Use of Social Media by Arthritis Patients with Multi-Morbidity: Implications for Self-Management

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Background

- The use of social media in healthcare is being widely advocated and is often associated with the emergence of the ‘e-patient’, a term describing individuals who are equipped, enabled, engaged and empowered to self-manage their health.1,4
- While much of the current literature focuses on how healthcare organizations or clinicians use this new technology, there is little evidence to describe patients’ use of social media and its implications for self-management from patients’ perspectives.5

Methods

- A secondary analysis of data collected in a larger study titled “E-health Ethics & Multi-Morbidity”.4
- Eligible participants:
  - had self-reported diagnosis of osteoarthritis (OA) and/or any other type of inflammatory arthritis (IA), plus at least one other chronic condition;
  - lived in British Columbia;
  - were English-speaking.
- Participants were recruited via online ads, notices in clinics of rheumatologists and rehabilitation professionals, and word of mouth.
- In-depth interview (60-90 mins) with phone follow-up; transcribed verbatim.
- A constant comparison analysis guided by ethnographic traditions applied to the data; member checking embedded in the process and peer-checking added rigour to analysis.

Findings

| Sample Characteristics (n=17) |  
|------------------------------|---|
| Female                       | 16 (82%) |
| Age Range (median)            | 23-67 yrs (55 yrs) |
| Caucasian                    | 15 (88%) |
| Urban                        | 15 (88%) |
| Level of Education            |  
| - Below Bachelor Degree      | 11 (65%) |
| - Bachelor Degree or higher   | 6 (35%) |
| - Self-reported diagnosis of OA; of IA | 5 (29%); 12 (71%) |

We focus on 3 main themes:

**Theme 1: Connecting**

While most participants described emotional benefits of feeling less isolated and more positive through different forms of connection with others, some participants identified barriers to finding meaningful connections via social media.

I was also looking at ways to describe pain. And what I found out is that everyone was in the same boat. It was very, very difficult to describe it to someone else or to a practitioner […] it was nice to see people going through the same thing and wondering if we were all nuts. You know, because nobody could explain why we’re feeling like this […] that sort of made me feel a little bit better in that I wasn’t the only feeling like that. [Alilly]

**Theme 2: Work**

Strong agreement among participants that using social media could drain energy, introduce new obligations, and add further strain to keeping going.

It can also be quite overwhelming and draining with energy … [I] feel sometimes there’s a feeling that comes with it from the blogs as well, an expectation to be providing information and content and to do it right. [Julia]

**Theme 3: Guarding Identity**

Participants were cautious not to share information about themselves on social media if it posed a threat to how they saw themselves as individuals and members of a community.

I have not in any way either face-to-face or online become part of a community of patients […] You know some people want to be in a community of like-minded people. Like I’m an avid knitter. I’m way more an arid knitter than I am an arthritis patient. [Lily]

Conclusion

Findings reveal insights into patient experiences that have implications for health professionals and inform self-management approaches. Recognition of these emerging issues may help reduce potential burdens on patients. Gaining greater understanding of patient experiences of social media could influence an empathetic and holistic view among health professionals in the digital age.

References:


