

Psychological distress and the desire to use an infertility-related online support board

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INTRODUCTION

- Feelings of isolation are common among people with infertility
- Online forums and chat rooms allow people to exchange information and experiences and to receive empathetic reactions from others who understand the medical and emotional challenges of infertility
- Infotility* is a mobile health app developed by researchers and fertility health care professionals to provide information and support to fertility patients.
 - The app includes a forum monitored by peer supporters with experience of infertility and its treatment.
- Little is known about the relationship between psychological distress and forum usage. This study explores how distressed infertility patients use and experience the *Infotility* forum.

OBJECTIVES

- To compare the mental well-being of **active posters** on the *Infotility* forum, **lurkers** who read messages but did not post, and **people who did not use the forum**.
- To analyze users' experiences on the forum through their responses to two open-ended questions.

METHODS

189 women and 73 men (n=262) were recruited at fertility clinics in Montreal and Toronto to test *Infotility*.

Study Design:

- Pre-app use questionnaires
- Background
 - GAD-7
 - PSS-4

6 to 8 weeks of app use

- Post-app use questionnaires and open-ended questions

- The PSS-4 is a self-report measure of the amount of stress encountered in daily life in the past month.
- The GAD-7 assesses symptoms of anxiety in the past two weeks.

For each scale, answers were summed to create total scores. The higher the score, the more stress or anxious symptomatology the participant expressed.

Infotility users were divided into three unique groups (determined by Google Analytics):

- active posters** on the forum (15.3%),
- lurkers** who read messages but did not post (24.8%), and
- non-users** of the forum (59.9%)

One-way analysis of variance and post hoc Bonferonni tests were used to compare the PSS-4 and GAD-7 scores of these 3 groups.

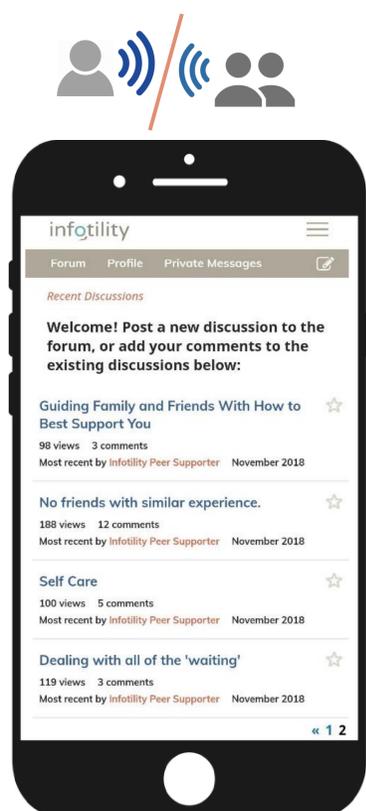
After using *Infotility*, participants answered follow-up questionnaires including two open-ended questions:

- Please tell us what you liked best about the app, and why.
- Please tell us what you liked least about the app, and why.

The responses that pertained to the forum were examined for general themes.

MAIN FINDINGS

Infertility patients appreciated the peer-monitored forum as part of a mobile app.



Participants reported that the forum:

- Reduced stress and social isolation
- Normalized the experience of infertility
- Provided useful information

"What I benefitted from was the opportunity to read how other people were coping with their situations and to be able to post my own thoughts/feelings. I felt less alone knowing I could contribute to the forum."

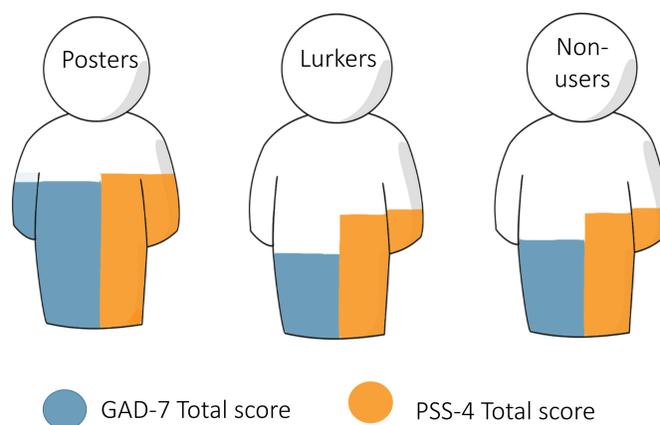
"Knowing there are real people going through the struggles of fertility. Although, I didn't use it as my own soundboard, I sought comfort in reading the support given to others."

"I was able to express myself without judgement and get answers to questions I had."

"I liked the peer support very much, it helped me calm down and feel like I have someone I can vent to."

"This app made me feel that I'm not the only one going through an infertility problem and gave me confidence and comfort."

Distressed participants were more likely to post on the forum.



Posters had **significantly higher GAD-7 scores and PSS-4 scores** than lurkers and non-users (p<0.01, Table 1).

PATIENT DEMOGRAPHICS

Characteristics	% or Mean (SD)	N
Age	35.6 (4.8)	259
Sex		262
Female	72.1	189
Male	27.9	73
Immigrant Status		256
Immigrant	41.8	107
Born in Canada	58.2	149
Annual Household Income (CAD)		256
Less than \$80,000	38.3	98
\$80,000 and more	61.7	158
Ethnicity		258
White	62.0	160
Non-white	38.0	98
Language		262
English	71.4	187
French	28.6	75
Months in fertility treatment	20.0 (21.5)	250
Infertility diagnosis		261
Female-factor only	29.5	77
Male-factor only	24.9	65
Mixed-factor	15.3	40
Unexplained / still testing	30.3	79

DISCUSSION

- The *Infotility* forum was of particular interest to users experiencing psychological distress. Participants who used the forum perceived it as comforting, supportive, and reliable. It provided participants a way to share their own experiences, and communicate with others in similar situations.
- This study highlights the importance of monitored forums and peer support for those undergoing fertility treatment, particularly for those experiencing distress.
- Furthermore, the fact that those with higher rates of distress were significantly more likely to use the peer support forum suggests a need within the community for forms of social support such as the *Infotility* forum, which have been lacking in the past.
- Infotility* was designed to provide support to all those undergoing fertility treatment. Future research should examine whether this type of intervention may serve to reduce stress and improve quality of life among people undergoing fertility treatment.