ARTICLE

Infertility patients' need and preferences for online peer support

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Abstract

This study sought to determine the level of interest in online peer support among infertility 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.

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Introduction

Infertility can be a devastating personal experience (Greil, 1997). It 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., 2010, 2011). 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 experiencing most of the physical procedures and negative social consequences associated with 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 and human immunodeficiency virus (Domar et al., 1993). Men also report increased distress associated with their own exclusion from treatment, concerns about the well-being of their partner (Malik and Coulson, 2008a), and perceived need to suppress their emotions to better support their partner (Hanna 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 for better understanding of intervention models aimed at improving the well-being of those undergoing treatment.

The internet may be important for delivering psychosocial interventions to infertility 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). 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 infertility 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 infertility patient population, which tends to be highly educated (Statistics Canada, 2017; Zelkowitz et al., 2011), and subject to psychological distress (Cousineau and Domar, 2007; Greil et al., 2010).

Interest in online supportive interventions may also be related to income and ethnicity. Whereas income may be related 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 particularly important among non-White infertility patients. Interestingly, low income or non-White ethnicity has been found to be related 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 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 relationship between treatment duration, time trying to conceive, and parity or interest or preferences may help to inform the content and structure of online interventions.

Despite burgeoning research into online infertility support, studies have largely examined qualitative data from current internet users (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 male or female support groups alone (Malik and Coulson, 2008a, 2008b) without further description of socio-economic 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 infertility patients from varied sociodemographic backgrounds. A better understanding of patient preferences 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). There were two objectives to the study, as follows:

- Objective 1: to determine the extent to which men and women undergoing fertility treatment are 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. Four hypotheses were proposed: (i) women are more likely to express interest in online peer support than men; (ii) those reporting higher socio-economic status (i.e. income, education) are more
likely to express interest in online peer support than those reporting lower socio-economic status; (iii) the likelihood of expressing interest in online peer support is greater for those with higher perceived stress; and (iv) fertility factors (i.e. time trying to conceive, treatment duration, parity) are related to interest in online peer support, such that patients with a longer duration of time trying to conceive and a longer 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 proposed 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: seeking fertility treatment, at least 18 years of age, and 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 access to a unique website address. Consent was implied when the participant accessed the online link. If necessary, those invited by e-mail received a reminder 1 and 2 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 2 weeks. Data were stored on Canadian servers using Fluid Surveys, meeting ethics board requirements for secure data. Ethical 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 technology (ART) treatment may differ from those with a heterosexual orientation. In addition, the small number of non-heterosexual participants (n = 25) prevented meaningful analysis.

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. Interest in online peer support was assessed by asking participants, ‘Would you consider using a fertility peer support network that is available online?’ , to which response options were ‘yes’, ‘maybe’ and ‘no’. Next, participants were asked to indicate which features an ideal online peer support network should have, by rating 13 online peer support features on a Likert scale (from 1 = strongly disagree to 5 = strongly agree). Features of online peer support comprised four themes: platform format, communication, individual support, and monitoring. Platform format included four features related to the technology or services provided, such as 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 (Malik and Coulson, 2008b). Communication comprised 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 an expert (i.e. health professional) or non-expert moderator to improve the safety and quality of communication (Moorhead et al., 2013); this theme relates to concerns about acquiring inaccurate information or experiencing negative interactions online (Malik and Coulson, 2010).

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 (α > 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 and preferences for features of this network. For interest in online peer support, ‘yes’ and ‘maybe’ were collapsed to differentiate those with any interest and no interest. This method of examining interest in online health interventions follows a similar approach used in other research (Crisp and Griffiths, 2014). Cronbach’s alpha (Cronbach, 1951) was used to assess the internal consistency of the four groups of online peer support features.

For chi-squared analyses, a dichotomous income variable was created based on the Canadian median family household income for couple families (Statistics Canada, 2017): ≤$79,000 and >$79,000. Similarly, education was collapsed into university graduate and below. 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 the relationship between interest in online peer support and potential determinants. Chi-squared 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 years), Spearman’s Rho was used to examine their relationship with online peer support features. A large number of tests were required to examine the relationship between preferences for features and study variables; therefore, alpha was set at 0.01 to reduce the likelihood of Type I error.

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

Results

Sample characteristics

Of 808 patients approached, 795 (98.4%) met the eligibility criteria. From this pool, 49 (6.2%) patients refused, reporting disinterest, time constraints, stress and unwillingness to discuss infertility experiences as reasons for not participating. Of the 746 patients 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 1. 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, and South and East Asian ethnicities. Fertility characteristics are shown in Table 2. Approximately one-third of participants reported male factor infertility alone and approximately one-third of participants reported female factor infertility alone. In-vitro fertilization was the most frequently reported treatment, followed by oral hormones then intrauterine insemination. Approximately one-third of participants indicated that they were attending an initial consultation/visit. Most participants were nulliparous (n = 373, 71.9%) at the time of the study.

Description of online peer support features

Definitions and mean ratings of the 13 online peer support features are presented in Table 3. Three of the four groups of features demonstrated acceptable to good internal consistency, with Cronbach’s alpha coefficients as follows: platform
Objective 1: interest in online peer support

In total, 516 participants reported having any interest (n = 443, 85.9%) or no interest (n = 73, 14.1%) in an online infertility peer support network. Women (n = 254/283, 89.8%) were significantly more likely to report interest than men (n = 189/236, 80.1%; χ²(1) = 10.465, P = 0.001). For men, income (χ²(1) = 6.003, P = 0.018), PSS (r = 0.148, P = 0.023) and ethnicity (χ²(1) = 4.364, P = 0.047) were associated with interest in online peer support. Specifically, men with lower incomes (n = 90/102, 88.2%) were more likely to report interest than men with higher incomes (n = 99/132, 75.0%); and 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, PSS was the only variable that related significantly to interest (r = 0.12, P = 0.046). Two logistic regressions were performed for men and women (see Table 4). For men, income, ethnicity and PSS were included as predictors; for women, PSS was included as the only predictor. Models were significant for men (P = 0.004) and women (P = 0.04), with PSS as the only significant predictor of interest in online peer support in both analyses. Regression models explained approximately 9.0% and 3.1% of variance in interest for men and women, respectively.

Objective 2: preferences for features of an online peer support network

Feature preferences were not significantly related to sex (see Supplementary Table 1 for all associations between explanatory variables and peer support features); therefore, data from men and women were combined in subsequent analyses. 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 topic (76.3%). Also highly endorsed were communication features, wherein participants were frequently interested in the opportunity to ask and answer questions (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. Approximately 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 = 0.12, P = 0.006). For communication and monitoring, ethnicity

Table 3  Patient survey questions, and means and proportions of participants who endorsed online peer support features.

| Variable                                      | Definition                                                                 | Mean (SD) | Proportion c |
|-----------------------------------------------|----------------------------------------------------------------------------|-----------|--------------|
| Interest in online peer support               | Would you consider using a fertility peer support network that is available online? a |           |              |
| Online peer support features                  | An ideal online peer support network should have b                          |           |              |
| 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 topic                        | 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         |

Q & A, questions and answers; SD, standard deviation.

a No, maybe, yes.

b 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strongly agree.

c Endorsement includes ratings of agree or strongly agree.
related to anonymous posting \( (r = 0.14, \ P = 0.001) \) and monitoring by health a professional \( (r = 0.12, \ P = 0.005) \).

Certain groups favoured individual support features. Specifically, ethnicity \( (r = 0.12, \ P = 0.007) \) and PSS \( (r = 0.12, \ P = 0.006) \) were significantly related to the desire to be matched to a peer supporter. Lastly, people reporting higher perceived stress more strongly endorsed connecting to peers offline \( (r = 0.13, \ P = 0.002) \), and younger participants expressed a greater preference for private messaging \( (r = -0.12, \ P = 0.009) \).

### Discussion

Burgeoning research supports the use of online peer support interventions for improving health outcomes in many patient groups, including those with infertility (Hoey et al., 2008; Malik and Coulson, 2008b). However, there has been little research on user preferences regarding online peer support. The present study addressed the lack of information regarding individual differences in the online support preferences of diverse infertility patients. Information about the preferences of potential users is essential in order to tailor interventions to improve uptake and effectiveness (Craig et al., 2008; Schubart et al., 2011). Overall, four out of five participants indicated some interest in using online peer support. This service was of particular interest to both 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.

With respect to the first hypothesis (women are more likely to express interest in online peer support than men), 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 programmes (DeAndrea and Anthony, 2013). However, it is important to note that a majority of men also reported possible interest. There is increasing evidence for men’s use of online support in general (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).

The second hypothesis, that higher socio-economic status (i.e. income, education) would be related to greater likelihood of interest, was partially supported. Among men alone, lower income and non-White ethnicity, but not education, were related to interest in online peer support at the univariate level. Low-income men more often face reduced work flexibility, impeding the ability to schedule health-related appointments or seek out and connect with similar people (Greil et al., 2010). Online support also presents 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 with White men, non-White men reported greater interest in online peer support. In general, non-White minorities are greatly under-represented in online support groups (Im et al., 2016; Im and Chee, 2008); therefore, it is interesting that minority men expressed greater interest. Research shows that some infertile men use the internet to communicate about infertility (Malik and Coulson, 2008a), yet very little is known about the sociodemographic characteristics of these men. Norms about privacy related to health have been found to differ between cultural groups, and are influenced, in part, by the extent to which group members predict negative social consequences as a result of public disclosure (Haynes-Maslow et al., 2016). Research is therefore needed to determine whether interest in online peer support is related to the desire for opportunities to engage in conversations about infertility. Online peer support provides an opportunity to connect with similar peers in a more convenient and discreet 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 which 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

### Table 4 Two logistic regression analyses predicting interest in online peer support for men and women.

| Variable | B  | SE  | OR  | 95% CI | Wald | P-value |
|----------|----|-----|-----|--------|------|---------|
| Men (n = 233) |    |     |     |        |      |         |
| Perceived Stress Scale-4 | 0.14 | 0.07 | 1.15 | 1.01–1.31 | 4.75 | 0.03   |
| Household Income |    |     |     |        |      |         |
| ≤$79,000 | 0.71 | 0.38 | 2.03 | 0.96–4.28 | 3.46 | 0.06   |
| >$80,000 | – | – | – | – | – | – |
| Ethnicity |    |     |     |        |      |         |
| White | –0.46 | 0.36 | 0.63 | 0.31–1.28 | 1.63 | 0.20   |
| Non-White | – | – | – | – | – | – |
| Women (n = 280) |    |     |     |        |      |         |
| Perceived Stress Scale-4 | 0.15 | 0.07 | 1.16 | 1.00–1.34 | 3.94 | <0.05 |

SE, standard error. OR, odds ratio; CI, confidence interval.

* Reference category.
Online peer support was of interest to participants with a variety of fertility characteristics (i.e. parity, treatment duration, time trying to conceive). This indicates that irrespective of fertility characteristics, patients who reported greater stress were more likely to express interest in online peer support. As there was little variability in women’s responses, few associations with the study variables emerged. Findings are, however, suggestive of the unique role of perceived stress in understanding patients’ interest in online infertility peer support.

With respect to the peer support features, participants most highly endorsed the ability to access a peer support network through mobile technology. Smartphones are the preferred means of internet access among those aged 18–49 years (Rainie, 2012), emphasizing the utility of mobile technology for infertility patients who typically fall within this age range. Online peer support offered through multiple internet sources, including desktop computer and smartphone, could yield greater uptake among diverse economic groups.

In addition to mobile accessibility, participants valued highly 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 (Porter and Bhattacharya, 2008; Read et al., 2014). Such interactions between people with similar health conditions is thought to promote patient empowerment through 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 given that infertility patients have expressed concerns about the veracity of online fertility information and discussions (Malik and Coulson, 2010). The inclusion of a professional moderator would offer a way to 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, as a lack of identifying information reduces concerns regarding disclosure of personal information (Coulson and Malik, 2012). 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, which is more pronounced among minority groups (Greil, 1997; Greil et al., 2010). Thus, it is possible that, for some, identity is strongly tied to fertility and relates to greater worry about 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 infertility 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). The infertility experiences of ethnic minorities differ in important ways, such as a greater sense of shame for being unable to conceive, and more frequent and severe social consequences including familial rejection and domestic abuse (Greil et al., 2010). Accordingly, minority infertility patients may value communication with peers who have insight into shared cultural experiences of infertility. Individuals reporting greater perceived stress also endorsed meeting peers offline. Therefore, perceived stress not only predicts interest in online peer support, but also the desire to use an online network to pursue more personalized support.

Lastly, younger infertility patients were also found to show greater preference for private messaging, which can be partially explained by younger people’s greater understanding of online privacy risks (Frost et al., 2014), and greater experience and preference for using modern private messaging technologies (e.g. text messaging; Greenwood et al., 2016; Smith, 2011, 2015). 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).

It is important to consider that although this 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 infertility patients, this study reveals several factors that warrant further research. An infertility-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, would 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 results of this study provide preliminary support for the proposed classification of features, except for monitoring. It is likely that monitoring by an expert health professional and monitoring by a non-expert are different constructs, with some people preferring to rely on trained experts and others desiring the perspective of peers; however, the presence of only two items within the monitoring group could have reduced Cronbach’s alpha (Tavakol and Dennick, 2011).

Limitations

This study has certain limitations. First, it had a cross-sectional design, which precludes inferences about the
causal relationship between explanatory variables and interest in online peer support. Second, in line with other research (Crisp and Griffiths, 2014), this study operationalized interest as the extent to which participants would consider using an online peer support network. This does not assess the extent to which participants would actually use online peer support. Next, the current sample was self-selected, meaning that those who elected not to participate could have had different views than those represented here. Notwithstanding these limitations, current methods resulted in a high response rate and a large and diverse sample, which mitigates this issue and allows for adequate generalizability. The current sample also reflects the population of people who have decided to seek treatment. As non-treatment-seeking individuals have been found to differ according to important psychosocial variables, including socio-economic status, ethnicity, lack of primary physician, negative perceptions of medical treatment and language barriers (Greil et al., 2010; White et al., 2005), the 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.

Implications

This research suggests that infertility 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. Existing online health-related support groups are much more likely to target women (Mo et al., 2009), but the high level of interest among men emphasizes the need to develop targeted online supportive interventions suitable for both men and women from diverse socio-economic and demographic backgrounds.

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.

Infertility 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 the user to contact people in similar circumstances who are perceived to have an 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.

This research highlights the need to examine the support requirements 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 infertility patients, especially those experiencing elevated stress. Examination of the feasibility of mobile platforms for offering infertility peer support is warranted.

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