



# The Importance of Online Community Support Groups in Infertility Populations: A Clinical Research Update

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## STRESS AND UNCERTAINTY IN FERTILITY

Infertility can be a devastating experience for couples. The physical, financial and emotional stress of infertility treatments may impact quality of life. Infertility treatment is comparable to life stressors such as divorce, bereavement and chronic illness.<sup>9</sup> Individuals diagnosed or being treated for infertility often experience a sense of loneliness, isolation, lack of control, social stigma and shame.<sup>7</sup> Many couples undergoing fertility treatments must undergo uncomfortable and invasive procedures such as daily injections, blood/sperm samples and daily scans.<sup>11</sup> This is coupled with the uncertainty of the outcome of treatment and the large investment of time, energy, hope and money from couples.<sup>11</sup>

## HOW ONLINE INFERTILITY SUPPORT GROUPS CAN HELP

Support groups can be utilized to alleviate the burden of infertility by allowing couples and/or individuals with common experiences to come together and discuss many aspects of this condition.<sup>4</sup> In the field of reproductive medicine, the Internet has become a popular source for information and support.<sup>1</sup> However, patients have expressed the wish to communicate online with their health care professionals, who can convey reliable information.<sup>1</sup> The reason support groups can be valuable is because most patients assume that both the medical and psychosocial aspects of infertility will be addressed by medical staff, when often the psychosocial aspects are not.<sup>15</sup>

In a study conducted at McGill University in 2014, the authors identified that there was a major need expressed by couples to provide support groups that discuss the impact of infertility.<sup>14</sup> Most men (80.1%) and most women (89.8%) have expressed interest in online peer support groups among infertility patients.<sup>7</sup> The lack of familiarity with the treatment protocol was another major reason couples desired both emotional and physical support.<sup>14</sup> Not surprisingly, it has been shown that infertile couples who participate in an 8-week support group report less depression and psychological distress than couples who receive no support.<sup>16</sup> Providing appropriate psychosocial services is an important part of infertility treatment and Naturopathic Doctors are able to provide a comfortable and caring environment for these patients and support them on their fertility journey. In this clinical update, we will explore the power of online community health for infertility patients, as well as barriers involved in implementing such communities.

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**Table 1: Summary of Recent Publications**

| Author, Year, Study Type                                 | Methods  | Key Findings  |
|--|--|---|
| <p>Sormunen et al, 2020</p> <p>Cross-sectional Study</p> | <ul style="list-style-type: none"> <li>• 132 participants completed an online self-administered 23-item questionnaire.</li> <li>• 87% of participants found the questionnaire online through Facebook.</li> <li>• 97.7% of the responses were from females.</li> <li>• There was a mix of open-ended and closed-ended questions. Open-ended questions explored participants' experiences regarding: the role of social media, participating in social media and infertility.</li> </ul>  | <p>Several themes emerged in participants' responses of the effects of infertility: viewing their body as "defective" or worthless, lacking meaning in life, loss of joy, depression and anxiety, withdrawing from social life.</p> <p><b>Social Media Benefits:</b></p> <ul style="list-style-type: none"> <li>• Solidarity (between forum members).</li> <li>• Receiving and giving support.</li> <li>• Understanding infertility.</li> </ul> <p><b>Social Media Challenges:</b></p> <ul style="list-style-type: none"> <li>• Advice from others was not evidence-based.</li> <li>• Women were emotionally affected by negative treatment results or miscarriages from forum members.</li> </ul>  |
| <p>Aarts et al, 2015</p> <p>Qualitative Study</p>        | <ul style="list-style-type: none"> <li>• Health care professionals used blog messages to inform their patients about relevant news and updates.</li> <li>• The online community had 99 members (72 patients and 27 professionals).</li> <li>• The community had two separate discussion forums: one in which patients could share experiences and communicate with each other, another in which patients could ask the medical team questions.</li> <li>• Staff agreed that these questions had to be answered within 24 h by one of the medical team members. A f/t medical assistant was responsible for ensuring that the community was running as intended.</li> <li>• Only professionals of the fertility clinic and their patients were allowed access to the community.</li> </ul>  | <p><b>Patient Benefits:</b></p> <ul style="list-style-type: none"> <li>• Peer support.</li> <li>• Reliable information.</li> <li>• Opportunity to post questions and find answers outside of working hours.</li> </ul> <p><b>Staff Benefits:</b></p> <ul style="list-style-type: none"> <li>• Learning from each other's answers to patient questions.</li> <li>• More insight into patients' needs and wishes.</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Hierarchy between patients and physicians was disrupted.</li> <li>• All health care professionals felt the community was an additional task on top of their daily work.</li> <li>• Not enough medical providers participated and trying to increase participation was challenging.</li> </ul>   |
| <p>Aarts et al, 2013</p> <p>Cross-sectional Study</p>    | <p><b>A members-only online community was created for three fertility clinics and offered:</b></p> <ul style="list-style-type: none"> <li>• A blog post space where professionals could share relevant news with patients.</li> <li>• Two separate discussion forums: one for patients to share experiences and communicate with one another, the other for patients to pose questions to the medical team.</li> <li>• A media gallery for patients to access digital information on infertility-related topics.</li> <li>• In every clinic, a nurse or a medical assistant managed the online community.</li> <li>• 278 men and women participated in the study (almost 70% actively participated in the online community).</li> <li>• All participants received a questionnaire six months after the setup of the online infertility community.</li> </ul> | <ul style="list-style-type: none"> <li>• Women were more likely to subscribe than men.</li> <li>• IVF patients were more likely to subscribe than non-IVF patients.</li> <li>• The longer the patient's wish for a child, the more likely they were to subscribe.</li> <li>• Patients perceiving patient-related barriers (e.g. prefer face-to-face interactions) were less willing to subscribe.</li> <li>• Patients perceiving intervention-related characteristics (e.g. sharing experiences and finding relevant information) were more likely to subscribe.</li> <li>• Community content is key when implementing an online community group.</li> <li>• Combination of peer-to-peer communication, patient-to-professional communication, and information provision facilitated active participation.</li> <li>• This implies that the different methods of communication tailored to their needs, generated value for subscribers.</li> </ul> |

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|--|---|--|
| <p>Kahlor &amp; Mackert, 2009</p> <p>Cross-sectional Survey</p>  | <ul style="list-style-type: none"> <li>• 567 infertile women responded to an invitation to an online self-administered questionnaire.</li> <li>• Average age range was 31-35 years of age.</li> <li>• The sample was predominantly white (88%), with the remainder being black (4%), Hispanic (3%), Asian (3%), and Native American, native Hawaiian, or Pacific Islander (2%).</li> <li>• 70% of the participants had been trying to conceive for more than two years.</li> <li>• Note: This sample is more educated, less ethnically diverse, and wealthier than the general U.S. population.</li> </ul>  | <ul style="list-style-type: none"> <li>• Participants strongly agreed that they felt comfortable speaking with their doctors about their infertility.</li> <li>• More than 10% felt that their doctors did not encourage them to find infertility information online. Approximately 34% felt neutral on the subject.</li> <li>• More than 70% reported they never relied on local support groups. 99% relied on the Internet for fertility information and support.</li> <li>• Most helpful information sources (from most to least helpful): partners/spouses, online support groups, friends, websites, family, and infertility specialists.</li> <li>• Ethnicity may play a role. Non-white subjects found both fertility specialists and online information to be more helpful than non-white subjects.</li> </ul>   |
| <p>Malik &amp; Coulson, 2008</p> <p>Qualitative Study</p>        | <ul style="list-style-type: none"> <li>• 95 participants were recruited from several online infertility support groups and completed an online questionnaire.</li> <li>• The online questionnaire focused on open-ended questions: reasons for accessing online support groups, perceived advantages and disadvantages of online support group participation, impact on coping with infertility and the impact of participation on marital relationships.</li> <li>• 93.7% of participants were female and the mean age was 35.6 years.</li> <li>• 89.5% of participants were active members of an online support group.</li> </ul>   | <p><b>Advantages:</b></p> <ul style="list-style-type: none"> <li>• Convenience and 24 h availability of online support groups. The potential to communicate their feelings and concerns at any time appeared to provide great comfort and helped them cope.</li> <li>• Ability to ask questions and express their feelings more fully without fear of embarrassment or stigma (in anonymous groups).</li> <li>• Led to positive effects in the participants' offline relationship with their partners (their partners were no longer the sole sources of social support).</li> <li>• Alleviated isolation as they could share and talk to others who understood what they were going through.</li> <li>• Some participants felt more knowledgeable concerning fertility issues than even their GP. This empowered respondents to take a more active role in their infertility journey and made making tough decisions easier.</li> </ul> <p><b>Disadvantages:</b></p> <ul style="list-style-type: none"> <li>• Reading stories about other people's grief made some participants feel overwhelmingly sad and distressed.</li> <li>• Group participation led to some participants becoming "obsessed" with using the online community.</li> <li>• Emotional reactions to success stories, especially for those couples who had been through repeated treatment attempts.</li> </ul> |
| <p>Cousineau et al., 2008</p> <p>Randomized Controlled Trial</p> | <ul style="list-style-type: none"> <li>• 190 female patients were recruited from three U.S. fertility centers and were randomized into two experimental and two no-treatment control groups.</li> <li>• Average age of participants was 36 years and 90% were married. Most women were white and highly educated.</li> <li>• Participants in the intervention group were asked to view the infertility support program in a semi-structured way for two 45-min sessions or in several sittings over a four-week period. A target goal was viewing the content for up to 90 min, based on an estimated amount of content available.</li> <li>• Assessment tool used was the Fertility Problem Index (FPI) – a 46-item validated questionnaire that assesses infertility related stress. It includes six subscales: <ul style="list-style-type: none"> <li>• <b>social concern</b> (sensitivity to comments about infertility by friends and family; social isolation).</li> <li>• <b>sexual concern</b> (reduced sexual enjoyment due to scheduled sex).</li> <li>• <b>relationship concern</b> (worries about the impact of infertility on the relationship).</li> <li>• <b>need for parenthood</b> (close identification with parenting as a life goal).</li> <li>• <b>rejection of childfree lifestyle</b> (negative view of living without children).</li> <li>• <b>global stress</b> (the total overall infertility related distress).</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>• Intervention group: 36% of participants spent the 'dose' of 90 min or more on the site; 50% spent 60 min or more. Those who used the program for 60 minutes or more manifested significantly lower FPI global stress scores and increased self-efficacy (e.g. "I can control negative feelings about infertility").</li> <li>• A significant reduction in the following FPI subscales was observed in the intervention groups vs control: social concern, sexual concern, and scores related to rejecting a childfree lifestyle.</li> <li>• The intervention group felt more informed about a medical decision they were facing.</li> <li>• The women who benefitted most from the intervention were women who were more anxious, further along in their treatment experience, had higher incomes, and had an explained infertility diagnosis.</li> </ul>   |

## CONCLUSION

Because online support groups consist of technological and organizational components, they are often not implemented into clinical practice.<sup>1</sup> However, from these publications, it is evident that patients value online communities as they make care more accessible, provide reliable information and emotional support from peers. Some women are unable to discuss infertility-related subjects with their spouse. Therefore, turning to infertility forums may be a way to process emotions and relations.<sup>17</sup> A multitude of helpful aspects were mentioned throughout the studies, such as being a member of a tight community, feelings of belonging and being surrounded by persons with similar experiences.<sup>18</sup> It is important to keep in mind that patients have reported

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Naturopathic Doctors with a fertility and women's health focus may wish to incorporate support groups into their own practices. How can NDs prepare to provide their patients with the

appropriate information to access these types of services? A closer look should be taken at non-white and lower-income women as these women had stronger opinions on the benefits of online sources of information and support. To better accommodate these women, infertility-related websites should have information that would better serve these populations. This is especially important given that these women place more importance on these online resources.

Spending more time identifying patients who may most benefit from this type of intervention will help promote the community actively among them.<sup>2</sup> The Internet has already revolutionized health care and improved communication between patients and health care practitioners. Introducing community care makes health care more affordable and provides reliable information. Perhaps more importantly it facilitates emotional support from peers who are going through or have gone through similar experiences. 🌱

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