Development and Evaluation of a Novel Online Infertility Peer Support Program

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Abstract

The treatment of infertility is comprised of costly and invasive medical assessments and procedures that relate to psychosocial, financial, and physical stress. Research has demonstrated a need among some fertility patients for contact with similar peers who understand the unique challenges of infertility diagnosis and treatment. Desire for contact with other patients is evident in the growing use of the Internet for peer support. The aim of the present research was to outline the development and evaluation of a mobile infertility peer support program, called Connect, delivered as a component of the Infotility educational app for fertility patients. Three studies are presented, which examined the feasibility, acceptability, and use of mobile infertility peer support.

To gauge interest in and preferences for online infertility peer support, a needs assessment survey was administered to 519 diverse fertility patients in two major Canadian cities. Findings indicated that more than 80% of the sample were interested in online peer support and that they desired a monitored and confidential discussion forum offered through mobile technology. Logistic regressions examined the associations of fertility characteristics, demographic characteristics, and perceived stress with interest in an online forum; for both men and women, only perceived stress explained unique variance in such interest. Study 1 therefore indicated a high level of interest in online infertility peer support, especially among fertility patients with higher stress.

Based on the results of study 1, peer supporters were trained to provide support as well as monitor the confidential forum. The aim of study 2 was to describe the development and evaluation of an evidence-based peer supporter training program. Peer supporters included only people with a history of fertility treatment who wished to support current fertility patients. Inclusion of peer training is important to online peer support interventions to ensure peer supporter competence and forum safety. Peer supporters found nearly all aspects of training very useful, often felt respected, appreciated, and helpful, and liked the ability to help others any time of day from any location. Results of Study 2 provide evidence for the feasibility and acceptability of online recruitment and training of infertility peer supporters.

The aim of Study 3 was to evaluate discussion on Connect between and among fertility patient app users and trained peer supporters to improve understanding about how patients cope with fertility treatment. Results of a thematic analysis showed that board members actively discussed ways of coping across four domains: interpersonal relationships, partner/spouse, lack of control and uncertainty, and negativity and general stress. A variety of coping strategies were identified, including practical management, cognitive reappraisal, and avoidance, with posts often describing the perceived helpfulness of coping strategies for specific stressors. Findings highlight online peer support as a context for acquiring new information about ways of coping with specific fertility-related stressors.

This dissertation provides evidence for the feasibility and acceptability of online infertility peer support and the online recruitment and training of infertility peer supporters. Online infertility peer support may benefit patients by permitting asynchronous and confidential discussion between people with similar lived experiences. In addition to providing emotional support, online peer supporters can tailor their responses to the unique concerns of each user based on their experiences with ways of coping during this stressful life period.

Résumé

Les traitements en procréation assistée comprennent des évaluations et des procédures médicales coûteuses et invasives qui sont associées au stress psychosocial, financier et physique des patients. Des recherches ont démontré un besoin parmi certains patients en procréation assistée d'être en contact avec des pairs qui comprennent les défis uniques du diagnostic et du traitement de l'infertilité. Le désir d’être en contact avec d'autres patients est évident dans l'utilisation croissante d'Internet pour le soutien par les pairs aidants. L'objectif de la présente recherche était d'esquisser le développement et l'évaluation d'un programme en ligne de soutien par les pairs en matière d'infertilité, appelé « Connecte », fourni en tant que composante de l'application mobile éducative « Infotilité » pour les patients en procréation assistée. Trois études sont présentées, qui ont examiné la faisabilité, l'acceptabilité et l'utilisation du soutien par les pairs aidants dans le contexte de l’infertilité.

Pour évaluer l'intérêt et les préférences en matière de soutien en ligne par les pairs aidants dans un contexte d’infertilité, une enquête d'évaluation des besoins a été menée auprès de 519 patients atteints d'infertilité dans deux grandes villes canadiennes. Les résultats ont indiqué que plus de 80 % de l'échantillon était intéressé par le soutien en ligne par des pairs aidants et qu'ils souhaitaient un forum de discussion modéré et confidentiel offert par l’application mobile. Des régressions logistiques ont examiné les associations entre les caractéristiques liées à la fertilité, les caractéristiques démographiques et le stress perçu, ainsi que l'intérêt pour un forum. Pour les hommes et pour les femmes, seul le stress perçu a expliqué la variance unique de cet intérêt. L'étude a donc indiqué un niveau élevé d'intérêt pour le soutien en ligne par les pairs aidants, en particulier chez les patients subissant un stress plus important.

En se basant sur les résultats de l'étude 1, des pairs aidants ont été formés pour fournir du soutien ainsi que pour surveiller le forum. L'objectif de l'étude 2 était de décrire le développement et l'évaluation d'un programme de formation des pairs aidants basé sur des données probantes. Les pairs aidants comprenaient uniquement des personnes ayant des antécédents de traitement en procréation assistée et souhaitant soutenir des patients actuels. L'inclusion de la formation des pairs est importante pour les interventions de soutien par les pairs en ligne afin d'assurer la compétence des pairs aidants et la sécurité du forum.

Les pairs aidants ont trouvé presque tous les aspects de la formation très utiles. Ils se sont souvent sentis respectés, appréciés et utiles, et ont apprécié la possibilité d'aider d'autres personnes à tout moment de la journée et en tout lieu. Les résultats de l'étude 2 démontrent la faisabilité et l'acceptabilité du recrutement et de la formation en ligne des pairs aidants en contexte d'infertilité.

L'objectif de l'étude 3 était d'évaluer les discussions sur « Connecte » entre et parmi les utilisateurs de l'application et les pairs aidants formés pour mieux comprendre comment les patients font face au traitement de l'infertilité. Les résultats d'une analyse thématique ont montré que les participants de « Connecte » ont discuté des moyens de faire face à la situation dans quatre domaines: les relations interpersonnelles, leur partenaire/conjoint, le sentiment de manque de contrôle et l'incertitude, et la négativité et le stress général. Diverses stratégies d'adaptation ont été identifiées, notamment la gestion pratique, la réévaluation cognitive et l'évitement, les postes décrivant souvent l'utilité perçue des stratégies d'adaptation pour des facteurs de stress spécifiques. Les résultats mettent en évidence le soutien en ligne par les pairs aidants comme contexte d'acquisition de nouvelles informations sur les moyens de faire face à des facteurs de stress liés à l’infertilité.

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Contribution to Original Knowledge

The present doctoral thesis provides original knowledge that improves our understanding of the feasibility, acceptability, and use of an online infertility peer support program among fertility patients and trained peer supporters. The present thesis makes novel contributions to literature regarding (1) fertility patient interest in, and preferences for, online peer support; (2) the development of online peer support training programs, and (3) online fertility-related communication and ways of coping with infertility and its treatment. Each article provides new knowledge about the feasibility and acceptability of an online infertility peer support program with implications for psychosocial resources for those undergoing fertility treatment.

Study 1 is the first to examine interest in, and preferences for, online peer support among a large, diverse sample of fertility patients. From a sample of 519 men and women seeking fertility treatment, results showed that more than four out of five participants held interest in this type of program. Results also showed that while controlling for demographic and fertility characteristics, only greater perceived stress related to increased interest, suggesting that online infertility peer support is particularly relevant to those with greater perceived stress during treatment. This study also provided a novel contribution to the literature by determining which features of online peer support are most preferable to men and women undergoing fertility treatment. The latter result provides useful information for the development of psychosocial resources that include online peer support.

Study 2 includes the first protocol for online infertility peer supporter recruitment, training, and supervision. By providing a description of evidence-based program development, this study can serve as a model for replication and refinement of online peer support programs for fertility patients and those with other chronic illnesses. Results of a novel peer supporter experiences questionnaire also provided knowledge about peer supporter satisfaction and experiences with various aspects of training and support provision. Peer supporters reported a high level of program satisfaction with all training materials and procedures and peer support coordinator engagement, and liked 'helping people' within the context of a professionally monitored forum. This study builds on study 1 by showing that peer supporters were also comfortable with professional monitoring of online communication, a necessary feature for ensuring forum safety.

Study 3 is the first study of ways of coping with fertility-related stress within a professionally monitored online infertility peer support forum. This study provides novel contributions to knowledge about infertility coping and peer support as a source of coping information for those with lived experience. Two hundred and forty four posts were made by 40 fertility patients (38 women, 2 men) and 169 posts were made by peer supporters. Results of a thematic analysis showed that discussions involved active requests for information about how others coped with four domains of fertility-related stressors. In contrast to avoidance strategies, which were discussed infrequently, practical management and cognitive reappraisal strategies were discussed often. Users discussed both the use of different strategies over time and the helpfulness of each strategy. Findings demonstrate that monitored online peer support can provide current fertility patients with rich, experience-based information about coping with infertility, while normalizing their concerns, uncertainty, and general stress.

This dissertation fills an important gap in the literature regarding the feasibility, acceptability, and use of an online infertility peer support forum. Results of three studies show that patients and peer supporters are interested in this type of program and value online communication to learn about ways of reducing infertility-related stress.

Contribution of Authors

The present thesis reflects independent doctoral work completed under the supervision of Dr. Phyllis Zelkowitz. The three manuscripts that comprise this thesis report on data collected as part of a larger study examining the development of a mobile application offering fertility-related information and support to men and women undergoing infertility treatment.

Phyllis Zelkowitz designed and wrote the larger study protocols for Articles 1, 2, and 3. For each article, Paul Grunberg developed the specific research questions and hypotheses, conducted the literature reviews, planned and conducted the statistical analyses, and wrote the manuscripts. All respective authors reviewed and approved the manuscript prior to journal submission. I completed all submissions, revisions, and resubmissions to peer-reviewed journals.

Article 1 was critically revised by Cindy-Lee Dennis, Deborah Da Costa, and Phyllis Zelkowitz and was published in *Reproductive BioMedicine & Society Online* in 2018.

For article 2, Paul Grunberg and Karolanne Gagné recruited participants. Paul Grunberg, Karolanne Gagné, Rachel Idelson, and Phyllis Zelkowitz developed and implemented the online peer supporter training program. Peer supporter training materials were developed and critically reviewed by Paul Grunberg, Karolanne Gagné, Rachel Idelson, Cindy-Lee Dennis, Deborah Da Costa, and Phyllis Zelkowitz. The demographic survey was developed by Paul Grunberg and Phyllis Zelkowitz. The Peer Supporter Experiences Questionnaire was developed by Paul Grunberg, Karolanne Gagne, Rachel Idelson, Cindy-Lee Dennis, and Phyllis Zelkowitz. Article 2 was published in *Patient Education and Counseling* in 2020.

For article 3, Siobhan O'Connell and Paul Grunberg led the qualitative analysis with contributions from Siobhan O'Connell and Alix Lahuec. Deborah Da Costa, and Phyllis Zelkowitz critically revised the final manuscript. Article 3 is accepted for publication in *Human Fertility*.

General Introduction

Literature Review

About one in six Canadian heterosexual couples experience infertility (Bushnik et al., 2012), a rate that is similar to estimates in other developed Western countries (Datta et al., 2016). Infertility is defined as the inability to conceive following 12 months of regular sexual intercourse or impairment in the capacity to reproduce as a result of individual or partner factors (Borght & Wyns, 2018). In developed countries, approximately half of those with infertility seek medical treatment (Boivin et al., 2007; Datta et al., 2016; Greil et al., 2010). Factors that may contribute to the inability to conceive include advanced paternal and/or maternal age, reproductive malformations, genetic abnormalities, environmental toxins, and cancer treatment. Infertility can be differentiated into male-factor, female-factor, and mixed factor; each of which contribute to approximately one third of diagnoses (Hade, 2017). Most commonly, treatments include hormone therapy and assisted reproductive technologies (ART), such as in-vitro fertilization (IVF) or intrauterine insemination (IUI).

Infertility and Stress

Infertility is a stressful life event (Greil et al. 2011). Similar to other chronic medical conditions, there are multiple psychosocial and physical stressors including invasive assessments and treatments (e.g., gamete collection procedures) and cycles of uncertainty during waiting periods (Boivin & Lancastle, 2018). Although men also experience stress associated with manual or technology-assisted sperm collection, a preponderance of medical assessments and procedures take place within the woman's body (Cousineau & Domar, 2007). In addition to considerable physiological stress, women have consistently reported greater psychological stress and anxious and depressive symptomatology during treatment. Overall, systematic review data support the claim that although fertility treatment does not associate with psychopathology, treatment is a highly stressful period, characterized within the descriptive literature as an ‘emotional rollercoaster’ by those with a history of treatment (Greil et al., 2010; Hanna & Gough, 2016). This description stems from the fact that when using their own oocytes, the live birth rate for women under 40 years of age is 32.3% after one treatment cycle and only reaches 68.4% after six treatment cycles. For women 40 to 42 years of age, live birth rates drop significantly to 12.3% after one treatment cycle and 31.5% after three treatment cycles (Smith et al., 2015). Accordingly, many fertility patients face periods of hope, anxiety, and excitement, followed by disappointment, guilt, shame, and anger, and grief (Greil, 1997; Greil et al., 2010). Lastly, for many people, the financial costs of treatment are burdensome. For example, in Ontario, provincial funding currently only covers the costs of the first treatment cycle, requiring patients to pay fees of up to approximately $15000 for assessment, treatment, and clinic processing in subsequent treatment (Ottawa Fertility Centre, 2020).

Among women with infertility, anxiety and depression scores have been found to equal those of women with cardiac rehabilitation, cancer, hypertension, and HIV-positive status (Domar, 1993). Men with infertility were also found to report similar levels of depressive symptomatology to men with cancer (Miner et al., 2018). A review of 14 studies found that quality of life was lower among women with a history of infertility treatment, compared to both infertile men and women with no fertility concerns (Chachamovich et al., 2010). The psychological stress of fertility treatment plays an important role in treatment persistence or dropout. Several studies have found that even with medical insurance covering some or all of the treatment-related costs, many patients still dropped out of treatment due to fertility-related psychosocial stress (Cousineau & Domar, 2007; Olivius et al., 2004; Schroder et al., 2004). A retrospective interview study of women who voluntarily discontinued fertility treatment found that among nine reasons for treatment dropout, psychological burden was most frequently rated as having a ‘severe impact’ on dropout (Van den Broeck et al., 2009). This underscores the importance of developing cost-effective resources for reducing psychosocial stress during fertility treatment.

Isolation and Need for Peer Support

Social support and integration is a well-documented determinant of physical and psychological health (Beck, 2007; Uchino, 2006; Wright & Miller, 2010). A review of psychophysiological effects of social support suggested that women with more social connections are less likely to have complications during pregnancy (Beck, 2007). The importance of social support for individuals undergoing fertility treatment is demonstrated by positive associations between perceived partner, family support, and friend support and lower fertility-related stress (Kroemeke & Kubicka, 2018; Martins et al., 2011; Martins et al., 2014). Interpersonal stressors include not only insufficient social support, but also unhelpful or critical comments, and sensitivity to fertility-related cues, such as the pregnancies of family and friends. (Hinton et al., 2010; Schmidt et al. 2009). Following unsuccessful fertility treatment, women with higher levels of self-reported unsupportive social interactions reported significantly greater depressive symptomatology and general psychological distress at six to 12 months (Mindes et al., 2003). Qualitative research also found that current and former fertility patients described a sense of isolation from friends and family who could not understand the challenges of infertility and its treatment (Cousineau & Domar, 2007; Greil et al., 2010; Hinton et al., 2010; Malik & Coulson, 2008a; Turnbull et al., 2017) and reported stigma due to their involuntary deviation from normative pronatalist culture (Sternke & Abrahamson, 2015; Turnbull et al., 2017). That lower perceived social support is related to increased perceived fertility-related stigma (Slade et al., 2007) suggests that certain patients may experience a greater sense of negative judgment and discrimination following infertility.

Support groups for infertility first began to flourish following the 1974 inception of the first fertility patient advocacy group, RESOLVE (Boivin & Gameiro, 2015). In more recent years, evidence has mounted regarding fertility patients' desire for support from people who have personal experience with infertility and its treatment (Malik & Coulson, 2008a; Porter & Bhattacharya, 2008; Read et al., 2014). A systematic review of fertility patients' needs concluded that fertility patients should be offered organized contact with former patients (Dancet et al., 2010). Unlike social support, which refers to any form of interpersonal support, peer support refers to the support between individuals with shared target characteristics, such as a history of infertility treatment. Using concept analysis, Dennis (2003) clarified the definition and meaning of peer support within the health literature. Results indicated that peer support is defined by the provision of emotional, informational, and/or appraisal support. Emotional support refers to expressions of caring, encouragement, attention, reflection, or reassurance and excludes criticism or giving advice. Informational support refers to advice, suggestions, factual input, and feedback that facilitate problem-solving; finally, appraisal support is a type of informational support where shared information may facilitate self-evaluation (e.g., appropriateness of current experiences; Dennis, 2003).

The physical and psychological effects of peer support interventions have been examined across numerous community and patient populations. A systematic review and meta-analysis found an association between peer support and lower blood pressure in those with diabetes (Patil et al., 2018); results of a multi-site two-arm unblinded randomized controlled trial found that first-time mothers who received telephone-based peer support targeting breastfeeding were significantly more likely to breastfeed at six months (Forster et al., 2019). Meta-analytic findings showed that peer support is beneficial in reducing women's perinatal depressive symptomatology (Huang et al., 2020). Evidence also suggests that mothers with postpartum depression experience significant decreases in depressive symptomatology following 12 weeks of supportive phone calls from a peer who recovered from postpartum depression (Letourneau et al., 2015). Another randomized controlled trial found that men who received peer support following heart surgery showed significant decreases in anxiety during and post-hospitalization, and higher levels of self-efficacy and physical activity (Parent & Fortin, 2000).

Studies investigating the mechanisms by which peer support relates to psychological outcomes are nascent; however, available research consistently emphasizes the importance and centrality of lived experience when providing peer support (Gridugu et al., 2015; Watson, 2019). These authors explain that by sharing personal experiences, peer supporters normalize concerns, allow for social comparison and stressor reappraisal, and provide experiential knowledge about coping with a specific stressor. It is important to note that the inclusion of training for peer supporters is also necessary to ensure peer supporter competence (Dennis et al., 2010). A recent systematic review of peer support interventions for women with breast cancer found that positive psychosocial effects of online peer support were only found when peer supporters were trained (Hu et al., 2019).

Online Peer Support

With the proliferation of the Internet, household Internet access, and online communities (Statistics Canada, 2019), seeking social support has extended beyond the traditional social group of family, friends, and partner. A recent investigation of online information and support-seeking behaviours among 567 men and women in fertility treatment found that over 10% of men and women had used the Internet to find peer support (Brochu et al., 2019). This rate is similar to that for those with chronic illness. Results of a national U.S. survey found that 8% of individuals with a chronic health condition reported using the Internet for online health-related communication (Fox & Purcell, 2010). In general, people with a stigmatized chronic illness are significantly more likely to use the Internet for health information (Berger et al., 2005). Data from a national probability sample of 1352 women with a history of infertility found that compared to those who did not seek any fertility health information online, those who sought online fertility health information reported greater stigma related to their condition (Slauson-Blevins et al., 2013). As such, online communication may be particularly valuable for those who desire increased support and experience fewer opportunities for supportive offline communication. Evidence suggests that when individuals feel misunderstood or stigmatized by members of their close social network, they may prefer the weak-tie social support afforded through computer-mediated support groups (Wright & Miller, 2010).

Studies have examined online infertility discussion forums and support groups, described by members as providing convenient access to communication with similar people and leading to a sense of reduced isolation (Malik & Coulson, 2010; Richard et al., 2017) and normalization of fertility concerns (Hinton et al., 2010; Richard et al., 2017). One qualitative study of 17686 online messages across 864 infertility-related discussion threads found that users most commonly shared support and empathy, personal experiences, and information related to infertility. Findings also indicated that online messages emphasized the importance of online anonymity and the ability to communicate one's concerns and feelings at any time of day, from any location (Malik & Coulson, 2010). The Internet therefore provides a context where fertility patients can openly share their concerns, questions, and mutual support while maintaining control over personal identifying information.

Fertility patients also want information about ways of coping with infertility (Cousineau et al. 2008) and may use online peer support as a way to acquire this type of information (Hanna & Gough, 2017; Hinton et al. 2010; Malik & Coulson, 2010). For example, a qualitative examination of 415 online posts from 20 men with infertility found that men discussed the importance of partner support and open communication as strategies for managing the impact of infertility (Hanna & Gough, 2017). Results from a qualitative study of online discussion between 95 participants also suggested that, for some, online communication might facilitate positive reinterpretations of interpersonal and emotional stressors (Malik & Coulson, 2008a). This research did not explicitly examine coping based on existing theoretical models, such as the Transactional Model of Coping (Folkman & Lazarus, 1986) or infertility-specific coping model (Benyamini et al., 2008). To integrate online peer support programs into fertility clinics, it is necessary to understand the types of coping information shared between patients. If patients can provide emotional support and information about managing treatment-related stressors, online peer support could offer a cost-effective and acceptable method for managing patient stress.

To date, two randomized controlled trials examined infertility programs offering online psychoeducation and peer support (See Aarts et al., 2012 for a scoping review of patient-focused interventions in reproductive medicine; Cousineau et al., 2004; Cousineau et al., 2008; Hämmerli et al., 2010). Only one (Cousineau et al., 2008) provided evidence for interest in online peer-to-peer communication as well as reduced global stress and improved self-efficacy among women with infertility who spent more than 60 minutes on the website. However, limitations of Cousineau et al. (2008) include the researchers' directing of participants to use the supportive program and the exclusion of men; the latter decision prevents knowledge acquisition regarding men's interest in and use of online infertility peer support. Further, given increased access to home Internet and Internet-connected smartphones (Statistics Canada, 2019), there is a need for up-to-date knowledge about current patients' interest in online peer support. This research supports the need to further examine both men's and women's need for online infertility peer support that also allows participants to use the program as much or as little as desired.

The available evidence strongly suggests that there is a need for online peer support among fertility patients; however, to date, it is unclear what proportion of men and women undergoing fertility treatment would want and use online peer support. This is because research documenting the peer support need among fertility patients comes from small interview studies (Read et al., 2014) and samples of individuals who are already using the Internet (Malik & Coulson, 2008a, 2008b; Hanna & Gough, 2017). Therefore, it is necessary for research to determine the interest in online peer support among larger, more diverse samples of people undergoing fertility treatment who may or may not be currently using the Internet for peer support. There is also a need for empirical research that rigorously documents the steps of program development and the experiences of key stakeholders in the development and evaluation process.

Literature Summary and Research Objectives

Fertility treatment is a highly stressful and financially costly process that leaves many of those in treatment in need of information and support. Online peer support can provide patients with desired peer-to-peer contact while ensuring accessibility and privacy through Internet technology. To date, however, it is unclear what proportion of individuals undergoing fertility treatment would want and use online peer support. Evidence suggests that fertility patients desire contact with other patients (Malik & Coulson, 2008a; Porter & Bhattacharya, 2008; Read et al., 2014) and that some individuals with infertility use the Internet for peer support (Malik & Coulson, 2008a; Richard et al., 2017). Accordingly, there is a need to determine the extent to which larger, more diverse samples of fertility patients have interest in online peer support and their preferences for this type of program. Patient preferences for an online peer support program can be used to tailor the program to the needs of the most likely end users, thereby maximizing program acceptability among key stakeholders (Eldridge et al., 2016; Lorig et al., 2013; Lyon &

Koerner, 2016; Olafsdottir et al., 2020; Sunderland et al., 2013). Following program development, there is then a need to pilot test the program to establish feasibility and acceptability (Beebe, 2007; Craig et al., 2013; Zauszniewski, 2012).

The aim of the present research was to outline the development and evaluation of a novel online infertility peer support program offered to diverse men and women undergoing fertility treatment. Three steps were taken to this end. First, it is important to determine the level of interest among patient stakeholders prior to program development. A needs assessment was conducted to determine whether fertility patients had interest in online peer support, what preferences fertility patients had for an online peer support program, and factors associated with interest and preferences. By examining the associations between interest in online peer support and demographic characteristics, infertility factors, and perceived stress, this study sought to contribute knowledge about which fertility patients have the greatest interest in online peer support. Needs assessments are also used to inform program development by determining patient preferences for a variety of program features. Results of the first study were therefore used to inform program development and contribute knowledge about infertility peer support preferences.

A second study was conducted to outline the development and evaluation of a novel online peer supporter training program. Although peer support protocols have been developed (Dennis, 2014), only one was found that described the process of online recruitment (Lorig et al., 2013) and none were identified that used both online recruitment and training of peer supporters. Results from Lorig et al. (2013) indicated that a combination of online and in-person training of peer supporters is both feasible and acceptable. Detailed protocols are necessary for both researchers and clinics to replicate and refine the program (Dennis, 2014). Further, as peer supporters are central to any peer support program, it is important to understand their experiences to inform future program iterations and ensure peer supporter satisfaction and retention.

Finally, a third study used qualitative methods to improve understanding of online peer support uptake and use. Knowledge about coping with infertility is important for improving supportive care during the stressful treatment process. Psychosocial guidelines describe coping as an important feature of infertility counselling (Canadian Fertility & Andrology Society, 2009; Cousineau & Domar, 2007; Crawshaw et al., 2013; Joy & McCrystal, 2015) and coping skills education has been emphasized in several psychosocial infertility programs (Ying et al., 2017) Research showed that online infertility forums may be a source of coping information for fertility patients (Hanna & Gough, 2017; Hinton et al. 2010; Malik & Coulson, 2010); however, there is limited knowledge about the types of coping information requested and shared in this context. The third study sought to contribute knowledge about how patients cope with fertility-related stressors and to elucidate patterns in coping among current and former patients through thematic analysis.

Article 1

Infertility Patients’ Need and Preferences for Online Peer Support

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Abstract

This study sought to determine level of interest in online peer support among fertility patients, factors associated with such interest, and preferences for features of an online peer support network. A sample of 236 men and 283 women (*n* = 519) seeking fertility treatment were recruited from four clinics in Ontario and Quebec, Canada. Participants completed an anonymous online questionnaire assessing demographics, perceived stress, and fertility characteristics, in addition to interest in and preferences for online infertility peer support. Most men (80.1%) and women (89.8%) expressed interest in online peer support, with perceived stress being related to interest among both men and women. Non-White ethnicity and lower income were related to greater interest among men. Patients reported a preference for mobile accessibility, monitored peer-to-peer communication, and links to information. Men and women, particularly those with high levels of perceived stress, expressed interest in online peer support and shared similar preferences for features irrespective of fertility characteristics. Demographic characteristics and perceived stress were related to a desire for more personalized support options.

Keywords**:** infertility, peer support, eHealth, Internet, patient preferences, stress

Introduction

Infertility can be a devastating personal experience (Greil, 1997), and has been shown to be related to impaired quality of life (Chachamovich et al. 2010; Luk and Loke, 2015) and psychological distress in both men and women (Cousineau and Domar, 2007; Fisher et al. 2010; Fisher and Hammarberg, 2012; Greil et al., 2011; Greil et al., 2010). Individuals diagnosed with and treated for infertility experience a sense of loneliness, isolation, lack of control, social stigma, and shame (Greil, 1997; Greil et al., 2010). Women often report distress related to undergoing most of the physical procedures and negative social consequences from childlessness (Greil, 1997; Greil et al., 2010). Importantly, women with infertility have been found to report similar levels of anxiety and depression to women suffering from heart disease, cancer, hypertension, or HIV (Domar et al., 1993). Men also report increased distress associated with their own exclusion from treatment, concerns about the well-being of their partners (Malik and Coulson, 2008a), and perceived need to suppress their emotions to better support their partners (e.g., Hannah and Gough, 2016).

Despite the distress that often accompanies diagnosis and treatment of infertility, most patients neither require formal mental health services nor view psychotherapy as necessary (Boivin et al., 1999; Greil, 1997). Alternative options for support may better align with patient needs and preferences. As rates of infertility and use of fertility treatment are increasing (Bushnik et al., 2012; Gunby, 2012), there is a need to better understand intervention models that may improve well-being in those undergoing treatment.

The Internet may be important for delivering psychosocial interventions to fertility patients. Both men (Hanna and Gough, 2016; Malik and Coulson, 2008a) and women (Himmel et al., 2005; Kahlor and Mackert, 2009) communicate online to gather factual and experiential information and receive emotional support from others who understand the challenges of infertility and its treatment (Malik and Coulson, 2008b; Porter and Bhattacharya, 2008; Read et al., 2014; van Empel et al., 2010; Zillien et al., 2011). Online sites offer many of the benefits of in-person support groups, such as validation and normalization (Hinton et al., 2010; Paterson et al., 2013), in addition to 24-hour availability, anonymity, and opportunities for asynchronous communication (Malik and Coulson, 2008b). Participation in online infertility communities has been associated with improved partner relationships, reduced isolation, and increased knowledge and empowerment in treatment decision making among women (Malik and Coulson, 2008b). Therefore, online interventions may also benefit fertility patients by offering the option for peer support.

Peer support refers to the provision of emotional, instrumental, and/or appraisal support to an individual with similar characteristics (Dennis, 2003a). Peer support has been associated with positive physical and mental health outcomes for several patient groups, including men and women with diabetes (Dale et al., 2012), women with breast cancer (Hoey et al. 2008), mothers at risk for postpartum depression (Dennis, 2010, 2003b), and men following heart surgery (Parent and Fortin, 2000).

Interest in online peer support may vary according to demographic and psychological factors. In the general population, women, people with higher educational attainment and those experiencing psychological stress report greater interest in online supportive interventions (Cramer et al. 1997; Crisp and Griffiths, 2014; DeAndrea and Anthony, 2013). These factors have not been investigated in the fertility patient population, which tends to be highly educated (Statistics Canada, 2017; Zelkowitz et al. 2011), and subject to psychological distress (Cousineau and Domar, 2008; Greil et al., 2010).

Interest in online supportive interventions may also relate to income and ethnicity. Whereas income may relate to decreased Internet access and computer ownership (Anderson, 2017), cultural norms related to non-White ethnicity may inhibit disclosure of personal issues (Haynes-Maslow et al., 2016), such as infertility. Accordingly, anonymity may be especially important among non-White fertility patients. Interestingly, low-income or non-White ethnicity has been found to relate to greater perceived helpfulness of online support (Kahlor and Mackert, 2009), supporting the need to investigate online peer support interest within a sociodemographically diverse sample.

Fertility characteristics may arguably affect patient experiences and needs for support. For example, nulliparous patients starting treatment may have little information about the treatment process and therefore desire contact with other patients. An examination of the relations between treatment duration, time trying to conceive, and parity and interest or preferences may help inform the content and structure of online interventions.

Despite burgeoning online infertility support research, studies have largely examined qualitative data from current Internet users (e.g., Hanna and Gough, 2016; Himmel et al., 2005; Malik and Coulson, 2008b), preventing generalization to broader infertility patient populations. Online infertility support research is also limited by a lack of demographic variability, often investigating only male or female support groups (e.g., Malik and Coulson, 2008a, 2008b) without further description of socioeconomic or psychological characteristics of the users. Notably, there is an absence of research examining the support needs of infertile men and those of non-White and low-income backgrounds.

We addressed these gaps in the literature by undertaking an exploratory study of interest in online peer support in a sample of fertility patients from varied sociodemographic backgrounds. A better understanding of patient preferenes for online peer support will permit tailoring of this type of service and thereby enhance its relevance and uptake (Craig et al., 2008, Paterson et al., 2013; van Gemert-Pijnen et al., 2011). The objectives of the study were twofold:

Objective 1: to determine the extent to which men and women undergoing fertility treatment were interested in online peer support and to examine associations between demographics (i.e., age, sex, income, education), perceived stress, and fertility characteristics (i.e., number of children, time trying to conceive, treatment duration), with interest in online peer support.

Hypotheses

H_1: Women are more likely to express interest in online peer support than men;

H_2: Those reporting higher socioeconomic status (i.e., income, education) are more likely to express interest in online peer support than those reporting lower socioeconomic status;

H_3: The likelihood of expressing interest in online peer support is greater for those with higher perceived stress;

H_4: Fertility factors (i.e., time trying to conceive, treatment duration, parity) relate to interest in online peer support, such that patients with a longer duration of trying to conceive and duration of treatment, and those without children have greater interest in online peer support.

Objective 2: to explore preferences for various features of an online peer support network. The examination of online peer support features was exploratory in nature. Therefore, no a priori hypotheses were generated for feature preferences.

Materials and Methods

Participants and Study Procedures

Between July and December 2015, patients were recruited from four fertility clinics in Toronto and Montreal, Canada. Inclusion criteria were (1) seeking fertility treatment, (2) at least 18 years of age, and (3) ability to answer questions in English or French. Participants completed the survey either on a tablet at the time of recruitment or via e-mail that provided the participant with a unique website address. Consent was implied when the participant accessed the online link. If necessary, those invited by e-mail received a reminder one and two weeks following the invitation. Participants received a $10 gift card at study completion. The survey was completed anonymously; participants' e-mail addresses were discarded after two weeks. Data were stored on Canadian servers using Fluid Surveys, meeting ethics board requirements for secure data. Ethics approval was obtained from the research ethics committees of all participating institutions.

Only heterosexual participants in relationships were included in the current analysis, as the concerns of gay or lesbian people seeking assisted reproductive technologies (ART) may differ from those with a heterosexual orientation. The small number of non-heterosexual participants (n = 25) further prevented meaningful analysis.

Materials

Patient Survey. The patient survey examined interest in and preferences for types and sources of infertility information and support, and recorded demographic and psychological characteristics. The survey was designed in consultation with patients and physicians specializing in fertility diagnosis and treatment. Table 1 includes definitions of (1) interest in online peer support and preferences for online peer support features and (2) peer support features, grouped according to four themes: Platform Format, Communication, Individual Support, and Monitoring.

Platform Format comprised of four features related to the technology or services provided, including mobile accessibility, which some may prefer when accessing online health information (Kennedy et al., 2017). The Communication theme reflected research highlighting the presence of online infertility peer-to-peer communities (e.g., Malik and Coulson, 2008b). Communication comprised of four features that reflect ways of sharing and viewing online information (e.g., anonymous posting). Research suggests that social features may be important for patients seeking online health information (Kennedy et al., 2017). The Individual Support theme, which included three features, delineated those who preferred more personalized or intensive support, such as choosing to be matched to a peer supporter. The Monitoring theme included two features assessing preferences for the inclusion of either a health professional or non-professional moderator. Given the risk for acquiring inaccurate information or experiencing negative interactions online (Malik and Coulson, 2010a), it has been suggested that online interactions should be monitored in order to improve safety and quality of communication (Moorhead et al., 2013).

Perceived Stress. The Perceived Stress Scale-4 (PSS-4; Cohen et al., 1983) was used to measure participants' levels of stress. Adapted from the 14-item PSS, the PSS-4 contains four items that ask respondents to rate "…feelings and thoughts during the last month" on a Likert scale (0 = *never;* 1 = *almost never*; 2 = *sometimes;* 3 = *fairly often*; 4 = *very often*) with a maximum score of 16. The PSS-4 is normally distributed and has acceptable internal consistency (> 0.70; Warttig et al., 2013).

Data Analysis

Descriptive statistics were used to examine demographic (i.e., age, sex, education, income), perceived stress, and infertility variables (i.e., time trying to conceive, treatment duration, and number of children), in addition to interest in using an online peer support network. For interest in online peer support, *yes* (*n* = 194) and *maybe* (*n* = 249) were collapsed to differentiate those with any interest (*n* = 443) and no interest (*n* = 73). This method of examining interest in online health interventions follows a similar approach used in other research (Crisp and Griffiths, 2014). Three participants did not answer this question. For chi-square analyses, a dichotomous income variable was created based on the Canadian median family household income for couple families (Statistics Canada, 2017): less than or equal to $79,000 and greater than $79,000. Similarly, education was collapsed into university graduate and less than university. Fertility experiences and needs for support may also differ with primary versus secondary infertility; thus, number of children was collapsed into those with and without children.

We examined relations between interest in online peer support and potential determinants. Chi-square analysis was used to examine sex, education, income, number of children, time trying to conceive, and treatment duration; point-biserial correlation was used for age and perceived stress. Variables that were significantly associated with interest in online peer support were then included in separate logistic regressions for males and females.

To explore preferences for features of an online peer support network, associations between peer support feature ratings and sex, income, education, ethnicity, immigrant status, and number of children were determined using point-biserial correlations. Pearson correlation was used for associations between age, PSS, and ratings of online peer support features. As time trying to conceive and treatment duration each included variable interval distances and an open-ended response (i.e., 5 or more years), Spearman's Rho was used to examine their relations with online peer support features. A large number of tests was required to examine the relations between preferences for features and study variables; therefore, alpha was set at .01 to reduce chance for Type I error. Significant correlations are reported in the results section. Associations between all explanatory variables and peer support features are included in the supplementary Table 1.

Preferences for online peer support features were also summarized by calculating how many participants agreed or strongly agreed with the inclusion of each feature (See Table 1).

Results

Sample Characteristics

Of 808 patients approached, 795 (98.4%) met eligibility criteria. From this pool, 49 (6.2%) refused, reporting disinterest, time constraints, stress, and unwillingness to discuss infertility experiences as reasons for not participating. Of the 746 who accepted, 659 (88.3%) completed a survey. In total, 140 participants were excluded: 25 reported a non-heterosexual orientation, 23 reported being single, and three reported both. The remainder (n = 89) did not report sexual orientation and/or relationship type. The final sample of 519 participants included 236 males (45.5%) and 283 females (54.5%).

Participant characteristics are shown in Table 2**.** Participants were well educated, with 65.5% of the sample having completed at least a university degree. More than half of the sample reported working full time and a broad range of incomes was represented. Approximately half of the sample reported White ethnicity; the other half included Black, Latin American, Arab, South and East Asian ethnicities. Fertility characteristics are shown in Table 3. Approximately one third of participants reported only male factor infertility and approximately one third reported only female factor infertility. In vitro fertilization was the most frequently reported treatment followed by oral hormones, then intrauterine insemination. Approximately one third of participants indicated they were attending an initial consultation/visit. Most participants were nulliparous (n = 373, 73.4%) at the time of study.

Objective 1: Interest in Online Peer Support

The majority of participants reported interest in online peer support (n = 443; 85.4%), with women (n = 254, 89.8%) significantly more likely to report interest than men (n = 189, 80.1%; $\chi^2(1) = 10.465$, $p = .001$). For men, income ($\chi^2(1) = 6.003$, $p = .018$), PSS ($r = .148$, $p = .023$), and ethnicity ($\chi^2(1) = 4.364$, $p = .047$) were associated with interest in online peer support. Men with lower incomes (n = 90/102, 88.2%) were more likely to report interest than those with higher incomes (n = 99/132, 75.6%). Non-White men (n = 94/109, 86.2%) were more likely to report interest in online peer support than White men (*n* = 95/126, 75.4%). For women, only PSS significantly related to interest (*r* = .12, *p* = .046). Two logistic regressions were performed. For men, income, ethnicity and PSS were included as predictors; for women PSS was included as the only predictor. The regressions were significant (*p* = .004) with PSS as the only significant predictor of interest in online peer support for men (b = 0.14, *SE* = 0.07, 95% CI [1.01, 1.31], OR = 1.16, *p* = .030) and women, (b = .15, *SE* =.07, 95% CI [1.00, 1.34], OR = 1.16, *p* = .047). Regression models explained approximately 9.0% and 3.1% of variance in interest for men and women, respectively. Interest in online peer support did not relate to age, education, or fertility characteristics.

Objective 2: Preferences for Features of an Online Peer Support Network

Feature preferences were not significantly related to sex; therefore, data from men and women were combined in subsequent analyses. See Table 1 for mean ratings for features and proportions of participants who endorsed each online peer support feature. Of the five most highly endorsed features, three fell under Platform Format: mobile accessibility (86.6%), links to other information, and having a message board by topics (76.3%). Also highly endorsed were Communication features, wherein participants were frequently interested in the opportunity to ask and answer questions to peers (81.9%), see other people's stories or profiles (71.1%) and post anonymously (70.7%). Endorsement for Monitoring was high, but only for monitoring by a health professional (75.7%).

Features of Individual Support were less favoured, ranging from 37.9% for connecting to meet offline to 67.0% for private messaging. About half (51.3%) of participants endorsed being matched to a peer supporter through an online peer support network.

Features of Platform Format, Communication, and Monitoring were unrelated to most study variables (see Supplementary Table 1 for all correlations between explanatory variables and online peer support features). For Platform Format, only income related to Mobile Accessibility (*r* = .12, *p* = .006). For Communication and Monitoring, ethnicity related to anonymous posting (*r* = .14, *p* = .001) and monitoring by health professional (*r* = .12*, p* = .005).

Certain groups favoured Individual Support features. Specifically, ethnicity (*r* = .12*, p* = .007) and PSS (*r* = .12, *p* = .006) were significantly related to the desire to be matched to a peer supporter. Last, people reporting higher perceived stress more strongly endorsed connect to peers offline (*r* = .13, *p* = .002), and younger participants expressed a greater preference for private messaging, (*r* = -.12, *p* = .009).

Discussion

Access to online peer support may be of benefit to many patient groups, including those with infertility. The present study addressed the lack of information regarding individual differences in the online support preferences of diverse fertility patients. Overall, four out of five participants indicated some interest in using online peer support. This service was of particular interest to men and women reporting greater perceived stress. Factors such as ethnicity and perceived stress were associated with preferences for more individualized and professionally monitored online peer support.

As expected, we found that more women expressed interest in online peer support than men. This is consistent with research showing that women participate in online mental health support groups at higher rates than men (Mo et al., 2009) and that female gender predicts interest in online mental health programs (DeAndrea and Anthony, 2013). However, it is important to note that a majority of men also reported possible interest. There is burgeoning evidence for men's use of online support in general (e.g., Ellis et al., 2013), as well as following diagnosis and/or treatment of infertility (Hanna and Gough, 2016; Malik and Coulson, 2008a; Richard et al., 2017).

Our second hypothesis, stating that higher socioeconomic status (i.e., income, education) would relate to greater likelihood of interest, was only partially supported. Among men only, lower income and non-White ethnicity, but not education were related to interest in online peer support at the univariate level. Men with lower income may experience greater stress during fertility treatment. Low-income men may face reduced work flexibility, impeding the ability to schedule health-related appointments or seek out and connect with similar people. Online support may also present less risk for stigmatization (Haemmerli et al., 2010), important for infertile men who view psychological treatments as incongruent with traditional masculine norms (Read et al., 2014).

Similarly, when compared to White men, non-White men reported greater interest for online peer support. In general, non-White minorities are greatly underrepresented in online support groups (Im et al., 2016; Im and Chee, 2008); therefore, it is interesting that minority men expressed greater interest. Minority patients may have fewer opportunities to engage in fertility-related communication due to cultural norms about privacy (Haynes-Maslow et al., 2016). Accordingly, interest in online peer support may be greater among those patients who do not perceive opportunities to engage in conversations about infertility. Online peer support may provide an opportunity to connect with similar peers in a more convenient and discrete way that also avoids the potential stigma and cost of traditional support options.

For both men and women, only perceived stress explained unique variance in interest in online peer support. This finding supports research in other patient populations that shows that psychological stress relates to greater interest in online support beyond demographic factors (Crisp and Griffiths, 2014; DeAndrea and Anthony, 2013; Epstein et al., 2002,) and is more pronounced within online communities for stigmatized conditions (Darcy and Dooley, 2007;

Frost and Casey, 2016). As fertility characteristics did not relate to interest for men or women, online peer support may be of interest to a wide range of patients at varying stages of treatment.

With respect to the peer support features, participants most highly endorsed the ability to access a peer support network through mobile technology.) Smartphones may be the preferred means of Internet access among those aged 18-49 (Rainie, 2012), emphasizing the utility of mobile technology for fertility patients who typically fall within this age range. As cost may impede smartphone ownership, online peer support offered through multiple Internet sources, such as desktop computer and smartphone, may yield greater uptake among diverse economic groups.

In addition to mobile accessibility, participants highly valued an organized and monitored platform where questions can be posed to peers. Participants were also interested in online peer support offering links to external content. This is in line with past work showing that patients appreciate having access to information about fertility treatment (Dancet et al., 2010), particularly when shared by similar peers who are viewed as good sources of experience-based information regarding treatment (e.g., Porter and Bhattacharya, 2008; Read et al., 2014). Such interactions between people with similar health conditions may promote patient empowerment through an exchange of information and recognition of difficulties (van Uden-Kraan et al., 2009). An online peer support network could provide both peer support *and* information to individuals undergoing treatment. Lastly, patients reported a preference for online peer support that is monitored by a health professional. The inclusion of a moderator or health professional aligns with patient preferences and provides a way to monitor the scope and nature of peer interactions (Schubart et al., 2011). This is important as fertility patients have been found to express concern about the veracity of online fertility information and content of online fertility discussion (Malik and Coulson, 2010a). The inclusion of a professional moderator may enhance perceived reliability and credibility of online information, help thwart negative comments and inappropriate posts, and provide supportive posts to users.

As part of this study, we explored how patient characteristics and perceived stress relate to preferences for various features of an online peer support network. Ethnicity was found to relate to preference for both anonymity and being matched to a peer supporter. Anonymity is consistently cited as an important feature of online communication (Coulson and Malik, 2012), as a lack of identifying information may reduce concern regarding disclosure of personal information. Interestingly, non-White participants rated this feature more highly than those reporting White ethnicity, consistent with findings showing that minorities are more concerned about maintaining Internet privacy (Im and Chee, 2008). The social repercussions of infertility often involve social stigma, more pronounced among minority groups (Greil et al., 2010; Greil, 1997). Thus, it is possible that, for some, identity is strongly tied to fertility and relates to greater concern regarding social stigmatization, leading to more concern about revealing one's identity online.

Ethnic minorities and those reporting higher perceived stress were also found to report greater interest in being matched to a peer supporter, suggesting that for certain people, online peer support offers a tool to obtain one-on-one supportive relationships with other fertility patients. African American women have been found to desire greater similarity to peer supporters in terms of ethnicity (Haynes-Maslow et al., 2016), sex, and medical condition (Haynes-Maslow et al., 2017). Thus, fertility patients may also desire peer support from others who can understand their particular cultural infertility experiences (e.g., social exclusion, shame; see Greil et al. 2010). Individuals reporting greater perceived stress also endorsed meeting peers offline. Therefore, perceived stress may not only predict interest in online peer support, but also the desire to use an online network to pursue more personalized support.

Lastly, younger fertility patients were also found to show greater preference for private messaging, which may reflect a greater understanding of online privacy risks among young people (Frost et al., 2014), or a pattern of using modern private messaging technologies (e.g., text messaging; Greenwood et al., 2016; Smith, 2011). This finding is in line with research investigating online privacy concerns among cancer patients, which found that intentions to share general and identity information increased with age (Frost et al., 2014).

Limitations

This study has certain limitations. First, the current study used a cross-sectional and quantitative design. Qualitative interview methods may contribute a richer understanding of interest in, and intent to utilize, online peer support, as well as allow further exploration of issues surrounding infertility-related stigma and privacy concerns. Related to this point is our operationalization of interest in online peer support. Specifically, and in line with other research (Crisp and Griffiths, 2014), interest was assessed by asking whether participants would consider using an online peer support network. It is possible that this formulation did not capture participants' level of interest. Future studies could employ different terminology to assess interest in an online peer support network for infertility, in order to corroborate the findings of the present study. Low variability within women's responses may have affected detection of significant associations. The current sample was also self-selected. Therefore those who elected not to participate may have had different views than those represented here. Notwithstanding these limitations, current methods resulted in a very high response rate and a large and diverse sample, which may mitigate this issue and allow for adequate generalizability. It is important to consider that although our investigation revealed several factors related to online peer support interest and preferences, the effect sizes and proportion of explained variance for men and women were small. As a first step in investigating interest and preferences for online peer support among fertility patients, this study reveals several factors that warrant further study. A fertility-specific stress measure encompassing various facets of stress (e.g., finances, relationship to spouse) may have revealed different findings. Other factors, such as level of perceived social support, may be important for understanding desire for online peer support. Low levels of partner and family support are associated with fertility-related stress in men and women (Martins et al., 2014), thereby influencing online versus offline support preferences in those with medical conditions (Chung, 2013). The current sample reflects the population of people who have decided to seek treatment. As non-treatment seeking individuals may differ according to important psychosocial variables including socioeconomic status, ethnicity, lack of primary physician, negative perceptions of medical treatment, and language barriers (Greil et al., 2010; White et al., 2005), current findings must be considered within this context. Lastly, the current study did not examine history of online peer support use, which may arguably affect perceptions of the utility of peer support and preferences for its features. Research should examine whether features of extant online peer support groups relate to positive psychosocial outcomes and preferences among fertility patients.

Implications

Our research suggests that fertility patients have considerable interest in an online peer support network. To improve current psychosocial interventions for this patient group, we recommend the development and provision of online resources that provide links to information as well as anonymous and private communication with other patients.

Further, existing online health-related support groups are much more likely to target women (Mo et al., 2009). Men's high level of interest highlights the need to develop targeted online supportive interventions for both men and women. This may be especially beneficial for non-White or low-income men who face additional barriers to connecting with similar peers.

Conclusion

Online models of peer support offer the opportunity to provide information and support to those with infertility in an anonymous, accessible, and cost-effective manner. The present findings highlight the importance of tailoring an evidence-based and patient-centred infertility peer support intervention in accordance with user characteristics (Craig et al., 2008) such as gender, ethnicity and perceived stress, to facilitate user engagement and intervention efficacy (Schubart et al., 2011). Findings contribute to knowledge about infertility peer support by revealing considerable interest in online peer support among both men and women and, further, that men's and women's preferences for online peer support features are similar.

Fertility patients expressed interest in online peer support that is accessible through mobile technology and offers monitored peer-to-peer communication and access to fertility-related information. Both men and women desire convenient access to a supportive app that allows one to contact people in similar circumstances who are perceived as understanding of the challenges of diagnosis and treatment. Interest in online peer support is greatest among people reporting higher levels of perceived stress. In addition to demographics, perceived stress also relates to a desire for more personalized support in a one-to-one format, such as being matched to a peer supporter. Being matched to an online peer supporter affords the anonymity and convenience of an online support group, while also providing direct and personal communication. In order to meet the needs of diverse patients, individual support options should be incorporated in an online peer support intervention.

Our research brings attention to the need to examine the support needs of low-income or minority men who are seldom represented in the online infertility support literature. It is possible that low-income and minority men with infertility are constrained by social and economic barriers from seeking other modes of support. An online peer support group serves as an accessible mechanism for obtaining one-on-one support, appropriate for a wide range of fertility patients, especially those experiencing elevated stress. Examination of the feasibility of mobile platforms for offering infertility peer support is warranted.

References

Anderson, M., 2017. Digital divide persists even as lower-income Americans make gains in tech adoption. Pew Research Center: Internet & Technology. Retrieved from http://www.pewresearch.org/fact-tank/2017/03/22/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/ on September 22, 2017.

Anderson, M., Perrin, A., 2016. 13% of Americans don’t use the Internet. Who are they? Pew Research Center: Internet & Technology. Retrieved from http://www.pewresearch.org/fact-tank/2016/09/07/some-americans-dont-use-the-internet-who-are-they/ on September 22, 2017.

Boivin, J., Scanlan, L.C., Walker, S.M., 1999. Why are infertile patients not using psychosocial counselling?. Hum. Reprod. 14, 1384-1391.

Bushnik, T., Cook, J.L., Yuzpe, A.A., Tough, S., Collins, J., 2012. Estimating the prevalence of infertility in Canada. Hum. Reprod. 27, 738-746.

Chachamovich, J.R., Chachamovich, E., Ezer, H., Fleck, M.P., Knauth, D., Passos, E.P., 2010. Investigating quality of life and health-related quality of life in infertility: a systematic review. J. Psychosom. Obst. Gyn. 31, 101-110.

Chung, J.E., 2013. Social interaction in online support groups: preference for online social interaction over offline social interaction. Comput. Hum. Behav. 29, 1408-1414.

Cohen, S., Kamarck, T., Mermelstein, R. 1983. A global measure of perceived stress, J. Health Soc. Behav. 24, 385-396.

Coulson, N.S., Malik, S.H., 2012. Health-related online support communities, in: Zheng Y. (Ed.), Encyclopedia of Cyber Behavior, IGI Global, Hershey, PA, pp. 671-688.

Cousineau, T.M., Domar, A.D., 2007. Psychological impact of infertility. Best Pract. Res. Cl. Ob. 21, 293-308.

Cousineau, T.M., Green, T.C., Corsini, E., Seibring, A., Showstack, M.T., Applegarth, L., Davidson, M., Perloe, M., 2008. Online psychoeducational support for infertile women: a randomized controlled trial. Hum. Reprod. 23, 554-566.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., 2008. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ-Brit. Med. J. 337, 979-983.

Cramer, D. Henderson, S., Scott, R., 1997. Mental health and desired social support: a four-wave panel study. J. Soc. Pers. Relat. 14, 761-775.

Crisp, D.A., Griffiths, K.M., 2014. Participating in online mental health interventions: who is most likely to sign up and why?. Depress. Res. Treat. 2014, 1-11.

Dale, J.R., Williams, S.M., Bowyer, V., 2012. What is the effect of peer support on diabetes outcomes in adults? a systematic review. Diabetic Med. 29, 1361-1377.

Dancet, E.A.F., Nelen, W.L.D.M., Sermeus, W., De Leeuw, L., Kremer, J.A.M., D'Hooghe, T.M., 2010. The patients' perspective on fertility care: a systematic review. Hum. Reprod. Update. 16, 467-487.

Darcy, A.M., Dooley, B., 2007. A clinical profile of participants in an online support group. Eur. Eat. Disord. Rev. 15, 185-195.

Davison, K.P., Pennebaker, J.W., Dickerson, S.S., 2000. Who talks? the social psychology of illness support groups. Am. Psychol. 55, 205-217.

DeAndrea, D.C., Anthony, J.C., 2013. Online peer support for mental health problems in the United States: 2004-2010. Psychol. Med. 43, 2277-2288.

Dennis, C., 2010. Postpartum depression peer support: maternal perceptions from a randomized controlled trial. Int. J. Nurs. Stud. 47, 560-568.

Dennis, C., 2003a. Peer support within a health care context: a concept analysis. Int. J. Nurs. Stud. 40, 321-332.

Dennis, C., 2003b. The effect of peer support on postpartum depression: a pilot randomized controlled trial. Can. J. Psychiat. 48, 115-124.

Dow, H.D., 2011. Migrants' mental health perceptions and barriers to receiving mental health services. Home Health Care Management & Practice. 23, 176-185.

Ellis, L.A., Collin, P., Hurley, P.J., Davenport, T.A., Burns, J.M., Hickie, I.B., 2013. Young men's attitudes and behaviour in relation to mental health and technology: implications for the development of online mental health services. BMC Psychiatry 13, 119.

Epstein, Y.M., Rosenberg, H.S., Grant, T.V., Hemenway, B.A.N., 2002. Use of the internet as the only outlet for talking about infertility. Fertil. Steril. 78, 507-514.

Fisher, J.R.W., Baker, G.H.W., Hammarberg, K., 2010. Long term health, well-being, life satisfaction and attitudes towards parenthood in men diagnosed as infertile: challenges to gender stereotypes and implications for practice. Fertil. Steril. 94, 574-580.

Fisher, J.R.W., Hammarberg, K., 2012. Psychological and social aspects of infertility in men: an overview of the evidence and implications for psychologically informed clinical care and future research. Asian J. Androl. 14, 121-129.

Frost, J., Vermeulen, I.E., Beekers, N., 2014. Anonymity versus privacy: selective information sharing in online cancer communities. J. Med. Internet Res. 16, e126.

Frost, M. Casey, L., 2016. Who seeks help online for self-injury, Arch. Suicide. Res. 20, 69-79.

Golbertstein, E., Eisenberg, D., Gollust, S.E., 2008. Perceived stigma and mental health care seeking. Psychiat. Serv. 59, 392-399.

Government of Canada, 2013. Fertility. Retrieved from https://www.canada.ca/en/public-health/services/fertility/fertility.html on August 14 2016.

Greenwood, S., Perrin, A. Duggan, M., 2016. Social media update 2016: Facebook usage and engagement is on the rise, while adoption of other platforms holds steady. Pew Research Center: Internet & Technology. Retrieved from http://www.pewinternet.org/2016/11/11/social-media-update-2016/ on July 3 2017.

Greil, A.L., 1997. Infertility and psychological distress: a critical review of the literature. Soc. Sci. Med. 45, 1679-1704.

Greil, A.L., McQuillan, J., Lowry, M., Shreffler, K.M., 2011. Infertility treatment and fertility-specific distress: a longitudinal analysis of a population-based sample of U.S. women. Soc. Sci. Med. 73, 87-94.

Greil, A.L., Slauson-Blevins, K., McQuillan, J., 2010. The experience of infertility: a review of recent literature. Sociol. Health Ill. 32, 140-162.

Gunby, J. 2012. Assisted reproductive technologies (ART) in Canada: 2012 results from the Canadian ART Register. Canadian Fertility & Andrology Society. Retrieved from https://cfas.ca/public-affairs/canadian-art-register/report-2012/ on June 28 2017.

Haemmerli, K., Znoj, H., Berger, T., 2010. Internet-based support for infertile couples: a randomized controlled study. J. Behav. Med. 33, 135-46.

Hanna, E., Gough, B., 2016. Emoting infertility online: a qualitative analysis of men's forum posts. Health, 20, 363-382.

Haynes-Maslow, L., Allicock, M., Johnson, L., 2017. Peer support preferences among African-American breast cancer survivors and caregivers. Support. Care Cancer 25, 1511-1517.

Haynes-Maslow, L., Allicock, M., Johnson, L., 2016. Cancer support needs for African American breast cancer survivors and caregivers. J. Cancer. Educ. 31, 166-171.

Himmel, W., Meyer, J., Kochen, M.M., Michelmann, H.W., 2005. Information needs and visitors' experience of an Internet expert forum on infertility. J. Med. Internet Res. 7, e20.

Hinton, L., Kurinczuk, J.J., Ziebland, S., 2010. Infertility; isolation and the Internet: a qualitative interview study. Patient Educ. Couns. 81, 436-441.

Hoey, L.M., Leropoli, S.C., White, V.M., Jefford, M., 2008. Systematic review of peer-support programs for people with cancer. Patient Educ. Couns. 70, 315-337.

Horrigan, J.B., Duggan, M., 2015. Home broadband 2015: 3. Barriers to broadband adoption: cost is now a substantial challenge for many non-users. Pew Research Center: internet & Technology. Retrieved from http://www.pewinternet.org/2015/12/21/3-barriers-to-broadband-adoption-cost-is-now-a-substantial-challenge-for-many-non-users/ on October 23 2017

Im, E., Ji, X., Zhang, J., Sangmi, K., Lee, Y., Chee, E., Chee, W., Tsai, H., Nishigaki, M., Yeo, S., Schapira, M., Mao, J. J., 2016. Issues in developing and evaluating a culturally tailored Internet cancer support group. *Computers, Informatics, Nursing*. 34, 462-469.

Im, E., Chee, W., 2008. The use of Internet cancer support groups by ethnic minorities. J. Transcult. Nurs. 19, 74-82.

Kahlor, L., Mackert, M., 2009. Perceptions of infertility information and support sources among female patients who access the Internet. Fertil. Steril. 91, 83-90.

Kennedy, R.A.K., Mullaney, L., Reynolds, C.M.E., Cawley, S., McCartney, D.M.A., Turner, M.J., 2017. Preferences of women for web-based nutritional information in pregnancy. Public Health 143, 71-77.

Luk, B.H., Loke, A.Y., 2015. The impact of infertility on the psychological well-being, marital relationships, sexual relationships, and quality of life of couples: a systematic review. J. Sex Marital Ther. 41, 610-625.

Lykeridou, K., Gourounti, K., Sarantaki, A., Loutradis, D., Vaslamatzis, G., Deltsidou, A., 2011. Occupational social class, coping responses and infertility-related stress of women undergoing infertility treatment. J. Clin. Nurs. 20, 1971-1989.

Malik, S.H., Coulson, N.S., 2010a. 'They all supported me but I felt like I suddenly didn't belong anymore': an exploration of perceived disadvantages to online support seeking. J. Psychosom. Obst. Gyn. 31, 140-149.

Malik, S.H., Coulson, N.S., 2010b. Coping with infertility online: an examination of self-help mechanisms in an online infertility support group. Patient Educ. Couns. 81, 315-318.

Malik, S.H., Coulson, N.S., 2008a. The male experience of infertility: a thematic analysis of an online infertility support group bulletin board. J. Reprod. Infant Psyc. 26, 18-30.

Malik, S.H., Coulson, N.S., 2008b. Computer-mediated infertility support groups: an exploratory study of online experiences. Patient Educ. Couns. 73, 105-113.

Martins, M.V., Peterson, B.D., Almeida, V., Mesquita-Guimarães, J., Costa, M.E., 2014. Dyadic dynamics of perceived social support in couples facing infertility. Hum. Reprod. 29. 83-89.

Mo, P.K.H., Malik, S.H., Coulson, N.S., 2009. Gender differences in computer-mediated communication: a systematic literature review of online health-related support groups. Patient Educ. Couns. 75, 16-24.

Moorhead, S.A., Hazlett, D.E., Harrison, L., Carroll, J.K., Irwin, A., Hoving, C., 2013. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. J. Med. Internet Res. 15, e85.

Newbigging, K., McKeown, M., French, B., 2011. Mental health advocacy and African and Caribbean men: good practice principles and organization models for delivery. Health Expect. 16, 80-104.

Parent, N., Fortin, F., 2000. A randomized, controlled trial of vicarious experience through peer support for male first-time cardiac surgery patients: impact on anxiety, self-efficacy expectation, and self-reported activity. Heart Lung 29, 389-400.

Paterson, B.L., Brewer, J., Stamler, L.L., 2013. Engagement of parents in on-line social support interventions. Hum. Reprod. 28, 114-124.

Porter, M., Bhattacharya, S., 2008. Helping themselves to get pregnant: a qualitative longitudinal study on the information-seeking behaviour of infertile couples. Hum. Reprod. 23, 567-572.

Rainie, L., 2012. Smartphone ownership update: September 2012. Pew Research Center: Internet & Technology. Retrieved from http://www.pewinternet.org/2012/09/11/smartphone-ownership-update-september-2012/ on April 15, 2017.

Read, S.C., Carrier, M.-E., Boucher, M.-E., Whitley, R., Bond, S., Zelkowitz, P., 2014. Psychosocial services for couples in infertility treatment: what do couples really want?. Patient Educ. Couns. 94, 390-395.

Richard, J. Badillo-Amberg, I., Zelkowitz, P., 2017. "So much of this story could be me": men's use of support in online infertility discussion boards. Am. J. Men's Health 11, 663-673.

Schubart, J.R., Stuckey, H.L., Ganeshamoorthy, A., Sciamanna, C.N., 2011. Chronic health conditions and Internet behavioral interventions: a review of factors to enhance user engagement. Comput. Inform. Nurs. 29, 81-92.

Slaunwhite, A.K., 2015. The role of gender and income in predicting barriers to mental health care in Canada. Community Ment. Hlt. J. 51, 621-627.

Slauson-Blevins, K.S., McQuillan, J., Greil, A.L., 2013. Online and in-person health-seeking for infertility. Soc. Sci. Med. 99, 110-115.

Smith, A., 2015. U. S. smartphone use in 2015: Chapter one: A portrait of smartphone ownership. Pew Research Center: Internet & Technology. Retrieved from www.pewinternet.org/2015/04/01/chapter-one-a-portrait-of-smartphone-ownership on April 15, 2017.

Smith, A., 2011. How Americans use text messaging. Pew Research Center: Internet & Technology. Retrieved from http://www.pewinternet.org/2011/09/19/how-americans-use-text-messaging/ on July 3 2017.

Statistics Canada, 2017. Family characteristics, by family type, age of older adult, and family income: annual (CANSIM table 111-0012). Retrieved from http://www5.statcan.gc.ca/cansim/a26?lang=eng&id=1110012&p2=33 on April 4 2017.

van Empel, I.W.H., Nelen, W.L.D.M., Tepe, E.T., van Laarhoven, E.A.P., Verhaak, C.M., Kremer, J.A.M., 2010. Weaknesses, strengths and needs in fertility care according to patients. Hum. Reprod. 25, 142-149.

Van Gemert-Pijnen, J.E., Nijland, N., van Limburg M., Ossebaard H.C., Kelders, S.M., Eysenbach, G., Seydel, E.R., 2011. A holistic framework to improve the uptake and impact of ehealth technologies. J. Med. Internet Res. 13, e111.

van Uden-Kraan, C.F., Drossaert, C.H., Taal, E., Seydel, E.R., van de Laar, M.A., 2009. Participation in online patient support groups endorses patients' empowerment. Patient Educ. Couns. 74, 61-69.

Warttig, S.L., Forshaw, M.J., South, J., White, A.K., 2013. New, normative, English-sample data for the Short Form Perceived Stress Scale (PSS-4). J. Health Psychol. 18, 1617-1628.

White, L., McQuillan, J., Greil, A.L., 2005. Explaining disparities in treatment seeking: the case of infertility. Fertil. Steril. 85, 853-857.

Yousaf, O., Grunfeld, E.A., Hunter, M.S., 2015. A systematic review of the factors associated with delays in medical and psychological help-seeking among men. Health Psychol. Rev. 9, 264-276.

Zillien, N., Haake, G., Frohlich, G., Bense, T., Souren, D., 2011. Internet use of fertiity patients: A systematic review of the literature. J. Reproduktionsmed. Endokrinol. 8, 281-287.

Table 1

Descriptions of patient survey questions, and means and proportion of participants who endorsed online peer support features.

Variable	**Definition**		
Interest in Online Peer Support	[a] *Would you consider using a fertility peer support network that is available online?*		
Online Peer Support Features	[b] *An ideal online peer support network should have:*	**M (SD)**	**Proportion Endorsed**
Platform Format	***Aspects of technology or services provided***		
Mobile Accessibility	*Access online peer support through Smartphone*	4.28 (0.78)	86.6
Links to Other Information	*External content offered through online peer support network*	4.00 (0.82)	79.4
Message Board by Topics	*Organized forum with content categories*	3.98 (0.78)	76.3
ListServ	*Option to join electronic mailing list*	3.55 (0.89)	48.5
Communication	***Ways to share or view information***		
Q & A with Similar Peers	*Ask and answer questions with peers*	4.11 (0.79)	81.9
See Others' Stories/Profiles	*View other individuals' personal information*	3.89 (0.86)	71.1
Anonymous Posting	*Communicate without identification*	3.89 (0.93)	70.7
Space to Share Own Story	*Ability to present one's fertility narrative*	3.68 (0.84)	57.7
Individual Support	***Methods of engaging in more personal or intensive support***		
Private Messaging	*One-on-one communication not visible to other users*	3.85 (0.91)	67.0
Match to Peer Supporter	*Partner with trained fertility support volunteer*	3.59 (0.91)	51.3
Connect to Meet Offline	*Opportunity to meet face-to-face*	3.37 (0.94)	37.9
Monitoring	***A health professional or non-professional to review communication and content***		
Monitoring by Health Professional	*Presence of health professional who reviews content and communication of users*	4.03 (0.85)	75.7
Monitoring by Non-Professional	*Presence of non-professional who reviews content and communication of users*	2.94 (1.05)	25.0

Note: Endorsement includes ratings of *agree* or *strongly agree*.

[a] *no, maybe, yes*; [b] 1 = *strongly disagree*, 2 = *disagree*, 3 = *neutral*, 4 = *agree*, to 5 = *strongly agree*

Table 2

Participant Characteristics (n = 519).

Characteristic	*n*	%
Age	$M = 36.45$	$SD = 5.55$
Education Level[b]		
Less than University	178	34.3
University Graduate	340	65.5
Average Annual Household Income[c]		
≤ $79, 000	239	46.1
> $79, 000	274	52.8
Ethnicity		
White	260	50.1
Non-White	259	49.9
Immigrant Status		
Born in Canada	274	52.8
Born Outside of Canada	245	47.2
Years in Canada	$M = 10.76$	$SD = 9.67$

[a] *Collège d'enseignement général et professionnel.* A post-secondary institution offering professional diplomas and pre-university training.

[b] 1 missing case, [c] 6 missing cases

Table 3

Frequency and Proportion of Fertility Characteristics.

	n (519)	%
Diagnosis		
Male Factor	171	32.9
Female Factor	178	34.3
Male and Female Factors	41	7.9
Unexplained	93	17.9
Assessment Stage	29	5.6
No Diagnostic Information	7	1.3
Type of Treatment[a]		
In Vitro Fertilization	231	44.5
Initial Consultation/Visit	189	36.4
Hormone: Oral	164	31.6
Intrauterine Insemination	162	31.2
Hormone: Injection	135	26.0
Time Trying Before Treatment		
0 to 6 Months	29	5.6
6 Months to 1 Year	125	24.1
1 to 2 Years	226	43.5
3 to 5 Years	98	18.9
≥ 5 Years	39	7.5
Missing	2	0.4
Treatment Duration		
0 to 6 Months	199	38.3
6 Months to 1 Year	114	22.0
1 to 2 Years	121	23.3
3 to 5 Years	58	11.2
≥ 5 Years	22	4.2
Missing	5	1.0
Number of Children		
None	373	71.9
≥ 1	135	26.0
Missing	11	2.1

[a] Categories are not mutually exclusive

Supplementary Table

Correlations Between Demographic, Perceived Stress, and Fertility Variables and Online Peer Support Features

	Platform format (1–4)								Communication (5–8)							
	1. Mobile accessibility		2. Message board		3. Links to information		4. Listserv		5. Anonymous posting		6. Q & A similar peers		7. See others' stories/profiles		8. Space to share story	
	r	*P*-value	*r*	*P*-value	*r*	*P*-value	*r*	*P*-value	*r*	*P*-value	*r*	*P*-value	*r*	*P*-value	*r*	*P*-value
Age	-0.10	0.032[a]	-0.04	0.378	-0.02	0.611	0.03	0.465	-0.10	0.032[a]	-0.09	0.036[a]	-0.10	0.025[a]	-0.08	0.075
Sex	-0.02	0.704	0.07	0.103	0.07	0.091	-0.05	0.296	0.04	0.371	0.07	0.105	0.03	0.465	0.04	0.417
Income	0.12	0.006*	0.00	0.975	0.01	0.788	-0.03	0.495	0.01	0.860	0.00	0.952	0.04	0.408	-0.02	0.717
Education	-0.01	0.911	0.09	0.037[a]	0.02	0.648	-0.02	0.605	0.01	0.805	0.07	0.133	0.03	0.483	0.01	0.753
Ethnicity	-0.01	0.846	0.06	0.217	-0.03	0.552	0.03	0.562	0.14	0.001*	0.10	0.020[a]	-0.01	0.873	0.03	0.576
Immigrant status	0.03	0.528	-0.03	0.521	0.04	0.356	0.02	0.660	-0.07	0.123	-0.08	0.081	0.00	0.977	-0.01	0.872
PSS	0.00	0.986	0.06	0.151	0.04	0.321	0.00	0.986	0.09	0.041[a]	0.10	0.028[a]	0.08	0.086	0.11	0.015[a]
Number of children	-0.06	0.156	-0.05	0.255	0.03	0.494	0.07	0.111	0.05	0.255	0.00	0.961	0.02	0.600	0.03	0.441
Time trying before treatment[b]	-0.03	0.473	-0.02	0.727	0.00	0.978	0.00	0.973	-0.04	0.349	-0.04	0.347	-0.04	0.391	-0.09	0.053
Treatment duration[b]	-0.06	0.162	-0.01	0.863	0.01	0.847	0.01	0.813	-0.05	0.276	0.00	0.981	-0.04	0.416	0.01	0.759

	Individual support (9–11)						Monitoring (12–13)			
	9. Match me to peer supporter		10. Connect to meet offline		11. Private messaging		12. Monitoring by health professional		13. Monitoring by non-professional	
	r	*P*-value	*r*	*P*-value	*r*	*P*-value	*r*	*P*-value	*r*	*P*-value
Age	-0.04	0.345	-0.00	0.949	-0.12	0.009*	-0.05	0.310	-0.05	0.275
Sex	0.02	0.679	0.04	0.363	0.11	0.015[a]	0.09	0.054	-0.02	0.694
Income	-0.10	0.029[a]	-0.10	0.031[a]	0.01	0.804	-0.09	0.045[a]	0.02	0.617
Education	-0.02	0.614	0.01	0.892	0.03	0.474	-0.03	0.542	-0.02	0.707
Ethnicity	0.12	0.007*	0.06	0.185	0.09	0.047[a]	0.12	0.005*	-0.03	0.502
Immigrant status	-0.11	0.010[a]	-0.10	0.026[a]	-0.05	0.274	-0.07	0.107	0.04	0.319
PSS	0.12	0.008*	0.13	0.002*	0.08	0.074	0.08	0.072	0.01	0.891
Number of children	-0.02	0.617	0.03	0.469	0.01	0.836	0.05	0.251	-0.03	0.567
Time trying before treatment[b]	-0.04	0.366	-0.04	0.431	-0.05	0.307	0.05	0.289	-0.02	0.661
Treatment duration[b]	0.10	0.023[a]	0.09	0.033[a]	-0.01	0.861	0.04	0.383	0.02	0.667

[a] Not significant at = .01   [b] Spearman's Rho Coefficient

Note: 0 = male, income ≤ $79,000, < university education, White, born outside of Canada, and no children.

Linking Studies One and Two

Prior to the development of this peer support program, it was necessary to establish interest in, and preferences for, online peer support among diverse stakeholders. Including patient stakeholders in the program development process is important for ensuring that program features match the needs of the target population. The objectives of study 1 were therefore to (1) determine whether diverse fertility patients held interest in online infertility peer support and which factors associated with interest, and (2) to identify patients' preferences for features of an online peer support program.

Results of the needs assessment study revealed a high level of interest in online peer support among 519 fertility patients, with perceived stress emerging as the only determinant of interest among men and women. Although previous literature had intimated such interest, study 1 reflects the first survey of interest in online peer support among men and women undergoing fertility treatment. In addition, results indicated that fertility patients preferred access to a professionally monitored online discussion forum that provided links to information and opportunities for anonymous communication with peers using mobile technology. As a result, the online peer support program was developed to be accessible through multiple devices, including desktop and smartphones, and included links to external information, discussion threads, and professional monitoring.

The next stage in program development was to describe the development and evaluation of the online peer supporter training program. Including peer supporters in program evaluation was necessary to establish feasibility and acceptability among a second group of key stakeholders. To assess feasibility and acceptability, a mixed method survey study was conducted to assess peer supporter experiences with online training and support provision.

Article 2

Development and Evaluation of an Online Infertility Peer Supporter Training Program

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Abstract

Objective: To outline the development and evaluation of an online infertility peer supporter training program. Methods: Men and women with diverse infertility backgrounds were recruited and trained to provide online peer support to people undergoing fertility treatment. Training required volunteers to (1) read a peer support training manual, (2) watch a webinar, and (3) complete practice questions, each of which was evidence-based and reviewed by key stakeholders. Results: Seventeen women and one man were trained and provided online peer support. Program satisfaction was high and training materials were rated as helpful. Peer supporters felt comfortable providing support and having their discussions monitored. They liked helping others and the convenience of a mobile application. Conclusion: Online recruitment and training of infertility peer supporters is feasible. The current program was acceptable and offers steps for improving future online peer support interventions. Practice implications. Current evidence supports the acceptability and feasibility of this training and supervision program, and provides service providers with information guiding its development and implementation.

Key Words: Peer support; Infertility; Program evaluation; eHealth; mHealth; Training

1. Introduction

An infertility diagnosis is a stressful experience for both men and women desiring children. Fertility treatment engenders physical, psychological, and financial stresses [1], with overall psychological burden being the strongest predictor of treatment discontinuation [2]. Social support during treatment contributes to life satisfaction [3,4]. Increasing social connectedness via peer support may improve fertility-related quality of life [3] by reducing social isolation and distress associated with infertility [5,6]. The current study describes the development and evaluation of a training program for infertility peer supporters that aimed to improve the delivery and sustainability of an online peer support program.

Peer support is the exchange of support between individuals with similar characteristics and problems. It involves three types of support [7]: (1) emotional support refers to empathic responses including expressions of care, encouragement, attentiveness, reflection, and reassurance; (2) informational support refers to the provision of knowledge; and (3) appraisal support refers to giving information that helps a person engage in self-evaluation.

Many people undergoing fertility treatment desire connection with other patients [8,9] who can provide experiential information and support about infertility issues [10]. Online peer support is of interest to many fertility patients [11] and, compared to in-person support groups, allows for asynchronous and anonymous communication at any time or location, improving the financial and geographical accessibility of psychosocial services for people with infertility.

For people with chronic illnesses, peer support assists with disease management and medical decision-making and improves psychosocial well-being [12]. For example, access to peer support may improve glycemic control [13] and self-efficacy of disease self-management for those with diabetes [14]. Other research has shown that mothers at high risk for postpartum depression perceived peer support to be effective in preventing depression onset [15].

Peer supporters cite desire to help others as an important motivation for providing support [16], and they may experience a sense of personal growth as a result of providing peer support for postpartum depression, cancer, or HIV/AIDS medication adherence [16,17,18]. In this way, peer support may be seen as a mutually beneficial process to those providing and receiving support.

To ensure the effectiveness of peer support interventions, training is required. If peer supporters are not trained, peer-to-peer interactions may become overly focused on negative aspects of treatment [19]. There is also a potential for reinforcement of social isolation by emphasizing that fertile people cannot understand infertility experiences and that the forum is the only place to acquire such support [5]. Other qualitative research has found that some users perceived themselves as becoming preoccupied with infertility and spending too much time in online forums [6]. The use of trained peer supporters may mitigate some of the negative aspects of online peer support, by describing positive aspects of social support and normalizing and validating experiences, thereby instilling a sense of hope in early treatment-seekers [19].

To support fertility patients experiencing psychological distress and to meet their needs for accurate information and empathetic support, our research team developed a mobile health peer support application (app) called Infotility. A major feature of Infotility was a discussion forum where anonymous posts were reviewed by peer supporters, who had themselves experienced infertility and were trained to provide support to people currently undergoing fertility treatment. This study describes the (1) development of the peer supporter training materials (i.e., training manual, online webinar, practice questions); (2) recruitment procedures;

and (3) evaluation of the program through a survey provided to the peer supporters. By including peer supporter evaluations, this study sought to increase understanding about the acceptability and feasibility of peer supporter programs.

2. Methods

2.1. Recruitment and training

2.1.1. Recruitment

Potential participants were recruited online and offline through two Canadian fertility organizations, one fertility clinic, and word-of-mouth. Eligibility criteria were: (1) personal history of infertility, (2) ability to read and write in English and/or French, (3) ability to volunteer 4 h per week, and (4) access to Internet technology for app use (e.g., smartphone, laptop). Fertility organizations were initially contacted by a member of the research team who explained the purpose and nature of the study. The first organization e-mailed study information to their own leaders of in-person support groups. Interested volunteers sent their contact information to the fertility organization member who then forwarded contact information to our team for follow-up. The second fertility organization placed study information on their organizational Facebook page; those interested contacted the research team directly. Recruitment flyers were also left at a participating fertility clinic as physical copies and digital advertisement on waiting room screens. Lastly, recruitment information was added to our laboratory website, twitter, and Facebook pages. Peer supporters who completed the study were compensated with a $25 Amazon gift card.

2.1.2. Training

Following informed consent procedures approved by a university research ethics committee, participants completed a 4 h training program, developed by our research team.

Training involved (1) reading a peer support training manual, (2) watching a 35-minute training webinar, and (3) responding to practice discussion posts created by the research team to reflect the type of messages volunteers might view on the discussion forum. At the start of training, volunteers received an email instructing them to familiarize themselves with the training manual, complete an online survey assessing demographic and fertility characteristics, and watch the webinar. Finally, volunteers were asked to write and return responses to three hypothetical practice posts about infertility-related problems (e.g., medication side-effects), using information from the manual and webinar.

Three peer support coordinators (PHG, KG, RI) developed and implemented the peer support training materials and procedures. The coordinators were part of the research team; PHG was completing PhD training in clinical psychology; KG was a couple and family therapist; and RI was a clinical social worker. Training materials were evidence-based, accessible and appropriate in terms of language and content [20,21], and explained the purpose of the materials. All materials were reviewed and critically revised by members of the research team, collaborating professionals, and patient stakeholders (i.e., one man and one woman with a history of infertility) prior to final approval. Key stakeholders (i.e., patients and professionals) were included in training material development to tailor information to the specific needs of those most likely to use the intervention [20] and to ensure that materials were both interesting and relevant to people with lived infertility experience. Once feedback was reviewed and incorporated, all materials were translated into French by members of the research team. Reverse translation was conducted to ensure accuracy of original translations.

2.2. Peer support training manual

The peer support training manual is a 79-page document (see Fig. 1 for table of contents) informed by guidelines for a telephone-based peer support training program for postpartum depression [7,16]. The manual provides volunteers with knowledge about their role as a peer supporter, factual information about infertility, and the use of different types of peer support (e.g., emotional support). The manual also includes information about expected conduct, including rules, guidelines, and ways to monitor the forum for ‘red flags’ (e.g., severe depressive language) [23]. Lastly, the manual includes procedures for contacting the peer support coordinators, frequently asked questions, and a glossary of medical terms and abbreviations.

An important feature of the manual was the inclusion of example posts and acceptable responses in relation to 10 fertility-related topics. The topics were deductively generated [24] by 3 peer support coordinators who examined research literature related to online infertility communication [6,25] and surveyed popular online fertility discussion forums. See Fig. 2 for an example of a post and response from the Medical section of the manual. Posts were intended to provide concrete examples of how to assess the intention of an app user’s message and respond with emotional, informational, and/or appraisal support. Given research suggesting that men and women with infertility seek contact with people who have similar lived experience [9,10], volunteers were instructed to validate users, normalize problems, and share personal experiences.

The layout of the manual was also considered to ensure that information was readable, engaging, and appropriate to the volunteers. The inclusion of colour, graphics, headings, subsections, simple vocabulary and culturally sensitive images ensured ease of use and acceptability (see Fig. 2) [26]. Reading level was evaluated with Flesch-Kincaid [27] in Microsoft Word (version 16). Excluding the glossary of medical terms and abbreviations, the manual had a grade level of 8.8, indicating accessibility to the intended readers.

2.3.1. Webinar

To supplement the peer support training manual, all volunteers watched a 35-minute webinar that highlighted key information from the training manual and provided additional practice questions with discussion of ideal responses (See Fig. 3). The webinar consisted of PowerPoint slides and was recorded with the online conference program GoToMeeting. Two peer support coordinators recorded English and French webinars, which were reviewed by all peer support coordinators and the principal investigator followed by audio-video editing by the first author. Videos were uploaded as *unlisted* to YouTube and privately shared to volunteers using a unique URL.

2.3.2. Practice posts

Research on peer supporter experiences has suggested that volunteers value pre-intervention practice [16]. Accordingly, once volunteers confirmed webinar completion, each volunteer was sent three hypothetical discussion posts, developed by the research team by reading posts from online fertility-related forums and incorporating salient content (e.g., anxiety about medical complications). Participants then sent their responses back by e-mail. Participants received feedback, which included increased use of personal stories to convey understanding and empathy, avoiding any medical or product recommendations, and being more specific to aid in app user comprehension.

2.4. Peer supporter experiences questionnaire

Following study completion, peer supporters completed a 21-item survey about experiences with training, interacting with peer support coordinators, and providing peer support, adapted from other research with peer supporters [16]. Most items provided 5-point Likert scale options; for example, "*How helpful were the following aspects of training?*" was rated 1 = very unhelpful to 5 = very helpful. For the question, "*When providing support, rate how often you felt*: *knowledgeable, respected, appreciated, helpful, that you made a difference*", responses were coded as 1 = always to 5 = never. Two questions were dichotomous (i.e., yes or no): *"Were you comfortable contacting the coordinators?"* and *"Were the coordinators easy to reach?"* Multiple response checklists were used to assess what peer supporters liked most and least about the program and about using an app to provide peer support. Open-ended questions were asked regarding preferred changes to training and any comments on their peer supporter experience.

2.5. Schedule

Peer supporters were scheduled to monitor the message board for four hours per week, based on previous peer support research [28] and the finding that lack of time is the most commonly reported reason for not volunteering [29]. Peer supporters arranged their volunteer time in discussion with peer coordinators by phone or e-mail. Actual volunteer times ranged from two to four hours, with some volunteers splitting their time into two two-hour slots.

3. Results

3.1. Sample characteristics

Recruitment took place from June to November 2018. Overall, 41 people were contacted, with 27 consenting to participate. Reasons for refusal (n = 7) all related to having insufficient time for either training or volunteering. Refer to Table 1 for recruitment and training statistics by primary spoken language. Overall, 18 peer supporters were scheduled for peer support provision. Two volunteers (1 man, 1 woman) dropped out of the study before completion. The woman who dropped out was available for the majority of the study and left because of time constraints. The man sent an e-mail explaining that he did not feel useful because most of the posters were women.

Nineteen participants completed the background questionnaire. Age ranged from 28 to 65 (*M* = 39.26, *SD* = 8.40). Seven (36.8 %) were bilingual, 8 (42.1 %) spoke English only, and four (21.1 %) spoke French only. Fifteen (78.9 %) were born in Canada and all were in a current relationship. Twelve (63.2 %) reported having biological children of which 8 (66.7 %) reported that one or more of their children were conceived using ART. One (5.3 %) peer supporter had an adopted/foster child.

Six peer supporters reported currently receiving fertility treatment (31.6 %) for which the average treatment length was 3.83 years (*SD* = 2.23). Those not currently in treatment (*n* = 13) reported treatment durations between 0 and ≥10 years, with average duration of 4 years (*SD* = 2.61). Only one volunteer had not undergone treatment and another one had been in treatment for ≥10 years. The participant without a treatment history was accepted given their interest and history of trying to conceive without success. A range of treatments was reported, including in-vitro fertilization (*n* = 13, 68.4 %), intracytoplasmic sperm injection (*n* = 6, 31.6 %), and intrauterine insemination (*n* = 12, 63.2 %).

Eleven (57.9 %) reported a female-factor diagnosis (e.g., blocked fallopian tubes) and six (31.6 %) were diagnosed with a male-factor diagnosis (e.g., low sperm count). Two reported unexplained diagnoses.

3.2. Implementation and app functioning

The discussion forum was open to app users from November 2018 to May 2019, resulting in a time commitment of approximately six months for peer supporters recruited pre-intervention (n = 16). In the first month of app use, several peer supporters reported technical issues related to logging in and staying logged in to the app. Peer coordinators created and sent peer supporters a document specifying how to log-in without difficulty.

Volunteers generally fulfilled their commitments, with a few exceptions. Specifically, some volunteers asked for a schedule change due to work schedule or family events, including childbirth, child care, and family illness.

3.3. Discussion forum data

App users (*n* = 40) made a total of 244 posts in English (*n* = 231; 94.7 %) and French (*n* = 13; 5.3 %). The number of posts per app user ranged from 1 to 36 (*Median* = 3, IQR = 4.5). Peer supporters responded to all original posts, making a total of 169 English (*n* = 149; 88.2 %) and French (*n* = 20; 11.8 %) posts. On average, peer supporters took 23 h and 34 min to respond to the first post from an app user. Outliers were identified as those above and below the third and first quartiles, respectively, then removed, resulting in an average response time of 19 h and 14 min.

3.4. Peer supporter experiences questionnaire

The Peer Supporter Experiences Questionnaire asked volunteers about their experiences with training and support provision, the experience of being a peer supporter, and using a online application to provide support. Seventeen of 18 volunteers completed the questionnaire. Four (23.5 %) reported prior experience providing peer support. Sixteen (94.1 %) reported that they would recommend this peer support program to someone experiencing infertility. Program satisfaction was high and most volunteers agreed that the Infotility app was helpful for those looking for information or support (See Table 2).

3.4.1. Experiences of peer support training and provision

Ratings for training components are provided in Table 3. All components were rated as helpful overall, with the *App Map* (i.e., PDF files with text and images describing app layout and flow) having less favourable ratings. Volunteers reported that role expectations were clear and rated the amount and quality of coordinator assistance/support as good to very good. Similarly, ratings for comfort regarding coordinators reviewing discussion content was high. Participants reported that training could be improved by: having a clearer introduction to the Infotility app content and resources, a conference call prior to volunteering, personalized passwords and usernames, and shorter surveys and training.

On average, volunteers reported feeling frequently or always *respected*, *appreciated*, *helpful*, *knowledgeable*, and that they *made a difference* (See Table 4 for descriptive statistics). Responses to open-ended questions indicated that some volunteers felt unhelpful due to the limited number of posts needing a response and, despite training, unprepared to discuss fertility-related issues of which they had no experience (e.g., supporting someone with a different diagnosis or treatment).

All but two volunteers who accessed the survey (88.2 %) reported never feeling uncomfortable while supporting app users; one participant who reported discomfort was the same man who dropped out of the study because he perceived his male experience to be of little value to the predominantly female forum.

3.4.2. Experience with being a peer supporter

Volunteers rated their most and least liked aspects of being a peer supporter (See Table 5). The most liked aspect was *helping people* followed by *acquiring skills*; the most disliked aspect was *scheduling conflicts*. Four respondents reported *other* disliked aspects of providing support, including: limited opportunity or perceived need for their input, the anonymous username provided to all volunteers (i.e., Infotility Peer Supporter), fear of saying the wrong thing, and difficulties related to not having app notifications for new posts. One volunteer suggested that peers be organized by fertility history so that those with histories most similar to the app user would be providing support. Although only four volunteers disliked technology issues, nine (52.9 %) reported technology issues that were problematic. These issues related to logging in and staying logged in to the app.

3.4.3. Experience with using a mobile app for peer support

Volunteers rated their preference for providing in-person versus app support ($n = 14$); nine reported no preference (52.9 %), one reported in-person (5.9 %), and 3 preferred providing support through an app (17.6 %).

A multiple response checklist was used to assess most and least liked aspects of providing support through a mobile app (Table 6). Volunteers most frequently liked being able to use the app any time of day (76.5 %) and in any location (76.5 %). With respect to least liked aspects, five (29.4 %) volunteers reported difficulties with expressing feelings through text, and four (23.5 %) reported technical issues. Overall, peer supporters rated the program, training, and online format highly, and provided feedback as to areas for future improvement.

4. Discussion and conclusion

4.1. Discussion

This study describes the development and evaluation of a peer support training program. Results provide evidence for the acceptability and feasibility of online peer supporter training and supervision. Overall, peer supporters were satisfied with their training and felt the Infotility app would be very helpful for fertility patients seeking information or support.

Most peer supporters were recruited from two national organizations, necessitating an online program that could reach individuals across Canada. Although the peer supporters were predominantly female, fertility characteristics were diverse, thereby allowing for greater opportunity for normalizing patient experiences. Normalization of infertility-related issues relates to better quality of life among fertility patients [30] and is a perceived benefit of accessing online peer support for infertility [5].

Novel to our program were training materials that included information about, and examples of using different types of support (e.g., emotional). Several peer supporters liked learning new skills, suggesting that this type of information may foster program satisfaction and capacity development. Peer supporters also liked being able to use the app any time of day from any location, highlighting the practical utility of online, compared to in-person, peer support training and provision. The flexibility may also enable peer supporters to remain in the program longer than typical face-to face programs. Previous research has documented the perceived convenience of online infertility support only among those seeking support [5]. The present findings add new knowledge by showing that trained peer supporters also value these features.

An important app feature was the presence of peer support coordinators who monitored and reviewed online discussion. Monitoring content is important to mitigate harm for participants and peer supporters [18] and to edit messages that identify specific clinics or people, recommend medical products, or provide medical advice. The fact that peer supporters were satisfied with the review process indicates that this is an acceptable way to promote forum safety and participant satisfaction.

Technological issues emerged as a disliked feature among some peer supporters. Presence of technical issues may relate to more negative perceptions of app usability [31] or functionality. Although it is unclear to what extent usability and functionality contribute to user satisfaction, these attributes nonetheless reflect core facets of app quality [32].

In evaluating their experience as peer supporters, the participants in this study highlighted feelings of respect and appreciation, but were less certain whether their support was actually helpful to the app users. Research in other patient groups has found that a subset of peer supporters doubted their effectiveness or ability to help their peers (16,18]. It may be beneficial to include information about peer supporters' emotional experiences during training as a means of preparing volunteers [16]. Doing so could normalize these experiences and encourage volunteers to contact coordinators for support and guidance. Peer supporter confidence may also be improved by relaying positive experiences from the app users themselves. Comments about the small number of app users to respond to may have related to lower perceived effectiveness as a peer supporter. The current program attempted to have a peer supporter available for each of three four-hour shifts each day to ensure timely response to posts, the number of peer supporters may have been greater than was needed for the limited number of app user posts on our closed forum. Accordingly, future research is needed to understand how the number of support group members affects peer supporter self-efficacy, helpfulness, or effectiveness.

Scheduling conflicts were also reported by nearly half of the sample as a disliked feature of being a peer supporter. The four-hour commitment may have been too great for some volunteers. The inclusion of mobile notifications, such as a sound or display, could allow peer supporters to engage in other tasks, rather than continually monitoring the discussion board.

The current study aimed to have both men and women provide peer support, but we were unable to recruit many men. Multiple recruitment strategies may be needed to recruit men, including approaching personal contacts (e.g., friends, family), advertising, and snowball sampling, whereby recruited men are then asked about other men they might know [33]. Other possibilities for future recruitment of men as peer supporters and intervention users may include advertising to a wider range of fertility clinics, and using existing online male infertility forums [34]. Of the two men recruited, only one completed training and after several weeks of monitoring the board decided that his participation was not needed due to the paucity of male fertility patients using the message board. Training materials emphasized that it was not important to have the exact same experiences as peers (e.g., same treatment or diagnosis); rather, peer supporters were encouraged to identify any way to relate to peers, whether it was in terms of emotional experience (e.g., anxiety) or treatment features. The man who dropped out, however, did not believe that he could provide such support to infertile women. Further research into male experiences in the provision of peer support and satisfaction are warranted.

All app user posts were responded to in the current study; however, response time was longer than anticipated. Because of the anonymous shared log-in used by all peer supporters, it was unclear when specific peer supporters responded. More timely responses may be facilitated through the use of weekly reminders.

The current study is limited by the primarily female sample, which precludes generalizability to male peer supporters. Research should examine men’s perceptions of online peer support to better understand their perspectives and preferences regarding online peer support interventions. Several peer supporters also omitted questions from the peer supporter experiences survey. It is possible that these volunteers held different views about the program than those who responded. Research is needed to clarify whether certain peer supporter characteristics (e.g., demographics) relate to peer supporter experiences. Mixed method research may also be useful for examining the types of support provided by peer supporters and whether app users experience this type of peer support as beneficial.

4.2. Conclusion

In order to provide safe and effective peer support interventions to people with infertility, adequate protocols are required for training peer support volunteers. The current study provides evidence of the acceptability and feasibility of an online infertility peer supporter training/supervision program to women with a history of infertility. Peer supporters valued being able to help others, learn new skills, and provide support through a convenient mobile app.

4.3. Practical implications

The Internet can be used to recruit and train volunteers to provide peer support to fertility patients. The present study provides service providers with information guiding the development and implementation of peer support training programs. The accessibility of online peer support reflects a potentially cost-effective resource for clinics and healthcare providers [19]. The Internet also allows for long-distance recruitment, training, and monitoring of peer supporters, which may increase access to patients in remote locations. Lastly, peer supporters can provide support to patients, something valued by patients and which busy clinicians may lack the time to provide.

References

[1] A.D. Domar, Quality of life must be taken into account when assessing the efficacy of infertility treatment, Fertil. Steril. 109 (2018) 71–72.

[2] A.D. Domar, Impact of psychological factors on dropout rates in insured infertility patients, Fertil. Steril. 81 (2004) 271–273.

[3] M. Kiesswetter, H. Marsoner, A. Luehwink, M. Fistarol, A. Mahlknecht, S. Duschek, Impairments in life satisfaction in infertility: associations with perceived stress, affectivity, partnership quality, social support and the desire to have a child, Behav. Med. (2019) 1–12, doi:http://dx.doi.org/10.1080/ 08964289.2018.1564897.

[4] A. Kroemeke, E. Kubicka, Positive and negative adjustment in couples undergoing infertility treatment: the impact of social support exchange, PLoS One 13 (2018)e0200124, doi:http://dx.doi.org/10.1371/journal. pone.0200124.

[5] L. Hinton, J.J. Kurinczuk, S. Ziebland, Infertility; isolation and the internet: a qualitative interview study, Patient Educ. Couns. 81 (2010) 436–441.

[6] S.H. Malik, N.S. Coulson, Computer-mediated infertility support groups: an exploratory study of online experiences, Patient Educ. Couns. 73 (2008) 105–113.

[7] C.-L. Dennis, Peer support within a health care context: a concept analysis, Int. J. Nurs. Stud. 40 (2003) 321–332. [8] E.A.F. Dancet, W.L.D.M. Nelen, W. Sermeus, L. De Leeuw, J.A.M. Kremer, T.M. D'Hooghe, The patients' perspective on fertility care: a systematic review, Hum. Reprod. Update 16 (2010) 467–487.

[9] S.C. Read, M.E. Carrier, M.E. Boucher, R. Whitley, S. Bond, P. Zelkowitz, Psychosocial services for couples in infertility treatment: what do couples really want? Patient Educ. Couns. 94 (2014) 390–395.

[10] M. Porter, S. Bhattacharya, Helping themselves to get pregnant: a qualitative longitudinal study on the information-seeking behaviour of infertile couples, Hum. Reprod. 23 (2008) 567–572.

[11] P.H. Grunberg, C.-L. Dennis, D. Da Costa, P. Zelkowitz, Infertility patients' need and preferences for online peer support, Reprod. Biomed. Soc. Online 6 (2018) 80–89.

[12] S.D. Kowitt, K.R. Ellis, V. Carlisle, N.L. Bhushan, K.Z. Black, K. Brodar, N.M. Cranley, K.L. Davis, E. Eng, M.Y. Martin, J. McGuirt, R.L. Sokol, P.Y. Tang, A.I. Vines, J.S. Walker, E.B. Fisher, Peer support opportunities across the cancer care continuum: a systematic scoping review of recent peer-reviewed literature, Support. Care Cancer 27 (2018) 97–108.

[13] J.R. Dale, S.M. Williams, V. Bowyer, What is the effect of peer support on diabetes outcomes in adults? A systematic review, Diabet. Med. 29 (2012) 1361–1377.

[14] L.-N. Kong, P. Hu, L. Yang, D. Cui, The effectiveness of peer support on selfefficacy and quality of life in adults with type 2 diabetes: a systematic review and meta-analysis, J. Adv. Nurs. 75 (2019).

[15] C.-L. Dennis, Postpartum depression peer support: maternal perceptions from a randomized controlled trial, Int. J. Nurs. Stud. 47 (2010) 560–568.

[16] C. Dennis, Peer support for postpartum depression: volunteers' perceptions, recruitment strategies and training from a randomized controlled trial, Health Promot. Int. 28 (2013) 187–196.

[17] P. Marino, J.M. Simoni, L.B. Silverstein, Peer support to promote medication adherence among people living with HIV/AIDS: the benefits to peers, Soc. Work Health Care 45 (2007) 67–80.

[18] N. Pistrang, Z. Jay, S. Gessler, C. Barker, Telephone peer support for women with gynaecological cancer: benefits and challenges for supporters, Psycho-Oncol. 22 (2013) 886–894.

[19] J. Hu, X. Wang, S. Guo, F. Chen, Y.-y. Wu, F.-j. Ji, X. Fang, Peer support interventions for breast cancer patients: a systematic review, Breast Cancer Res. Treat. 174 (2019) 325–341.

[20] P. Craig, P. Dieppe, S. Macintyre, S. Michie, I. Nazareth, M. Petticrew, Developing and evaluating complex interventions: the new Medical Research Council guidance, Br. Med. J. 337 (2008) 1–6, doi:http://dx.doi.org/10.1136/bmj.a1655.

[21] Jewish General Hospital, How to Create Effective Written Patient Learning Materials: Adapted by the JGH Patient Education Network (PEN) Working Group From the McGill University Health Centre Standards for Developing Effective Written Patient Learning Materials 2007, (2008) . https://cdn.ciussscentreouest.ca/documents/hgj/HSL/PEN/Website_Specific/HandbookEngJan20.pdf?1554833096.

[22] C.-L. Dennis, The effect of peer support on postpartum depression: a pilot randomized controlled trial, Can. J. Psychiatr. 48 (2003).

[23] A.A. Gits, P.L. Ritter, K. Plant, K. Lorig, Coding and evaluating facilitator posts for an online Cancer survivor workshop, J. Psychosoc. Oncol. 31 (2) (2013) 219– 234.

[24] S. Elo, H. Kyngäs, The qualitative content analysis process, J. Adv. Nurs. 61 (2008) 107–115.

[25] E. Hanna, B. Gough, Searching for help online: an analysis of peer-to-peer posts on a male-only infertility forum, J. Health Psychol. 23 (2018) 917–928.

[26] C.G. Doak, L.G. Doak, J.H. Root, Teaching Patients With Low Literacy Skills, Lippincott, Philadelphia, PA, 1996. https://www.hsph.harvard.edu/ healthliteracy/resources/teaching-patients-with-low-literacy-skills/.

[27] J. Kincaid, R. Fishburne, R. Rogers, B. Chissom, Derivation of New Readability Formulas (Automated Readability index, FOG Count, and Flesch Reading Ease Formula) for Navy Enlisted Personnel, Research Branch Report, 40, Institute for Simulation and Training, 1975. https://stars.library.ucf.edu/cgi/viewcontent. cgi?article=1055&context=istlibrary.

[28] C.-L. Dennis, The process of developing and implementing a telephone-based peer support program for postpartum depression: evidence from two randomized controlled trials, Trials 15 (2014) 1–8.

[29] Statistics Canada, Canadian Social Trends: Volunteering in Canada. Catalogue No. 93, (2012) 11-008-X, 2012001.

[30] Y. Benyamini, M. Gozlan, A. Weissman, Normalization as a strategy for maintaining quality of life while coping with infertility in a pronatalist culture, Int. J. Behav. Med. 24 (2017) 871–879.

[31] B.C. Zapata, J.L. Fernández-Alemán, A. Idri, A. Toval, Empirical studies on usability of mHealth apps: a systematic literature review, J. Med. Syst. 39 (2015) 1–19.

[32] R. Nouri, S.R.N. Kalhori, M. Ghazisaeedi, G. Marchand, M. Yasini, Criteria for assessing the quality of mHealth apps: a systematic review, J. Am. Med. Inform. Assn. 25 (2018) 1089–1098.

[33] C. Law, Men on the margins? Reflections on recruiting and engaging men in reproduction research, Method Innov. 12 (2019), doi:http://dx.doi.org/10.1177/ 2059799119829425.

[34] J. Richard, I. Badillo-Amberg, P. Zelkowitz, "So much of this story could be me": men’s use of support in online infertility discussion boards, Am. J. Mens Health 11 (2016) 663–673.

Table 1

Recruitment and retention by primary language.

	Anglophone	Francophone
Contacted	25	16
Could not be Reached	5	2
Declined	5	2
Consent Obtained	15	12
Completed Training	11	9
Active Peer Supporter	11	7
Attrition	0	2[a]

[a] The two peer supporters who dropped out completed the peer supporter experiences survey and are included in survey results.

Table 2

Volunteer ratings of program satisfaction and helpfulness for those seeking information and support.

Overall, how satisfied were you with this peer support program?

	Very Satisfied	Somewhat Satisfied	Neither	Somewhat Dissatisfied	Very Dissatisfied	Missing
n (%)	3 (17.6)	8 (47.1)	1 (5.9)	0 (0.0)	0 (0.0)	5 (29.4)

'I think Infotility is helpful for those looking for information about infertility'

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Missing
n (%)	8 (47.1)	7 (41.2)	1 (5.9)	0 (0.0)	0 (0.0)	1 (5.9)

'I think Infotility is helpful for those looking for support about infertility'

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Missing
n	10 (58.8)	6 (35.3)	0 (0.0)	0 (0.0)	0 (0.0)	1 (5.9)

Table 3

Volunteer ratings of training materials, clarity of role expectations.

[a]*How helpful were these aspects of training?*			
	M	***SD***	***n***
Training manual	4.50	0.89	16
Online Format	4.60	0.91	15
Answering Sample Posts	4.19	1.33	16
App Map	3.87	0.83	15
Information about Types of Support	4.31	0.48	16
[b]*Rate the extent to which the expectations of your role as a peer supporter were clear:*	4.50	0.52	12
Please rate the following:			
	M	***SD***	***n***
[c]Quality of Coordinator Assistance	4.75	0.45	12
[c]Amount of Coordinator Assistance	4.83	0.39	12
[d]Comfort that Coordinators Reviewed Discussions	4.85	0.38	13
	Yes	**No**	**Missing**
Were you Comfortable Contacting Coordinators?	12	0	5
Were Coordinators Easy to Reach?	12	0	5

[a] 1 = very unhelpful, 2 = somewhat unhelpful, 3 = neither, 4 = somewhat helpful, 5 = very helpful
[b] 1 = very unclear, somewhat unclear, 3 = neither, 4 = somewhat clear 5 = very clear
[c] 1 = very poor, 2 = somewhat poor, 3 = neutral, 4 = somewhat good, 5 = very good
[d] 1 = never, 2 = rarely, 3 = half the time, 4 = frequently, 5 = always

Table 4

Volunteer ratings of personal peer supporter qualities

[a]When providing support, rate how often you felt:	*M*	*SD*	*n*
Knowledgeable	3.81	.75	16
Respected	4.87	.35	15
Appreciated	4.37	1.09	16
Helpful	4.00	1.03	16
That you made a difference	3.47	1.19	15

[a]When providing support, rate how often you felt:	*M*	*SD*	*n*
Knowledgeable	3.81	.75	16
Respected	4.87	.35	15
Appreciated	4.37	1.09	16
Helpful	4.00	1.03	16
That you made a difference	3.47	1.19	15

[a] 1 = never, 2 = rarely, 3 = half the time, 4 = sometimes, 5 = always

Table 5

Frequency of most liked and disliked aspects of being a peer supporter.

What did you like the most about being a peer supporter in this program?	
	***n* (%)**
Helping People	16 (94.1)
Acquiring Skills	7 (41.2)
Feeling Valued	4 (23.5)
Learning About Myself	4 (23.5)
Becoming Familiar With New Tech	4 (23.5)
Other	1 (5.9)
What did you dislike the most about being a peer supporter in this program?	
	***n* (%)**
Scheduling Conflicts	8 (47.1%)
Technology Problems	4 (23.5)
Time Consuming	3 (17.6)
Pressure of Providing Support	2 (11.8)
Knowing my Posts were Being Reviewed	0 (0.0)
Using Mobile Tech	1 (5.9)
Did not Dislike Anything	3 (17.6)
Other	7 (41.2)

Note. Categories not mutually exclusive and completed using checklist format.

Table 6

Frequency of liked and disliked aspects of providing support through a mobile app.

What did you like about supporting someone through a mobile app?	
	n
Use Any Time of Day	13 (76.5)
Use Anywhere	13 (76.5)
Easy to Use	10 (58.9)
Anonymous	6 (35.3)
Easily Accessible Information	3 (17.6)
Other	1 (5.9)
What did you dislike about supporting someone through a mobile app?	
Difficult to Express Feelings Through Text	5 (29.4)
Technical Issues	4 (23.5)
Typing Long Messages	2 (11.8)
Difficult to Understand Experiences Through Text	1 (5.9)
Other	4 (23.5)

Note. Categories not mutually exclusive and completed using checklist format.

Figure 1

Table of contents for peer supporter training manual.

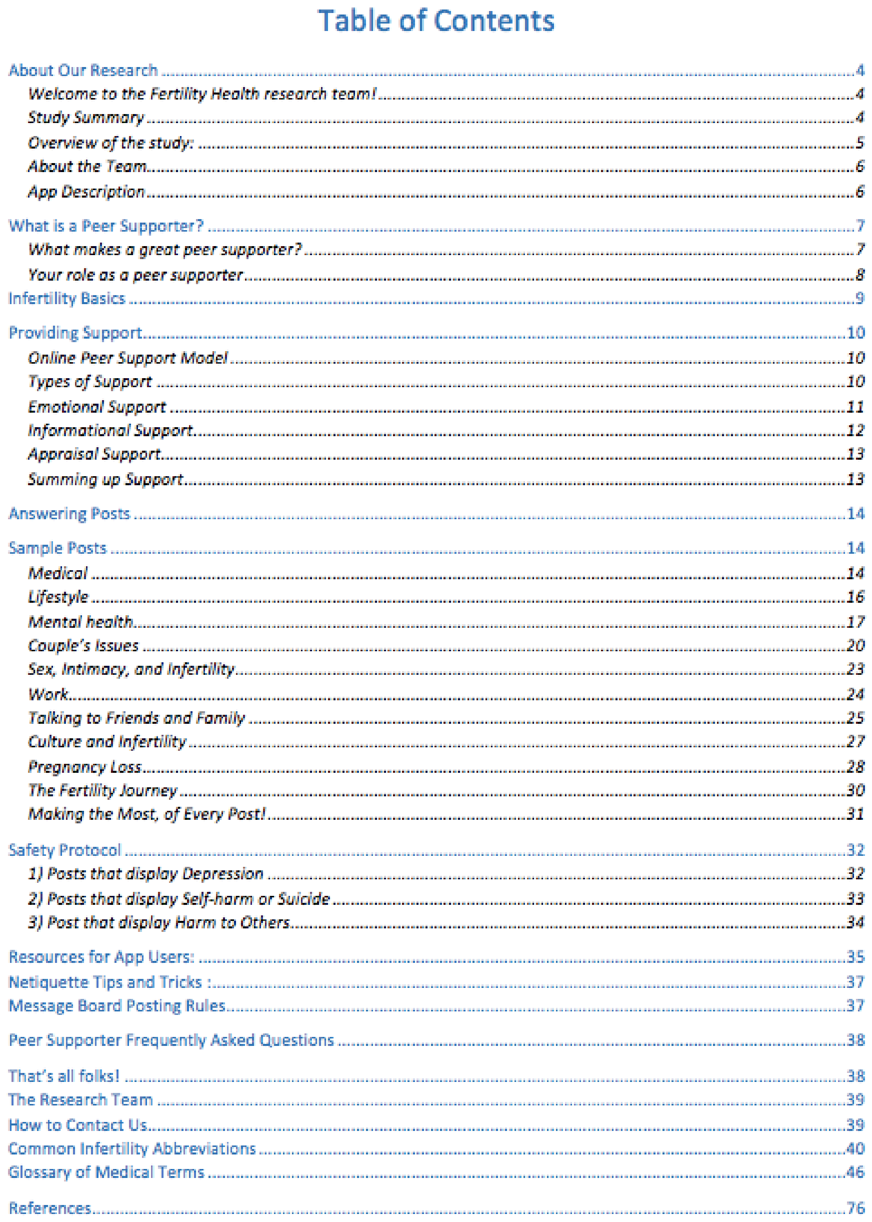

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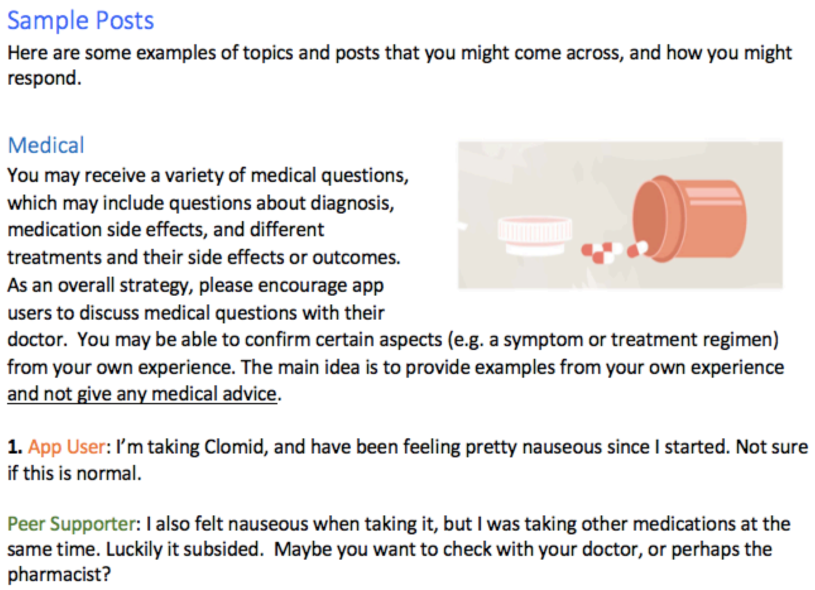
Figure 2

Sample post section of the peer support training manual that explains the topic and provides a sample discussion post from an app user and peer support volunteer.



Sample Posts

Here are some examples of topics and posts that you might come across, and how you might respond.

Medical

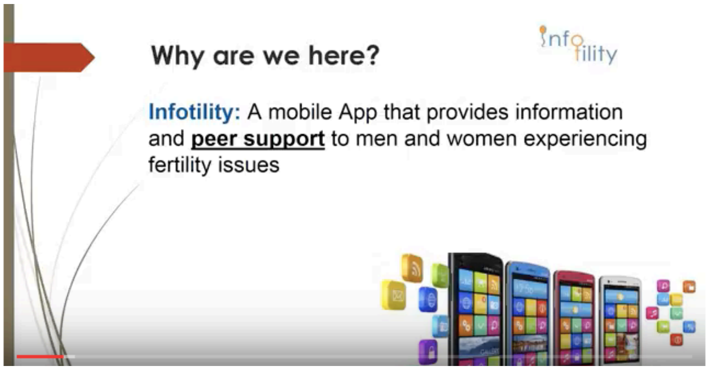
You may receive a variety of medical questions, which may include questions about diagnosis, medication side effects, and different treatments and their side effects or outcomes. As an overall strategy, please encourage app users to discuss medical questions with their doctor. You may be able to confirm certain aspects (e.g. a symptom or treatment regimen) from your own experience. The main idea is to provide examples from your own experience and not give any medical advice.

1. App User: I'm taking Clomid, and have been feeling pretty nauseous since I started. Not sure if this is normal.

Peer Supporter: I also felt nauseous when taking it, but I was taking other medications at the same time. Luckily it subsided. Maybe you want to check with your doctor, or perhaps the pharmacist?

Figure 3

Webinar slide describing purpose of the Infotility application and peer support.



Why are we here?

Infotility: A mobile App that provides information and **peer support** to men and women experiencing fertility issues

Linking Studies 2 and 3

The aim of study 2 was to (1) describe the development of an online peer supporter training program and (2) evaluate program feasibility and acceptability among infertility peer supporters. This study firstly provided a detailed description of online recruitment, training, and supervision of peer supporters, thereby providing a model for future online peer support programs. Secondly, responses to quantitative and open-ended items of the Peer Supporter Experiences Questionnaire provided evidence for the acceptability of the online peer supporter training program among individuals with a history of infertility.

Among 17 women and one male who provided peer support, there was a high level of satisfaction with the program overall and 16 reported that they would recommend the app to patients looking for support. Peer supporters found the training materials (e.g., training manual) and online format very helpful and liked receiving information about different kinds of support (i.e., informational, emotional, appraisal). Peer supporters also felt very comfortable having their posts reviewed by the peer support coordinators. The latter finding extends findings from study 1, showing that professional monitoring is acceptable among peer supporters and patient users. This study also provided insight into challenging aspects of online peer support among peer supporters. Specifically, technology issues emerged as the most common difficulty experienced by peer supporters; this finding is useful for ensuring pre-program trials in the future ensure program satisfaction.

The third and final study of this thesis used a qualitative method to examine online communication between patient users and trained peer supporters. The purpose of study 3 was to improve understanding about how current and former fertility patients cope with fertility-related stressors. In this way, study 3 extends feasibility and acceptability testing by (1) demonstrating program engagement and (2) determining core themes of online communication related to infertility coping.

Article 3

"How did you cope with such concerns?": Insights from a Monitored Online Infertility Peer Support Forum

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Abstract

Research Question: What coping strategies do fertility patients and trained peer supporters discuss in an online infertility peer support forum? Design: Thematic analysis was used to examine 244 online posts from a sample of 39 users (37 women and 2 men) for themes in coping with fertility-related stressors. Data were collected from Connect, a monitored online discussion forum with trained peer supporters. Results: Connect users ranged from 27 to 44 years of age (*M* = 34.38) and 33 (84.6%) were nulliparous at the time of study. A variety of cognitive-reappraisal and practical management coping strategies were discussed across four themes: balancing interpersonal relationships, partner support, uncertainty and lack of control, and positivity and negativity. Experiences of uncertainty and lack of control related to time and schedule, outcomes and waiting, physical symptoms, and the clinic. Connect users commonly discussed the helpfulness of coping strategies. Discussion: Connect users actively requested experiential information about ways of coping from other patients and peer supporters, highlighting the importance of lived experience to those currently in treatment. Findings support conceptualizations of infertility coping as a process that is unique to the infertility treatment context and that may change over the course of a patient's treatment. Trained peer supporters may benefit fertility patients by normalizing, reappraising, and providing practical strategies to ameliorate difficult infertility-related challenges.

Key Words: infertility; peer support; coping; qualitative; ehealth

1. Introduction

Infertility is defined as the inability to conceive following at least one year of sexual intercourse (Berg, 2017; Zurlo et al., 2019). This reproductive issue affects up to one in six people (Boivin et al., 2007) and is associated with diminished quality of life and depressive and anxious symptomatology. Global psychological distress has been found to be comparable to those experiencing cancer, cardiac rehabilitation, and hypertension (Domar et al., 1993; Miner et al., 2019).

Like other chronic health conditions, infertility has numerous adverse physical and emotional consequences, including the complexity of diagnosis and treatment, uncertainty of treatment outcome, and stigma (Cousineau and Domar, 2007; Greil et al., 2010; Kingod et al., 2017). Infertility and its treatment associate with increased physical, personal, marital, and social stress, which in turn may be related to treatment dropout, more severe psychological symptomatology (Boivin et al., 2012; Cousineau and Domar, 2007) and symptoms of anxiety and depression following treatment failure (Maroufizadeh et al., 2015). This underscores the need to improve understanding of how fertility patients manage fertility-related stress.

Counselling guidelines have emphasized the importance of helping patients develop and implement adaptive methods of coping (Canadian Fertility and Andrology Society, 2009; Cousineau and Domar, 2007; Crawshaw et al., 2013; Joy and McCrystal, 2015). As such, coping skills information is included in psychoeducational infertility interventions (Cousineau et al., 2008). Coping can be defined as the "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus and Folkman, 1984, p. 141).

Online infertility forums may provide an anonymous arena for learning how to cope with, or manage, fertility-related stressors (Hanna and Gough, 2017; Hinton et al., 2010; Malik and Coulson, 2010). Connecting with similar people—namely those undergoing fertility treatment—is of importance to some fertility patients (Read et al., 2014; Van den Broeck et al., 2010) and may help to normalize infertility concerns and reduce feelings of social isolation (Malik and Coulson, 2008, 2010). The benefits of peer support may operate through a sharing of support and personal experiences (Malik and Coulson, 2010; Read et al., 2014; van Uden-Kraan et al., 2008), including discussion of coping resources and techniques (Dennis, 2003) and practical advice. A review of the effects of peer support for people undergoing cancer treatment found that peer support was associated with better medical management and decision-making, and improved psychosocial well-being (Kowitt et al., 2019). Meta-analytic findings also suggest that there is a positive correlation between self-disclosure and anonymity (Clark-Gordon et al., 2019), suggesting that compared to in person, online peer support may reduce disclosure inhibitions. Online peer support may be particularly useful during treatment waiting periods (Malik and Coulson, 2008) where patients have reduced access to staff and other patients at the clinic (Lancastle and Boivin, 2008), and report increases in both anxiety and social-support seeking (Boivin and Lancastle, 2010; Şahiner & Boz, 2021). A better understanding of online communication among fertility patients is important as those who post to such forums may also experience greater anxiety and stress than those who do not post (O'Connell et al., 2021). Examining online discussions of infertility coping may increase knowledge about how fertility patients manage a variety of fertility-related stressors.

The Transactional Model of Coping (Lazarus and Folkman, 1984) conceptualized coping as an active and transactional process between the person, stressor, and context. In this model, coping was originally divided into problem-focused and emotion-focused coping, depending on whether one was managing an external or internal stressor (Terry and Hynes, 1998). Further refinements to the model included the addition of meaning-focused coping (Folkman, 1997), and approach and avoidance coping (Billings and Moos, 1982). Most recently, researchers have moved toward developing infertility-specific measures of coping (Benyamini et al., 2004; Benyamini et al., 2008). Benyamini et al. (2008) found evidence for three superordinate coping factors: approach-avoidance (i.e., inward-anger, disclosure, acceptance, re-interpretation), relationship coping (i.e., recruiting partner support), and practical management (i.e., self-nurturing, problem management, faith).

Avoidance coping in general has shown a consistent link to greater distress, anxiety, and depressive symptomatology, and worse medical recovery trajectories among those with physical illness (Taylor & Stanton, 2007). In those with infertility, avoidance coping relates to lower quality of life, greater social stress (Swift et al., 2021), greater fertility-related stress (Benyamin et al., 2004; Gouranti et al., 2012; Peterson et al., 2006a, 2009; Schmidt et al., 2005), depression (Peterson et al., 2006b), and poorer psychological well-being (Hynes et al., 1992). Findings also generally align with the goodness-of-fit hypothesis, which states that the effectiveness of coping is in part dependent on the match between type of coping and the perceived controllability of the stressor, which may help to explain mixed findings regarding coping strategies and psychological outcome (Swift et al., 2021). Specifically, problem-focused coping is thought to lead to more positive outcomes when the stressor is appraised as controllable. With respect to infertility, problem-solving coping may be less effective when the desired outcome is a low-control outcome like live birth. Overall, among fertility patient samples, there is evidence that whereas problem management coping (e.g., seeking information) associates with greater distress

(Benyamini et al., 2004; Terry and Hynes, 1998), problem reappraisal coping associates with lower distress (Benyamini et al., 2008; Gourounti et al., 2012), better adjustment (Terry and Hynes, 1998), and greater well-being (Benyamini et al., 2008; Hynes et al. 1992). Emotional approach coping has also been found to associate with positive psychological outcomes among women undergoing fertility treatment (Benyamini et al., 2004; 2008).

Notwithstanding the importance of extant infertility coping research, findings are largely based on results of quantitative self-report measures. Use of general quantitative measures may fail to capture information specific to a given context and stressor being evaluated (Coyne and Racioppo, 2000). The importance of qualitative infertility research is demonstrated through the development of coping questionnaires based on prior interviews (e.g., Schmidt et al., 2005). The inability to conceive may be viewed as only one—albeit primary—stressor. Stress is found to relate to the complexity and length of medical treatments (Childress et al., 2014), financial costs, sensitivity to fertility-related stimuli (e.g., pregnancy announcements), and perceived negative comments about infertility from others (Cousineau and Domar, 2007; Greil et al., 2010). The situational specificity and the perceived controllability of a stressor contribute to both the chosen coping strategy and its outcome (Folkman and Lazarus, 1984). Although infertility is often considered a low-control stressor, fertility-related stressors may vary in their perceived controllability.

1.1. Current Study

The current study examined patterns in coping discussion among and between current fertility patients and trained infertility peer supporters. Data included discussion posts from a private online infertility peer support forum, accessible only to patients, peer supporters, and designated research staff. Online discussions were analyzed using thematic analysis to describe how patients and peer supporters discussed coping and associated stressors. A qualitative approach may provide a more nuanced account of the coping behaviour of fertility patients that is less accessible with general quantitative coping measures. The goal is to elaborate context-specific models of infertility coping (Benyamini et al. 2008) by elucidating specific infertility-related stressors and ways of coping.

2. Materials and Methods

2. 1. Participants

Data were collected as part of a larger study evaluating the development and implementation of a mobile health application (app) called *Infotility*. This app provided information and access to peer support through *Connect*, a confidential and asynchronous discussion forum where app users could post comments or questions to other app users or trained peer supporters. Eighteen peer supporters were recruited and trained to monitor Connect and offer supportive responses that emphasize personal experience with infertility and its treatment (Grunberg et al. 2020).

Recruitment took place at four fertility clinics in Montreal and Toronto, Canada between October and December 2018. Initial eligibility criteria required participants be: (1) at least 18 years of age, (2) undergoing a first round of in-vitro fertilization (IVF), (3) self-identified as male or female, (4) able to complete measures in English or French, and (5) have access to the Internet. In November 2018, eligibility criteria were broadened to allow participants to be at any stage of any fertility treatment. This change was made following a clinician suggestion that patients at others stages of treatment would be interested in fertility information and access to peer support.

A total of 969 people *(n* = 336 men, *n* = 633 women) were approached, of which 661 (68.0%; *n* = 220 men, *n* = 441, women) agreed to screening for eligibility. Of 661, 505 (76.0%, *n* = 164 men, *n* = 341 women) were eligible. Of 505, 387 (77.0%, *n* = 124 men, *n* = 263 women) provided express written consent to be in the study. Reasons for refusal (*n* = 49/505, 9.7%) included lack of interest, busy schedule, mental or physical distress, and privacy concerns. Of the 387 who consented, 267 participants (69.0%, n = 77 men, n = 190 women) completed baseline questionnaires and 220 (56.8%, n = 50 men, n = 170 women) visited at least one page of the app. Of the 220 who opened the app, 40 (18.2%, *n* = 38 women, *n* = 2 men) posted to the discussion forum, making 244 English (*n* = 231) and French (*n* = 13) posts between October 29, 2018 and April 31, 2019. Infotility peer supporters made a total of 169 English (*n* = 149) and French (*n* = 20) posts.

2.2. Procedure

Consenting participants completed measures at baseline, six weeks, and eight weeks following access to Infotility. Baseline measures assessed demographic and fertility characteristics (e.g., type of diagnosis), Internet use, and psychological symptoms (e.g., perceived stress scale). Six weeks after downloading the app, participants received a questionnaire assessing participant ratings of app engagement, functionality, aesthetics, and information. Follow-up measures assessed the same constructs as baseline in addition to their experiences with using *Connect*, the online peer support discussion forum. At the end of the study period (May 1st, 2019), posts were saved into a Microsoft Word document and were unchanged in spelling, grammar, and punctuation. Although each app user chose a unique username, all user names have been changed to increase anonymity. After submitting the final questionnaires, participants received a $25 gift certificate to a coffee chain or online retailer.

Ethics approval was granted by the McGill University Health Centre's Research Ethics Board (REB approval number: MP-37-2019-4664).

2.3. Data analysis

First, the thirteen French discussion posts were translated by a bilingual member of our research team. The translated posts were then checked by the fifth author who confirmed accurate translation. Discussion posts were analyzed according to the six steps of thematic analysis described by Braun and Clarke (2006). A bottom-up, or data-driven, approach to analysis was used (i.e., inductive thematic analysis), whereby the data were read and re-read without trying to compare observed themes to past research. A list of coping strategies was taken from a previous infertility-specific taxonomy of coping (Benyamini et al., 2008). Coping strategies from Benyamini et al. (2008) were used as a primary guide for identifying initial codes (e.g., seeking social support), which were further analyzed for larger themes; that is, patterns in coping in response to specific stressors (e.g., relationships). For present purposes, however, any description of altering how one views a stressor (i.e., acceptance, positive reinterpretation) was classified as cognitive reappraisal. Themes were based not only on prevalence, which can indicate importance, but also on their ability to organize the data cohesively. That is, while it is not the aim of thematic analysis to eliminate all overlap between themes, maximizing distinctiveness of each theme was emphasized. First, PHG generated preliminary notes regarding (1) use of terms related to coping (e.g., coping, dealing, or managing), (2) explicit description of a stressor (e.g., relationship difficulty, uncertainty about treatment outcomes), and (3) specific coping strategies (e.g., avoidance of social situations associated with fertility/pregnancy). Next, codes were compiled into themes and posts were re-read again by the first author. After a meeting with the first three authors, the second and third authors independently checked each code and theme across the data for logical consistency and missing themes. Next, themes were named and agreed upon by all authors. The data set was read until no new patterns emerged from the data. Lastly, the report was drafted by the first author who re-read the data for salient examples of each theme. The fourth and sixth author reviewed the appropriateness of each example prior to final manuscript production.

A description of underlying theoretical considerations is important for assessing the trustworthiness of qualitative research (Nowell et al., 2017). The present analysis assumed an essentialist/realist perspective (see Braun and Clarke, 2006; e.g., Malik and Coulson, 2008), a theory of knowledge stating that meanings and experiences are directly related to an individual's language. In contrast to a constructionist perspective, the essentialist perspective does not examine participant data in relation to broader social contexts and discourses. That is, analysis focused as closely as possible on participants' explicit language and meaning.

3. Results

3. 1. Participant characteristics

Connect users ranged from 27 to 44 years of age (*M* = 34.38, *SD* = 4.02). Annual income ranged from <$40,000 (*n* = 1, 2.6%) to $160,000 (*n* = 9, 23.1%), with a median of $100,000-$119,999. With respect to education, 15 participants reported a university degree (38.5%) and 15 reported a graduate degree (38.5%). Approximately two thirds were White (*n* = 26, 66.7%), followed by 'West Central Asian/Middle Eastern' (*n* = 5, 12.8%). Twenty-four participants were born in Canada (61.5%), with immigrants (*n* = 15, 38.5%) reporting an average 12.07 years in Canada (*SD* = 8.93). Almost three quarters of users reported that they affiliated with a particular religion (*n* = 28, 71.8%).

3.2. Fertility Characteristics

Eleven Connect users reported only a female-factor diagnosis (28.2%), eight reported only a male-factor diagnosis (20.1%), seven reported both male and female-factor diagnoses (17.9%), and 13 (33.3%) were still going through testing or had an unexplained diagnosis. Diverse diagnoses were reported (e.g., sperm parameters, maternal age, polycystic ovarian syndrome, recurrent miscarriage).

Time trying to conceive ranged from less than one year to seven years before starting treatment (Median = 1 year; Mode = 1 year) with just over half of the users trying for 1 year (n = 20, 51.3%). Approximately one quarter tried for two years (n = 10, 25.6%). Most users reported no children at the time of study (n = 33, 84.6%). During the study period, 4 Connect users (10.8%) stopped fertility treatment and 9 (23.7%) achieved a pregnancy.

3.3. Thematic analysis

Four coping themes were identified through thematic analysis: interpersonal relationships, partner support, uncertainty and lack of control, and negativity and stress. See Figure 1 for a map of themes and associated general and specific coping strategies.

3.3.1. Theme 1: interpersonal relationships

Several app users and peer supporters agreed that a major challenge of infertility and its treatment was interpersonal relationships. Interpersonal stressors included receiving hurtful comments or criticism, sensitivity to the pregnancies of family and friends, disappointing others, and having one’s fertility issues ignored. In relation to these stressors, posts often emphasized the use of cognitive reappraisal, problem management, such as seeking social support, and to a lesser extent, avoidant coping strategies. Reappraisal was sometimes used to cope with hurtful comments that were often described as being unintentional, as in the following:

“In our case, my family supported us and my husband’s family were shocked that we went to such lengths to get pregnant. They accused us of being impatient and told us we wasted our money the first time around and when they found out we were doing it again: we got the comment: « didn’t you learn from your first mistake? » Suffice it to say that my relationship with my in-laws has been strained since this journey has begun. Look towards the positive, whether it isn’t what you want to hear at least they are trying to be somewhat helpful and supportive.” [01-01].

This type of reappraisal was used in another thread and also highlighted the difficulty of getting one’s desired level of support:

“I think its a tough balance to get support in a safe manner, when you are doing education at the same time. I mean, we are being educated as we go into treatments, and it is all very new and surprising to ourselves as well, so it is no wonder others dont get it, it’s still a bit taboo. So it’s tricky to educate others of the facts and the emotional difficulties…And yet…How else would this become more common knowledge? Maybe we are just the generation that has to open trails while the knowledge about the experience of infertility comes out into the mainstream (sigh).” [01-02].

In response, a peer supporter agreed, highlighting the importance of peer support and providing the user with practical advice for obtaining appropriate support. In line with cognitive reappraisal strategies, the peer supporter implies that others’ lack of understanding about infertility may have been a cause of their insufficient support. Note that both the app user and peer supporter describe educating others as a way to manage this stressor:

“I agree. It’s often difficult for those who don’t know much about infertility to know how to be supportive. That’s part of the reason peer support can be helpful. Also, sometimes telling

people what we need can help them and us. If you want someone to listen and not give any advice, sometimes it works to just tell them that (it doesn't always work with everyone). In my experience, most of the people who care about you really want to help, but they don't know how." [Peer Supporter].

Although most posts of this theme discussed more active strategies for coping, some app users described difficult comments from others and subsequent feelings of self-blame and avoidance. The following post acknowledges both self-blame and the unintentionality of hurtful comments from family:

"I'm starting to feel different pressures around disappointing family, like when they ask…"wouldn't it be great if your period didn't come this month?"…all positive comments but I just feel so bad when I can't follow through for them" [01-03].

Several other posts noted the challenge and importance of managing interpersonal relationships—emphasizing the need for social support while also trying to minimize negative interactions or experiences. The following post shows how getting social support involves navigation of not only the infertility diagnosis, but treatment as well:

"In our case, me and my wife decided to share a portion of what we are going through with our parents, but we avoided sharing much with everyone else…We are afraid of sharing everything with everyone mainly because we are afraid of hearing back hurtful comments…We are about to approach IVF. Our parents don't know. Some friends do…What I can say, is that each and every time we opened up and talk to a friend about what we are going through.. I can really say that it felt great. For a few hours/days you feel lighter. At the same time, if the person that knows make a "wrong" comment, well that can be very painful too. Overall, I would suggest

talk to someone about this, just make sure the people you are talking to will be enough empathic to respect and understand your situation." [01-04].

One peer supporter elaborated that disclosure can be helpful or unhelpful depending on those involved:

"I hope things go well with your upcoming IVF! Navigating how much and who to tell about the infertility journey is a very complex thing and I know people who have handled it both ways successfully; some being very public and open with everyone and some only telling a close friend…".

Finding a balance of social support was described as a difficult process, with one user even ending relationships. One user stated that she doesn't want, *"…advice as to how it has worked for others or how I should be if I want it to work. That is unhelpful and I even had to cut ties with those who just didn't understand it all together…I think we just need to surround ourselves with people who want what is best for us and who support us and give distance to those who do not."* [01-01].

And still others stated that disclosing to others was a proactive way to prepare for social support: *"I wondered about that choice too – not to tell people. Ultimately we decided to choose to tell people so if/when we need support it's not new information in the moment"* [01-03]. Overall, peer supporters and app users agreed on the need to garner sufficient social support and that the level and provider may be unique to each person. Participants used reappraisal coping to look at alternative reasons for interpersonal stressors. Practical management coping strategies included seeking social support (including peer support), selective disclosure (e.g., to parents, not friends), and educating others about infertility. Lastly, avoidance coping was identified through use of self-blame and ending relationships; however, ending relationships may also be seen as an active problem-solving strategy where the stressor is the relationship itself.

3.3.2. Theme 2: partner support

Spouses/partners were discussed as both a cause of stress and an aid to coping. Several app users and peer supporters discussed an inadequacy of partner support and concern regarding overwhelming their partner with their own stress. To cope with these stressors, users discussed reappraisal of their partners' actions, practical management (e.g., social support, self-nurturing), and avoidance strategies; the latter of which was only mentioned by app users. As an aid to coping, partners were described as helpful in the practical management of treatment procedures and increasing the user's positivity.

Regarding the inadequacy of support, one peer supporter asked the forum, "*Do you feel you have enough support from your partner/spouse*?". This user expressed her concerns and asked the forum for ways to manage this problem:

"I often feel that I don't have as much support from my husband as I need during the fertility treatments. It seems that he doesn't realize what I have to go through emotionally and physically…I was hoping for more encouragement from his part since I'm doing these treatments so that we can have a baby. Does anyone had a similar situation and how did you deal with this?" [01-06].

This concern was normalized and shared by users and peer supporters, who described their experiences and ways of coping with partner support. One peer supporter discussed her reappraisal of this difficulty and suggested problem management through social-support seeking as coping strategies:

"I do believe men and women deal with their emotions quite differently, and women need to verbalize more than men. What helped me was to join a support group…If it is an option, maybe let him know you need more support since you both have decided on not telling your friends. Set a time in the week to talk about it if he prefers. And maybe guide him by telling him your expectations when you are going through a cycle. Sometimes we do have to remind ourselves that as much as they love us, they just can't read our minds." [Peer Supporter].

One app user expressed her desire to communicate with her partner, but acknowledged that she was unclear about what her needs were:

"I love my partner and he is trying so hard to be supportive. I feel like a big part of our problem is that I can't articulate what I need from him. Because this is unknown territory, I can't figure out what would make me feel better when I'm having a tough day or week. Has anyone got tips of what words or actions were helpful from their partner…" [01-07].

One app user mirrored the peer supporter's suggestion to communicate needs to one's partner:

"*Well my husband had to be given a wake up call. Let's just say I blew a gasket at one point and he realized that he needed to do stuff too…So I told him…look do you want a baby or not because this is not a one sided thing…so suck it up and take your vitamins. Well, since then my husband has taken even herbal supplements and has gone to an osteopath as well to improve our chances. I think sometimes when our men are blind we just gotta lay it out for them to understand and see it from our perspective."* [01-01].

Other posts discussed the practical use of one's partner to communicate with staff. Following a discussion about post-procedure pain and feeling "groggy", one app user stated:

"I would suggest going in with a partner for support, and speaking with them about being your advocate." [01-08].

The importance of partners engaging in pleasurable activities together during treatment was also discussed:

"…Using this time to connect with your partner doing things you like is one of the best ways for both of you to have the strength and resilience it takes to go through fertility treatments." [Peer Supporter].

In contrast to posts about the importance of partner support, two app users agreed on their desire to protect their partner from their negative emotion, as exemplified in the following post:

"Hi…our feelings are the same! I'm trying to hide it from hubby, cause he's just been so great with all of it and I don't want him to feel like he has to carry all the weight of my frustrations and disappointments." [01-09].

Interestingly, one of the only posts from a male was in regard to supporting his female partner with, "*…how difficult it is to her to deal with the idea of our embryos after IVF left to die…"* [01-05]. However, his post was not to help himself, but to ask other members how they coped with this type of concern: *"I would like to ask to any of you that did IVF, did you share the same concerns? If yes, how did you cope with such concerns?"*.

There was agreement between app users and peer supporters regarding the challenge of receiving adequate support from one's partner. There was consensus regarding the need for practical management of the relationship through open communication of emotional experiences with the (typically) male partner. The male app user wished to better understand how others coped with issues his female partner was facing. As with interpersonal relationships, users emphasized practical management of the relationship and treatment procedures through communication, seeking information, and preparing for appointments.

3.3.3. Theme 3: Lack of Control and Uncertainty

Posts often discussed lack of control and uncertainty with respect to time/schedule, treatment outcomes, medical symptoms, and clinic experiences. Users discussed both active and passive coping strategies in response. In terms of active coping, reappraisal was used in the form of acceptance of the lack of control one has over outcomes. Practical management strategies were also used and included distractions when waiting and problem-solving issues at the clinic (e.g., maintaining privacy when undressed). Although distractions were commonly discussed, there were more mixed opinions about the utility of this coping strategy. Lastly, passive avoidant coping was also discussed as in the case of using hope or wishful thinking.

3.3.3.1. Time and Schedule. Several users discussed their difficulties with their limited control over time or schedule. The following examples show how users share this concern and request information from other users to manage this lack of control.

"I really feel like my time isn't my own – never being able to make plans because of waiting for cycles to be right, medications to take at the right time, getting to the clinic at the right time… how have you been able to manage your time (lack of control over time)?" [01-03].

After normalizing and validating this user's experience, a peer supporter noted her own reappraisal and use of practical strategies to manage her schedule:

"What helped for me is to remember that it was only for a short period of time. We took some breaks between treatments as well" [Peer Supporter].

Another user discussed her lack of control over her schedule and stress associated with schedule adjustment and waiting. This user describes using distraction and organization to cope:

"Does anyone else feel pressure from no longer being in control of (among other things) your schedule?... vaguely mentioning I have a doctor's appointment in order to miss work; having to rely on other colleagues to back me; and arriving for a scheduled appointment only to be seen within a 3 hour window are all really tough…I generally cope with stress by keeping busy and organized. Waiting around to be seen creates this deep anxiety because I have no choice but to sit and focus on my treatment/infertility…" [01-07].

Distractions included having activities for oneself in the waiting room (e.g., cross-stitching, reading). In addition to offering practical strategies for occupying one's time at the clinic, one peer supporter described her own reappraisal process, stating, "*I eventually just had to give in to the waiting*.".

3.3.3.2. Outcomes and Waiting. Other posts described use of reappraisal of control over outcome as helpful, as in the following:

"What helped us was to accept that we couldn't control the outcome and that we shouldn't stress about the what if's until we knew what we were dealing with" [Peer Supporter].

A common theme was that of coping with waiting for treatment outcomes (e.g., the "2-week wait" period during intrauterine insemination; IUI) and associated anxiety or stress. Users and peer supporters discussed use of waiting time to distract, engage in self-nurturing, and interact with others. For example:

"*I found it helpful to do the things that I enjoy and gave myself time to be alone as well as to spend time with others…*" [Peer Supporter].

Lastly, the avoidant coping strategy of self-blame was seen in posts describing a sense of failure after doing everything possible to conceive:

"I have no idea what I'm doing wrong. There must be something, since all my testing came back with no problems. I'm just a basket case of feelings right now" [01-09].

3.3.3.3. Physical Symptoms. App users commented on the uncertainty surrounding physical symptoms following assessment and treatment. Several users discussed their hypervigilance in interpreting physical symptoms. The following user also discusses how social support from the forum is useful for normalization of symptoms:

"I wanted to share how hard it is to cope with what I think are secondary effects of the meds…Is this a pregnancy or is it the meds or is it the take out food from yesterday??? ☺ I even became_hypervigilant of some symptoms (frequency, intensity…) in my futile attempt to understand some of what my body was going through. I know that everyone's body is different, but I think having a place to normalize symptoms…would probably appease some unnecessary anxiety." [01-02].

In a way, the hypervigilance is framed as a way to do everything one can to improve one's chances of conceiving. However, not everyone described hypervigilance this way. Here, one user describes the futility of hypervigilance to symptoms, minimal helpfulness of distraction, and reappraisal of her level of control over treatment outcome:

"…I would drive myself crazy trying to find the early pregnancy symptoms, all that to get a negative result…now, I try to stay busy with work and other activities…but even then these thoughts cross my mind every day. We can't really control the outcome, if the treatment was successful or not, so I try not to stress that much about it." [01-06].

The use of cognitive coping strategies were viewed as more helpful than physical distractions:

"I think the infamous 2ww is the epitome of the fertility treatment… you have no control, your body is doing its thing without consulting you… there is no nice way about it but to cope in whatever way you cope best with the unknown… at first, I worked out, walked, did some sewing…but mostly worried….I am back to positive surrender affirmations, meditation, and trying to laugh and be grateful….without a doubt the 2ww test our capacity to accept, let go and endure." [01-02].

The desire for increased information about what to expect regarding physical stress was common, as in the following post:

"*I took 5 days off of work and it took me 10 to feel better. I don't like to be a bummer but there should be notes likes this so that other women know you're not alone and pain happens…just would have appreciated a frank conversation of "yes you will be swollen and yes it will affect your whole body and you will get through it and it may take longer than a couple of days*"" [01-03].

Highlighting the importance of gathering more information for dealing with uncertainty and lack of control, one user adds:

"Knowledge is power, it makes you feel like you have some sort of control over what is happening even when you aren't feeling there is a lot of hope." [01-01].

Feelings of not having control over one's symptoms and outcomes was common and was also met with more passive emotional coping strategies, such as hope or wishful thinking:

"They scheduled me for another blood test Tuesday but I woke up with a bit of brown blood on my pad. I'm obviously stressed and nervous…am I going to have a miscarriage? I'm trying to stay positive and hope for the best…Has anyone experienced something similar?" [01-12].

Other problem management strategies were discussed, such as using complimentary/alternative medicine (CAM) to feel in control. With respect to CAM, *"...I felt it made me feel like I was doing something to help my body want to have a baby. It was more of a need to feel like I can do something to help myself improve my chances."* [01-01].

3.3.3.4 Clinic. Another area of uncertainty was that of the clinic and treatment room. For example:

"…today there was a trainee/med student in the room while I had my ultrasound…I'd like to be told that it's happening. I feel like I have a right to know who's going to be looking at the most private area of my body. Also, the Dr coming past the screen before I'm ready…I'd hate for the door to be opened while I'm in a state of undress/legs wide open on the chair. I don't really have a question or anything, it just bothers me" [01-13].

In response, two peer supporters offered their opinions for dealing with this type of discomfort. In both responses, the peer supporters reappraised the situation. The following example shows this reappraisal while also acknowledging the importance of social support:

"It's helpful to voice them [feelings] to someone. I understand how it must seem that the doctor didn't make you feel comfortable. While I'm sure it wasn't his/her intention, it's definitely bothersome…When I had feelings like yours, I had to remind myself how fortunate I was to have access to medical care when so many don't and, never will. It helped me to keep things in perspective. I also tried to keep focused on how much I wanted to conceive our baby and how I was more than willing to do whatever I needed to do, including having to put up with annoyances along the way." [Peer Supporter].

Whereas the peer supporters offered reappraisals for the situation, an app user discussed the practical management of this situation.

"I agree with the above Infotility supporter…So I have since always moved the curtain thing which is on wheels to keep anyone who opened the door from seeing me in a state of undress or so I know that someone is coming because they got to move it." [01-01].

3.4. Theme 4: Stress and Negativity

Stress was often discussed as a general negative state that needed to be managed or avoided. Most notably, app users and peer supporters alike described 'staying positive' as important throughout treatment. Staying positive may be seen as an attempt at coping through reappraisal. In addition to encouraging users to stay positive, self-nurturance was frequently discussed to manage stress and/or negativity.

The following post exemplifies the generalized encouragement commonly offered to thwart painful experiences:

"Try to remain optimistic as much as you can even though I know it is very difficult." [01-01].

Multiple peer supporters further emphasized self-nurturing and reappraisal, as in the following post:

"Sometimes we need to acknowledge that we are upset and that our energy is lower. And noticing that these negative thoughts are your fear talking. We don't have to listen. And take steps towards nurturing that positive and raising up our energy. Self care practices are a wonderful way. I also used a gratitude journal…focusing on the positive things. Sending positive vibes your way my dear strong warrior!" [Peer Supporter].

Another app user asked how others have managed to stay positive:

"I'm feeling pretty upset by the outcome. I don't know if it's even worth trying another cycle if the outcome is only going to be one…I'm hoping that at some point my bad luck will turn

into good luck but I just don't know anymore. Staying positive is getting increasingly difficult. Any ideas?" [01-14].

Again, a peer supporter described reappraising the situation by focusing on positive outcomes, sharing personal experiences, and engaging in self-care activities:

"I feel it's important to remind ourselves of the positive outcomes that are possible…we tend to focus only on what can go wrong. Take some time to take care of yourself…also sometimes just talking about it like you are…can make a difference. We are always here." [Peer Supporter].

In other cases, negativity and stress were framed as potentially detrimental to treatment outcomes:

"*I decided to stay hopeful for the next IVF, thinking that this way at least I did my best, in case negativity had an effect on the treatment. I too did yoga, meditation, and tried not to think negatively*" [Peer Supporter]; and,

"*I was also very stressed and yes its very bad to have stress…I've learned that its best to nest for 2ww and take it easy even for smallest things you want to do. Also try to drink tea and add legumes to your diet also replace red meat with fish and chicken breast*." [01-10].

4. Discussion

The aim of the present qualitative study was to advance our understanding about ways of coping with infertility among fertility patients and trained peer supporters. By qualitatively analyzing the unprompted accounts of current patients we were able to provide a more nuanced understanding of the different situations in which coping strategies were applied and the extent to which these strategies were viewed as helpful. Specifically, cognitive reappraisal, practical management, and to a lesser extent avoidance, were used to cope with stressors related to relationships, uncertainty/lack of control, and general stress.

Research has shown that people communicate online to share experiences, provide and receive support and cope with fertility-related (Hinton et al., 2010; Malik and Coulson, 2010) and other negative (van Ingen et al., 2016) life events; however, the present research adds that fertility patients make explicit requests for information about coping, aligning with the finding that breastfeeding mothers used online support to seek *tailored* solutions to their problems (Moon & Woo, 2021). These findings highlight the complexity of coping with infertility by showing that a variety of strategies were used across different stressors and over time. The inclusion of trained peer supporters served to normalize patient experiences and provide patients with knowledge about ways of coping with diverse fertility-related stressors. In this way, peer supporters may be optimally suited to provide both social support and coping information to patients who experience elevated anxiety and stress during treatment and after pregnancy outcome results (Boivin & Lancastle, 2010).

Although psychoeducational and cognitive-behavioural interventions do emphasize cognitive reappraisal and problem-solving, the present online peer support forum was characterized by its provision of individualized support from current and former fertility patients. Peer supporters underwent training to ensure responses included personal experiences and emotional, informational, and/or appraisal support, depending on the unique needs of each post (Grunberg et al. 2020). In this way, peer supporters may be seen as a source of 'human contact' (Read et al. 2014, p. 392), offering support rooted in their own lived infertility experience and matched to the user's needs. Further, the current support format may offer some of the benefits of in-person support groups, characterized by opportunities for normalization and learning through interactions with people who understand fertility-related challenges (Hinton et al. 2010; Van den Broeck et al. 2010).

Peer supporters discussed the helpfulness of different coping strategies depending on the given circumstance, illustrating the context- and person-specific nature of infertility. For example, whereas effective communication is a general coping strategy, managing others' fertility-related ethical concerns or hurtful comments are specific to infertility. On the level of the individual, coping with these issues requires consideration of the costs and benefits of a specific choice of strategy. For one user, this meant ending a relationship to remove the stressor; for others, emphasis was placed on reappraising others' intentions or resolving interpersonal stress through effective communication. Taken together, responses normalized relationship and support concerns and also described ways to reappraise or ameliorate the concern. Similar to Hinton et al. (2010), Infotility users discussed the issue of fertile people not understanding infertility challenges. However, we found that in addition to normalizing the patient's lack of social support and providing relationship problem-solving strategies, board members also normalized the experiences of the fertile others who might wish to, but struggle with, conveying their understanding of fertility issues. In this way, online peer support may not necessarily reinforce isolation, but provide new appraisals and behaviours that encourage adaptive coping.

The present findings portrayed a complex picture of coping with uncertainty and its associated sense of lack of control over time, outcomes, physical symptoms, and treatment procedures. In fact, many posts emphasized the helpfulness of accepting lack of control while also engaging in practical management strategies, such as self-nurturing, seeking social support, and distracting oneself or staying busy. Distraction in particular was described in several posts as important, but not always helpful, in coping with waiting. Rather than dismiss this way of coping, users more often considered distraction in combination with reappraisals and other problem management strategies, such as self-nurturing or seeking social support. The use of different combinations of coping strategies over time to manage a given stressor supports the conceptualization of infertility coping as a process rather than a static phenomenon (Benyamini et al. 2008; Folkman and Lazarus, 1984). The combination of reappraisal (e.g., acceptance), self-nurturing, and distraction is important given recent evidence suggesting that relaxation, distraction, and reappraisal strategies are associated with positive emotional well-being among women with infertility (Chernoff et al., 2021).

Information-acquisition and hypervigilance about fertility-related events and experiences, such as physical symptoms, were also described by some users as increasing personal control over infertility. Attempts to alter an external stressor may become more maladaptive with decreased potential for such change (Folkman et al. 1979). However, whereas perceived control over fertility treatment procedures and emotional reactions relates to better psychological adjustment, perceived control over the live birth outcome may not (Campbell et al. 1991). In a small minority of posts, participants criticized themselves for negative treatment outcomes and alluded to a sense of personal control over outcomes. In the case of a low-control stressor like infertility, such attributions of personal control over birth outcome may lead to self-blame (Porter & Bhattacharya, 2008). That is, if a person believes that he/she is in control over the outcome, failures may be attributed to personal inadequacy. Alternatively, self-blame as anger directed inward (Benyamini et al. 2008) or as guilt may also reflect a motivation to regain control, or certainty, over the stressor (Cook, 1987). In response to such posts, app users and peer supporters both validated self-blame, and discussed the helpful nature of acceptance, lack of personal control over outcome, and use of self-nurturing to maintain positivity.

Results from a recent survey found that nearly one third of fertility patients thought stress was a determinant of infertility (Negris et al., 2021). The present findings extend this research, showing that fertility patients have concerns surrounding the assumed association between stress and fertility and wish to discuss this with other patients. Although some research suggests that higher levels of stress do in fact associate with unsuccessful pregnancy outcomes (Sominsky et al. 2017) and longer time to pregnancy (Lynch et al. 2014), findings remain inconclusive. The idea that stress can cause successful treatment outcomes may be problematic for patients, as unsuccessful attempts at reducing stress may serve to further exacerbate stress through thoughts of personal inadequacy or guilt.

4.1. Implications and Research Directions

Connect meaningfully differed from other publicly available online forums as it was monitored by the research team and peer supporters received training to provide tailored and empathic responses (Grunberg et al., 2020). Monitoring and training of peer supporters may have minimized the potential for reinforcement of overly negative discussion and perceived isolation (cf. Hinton et al., 2010). Training also included pre-program practice, where peer supporters received feedback about responding to all aspects of user posts and relating with more shared experience than advice. The standardization of training, as well as app users' value of the reliability of a university- and clinic-approved app (Lemoine et al., 2021), may engender greater trust in the information and support provided.

The active nature of discussions suggests that some patients not only wanted to reduce their stress, but to understand what was helpful for others with a history of fertility treatment. Fertility patients may be using whatever coping strategies are currently available to them (Boivin & Lancastle, 2010) and peer support could provide both social support and information about coping with personally relevant stressors. Accordingly, online peer support may be a useful addition to psychoeducational interventions by providing access to trained peer supporters who can engage in nuanced conversation about coping. Prospective longitudinal research would improve understanding about fertility patients' intentions to learn about coping and whether online engagement with trained peer supporters results in changes to enacted coping strategies and psychological health. Mixed methods may also be helpful for understanding links between validated psychosocial measures of psychological adjustment or quality of life and online accounts of coping.

The findings also contribute to knowledge about how some fertility patients want to find ways for managing fertility-related uncertainty and lack of control (Boivin & Lancastle, 2018). Indeed, controllability was identified in relation to patients' time, treatment outcomes, medical symptoms, and clinic experiences. Fertility patients may benefit from increased information about all aspects of the treatment (Lemoine et al., 2021; Porter & Bhattacharya, 2008; Wischmann, 2008); especially for physical symptoms, which users often discussed as highly distressing and anxiety-provoking. Seeking information was found to be the primary reason for using the Infotility app, and the most common app user feedback was a desire for the inclusion of more medical information (Lemoine et al., 2021). This appears to be the case even for educated patients who may generate many questions about medical and psychosocial aspects of treatment (Gelgoot et al., 2020) and whose healthcare professionals may lack the time to discuss aspects of diagnosis and treatment (Lemoine et al., 2021). Importantly, some fertility patients also seek information to prepare for future medical appointments (Sykes & Wills, 2019). Addressing patient fears through online educational and supportive programs reflects an accessible and discrete method for improving the psychosocial experiences of fertility patients (Boivin et al., 2012; Dancet et al., 2010; Wischmann, 2008).

The inclusion of online peer support programs may be useful to this end by allowing patients to communicate about ways of managing the emotional *and* practical aspects of treatment. As clinics may not have the time to address all patient questions and concerns, trained peer supporters may meet the patient's need for professionally monitored peer support during times of uncertainty.

Our findings highlight the relevance of cognitive-behavioural strategies for current and former fertility patients (Chernoff et al., 2021). Cognitive-behavioural (CBT) and Acceptance and Commitment Therapy (ACT) approaches are the most common intervention frameworks for people with infertility (Luk and Lok, 2016). These models highlight the importance of promoting more adaptive cognition and meta-cognition, the latter of which reflects ways of thinking about thinking. CBT and ACT could be useful for promoting acceptance and reappraisal of inevitable stress and use of practical strategies for managing, rather than eliminating stress.

It is noteworthy that only two men actively posted to the online forum. This finding is consistent with some qualitative research (Hinton et al., 2010), but inconsistent with research showing high levels of interest in online peer support among male and female fertility patients (Grunberg et al., 2018). Research indicates that men and women prefer same-sex online communication (Durant et al., 2012; Richard et al., 2017; Liu et al., 2018), suggesting that an insufficient number of men may have been recruited for the present study. Because online peer support is important for some men (e.g., Hanna & Gough, 2017), future research may benefit from broader recruitment strategies, coordinated across multiple clinics or regions.

4.3. Limitations

Participants were self-selected from a larger infertility app study and may only reflect the views of those who opted to use the forum. Further, the larger app study only included those with the desire and resources to complete treatment. For example, those with religious or financial restrictions may not have participated. Although the intention of the present study was to offer an educational and supportive resource to people going through treatment, it is important to recognize that those with fertility issues who do not seek treatment may still experience—albeit to a lesser extent (Greil et al., 2011) medical and psychosocial challenges and desire peer support. Accordingly, the present findings cannot speak to the ways in which non-treatment seekers would utilize online peer support.

That a preponderance of posts were made in English also raises the question of whether some participants were less comfortable with sharing and receiving information and support in their non-native language. Ethnographic research into online communities raises questions about the literacy required to exchange online information (Xun & Reynolds, 2010), suggesting the presence of barriers to those who learned English as a secondary language. Next, the decision to monitor Connect was based on research suggesting a majority of fertility patients agree with professional monitoring of an online infertility discussion forum (Grunberg et al. 2018). Such monitoring, however, could still have influenced the decision of whether and what to post. For example, sexual concerns were not discussed on the forum, but are known to be a salient issue for many infertile couples (Cousineau et al. 2008). Only a small proportion of study participants accessed the Connect forum. Online social support itself may be viewed as an active coping strategy, distinguishing the current sample from those who elected not to communicate with peers and peer supporters. Current findings therefore cannot be generalized to those who don’t use online forums.

4.4. Conclusion

The current study sought to improve understanding about fertility patient coping through a qualitative analysis of discussion posts on an online peer support forum called Connect. Fertility patients who use online forums may be actively searching for more adaptive ways of coping by engaging with current and former patients who have similar lived experience. The online peer support format allows patients to discuss advantages and disadvantages to coping strategies while normalizing and validating fertility-specific concerns. Some fertility patients may benefit from interventions that offer access to information and peer supporters, who can share personal experiences with stressors and ways of coping.

References

Abbey, A., Andrews, F. M., Halman, L. J. (1991). The importance of social relationships for infertile couples' well-being. In A. L. Stanton & C. Dunkel-Schetter (Eds.), *Infertility: Perspectives from Stress and Coping Research* (pp. 61-86). Springer.

Berg, S. (2017) AMA backs global health experts calling infertility a disease. American Medical Association. Retrieved on Feb 2, 2020, from https://www.ama-assn.org/delivering-care/public-health/ama-backs-global-health-experts-calling-infertility-disease

Benyamini, Y., Gefen, Bardarian, Y., Gozlan, M., Tabiv, G., Shiloh, S., Kokia, E. (2008) Coping specificity: the case of women coping with infertility treatments. *Psychology & Health*, *23*, 221-241.

Benyamini, Y., Gozlan, M., Kokia, E. (2004) On the self-regulation of a health threat: cognitions, coping, and emotions among women undergoing treatment for infertility. *Cognitive Therapy and Research*, *28*, 577-592.

Benyamini, Y., Nouman, H., Alkalay, Y. (2016) Perceived control over the medical procedure and its association with adjustment to a low-control situation: the case of infertility. *Psychology, Health & Medicine*, *21*, 476-482.

Billings, A. C., Moos, R. H. (1982) Psychosocial theory and research on depression: an integrative framework and review. Clinical Psychology Review, *2*, 213-237.

Boivin, J., Bunting, L., Collins, J. A., Nygren, K. G. (2007) International estimates of infertility prevalence and demand for infertility medical care. *Human Reproduction*, *22*, 1506-1512.

Boivin , J., Domar, A. D., Shapiro, D. B., Wischmann, T. H., Fauser, B. C. J. M., Verhaak, C. (2012). Tackling burden in ART: An integrated approach for medical staff. *Human Reproduction*, *27*, 941-950.

Boivin, J., Lancastle, D. (2010) Medical waiting periods: imminence, emotions and coping. *Women's Health*, *6*, 59-69.

Braun, V., Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77-101.

Campbell, S. M., Dunkel-Schetter, C., Peplau, L. A. (1991). Perceived control and adjustment to infertility among women undergoing in vitro fertilization. In A. L. Stanton and C. Dunkel-Schetter (Eds.), *Infertility: perspectives from stress and coping research* (pp.133-156). Plenum Press.

Canadian Fertility and Andrology Society: Counselling Special Interest Group (CSIG). (2009). Assisted Human Reproduction Counselling Practice Guidelines. Retrieved on March 2 2020 from https://cfas.ca/_Library/clinical_practice_guidelines/CSIG_Counselling_Practice_Guidelines_August_2009_.pdf

Chernoff, A., Balsom, A A., Gordon, J. L. (2021). Psychological coping strategies associated with improved mental health in the context of infertility. *Archives of Women's Mental Health*, *24*, 73-83.

Childress, K. J., Lawson, A. K., Ghant, M. S., Mendoza, G., Steinberg, M. L., Confino, E., Marsh, E. E. (2014). Toward an ideal patient experience: Longitudinal assessment of patient kowledge, experience, and reasons for discontinuation of infertility treatment. *Fertility and Sterility*, *102*, e14.

Clark-Gordon, C. V. (2019). Anonymity and online self-disclosure: A meta-analysis. *Communication Reports*, *32*, 98-111.

Cook, E. P. (1987). Characteristics of the biopsychosocial crisis of infertility. *Journal of Counseling & Development*, *65*, 465–470.

Cousineau, T. M., Domar, A. D. (2007). Psychological impact of infertility. *Best Practice & Research Clinical Obstetrics & Gynaecology*, *21*, 293-308.

Cousineau, T. M., Green, T. C., Corsini, E., Seibring, A., Showstack, M. T., Applegarth, L., Davison, M., Perloe, M. (2008). Online psychoeducational support for infertile women A randomized controlled trial. *Human Reproduction*, 23, 554-566.

Crawshaw, M., Hunt, J., Monach, J., Pike, S., Wild, R. (2013). British infertility counselling association – guidelines for good practice in infertility counselling. Third edition 2012. *Human Fertility*, *16*, 73-88.

Coyne, J. C., Racioppo, M. W. (2000). Never the twain shall meet? Closing the gap between coping research and clinical intervention research. *American Psychologist*, 55, 655-664.

Dennis, C-L. (2003). Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies*, *40*, 321-332.

Domar, A. D., Zuttermeister, P. C., Friedman, R. (1993). The psychological impact of infertility: a comparison with patients with other medical conditions. *Journal of Psychosomatic Obstetrics & Gynecology*, *14*, 45-52.

Durant, K. T., McCray, A. T., Safran, C. (2012). Identifying gender-preferred communication styles within online cancer communities: a retrospective, longitudinal analysis. *PLoS ONE*, *7*. doi:10.1371/journal.pone.0049169

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine*, *45*, 1207-1221.

Folkman, S., Shaefer, C., Lazarus, R. S. (1979). Cognitive processes as mediators of stress and coping. In V. Hamilton and D. M. Warburton (Eds.), *Human Stress and Cognition: An Information Processing Approach* (pp. 265-298). Wiley.

Fox, S. (2014) The social life of health information. Pew Research Center. Retrieved on Feb 17, 2020, from https://www.pewresearch.org/fact-tank/2014/01/15/the-social-life-of-health-information/

Gelgoot, E. N., Kelly-Hedrick, M., Miner, S. A., Robins, S., Chan, P., Ells, C., Holzer, H., Lo, K., Mahutte, N., Ouhilal, S., Tulandi, T., Zelkowitz, P. (2020). Predictors of infertility-related concerns in a Canadian survey of man and women seeking fertility treatment. *Patient Education and Counseling*, *103*, 1812-1820.

Gourounti, K., Anagnostopoulos, F., Potamianos, G., Lykeridou, K., Schmidt, L., Vaslamatzis, G. (2012). Perception of control, coping and psychological stress of infertile women undergoing IVF. *Reproductive BioMedicine Online*, *24*, 670-679.

Greil, A. L., McQuillan, J., Lowry, M., Shreffler, K. M. (2011). Infertility treatment and fertility-specific distress : a longitudinal analysis of a population-based sample of U.S. women. *Social Science & Medicine*, *73*, 87-94.

Greil, A. L., Slauson-Blevins, K., McQuillan, J. (2010). The experience of infertility : a review of recent literature. *Sociology of Health & Illness*, *32*, 140-162.

Grunberg, P. H., Dennis, C-L., Da Costa, D., Zelkowitz, P. (2018). Infertility patients' need and preferences for online peer support. *Reproductive Biomedicine & Society Online*, *6*, 80-89.

Grunberg, P. H., Dennis, C-L., Da Costa, D., Idelson, R., Gagné, K., Zelkowitz, P. (2020). Development and evaluation of an online peer supporter training program. *Patient Education and Counseling, 103*, 1005-1012.

Hanna, E., Gough, B. (2017). Men's accounts of infertility within their intimate partner relationships: an analysis of online forum discussions. *Journal of Reproductive and Infant Psychology, 35*, 150-158.

Hinton, L., Kurinczuk, J. J., Ziebland, S. (2010). Infertility; isolation and the Internet: a qualitative interview study. *Patient Education and Counseling*, *81*, 436-441.

Hoey, L. M., Leropoli, S. C., White, V. M., Jefford, M. (2008). Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling*, *70*, 315-337.

Hu, J., Wang, X., Guo, S., Chen, F., Wu. Y-Y., Ji, F-J., Fang, X. (2019). Peer support interventions for breast cancer patients: a systematic review. *Breast Cancer Research and Treatment*, *174*, 325-341.

Hynes, G. J., Callan, V. J., Terry, D. J., Gallois, C. (1992). The psychological well-being of infertile women after a failed IVF attempt: the effects of coping. *British Journal of Medical Psychology*, *65*, 269-78.

Joy, J., McCrystal, P. (2015). The role of counselling in the management of patients with infertility. *The Obstetrician & Gynaecologist*, *17*, 83-89.

Kaunonen, M., Hannula, L., Tarkka, M. T. (2012). A systematic review of peer support interventions for breastfeeding. *Journal of Clinical Nursing*, *21*, 1943-1954.

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (2007). Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board. *Psycho-Oncology*, *16*, 763-771.

Kingod, N., Cleal, B., Wahlberg, A., Husted, G. R. (2017). Online peer-to-peer communities in the daily lives of people with chronic illness: a qualitative systematic review. *Qualitative Health Research*, *27*, 89-99.

Kowitt, S. D., Ellis, K. R., Carlisle, V., Bhushan, N., Black, K. Z., Brodar, K., Cranley, N. M., Davis, K. L., Eng, E., Martin, M. Y., McGuirt, J., Sokol, R. L., Tang, P. Y., Vines, A. I., Walker, J. S., Fisher, E. B. (2019). Peer support opportunities across the cancer care continuum: a systematic scoping review of recent peer-reviewed literature. *Supportive Care in Cancer*, *27*, 97-108.

Lancastle, D., Boivin, J. (2008). A feasibility study of a brief coping intervention (PRCI) for the waiting period before a pregnancy test during fertility treatment. *Human Reproduction*, *23*, 2299-2307.

Lazarus, R. S., Folkman, S. (1984). *Stress, appraisal, and coping*. Springer.

Liu, X., Sun, M., Li, J. (2018). Research on gender differences in online health communities. *International Journal of Medical Informatics*, 111, 172–181.

Luk, B. H-K., Loke, A. Y. (2016). A review of supportive interventions targeting individuals or couples undergoing infertility treatment: directions for the development of interventions. *Journal of Sex and Marital Therapy*. *42*, 515-533.

Lynch, C. D., Sundaram, R., Maisog, J. M., Sweeney, A. M., & Louis, G. M. B. (2014). Preconception stress increases the risk of infertility: results from a couple-based prospective cohort study—the LIFE study. *Human Reproduction*, *29*, 1067-1075.

Malik, S. H., Coulson, N. (2008). The male experience of infertility: a thematic analysis of an online infertility support group bulletin board. *Journal of Reproductive and Infant Psychology*, *26*, 18-30.

Malik, S. H., Coulson, N. (2008). Computer-mediated infertility support groups: an exploratory study of online experiences. *Patient Education and Counseling*, *73*, 105-113.

Malik, S. H., & Coulson, N. S. (2010). Coping with infertility online: an examination of self-help mechanisms in an online infertility support group. *Patient Education and Counseling*, *81*, 315-318.

Maroufizadeh, S., Karimi, E., vesali, S., Samani, R. O. (2015). Anxiety and depression after failure of assisted reproductive treatment among patients experience infertility. *International Journal of Gynaecology and Obstetrics*, *130*, 253-256.

Martins, M. V., Peterson, B. D., Almeida, V. M., & Costa, M. E. (2011). Direct and indirect effects of perceived social support on women's infertility-related stress. *Human Reproduction*, *26*, 2113-2121.

Martins, M. V., Peterson, B. D., Almeida, V. M., Mesquita-Guimarães, J., Costa, M. E. (2014). Dyadic dynamics of perceived social support in couples facing infertility. *Human Reproduction*, *29*, 83-89.

Miner, S. A., Daumler, D., Chan, P., Gupta, A., Lo, K., Zelkowitz, P. (2019). Masculinity, mental health, and desire for social support among male cancer and infertility patients. *American Journal of Men's Health*. *13*, 1-13.

Moon, H., Woo, K. (2021). An integrated review on mothers' experiences of online breastfeeding peer support: motivations, attributes and effectiveness. *Maternal & Child Nutrition*, e13200. https://doi.org/10.1111/mcn.13200

Negris, O, Lawson, A., Brown, D, Warren, C., Galic, I., Bozen, A., Swanson, A., Jain, T. (2021). Emotional stress and reproduction what do fertility patients believe? *Journal of Assisted Reproduction and Genetics*, *38*, 877-887.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: striving to meet the trustworthinesss criteria. *International Journal of Qualitative Methods*, *16*, 1-13.

O'Connell, S. B. L., Gelgoot, E. N., Grunberg, P. H., Schinazi, J., Da Costa, D., Dennis, C., Rosberger, Z., Zelkowitz, P. (2021). 'I felt less alone knowing I could contribute to the forum': Psychological distress and use of an online infertility peer support forum. *Health Psychology and Behavioural Medicine*, *9*, 128-148.

Peterson, B. D., Newton, C. R., Rosen, K. H., & Skaggs, G. E. (2006a). The relationship between coping and depression in men and women referred for in vitro fertilization. *Fertility and Sterility*, *85*, 802-804.

Peterson, B. D., Newton, C. R., Rosen, K. H., & Skaggs, G. E. (2006b). Gender differences in how men and women who are referred for IVF cope with infertility stress. *Human Reproduction*, *21*, 2443-2449.

Peterson, B. D., Pirritano, M., Christensen, U., Boivin, J., Block, J., & Schmidt, L. (2009). The longitudinal impact of partner coping in couples following 5 years of unsuccessful fertility treatments. *Human Reproduction*, *24*, 1656-1664.

Porter, M., Bhattacharya, S. (2008). Helping themselves to get pregant: a qualitative longitudinal study on the information-seeking behaviour of infertile couples. *Human Reproduction*, *23*, 567-572.

Read, S. C., Carrier, M-E., Boucher, M-E., Whitley, R., Bond, S., Zelkowitz, P. (2014). Psychosocial services for couples in infertility treatment: what do couples really want? *Patient Education and Counseling*, *94*, 390-395.

Richard, J., Badillo-Amberg, I., Zelkowitz, P. (2016). “So much of this story could be me”: men’s use of support in online infertility discussion boards. *American Journal of Men’s Health*, *11*, 663-673.

Şahiner, E., Boz, I. (2021). Experiences of women undergoing infertility treatment from embryo transfer until pregnancy test and their conceptualization of their embryo. *Journal of Psychosomatic Obstetrics and Gynaecology*. doi: 10.1080/0167482X.2020.1865909

Schmidt, L., Holstein, B. E., Christensen, U., & Boivin, J. (2005). Communication and coping as predictors of fertility problem stress: cohort study of 816 participants who did not achieve a delivery after 12 months of fertility treatment. *Human Reproduction*, *20*, 3248-3256.

Schwarzer, R., & Knoll, N. (2007). Functional roles of social support within the stress and coping process: a theoretical and empirical overview. *International Journal of Psychology*, *42*, 243-252.

Sominsky, L., Hodgson, D. M., McLaughlin, E. A., Smith, R., Wall, H. M., Spencer, S. J. (2017). Linking stress and infertility: a novel role of Ghrelin. *Endocrine Reviews*, *38*, 432-467.

Statistics Canada (2019). Canadian Internet use survey. *The Daily.* https://www150.statcan.gc.ca/n1/en/daily-quotidien/191029/dq191029a-eng.pdf?st=CEqHVNwo

Stubbs, B., Williams, J., Shannon, J., Gaughran, F., Craig, T. (2016). Peer support interventions seeking to improve physical health and lifestyle behaviours among people with serious mental illness: a systematic review. *International Journal of Mental Health Nursing*, *25*, 484-495.

Swift, A., Reis, P., Swanson, M. (2021). Infertility stress, cortisol, coping, and quality of life in U.S. women who undergo infertility treatments. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, *50*, 275-288.

Sykes, S., Wills, J. (2019). eHealth literacy and fertility – managing complex information in a digital environment. *European Journal of Public Health*, *29* (supp), 416.

Taylor, S. E., Stanton, A. L. (2007). Coping resources, coping processes, and mental health. *Annual Review of Clinical Psychology*, *3*, 377-401.

Terry, D. J., & Hynes, G. J. (1998). Adjustment to a low-control situation: reexamining the role of coping responses. *Journal of Personality and Social Psychology*, *74*, 1078-1092.

van den Broeck, E. M., Wischmann, T., Thorn, P. (2010). Counselling in infertility: individual, couple and group interventions. *Patient Education and Counseling*, *81*, 422-428.

van Ingren, E., Utz, S., Toepoel, V. (2016). Online coping after negative life events: measurement, prevalence, and relation with Internet activities and well-being. *Social Science Computer Review*, *34*, 511-529.

van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Lebrun, C. E. I., Drossaers-Bakker, K. W., Smit, W. M., Seydel, E. R., van de Laar, M. A. F. J. (2008). Coping with somatic illnesses in online suppot groups: Do the feared disadvantages actually occur? *Computers in Human Behavior*, *24*, 309-324.

Wischmann, T. (2008). Implications of psychosocial support in infertility – a critical appraisal. *Journal of Psychosomatic Obstetrics & Gynecology*, *29*, 83-90.

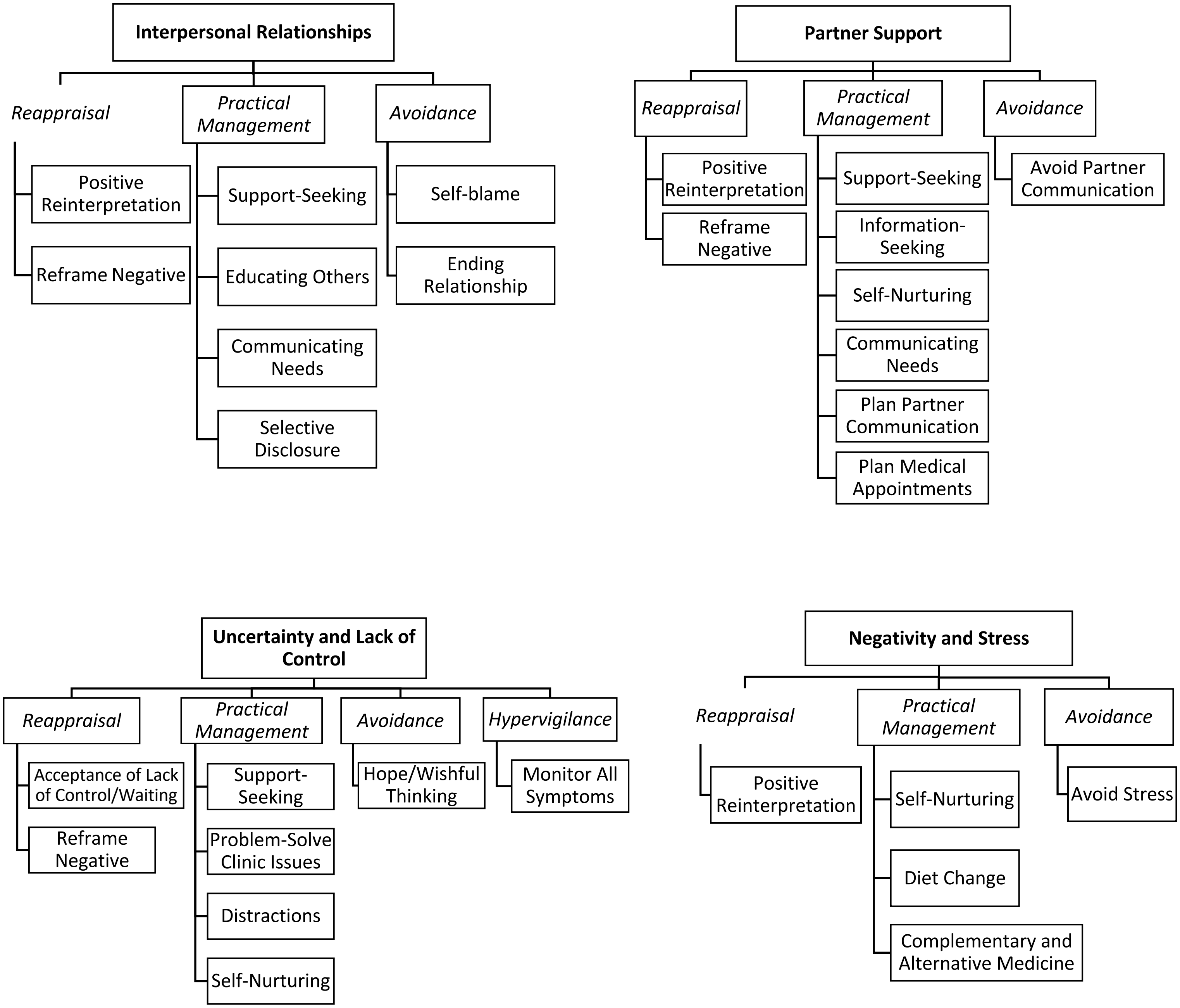
Xun, J., Reynolds, J. (2010). Applying netnography to market research: the case of the online forum. *Journal of Targeting, Measurement & Analysis for Marketing*, *18*, 17-31.

Yu, Y., Peng, L., Chen, L., Long, L., He, W., Li, M., Wang, T. (2014). Resilience and social support promote posttraumatic growth of women with infertility: the mediating role of positive coping. *Psychiatry Research*, *215*, 401-405.

Zurlo, M. C., Volta, M. F. C. D., Vallone, F. (2019). The association between stressful events and perceived quality of life among women attending infertility treatments: the moderating role of coping strategies and perceived couple's dyadic adjustment. *BMC Public Health*, *19*, 1-8.

Figure 1.

Thematic map of coping strategies within four domains: interpersonal relationships, partner support, uncertainty and lack of control, and negativity and stress.



General Discussion

Summary of Main Findings

The aim of the present thesis was to describe and evaluate the development and use of a novel online peer support program for individuals undergoing fertility treatment. This research built on available evidence highlighting the need for and utility of online infertility peer support and included key stakeholders in the development and evaluation process to tailor the program to the needs of the fertility patient population. Quantitative and qualitative methods were used to improve understanding of (1) fertility patients' needs and preferences for infertility peer support, (2) peer supporter program development and peer supporter experiences, and (3) ways of coping with fertility-related stressors.

The first manuscript in this thesis was designed to determine (1) level of interest in, and preferences for online infertility peer support (2) and factors associated with interest and preferences among a diverse sample of men and women undergoing fertility treatment. A needs assessment survey was completed by 519 men and women undergoing fertility treatment. More than four out of five participants expressed interest in online infertility peer support with perceived stress emerging as a unique determinant of interest among men and women. Results indicated that patients preferred monitored peer support offered through mobile technology and that provided opportunities to ask and answer questions and links to external information. Based on these results, a mobile infertility application was developed that provided access to a monitored peer support forum where patient users could share questions and experiences regarding infertility and its treatment.

The objective of the second manuscript was to (1) describe the development of the novel online peer supporter training program and (2) examine peer supporter experiences to evaluate program acceptance and areas for refinement. Seventeen women and one man with a history of fertility treatment were recruited and trained as peer supporters. At the end of the study peer supporters completed a mixed method survey asking about their experiences. Peer supporters rated all training components as helpful and were satisfied with the level and quality of coordinator supervision. Almost all peer supporters felt comfortable providing support, with ‘helping people’ and ‘acquiring skills’ as the most frequently liked aspects of providing support. Qualitative analysis of open-ended responses showed that although program satisfaction was high, technological difficulty was the most frequently disliked aspect of support provision. Peer supporters gave high ratings to their comfort with our monitoring the discussion forum. a preferred feature among fertility patients in study 1 and one that can ensure discussion safety. Findings indicated that the present peer supporter program was feasible and acceptable to peer supporters.

The third study used a qualitative approach to improve understanding of coping among fertility patients. Qualitative methods were used to capture rich accounts of coping experiences by examining patterns in online communication with trained peer supporters. A thematic analysis of 244 online posts from 39 users (37 women, 2 men) found that users actively sought out and shared information about coping with fertility-related stressors. Across four domains of stressors—interpersonal relationships, partner support, uncertainty and lack of control, and positivity and negativity—users and peer supporters discussed cognitive-reappraisal and practical management coping strategies. Users often discussed the helpfulness of different coping strategies, supporting the perspective that coping with infertility is best seen as a nuanced process that includes general and context-specific factors.

Taken together, results of these three studies provide evidence for the feasibility and acceptability of an online infertility peer support program among patient users and trained peer supporters. Results of the third study highlight the potential for online peer support to be a source of information about coping among individuals with lived experience.

Implications and Future Directions

The present thesis provides evidence for the feasibility, acceptability, and use of an online peer support forum among fertility patients. An online peer support program is cost-effective (Dukhovny et al., 2013; Hu et al., 2019), making it a useful and practical resource for fertility clinics to provide patients with experiential information about coping with fertility-related stressors. A peer support program may be particularly helpful during the numerous periods of waiting between assessments, treatments, and outcomes, as women in treatment tend to increase support-seeking behaviours leading up to pregnancy test results (Boivin & Lancastle, 2010). Findings of studies 1 and 2 showed that offering peer support programs that can be accessed through mobile technology is important to both fertility patients and peer supporters. Through their open-ended responses and conversations with staff, peer supporters often referred to challenges associated with busy schedules and daily changes in environmental context, especially given that many of the women were also caring for children. A smartphone device allowed the patients and peer supporters to connect with others from any location, improving geographical access beyond non-mobile web-based technology, such as desktops (Malik & Coulson, 2008a; McColl et al., 2014). Smartphones can also allow patients in waiting rooms to have an added source of support during a stressful waiting period. The acceptability of the present program is important as web-based communication becomes an increasingly normal aspect of social interaction. The online format overcomes geographical boundaries, reduces patient travel costs, and allows for increased anonymity and privacy. Recently, the need for online over in-person sources of support has been magnified with the COVID-19 pandemic. The imperative for social distancing has led to the suspension of fertility services for many (CFAS, 2020), further delaying couples' attempts to conceive. The need for ongoing supportive services is highlighted by survey results showing that among 3604 patients, both infertility and COVID-19 were the two most frequently rated as top stressors (Vaughan et al., 2020).

Prior to the present research, knowledge about online infertility peer support has largely been derived from studies with people already engaged in online infertility-related communication (e.g., Malik & Coulson, 2008a,2008b) and therefore could not speak to the general level of interest among the larger fertility treatment-seeking population. By targeting the general fertility patient population, present findings greatly increase confidence that online infertility peer support is relevant and desired by a nontrivial subset this population and particularly those with greater perceived stress. Social support by definition reflects a sharing of psychological or tangible resources to assist someone in managing a stressor. In addition to self-esteem and self-efficacy, perceived level and adequacy of social support are well-documented buffers of stress (Beck, 2007; Thoits, 2011). From the perspective of the Social Control Model (Beck, 2007), social support buffers the physiological stress response stemming from threats of social-evaluation and uncontrollability. For someone who appraises her resources as insufficient to cope, peer support may offer coping information that can assist the target individual in the reappraisal and practical management of a stressor. Results of study 3 are the first to demonstrate that this type of active sharing of coping information occurs online between fertility patients. Given the importance of adaptive coping on psychological and physical health, research is needed to investigate whether those who engage in peer support programs report alterations in coping throughout fertility treatment.

A randomized longitudinal study would be useful for assessing online peer support program effects on patient coping and psychological symptomatology. For example, fertility patients could be randomized into one of three groups providing online trained peer support, online psychoeducation about coping and stress, or both. Educational and skills-based interventions in group formats have garnered the most support for improving psychological outcomes in fertility patients (Boivin & Gameiro, 2015) and would therefore serve as a meaningful comparison to online peer support. A longitudinal pre-post design would also allow for mixed method analysis of perceived stress and coping skills over time and examine factors associated with stress and coping, including patient treatment variables (e.g., type of diagnosis, treatment history, parenting history), perceived offline support, self-efficacy, and psychological symptomatology (Schwarzer & Knoll, 2007). This line of research is needed to identify core outcomes of engagement with online infertility peer support forums.

The development of the Peer Supporter Experiences questionnaire allowed for the evaluation of peer supporters' experiences with training, supervision, and support provision. Questionnaire items were derived from previous literature demonstrating their utility in examining peer supporter experiences of a postpartum depression peer support program (Dennis, 2012). Research is needed to examine the psychometric properties and factor structure of this questionnaire, using larger samples of peer supporters. Doing so would create opportunities for studying predictors of satisfaction and perceived competence such as psychological variables and fertility treatment history.

Despite men’s high levels of professed interest in online peer support in study 1, men were largely absent from the online forum. There are several potential reasons for this finding. Firstly, it is important to note that fewer men were recruited for app participation with only 50 men logging into the app following consent. It may be that the population of men who seek online support is small compared to women (Hinton et al. 2010). This does not detract from the importance of online peer support for men, but does suggest that larger, more populated online communities are needed to connect disparate men wanting to communicate with other men about infertility. One possibility is for online peer support programs to be coordinated between clinics, so that a greater number of men are informed of the program. National fertility organizations such as Fertility Matters could also play an important role in helping to recruit and direct men and women to online peer support programs. Most peer supporters for this research were referred by Fertility Matters; given these peer supporters’ satisfaction with the current program, this organization may be optimally positioned to offer online peer support to a greater number of men.

Interestingly, the withdrawal of the only active male peer volunteer provides a clue as to the absence of male patient users. Specifically, in study 2, the male peer supporter dropped out because of the absence of male users and his own perceived lack of utility on the forum. The discussion forum quickly populated with posts from female users and peer supporters, which may have affected men’s decision not to post. Research suggests that in general, men and women prefer online communication with peers of the same sex (Durant et al., 2012; Richard et al., 2017; Liu et al., 2018). A social network analysis of 8388 members of six online cancer forums found that men and women were more likely to form relationships with members of the same sex. Further, compared to women whose posts were more intimate and emotionally expressive, men's forums were characterized by less intimate communication with greater numbers of men (Durant et al., 2012). Analysis of 19976 posts from diabetes forums also showed that men and women generally prefer same-sex bonds and that women use significantly more emotional expression than men who are more likely to discuss medical and research aspects of diabetes (Liu et al., 2018).

Examining existing large-scale men's discussion forums could provide information about what encourages men's participation. For example, Richard et al. (2017) identified 199 unique male users who discussed their infertility on Reddit, an online network of communities surrounding diverse topics that is currently ranked sixth in Canada for web traffic and engagement (Alexa, 2020). Reddit is optimal for investigating men's issues as there are approximately twice as many male as female users (Amaya et al., 2019); this suggests that there are unique features of Reddit that encourage participation among men. Richard et al. (2017) reported that there are a number of Reddit communities targeting men's psychological and physical health issues, which may aid in capturing a greater number of men seeking online peer support than a mobile application solely for fertility-related issues. This also suggests that having designated male topics, threads, or entire forums may encourage men's participation. As part of a larger study, semi-structured interviews were conducted with 11 men who used the present app. Consistent with results of Richard et al. (2017), we found that some men wanted more specific information about medical aspects of diagnosis and treatment and would have appreciated this type of information as threads on the forum. Longitudinal randomized studies would help to determine whether the addition of either (1) distinct gender-specific forums or (2) male-specific infertility threads increase participation among men. If men who are randomized to an online peer support forum with male-specific forum threads show increased likelihood of forum engagement than men without such forum threads, such gender-specific tailoring would be beneficial in future infertility peer support programs.

Finally, the time window for accessing the present forum may not have been sufficiently wide for some men to post. Qualitative research into men's online infertility-related communication analyzed messages posted over approximately 18 months (Malik & Coulson, 2008; Richard et al., 2017), compared to the present discussion forum that was accessible for a maximum of 5 months, depending on recruitment date. Therefore, future peer support programs may benefit from maintaining open participation over longer periods of time.

Similar to the above, the vast majority of posts were made to the English forum, with the French forum relatively empty. This is notable as it may indicate that francophone patients are either less desirous of online infertility peer support or were not motivated to post due to study or program factors. In response to discussion about the unpopulated French forum, one bilingual peer supporter who had monitored both French and English forums, hypothesized that there are more in-person French support programs in Montreal, leaving unilingual anglophone patients with fewer opportunities for offline support. This finding is important and is in need of further investigation. A first step would be to identify all available support group services provided in the Montreal and Quebec area to determine the ratio of anglophone to francophone support groups. This could also be explored by conducting interviews with both francophone and anglophone fertility patients to understand what factors they perceive as influencing their interest or lack of interest in online peer support.

Limitations

The present research should be considered within the context of certain limitations. Firstly, for study 1, interest in online peer support, as well as several participant background variables, were examined using dichotomous items. The dichotomization of items is common in clinical research (Altman & Royston, 2006), and was decided for in the present research based on optimal cut points; for example, based on research showing that a history of successful live birth is a significant predictor of lower stress among those in treatment (Greil et al., 2011). Additionally, ethnic background was categorized as White and non-White, which may not have captured important variability across ethnic groups. The sample size for sample 1 was not large enough to examine the numerous ethnic groups, leaving an important avenue for future research. Further, the aim of study 1 was to provide a first estimate of interest in online infertility peer support and preferences. Factors other than perceived stress may have been found to relate to interest if it was continuous, as continuous response options can increase power for detecting an existing effect (Altman & Royston, 2006). Therefore, although evidence from study 1 highlights perceived stress as an important factor in understanding online peer support interest, more research is needed to examine the associations between interest and diagnostic, treatment, demographic, and other psychological factors.

Second, although a large and diverse population of current treatment-seekers was recruited for needs assessment, it is possible that present findings only generalize to the interest and preferences of men and women seeking treatment in Montreal and Toronto. Replication studies are needed to determine level of interest and preferences for an online peer support program in other countries and Canadian provinces.

Participation in the present research is also limited by its inclusion of only fertility patients fluent in English and/or French. The diverse population of fertility patients found in the current study suggests there could be variability in English or French language competence. The results of study 3 may generalize only to patients with the confidence in their ability to read and communicate in French or English. As such, results of study 3 may not reflect the diverse coping strategies used by those of different cultural backgrounds. Religious or spiritual coping methods, for example, may be more prominent among immigrant fertility patients.

Next, it is necessary to consider the level of missing data from the Peer Supporter Experiences Questionnaire. It is unknown why certain peer supporters did not complete the questionnaire or every item and therefore some caution must be used when interpreting findings from Study 2. Specifically, those who did not respond or complete items may have felt differently than those who did respond; however, the high levels of satisfaction among those who completed the survey indicates that the program was acceptable to the majority of peer supporters.

The sample size in study 3 was also small, with a subset of forum users also posting more frequently. Also, because participants were limited to a maximum of 5 months to post on the forum, knowledge of more long-term discussion content could not have been identified. Longitudinal studies of fertility patient participation in online peer support forums is needed to determine whether coping is a common topic of such forums and whether similar patterns in coping discussion are found over time. As many patients undergo treatment for several years, it is likely that discussions about coping would be influenced by cycles of treatment failures experienced by a majority of patients.

Conclusion

Individuals undergoing fertility treatment frequently experience elevated stress and lowered quality of life as a result of treatment-related physical and psychological stressors. Such stressors include the physical challenges of medical assessment and treatment, financial burden, and psychosocial stress related to the repeated cycles of hope leading up to results and disappointment and grief following negative outcomes. Fertility patients may also receive hurtful comments from others and experience a sense of social isolation from fertile friends and family (Hinton et al., 2010; Schmidt et al. 2009). Perceiving an adequate level and quality of social support is related to better psychological adjustment (Kroemeke & Kubicka, 2018) and lower infertility-related stress (Martins et al., 2011; Martins et al., 2014) among infertility samples, emphasizing the need to develop supportive resources for men and women in treatment.

Fertility patients reported a desire for organized contact with other fertility patients (Dancet et al., 2010; Read et al., 2014). As Internet access and use became nearly ubiquitous in the developed world, some of those with a history of infertility went online to communicate with similar people, primarily to share personal experiences and mutual support (Malik & Coulson, 2010). Research has also indicated, however, that some level of peer supporter training is required to ensure peer support efficacy (Hu et al., 2017). Accordingly, the present thesis aimed to evaluate the feasibility and acceptability of a monitored online infertility peer support program with trained peer supporters.

The present research addressed several gaps in the literature related to the development and use of an online infertility peer support program. Firstly, the findings extended previous literature about online infertility communication by demonstrating a high level of interest in an online peer support program among current fertility patients, particularly those with greater perceived stress. Both fertility patients and peer supporters were comfortable with professional monitoring of the forum and appreciated the convenience and privacy afforded through confidential usernames and mobile technology. The online forum was found to be a source of information about coping with fertility-related stressors. That is, fertility patients actively sought out information about ways of coping, with users and peer supporters describing the helpfulness of cognitive reappraisal and practical management strategies. Notably, nearly all users were women, highlighting the need to further examine predictors of men’s participation in online peer support programs.

Together, present findings provide evidence for the feasibility and acceptability of an online infertility peer support program. The detailed description of the development and evaluation process provides a framework for online recruitment, training, and supervision of peer supporters and the provision of peer support to patients in need. Findings highlight the need to elucidate peer support mechanisms, particularly with respect to the effects of receiving information about coping from peers and peer supporters.

References

Aarts, J. W. M., van den Haak, P., Nelen, W. L. D. M., Tuil, W. S., Faber, M. J., & Kremer, J. A. M. (2012). Patient-focused internet interventions in reproductive medicine: a scoping review. *Human Reproduction Update*, *18*(2), 211-227.

Alexa (2020). Website traffic analysis. Retrieved July 30, 2020 from https://www.alexa.com

Altman, D. G., & Royston, P. (2006). The cost of dichotomising continuous variables. BMJ, *332*(7549), 1080.

Amaya, A., Bach, R., Keusch, F., Kreuter, F. (2019). New data sources in social science research: Things to know before working with Reddit data. doi: https://doi.org/10.1177/0894439319893305

Beck, L. (2007). Social status, social support, and stress: A comparative review of the health consequences of social control factors. *Health Psychology Review*, *1*(2), 186-207.

Boivin, J., Buntin, L., Collins, J. A., & Nygren, K. G. (2007). International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. *Human Reproduction*, *22*(6), 1506-12.

Boivin, J., & Gameiro, S. (2015). Evolution of psychology and counseling in infertility. *Fertility & Sterility*, *104*(2), 251-259.

Boivin, J., Scanlan, L. C., & Walker, S. M. (1999). Why are infertile patients not using psychosocial counselling? *Human Reproduction*, *14*(5), 1384-1391.

Boivin, J., Takefman, J., & Braverman, A. (2011). The fertility quality of life (FertiQoL) tool: development and general psychometric properties. *Human Reproduction*, *26*(8), 2084-2091.

Borght, M. V., & Wyns, C. (2018). Fertility and infertility: Definition and epidemiology. *Clinical Biochemistry*, *62*, 2-10.

Brochu, F., Robins, S., Miner, S. A., Grunberg, P. H., Chan, P., Lo, K., Holzer, H. E. G., Mahutte, N., Ouhilal, S., Tulandi, T., & Zelkowitz, P. (2019). Searching the Internet for infertility information: A survey of patient needs and preferences. *Journal of Medical Internet Reearch*, *21*(12), e15132. doi: 10.2196/15132

Chachamovich, R. J., Chachamovich, E., Ezer, H., Fleck, M. P., Knauth, D., & Passos, E. P. (2010). Investigating quality of life and health-related quality of life in infertility: A systematic review. *Journal of Psychosomatic Obstetrics & Gynecology*, *31*, 2, 101-110. doi: 10.3109/0167482X.2010.481337

Cousineau, T. M., & Domar, A. D. (2007). The psychological impact of infertility. *Best Practice & Research Clinical Obstetrics and Gynaecology*, *21*(2), 293-308.

Craig, P, Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2013). Developing and evaluating complex interventions : The new Medical Research Council guidance. *International Journal of Nursing Studies*, *50*, 585-592.

Dancet, E. A. F., Nelen, W. L. D. M., Sermeus, W., De Leeuw, L., Kremer, J. A. M., & D'Hooghe, T. M. (2010). The patients' perspective on fertility care : A systematic review. *Human Reproduction Update*, *16*(5), 467-87.

Datta, J., Palmer, M. J., tanton, C., Gibson, L. J., Jones, K. G., Macdowall, W., Glasier, A., Sonnenberg, P., Field, N., Mercer, C. H., Johnson, A. M., & Wellings, K. (2016). Prevalence of infertility and help seeking among 15 000 women and men. *Human Reproduction*, *31*(9), 2108-2118.

Davidson, L., Rakfeldt, J., & Strauss, J. S. (2010). The roots of the recovery movement in psychiatry: Lessons learned. John Wiley & Sons. pp. 23-60. doi: 10.1002/9780470682999

Dennis, C-L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, *40*(3), 321-332.

Dennis, C-L. (2010). Postpartum depression peer support: Maternal perceptions from a randomized controlled trial. *International Journal of Nursing*, *47*, 560-568.

Dennis, C-L. (2014). Peer support for postpartum depression: volunteers' perceptions, recruitment strategies and training from a randomized controlled trial. *Health Promotion International*, *28*(2), 187-196.

Ditzen, B., & Heinrichs, M. (2014). Psychobiology of social support: the social dimension of stress buffering. *Restorative Neurology and Neuroscience*, *32*, 149-162.

Forster, D. A., McLardie-Hore, F. E., McLachlan, H. L., Davey, M-L., Grimes, H. A., Dennis, C-L., Mortensen, K., Moorhead, A. M., Tawia, S., Gold, L., Shafiei, T., Small, R., East, C. E., & Amir, L. H. (2019). Proactive peer (mother-to-mother) breastfeeding support by telephone (Rining up About Breastfeeding Early [RUBY]): A multicentre, unblinded, randomised controlled trial. *EClinicalMedicine*, *8*, 20-28.

Dukhovny, D., Dennis, C-L., Hodnett, E., Weston, J., Stewart, D. E., Mao, W., Zupancic, J. A. F. (2013). Prospective economic evaluation of a peer support intervention for prevention of postpartum depression among high-risk women in Ontario, Canada. *American Journal of Perinatology*

Eldridge, L. K. B., Markham, C. M., Ruiter, R. A. C., Fernández, M. E., Kok, G., & Parcel, G. S. (2016). Planning health promotion programs: Intervention mapping approach (4th ed.). San Francisco, CA: Wiley, 3-56.

Fox, S., & Purcell, K. (2010). Chronic disease and the Internet. Pew Internet. Retrieved July 28 2020, from https://www.pewresearch.org/internet/wpcontent/uploads/sites/9/media/Files/Reports/2010/PIP_Chronic_Disease_with_topline.pdf

Greil, A. L. (1997). Infertility and psychological distress : A critical review of the literature. *Social Science and Medicine*, *45*(11), 1679-1704.

Greil, A. L., Shreffler, K. M., Schmidt, L., McQuillan, J. (2011). Variation in distress among women with infertility : Evidence from a population-based sample. *Human Reproduction*, *26*(8), 2101-2112.

Gidugu, V., Rogers, E. S., Harrington, S., Maru, M., Johnson, G., Cohee, J., & Hinkel, J. (2015). Individual peer support: A qualitative study of mechanisms of its effectiveness. *Community Mental Health Journal*, *51*, 445-452.

Hade, J. (2017). The infertility workup. In S. R. Bayer, & M. J., Berger (eds.) The Boston IVF handbook of infertility: A practical guide for practitioners who care for infertile couples (4th ed.). Boca Raton, FL. CRC Press, pp. 21-38.

Hanna, E., & Gough, B. (2016). Emoting infertility online: A qualitative analysis of men's forum posts. *Health*, *20*(4), 363-82.

Hanna, E., & Gough, B. (2017). Men's accounts of infertility within their intimate partner relationships: An analysis of online forum discussions. *Journal of Reproductive and Infant Psychology*, *35*(2), 150-8.

Huang, R., Yan, C., Tian, Y., Lei, B., Yang, D., Liu, D., & Lei, J. (2020). Effectiveness of peer support intervention on perinatal depression : A systematic review and meta-analysis. *Journal of Affective Disorders*, *276*, 788-796.

Kroemeke, A., & Kubicka, E. (2018). Positive and negative adjustment in couples undergoing infertility treatment: The impact of support exchange. *PLOS One*, *13*(6). https://doi. org/10.1371/journal.pone.0200124

Letourneau, N., Secco, L., Colpitts, J., Aldous, S., Stewart, M., & Dennis, C-L. (2015). Quasi-experimental evaluation of a telephone-based peer support intervention for maternal depression. *Journal of Advanced Nursing*, *71*(7), 1587-1599.

Lorig, K., Ritter, P. L., Plant, K., Laurent, D. D., Kelly, P., & Rowe, S. (2013). The South Australia health chronic disease self-management Internet Trial. *Health Education & Behavior*, *40*, 67-77.

Lyon, A. R., & Koerner, K. (2016). User-centered design for psychosocial intervention development and implementation. *Clinical Psychology: Science and Practice*, *23*, 180-200.

Malik, S. H., & Coulson, N. S. (2008a). Computer-mediated infertility support groups: An exploratory study of online experiences. *Patient Education and Counseling*, *73*, 105-113.

Malik, S. H., & Coulson, N. S. (2008b). The male experience of infertility: a thematic analysis of an online infertility support group bulletin board. *Journal of Reproductive and Infant Psychology*, *26*, 18-30.

Malik, S. H., & Coulson, N. S. (2010). Coping with infertility online: An examination of self-help mechanisms in an online infertility support group. *Patient Education and Counseling*, *81*, 315-318.

Martins, M. V., Peterson, B. D., Almeida, V., Mesquita-Guimarães, J., & Costa, M. E. (2014). Dyadic dynamics of perceived social support in couples facing infertility. *Human Reproduction*, *29*, 83-89.

Martins, M. V., Peterson, B. D., Almeida, V., & Costa, M. E. (2011) Direct and indirect effects of perceived social support on women's infertility-related stress. *Human Reproduction*, *26*(8), 2113-21.

Miner, S. A., Daumler, D., Chan, P., Gupta, A., Lo, K., & Zelkowitz, P. (2018). Masculinity, mental health, and desire for social support among male cancer and infertility patients. American Journal of Men's Health. doi: 10.1177/1557988318820396

Mindes, E. J., Ingram, K. M., Kliewer, W., & James, C. A. (2003). Longitudinal analyses of the relationship between unsupportive social interactions and psychological adjustment among women with fertility problems. *Social Science & Medicine*, *56*, 2165-2180.

Olivius C, Friden B, Borg G & Bergh C. Why do couples discontinue in vitro fertilization treatment? A cohort study. Fertil Steril 2004; 81: 258e261.

Olafsdottir, S. A., Jonsdottir, H., Magnusson, C., Caltenco, H., Kytö, M., Maye, L., McGookin, D., Bjartmarz, I., Arnadottir, S. A., Hjaltadottir, I., & Hafsteinsdottir, T. B. (2020). Developing activABLES for community dwelling stroke survivors using the Medical Research Council framework for complex interventions. *BMC Health Services Research*, *20*, 1-14.

Ottawa Fertility Centre. (2020). Fees. Retrieved on July 29 from https://conceive.ca/fees/#In-Vitro-Fertilization-IVF

Parent, N., & Fortin, F. (2000). A randomized, controlled trial of vicarious experience through peer support for male first-time cardiac surgery patients: Impact on anxiety, self-efficacy expectation, and self-reported activity. *Heart & Lung*, *29*(6), 389-400.

Patil, S. J., Ruppar, T., Koopman, R. J., Lindbloom, E. J., Elliot, S. G., Mehr, D. R., & Conn, V. S. (2018). Effect of peer support interventions on cardiovascular disease risk factors in adults with diabetes: A systematic review and meta-analysis. *BMC Public Health*, *18*, 1-10.

Petraglia, F., Serour, G. I., Chapron, C. (2013). The changing prevalence of infertility. *International Journal of Gynecology and Obstetrics* 123, S4-S8.

Plinsinga, M. L., Besomi, M., Maclachlan, L., Melo, L., Robbins, S., Lawford, B. J., Teo, P. L., Mills, K., Setchell, J., Egerton, T., Eyles, J., Hall, L., Mellor, R., Hunter, D. J., Hodges, P., Vicenzino, B., Bennell, K. (2019) . Exploring the characteristics and preferences for online support groups: Mixed method study. *Journal of Medical Internet Research*, *21*(12), e15987.

Porter, M., & Bhattacharya, S. (2008). Helping themselves to get pregnant: A qualitative longitudinal study on the information-seeking behaviour of infertile couples. *Human Reproduction*, *23*(3), 567-572.

Read, S., C., Carrier, M-E., Boucher, M-E., Whitley, R., Bond, S., & Zelkowitz, P. (2014). Psychosocial services for couples in infertility treatment: What do couples really want? *Patient Education and Counseling*, *94*, 390-395.

Richard, J., Badillo-Amberg, I., & Zelkowitz, P. (2017). “So much of this story could be me”: Men’s use of support in online infertility discussion boards. *American Journal of Men’s Health*, *11*(3), 663-673.

Schroder AK, Katalinic A, Diedrich K & Ludwig M. Cumulative pregnancy rates and drop-out rates in a German IVF programme: 4102 cycles in 2130 patients. Reprod Biomed Online 2004; 8: 600e606.

Slade, P., O'Neill, C., Simpson, A. J., & Lashen, H. (2007). The relationship between perceived stigma, disclosure patterns, support and distress in new attendees at an infertility clinic. *Human Reproduction*, *22*(8), 2309-2317.

Slauson-Blevins, K. S., McQuillan, J., & Greil, A. L. (2013). Online and in-person health-seeking for infertility. *Social Science and Medicine*, *99*, 110-115.

Smith, A. D. A. C., Tilling, K., Nelson, S. M., & Lawlor, D. A. (2015). Live-birth rate associated with repeat in vitro fertilization treatment cycles. *JAMA*, *314*(24), 2654-2662.

Statistics Canada (2017). Families, households and marital status: Key results from the 2016 census. The Daily. Retrieved from https://www150.statcan.gc.ca/n1/daily-quotidien/170802/dq170802a-eng.htm

Statistics Canada. (2019). Canadian Internet use survey. The Daily. https://www150.statcan.gc.ca/n1/daily-quotidien/191029/dq191029a-eng.htm

Sunderland, N., Beekhuyzen, J., Kendall, E., & Wolski, M. (2013). Moving health promotion communities online: A review of the literature. *Health Information Management Journal*, *42*(2), 9-16.

Turnbull, B., Graham, M. L., & Taket, A. R. (2017). Pronatalism and social exclusion in Australian society: experiences of women in their reproductive years with no children. *Gender Issues*, *34*(4), 333-354.

Uchino, B. N. (2006). Social support and health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine*, *29*(4), 377-387.

Van den Broeck, U., Holvoet, L., Enzlin, P., Bakelants, E., Demyttenaere, K., & D'Hooghe, T. (2009). Reasons for dropout in infertility treatment. *Gynecologic and Obstetric Investigation*, *68*, 58-64.

Vaughan, D. A., Shah, J. S., Penzias, A. S., Domar, A. D., & Toth, T. L. (2020). Infertility remains a top stressor despite the COVID-19 pandemic. *Reproductive BioMedicine Online*. doi: https://doi.org/10.1016/j.rbmo.2020.05.015

Watson, E. (2019). The mechanisms underpinning peer support: A literature review. *Journal of Mental Health*, *28*(6), 677-688.

Wright, K. B., & Miller, C. H. (2010). A measure of weak-tie/strong-tie support network preference. *Communication Monographs*, *77*(4), 500-517.

Ying, L., Chen, X., Wu, L. H., Shu, J., Wu, X., & Loke, A. Y. (2017). The partnership and coping enhancement program for couples undergoing in vitro fertilization treatment: development of a complex intervention in China. *Journal of Assisted Reproduction and Genetics*, *34*, 99-108.