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## RESEARCH PAPER

# Social interactions in an online self-management program for rheumatoid arthritis

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**Objective:** To evaluate social interactions among individuals with rheumatoid arthritis (RA), participating in an empirically based, cognitive-behavioural, self-management (SM), and peer-support program, delivered in an online format.

**Methods:** Thirty individuals with RA were recruited online. Subjects were a subset of participants in the treatment arm of a waiting-list controlled study testing the effectiveness of a 10-week, online, SM education and peer support program. Primary outcomes were process variables describing social activity in the online environment during active treatment. Qualitative review of discussion board posts was undertaken to gain insight into participants' perceptions of social interactions.

**Results:** Participants spent a large proportion of logged-in time accessing educational materials and community-level activity was vibrant, with members utilizing the discussion board and e-mail. The Chat feature was less well-used. Discussion board posts regarding RAHelp were very positive, especially in regard to perceived supportiveness and bonding among participants, and a sense of feeling uniquely understood by others who have RA. Concern arose in response to periods in which the discussion board was 'too quiet.'

**Discussion:** Our work complements the emerging literature supporting acceptance and utility of Internet-based programming as a venue for SM education and social interaction among individuals with chronic illness.

**Keywords:** Arthritis, chronic illness, internet, self-management, social support.

## INTRODUCTION

Patients with chronic conditions must manage the day-to-day aspects of their disease activity, and enhancing patients' ability to do self-management (SM) is central to chronic

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illness care.<sup>1</sup> Social cognitive theory and specifically, Bandura's self-efficacy construct provide the theoretical framework underlying most formal SM programs.<sup>2</sup> Intervention techniques, which may be delivered in individual or group format, frequently include skill-building in problem-solving, goal-setting, self-monitoring, interpersonal effectiveness, and self-esteem building. These skills have been shown to enhance self-efficacy for disease management, emotional regulation, and general coping.<sup>3,4</sup> Group SM programs have been used effectively in a variety of chronic illness populations, such as rheumatoid arthritis (RA), osteoarthritis, HIV-AIDS, chronic back pain, and also in heterogeneous chronic disease groups.<sup>5-10</sup>

Enhancing social support, particularly among peers, is a core component of most chronic illness SM programs and there is evidence to suggest that social support is positively related to both health and chronic illness SM.<sup>11,12</sup> While group SM interventions traditionally are delivered in face-to-face format, an emerging literature indicates the feasibility of Internet-based SM programs.<sup>13-15</sup> Most Internet-based programs offer features to facilitate provider-participant and/or peer-to-peer social interaction, such as messaging, discussion forums and discussion boards; features which can be effective in increasing perceived support.<sup>16</sup> Qualitative studies of Internet support group communications reveal both a willingness to self-disclose, and similarity between supportive communications among group members in computer-mediated interactions and face-to-face interactions.<sup>17,18</sup>

Internet users frequently seek health information on the web and this appears to be especially true among Internet users with chronic conditions or disability.<sup>19</sup> Further, a majority of Internet users have at one time or another contacted an online group.<sup>20</sup> While Internet penetration has been slower among individuals from underserved populations, including ethnic minorities and the elderly,

there is evidence in the literature that these populations accept, use and benefit from online resources for chronic illness.<sup>14</sup>

In this report we share findings on social interaction in the context of an empirically based, online SM program, targeting natural Internet users with RA.<sup>21</sup> Our findings complement the limited existing literature base, suggesting that Internet venues can be used to create positive environments for social interaction and support among diverse populations of individuals with chronic illness.

## METHOD

This research was approved by and conducted under the auspices the Health Sciences Institutional Review Board of the University of Missouri (MU). Results presented here reflect secondary analyses of a subset of data from a larger, randomized, waiting-list controlled study, with target enrolment of 100 subjects, designed to evaluate the effects of participation in an online SM and peer support program (RAHelp).

RAHelp is a 10-week, online, SM program, with community resources available as part of the secure program environment. Participants in the treatment condition of the study completed one SM educational module each week, in the prescribed sequence. The program, which was adapted from a clinician-administered model described elsewhere, utilized an empirically based, cognitive-behavioural approach to encourage positive coping strategies for enhancing self-efficacy.<sup>5</sup>

RAHelp features for individualized use included the SM educational modules, a personalized 'To do' list, a news feature, a resource library, and a journal with tools for tracking ratings of pain and stress and text boxes for describing pleasant events and weekly challenges. The 'RAHelp Village' provided the community of participants with structured profiles of members,

but did not reveal participants' names or other identifying information. Features for community interaction included a discussion board with postings on a variety of RA-related topics; spontaneous and bi-weekly scheduled chats, and a secured messaging system. In addition to having unlimited access to these features, the SM educational modules directed participants to try each feature in the online environment. Activity was monitored by a trained clinician for appropriateness.

Outcome data collected from the parent study included self-report of pain, physical functioning and self-efficacy in managing RA. Pre-post analyses for the treatment group at three months ( $N=89$ ) indicate a significant and positive effect of the SM program and peer community on measures of self-efficacy for managing arthritis pain, function and 'other symptoms,' and on quality of life.<sup>21</sup> Additionally, analyses indicate significant and positive differences at post-treatment assessment for the treatment group, relative to the waiting-list control group, on measures of self-efficacy and quality of life.<sup>21</sup>

Participant self-referrals to the study were elicited via notices posted to online venues (e.g. arthritis-specific discussion groups, public Yahoo™ groups). In addition, Rheumatologists at MU clinics were informed of the study by letter and asked to provide interested patients with contact information. Volunteers contacted the study by phone or logged onto a secure website to register. Participants were consecutively enrolled, following telephone screening and verification of RA from their Rheumatologist.

The current study reports findings for a sample of 30 individuals, who were randomly assigned to the active treatment arm of the parent study. The primary outcomes of interest for this report were process variables describing social activity in the online environment, quantified as the average number of times each feature was accessed and the average length of time

participants engaged in interactive activities during active treatment.

*Post hoc* qualitative analysis of a set of discussion board posts also was undertaken to gain insight into participants' perceptions regarding social interactions within the RAHelp environment. A keyword search tool built into the discussion board feature was used to identify posts containing comments relating to RAHelp. We defined the time frame as starting with the initiation of treatment for our sample (10/30/2005) and extending to the present (06/20/2008); allowing for capture of all comments made by our sample regarding RAHelp.

A 'pearl growing' strategy was used to search for relevant posts.<sup>22</sup> Two members of the research team (CLS, KDH) reviewed random posts in order to generate an initial list of search terms or 'pearls.' This list of terms was searched and returns were culled for posts, or segments of posts, that were made by members of our sample and that referred to RAHelp in some way. Four members of the research team (CLS, KDH, KLS, YG) coded the data individually and assisted in identifying additional search terms. The search process was repeated until emerging themes stabilized and evaluation posts became exhaustive. Search terms included: *advice, answers, asking, belong, benefit, calls, community, confidence, control, feedback, friend, group, happy, help, hesitant, hesitate, information, learn, living/life, love, lurk/-er, post, questions, RAHelp, research, resources, safe, share, special, suggestion/s, support/-ive, tips, tricks, website, welcome, wrong, understand, and unhappy*. Throughout the process, members from the larger team met to review the dataset and develop validity and consistency of the coding scheme. Discussion and debate were used to develop consensus and confidence regarding the emerging themes.

Notably, the majority of posts focused on issues relevant to members, such as questions about medical treatment issues (e.g. medications, physicians, upcoming procedures), discussion of life events (e.g.

vacations, holidays, personal problems), or providing support to individuals. Some individuals commented spontaneously on RAHelp, but many posts referring to RAHelp occurred in response to 'Welcome' messages; in which the leaders introduced a new member from the waiting list control group to the existing community (marked with '\*' below). It was recognized that these circumstances likely 'pulled' for positive comments, and likely increased the frequency with which positive comments were made. Additionally, participants were aware that the discussion board was monitored. Given these factors, special effort was made to search for and identify posts containing negative comments. We identified 32 posts, made by eight participants providing critical commentary, suggesting that individuals were comfortable expressing concerns.

## RESULTS

Descriptive statistics for the sample can be seen in Table 1. The sample was predominantly female, with broad socioeconomic and employment representation. During the course of the 10-week treatment phase, members logged-in a median of 32 times, with a mean of 23 min per login. Use of community-level features during this interval can be seen in Table 2.

Not all members accessed the Chat feature and there was considerable variability in time spent participating in these scheduled events (range = 5–55 min). A complicating issue for the Chat feature was the broad geographical spread of members. Many were several time zones apart and it was difficult

to set up chat times that were convenient for everyone.

One hundred forty-one unique discussion board posts were identified for qualitative review. All qualifying posts were made by women, who were between the ages of 35 and 66, and almost half of sample participants made at least one qualifying post ( $n = 13$ ). Comments regarding RAHelp were overwhelmingly positive. Approximately half of the comments deemed to be 'positive' in nature (56 of 114) were made spontaneously, while the rest were made in the context of 'Welcome' messages. The primary theme identified was a very positive perception of the RAHelp community. Nine participants (32 posts) expressed appreciation for 'perceived support' from the community, which was expressed as positive interpersonal qualities such as friendliness and helpfulness, and through activities such as providing information and advice.

*... We have lots to share and LOTS of combined wisdom!... Don't be afraid to ask as we are truly the experts and if we don't know something, we certainly know where to look. This is the best help that I have had in managing my disease and it is my hope that you will find it to be the same for you!... (#4–55 years)\**

*I sure hope you find good benefit from the discussion, as I know I have. Share your thoughts, concerns, ask*

TABLE 2. Member–member communications using online community features ( $n = 30$ )

Feature	Median times accessed	Median total time (min)
Discussion board	150	150
Messaging	77	40
Chat ( $n = 26$ )	12	21

TABLE 1. Descriptive statistics for the study sample ( $n = 30$ )

Age (mean/range)	49.4/(30.1–68.5)
Female	28 (93%)
Married	19 (63%)
Educational level (years; mean/range)	15/12–20
Family income (median/range)	>\$50,000–75,000/(<15,000–\$75,000+)
RA duration (years; median/range)	4.79/(0.5–38)

questions – and this group gives great feedback, suggestions, answers. (#6–39 years)\*

\*Marked quotes were made in the context of messages welcoming new members.

Participants (6 individuals, 21 posts) also expressed appreciation for positive relational aspects of the community (e.g. acceptance, being personal, belonging, feeling part of, and other expressions of perceived intimacy); suggesting a theme of ‘bonding’ within the community.

*This is a wonderful place for all of us to share the things we have in common – the biggest one of course is RA and the many parts of our lives that this affects. This is the best place to bring your “stuff” and to make you feel part of something that is helping in controlling this disease. It has been the best help available in all ways and I hope that you come to share these feelings. (#4–55 years)\**

*... your enthusiasm is contagious. I love coming here and seeing you! (#5–62 years)*

An important bonding feature was the perception that people who did not have RA had difficulty understanding what participants were going through. Seven participants (15 posts) voiced appreciation for the RAHelp community as a place where they experienced validation and their problems were understood.

*The communication between the membership has been a true blessing. Since I did not know anyone else with RA, I didn’t know if what I was going through was ‘normal’ for the illness or if I was developing other problems. It is wonderful to ask questions to others about pain, drugs, doctors, fatigue and coping. (#3–60 years)\**

*Building a support system is hard even in the best of situations, for even among those we CAN rely on, they often really don’t understand what we are going through. (#5–62 years)*

*I’m almost done (with the sessions) too, but I intend to stick around with you-all. I agree that it’s good to “talk” to the people who really understand how you’re feeling. (#12–35 years)*

\*Marked quotes were made in the context of messages welcoming new members.

Participants gave general praise regarding the weekly lessons (4 individuals, 8 posts) and some identified specific lessons or

concepts learned that had been meaningful or beneficial to them (6 individuals, 12 posts). Posts also indicated a perception of the community as being a good place to find useful resources (5 individuals, 8 posts).

Relatively few posts contained negative comments about technical aspects of the website. Most notably, four participants (7 posts) complained about being ‘timed out’ and losing their work before being able to post it. More relevant to the ‘community’, four participants (15 posts) expressed concern or dissatisfaction when the discussion forum became ‘too quiet’. Comments were sometimes placed in the context of how much more active the board had been earlier in the study. These posts frequently encouraged previously active members to reconnect, and ‘lurkers’ to become active.

*There are 35 members that are in this currently and we only hear from five or six of them and the rest seem to be on the side lines. I would like to invite all of you to come join us in our discussions, to post some questions or concerns and for us all to learn and support each other. (#8–37 years)*

*Hope to hear more from you and of course anyone else who is “out there” in the shadows. I want to say that I am pleased that all of you are there even if you are quiet. (#19–60 years)*

Relatedly, four members made posts indicating difficulty finding time to be as active in RAHelp as they would like. This included one member who had previously made eight posts expressing dissatisfaction with discussion board activity level. Thus, while participants expressed a high level of satisfaction with RAHelp community and content overall, the momentum of community activity may have declined over time.

## DISCUSSION

Previous demonstration projects have indicated the acceptance of online SM education and peer support among consumers with chronic conditions. Our results complement these findings by demonstrating that

individuals with RA, who were recruited online for participation in online SM training, engaged actively in both the educational and social aspects of the program. Content from our discussion board specifically pertaining to RAHelp suggests that participants appreciated not only the skills training offered, but also the support, bonding, and understanding among the group.

Among trials of Internet-based SM programs, some have been designed primarily to enhance support and communications with healthcare providers.<sup>23,24</sup> Others, including CHES, Diabetes Network (D-Net), and Schizophrenia Guide, have combined peer group support features with core educational material and resources.<sup>13,14,25</sup> Among both types of programs, positive outcomes have been documented for health indicators (e.g. improved blood pressure and hemoglobin A1C levels), and subjective reports (e.g. perceived stress, social support, and quality of life).<sup>13-16,24</sup>

Unfortunately significant resources have been required to initiate and maintain these early programs. In addition to receiving hardware, software and installation, participants from most of the major randomized trials received individualized training to use their computer systems and the Internet. Problems have been documented, especially among older, novice Internet users, including difficulty using the mouse and keyboard, navigating menus, and understanding of graphical objects (e.g. links and buttons).<sup>23</sup> While valuable lessons have been learned from these projects, the burdens and complications associated with creating unnatural samples of computer-users limits their feasibility for widespread implementation.

Lorig and colleagues have adapted their peer-led, Chronic Disease SM program model to an online format and as in our study, targeted natural Internet users.<sup>15</sup> These works are strengthened by recruitment of individuals with ready access and natural inclination toward Internet use; consumers who would be likely to utilize online clinical services, and who more

likely represent healthcare consumers of the near-future. Gross measures of program activity among our participants were roughly equivalent to Lorig and colleagues, whose participants averaged 26.5 logins over 6 week intervention. McKay and colleagues noted a high level of variability among participants for engagement in community activities.<sup>25</sup> In our study, the asynchronous bulletin board was much more widely used than the synchronous Chat feature. This may indicate that time flexibility is a valuable asset for Internet-based service users and scheduled features may be of interest to a narrower, subset of users.

Barrera and colleagues note that the ability to demonstrate manipulations of social support via online interventions represents an important step in studying health-related changes mediated by changes in social support.<sup>16</sup> Theoretical commentary by Wright and Bell suggests that online participants may especially value support that provides diversity of perspectives which, by virtue of its broad reach, may be garnered online more easily than through local or family sources of support.<sup>26</sup> Our experience provides a complementary view as we have participant representation ranging from factory and construction workers, homemakers and retirees, to health care professionals, IT professionals, educators, brokers, administrators, and executives. Gustafson and colleagues have observed that in comparison to face-to-face encounters, computer-based communications tend to be more 'color-blind,' and that underserved and affluent people interact with each other quite well in an anonymous environment.<sup>14</sup> Discussion board posts from our study reveal that some of our parent study participants have never met another individual with RA, and were glad to be in the company of others who share their experience.

There is much to do in furthering our understanding of integrating Internet-based services with basic clinical care. To date, two general categories of Internet-based SM program models have been studied,

each with strengths and shortcomings. The first has targeted local participants, offering potential for augmenting usual clinical services. A shortcoming associated with these studies however, stems from limited computer access and experience among this relatively small pool of participants. The burden of costs associated with providing hardware, software, and training for participants limits the feasibility and sustainability of programs in real-world settings.

The second model, which is evidenced by the current study and the work of Lorig and colleagues, are SM programs, which have targeted natural computer/Internet users across broad geographical areas.<sup>15</sup> Because of the breadth of reach in these studies, however, integration of Internet-based services with usual care is virtually impossible. Penetration of computer and Internet access is increasing rapidly and future research should focus on merging the strengths of these approaches. A majority of Americans with Internet access already look online for health-related information and support. Thus, need for Internet-based services in clinical settings is a quickly emerging reality. Such services are especially relevant for individuals with low-frequency chronic conditions such as RA, who frequently must manage self-care without support from local peers.

Finally, future research should investigate the effectiveness of online venues for maintaining SM skills and self-efficacy gains, over time, for individuals with chronic conditions. Our results suggest that participants perceived a decline in message board posts over time. While online social support may be less burdensome, there is little research to support the premise that online maintenance can more effectively support long-term behaviour change than face-to-face formats.

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