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Interactions and Perceptions of Patients with Rheumatoid Arthritis Participating in an Online Support Group

Jude K. A. des Bordes, MBChB, DrPH¹, Jessica Foreman, BA¹, Tiffany Westrich-Robertson, BFA², Maria A. Lopez-Olivo, MD, PhD¹, Susan K. Peterson, PhD, MPH³, Catherine Hofstetter⁴, Anne Lyddiatt⁵, Irmgard Willcockson, PhD⁶, Amye Leong, MBA⁷, Maria E. Suarez-Almazor, MD, PhD¹

¹Department of General Internal Medicine, The University of Texas MD Anderson Cancer Center, Houston TX

²International Foundation for Autoimmune and Autoinflammatory Arthritis, St. Louis, MO

³Department of Behavioral Science, The University of Texas MD Anderson Cancer Center, Houston TX

⁴Patient Advocate, Toronto, Canada

⁵Patient Partners in Arthritis, Ontario Canada,

⁶School of Biomedical Informatics, University of Texas Health Science Center, Houston TX

⁷Healthy Motivation and the Global Alliance for Musculoskeletal Health of the Bone and Joint Decade, Santa Barbara, CA, USA

Abstract

Objective: Peer support is important for psychosocial well-being in patients with rheumatoid arthritis (RA). Our objective was to assess the interactions, engagement and perceptions of participants in an online support group for patients with RA.

Methods: Participants were 18 years or older, diagnosed with RA within 10 years, and residing in the United States or Canada. All participated in a closed Facebook online support group. Membership was by invitation only, and discussions were visible only to members, moderators,

Corresponding author: Maria E. Suarez-Almazor, MD, PhD, The University of Texas MD Anderson Cancer Center, 1515 Holcombe Boulevard, Unit 437, Houston, TX 77030 (msalmazor@mdanderson.org). Phone: 713-563-6209. Fax: 713-563-4491.

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and two research staff. Each week, participants discussed a topic posted by a moderator. They also shared other disease-relevant information beside the topics posted. We assessed participants' engagement and qualitatively analyzed the content of their postings in the first 5 weeks of participation.

Results: The group had 90 participants: 94% were female and 83% white. Median age was 54 (24–84) years. Mean number of contributors per week was 50 (range 42–62); 10% of participants never contributed to the discussions. Participation in discussions declined over time. Over three-quarters of participant posting were about information sharing. Participants shared information on disease experiences, medications, social lives (including pictures of themselves, families and pets), online resources on RA, frustrations, messages of encouragement and satirical depictions of their disease experience. Many expressed gratitude for the social support provided.

Conclusion: Participants were generally enthusiastic, and shared disease-related information and personal experiences. Social media groups may provide alternative means of providing education and peer support often lacking in traditional models of care.

INTRODUCTION

Social support, the support accessible to individuals through their interaction with networks of other individuals, groups or community, is an essential component in the management of chronic diseases [1]. Support is mainly derived from family, friends and significant others and may be in the form of emotional, instrumental or informational support [2,3]. Research shows that social support may be associated with improved quality of life, enhanced decision making and empowerment [3–5].

Traditional models of social support have been available in the form of individual or small group face-to-face settings where patients and others meet to share information on their disease, resources and receive support. With patients increasingly turning to the internet for health information and support, social media have assumed a critical role in providing fora for patients who desire to interact and share experiences with others [6–8].

Online support has a number of advantages. There is no geographic limitation as patients can receive support on their computers or mobile devices. This may be even more helpful to people suffering from diseases like rheumatoid arthritis (RA), who may find it difficult to attend traditional social support sessions because of mobility issues. There are also no time constraints or scheduling processes once access is established. The internet provides a cloud of anonymity and participants may be less inhibited to discuss uncomfortable topics. Online support groups may however, present challenges. If not moderated, discussions may go off topics and there may be misinformation. Greater anonymity may be associated with less credibility [9].

In RA, social support is particularly important in dealing with the psychosocial aspects of the disease. Patients may require all forms of social support namely, instrumental (e.g. in the form of physical or housekeeping support), emotional, and informational. Although most patients with RA derive their social support from family and peers, research shows they

often have a preference for support from their peers because they perceive those without the disease lack understanding of their condition [10,11].

There are numerous online patient support groups. Facebook (Menlo Park, CA), for instance, houses many social networks for health-related purposes [12]. Despite the growing literature on online social support groups, not many studies have examined how participants interact in such networks. The aim of this study was to assess participant engagement in a small, closed, online Facebook support group of patients with RA, and to explore their interactions and perceptions.

PATIENTS AND METHODS

We conducted a study to assess the interactions among patients with RA who participated in an online, closed, RA Facebook support group, moderated by patient advocates, during the first 5 weeks of participation. This report is part of a larger, 6-month randomized controlled trial that evaluated the potential benefits of participating in an online support group [unpublished study]. Eligibility to participate included being 18 years or older, residing in the United States or Canada, and diagnosed with RA within 10 years. We restricted the study to those within 10 years of diagnosis to reduce the confounding effects of longstanding disease. Patients were recruited through advertisements in Facebook, selected rheumatology websites, newspapers, and by directly inviting patients with RA who contribute data to the FORWARD Data Bank (formerly known as the National Data Bank for Rheumatic Diseases, Wichita, KS)[13]. The International Foundation for Autoimmune and Autoinflammatory Arthritis (St. Louis, MO) also directly recruited for this project.

The Facebook online support group was created as a closed group ('secret' in Facebook terminology) to keep participants' identity, and their interactions, invisible to non-members. 'Secret' groups provide a layer of invisibility as no one can search for them on Facebook or request to join. The only pathway to joining the group was to accept an invitation from the research staff. Information shared in the group was visible only to members, moderators and two research staff (JD and JF). There were three moderators who were all patients with RA and had experience working with RA advocacy groups. They were contacted to moderate the study. Each week a moderator posted a topic for discussion on the forum. The topics posted had been selected *a priori* as being important concerns in RA by a team of disease experts, patient advocates, and patients. Topics posted were: Week 1: physical challenges, Week 2: emotional health, Week 3: self-care, Week 4: exercising, and Week 5: socializing. Participants contributed by posting their perspectives on the topic for the week and/or by reacting to the postings of other participants. Participants could also share other relevant information not directly related to the discussion of the week. The moderator would guide the discussion by responding to some of the comments or by prompts. Participants who posted any comments for the week were referred to as contributors. Participants who signed in to the forum but did not post any comments were referred to as non-contributors.

The study was conducted from February 2017 to August 2017 and the data reported here describe the patient interactions over the first 5 weeks.

Data analysis -

Postings were abstracted each week. Data analysis consisted of two phases: participant engagement, as evaluated by number of postings and number of participants contributing with original postings or responding to those of others, and qualitative analysis of content posted. At the end of each week, we assessed the number of contributions (i.e., the number of postings on the posted topic for the week), the number of contributors and non-contributors, by counting the numbers from the forum.

We conducted a qualitative content analysis of the information posted by participants by using a constant comparative methods approach. Abstracted postings were coded line by line, the codes aggregated into categories, and synthesized into themes by one of the authors (JD).

We also analyzed content of postings outside the topic of the week, summarizing the major content areas. Supporting quotations were included. We employed Dedoose Version 8.0 (SocioCultural Research Consultants, LLC, Los Angeles, CA), in the analysis of the data.

All participants provided informed consent electronically. The study was approved by the Institutional Review Board of The University of Texas MD Anderson Cancer Center (Houston, TX).

RESULTS

Of the 105 patients invited to participate in the group, 90 had accepted the invitation by the end of Week 5. Characteristics of the 90 participants are shown in Table 1.

Participant engagement

All 90 participants signed in to the Facebook group weekly, for each of the 5 weeks, but not all contributed with postings. Mean number of participants who contributed to the topic for discussion (i.e. contributors) per week was 50 (range 42–62). Ten percent (9/90) of participants had not contributed to any discussion by the end of Week 5. Figure 1 shows the number of contributors and number of postings per week. Fifteen (17%) participants posted comments every week throughout the period while 19 (21%), 18 (20%), 14 (16%) and 15 (16%) contributed over 4, 3, 2 or 1 week respectively. The average number of postings to the discussion topic per contributor over the 5-week was 12, and the median was 7 (Range: 1–145).

Participants shared their perspectives, experiences and concerns on their physical challenges, emotional health, self-care, exercising and socializing. Five major themes emerged from the content analysis of participants' postings, about the nature of their interactions. These are information sharing, information seeking, provision of specific information or advice, emotional support and expressions of gratitude. Over three-quarters (76%) of the data units were about information sharing, a third (34%) of which were about information on their personal lives. Emotional support accounted for 7% of the data units with 6.6 % each on provision of information or advice and expression of gratitude. Only 3.3% of the data units were about information seeking. Most quotes presented were posted by different individuals.

Their demographic information is not presented because of privacy concerns given the size of the group.

Information sharing –

Nearly three-quarters of all postings were about information sharing. Under this theme, participants shared disease experiences as related to the topic of the week, their diagnosis, how they dealt with the disease, their medications, and their frustrations living with RA. They also shared information about their emotions.

Some of the words participants associated with their emotions include depression, guilt, fear, anger and irritability.

“...looking back a couple of years I believe my first emotion when I began to accept it [the diagnosis], was anger at RA.”

“Unfortunately, I don’t handle them gracefully at all. I’m irritable, mean, impatient, irrational and snarky even though I try not to be.”

Many shared their frustrations from their inability or difficulty in performing simple daily tasks, not being able to keep up with social engagements, and the need to ask for assistance with some activities. It was perceived that people without the disease do not appreciate what patients are going through, are doubtful as to whether they are really sick, or just not interested in their predicament. Some participants felt that telling people about the disease made them appear like ‘whiners’ (*verbatim*). They therefore kept the disease to themselves.

“It’s very troubling. I struggle to look as solid as I am big. But I get fatigued so quickly. I really avoid social situations. Too often a tiny man would give me that look, the one where he has something to prove or shows his disapproval of my “weakness”. So I stay home.”

“I think it’s hard to expect anyone to understand what we’re feeling, so I agree that sometimes it’s easier to not say anything.”

Some shared how they have been trying to cope with the disease on their own.

“I make it a point to shower first thing every morning...it allows for some “me” time from the baby and the warmth helps loosen up my joints, and then put on “real” clothes. Otherwise, it’s easy to get trapped in feeling down about things and having a reason to not get out or do anything.”

“I’ve always been very active. I try my best to keep moving with yoga, pilates, stationary bike, walking.....some days are certainly more challenging than others but I do the best I can on that day.”

Information seeking -

A few participants sought information from others on a range of issues from general information about the disease, medications and their adverse events, potential complications of the disease, and their social lives.

“I don’t understand the concept of remission in RA. I’ve only been diagnosed for a year so it’s still all new to me. Remission means you have no symptoms anymore, but remission in RA...there are still symptoms. So what’s the difference between being in remission and not being in remission?”

“Do you find NSAIDS helps with mental fatigue? I try not to take them often so I’m not sure if it helps”

“Has anyone had eczema as a physical side effect?”

“Do you have suggestions? Can you share your exercise journey with us? What has worked for you? What do you do when in flare mode?”

“I have a question that I need to ask! You all have been so frank about your issues with this disease some of you are in such pain and have so many joint issues! I’m so blessed, I am not nearly as bad off as most of you are. I was diagnosed three years ago things were pretty painful in the beginning and I couldn’t make a fist but now other than the fatigue and occasional flares, I’m good. So finally the question, am I going to get to the point where I can’t cut my food, can’t walk, etc...?”

Provision of information or advice –

Some participants also offered information or advice to others in the forum. This included solicited information such as a response to a specific question by another participant, or unsolicited advice on issues of importance in RA. Participants also posted links to websites addressing RA issues.

“...a few others brought up an important issue, which is tooth decay. My RA physician never mentioned this, but RA patients should get teeth cleaned about 4 times/year to maintain your teeth. Also, several participants brought up the issue of being diagnosed with several autoimmune disorders. It seems common and I wonder how many people have only been diagnosed with RA but have other illnesses...”

“Have you tried online pilates videos? They’re free and you don’t have to go out far. I’ve resorted to those now. Can’t do all the moves but I improvise. If you’re interested, I can send you some YouTube channels I love.”

Emotional support –

These were expressions of empathy or encouragement to participants who shared difficult situations.

“...am so sorry to hear how much your RA has progressed, I hope you find meds that make your life easier”.

“Me too...that’s what this life is all about...love and support of each other...glad you had a great night...hope you bounce back quick..I would have totally went also were it my hubby...I feel the same! I push myself to see that smile of his because he is always there for me. Great post...and awesome addition to our topic this week. Just what we all needed...”

Expressions of gratitude –

There were expressions of gratitude for the support and encouragement offered by participants.

“Thank you for sharing so honestly. I realize that I have these same questions/worries in the back of mind and that it is contributing to my fatigue, pain and willingness to get out of house. My faith is wavering and I no longer believe in miracles. As a nurse, I have seen my share.....Your thoughts were inspirational to me.”

“I feel so connected on line as we are being real and honest with each.”

Other subject areas that emerged from postings not specifically related to the topics for discussion included:

Personal disease experiences –

Some participants shared with the group some of their disease experience which were very personal.

“This morning I was feeling “weird” and checked my BP which was high and all over the place so we called 911 and I got transported to the ER. It was a longggggg day I didn’t get called to be checked out for over 8 hrs. What they came up with was I may have an infection and because of my autoimmune issues my body was fighting the infection”.

Medication information –

Other participants shared some experiences about their RA medications with the group

“I was started on a daily dose of 5mg. prednisone back in Sept. I’ve gained weight because of it. My appetite has increased! I was wondering if folks have been able to lose weight they’ve gained and what did they do to do that.”

Social life –

There were also postings about social lives by some participants.

“Yesterday I went out with my best friend, I had so much fun. I thought to myself how much I had missed over the winter with a lot of flares....I was not going to go but something inside me said you got to get up and go or get worse. I was happy I decide to go...”

Frustrations –

Frustrations – with the disease or the health care system.

“Emotionally with RA, every time I think I have finally accepted this dang disease I have a setback or I get angry all over again. I just worry about the future. Will it bankrupt us in retirement? Will I be physically capable of keeping up with my husband? Grandchildren? Will they ever find a cure? I hate everything about this disease but the inability to plan my future is maddening.”

“I’m heartbroken...my prior authorization for Humira every 10 days was refused....”

Messages of encouragement –

Many participants who shared their problems received emotional support in the form of messages of encouragement and empathy from the group

“Exactly! Stand your ground we all have your back!!!”

“Oh my gosh, of course I wish you well. Please keep us updated and I will pray for healing. Just keep telling yourself that you are strong and you are able to overcome this. Gentle hugs coming your way.”

Appreciation –

There were also messages expressing appreciation to the group for their support and well wishes.

“I wasn’t sure how this would work, but learning there are people out there that have the same feelings and pain and thoughts I have is so enlightening...and helpful...kudos to all of you...”

“Thank you all for your honest comments and participation. I woke with a smile today and couldn’t wait to speak with my daughter.... I told her ‘I’ve met wonderful people all over US and Canada who have RA and have same pain, depression, doctor complaints ...and I don’t feel alone anymore and less overwhelmed’. That made her smile.”

Satirical depictions –

“Dear Pain, we need to talk. We’re not just right for each other....I deserve to be treated better. You are mean and evil”

Participants also shared pictures of themselves, their families and pets, and other websites with information on RA..

DISCUSSION

Our study is the first to evaluate interactions of patients with RA participating in a closed Facebook support group. Participants shared their experiences and perceptions on aspects of the disease, sought emotional and informational support, and provided information, advice, and support and encouragement for others.

In general, what transcended most of the discussions was information sharing. Participants shared their knowledge and disease experiences including symptoms, medications, coping mechanisms and frustrations. This finding corroborates that of Hadert et al. in their study of discussions posted on an online message board by patients with arthritis, which found information exchange as one of the major themes [14]. One recurrent observation was the notion that people without the disease experience do not appreciate the predicament of RA

patients. This appears to be a widely held view among patients with RA [10,14]. Patients who shared difficult circumstances received emotional support and encouragement.

Studies on the use of social media platforms in the management of chronic diseases have varied in the types of social media, methodology, population, disease studied and health outcomes and other effects. A systematic review of 42 studies on social media use in chronic diseases showed that 38% used Facebook, 31% used blogs with the rest using Twitter (San Francisco, CA), Wikis (San Francisco, CA) and YouTube (San Bruno, CA). Methods employed included case reports/series, cross-sectional, cohort and randomized trials [15]. Positive outcomes resulting from social support received via social media include a sense of hope, a feeling of connectedness and relief [15]. In patients with chronic disease, participation in online social support groups has led to patient empowerment by making them better informed and enhancing their social well-being [16]. As in our study, Greene et al evaluated communication of patients with diabetes on Facebook and reported that the information exchanged involved sharing of disease management strategies, provision of specific feedback to information requested and provision of emotional support by the poster to other members of the community [17].

Little information is available on online interactions of patients with RA participating in social media, and on platforms such as Facebook. One study evaluated participation of patients with RA in a 10-week online self-management educational modules with features for community interaction, including a discussion board with postings on RA-related topics, chats, and a secured messaging system. This study found that participants spent most of their time accessing educational materials, and less time chatting [10]. In another study assessing engagement and satisfaction with an Internet-based physical activity intervention in patients with rheumatoid arthritis, the discussion board was unpopular [18].

In our study, every participant signed in to the forum each of the 5 weeks. However, not everyone actively participated in the discussions for the week. Eighteen percent (18%) of participants made contributions every week, while 10% never took part in the discussions. While enthusiasm was high initially, it gradually declined over time, with both numbers of contributors and postings decreasing. Level of participation varied for members of the group with less than one-fifth consistently posting each week. It is unclear whether the decline in participation over time was related to disinterest in specific topics, loss of initial enthusiasm, or by indisposition. In the study by van den Berg et al., the mean number of patients logging into the website at least once a week was 53 (70%) over 12 months [18]. Although our sign-in rate was better, our study was over 5 weeks and participant disinterest had probably not set in. In their systematic review to assess factors that influence user engagement in internet behavioral interventions in chronic diseases, Schubart et al., found that patients are engaged when they are provided with health information, interactive tools to manage their condition and decision support for treatment and social support [19]. Ten percent of our group did not actively participate even though they visited the forum each week. This could be partly be due to their being uncomfortable with sharing their perspectives online. A study of young adult survivors of childhood cancers found that participation in online social networking interventions is more likely in those with less face-to-face social support and as well as those with less family interaction, among other factors [20]. Actively sharing one's

disease experience online may be associated with better outcomes. However, Setoyama et al., exploring the benefits of peer support in online breast cancer communities, reported that, although more psychosocial benefits accrue to active participants of peer support groups, those lurking in the background also obtain some benefits [21]. The lack of inclusion of new members to stimulate continuous conversation could also have contributed to the decline in participation over time.

Online interactions and discussions were civil and mostly focused. A number of factors could have contributed to this. First, participants were given some ground rules about expectations of participation, what one could or could not do. Secondly, participants could share other disease-relevant information not directly related to the week's discussion topic separately, with a new string of postings. This allowed discussions on a posted topic to proceed with no interjections of unrelated material. Finally, each discussion was moderated by a person with experience in both the disease and working with RA patient groups, who guided discussions, and engaged the group with comments and questions related to the topics under discussion. It is uncertain how moderating support groups may impact outcomes. A study of moderated and peer-led online support groups in women with breast cancer, found no group differences in depressive symptoms and extent of participation between groups, but the moderated group read and posted more messages [22].

Our study had some limitations. Most of the participants were white women with generally high level of education, and thus results cannot be generalized to other groups. It must be noted however, that RA is most prevalent in white female population. This bias could be a result of our sampling frame, our sources of recruitment being composed mostly of white, well educated women. Our study was restricted to Facebook only. Therefore, perspectives of patients who use other social media platforms were not explored. There may also be the possible bias associated with the patients being asked to participate in the group, and thus may have felt some pressure to contribute to the group. Our use of qualitative approach did not permit an objective assessment of benefit. Finally, the data collection and analysis were performed by only one of us, as our confidentiality agreement with participants only allowed for selected participation of research staff.

Our findings suggest that social media support groups could be viable options, or complementary to other traditional approaches of providing social support to patients with RA such as face-to-face groups, or educational self-management groups. Online interactions foster health information exchanges and emotional support. Yet, there is the need to find ways of sustaining participant engagement if online support systems are to be fully exploited. Finally, while participants seemed appreciative of the peer support received, it is unclear whether this support will have any significant impact on disease outcomes although there is evidence that social support may be associated with improved quality of life and possibly even with disease activity [23].

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KEY POINTS

- The study examines how patients with rheumatoid arthritis engage in an online support group and the nature of their interactions
- This study reveals that social media platforms could provide viable options or complements to the traditional face-to-face small group patient support system
- It may be necessary to pay special attention to how to ensure a sustained participant interest in online social support group among patients with rheumatoid arthritis.

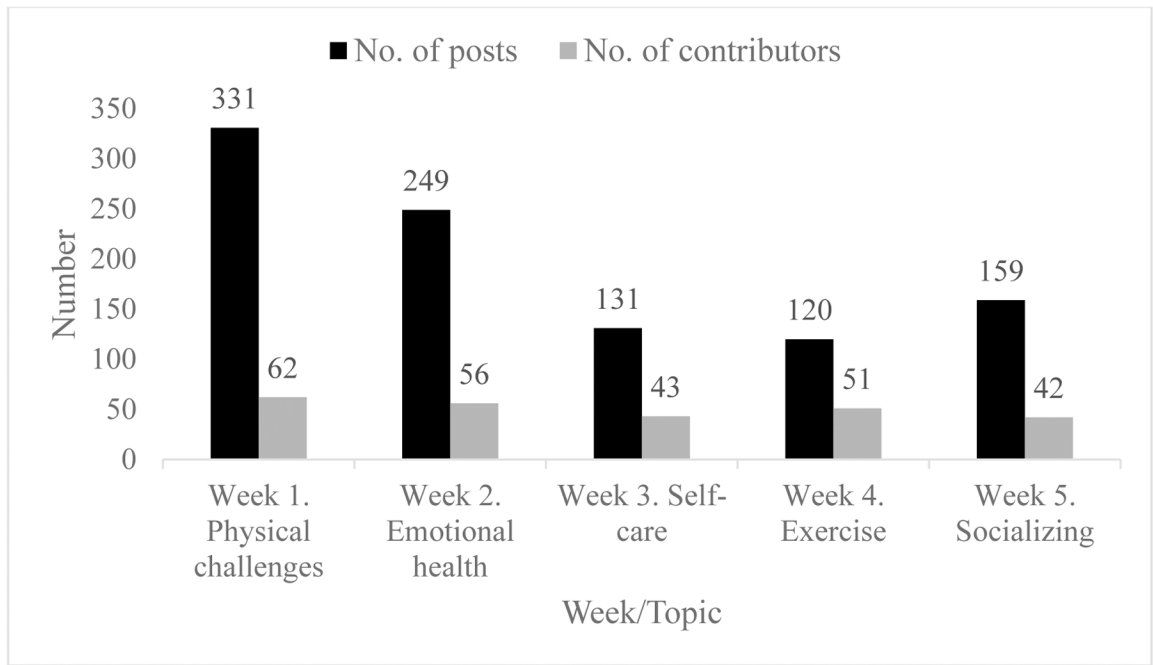


Figure 1.
Participant engagement.

Table 1.

Demographic characteristics.

Characteristic	Number (%)
Age (years)	
<40	14 (15.2)
40–59	51(56.2)
60–69	20 (21.9)
70	5(5.7)
Race	
White	75 (83.3)
Black	7 (7.7)
Alaskan Native/ American Indian	5 (5.5)
Other	3 (3.3)
Sex	
Female	85 (94.4)
Educational Level	
High school	8 (8.8)
Some college/Bachelor's degree	55 (61.1)
Master's degree or higher	27 (30.0)
Marital status	
Currently married	59 (65.5)
Years since diagnosis	
5	41 (45.5)
>5	46 (51.1)