

FACEBOOK AS AN ONLINE SUPPORT GROUP FOR ARTHRITIS NZ – A MIXED METHODS STUDY

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LAY REPORT

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Arthritis is the single greatest cause of disability in many parts of the world, affecting between 13-28% of people, with the burden expected to increase with the aging of developed populations. Similar to other long-term conditions, specialist care usually focuses on medical management, with less attention on the psychological and functional impacts of arthritis. Many people therefore seek further information and support from other sources, which includes the internet. Arthritis NZ is the leading NGO providing support for people with arthritis in NZ and has a Facebook page for people with arthritis, which includes scheduled time for interactions between Arthritis Educators and directly between people with arthritis. This page may be a valuable source of information about unmet health needs of people with arthritis. Therefore an analysis of this page was undertaken, including description of its users and an analysis of the page content.

Users of the Arthritis NZ Facebook page were predominately female and aged between 18-54 years. The page was mostly used for seeking or giving support, sharing information, or asking for advice. Unfortunately, there was limited interaction directly between people with arthritis but the page still provided a forum for informational and emotional support for users. This forum could be enhanced by encouraging user participation and training the page facilitators in engaging users and enabling online discussion. Further research should focus on barriers to user participation in online support groups.

Abstract

Background: Many people use the internet to seek health related information and social support. Arthritis NZ (ArNZ) has a Facebook page for people with arthritis. This online forum may provide insights into unmet health needs of people with arthritis.

Objective: To determine if user activities a social media platform like Facebook can provide useful insights into consumers' health care needs.

Method: The study was designed as an interpretive mixed-methods study. We used Facebook Analytics and the Gephi to describe the users and their activities on the Arthritis NZ Facebook page (ArFB). Principles of thematic analysis were employed to interpret transcripts from 10 weekly scheduled Facebook "chat" groups facilitated by Arthritis Educators (AEs).

Results: Users of ArFB were predominately female (81%), aged 18-54 years. Three major activities occurred during ArFB "chat" groups: (1) seeking or giving support; (2) information enquiry; and (3) information sharing. There was limited peer-to-peer interaction, with 55% of all discussion threads only two comment exchanges between users and the AE facilitators.

Conclusion: The ArFB provides a forum for informational and emotional support for users. The facilitated discussion forum for people with arthritis on Facebook could be enhanced by encouraging increased user participation, maximising peer-to-peer interactions and further training of AEs in facilitation of online discussion. Future research should focus on understanding barriers to user participation. The impact of AE facilitation training could also be assessed using the action research paradigm.

Introduction

Arthritis is the single greatest cause of disability in many parts of the world, affecting between 13% to 28% of people, with the burden expected to increase with the aging of economically advanced countries (Wong, Davis, Badley, Grewal, & Mohammed, 2010). In the USA, the total financial cost of musculoskeletal diseases, most of which is arthritis, was estimated at USD\$926 billion in 2011, 5.7% of GDP (United States Bone and Joint Initiative, 2014). Whilst arthritis is rarely fatal, it has no cure and can affect function and quality of life (Hadert & Rodham, 2008; Pimm & Weinman, 1998), which is reflected in high indirect financial costs which include loss of employment, informal care, aids and travel costs. Difficulties with daily tasks may also cause psychological distress both in people with arthritis and their families and carers (Gettings, 2010; Matcham, Rayner, Steer, & Hotopf, 2013).

New Zealand citizens and permanent residents are eligible for free medical treatment in public hospitals while other health services e.g. primary care and medicines, are subsidised. People must visit their General Practitioner (Primary Care Physician) to be referred to a hospital specialist. Waiting times vary between hospitals. Specialist care usually focuses on medical management, with less attention on the psychological and functional impacts of arthritis. Appointments are short and clinicians often use medical jargon, possibly leaving people affected by arthritis feeling marginalised, which causes further psychological distress (Castro, Wilson, Wang, & Schillinger, 2007; Mechanic, McAlpine, & Rosenthal, 2001; Thompson, Dorsey, Parrott, & Miller, 2003). Non-governmental organisations including Arthritis New Zealand (ArNZ) provide information,

advice, and support services to people with arthritis to supplement care provided in government-funded health services.

ArNZ's mission is to improve the lives of people with arthritis. Its activities include advocacy, provision of information and advice and support services. These have been delivered to individuals and groups by Arthritis Educators (AEs), who are health professionals employed by ArNZ, traditionally in-person and via telephone. The Internet age has had a huge impact on the way people seek information and interact. Nearly 80% of people in high income countries access the Internet for more than one hour each day (Fox & Duggan, 2013; Gibson, Miller, Smith, Bell, & Crothers, 2013; International Telecommunication Union, 2013) with social networking sites a key activity (Gibson et al., 2013; Pew Research Centre, 2014). As many people use the Internet to seek health related information (Fox, 2011; Fox & Jones, 2009) many health organisations now have a significant presence online. In 2013 ArNZ established a Facebook page for staff and consumers to post on, and in addition has a weekly "chat session" led and moderated by an AE. Facebook users who "liked" or were "likers" of the page get passive updates in their Facebook newsfeed and can comment on the page. This has provided an online forum for people affected by arthritis to connect with an AE and one another. Similar online communities have been shown to support reciprocal information sharing and facilitate people moving from simple information gathering to behavioural change (Bonniface & Green, 2007).

It is important to understand what is happening in this new ArNZ service, and if it should supplement or replace other services. The demographics of the Facebook page users and the participation of ArFB users in the discussion threads have not been quantified. Nor has the content of the discussion threads been analysed. The ArFB may also be able to provide insights into unmet health needs of people with arthritis.

The aim of this research project was to conduct an analysis of participants, use, and content of ArFB's online chat service to:

1. Develop a comprehensive understanding of "what is happening" in this online environment
2. Determine if using a social media platform like Facebook provides useful insights into consumers' health care needs, in particular
 - a) Can unmet health needs for people living with arthritis be identified?
 - b) Is social media better positioned to meet psychological needs of people with arthritis?

Methods

The overall methodological framework was interpretive (Klein & Myers, 1999) using mixed methods.

Study setting and participants

Data were collected from the Arthritis New Zealand Facebook page (ArFB) between 12th October and 21st December 2015 and included all content of the page. This comprised all posts by ArNZ (a short update which allows users to discuss their thoughts or important information) and comments (a short update on a post). Once a week, on Monday evenings, Arthritis Educators (AEs) are available to respond to questions and moderate discussions. The research focussed on these weekly conversations. We excluded updates and other posts by ArNZ that occurred outside the AE-led sessions. All AE sessions were run by AEs except for the final session, which was run by the leader of the ArNZ advocacy programme.

The participants were Facebook users who had clicked 'like' on the ArFB page to be able to follow the page and participate in conversations (by commenting, clicking the 'like' button associated with a comment, and/or sharing content) and AE's moderating the page.

Ethical approval

Ethical approval was obtained through the University of Otago Human Ethics Committee (OUHEC (Health)) (D15/316). A 'pinned post' was displayed at the top of the Facebook page throughout the study period informing viewers that page activities were being collected and anonymised for research. A link to the full participant information sheet was provided, as were opt-out mechanisms.

Data collection procedures and analysis

The study had two main components. The first consisted of the content of the ArFB AE sessions. CM (from ArNZ) copied and pasted the content of ten weekly AE sessions into 'transcripts', recording the coded (anonymised) names of participants, and steps in discussion streams, e.g. PN commented and SB replied and they posted more comments and DC joined with one comment. BW performed the remainder of the analysis. Each transcript was printed, cut, and coded, and then manually grouped by theme, e.g. information seeking. Transcripts were kept as MS Word documents and imported into an MS Excel file for detailed coding and analysis.

The second component was quantitative analysis of user demographics using Facebook analytics. The data were extracted using the Page Insights function of Facebook on 7th December 2015. Activity data were collected including the number of posts (a comment), conversations (defined as a comment on new topic with no reference to previous posts with the subsequent posts directly in reply to the initial post), replies (a comment replying directly to a previous comment), and the frequency of contributions by participants, and who conversed with whom about what.

Some data such as when 'likes' occurred in the discussion threads and network analyses of interactions between users and AEs were collected but will be analysed and reported on at a later date.

The data were analysed using the following steps (Auld et al., 2007)

1. Each transcript was analysed as a sequence of comments (i.e. as it appeared in the ArFB). A form of line-by-line coding was used to identify concepts, and connections between the concepts were noted, e.g. cold weather affects arthritic joints, and how the conversation changed as participants contributed their own observations.
2. Memos were written about the codes, to enhance the analysis.
3. ArFB comments were separated into three Excel sheets for each of the three themes: 1) seeking or giving support; 2) information inquiry; or 3) information sharing. Comments were further separated by topic (e.g. symptoms, medication, alternative therapy, solutions offered).
4. The transcripts of two weeks' AE sessions were double coded by RG to check coding reliability and refine the coding system.

Results

Users and page activity

A total of 1778 people ‘liked’ or followed ArFB when this study commenced (12th October 2015). The majority of “likers” were female (81%) and 25-54 years of age (Table 4.1). In a four week period in the second half of the study period (ending 7th December 2015), only 392 (22%) of “likers” clicked on any aspect of ArFB and 149 (8%) actively participated on the page (liking the page, posting to the timeline, commenting or sharing a page post, or responding to an event).

Table 4.1 User demographics of likers of Arthritis New Zealand Facebook page**

| Age | Likers n(%)* | Female n(%) | Male n(%) |
|-------|--------------|-------------|-----------|
| 13-17 | 19(1) | 15(0.85) | 4(0.23) |
| 18-24 | 160(9) | 124(7) | 36(2) |
| 25-34 | 391(22) | 320(18) | 71(4) |
| 35-44 | 427(24) | 356(20) | 71(4) |
| 45-54 | 373(21) | 302(17) | 71(4) |
| 55-64 | 249(14) | 213(12) | 36(2) |
| 65+ | 125(7) | 107(6) | 18(1) |
| | 1778** | 1437(81%) | 307(17%) |

*2% of people did not define their age or gender but are included in the total “likers”.

** Data collected 7th December, 2015.

The AE sessions were relatively small, with a median of eight users (including the AE) posting (range 3-28), a median of 5.5 conversations (range 1-24), including a median of 25.5 posts (range 10-77) (Table 4.2). AE sessions 1-9 were all of similar size, with a median of 22 comments and 7 active users. The final AE session (facilitated by the leader of the ArNZ advocacy programme) was larger with 27 users contributing 77 comments. In addition, 14 users commented to reply to other users conversations during this final session whereas a total of 11 users had replied to others over weeks 1-9 combined.

AE comments were 44% of all comments over the 10 week study period (50% for weeks 1-9). Excluding AEs, most users commented infrequently and nearly half (48%) of all comments came from the 10 most frequent users. Over half (55%) of all conversations were two comment exchanges between users and AEs. Most users did not reply to any subsequent comments by AEs or other users. Only 28% (or 13% over the first 9 sessions) of all user comments were replies to other users’ comments.

Table 4.2 Quantitative descriptors of all AE sessions

| | Number of active participants (including AE’s) | Number of conversations | Number of comments |
|--------------|--|-------------------------|--------------------|
| Mean | 9.6 | 7.4 | 29.5 |
| Median | 8 | 5.5 | 25.5 |
| Range | 3-28 | 1-24 | 10-77 |
| Total | 96 | 74 | 295 |

Activity of the Arthritis NZ Facebook page

Three key themes were identified in the content of the comments. The major theme was seeking and giving support, through sharing of experiences (from other users) or information (usually from AEs). Two smaller themes of, information inquiry and information sharing were also identified.

Seeking and giving support

Seeking support

Comments seeking support included expressions of negative impacts of arthritis regarding symptoms, emotional wellbeing, daily function and participation. Users expressed frustration and dissatisfaction with health care.

Users indicated that the diagnosis of arthritis often invoked fear, uncertainty and isolation. Users felt they were on their own and perceived a lack of emotional support from the health system. Suboptimal symptom control, particularly pain, impacted on emotional wellbeing.

"It's terrifying for me I got told I have psoriatic arthritis and handed some steroid meds and a pamphlet on methotrexate which they told me to go on it's a scary, scary sounding medication."

Comments on impaired function and participation referenced the social construct of disability e.g. use of crutches or wheelchairs and limited parking space restricted access to public spaces. Some users expressed that workplaces may not be supportive of people with arthritis which could impact work participation.

"Many workplaces/managers think it's just too hard to employ someone with a chronic disease and say it's a performance issue when they take sick leave."

Commonly expressed barriers to optimal healthcare were financial and wait time for appointments.

"My doc referred me to the public hospital but they don't want to know. I do have [health insurance] but as I am a single working mum finding the extra 20% is just unobtainable...."

There were several comments regarding perceptions of insufficient doctor knowledge and a lack of emotional support from doctors.

"Would like to see GPs educated more on giving out support group info. Just doesn't happen, usually diagnosis, drugs, and off you go."

Giving support

The AEs offered emotional support with positive feedback and endorsement of constructive lifestyle changes. Informational support was offered including non-pharmacological management options, strategies for coping, promoting emotional wellbeing, and suggesting the most appropriate health care professionals for specific user concerns.

"Fatigue is such a common symptom, even when you are not in a "flair" [sic] period of RA. It is certainly worth investigating to see if there is any underlying reason like anaemia. However pacing, regular moderate exercise, and dedicated time for relaxation may help. Low energy is one of the possible side effects of methotrexate. There are other hints about fatigue that might help, one of the educators could have a chat if you want to give us a call..... or PM [private message] with your number and we will call you."

“This is something you need to talk over with your Rheumatologist. People tend to have differing experiences with these treatments. Your Rheumatologist will have the experience and expertise when discussing these treatments.”

Users acknowledged informational support from ArNZ but expressed a need for more emotional support. There was also a preference for peer-to-peer emotional support, which could occur online, although direct user-to-user expressions of emotional were infrequent.

“In terms of support [from ArNZ] mostly it's just sending out information about your illness. I understand there are some support groups for some forms of arthritis but mostly the real support you will get will be from others who suffer. I've found online groups way better in terms of support so google them and make contact.”

Information enquiry

Users requested information for the following reasons.

1. To contextualise symptoms and/or co-morbidities in relation to arthritis or its' treatments (e.g. is arthritis pain worse in cold weather?).

“I am getting a burning in the knee joint and am wondering if the inflammation is causing it and what I can do to relieve it?”

2. To find solutions to mitigate functional impairments (e.g. access in and out of cars, walking shoes, and packaging).

“Can you recommend good men's shoes, ones that are supportive for arthritis ... We would love to do some walking.”

3. To understand usefulness or implementation of lifestyle changes (e.g. exclusionary diets, improving sleep quality, benefits or harm from complementary or alternative therapies)

“Can you recommend good men's shoes that are supportive for arthritis that is causing inflammation in the Achilles? We would love to do some walking. Thanks.”

4. To optimise their experience or understanding of medical care. This included recommendations for knowledgeable or sympathetic doctors, medication use including side-effects of methotrexate and biologic disease-modifying anti-rheumatic drugs (DMARDs), and the utility of deferring medication recommended by their rheumatologist.

“I have RA and over the last few weeks fatigue has really been hitting me hard. My joints aren't any worse than usual. I'm on Enbrel and Leflunomide. Any tips on managing it better?”

Information sharing

Shared information included triggers for symptoms and experiences of symptom management strategies. AEs offered the most information, often detailing scientific rationales for treatments and including external links to more information. Almost half the information offered by AEs recommended consultation with a doctor, implying recognition of the limitations of professional boundaries and the online environment. When users offered solutions to others, more conversation was stimulated. Solutions offered included non-

pharmacological treatment (exercise, weight loss), surgery and alternative approaches to completing activities of daily living.

“Did my first yoga class last week was a bit worried whether my RA joints and body would cope but it was brilliant. The graceful stretching and meditation was amazing but it certainly made me realise how tight my body gets from holding pain all the time. Really think yoga might be my thing for helping me relax and destressing.”

Information regarding solutions to difficulties with activities of daily living included opening packaging and personal grooming, often expressed empathetically and with humour.

“I related to this tweet today” [Tweet: “You can tell the state of my arthritis by my eyeliner; my purple eyeliner opens easily but the black one’s cap requires grip and pull strength”]. My fingers were so swollen this morning (still are) I laughed when I read this and spent the extra money buying a can of V rather than a bottle because I knew I wouldn’t be able to open the bottle.”

Discussion

This study provided insight into “what is happening” in the ArFB environment. The ArFB is used predominantly by younger women. This is consistent with other studies which show women seek health information online more frequently than men, are more likely to use social media and blogging for health reasons, and have a lower dropout rate in online self-help interventions compared with men (Fox & Duggan, 2013; Karyotaki et al., 2015; Mattsson, Olsson, Alfonsson, Johansson, & Carlsson, 2015; Rice, 2006). Although Internet use is highest amongst younger people (Mattsson et al., 2015) use is increasing in older age groups (Fox & Duggan, 2013; Gibson et al., 2013). Consistent with other studies a small proportion (3%) of the users who ‘liked’ ArFB actively participated by creating content (Fox & Jones, 2009; Fox & Purcell, 2010; Nonnecke & Preece, 2000). Many users commented directly to the AE and did not reply to any further comments once the AE had replied to their original question.

Conversely, a qualitative study of RAHelp, an online 10-week programme for rheumatoid arthritis, found the discussion board was well utilised by all members (n=30) (Shigaki et al., 2008). The difference may be due to the perceived purpose of the online forum and the tight-knit small community of RAHelp. On the other hand, the low engagement with ArFB may be attributable to the perception of Facebook’s value as an information source. Lampe and colleagues reported many Facebook users found it inappropriate to seek information on Facebook (Lampe, Vitak, Gray, & Ellison, 2012). To counter this perception, AEs need to generate a social presence on ArFB, but avoid becoming the centre of all discussions by emphasising peer-to-peer interactions (Rovai, 2007). One study found that frequent posting by page facilitators was associated with shorter discussion threads and did not lead to more user comments (Mazzolini & Maddison, 2003). However, page facilitators who do post frequently may be viewed as enthusiastic, and more expert than those who do not (Mazzolini & Maddison, 2003).

The unmet health needs identified in the study revolved around support, the majority of which was informational support although instances of emotional support occurred (House, 1981; Mattsson et al., 2015) (Figure 4.4). While the majority of interactions were between users, there was some peer-to-peer interaction, which was highly valued and often stimulated deeper discussion. As expected, users tended to seek support while AEs tended to provide support. The online environment is ideal for informational

support, which can be tailored to individual needs and can also be used successfully for emotional support (Mattsson et al., 2015). However other types of support, such as instrumental support, (the provision of childcare, transportation, or money), are not feasible in the online format.

Discussion threads focused on symptoms, function, medication concerns, and the wider health care system. Most of the shared unmet health needs were minor concerns rather than serious symptoms or personal information. These findings concur with those from De Choudhury and colleagues who concluded that social media may be preferable for sharing minor concerns given the lack of anonymity of Facebook as all information is linked to a personal account (De Choudhury, Morris, & White, 2014). Sharing may also be influenced by the perceived depth and quality of information that can be accessed in an online forum. Individuals are unlikely to share highly sensitive medical information on a public source such as Facebook if the likelihood of them gaining knowledge from sharing the information is low.

With regard to the position of social media for meeting psychological needs, many enquiries were focused on ‘making sense’ of illness experiences. In terms of health, sense making is the transition between feeling unwell to being sick, and the perception of bodily changes as symptoms (Radley, 1994). Users asked questions about diagnoses, medications, and symptoms, perhaps as they viewed the ArFB as a reliable forum to make sense of their illness experiences. While this study cannot conclude if social media *met* psychological needs of people with arthritis, it is plausible that it *can*. A few ArFB users praised the page, saying it was very helpful both to share experiences and read about other people’s experiences. Sharing experiences through online social support groups is an valuable way of building a sense of community and comradeship (Barak, Boniel-Nissim, & Suler, 2008).

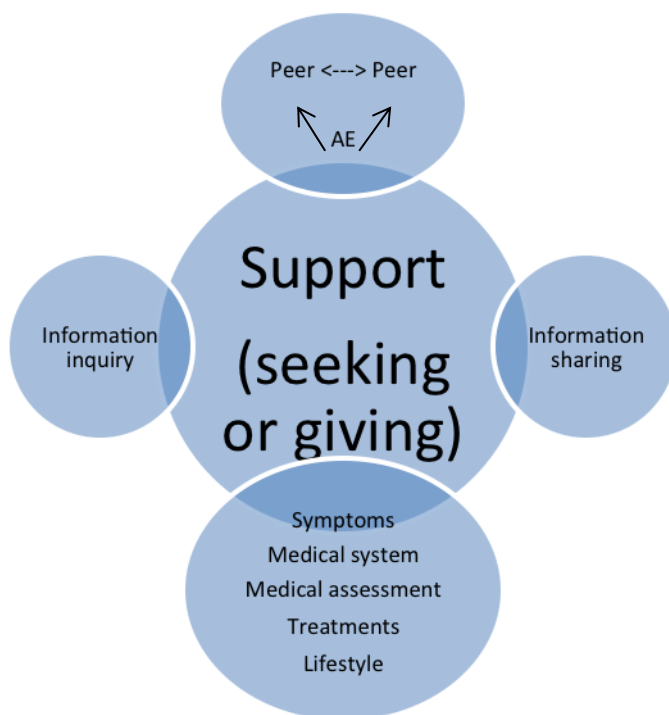


Figure 4.4 Factors contributing to personal use of the Arthritis NZ Facebook page

While a large number of users followed the ArFB, less than 12 members engaged with the AE or each other during each session, with the exception of the final advocacy session where 27 members took part in the conversations. A total of 55 members (excluding AEs) commented on any AE session over the 10 week

period (recall that 1778 people 'liked' the ArFB). This is consistent with other online behaviour; less than 20% of people who read other people's health experiences actually posted health-related comments themselves (Fox & Purcell, 2010). Those who 'lurked' (followed the discussion thread but did not comment) probably benefit from reading information on online support groups but sharing information on online support groups is more effective in enhancing mental and social well-being (Setoyama, Yamazaki, & Namayama, 2011; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008).

The limitations of this descriptive study include change in behaviour as a result of being observed (Hawthorn effect) and the generalisability of the results. In order to collect data ethically, all users of the Facebook page were notified of the data collection and posting comments implied consent. Users may have changed posting behaviour or chosen not to post during the study period, biasing data. Furthermore the passive data collection and interpretation may not accurately capture the user's intentions for their post meaning.

The proportion of page followers who posted or commented during the study period was low (3%), and nothing can be inferred about the reasons the majority of "likers" follow the ArFB. This phenomenon of "lurkers" and low proportions of "commenters" is typical of online forums (Fox & Purcell, 2010; Setoyama et al., 2011; van Uden-Kraan, Drossaert, Taal, Seydel, et al., 2008). Other mechanisms of data collection, such as focus groups or direct questionnaires are necessary to understand the purpose and benefits of following the ArFB for these people. Further research should also explore users' perceived norms surrounding the use of Facebook and how these norms influence disclosure of health conditions, seeking information, and providing support to others. This information could be utilised to stimulate greater discussion on online forums such as Facebook.

These findings have practical implications regarding the facilitation of online health forums. Through the forum, health service providers can reach people who are unable or do not wish to attend face-to-face support groups. Participation in online communities for medical conditions is also thought to foster a sense of wellbeing and control and increase self-confidence and independence (Barak et al., 2008; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). This, along with increased medical knowledge can increase quality of doctor-patient interactions (Wicks et al., 2010). These benefits of are hypothesised to translate into positive behavioural change (Barak et al., 2008; Wicks et al., 2010).

Second, users have the ability to connect with each other to exchange information and support with moderation by a health care professional to maintain a safe and supportive environment. An online forum, like that provided on the ArFB can be used to keep users informed of advances in treatments and support services and provides a sense of community and comradeship for people affected by arthritis (Barak et al., 2008). The online environment has many opportunities for peer-to-peer support including helping other understand medical science and care (Hoch & Ferguson, 2005), empowering each other find supportive and knowledgeable doctors (Barker, 2008; van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008). By encouraging patients to access Internet support groups, clinicians may help mitigate the negative effects of time-pressured medical practice (Hoch & Ferguson, 2005). The peer-to-peer interactions may also meet psychological needs of people with arthritis.

Most conversations on the ArFB were short and between the moderators and one or two users. Specific training in techniques to facilitate interaction between more users and directly peer to peer should be encouraged and use of users as facilitators should be explored. More user interactions may occur in a private discussion forum, for example a closed Facebook group, where the moderator of the group authorizes entry to the group and only users can view the comments. Focus groups could provide more

information on the participant's perspective in order to tailor discussion forums to meet unmet needs of people with arthritis and other long-term conditions.

Conclusion

This study shows a moderated discussion forum for people with arthritis has potential for use in a therapeutic context. The discussion forum fulfils some informational and supportive needs of people affected by arthritis and may be particularly useful for those who exclude themselves from traditional programs or experience barriers to making contact with professionals. It should be used to supplement other therapeutic strategies offered by clinicians and ArNZ, but is not yet comprehensive enough as a sole therapeutic option. We will make recommendations to ArNZ that may enhance their discussions and encourage interaction among users, although 'lurking' on SNS still provides a sense of camaraderie. Facilitators should attend training sessions to engage users and maximise discussion.

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