weeks with participants commencing at different times because of staggered recruitment.

2.3 Data Collection and Analysis

Qualitative data was collected at monthly intervals via semi-structured phone interviews. Interviews were brief (10-15 minutes), giving patients the opportunity to

discuss participation and study progress free of coercion. Interview data were analyzed using thematic content analysis (TCA). Firstly, to categorize data according to five therapeutic affordances: a) self-presentation – interaction preferences regarding one’s online identity, b) connection – connecting with others via social media c) exploration – being guided to useful information, d) narration – the shared experience of chronic pain and finally, e) adaptation - motivation, frequency and type of use. Secondly, to examine any emergent themes surrounding barriers to participation.

3. Results

3.1 Participation in the Study

17 chronic pain patients were enrolled into the study. There were slightly more females than males (10/17, 59%) and age was spread, with 13/17 (76%) between 18-39 years old, and only 1 patient aged older than 50. 10/17 (59%) were never married and level of education varied, with 9/17 (53%) completing high school or less and 8/17 (47%) obtaining a university degree or greater. Work status showed over half were not working due to their health (9/17, 53%). 16/17 were contactable during the study (a 94.1% success rate). Of these, 12/17 (70.6%) said they had engaged with the resources. In total, 9.5 hours of qualitative data was collected from 38 phone interviews.

3.2 Therapeutic Affordances of Social Media

35 quotes were tabulated and categorized according to therapeutic affordance; sample quotes are included here. No quotes were negative about social media use and no adverse events were reported. The “exploration” affordance was most noted in quotes (20/35, 57.1%), followed by “connection” (7/35, 20%), “narration” (5/35, 14.3%) and “adaptation” (3/35, 8.6%). No qualitative semi-structured interview data described “self-presentation”.

Descriptive language describing “exploration” included: finding, watching, searching, exploring. Using social media to consume information, and precipitating learning about managing the underlying condition. As SM034 stated: *“I watch a video and all of a sudden I learn something new and I’m like ‘wow’, I didn’t know that!”*. Also described was the utility of using the social media resources to filter useful information/guide towards other management strategies.

Value of the “connection” affordance was supported, with ‘support’ the primary underlying reason suggested for connecting with others via social media. Language used included: connecting, listening, supporting and communicating. SM028 suggested that *“..you feel really connected to other people and supported to do something to help the situation”*.

“Narration” comments described the emotionally cathartic effect of sharing experiences with others. This was entirely skewed towards engaging with the experiences of others. Descriptive language used included: experiences, stories and therapeutic. SM077 said *“it’s good to see this side of things in the videos and learn what other people are going through and suggest”*.

Comments pertaining to “adaptation” demonstrated how patients were able to change their self-management behaviors and social media use dependent on their unique needs at different points in time. These were described using language as

follows: when pain is bad, drowsy, concentrate and when I'm in a hurry. For example: *"I find too much text to read makes it hard to concentrate when the pain is bad or if my meds make me drowsy. Video content is easier to digest"* (SM034).

3.3 Barriers to Participation

Most reported barriers to participation were: being time poor (7/17, 41%), low specificity of resources to patient's own condition (6/17, 35%) and effects of medication on patient concentration (4/17, 24%). Once participant captured the essence of resource specificity: *"I have a more localized pain condition and most of the resources were for generalized conditions so I had trouble relating to many of them"* (SM021).

4. Discussion

The findings of the present clinical study validate previous findings into therapeutic affordances of social media [21, 22]. The findings also highlight that certain factors can interfere with reaping the benefits of therapeutic affordances of social media. Lack of time, effects of medication and lack of personal relevance are human factors rather than reflections of the functionality of social media tools.

The present study tried to replicate social media use in everyday life, that is, free of coercion (i.e. engaging, autonomous, collaborative and participatory) rather than to deliver a regimented online intervention directing what patients are required to engage with and how. This study is thus aligned with participatory models of healthcare, suggesting rather than prescribing online resources to place greater emphasis on the patient's preferences and perceptions for their management. However, this does then mean study findings are open to analytical bias. This is because freer participant choice as to which resources could be used meant the research team could not clearly verify exactly which resources patients used. The challenge for future research is to balance evidence based practice with patient preferences in shared decision-making between clinicians and patients about social media use [16].

5. Conclusion

Results suggest social media use in chronic pain management is perceived positively. Knowing which therapeutic affordances underlie social media use will lead to more personalized and tailored social media use, and ultimately improve health outcomes. However, further larger scale clinical trials and longitudinal follow-up is warranted. Findings also show patients have differing perceptions regarding social media's therapeutic utility. In the future, social media resources must resonate with patients on an individualized level for them to be more accepted and useful. This will influence shared-decision making.

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