Original Paper

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Using social media to elicit support for arthritis-related health issues

Abstract

Background: People with arthritis are increasingly seeking support online, particularly for information about social role participation while experiencing symptoms of chronic arthritis. Social media enables support to be provided peer-to-peer on how hobbies and leisure activities can be adapted to allow participation. Research is needed to understand what type of peer support is provided online and how this support occurs.

Aim: To describe how people support one another while experiencing arthritis-related issues that affect their ability to complete craft activities.

Method: Three vignettes were posted in a Facebook quilting group regarding arthritis-related symptoms or impairments that affect how people quilt. Facebook analytics were used to examine the groups’ demographics and responses were analysed thematically.

Results: Members of the quilting Facebook group were mostly women (99.45%), aged 55 to 64 years and were located in the United States of America. As evident through the vignettes, participants predominantly offered emotional support and shared information. Participants shared their real-life experiences and creative means in adapting medical best practice to their crafting. More than half (55.6%) of the advice that was offered aligned with the OrthoInfo medical best practice guidelines relevant to the vignettes.

Conclusions: Hobby-related social media groups can be important forums for facilitating emotional support and sharing information for arthritis-related issues. Health providers could support their patient’s recovery and lifestyles by stimulating and manoeuvring peer-to-peer conversations on similar hobby-related social media sites to ensure that shared advice aligns with medical best practice. Future research could explore the extent to which support provided online has the ability to adapt offline behaviours.

Keywords

Arthritis; chronic illness; social media; Facebook; support; Internet
Introduction

Arthritis and painful musculoskeletal conditions affect 13-28% of people and are a leading cause of disability [1]. Arthritis often occurs in a person’s productive age range in adulthood and affects function and participation potentially with large direct and indirect costs [2, 3]. This burden is projected to increase with ageing populations [1].

Social media sites provide an opportunity for people with specific health conditions to elicit support and advice in adapting their activities to accommodate their condition. Social learning theory explains how people learn from others on social media, e.g. through modeling, whereby users share experiences and practices that produce desired outcomes that others observe and imitate [4]. Support seeking via social media may provide validation of illness, increasing knowledge, health literacy, empowerment, and hope, community building, and learning behaviours from shared experiences, which may in turn promote self-management of chronic conditions and improve quality of life [5-8]. Social media use can support self-management of arthritis by facilitating medical, role, and emotional management through skill development, such as self-tailoring, problem solving, resource utilisation, action planning and decision-making [9]. Social media transcends geographical boundaries and physical limitations for people with physical or mobility impairments and can provide support at any time of day [10]. Consequently, social media pages set up for people with arthritis offer practical and emotional support on individualised peer-to-peer and online community-based levels any time, any place.

Research about social media sites for people with arthritis and painful musculoskeletal conditions examines both patient-initiated sites (e.g. closed Facebook groups) and provider-initiated online support groups and forums. On these sites support or advice offered can be broadly categorised into psychosocial support, information sharing, and adaptation and management. People elicit support by sharing written personal experiences or stories; lived experience of a disease brings expertise in health literacy related to the condition [7, 11]. Social media users tend to seek or give support, ask for information on specific issues, and share information online [12].

Previously identified forms of online psychosocial support have included validation, emotional support and social support [13-16]. Validation has been explained as ‘illness-associated identity work’ whereby replies of solidarity encourage the sharing of illness stories and acknowledge and validate an illness, which ultimately may offer emotional relief [14]. Emotional support is characterized broadly and includes catharsis (or the ability to rant or express primarily negative emotions), acceptance, amusement, bonding and a sense of belonging [10, 13, 15-17]. Social support is seen in new friendships, in both online and offline relationships [10, 13, 14, 16, 17].

Support for people with arthritis can occur online via information sharing. This is often experiential - information shared online is based on ‘real’ understandings of living with the condition [13, 16-18].
Van Uden-Kraan et al. reported that lay language was used rather than technical medical language [16]. The information and resources shared online can be categorized into condition-specific information (e.g. medication and side effects), research findings, and how to interact with health systems (e.g. what to talk to doctors about) [10, 13, 18, 19]. Other information requested and shared included advice on benefits, employment, additional resources and impact on specific aspects of life such as pregnancy or personal finances [10, 16].

Researchers have identified that people elicit online support on adapting daily life and related activities to a condition. This advice was experiential in nature and included pain management, medication changes, fatigue, sleep problems, bodily changes, adapting in situations, coping with the unpredictable nature of a condition, diet-related issues, and restrictions in daily life and exercise [14, 16-19]. Whilst this was generally related to the medical condition itself, Mendelson identified other forms of advice that fell under this category including dealing with others’ reactions, and the continuity of life and events despite diagnosis [17].

Using social media for support and advice has limitations, including the sharing of inappropriate or inaccurate information [10, 16, 18] or being confronted by the negative aspect of a disease, such as members passing away or observing how a condition may progress [16, 18]. Seeking support online may lead to alienation, as users may seek support online rather than from their family or friends [13]. Provider-initiated online resources may provide informational support but fail to cultivate peer-to-peer communication and support [12].

Research using social media ‘reference’ groups has shown a dominance of female participants, which may limit generalisability [7, 12]. The ethical processes in gaining informed consent and protecting privacy on the Internet are debated and remain undefined [20, 21] leading to methodological limitations such as aggregating data to protect individual privacy or identity resulting in lost richness of data [17]. An alternative approach requires researchers and participants to engage in dialogic agreements, which may ultimately impinge on privacy [22].

Social media sites may be useful for psychosocial support, information sharing and promotion of self-management for musculoskeletal conditions. Research has primarily examined social media sites that focus on health conditions, rather than the conversational nature of the interactions and types of support elicited opportunistically amongst members in online groups unrelated to health. Research is needed to understand how people with shared life interests offer support regarding health conditions via social media pages unrelated to health conditions. Thus, our research asks how people support one another while experiencing arthritis-related issues that affect their ability to work on their craft in hobby-related crafting groups on Facebook.
Methods

Study setting
A quilting Facebook group was chosen as the research site because older women are predominantly affected by arthritis, quilters are often older women and increasingly use Facebook groups for quilting advice [1, 23]. The Quilting in America 2017 survey estimates there are 7 to 10 million quilters in the United States, most are female, have a mean age of 63 years, and are educated (70% attended college/university) and affluent [23]. Compared with the 2014 survey, time spent online in quilting-related sites has increased from 2.5 to 7.9 hours weekly and Facebook users from 14% to 50% [23]. Textile art has been shown to enhance wellbeing and quality of life and can have therapeutic benefits [24, 25]. Given the widespread engagement with quilting-related social media sites and possible health benefits, a quilting Facebook group is appropriate for this research.

The chosen quilting Facebook group was private, international and had 18,478 members at commencement of data collection. The group was chosen as members had previously posted relevant threads, supporting one another with arthritis-related conditions affecting their ability to work on their craft.

Ethics
The University of Auckland Human Participants Ethics Committee approved this study on 12 September 2017 (reference 019783). The administrator of the Facebook group signed a consent form on behalf of the group’s members after consulting with the group. Group members were informed that they could participate in the research by responding to scenarios. An explanation was provided with each post informing members that responses were being collected for research. A link to a summary of the study and full participant information sheets was also included in each post [26]. One researcher was a member of the group (KD) and collected the data, which was sent to the other researchers for analysis and reflection (NG and RG). The discussion threads have been deleted to ensure privacy of the participants, as quotes used in this paper could lead to identification of research participants by new or existing members of the Facebook group.

Data Collection
Three vignettes (case scenarios) were posted as threads in the Facebook group, which members responded to (Figure 1). Vignettes were appropriate as they enable sensitive qualitative data collection and are an effective tool for eliciting judgements and perceptions [27]. The vignettes alluded to arthritis-related issues that affect how people quilt, and included a person undergoing knee joint arthroplasty (replacement) for knee osteoarthritis, a person with hand pain from hand osteoarthritis and a person with chronic non-specific lower back pain (Figure 1).
Figure 1. Screen-shot of the vignettes as posted in the quilting group

The vignettes were developed by a nurse (KD) and rheumatologist (RG). After no responses to the first vignette, it was removed, shortened, simplified and re-posted, which encouraged discussion. Vignettes were left on the Facebook page (30 November, 9 & 19 December 2017) for approximately one week, until no new responses were made. KD posted a summary of each discussion a week after the initial post to allow for further commentary or correction, which did not occur.

**Data Analysis**

Before the vignettes were posted, the Facebook group’s administrator extracted demographic data from the group using the ‘Page Insights’ function. The resulting Excel spreadsheet was sent to the researchers for quantitative analysis of demographic characteristics, including summary statistics of age and gender. A map of the distribution of group members internationally (Figure 2) was created using ArcGIS [28].

Responses to each thread were screenshot, cut and pasted and then transcribed onto a MS Word document for analysis and reflection using Williams’ reflective diary guide [29], (see Textbox 1). The discussion threads and reflections were analysed thematically. This consisted of coding the qualitative data and identifying themes that maintain the richness of the data and accurately represent and explain the phenomena [30]. Interactions between themes were examined and their relevance to the research aim was explained. All of the researchers reflected on the data and made comments on the analysis.
Textbox 1. Reflection tool questions, adapted from Williams (2001) [29]

At the end of the period covered by each vignette note down and reflect on:
1. The most interesting issue.
2. What worked well (e.g. significant achievements).
3. What did not work well?
4. The most puzzling or confusing issue.
5. The most unexpected issue.
6. Any risks and threats to the project.
7. Any opportunities for the project.
8. Any implications for the principles and purpose underpinning the project.
9. Differences between the plan and the action.
10. What was noticed but not addressed? Why? Would addressing that have improved the outcome?
11. Any other comments or observations.

The discussion thread data was compared with medical ‘best practice’ for each vignette using the following steps.

1. The peer advice from the posted comments was coded (e.g. exercise or medication use) and grouped by codes in a table.
2. Information for patients about recommended management and self-care from OrthoInfo [31] was summarised by RG (a rheumatologist) in MS Word. OrthoInfo is a website for lay people, developed and reviewed by members of the American Academy of Orthopaedic Surgeons, and provides evidence-based information about treatment of, and self-care for, musculoskeletal conditions [31].
3. The ‘self-care’ management options (i.e. recommendations that could be implemented by an individual) recommended by OrthoInfo were identified from the summary.
4. Coded peer advice that was congruent with self-care recommendations from OrthoInfo were matched in Table 2.
5. Summary statistics about frequency of peer advice congruent (or not) with OrthoInfo recommendations were prepared.

Results

Group Demographics and Participation
The Facebook group had 18,478 members when the first vignette was posted. Facebook Page insights showed the country with the most members was the United States of America, followed by Canada, the United Kingdom and Australia. Members were spread all over the world, with high numbers in India, China, Europe, South Africa, Nigeria and lowest density of members in South America, China, Europe and parts of Africa (Figure 2).
Figure 2. Location of quilting closed Facebook group members around the world.

Most of the quilting Facebook group members identified as female (18376/18478, 99.45%) (Fig. 3) with a very small proportion identifying as male (92/18478, 0.5%) or custom (10/18478, 0.05%) (Fig. 4). The biggest proportion of female members (35%) was 55-64 years and for male members (21.57%) was 45-54 years. Those with custom genders were distributed more evenly across the age categories. None of the members who identified as male or custom were in the youngest age group, 13-17 years.

Figure 3. Number of female members by age in quilting closed Facebook group.
A total of 22 people participated in the study by commenting or replying to comments in the vignettes (Table 1). There were 38 contributions (comments and replies) in total across the vignette discussions, with 27/38 (71%) original comments and 11/38 replies to comments (29%). Participation was similar in all three case scenarios (Vignette 1 n= 12, Vignettes 2 and 3 n=13 each). Participants contributed an average of 1.7 times each.

Table 1. Comments and replies for each vignette.

<table>
<thead>
<tr>
<th>Vignettes</th>
<th>Number of participants</th>
<th>Number of comments</th>
<th>Number of replies</th>
<th>Mean number of contributions per participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>8</td>
<td>8</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>Two</td>
<td>5</td>
<td>8</td>
<td>5</td>
<td>2.6</td>
</tr>
<tr>
<td>Three</td>
<td>11</td>
<td>11</td>
<td>2</td>
<td>1.18</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>27</td>
<td>11</td>
<td>1.7</td>
</tr>
</tbody>
</table>

**Emerging Themes**

**Emotional Support**

Members offered emotional support in Vignette 1 (V1) and Vignette 2 (V2) through encouragement and reassurance. Members responding in V1 made encouraging comments such as wishing the
hypothetical person good luck for their knee replacement surgery. Some members also encouraged the hypothetical person to do their therapy by emphasizing that this was crucial to good recovery. One member justified that she gave advice to encourage the hypothetical person to continue quilting. She later reinforced the value of offering support.

“I hope this advice encourages your “pretend” person to continue quilting…. My pleasure if it helps someone else.”

Reassuring comments in V1 supported the decision for having a knee replacement surgery and emphasized that recovery is only temporary and short-term. Some members referenced activities that they were able to do again within a short time frame post-surgery.

“Was back at sewing machine for short periods 3 weeks post op.”

Comments that encouraged positive mindset were made in response to V1. These related to participants staying positive and hopeful throughout recovery and reassured that they were content during this time.

“Keep cheerful, and remember you’ll soon be able to continue normal activities… look forward to quilt shows for more ideas for even more quilts to make.”

Information Sharing
Participants shared a range of information on arthritis-related topics. Advice offered in V1 (knee replacement) was specific to recovery, whilst that given in V2 (hand arthritis) and Vignette 3 (V3) (back pain) were related to everyday life with arthritis. This included medical information, adapting quilting to their condition and using assistive tools. Experience was mentioned to support a recommendation or to acknowledge a lack of knowledge. Those who had lived experience provided more in-depth and personal information and also provided external links to information.

Medical information across the cases included additional treatments such as massage, exercises such as yoga or Pilates, applique quilting, dance, correct posture, pain and symptom management through the use of arthritis gloves, anti-inflammatory gel, heated massage pillows, and resting. Some recommendations, such as this advice from V3, were couched in humour:

“Get up and boogie. LoL. Or limbering yoga moves.”

Members commenting in V1 emphasized the importance of trusting medical professionals and following instructions. They specifically recommended following medical instructions, asking questions and attending physiotherapist appointments.

“I fully followed all medical instructions, and had asked enough questions to know what to expect.”
Members commenting in V1 also valued preparation as they assumed that exercise would be detrimental following a knee replacement surgery. They suggested resting, recovering and staying off the stairs. As some of their craft rooms were downstairs they recommended being prepared with kits, handwork and smaller quilts to work on. They also suggested having someone retrieve their gear when necessary.

“If I needed something from my craft area I got someone else to fetch it for me until I was allowed on the stairs again. I suppose the best advice I could give would be to resolve yourself to limited activity for a short period of time and plan toward that end.”

Members’ comments in all three cases emphasized the importance of taking breaks. Whilst comments in V1 referred to prioritizing recovery, those in V2 related to resting during flare ups until they passed, and taking breaks to stretch hands. Comments by members in V3 acknowledged that they were unable to quilt on some days due to back pain and would watch people quilt instead.

“Choose your battles. Some days I can deal with it and some days I can’t. When I can’t, I watch other people sew on YouTube :D”

Responses to V3 also revealed the importance of posture to minimize back pain. Interestingly, members suggested applying good office ergonomics to their quilting environments. This included correct posture by using back braces or pillows to sit straight and adjusting their chairs. One member suggested tilting the sewing machine forward to alleviate stress on the back, shoulders and neck. Another transferred posture advice from their employer to their sewing.

“I worked at a fortune 500 company and posture is critical working at a station all day working on a computer. Along w/your breaks, make sure you have good posture at your sewing station. Sit up straight and make sure your chair adjusts for good posture.”

The use of assistive and labour-saving tools were recommended in V2, as hands often felt weak, tired or sore. Participants suggested using branded spring-loaded scissors, ergonomic rotary cutters, and suction cups to hold down rulers. Members provided an external link to purchase the spring-loaded scissors.

“Absolutely get spring-loaded scissors. I also use the smaller spring-loaded nippers for handwork/quilting- so much easier than regular scissors. The blades on the nippers are so pointy that I can use them to rip stitches out which is much easier on my hands.”
Experience with arthritis or lack thereof was often referred to, either to reinforce or endorse information or to display a lack of certainty about advice. Some members shared their personal lived experiences and implied that their advice was more credible due to their experience with arthritis. Members with lived experience also endorsed other’s advice.

“I had knee replacement 1 year ago yesterday. I agree with the ladies above me.”

Conversely, some people without arthritis or those who had not tried a treatment or tool acknowledged their lack of experience. For example, one member suggested trying arthritis gloves but then acknowledged that she has no lived experience with them, assuming that: “I’m not much help.”

Medical Guideline Alignment

Of all of the self-care advice offered, just over half (30/54, 55.6%) aligned with the OrthoInfo recommendations for knee replacement surgery (V1 - 15/22, 68.18%), hand arthritis (V2 - 2/9, 22.22%) and back pain (V3 - 13/23, 56.52%) (Table 2).

Table 2. Alignment between best practice and advice given.

<table>
<thead>
<tr>
<th>Best Practice</th>
<th>Times mentioned</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case One</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Knee Replacement</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Modify home/environment</td>
<td>9</td>
<td>40.9</td>
</tr>
<tr>
<td>Wound care, balanced diet</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Resume normal activities</td>
<td>1</td>
<td>4.55</td>
</tr>
<tr>
<td>Exercise programme</td>
<td>5</td>
<td>22.7</td>
</tr>
<tr>
<td>Use gait aid until advised to discontinue,</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>graduated walking programme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other advice</td>
<td>7</td>
<td>31.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>22</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Case Two</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hand Arthritis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>1</td>
<td>11.11</td>
</tr>
<tr>
<td>Splinting</td>
<td>1</td>
<td>11.11</td>
</tr>
<tr>
<td>Other advice</td>
<td>7</td>
<td>77.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>9</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Case Three</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Back Pain</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Count</td>
<td>Weight (mode)</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------</td>
<td>---------------</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>3</td>
<td>13.0</td>
</tr>
<tr>
<td>Braces</td>
<td>2</td>
<td>8.70</td>
</tr>
<tr>
<td>Yoga/pilates</td>
<td>3</td>
<td>13.0</td>
</tr>
<tr>
<td>Aerobic exercise</td>
<td>1</td>
<td>4.35</td>
</tr>
<tr>
<td>Healthy weight, avoid smoking, chiropractic, care with lifting</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Good posture</td>
<td>4</td>
<td>17.3</td>
</tr>
<tr>
<td>Other advice</td>
<td>10</td>
<td>43.4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>23</strong></td>
<td></td>
</tr>
</tbody>
</table>

As suggested by the advice that aligned with the medical guideline, participants appeared to adapt their environments and craft to accommodate the best practice guidelines. Most of the information that did not align was valuable but was too diverse and quilting-specific. This was particularly evident in V1, where four comments referred to resting after a knee replacement surgery whereas the guideline suggests resuming normal activity. Two other comments included advice on pain management.

In regard to quilting-specific advice, the guideline did not mention assistive tools for hand arthritis, yet in V2 most of the comments consisted of suggestions for adapting their quilting environment through the use of tools such as suction cups to hold rulers down or spring-loaded scissors. Other comments included resting and keeping fingers active.

Comments that did not align in V3 were diverse. These included varying positions, wearing supportive shoes, finding a comfortable chair or one that is on wheels, taking breaks and using an orthopedic pillow. A lack of commentary on the best practice recommendation of ‘care with lifting’ in V3 may have been explained by members having craft rooms dedicated to their quilting or assuming that others have craft rooms. These bespoke craft rooms may alleviate the need to carry heavy equipment.

**Discussion**

This study gave insights on how people elicit support for arthritis-related health conditions on social media sites unrelated to health, namely hobby groups. The study also contributed to literature on Internet research.
Principal Results and Comparison with Prior Work

Participation Patterns

Patterns in participation by demographics were consistent with previous research and the profile of the average quilter. Similar to prior research, female members dominated the quilting Facebook group [7, 12]. This may be because women are more likely to seek health-related information online and to engage with social media sites for health reasons [32-34]. Likewise, those who are affluent and have college degrees are more likely to seek health-related information online [32], with older people increasingly engaging with the Internet [34, 35]. Interestingly, these characteristics are consistent with the profile of the average quilter in the United States [23] and could explain the dominance of older women in the Facebook group.

Low participation rates were also notable, as only 22 people or 0.12% (22/18,478) of the Facebook group members participated in the study. A combination of factors may explain the low participation rates. Members may have not seen the relevance of the research to quilting or felt it was not the right place to conduct the research. Likewise, as explained in prior research, some members may have not wanted to be confronted with the reality and negative aspects of their condition [16] so could have ignored the vignettes. Due to the international nature of the group, members may have differing activity times as dependent on their time zones. Members in countries with different time zones to the United-States based administrator could have therefore missed the vignettes entirely. Likewise, other photos or comments may have obscured the vignettes, which were not pinned (prioritized). Additionally, given that 13-28% of people are affected by arthritis [1], only 2,340 to 5,040 of the group’s members may have had experience with arthritis and felt knowledgeable enough to participate.

Emotional Support

Participants offered emotional support through reassuring and encouraging comments. Some participants justified their contributions by acknowledging that their encouragement is valuable and could ultimately benefit others. This is interesting as previous research shows that the act of offering others support online can act as a vehicle for emotional support, as self-worth for example is enhanced by helping others [18]. Members indicated that recovery after knee replacement surgery is short-term and encouraged maintaining a positive mindset. This exemplifies a form of advice that Mendelson [17] identified regarding continuity of life and events (despite diagnosis). Emotional support, and more specifically, advice on continuity of life is extremely beneficial, as anxiety and depression are prevalent in rheumatoid arthritis cases [36]. It appears that acts of providing and receiving emotional support are invaluable to people with arthritis.
Information Sharing and Medical Guideline Alignment

About half of the advice offered aligned with medical best practice for self-care and half was noncompliant. Advice that conflicted best practice recommendations appeared to be laden with assumptions, e.g. avoiding stairs after knee replacement surgery was the right thing to do, although guidelines recommend continuing normal activities and exercising [31]. Research shows that noncompliance for physiotherapy and physical exercise programmes is common, and may be as high as 70% [37, 38]. Various explanations have been offered for non-compliance, including that highly educated people are less compliant and those with more severe, painful and disabling conditions are more compliant [37, 38]. However, people who assume exercising would not help or experienced barriers to exercising such as pain were less compliant in doing so [37, 38]. Health providers should be aware of assumptions that can create barriers to compliance, especially in regard to physical exercise.

These assumptions highlight the need for safety concerns. From a medical perspective information shared online can be inaccurate, inappropriate and misinformed [10, 16, 18]. The non-specificity of the comments meant that they were open to interpretation by other members and did not consider potential safety impacts. For example, recommendations to tilt the sewing machine may have been creative or helpful but there was no conversation about the possibility of the machine falling onto the user’s lap, or manufacturer development of an ergonomically tilted machine. People have the opportunity to become more informed and empowered with access to health-related information online, but they also are at risk from the consequences of incorrect information due to the volume of shared advice, or the inability to discern good from bad advice [39]. With an increase of some age groups using social media for health-related information [34, 35] health professionals should be prepared to assist their patients in discerning the quality of information available online [39, 40].

Some of the advice that did not align and carried minimal safety risk was still valuable. This was exemplified in the suggestion for using assistive tools, which was not explicitly included in the OrthoInfo guideline [31]. The advice is still useful. Best practice guidelines differ, as evidenced in other guidelines recommending the use of joint protection techniques and assistive tools for the non-pharmaceutical management of hand osteoarthritis [41]. Whilst some advice with minimal safety risk is useful, it is important to recognise that the advice offered online might raise safety concerns, as advice is open to interpretation and implementation by those who read it.

**Limitations**

The results of our research may not be generalisable to other social media sites and the wider population that are affected by arthritis. This is because the study had a low participation rate and only female members in the Facebook group responded to the vignettes. However, the consistency of
findings with previous research suggests that findings may be transferable to similar contexts and Facebook groups, such as those on other textile or craft-related hobby groups.

Another limitation is social desirability bias, as data was collected over the course of a week, so participants may have had time to alter their comments to be perceived as more helpful, polite, informed, or as they believe is expected by the researchers. Furthermore, as participants were responding to hypothetical scenarios, it is impossible to determine any behavioral changes that may have occurred from the advice shared or the impact and value of the advice to the participants.

Conclusions

This study suggests that hobby-related social media groups can be important forums for facilitating emotional support and sharing information for arthritis-related issues. The Facebook group members had a mutual interest (quilting) and elicited advice on how to adapt their hobbies and lifestyles to their condition, to continue to live life as normally as possible. Participants shared their real-life experiences and creative means in adapting medical best practice to their crafting. Arthritis health providers could draw on this advice to further encourage and support their patients’ recovery and active lifestyles. They could also stimulate, support and manoeuvre peer-to-peer conversations on similar hobby-related social media sites that may be popularly engaged with by their patients, to ensure that accurate information that aligns with medical best practice is shared.

The present study has contributed to filling a gap in literature on how support is elicited in online sites unrelated to health conditions, namely hobby groups. Future research should continue to contribute to this gap. Specifically, Internet research could ensure that posts are pinned to increase participation and engagement. Research could explore whether providing support online has the ability to adapt offline behaviours. Furthermore, researchers should continue to partner with community members to conduct Internet research, as these members are not only stakeholders in the research but also experts in navigating the online world and in facilitating discussions within their communities.

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Author Contributions

KD and RG contributed to the study design and data collection. All authors contributed to the data analysis and interpretation. NG drafted the manuscript, which RG and KD edited and reviewed. All authors read, reviewed and approved the final manuscript.
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