Promoting Patient Empowerment in Men and Women Undergoing Fertility Treatment Through the Provision of Mobile Informational and Emotional Support

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Abstract

Infertility, the inability to become pregnant after 12 months of regular unprotected sex, affects approximately 16% of Canadian couples and is associated with psychological distress, stigma and feelings such as loneliness, uncertainty and loss of control. Fertility patients may benefit from interventions that foster patient empowerment (PE), which refers to patients' sense of control over their health and ability to cope with their illness and manage their treatment. Mobile health (mHealth) is the delivery of health care services through communication devices such as smartphones, and may represent an effective approach to deliver empowering interventions through improved access to targeted and suitable information and increased connectivity with peers.

The present project involved the testing of an mHealth application (app) *Infotility* containing practical information on infertility, treatment options and associated psychosocial issues, as well as a forum providing access to peer support. A pre-post study design was used to address the following study objectives: (1) to assess which patient characteristics were related to PE, (2) to examine the relationship between PE, perceived stress and fertility-related quality of life, (3) to explore how PE relates to engagement with the app, and (4) to evaluate whether PE changed during the study and in relation to engagement with the app. Standardized questionnaires assessing PE, perceived stress, fertility-related quality of life and participant characteristics were administered prior to (Time 1) and following (Time 2) app use. A total of 152 participants, including 122 women and 30 men, tested the app for a period of 8 weeks during which time activity on the app was monitored via Google Analytics.

Results indicated that being older was associated with greater PE in both women and men. In women, having sought psychological counselling during fertility treatment was related to lower PE. In addition, PE correlated negatively with perceived stress ($r = -.549$, $p < .005$) and positively with quality of life ($r = .602$, $p < .005$). Women reporting lower PE at Time 1 engaged significantly more with the app as a whole, and particularly the information section while men reporting lower PE at Time 1 engaged significantly more with the app. Even though overall PE scores did not change between Time 1 and 2, engagement with the forum was found to moderate the relationship between stress and change in PE for men ($\beta = 5.876$, $t = 2.176$, $p < .05$), such that men who reported high stress and who used the forum reported increased PE. The present findings suggest that the

Infotility app may be a helpful resource for patients who feel less empowered, especially men who are highly stressed, as it provides tools to better understand infertility, navigate treatment, cope and feel supported.

Résumé

L'infertilité, c'est-à-dire l'incapacité d'obtenir une grossesse après plus de 12 mois de relations sexuelles non-protégées, affecte environ 16% des couples Canadiens et est associé à un important stress psychologique, à de la stigmatisation ainsi qu'à des sentiments tels que la solitude, l'incertitude et la perte de contrôle. Les patients aux prises avec l'infertilité pourraient bénéficier d'interventions promouvant l'*empowerment*, qui fait référence au sentiment de contrôle qu'ont les patients par rapport à leur santé ainsi qu'à leur capacité à gérer leur maladie et leur plan thérapeutique. Le terme *santé mobile* (mHealth) désigne les interventions utilisant la technologie de communication, tels les téléphones intelligents, dans le but de fournir des services de santé. La santé mobile pourrait représenter une approche efficace pour promouvoir l'*empowerment* des patients en améliorant l'accès à de l'information ciblée à leurs besoins et à du support par les pairs.

Le présent projet impliquait une étude pré-post évaluant *Infotilité*, une application de santé mobile contenant des informations pratiques sur l'infertilité, les options de traitement et les problèmes psychosociaux qui y sont reliés, ainsi qu'une plateforme de soutien social par les pairs. Les objectifs principaux étaient d'explorer: (1) la relation entre l'*empowerment* et les caractéristiques des patients, (2) la relation entre l'*empowerment*, le stress perçu et la qualité de vie liée à fertilité, et (3) la relation entre l'*empowerment* et l'engagement avec l'application, ainsi que d' (4) étudier les changements d'*empowerment* au cours de l'étude en relation avec l'engagement avec l'application. Des questionnaires standardisés mesurant l'*empowerment*, le stress perçu, la qualité de vie liée à la fertilité, et les caractéristiques des patients ont été administrés avant (Temps 1) et après (Temps 2) l'utilisation de l'application. Au total, 152 participants, dont 122 femmes et 30 hommes, ont testé l'application pendant 8 semaines, au cours desquelles l'activité sur l'application était surveillée via Google Analytics.

Les résultats indiquent qu'un âge plus avancé était associé à un plus grand *empowerment* chez les femmes et les hommes. Chez les femmes, le fait d'avoir sollicité un soutien psychologique pendant le traitement de fertilité était lié à un *empowerment* réduit. De plus, l'*empowerment* était reliée négativement avec le stress perçu (r = -5,49, $p < .005$) et positivement avec la qualité de vie (r = 0,602, $p < .005$). Les femmes indiquant un *empowerment* inférieur au Temps 1 ont davantage utilisé l'application, et en particulier la section d'information. À l'inverse, les hommes indiquant un *empowerment* inférieur au Temps 1 ont davantage utilisé le forum de l'application. Bien que,

globalement, les scores d'*empowerment* n'ont pas changé de manière significative entre les temps 1 et 2, il a été constaté que, chez les hommes, la participation au forum modérait la relation entre le stress et le changement d'*empowerment* entre les temps 1 et 2 (β = 5,876, t = 2,176, p < .05), de sorte que les hommes vivant un stress élevé et ayant beaucoup utilisé le forum ont indiqué une augmentation quant à leur sentiment d'*empowerment*. Les présents résultats suggèrent que l'application *Infotilité* pourrait être une ressource utile pour les patients qui se sentent moins *empowered*, en particulier les hommes vivant un stress élevé, puisqu'elle fournit des outils permettant de mieux comprendre l'infertilité, de gérer les traitement, et de se sentir soutenu.

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Contribution of Authors

The present thesis project was conducted under the supervision of Dr. Phyllis Zelkowitz, as part of a larger research funded by the Canadian Institute of Health Research (CIHR) whose principal investigator is Dr. Phyllis Zelkowitz and co-investigators include Dr. Peter Chan, Dr. Deborah Da Costa, Dr. Cindy-Lee Dennis, Dr. Carolyn Ells, Dr. Nancy Feeley, Dr. Hananel Holzer, Dr. Kirk Lo, Dr. Neal Mahutte, Dr. Sophia Ouhilal, Dr. Zeev Rosberger, Dr. Janet Takefman, and Dr. Togas Tulandi.

The above-mentioned team designed the study and wrote the protocol. The development of the mHealth intervention (app) being evaluated in this study was overseen by Dr. Phyllis Zelkowitz. French translations of the content and questionnaires without a valid French version were performed by a hired translator, then revised and edited by Karolanne Gagné and me. The questionnaires included in the pre-post survey were selected by our team. During the data collection phase, I contributed to the recruitment and follow-up of participants along with Shinkhala Dawadi, Eden Gelgoot, Paul Grunberg, Rachel Idelson and Asa Kazerani. Stephanie Robins and Siobhan O'Connell resolved all technical problems experienced by participants, managed the online data collection, downloaded the data, and sent compensations to participants. Once the data were collected, the final dataset used in this thesis was created, organized and cleaned by Shinkhala Dawadi, Eden Gelgoot, Siobhan O'Connell and me.

More specifically to this thesis, I performed the literature search described in the introduction, generated research questions, adapted the Patient Empowerment Questionnaire, planned and conducted statistical analyses and reported and interpreted the results.

Introduction

Infertility

Definition and Prevalence

The World Health Organization recognizes infertility as a global public health problem (World Health Organization, 2018). Infertility is defined as the inability to achieve pregnancy after 12 months of regular unprotected sexual intercourse (Zegers-Hochschild et al., 2017). In Canada, the prevalence of couples who experience infertility in their lifetime is estimated between 11.5% and 16% (Bushnik, Cook, Yuzpe, Tough, & Collins, 2012). This rate represents a considerable increase from the infertility prevalence of 5.4% and 8.5% reported in 1984 and 1992 respectively (Bushnik et al., 2012).

The Psychosocial Burden

In addition to the clear physical burden of fertility treatment, characterized by painful and intrusive procedures, a body of research underscores the psychological consequences of infertility. Undergoing the diagnosis of, and treatment for, infertility can be devastating. Numerous studies have shown that people with infertility demonstrate undermined quality of life (Chachamovich et al., 2010) and high levels of emotional distress, including symptoms of depression and anxiety (Cousineau & Domar, 2007; Arthur L. Greil, Slauson-Blevins, & McQuillan, 2010; Volgsten, Skoog Svanberg, Ekselius, Lundkvist, & Sundström Poromaa, 2008). Fertility patients have described their experience with infertility as a “rollercoaster of emotions”, a loss of control, a life crisis and an alienating, isolating and stigmatizing experience (Cousineau & Domar, 2007; A. L. Greil, 1997; Luk & Loke, 2015). In developed countries such as Canada, where it is common for people to choose not to have children, infertile couples tend to experience a “secret stigma”, characterized by a condition that is invisible to others but nonetheless alienating (Whiteford & Gonzalez, 1995). For those that suffer from fertility concerns, the impact of stigma can involve feelings of abnormality and shame (Whiteford & Gonzalez, 1995). Importantly, it may repress overt discussions regarding infertility and decrease couple’s perceptions of social support (Slade, O'Neill, Simpson, & Lashen, 2007). Couples who attempt to talk about their condition with their social network often feel misunderstood by their friends and family (Katz, Millstein, & Pasch, 2002; Read et al., 2014). Others may fear disclosure as they experience additional stigma and pressure from their community and family due to social or cultural reasons (Batool & de Visser, 2016; Behboodi-Moghadam, Salsali, Eftekhar-Ardabily, Vaismoradi, & Ramezanzadeh, 2013)

Furthermore, infertility can be considered a chronic condition in view of its lengthy diagnostic and treatment process, numerous medical appointments and procedures, and series of setbacks and successes. Although not life threatening, the long-lasting, time-consuming and costly nature of infertility and its treatment causes a chronic burden that may involve psychological, emotional, social, marital and/or financial strain(s). In fact, the psychological impact of infertility was found to be comparable to that of other chronic conditions such as cardiovascular diseases and cancer (Domar, Zuttermeister, & Friedman, 1993). Some have described the long-lasting distress and identity challenge associated with infertility as a "chronic crisis" (Whiteford & Gonzalez, 1995).

Although assisted reproduction technologies (ARTs) now offer a solution for couples who face difficulties getting pregnant, this treatment process involves numerous therapeutic options; each of them comprising a variety of medications, procedures, side effects and success rates. It can be difficult for couples to navigate through this complicated treatment process and to cope with the stress it inflicts on their identity, their relationships and their mental and physical health. Thus, it is important to think about ways to support fertility patients through this challenging experience. Interventions that enhance patient empowerment might offer a viable solution for helping patients with infertility gain control over their situation, increase their ability to cope, and protect both their overall and fertility-related quality of life.

Patient Empowerment

The importance of empowering patients is becoming increasingly recognized in health care globally. A recent scoping review of the PubMed database for articles including the term "Patient Empowerment" in the title demonstrated a steep increase of research on this topic between 2000 and 2017 (Garattini & Padula, 2018). Patient empowerment (PE) challenges traditional health care practices which tend to be authoritative, and instead, suggests "a paradigm shift from provider-centered care to patient-centered collaborative care" (Funnell & Anderson, 2003, p. 456).

Specifically, practices that support PE encourage patients to acquire the necessary health knowledge and competence to take an active role in their care and make informed health decisions.

Definition of PE

PE is a broad construct that can occur at different levels of health care; that is, it can occur within the patient-physician relationship, in the health care system, in the community as well as in policy. It can also be understood from multiple perspectives including that of a patient, a provider, a family or an institution (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). According to three systematic reviews on the conceptualization of PE (Bravo et al., 2015; Castro et al., 2016; Fumagalli, Radaelli, Lettieri, Bertele', & Masella, 2015), there exists different interpretations and use of PE in research. Some researchers construe PE as a transformative *process* through which patients gain the necessary knowledge and ability to manage and cope with their illness. Others interpret PE as an *outcome* (or an emergent state) involving a set of cognitive abilities, motivations and affects that enable patients to take a more active role in their care. Yet others describe PE as *behaviors,* such as self-management and shared decision-making, and as *interventions* that promote patient participation and better health management. There exist no real consensus on the best way to define PE in the scientific literature. For example, a recent review identified that the most frequently cited definition was present in only 11% of all articles including a definition of PE (Bravo et al., 2015).

For the purpose of this thesis, PE will be defined as a measurable *outcome* as opposed to a *process* or a set of *behaviors*. This outcome will emerge following patients' acquisition of new knowledge, capacities and skills pertaining to the treatment of their infertility. Although PE inherently leads to active behaviors and transformative processes such as taking part in shared decision-making about care and exchanging information, in and of itself, "being empowered" is a desirable outcome for patients with infertility as it has the potential to facilitate their journey through fertility treatments, improve patients quality of life (Nelson, 2012) and promote a sense of personal growth (Parry, 2005). For example, some women report that their experience with infertility and assisted reproductive technologies (ARTs) made them feel stronger (Parry, 2005). Such a sense of PE may present itself through feeling better informed, more confident about the care process, optimistic and in control, as well as through better self-esteem, social well-being and acceptance of the disease (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008).

> “Fundamentally, patient empowerment is an outcome. Patients are empowered when they have knowledge, skills, attitudes, and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives”
>
> - (Funnell et al., 1991, p. 38)

Theoretical Frameworks

Most researchers agree that empowerment is a multidimensional construct involving individual, social, organizational/institutional, economic and political factors which are all interdependent (Barak, Boniel-Nissim, & Suler, 2008; Rappaport, 1987). Zimmerman (1995) proposed an empowerment framework centered around the individual, thereby providing a basis for understanding how empowerment may occur in patients. Zimmerman grounded his “psychological empowerment” framework on three main assumptions. First, psychological empowerment can present itself differently in different individuals, suggesting that personal characteristics, concerns and goals may influence psychological empowerment and that an intervention may effectively empower certain people more than others. Second, psychological empowerment can present itself differently across contexts and across life domains. This assumption suggests that characteristics of distinct settings (e.g. whether a provider supports or prevents active participation of patients in the decisions regarding their care) may foster skills, knowledge and actions that are specific to that setting. Accordingly, it is possible for an individual to experience a high level of empowerment in one life domain (e.g. work) and a low level of empowerment in other domains (e.g. health care). Third, psychological empowerment is a dynamic construct rather than a fixed trait. This suggests that it may develop over time and fluctuate with the experience of empowering and disempowering processes (Zimmerman, 1995). In short, Zimmerman’s model of psychological empowerment involves three components: an intrapersonal component involving one’s perceptions of oneself and including variables such as perceived control, self-efficacy and perceived competence; an interactional component which includes one’s understanding of their environment, skills development and resource mobilization; and a behavioral component involving actions taken to influence outcomes or to manage stress and adapt to change.

Applying psychological empowerment theory to health care (e.g. chronic illness) offers an opportunity to promote patient's autonomy, knowledge and skills, thus improving health behaviors, overall health and other personal and social aspects of living with illness and undergoing treatment (Funnell et al., 1991). Some suggest that the traditional model of medicine is not appropriate for the treatment of long-lasting conditions such as infertility, and that an empowerment model may provide a more suitable strategy (Anderson, 1995a). The core difference between empowerment and other models of care is that it places patients and providers on equal ground, such that patients are considered experts with regards to their own experience and participate actively in decisions about their care. Thus, the role of health care professionals is to provide patients with the resources and support that they need in order to gain mastery, better manage their condition and overcome barriers (e.g. identity crisis or treatment failure) (Funnell et al., 1991).

The term "Patient empowerment" (PE) applies psychological empowerment theory to the health care environment. Systematic reviews have attempted to generate a clear and comprehensive model of PE (Bravo et al., 2015; Castro et al., 2016; Fumagalli et al., 2015). The model proposed by Castro et al. (2016) highlights the need for effective patient-physician communication, patient-centered care, growth of patient knowledge, skills and abilities, as well as patients' active participation in their care to foster empowerment. Supportive conditions such as these would enable a process that, guided by self-determination, would bring about personal change in terms of behavioral, social and organizational structures in the life of patients. Noted consequences of this process include: a sense of identity, reinterpretation of the illness, a sense of control, self-management and a better quality of life (Castro et al., 2016). Together, these systematic reviews reveal the multiple components that comprise the complex construct of PE. They also indicate a range of advantages, which can be expected to arise from empowering patients.

Benefits of PE for Fertility Patients

Because PE strategies promote engagement with care and adjustment to long-term conditions (Bravo et al., 2015; Castro et al., 2016), they may be especially well-suited to long and challenging treatment processes such as those involved in fertility care. In fact, PE was first applied in the context of diabetes because of its chronic nature and self-management requirements (Garattini & Padula, 2018). It was later introduced in the treatment of other chronic illnesses including cardiovascular disease and cancer (Kuijpers, Groen, Aaronson, & van Harten, 2013), emphasizing its potential for helping those living with long-lasting conditions. Empowering patients is thought to implicate a range of benefits for those with chronic conditions including improved: perception of one's health (Rohrer, Wilshusen, Adamson, & Merry, 2008), relationship and communication with health care providers (Rohrer et al., 2008), satisfaction regarding received health care and support (Rossi et al., 2015), disease management and monitoring (Anderson, 1995b; Rossi et al., 2015), clinical outcomes (Anderson, 1995b; Rossi et al., 2015; Wong et al., 2016), health literacy (Y.-J. Lee et al., 2016), and psychological well-being (Anderson, 1995b; Rossi et al., 2015; Segal, 1998). Similarly to the treatment of other chronic conditions, fertility treatment entails committing to a medication plan, going to multiple doctor's appointments and using long-term coping strategies. By enhancing fertility education, self-management skills and coping abilities, PE may be especially valuable for preparing couples with infertility to the physical and psychosocial demands of treatment and for helping them navigate and participate in fertility care. Indeed, partaking in the decisions related to their care and assuming small actions to "help themselves" such as gathering information or improving their lifestyle may engender a sense of strength, personal growth and empowerment in fertility patients (Porter & Bhattacharya, 2007).

Furthermore, PE involves feeling in control of one's health and health care (Bravo et al., 2015). Improving fertility patients' sense of PE may be especially helpful given that fertility treatment involves passive participation of patients while they are subject to a battery of diagnostic tests and treatment procedures, stressful waiting periods in between tests and procedures, and a series of failures and successes. Indeed, infertility is often described as a low-control situation. Women suffering from this condition state that lack of control and uncertainty is one of the most difficult aspects of the infertility experience (Benyamini, Gozlan, & Kokia, 2005). While perceived control over the infertility diagnosis and treatment outcomes was unrelated to better adjustment, perceived control over fertility treatment procedures has been shown to be related to greater well-being (Benyamini, Nouman, & Alkalay, 2016). Thus, in a context where patients have no control over their diagnosis and the success of their treatment, feeling in control of their care process seem to help reduce psychological distress. There is also evidence that perceptions of locus of control are negatively associated with depression and anxiety in infertile patients (Omani Samani, Maroufizadeh, Navid, & Amini, 2017), such that those with greater perceived control are less depressed and less anxious than those with lower perceived control. Considering the importance of perceived control for the well-being of patients with infertility and that perceived control is a main component of PE, using interventions that aim to empower infertile patients seems a promising strategy for protecting the mental well-being of patients through the course of their treatment. Accordingly, Johnson et al. (2012)'s model of empowerment in the context of health care suggests that being empowered allows patients to build a resilience when faced with treatment uncertainties or failures (Johnson, Rose, Dilworth, & Neilands, 2012).

Lastly, PE may effectively enhance fertility patients' quality of life, which is essential given that the experience of infertility has been shown to decrease quality of life (Mousavi, Masoumi, Keramat, Pooralajal, & Shobeiri, 2013). According to Chachamovich et al. (2010)'s systematic review on the impact of infertility on quality of life (QoL) and health-related quality of life (HRQoL), infertile women are at greater risk of displaying low QoL and HRQoL as compared to both infertile men and non-infertile women. For those undergoing IVF, social and emotional well-being were most affected, and reduced quality of life could be explained in part by negative cognitions regarding parenthood (e.g. "needing a child to live a happy life"), especially in women (Fekkes et al., 2003). Although fewer studies directed their attention towards infertile men, there is evidence that male partners also experience decreased quality of life (Chachamovich et al., 2010). On the other hand, PE has been shown to be positively related to health-related quality of life (Kaal et al., 2017), suggesting that interventions that foster patients' knowledge, competence and active engagement with their care may have a direct influence on patients' quality of life regardless of health and treatment outcomes.

PE Measurement

The measurement of PE remains a challenge. Zimmerman (1995) noted that building a single instrument measuring psychological empowerment can be problematic because: the presentation of empowerment varies across individuals in terms of perceptions, skills and behaviors; it varies across context as different settings involve different beliefs, competencies and actions; and it changes over time (Zimmerman, 1995). However, Zimmerman argues that it is possible to measure context-specific levels of empowerment in an individual when considering the knowledge, skills and competencies relevant to that particular setting.

In the literature, there is a variety of both disease-specific and generic questionnaires that aim to evaluate PE or some aspects of it. Due to the complexity and broadness of the construct, the majority of available validated measures used to assess PE, such as the Patient Activation Measure (Hibbard, Stockard, Mahoney, & Tusler, 2004) and the Patient Enablement Instrument (Howie, Heaney, Maxwell, & Walker, 1998), are limited in their assessment as they evaluate only part of the construct. So far, there seems to be no agreement or preference as to which of the available instruments best captures the concept. According to four reviews on the existing measures of PE (Barr et al., 2015; Cyril, Smith, & Renzaho, 2016; Eskildsen et al., 2017; Herbert, Gagnon, Rennick, & O'Loughlin, 2009), there is no gold standard measure to assess this construct. Indeed, no single instrument was consistently included in all four reviews due to the reviews' diverging definitions of PE, or was consistently judged as having superior psychometric value.

Because of the absence of a consensus on a single best measure and because of the context-specific nature of PE, the measure used in this project was chosen based on the comprehensiveness of the scale and its previous use with fertility patients (Nelson, 2012). The Patient Empowerment Questionnaire (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008) assesses a wide range of empowering outcomes such as being better informed, accepting the illness, optimism, perception of control and social well-being. It evaluates patients' knowledge and competence while also addressing patients' psychosocial experience through perceptions of control, identity and social support, which makes it more comprehensive and relevant to the infertility experience than other available measures.

Promoting Empowerment in Fertility Patients

Types of Intervention

The benefits associated to PE are likely to help fertility patients get through the strenuous characteristics of infertility and its treatment, hence the need to design empowering interventions that target fertility patients and to incorporate those as part of fertility care. Couples undergoing fertility treatments have expressed an unmet need for psychosocial support, particularly social support from others in a similar situation, and for practical information about infertility and its therapeutic options (Read et al., 2014). Thus, an intervention that includes an educational and social support component may be effective in developing a sense of PE in fertility patients.

I. Providing Patient Education

Because competence and knowledge are central elements to the concept of PE, the provision of health information and educational interventions to patients are potential strategies for promoting their ability to ask more questions and make informed decisions, and as a result, their sense of PE. Recent studies indicate that patients who report receiving adequate education score higher on measures of PE and health-related quality of life (Koekenbier et al., 2016; Yeh, Wu, & Tung, 2018). Moreover, a systematic review identified information provision and knowledge acquisition as the most important enabling factors promoting the involvement of patients in shared decision-making (Joseph-Williams, Elwyn, & Edwards, 2014).

People with infertility report informational needs, as well as positive attitudes towards fertility education programs (Ezabadi, Mollaahmadi, Mohammadi, Samani, & Vesali, 2017; Read et al., 2014). Most couples attending fertility clinics feel a need to seek additional information from books, magazines and the Internet to complement the information received from their fertility provider, and those who subsequently achieve pregnancy report feeling empowered by their efforts at information gathering and by the proactive behaviors undertaken as part of their treatment process (Porter & Bhattacharya, 2007). Amongst fertility patients, the use of educational and counselling interventions have been shown to effectively enhance psychological empowerment, well-being and quality of life outcomes (Taebi, Simbar, & Abdolahian, 2018). In fact, psychosocial interventions involving an educational and skill training component are reportedly more successful at improving the well-being of people with infertility than counselling interventions (Boivin, 2003), which stresses the importance of feeling informed for patient well-being. For these reasons, an intervention that provides relevant and accurate information about infertility is likely to help patients feel more knowledgeable about their condition, more involved in their care and more empowered.

II. Providing Peer Support

Social support is another core component of PE. Belonging to a group and exchanging with others provide an opportunity to share information, amongst other relational benefits (Jørgensen et al., 2018). Patient populations using online community forums report positive outcomes in terms of (1) illness acceptance and identity work, (2) social connectivity, (3) experiential knowledge sharing and (3) being part of a collective voice (Kingod, Cleal, Wahlberg, & Husted, 2017). Peer support, which refers to the provision of emotional, informational and appraisal support by others who share similar characteristics (Dennis, 2003), is particularly important for fertility patients as they often feel misunderstood when discussing infertility with their friends and family (Katz et al., 2002; Read et al., 2014). Social stigma makes it even harder for patients (especially men) to openly talk about the infertility experience with their social network (Dooley, Dineen, Sarma, & Nolan, 2014; Slade et al., 2007). Peer support groups, on the other hand, can produce a sense of community and social acceptance, as well as encourage the sharing of knowledge, feelings and concerns, thereby promoting PE and agency (J. Ussher, Kirsten, Butow, & Sandoval, 2006). Thus, fertility patients are likely to benefit from interventions that offer a peer support feature. In fact, a recent Canadian survey demonstrated that most fertility patients are interested in online peer support, especially if they experience elevated levels of perceived stress (Grunberg, Dennis, Da Costa, & Zelkowitz, 2018).

Online peer support groups are widespread and used extensively by people in distressing situations such as infertility (Barak et al., 2008). Burgeoning research suggests that both active ("posting") and passive ("lurking") participation in online peer support groups is associated to a greater sense of PE (Barak et al., 2008; van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). Inherent characteristics of online support groups, including the text-communication format, delayed responses and anonymity, promote the expression of thoughts and feelings, the development of a sense of belonging and the sharing of advice and informational support, which foster PE (Barak et al., 2008). Furthermore, online communities allow people to discuss specific topics related to a health condition, which generate the feeling of a common language and mutual understanding that may help patients feel empowered (Barak et al., 2008). A qualitative study by Malik & Coulson (2008) showed that people with fertility concerns report feeling empowered, more knowledgeable and in control of their situation as a result of participating in online support groups. These sentiments further motivated participants to take a more active role in their fertility care, and the newly acquired knowledge helped develop their decision-making skills and promote discussions with their health care providers (Malik & Coulson, 2008a). Online peer support boards may also act as a safe place for particular groups of fertility patients who are likely to face greater stigma and feel less supported, such as men, to obtain informational and emotional support and become empowered (Richard, Badillo-Amberg, & Zelkowitz, 2017).

Considering Patient Characteristics

How people experience infertility and PE may vary according to sociodemographic characteristics. Gender and socioeconomic status (SES) are considered important factors influencing both the psychological experience of infertility and levels of PE. These characteristics should be considered when designing interventions that aims to empower fertility patients.

I. Gender

Infertility is often perceived as a women's issue. For this reason, men have long been marginalized in both fertility research and care (Culley, Hudson, & Lohan, 2013). While some studies are now investigating how men experience infertility and how their experiences differ from those of infertile women and men without fertility problems (Fisher & Hammarberg, 2012; A. L. Greil, 1997), there is a need for more research involving the male perspective. Most studies agree that infertile women generally show a greater risk of experiencing clinical levels of distress and higher levels of negative emotions compared to infertile men (A. L. Greil, 1997). These feelings include low self-esteem, poor physical health, elevated stress, stigma and high depression and anxiety symptomatology (Ying, Wu, & Loke, 2015). Nevertheless, this may only reflect a difference in the way that men and women manage and express their emotional distress with regards to infertility (Wischmann & Thorn, 2013). Furthermore, there is emergent evidence supporting men's desire for fatherhood and psychological distress in the face of infertility (Fisher & Hammarberg, 2012; Arthur L. Greil et al., 2010). For some men, infertility can give rise to a life crisis, characterized by feelings of low self-esteem and undermined masculinity (Cousineau & Domar, 2007; Esmée Hanna & Gough, 2015). Challenges specific to the male experience of infertility include feeling excluded from the treatment process, which is primarily centered on women, and suppressing emotions in an effort to support their female partner (Malik & Coulson, 2008b). Lastly, gender has been shown to influence the use of coping strategies (Peterson, Newton, Rosen, & Skaggs, 2006), help seeking (Petok, 2015), information seeking (Zelkowitz, Robins, & Grunberg, 2016) and treatment-seeking (Hudson & Culley, 2013) behaviors as well as the use of counseling services (Petok, 2015) in the context of infertility.

Similarly, gender may influence the experience of PE. Some evidence suggests that male patients have a tendency to show greater levels of empowerment relative to female patients (Kaal et al., 2017). Again, it may be that men and women experience and express empowerment differently, and that separate strategies serve to empower men and women. There is a lack of evidence on the relationship between gender and PE. In the context of infertility, women have been shown to report greater external locus of control compared to men, entailing that women have a greater tendency to attribute their treatment failures and successes to luck or powerful entities rather than to their own efforts (Beaurepaire, Jones, Thiering, Saunders, & Tennant, 1994). Therefore, an intervention that educates women about things that they can do to improve their chances of success in treatment might serve to empower them. In contrast, men usually prefer to receive oral as compared to written information about treatment and to find social support from friends, online support groups and fertility care professionals rather than from mental health specialists (Fisher & Hammarberg, 2012), suggesting that interventions that do not heavily rely on text and offer alternatives to obtain psychosocial support may better serve to empower infertile men.

II. Socioeconomic Status (SES) and Education

A number of SES indicators, including education level, income and immigrant status, are likely to be related to PE in fertility patients. Patients of varying socioeconomic statuses may be exposed to different fertility information. For example, SES may influence how patients and providers interact, suggesting that doctors may provide less information, directions, empathy and participative opportunities to patients who come from lower education and socioeconomic backgrounds compared to those of higher SES (Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005). Such behaviors from health care providers are likely to affect levels of PE in patients who do not receive as much information and emotional support. In addition, given the importance of knowledge and competence in the empowering process, PE is likely to depend on patients' level of education. Some evidence suggests a direct association between level of education and PE (Anderson, Funnell, Fitzgerald, & Marrero, 2000). Furthermore, several interventions aiming to improve PE have an educational nature or include an educational component (Aujoulat, d'Hoore, & Deccache, 2007), demonstrating the importance of education for PE.

Because of the elevated costs of ARTs, fertility patients are generally of higher socioeconomic status compared to the general population, and previous studies involving fertility patients report overall well-educated and wealthy samples (Jain & Hornstein, 2005; Tulandi, King, & Zelkowitz, 2013). Well-educated patients are likely to be more knowledgeable about fertility-related issues and therefore have higher baseline levels of PE. For that reason, it is important to consider education when assessing the impact of an intervention that aims to enhance PE. An educational intervention may have a smaller empowering impact on well-educated patients. On the other hand, such an intervention may be very effective at empowering the lesser proportion of patients who have a lower education level or poor knowledge regarding the concerned health issue by helping them to understand their treatment, make informed decisions and communicate effectively with their provider.

Regardless of education level, immigrants may encounter language barriers and communication difficulties when accessing information about infertility and navigating through fertility care due to cultural and linguistic differences (Nachtigall et al., 2009). For these reasons, some people may decide not to seek treatment and if they do, they may find it difficult to understand medical information, ensure that their beliefs and concerns are being heard and participate in shared-decision making (Ahmed, Lee, Shommu, Rumana, & Turin, 2017), thereby reducing their chances of feeling empowered. Others may face additional accessibility challenges when seeking fertility care and support because of difficulty taking time off work and the elevated costs of treatment and counselling services (Nachtigall et al., 2009). In view of these challenges, it is important that an intervention which aims to provide information do so in a language that is accessible and easy to understand. In addition, empowering interventions should recognize people's diverse cultural and religious beliefs. As demonstrated by a recent Canadian study, immigrants undergoing fertility treatment are at-risk of experiencing poorer fertility-related quality of life compared to non-immigrants, which may be due to sociocultural differences in how they perceive infertility and its treatment (Hasson et al., 2017). Empowering this group of fertility patients may serve to protect their quality of life.

A Mobile Health (mHealth) intervention

While fertility patients commonly access the Internet to seek information and support, the Internet may not be the best medium to empower patients. Evidence indicates that one third of patients find that online resources do not meet their needs (Brochu et al.; manuscript in progress). Furthermore, research suggests that there is a lack of online resources addressing male fertility issues and that websites that do contain this information are generally of "poor" or "fair" quality, readability and suitability (de Man et al., 2018; Robins, Barr, Idelson, Lambert, & Zelkowitz, 2016), which may limit access to those resources. Patients are likely to experience difficulty finding information online, understanding complicated terms and judging the quality of sources (Benigeri & Pluye, 2003). Alternatively, mobile health (mHealth) may provide an innovative, well-suited and effective approach to deliver interventions that are evidence-based, patient-centered and easily accessible.

Emergence and Definition of mHealth

According to the World Health Organization, mHealth is defined as a "medical and public health practice supported by mobile devices, such as mobile phones […]." (World Health Organization, 2011). The use of mHealth, a branch in the field of electronic health (eHealth), is becoming increasingly prevalent in health care (World Health Organization, 2011). mHealth has the potential to revolutionize health care with its ability to overcome geographical, temporal and organizational barriers. It may represent a low-cost option to reach people of diverse locations and socioeconomic backgrounds, therefore reducing disparities in access to health resources (Martin, 2012) and empowering large populations of patients to manage or improve their health. It is currently being used for diverse purposes including to: improve treatment compliance and monitoring, facilitate disease prevention and management, provide health education, increase awareness to health problems, and enhance patient-provider communication (Marcolino et al., 2018; Silva, Rodrigues, de la Torre Díez, López-Coronado, & Saleem, 2015).

Advantages of mHealth

I. Accessibility

The distribution of mobile technology is widespread, thus making interventions that use an mHealth strategy highly accessible. Patients in Canada are likely to have access to a mobile device; it is estimated that 77% of Canadians own a smartphone and that another 54% own a tablet (Canadian Radio-Television and Telecommunications Commission (CRTC), 2017). In addition, more than half of mobile phone users report that they have downloaded a health app; these people tend to be young adults, more educated and have higher incomes (Krebs & Duncan, 2015). Individuals who undergo fertility treatments are likely to correspond to this description. Furthermore, the use of an mHealth resource would allow at-home access to information. Given that fertility treatment can involve difficulties regarding transportation to the doctor's office, scheduling of multiple medical appointments, navigation of the health system and financing of fertility-related expenses, increased access to fertility information and support through mHealth has the potential to relieve some of the burden of infertility. Hence, the prevalence of mobile devices and accessibility of mHealth offer an opportunity to improve access to fertility resources and empower fertility patients, especially groups of patients such as language minorities and men, which tend to face barriers when seeking help through other means (e.g. the Internet or the doctor's office).

II. Usability

Usability refers to the attractiveness, learnability, operability and understandability of a type of technology (Zapata, Fernández-Alemán, Idri, & Toval, 2015). Mobile devices, such as smartphones, may represent a convenient and usable way to access health-related information and support. In particular, mHealth apps may offer an easy to use alternative to accessing fertility information online; apps provide a simple, organized and attractive interface to navigate through a more manageable amount of information. Accordingly, research shows that users' perceptions of interface design, specifically with regards to visual simplicity, are positively associated to perceived ease of use, which in turn predicts assessments of usefulness (Lazard et al., 2015). These results support the use of mHealth, which enables the use of multimodal strategies such as images, charts, and videos, thereby presenting the information in a way that is easy to understand and engaging for users. A mobile app that is well-organized and specifically designed for fertility patients can help them locate and access information that is accurate, suitable and tailored to their needs, thus facilitating the gathering of relevant and credible information and promoting PE.

III. Connecting with Peers

Online and mobile platforms are helpful to empower fertility patients as they facilitate patients' connectivity and sense of community, thereby reducing social isolation and building meaningful and supportive relationships between people who are going through a similar situation and share similar concerns and emotions (Hinton, Kurinczuk, & Ziebland, 2010; Malik & Coulson, 2008a). Users of online fertility support groups report that these platforms hold a number of advantages over face-to-face types of support. These include: the convenience and 24-hour availability of the platform, asynchronous and anonymous conversations, lack of real time pressure and control over one's involvement (Malik & Coulson, 2008a). The portability and interactive nature of mobile technologies may provide yet greater opportunities for patients to connect with peers and benefit from sharing experiences and knowledge with others who understand.

Supporting Evidence for mHealth

While substantial evidence suggests that the provision of information and support through online resources can serve to empower people with health concerns, including infertility, the benefits and effectiveness of mHealth resources to empower patients are less well established. Promising research supports the use of mHealth to improve disease management (Kitsiou, Paré, Jaana, & Gerber, 2017), treatment adherence (Hamine, Gerth-Guyette, Faulx, Green, & Ginsburg, 2015), health behaviors (S. H. Lee et al., 2016), as well as mental health care and patient well-being (Berrouiguet, Baca-García, Brandt, Walter, & Courtet, 2016; Naslund, Marsch, McHugo, &

Bartels, 2015). Unfortunately, research investigating the development and use of mobile technologies for health purposes and their consequential benefits often involve studies of poor methodological quality that lack the robustness necessary to assess the potential impact of mHealth interventions (Free et al., 2013; Marcolino et al., 2018).

As for the use of mHealth for promoting PE, empirical evidence in this area is scarce. A recent systematic review and meta-analysis of RCTs evaluating empowering interventions identified only two interventions using mobile devices out of 17; both were using text messages (SMS) as their means of intervention and only one was found to have a significant positive effect on PE (Werbrouck et al., 2018). This result suggests a gap in high-quality research evaluating the empowering impact of mHealth apps. With regards to the empowering potential of mHealth resources available to people with fertility concerns, one study by van Dijk et al. (2017) testing an mHealth intervention using SMS to provide individualized coaching to fertile and subfertile patients found that it was effective for empowering both men and women, fertile and infertile, to change unhealthy habits and improve their chances of pregnancy (van Dijk et al., 2016; van Dijk et al., 2017). However, this study measured PE indirectly using behavioral and clinical outcomes as indicators, rather than directly through a self-report instrument dedicated to the assessment of PE. Therefore, the potential of mHealth interventions for empowering fertility patients has yet to be evaluated using a valid, reliable and comprehensive measure that reflects the multidimensional nature of PE. In addition, while the provision of medical and technical information about infertility is important, providing psychosocial information about ways to cope with this condition, maintain a healthy relationship and discuss treatment with others may also contribute to empowering fertility patients given that they experience a heavy psychosocial burden. Currently, no study has examined how an intervention that includes such psychosocial content may empower people undergoing fertility treatments.

The Current Study

Purpose and Research Questions

This research project is building upon and extending previous research using eHealth technologies to empower fertility patients through the evaluation of a novel mHealth intervention, *Infotility*, which was developed by a multidisciplinary team of researchers and health professionals. This mHealth app was designed to provide targeted informational and peer support resources to patients undergoing fertility treatments in order to address their expressed needs for accurate, up-to-date and accessible information as well as for social connections with others who understand their situation and share their concerns. The main objective of the current study was to investigate the effectiveness of this app in enhancing levels of PE in men and women with infertility problems, thereby improving their experiences with fertility care, their well-being and their quality of life.

Specifically, this study addressed the following research questions and hypotheses:

RQ1. Which patient characteristics, including sociodemographic variables and fertility history, were related to PE? We explored whether sociodemographic variables such as age, education, income and immigrant status, as well as variables relating to patients' fertility experience, would be related to PE.

RQ2. Were scores on the PE questionnaire correlated to perceived stress and fertility-related quality of life? We hypothesized that greater PE would be associated with less perceived stress and better fertility-related quality of life.

RQ3. How does PE relate to app usage? The relationships between PE at Time 1 and engagement with the app were examined.

RQ4. Did PE change during the course of the study and in relation to engagement with the app? We hypothesized that exposure to the *Infotility* app would be helpful in developing patients' sense of PE with respect to infertility and fertility care. In other words, we expected to observe an increase in patients' levels of PE post-app use compared to pre-app use. Moreover, we hypothesized that people who engaged more with the app during the study would report greater increases in PE.

Methodology

Participants and Recruitment

Recruitment of patients was conducted by a team of eight recruiters between October and December 2018. Patients undergoing fertility treatments were recruited from four clinics in the

Montreal and Toronto areas: McGill University Health Centre (MUHC)'s Reproductive Centre, the Montreal Fertility Centre, Mount Sinai Fertility and the Murray Koffler Urologic Wellness Centre. Recruitment took place in both hospital-based and private fertility clinics to ensure the inclusion of people from diverse socioeconomic backgrounds. All participants were recruited in fertility clinic waiting rooms. Eligible participants had to (1) be of at least 18 years of age, (2) identify as male or female, (3) be in a heterosexual relationship at the time of recruitment and (4) be able to answer questions in either French or English in order to enter the study. Eligible participants also needed to (5) own at least one of the following electronic devices in order to have access to the Internet, and therefore to the app: smartphone device, tablet, laptop or desktop.

The rationale for excluding single individuals and non-heterosexual couples was that their concerns regarding infertility and its treatment were likely to differ from those experienced by heterosexual couples. We recruited both French-speakers and English-speakers to better represent the diversity of the population. Men and women were recruited separately rather than as a couple to ensure that we got independent data for men and women.

Procedure

Pre-post methodology

Participants' experience was assessed pre- and post-intervention by means of questionnaires hosted on a secured server at the Jewish General Hospital to determine whether exposure to the app was related to outcomes. After providing written informed consent, participants were invited to complete the set of pre-questionnaires (Time 1) either via a tablet provided by the recruiter in the clinic's waiting room or on their own devices through an e-mailed link. Participants received email reminders to do the questionnaires in the first week following consent, followed by reminder phone calls from members of our team. After completing the pre-questionnaires, participants automatically received a second link granting them access to the *Infotility* app. Participants had to sign into the app using their email address as their account's username and a password that they created. After logging on to the app for the first time, participants went through an onboarding tutorial that gave instructions on how to use the app. As part of the onboarding, participants were instructed to choose an "avatar" and use a different name for confidentiality reasons.

For a period of eight weeks, participants used the app as little or as much as they wished. During this time, participants' frequency and patterns of app use were monitored via Google Analytics. Automatic reminders were sent by email to those who did not open the app for several days. At the six week mark, participants received an email with a link inviting them to complete the user Mobile App Rating Scale (uMARS) assessing app quality. At the end of the usage period, participants received the set of post-questionnaires (Time 2) consisting mostly of the same measures as in the pre-questionnaires. The uMARS was added to the post-questionnaires for those who did not complete it at 6 weeks. Again, participants were reminded to do the questionnaires via email and phone. After they finished the post-questionnaires, participants received a 25$ gift card from either Amazon or Starbucks.

Ethical considerations

Our research protocol was approved by the ethics board of every institution where recruitment took place, ensuring that our methods were in accordance with the Declaration of Helsinki. All participants provided written informed consent prior to entering the study. The consent forms included an explanation of the study along with its aims and associated risks, benefits and confidentiality protections.

Materials

Design of an mHealth app: Infotility

The present study involved an mHealth intervention that aimed to provide patient-centered and targeted informational and emotional support to men and women undergoing fertility treatments. The design of the intervention was informed by expert knowledge, existing scientific literature and a needs assessment survey which was distributed to 659 men and women undergoing fertility treatments to investigate patients' needs and preferences regarding information and support about fertility issues as well as patients' attitudes towards the use of a mobile app to access this support. The educational and social support components of the app are described below, and screen captures of the *Infotility* app are presented in Appendix A.

I. Educational component

The educational component of the intervention was developed and reviewed by a multidisciplinary team comprised of researchers, health professionals, students and expert patients, which ensured the appropriateness, credibility and reliability of information that was on the app. Informational content included: (1) medical information about reproduction, infertility causes and diagnoses, (2) treatment options, (3) fertility health promotion, (4) fertility laws and regulations, and (5) psychosocial information on how to navigate treatments and how to cope with common issues surrounding infertility such as identity crisis, marital problems and stigma. The app content was divided in two main sections: the "what you need to know" section which aimed to provide useful information about infertility and its treatment and the "what you can do" section which intended to promote patients' relationships as well as physical and mental well-being.

To enhance both the attractiveness and effectiveness of the intervention, app content was tailored based on gender; that is, gender-specific content was created for issues relating specifically to men or to women and a different voice was used for men and women (i.e. straightforward and action-oriented with accents of humor for men).

Furthermore, the content of the app was developed in both French and English as well as in a language that aimed to be accessible to people with a range of educational and literacy levels. Given the complexity of the medical jargon used in the context of infertility, particular attention was given to the level of language complexity included in the app and efforts were made to make the content easy to understand. The use of a multimodal strategy to present the information by means of graphics, charts, diagrams and links to external resources such as websites, videos and books made it user-friendly, interesting and engaging to users. Such diverse modes of presenting the content were incorporated to promote better understanding of the information for people whose first language was neither English nor French and for patients of lower education or health literacy levels as it was less reliant on text. The app further provided a glossary section which contained a list of medical terms likely to come up in the context of fertility treatments; these were explained in simple language. Lastly, it contained links to external resources (i.e. websites, books) to offer additional information on particular topics.

A readability assessment of the app content was performed using online readability analysis tools. After all visual and formatting elements (images, tables, bullet points, bolding, etc.) were removed from the English content, the remaining text was evaluated using an online utility tool ("Utilities for Online Operating System Tests Document Readability,") which has been commonly used to measure English readability (Mcinnes & Haglund, 2011; Shedlosky-Shoemaker, Sturm, Saleem, & Kelly, 2009; Stossel, Segar, Gliatto, Fallar, & Karani, 2012; Taylor & Bramley, 2012). This tool provided a score for the Flesch Kincaid Grade Level (Kincaid, Fishburne Jr, Rogers, & Chissom, 1975), a valid and reliable formula that gauges language complexity and educational knowledge required to access written information. This assessment revealed that the language of the English app content was written at a 10th grade level, which is somewhat higher than recommended guidelines for patient education materials (JGH Patient Education Network, 2008) but in line with other readability assessment of online medical information (Walsh & Volsko, 2008). As for the French content, readability was assessed using SATO-Calibrage ("Système d'analyse de textes par ordinateur (SATO),"), an online readability instrument adapted to Quebec's French educational material and developed by Quebec's Ministry of Education in collaboration with the Université du Québec à Montréal (UQAM) (Daoust, Laroche, & Ouellet, 1996). This tool provides a global indication of reading difficulty in grade level using Gunning's Fog readability index. The French content obtained an overall score of 12.5 on the Gunning Fog Index. According to the SATO 4.4 Reference Manual ("SATO 4.4 Manuel de référence," 2007), a score located between 12 and 15 indicates a text that is difficult to read, suggesting that the French content may be better suited for an educated audience. Overall, these results indicate better readability compared to that reported in a recent assessment of North American websites related to fertility (Robins et al., 2016), which found that the information available online had a mean readability score of 14.19 for English websites and 16.62 for French websites, making it only accessible to those with at least some university education.

II. Social support component

The second component of the mobile intervention, called *Connect*, aimed to provide participants with social support from peers who also had experience with infertility and its treatment and who could therefore understand the difficulty of their situation. The *Connect* section consisted of a peer support network to help connect patients with other users as well as with trained peer supporters who had undergone fertility treatment in the past and who volunteered to share experiential knowledge and offer emotional support to current patients. It involved two components: (1) discussion boards where app users could communicate anonymously with each other as well as with peer supporters, and (2) a private messaging function allowing users to have private conversations with peer supporters. Recruitment of peer supporters was done on a volunteer basis; they were all previous fertility patients. Supporters received a 4-hour training program and were given a peer support manual, developed by members our team, for peer support guidelines and examples. Members of our team were responsible to train and to assist peer supporters throughout the duration of the study. Supporters were available to respond to private messages and forum discussion posts seven days per week and usually responded within a few hours.

Pre-post survey

I. Background Questionnaires

The pre-background questionnaire gathered information about participants' characteristics. These included demographic data such as age, education level, ethnicity, immigration status, household income, as well as information about participants' fertility history such as how long they had been trying to conceive, their fertility diagnosis and which types of treatment they had undergone.

The post-background questionnaire asked about treatment procedures that participants pursued during the eight week period of the study as well as whether they achieved pregnancy, experienced a pregnancy loss or sought psychological support. In addition, it included questions relating to participants use of the app and whether they accessed other forms of information and support resources during the study period.

II. Patient Empowerment Questionnaire (Empowering Outcomes)

PE was assessed using an adapted version of the Patient Empowerment Questionnaire (see Appendix B), developed by van Uden-Krann et al. (2009) following a qualitative study of online support groups (van Uden-Kraan et al., 2009). The scale evaluates the presence of empowering outcomes following exposure to the intervention. The questionnaire is a 34-item scale divided into 7 subscales: being informed, feeling confident in the relationship with my physician, acceptance of my fertility problems, feeling confident about the treatment, optimism and control over the future, self-esteem, and social well-being. Each item is rated on a 5-point Likert-type scale ranging from 1 “completely disagree” to 5 “completely agree”. Mean subscale scores can be calculated for every empowering outcome.

The scale demonstrates good face validity and has been used in diverse samples of people suffering from chronic health conditions including breast cancer, fibromyalgia and arthritis. It is also applicable to the context of infertility (Nelson, 2012). There is evidence supporting the internal consistency (Cronbach’s alpha) of each subscale, suggesting good reliability: being informed (.85), feeling confident in the relationship with my physician (.91), acceptance of the illness (.90), feeling confident about the treatment (.89), optimism and control over the future (.76), self-esteem (.93), and social well-being (.70) (van Uden-Kraan et al., 2009).

Since the scale was only available in English, it was translated in French by members of our team. In addition, we generated a total PE score by summing the scores of the 34 individual items. This total sum score can range from 0 to 170, with higher scores indicating a greater levels of PE. To test the reliability of our adapted version of the PE questionnaire on our sample of fertility patients, Cronbach’s alpha was obtained for each subscale and for the total scale at both timepoints (i.e. from the pre- and post-surveys). The total scale and its subscales each demonstrated satisfactory internal consistency (Streiner, 2003). The Cronbach’s alphas and inter-correlations between subscales are presented in Appendix B.

III. FertiQoL

The FertiQoL is a condition-specific measure of quality of life, that is, it measures the quality of life of men and women experiencing fertility problems. It contains a total of 36 items divided into three categories: (1) the Core module is comprised of 24 items which assess the impact of fertility problems on the emotional, mind-body, relational and social domains of quality of life, (2) two additional items measure respondents’ perceptions of their physical health and general quality of life, and (3) the Treatment module evaluates treatment environment and tolerability by means of 10 supplementary items. Participants are instructed to answer the questions based on their “current thoughts and feelings”. Items are rated on a four-point Likert-type scale. Seven items must be reverse-coded before summing up the scores across all items and multiplying by 25/k (k = number of items in scale or subscale). Final scores range between 0 and 100 and higher scores represent better quality of life.

The FertiQoL is a reliable and sensitive tool to measure fertility-related quality of life. The overall scale as well as its Core and Treatment modules demonstrated satisfactory internal consistency (Cronbach's alpha = 0.92, 0.92 and 0.81 respectively (Boivin, Takefman, & Braverman, 2011). Reliability analysis of individual subscales revealed good internal consistency for most (Cronbach's alpha = 0.83 (Mind/Body), 0.70 (Social), 0.83 (Emotional)) and lower internal consistency for the relational subscale (Cronbach's alpha = 0.65) (Donarelli et al., 2016). Both the Core and Treatment modules as well as individual subscales were shown to follow a normal distribution (Boivin et al., 2011). In addition, the scale has demonstrated high sensitivity to common moderators of QoL such as gender, parenthood status and treatment persistence (Boivin et al., 2011).

The FertiQoL is also a valid instrument. Kaiser-Meyer-Olkin measures of sampling adequacy were >.80 indicating sufficient inter-correlation between items (Boivin et al., 2011). In addition, scores on the FertiQoL are negatively related to distress scores, thereby supporting the convergent validity of the scale (Aarts et al., 2011; Chi, Park, Sun, Kim, & Lee, 2016; Maroufizadeh, Ghaheri, & Omani Samani, 2017). The FertiQoL is an international tool developed in English and translated in more than 40 different languages, including French (Cardiff University), and it has been validated cross-culturally (Chi et al., 2016; Dural et al., 2016; Hsu, Lin, Hwang, Lee, & Wu, 2013; Maroufizadeh et al., 2017).

IV. Perceived Stress Scale 4-items (PSS-4)

The construct of perceived stress involves whether a person appraises life events as being stressful and whether a person feels able to overcome those difficult life events. The Perceived Stress Scale 4-item (PSS-4) is a shortened version of the 14-item self-report questionnaire developed by Cohen et al. (1983) to assess perceived stress in community samples with at least an eight grade level of education (Cohen, Kamarck, & Mermelstein, 1983). These scales have been translated in multiple languages, including French, and validated in many different sociocultural contexts (Almadi, Cathers, Mansour, & Chow, 2012; Andreou et al., 2011; González-Ramírez, Rodríguez-Ayán, & Hernández, 2013; Lesage, Berjot, & Deschamps, 2012; Leung, Lam, & Chan, 2010; Mimura & Griffiths, 2008). In the PSS-4, each of the four items is ranked on a five-point Likert-type scale that ranges from 0 (never) to 4 (very often). Total scores are obtained by reversing the score of items 2 and 3 and summing across all four items. Total scores can range from 0 to 16 with higher scores indicating greater perceived stress.

Research evaluating the psychometrics of the PSS-4 provides supportive evidence for the PSS-4's internal consistency (Cronbach's alpha = 0.77) and normal distribution (Warttig, Forshaw, South, & White, 2013). In a previous study conducted by our team and involving the distribution of a survey to a large sample of fertility patients, the PSS-4 obtained a satisfactory internal consistency (Cronbach's alpha = 0.71). There is also support for the reliability of the French version of the PSS-4 (Cronbach's alpha = 0.73) (Lesage et al., 2012) and for strong criterion validity when compared to other well-established mental health instruments such as the Beck Depression Inventory or the State-Trait Anxiety Inventory (Lee, 2012).

Google Analytics

We used Google Analytics, a free online tool that is part of the Google Marketing Platform and that permits monitoring of people's activity on a website, to track participant's use of the app throughout the 8-week period of the study. We collected data on a number of key performance indicators (KPIs) including number of sessions (defined as a period of time during which the user is actively using the app; a session ends after 30 minutes of inactivity), average duration of sessions, number of pages visited and time spent on each page. Other KPIs specifically related to the use of the peer support network were number of posts made and number of posts lurked on the forum.

Three engagement indices were developed to assess overall app usage, use of the informational content of the app, and use of the *Connect* forum. Those were created by summing three log-transformed and standardized KPIs retrieved from Google Analytics: the number of pages viewed, the number of sessions and the total time spent on pages. The KPIs underwent a logarithmic transformation because they were highly skewed towards low values, and were standardized to account for their different measurement units. The rationale for using multiple KPIs to capture engagement was based on a paper by Taki and colleagues (Taki et al., 2017) describing the development of a multi-metric engagement index to monitor usage of an app. The engagement index for *Connect* included data for both lurkers, who are users who viewed the forum but did not create or comment on any thread, and active posters.

Data analysis

Data analysis was performed using the IBM® Statistical Package for the Social Science (SPSS) software version 25 Premium. The dataset used for the purpose of this thesis consisted of the pre- and post-survey data of all participants who completed the set of pre-questionnaires and at least one measure of interest in the post-questionnaires as of February 18th, 2019. In addition, the dataset included app usage data extracted from Google Analytics for the 8-week study period of each participant in the sample.

Missing Data

Multiple imputation, a general approach that aims to address the problem of missing data while accounting for uncertainty (or random error), was performed on the final dataset. This method generates multiple imputed datasets in which missing values are replaced by plausible imputed values based on the observed data and adequate variability. The results obtained from statistical analyses on the imputed datasets are then combined to produce a pooled result using Rubin's rules (Sterne et al., 2009). In cases when SPSS did not generate a pooled result for a specific test (e.g. F-statistic, R^2), the results obtained from the imputed datasets were averaged to produce a pooled result (Sterne et al., 2009). Precise details of the multiple imputation process can be found in Appendix C. Overall, 96.49% (n = 220) of variables (i.e. items) and 58.58% (n = 99) of participants had at least one missing value. However, only 3.46% (n = 1,332) of the total individual values were missing from the imputed variables. The amount of missing data in each imputed questionnaire can be found in Appendix C. Possible reasons for missingness include: less people responded to the post-survey compared to the pre-survey and longer questionnaires such as the FertiQoL and the Patient Empowerment Questionnaire were more likely to have missing values compared to shorter questionnaires. The missing at random (MAR) assumption, which stipulates that missing values do not differ from observed values in any other way than the systematic differences already present in the observed data, was made. To include as many people as possible in the analysis and because results from the original data and the multiply-imputed data did not differ considerably, the reported results were based on the multiply-imputed dataset.

Sample Characteristics

Descriptive statistics were used to obtain the sociodemographic characteristics and fertility history of the sample. Sociodemographic variables included gender, age, education, household income, immigrant status and parity. Fertility history variables included fertility diagnosis, fertility treatments and treatment duration. Data from men and women were analyzed separately as recommended by the Canadian Institute of Health Research (CIHR)'s guidelines on gender analysis (Heidari, Babor, De Castro, Tort, & Curno, 2016).

Description of Patient Empowerment

Paired-samples t-tests were employed to investigate whether there was a change in total and subscale scores obtained on the PE questionnaire between Time 1 and Time 2.

Research Questions

RQ1. Which patient characteristics, including sociodemographic variables and fertility history, were related to scores on the PE questionnaire? Bivariate correlation analyses and t-tests were used to explore the relationships between variables from the background questionnaire and PE scores of men and women prior to exposure to the app (at Time 1). The following variables were included in the analysis: whether participants looked online for fertility information, whether participants used online forms of support, treatment duration, time trying to conceive prior to seeking fertility care, age, parity, ethnicity, immigrant status, recent immigrant status (i.e. less than 5 years), education, annual household income, religiosity, fertility diagnosis, and whether they had sought psychological counselling during treatment.

RQ2. Were scores on the PE questionnaire correlated to scores on the PSS4 and the FertiQoL such that greater PE was associated with less perceived stress and better quality of life? This research question was addressed by performing bivariate correlations between total scores on the following measures at Time 1: the PE questionnaire, the FertiQoL and the PSS4.

RQ3. How did PE influence subsequent app usage? This third research question examined whether men and women's engagement levels with the app during the 8-week trial period were related to their PE scores at the start of the study (Time 1). To do so, bivariate correlation analyses were conducted between PE scores at Time 1 and the three engagement indices: the total engagement index, the information engagement index and the forum *Connect* engagement index.

RQ4. Did PE change during the course of the study and in relation to engagement with the app? This project investigated whether engagement with the app acted as a moderator in the relationship between change in PE and factors that influenced PE levels. This allowed to determine whether groups of people who were less empowered but who were highly engaged with the app experienced greater increases in PE. Multiple linear regression analysis with an interaction term was conducted to predict change in PE. PE change scores were calculated by subtracting the total scores obtained at Time 1 from total scores obtained at Time 2. Variables included in the regression were determined based on whether they correlated with PE change scores. The three engagement indices were examined as potential moderators. In addition, control variables were included in the multiple linear regression depending on whether they correlated with the outcome variable. Variables from the background questionnaire at Time 1 (listed in RQ1) were examined as potential control variables in addition to three variables in the background questionnaire at Time 2 (achieved pregnancy, pregnancy loss and stopping treatment) which could account for changes in the course of fertility treatments. The final predictors included in the regression were standardized and centered to reduce multicollinearity between the interaction term and the lower-order terms. The nature of the moderation effect was further investigated using simple slopes analysis.

Results

Sample Characteristics

A total of 970 fertility patients, including 633 women and 337 men, were approached in clinic waiting rooms. Of those, 662 (68.25%) patients were successfully screened for eligibility whereas 308 (31.75%) either refused screening or were missed because they were called in for their appointment or because of language barrier. A total of 506 (76.44%) patients, including 341 women and 165 men, were found eligible to participate in this study. Of those, 387 (76.48%) patients, including 263 women and 124 men, agreed to participate and signed the consent form. The remaining 118 (23.32%) patients were either missed because they were called in for their appointment (*n* = 69) or they refused to consent (*n* = 49) for the following reasons: not interested, no time to participate, emotionally unwell, they were not app users, they had privacy concerns, etc. Throughout the study, 13 (3.36%) participants were declared dropouts as they did not wish to pursue the study and two (0.51%) participants were withdrawn because they had insufficient contact information or because the app was irrelevant to their situation. Altogether, 264 (68.22%) participants completed the pre-questionnaires, 259 (98.11%) downloaded the app, and 163 (62.93%) completed the post-questionnaires as of February 18th, 2019. Six additional participants who had not finished completing the post-questionnaires were included in the sample because they had completed the post-background questionnaire and at least one of the post-measures of interest (i.e. the Patient Empowerment Questionnaire, the FertiQoL and the PSS-4). Following the combination of the survey data with the app usage data, 17 individuals were removed from the sample because they had not engaged with the app during their 8-week trial period even though they completed the pre- and post-questionnaires. Therefore, the final sample of participants consisted of 152 fertility patients, including 122 (80.26%) women and 30 (19.74%) men.

Most participants were recruited in Montreal, with 94 (61.84%) and 23 (15.13%) recruited from the McGill University Health Center (MUHC) and the Montreal Fertility Center (MFC), respectively. The remaining portion of the sample was recruited in Toronto from Mount Sinai's Murray Koffler Urologic Wellness Center (MSMK, *n* = 24, 15.79%) and Fertility Center (MSFC, *n* = 11, 7.24%). Sociodemographic characteristics and fertility history of participants are presented in Table 1 and Table 2, respectively.

Sociodemographic information

For female participants, mean age was 35.23 years old (*SD* = 4.66) and ranged from 26 to 54 years old. Women were generally wealthy, with a majority reporting an annual household income above 100,000$. As for their highest level of education, most had at least a university degree. A large majority of women reported having no children. Approximately two third of women identified as white and were born in Canada. Of the 42 immigrant women, 38.1% were considered recent immigrants as they had lived in Canada for less than 5 years.

As for male participants, mean age was 37.07 years old (*SD* = 5.60), ranging from 29 to 54 years old. Similarly to women, a majority of men in our sample reported an annual household income above 100,000$. Approximately one third of men had a CEGEP diploma, technical college degree or below, one third had a university degree and one third had a graduate degree. Only 3 men reported having 1 or more children, while other men had no previous child. Most men were white compared to non-white, and most were born in Canada. Of the immigrant men, half were classified as recent immigrants (see Table 1).

Table 1. Sociodemographic characteristics of the final sample of fertility patients.

Variable	Total sample (*N* = 152)		Men (*N* = 30)		Women (*N* =122)	
	N	% or *M* (*SD*)	*N*	% or *M* (*SD*)	*N*	% or *M* (*SD*)
Gender	**152**	**-**	**-**	**-**	**-**	**-**
Male	30	19.7%	-	-	-	-
Female	122	80.3%	-	-	-	-
Language						
English	104	68.4%	26	86.7%	78	63.9%
French	48	31.6%	4	13.3%	44	36.1%
Annual Household Income						
Below 100,000$	60	39.7%	12	40.0%	48	39.7%
100,000$ or above	91	60.3%	18	60.0%	73	60.3%
Education						
CEGEP/tech degree or below	38	25.0%	11	36.7%	27	22.1%
University degree	52	34.2%	10	33.3%	42	34.4%
Graduate degree	62	40.8%	9	30.0%	53	43.4%
Parity						
1 or more child	27	17.9%	3	10.3%	24	19.7%
No children	124	82.1%	26	89.7%	98	80.3%
Immigrant Status						
Yes	53	35.3%	11	36.7%	42	35.0%
No	97	64.7%	19	63.3%	78	65.0%
Recent Immigrant						
Yes	21	13.8%	5	16.7%	16	13.1%
No	30	19.7%	5	16.7%	25	20.5%
Affiliates to a religion						
Yes	87	57.2%	17	56.7%	70	57.4%
No	65	42.8%	13	43.3%	52	42.6%
Ethnicity						
White	100	65.8%	22	73.3%	78	63.9%
Non-white	52	34.2%	8	26.7%	44	36.1%
Age	**152**	**35.59 (4.89)**	**30**	**37.07 (5.60)**	**122**	**35.23 (4.66)**

Note. CEGEP = « Collège d'enseignement général et professionnel ». Recent immigrant = has been living in Canada for less than 5 years. For recent immigrant status, percentages are out of the sample of people who identified as immigrants rather than out of the total sample of participants as for the other variables.

Fertility history

Women's time trying to conceive prior to seeking fertility care ranged from less than a year to ten years or more, although 88.5% of women had spent three years or less trying to conceive before consulting a fertility clinic. A majority (58.2%) of women had been undergoing treatment for a year or more. Regarding infertility diagnoses, the most common cause (41.8%) was female-factor only, followed by unexplained infertility (22.1%), male-factor only (13.9%), mixed-factor (12.3%), and no infertility diagnosis as they were still undergoing diagnostic testing (9.0%).

Men's time trying to conceive before consulting a fertility clinic also ranged from less than a year to ten years or more, with most men having tried for three years or less (90.0%). Half the men had been in treatment for less than a year; the other half had a treatment duration of one year or more. In our sample of men, many (46.7%) reported male-factor diagnoses only, whereas 6.7% reported female-factor diagnoses only, 16.7% reported mixed-diagnoses, 10.0% reported having unexplained infertility and 20.0% were still undergoing diagnostic testing (see Table 2).

Table 2. Fertility history at time of recruitment.

Variable	Total sample (*N* = 152)		Men (*N* = 30)		Women (*N* =122)	
	N	%	*N*	%	*N*	%
Cause of infertility						
Male-factor	31	20.4%	14	46.7%	17	13.9%
Female-factor	53	34.9%	2	6.7%	51	41.8%
Mixed-factor	20	13.2%	5	16.7%	15	12.3%
Unexplained	30	19.7%	3	10.0%	27	22.1%
Still undergoing testing	17	11.2%	6	20.0%	11	9.0%
Other	1	0.7%	0	0%	1	0.8%
Treatment duration						
Less than a year	66	43.4%	15	50.0%	51	41.8%
1 year or more	86	56.6%	15	50.0%	71	58.2%
Time trying to conceive before treatment						
Less than 1 year	27	17.8%	9	30.0%	18	14.8%
1 year	62	40.8%	9	30.0%	53	43.4%

2 years	31	20.4%	6	20.0%	25	20.5%
3 years	15	9.9%	3	10.0%	12	9.8%
4 years	3	2.0%	1	3.3%	2	1.6%
5 years or more	14	9.2%	2	6.6%	12	9.9%

Description of Patient Empowerment

Mean scores of PE reported by female and male participants at Time 1 and 2 are presented in Table 3. On average, women's total score on the PE questionnaires was 86.757 (*SE* = 1.367; maximum possible score = 170) at Time 1 and 86.189 (*SE* = 1.365) at Time 2. Women's mean subscale scores were moderate, with scores ranging from: 2.207 for "optimism and control over the future" to 2.912 for "feeling confident about treatment" at Time 1, and from 2.243 for "acceptance of my fertility problems" to 2.926 for "feeling confident about treatment" at Time 2 (possible scores = 0 to 4). Men's scores of PE were slightly higher, with mean total scores of 93.420 (*SE* = 4.058) at Time 1 and of 95.093 (*SE* = 3.223) at Time 2. Mean subscale scores ranged from 2.477 for "being informed" to 3.133 for "social well-being" at Time 1 and from 2.620 for "optimism and control over the future" to 3.010 for "social well-being" at Time 2. Contrary to our hypothesis, a paired-samples t-test showed that PE scores did not change between Time 1 and Time 2 (see Table 3).

Table 3. A comparison of subscale and total scores on the Patient Empowerment Questionnaire at Time 1 and 2.

Variable	Time 1		Time 2		Paired-samples t-test	
	M	*SE*	*M*	*SE*	*t*	*p*
Women (*N* = 122)						
Being informed	2.284	0.082	2.268	0.087	.219	.827
Feeling confident with physician	2.713	0.045	2.677	0.049	.832	.405
Acceptance of fertility problems	2.218	0.081	2.243	0.081	-.383	.702
Feeling confident about treatment	2.912	0.054	2.926	0.049	-.296	.768

Optimism and control over the future	2.207	0.060	2.245	0.054	-.753	.451
Self-esteem	2.753	0.077	2.652	0.073	1.571	.117
Social well-being	2.782	0.072	2.658	0.072	1.728	.084
Total	86.757	1.367	86.189	1.365	.518	.604
Men (*N* = 30)						
Being informed	2.477	0.216	2.693	0.170	-1.561	.119
Feeling confident with physician	2.712	0.123	2.831	0.111	-1.505	.132
Acceptance of fertility problems	2.572	0.160	2.633	0.130	-.645	.519
Feeling confident about treatment	2.912	0.134	2.981	0.117	-.600	.549
Optimism and control over the future	2.682	0.135	2.620	0.125	.566	.571
Self-esteem	3.062	0.127	2.942	0.134	1.193	.235
Social well-being	3.133	0.126	3.010	0.126	.852	.394
Total	93.420	4.058	95.093	3.223	-.729	.466

RQ1: Individual Characteristics and Patient Empowerment

With regards to the first research question, the relationship between participants' characteristics, including sociodemographic factors and fertility history, and PE were investigated. Normality was assumed based on the observation of histograms representing the distribution of data for the total scale and subscales of the PE questionnaire, justifying the use of Pearson's correlations and independent samples t-tests.

I. Women

Pearson's correlations between women's continuous sociodemographic and fertility variables and PE at Time 1 are presented in Table 4. Women's age was found to be positively correlated with overall PE ($N = 122$, $r = .267$, $p < .005$), suggesting that older women felt a greater sense of PE compared to younger women. Age was specifically associated to the subscales:

“feeling confident with my physician”, “feeling confident about treatment” and “social well-being” (see Table 4), indicating that older women felt more confident in their relationship with their physician and about their treatment process and that they expressed greater social well-being compared to younger women. There were no consistent patterns of association with the other variables. The significant positive associations between treatment duration and “feeling confident with my physician”, as well as between time trying to conceive and “optimism and control over the future” (see Table 4) could be attributed to chance.

Table 5 outlines results from the independent samples t-tests conducted to investigate the relationship between women’s categorical sociodemographic and fertility variables and PE scores at Time 1. A significant independent samples t-test revealed that having sought psychological counseling during fertility treatment was related to overall PE ($t(117285) = 2.968$, $p < .005$), such that women who were less empowered ($M = 79.00$) were more likely to report that they had sought counselling during their treatment compared to those experiencing a greater sense of PE ($M = 88.76$). The same relationship was found significant for the following subscales: “being informed” ($M = 1.87$ vs. $M = 2.39$; $t(18600843) = 2.616$, $p < .01$), “feeling confident with my physician” ($M = 2.50$ vs. $M = 2.77$; $t(7284) = 2.446$, $p < .05$) and “self-esteem” ($M = 2.36$ vs. $M = 2.85$; $t(9790) = 2.645$, $p < .01$). This indicates that women who felt less informed, less confident with their physician or had lower self-esteem were more likely to have sought counselling during their treatment process compared to women who were better informed, more confident and displaying greater self-esteem. The patterns of association with the other variables were not consistent. Findings concerning ethnicity, religiosity and using social media to connect with peers could be attributed to chance (see Table 5).

II. Men

Similarly to women, men’s age was found to be positively correlated with overall PE ($N = 30$, $r = .480$, $p < .01$), signifying that older men were generally more empowered than younger men. Age was also positively correlated to the following four subscales: “being informed” ($r = .615$, $p < .001$), “feeling confident with my physician” ($r = .390$, $p < .05$), “acceptance of my fertility problems” ($r = .367$, $p < .05$) and “optimism and control over the future” ($r = .409$, $p < .05$). These results further indicate that older men felt better informed, more confident with their physician, more accepting towards their fertility problems and more optimistic and in control of their future (see Table 4).

Table 6 outlines results from the independent samples t-tests between categorical sociodemographic and fertility variables and PE scores for men at Time 1. Findings do not indicate a consistent pattern of association between any of the other sociodemographic and fertility history variables and PE (see Table 6).

Table 4. Pearson's correlations between participant's characteristics and patient empowerment at Time 1.

		PE Subscales						
Variables	Total PE	1	2	3	4	5	6	7
Women (N = 122)								
a. Age	.267***	.148	.207*	.164	.239**	.142	.123	.192*
b. Treatment duration	.166	.077	.219*	.041	.165	.062	.083	.037
c. Time trying to conceive	.091	.116	.033	.025	.068	.189*	.010	-.173
Men (N = 30)								
d. Age	.520***	.600***	.415*	.399*	.424*	.477**	.262	.268
e. Treatment duration	-.258	-.103	-.220	-.296	-.284	-.202	-.372[a]	-.074
f. Time trying to conceive	-.167	-.0.14	-.224	-.198	-.294	-.059	-.021	-.065

Note. Total PE = total score of patient empowerment. 1 = being informed. 2 = feeling confident with physician. 3 = acceptance of my fertility problems. 4 = feeling confident about treatment. 5 = optimism and control over future. 6 = self-esteem. 7 = social well-being.
[a]p = .05 *p < .05 **p < .01 ***p < .005.

Table 5. Independent samples t-tests between women's characteristics and patient empowerment at Time 1 (*N* = 122).

	t							
		PE Subscales						
Variables	Total PE	1	2	3	4	5	6	7
Sociodemographic characteristics								
a. Parity	-1.059	-.301	-.267	-.426	-.637	-.842	-1.731	-1.058
b. Ethnicity	.527	-.960	.421	-.515	-.700	1.404	2.343*	1.209
c. Immigrant status	.682	1.007	.974	-.458	1.035	-.603	.194	1.461
d. Recent immigrant	.717	-.282	1.687	-1.367	.941	.766	.306	.899
e. Income	.066	.901	-1.495	1.554	-.886	.909	-.728	.198
f. Education	.735	1.656	1.377	-.070	.084	1.367	-1.831	-1.559
g. Religiosity	-.899	.221	-.882	.459	-.193	-2.319*	-1.265	.780
Fertility history								
h. Searched fertility information online	.891	1.326	.395	.320	-.027	1.361	-.146	.394
i. Connected with peers online	.166	.253	-.680	-.988	-1.232	1.084	2.559	.951
j. Female diagnosis	.424	-.275	.532	-1.154	1.001	1.032	.636	.116
k. Sought counselling during treatment	2.968***	2.616**	2.446*	1.323	.867	1.643	2.645**	1.180

Note. Total PE = total score of patient empowerment. 1 = being informed. 2 = feeling confident with physician. 3 = acceptance of my fertility problems. 4 = feeling confident about treatment. 5 = optimism and control over future. 6 = self-esteem. 7 = social well-being.

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .005$

Table 6. Independent samples t-tests between men’s characteristics and patient empowerment at Time 1 (*N* = 30).

		t						
		PE Subscales						
Variables	Total PE	1	2	3	4	5	6	7
Sociodemographic characteristics								
a. Parity	.564	.494	.711	.231	.560	.287	.065	.756
b. Ethnicity	-.527	-.982	-1.171	.105	-1.426	.749	1.209	-.332
c. Immigrant status	1.535	1.468	2.104*	.749	1.845	.358	.259	1.375
d. Recent immigrant	.153	-.305	.418	.454	.175	-.278	.830	-.544
e. Income	-1.723	-1.521	-2.005*	-1.210	-1.094	-1.592	-.112	-1.431
f. Education	-.262	.476	-.184	-.553	-1.162	-.340	-.010	.564
g. Religiosity	.450	.492	.543	.382	.650	.395	-.961	.405
Fertility history								
h. Searched fertility information online	-.124	-.430	.840	-1.179	-1.029	.133	.569	-.281
i. Connected with peers online	1.171	.404	.923	1.265	.708	1.693	1.609	.195
j. Male diagnosis	-.519	-1.625	-.195	-.921	.267	.065	.097	-.801
k. Sought counselling during treatment	-.800	-.833	-1.251	.022	-.400	-.804	-.065	-.361

Note. Total PE = total score of patient empowerment. 1 = being informed. 2 = feeling confident with physician. 3 = acceptance of my fertility problems. 4 = feeling confident about treatment. 5 = optimism and control over future. 6 = self-esteem. 7 = social well-being.
$*p < .05$ $**p < .01$ $***p < .005$

RQ2: Patient Empowerment and Mental Well-Being

The second research question addressed the relationship between PE and two mental well-being constructs that are often impacted by infertility and its treatments: quality of life and perceived stress. For both women and men, total PE at Time 1 was found to be negatively correlated to perceived stress ($N = 122, r = -.511, p < .005$; $N = 30, r = -.644, p < .005$, respectively), suggesting that more empowered individuals perceived less stress. Both the core module and the treatment module of the FertiQoL were positively correlated to overall PE in women ($N = 122$, $r = .593$, $p < .005$; $N = 122$, $r = .617$, $p < .005$, respectively) and in men ($N = 30$, $r = .612$, $p < .005$; $N = 30$, $r = .651$, $p < .005$, respectively), such that more empowered individuals reported better fertility-related and treatment-related quality of life (see Table 7).

Table 7. Pearson's correlations between patient empowerment, perceived stress and fertility-related quality of life at Time 1.

Variables	1	2	3	4
Women (*N* = 122)				
1. Total PE	–			
2. Perceived Stress	-.511***	–		
3. FertiQoL Core module	.593***	-.712***	–	
4. FertiQoL Treatment module	.617***	-.576***	.672***	–
Men (*N* = 30)				
1. Total PE	–			
2. Perceived Stress	-.644***	–		
3. FertiQoL Core module	.612***	-.589***	–	
4. FertiQoL Treatment module	.651***	-.518***	.632***	–

Note. Total PE = total score of patient empowerment. FertiQoL = fertility-related quality of life.
$^*p < .05$ $^{**}p < .01$ $^{***}p < .005$

RQ3: Patient Empowerment and Engagement

Scores of PE reported at Time 1 were explored in relation to subsequent engagement with the overall app (total EI), the informational section of the app (information EI) and the *Connect* forum of the app (forum EI).

I. Women

In the case of women ($N = 122$), total scores of PE at Time 1 were found to be negatively related to the total EI ($r = -.195$, $p < .05$) and the information EI ($r = -.222$, $p < .05$), suggesting that women with lower levels of PE at Time 1 had greater engagement with the app overall, and in particular with the informational section of the app, during the study period. In addition, some PE subscales were found to be significantly associated with engagement. The subscales "optimism and control over the future" and "self-esteem" were found to be negatively related to both the total EI ($r = -.189$, $p < .05$; $r = -.229$, $p < .05$) and the information EI ($r = -.201$, $p < .05$; $r = -.207$, $p < .05$). These findings indicate that women who felt less optimistic and less control over their future as well as women with lower self-esteem at Time 1 were more engaged with the overall app, and in particular with its information portion, during the 8-week trial period. Furthermore, the subscales "feeling confident with my physician" and "feeling confident about treatment" were negatively associated with the information EI ($r = -.207$, $p < .05$; $r = -.181$, $p < .05$), such that women who were less confident in their relationship with their physician and about their treatment at Time 1 viewed the information significantly more that those who were more confident.

II. Men

In contrast, men's PE scores at Time 1 were not related to overall engagement with the app. However, a significant negative association was found between men's PE levels and engagement with the forum section *Connect* ($N = 11$, $r = -.759$, $p = .005$), indicating that men who reported lower levels of PE at the start of the study showed a greater subsequent engagement with the forum than those with higher levels of PE. Engagement with the forum was further associated negatively with four specific PE subscales: "feeling confident with my physician" ($r = -.854$, $p < .005$), "acceptance of my fertility problems" ($r = -.627$, $p < .05$), "feeling confident about treatment" ($r = -.671$, $p < .05$) and "optimism and control over the future" ($r = -.677$, $p < .05$). These results indicate that men experiencing lower confidence with their physician, less acceptance of their fertility problems, lower confidence about their treatment or lower optimism and sense of control were more likely to use the app to connect with people going through the same situation. Lastly, the subscale "self-esteem" was found to be associated positively with engagement with the informational section of the app ($N = 30$, $r = .389$, $p < .05$), suggesting that men with better self-esteem visited the information content more than men with lower self-esteem.

RQ4: Change in Patient Empowerment and Engagement

The last research question addressed in this thesis examined what factors were associated with change in PE during the length of the study and whether engagement with the app during the 8-week trial period affected change in PE. Although no significant change was found between PE scores reported at Time 1 and 2 for the overall samples of women and men (see Table 3 above), change in PE was further evaluated in relation to participants' sociodemographic and fertility history characteristics to identify subgroups of participants whose levels of PE might have changed during the length of the study.

I. Women

Independent t-test results show that women who had sought psychological counselling during their fertility treatment experienced a greater increase in PE ($M = 5.92$) during the study period compared to those who had not sought psychological counselling ($M = -2.24$; $t(22269) = -3.151$, $p < .005$). In addition, there was a marginal association between levels of perceived stress at Time 1 and change in PE ($N = 122$, $r = .176$, $p = .054$), which could suggest that women experiencing greater perceived stress had a greater increase in PE during the study period. Women's change in PE was not related to any of the three EIs.

A moderated multiple linear regression analysis was used to further examine the relationship between women's perceived stress (predictor), engagement with the total app (moderator) and change in PE (outcome) while controlling for having sought counselling during fertility treatment. While the model significantly predicted change in PE ($F = 3.608$, $p < .01$; $R^2 = .110$), no moderation effect ($\beta = .347$, $SE = .909$, $t = .382$, $p = .702$) nor main effects of the predictor

($\beta = 1.292$, $SE = 1.081$, $t = 1.195$, $p = .232$) and the moderator ($\beta = 1.448$, $SE = 1.126$, $t = 1.286$, $p = .198$) were found, meaning that having sought counselling during fertility treatment accounted for most of the model's predictive power ($\beta = 2.908$, $SE = 1.072$, $t = 2.713$, $p < .01$). When conducting the same moderation analysis with engagement with the informational section of the app, similar results were obtained. The model significantly predicted change in PE ($F = 3.504$, $p < .01$; $R^2 = .107$) and no moderation effect ($\beta = .704$, $SE = .910$, $t = .774$, $p = .439$) nor main effects of perceived stress ($\beta = 1.383$, $SE = 1.080$, $t = 1.281$, $p = .200$) and engagement with the information ($\beta = .943$, $SE = 1.170$, $t = .806$, $p = .420$) were found. The effect of having sought counselling during fertility treatment, however, was significant ($\beta = 2.964$, $SE = 1.073$, $t = 2.762$, $p < .01$).

II. Men

For men, a positive relationship between perceived stress and change in PE was evident ($N = 30$, $r = .470$, $p < .01$). None of the other participant characteristics were related to change in PE for men. However, scores on the forum EI were positively associated to men's change in PE during the study period ($N = 11$, $r = .662$, $p < .05$), suggesting that men who were more engaged with the forum *Connect* reported greater increases in PE between the pre- and the post-surveys. A moderated multiple linear regression analysis was conducted to further investigate the relationship between perceived stress, engagement with the forum and change in PE for men.

Because none of the other participant characteristics nor events of pregnancy, miscarriage and decision to stop treatment were significantly correlated with change in PE, no control variables were included in the model. The regression model containing perceived stress and engagement with the forum as predictors as well as a moderation term was found significant ($F = 5.053$, $p < .05$), and accounted for 68.4% of the variance in change in PE. Furthermore, the analysis revealed a significant moderation effect of engagement with the forum on the relationship between perceived stress and change in PE ($\beta = 5.876$, $SE = 2.701$, $t = 2.176$, $p < .05$; see Table 8).

Table 8. Regression analysis summary for perceived stress and engagement with the *Connect* forum predicting change in patient empowerment for men.

Variable	*β*	*SE*	*t*	*p*
Perceived stress	1.239	3.229	0.384	.701
Forum EI	5.515	3.261	1.691	.091
Interaction term	5.876	2.701	2.176	.030

Note. Forum EI = engagement index with the *Connect* forum. $R^2 = .684$ ($N = 11$, $p < .05$)

Simple slopes analysis was then used to test the conditional effect of perceived stress on change in PE at high and low values of engagement with the forum defined as one standard deviation above and below the mean engagement. As shown in Table 9, perceived stress was not related to change in PE at low levels of engagement with the forum ($\beta = -4.578$, $p = .316$). However, at high levels of engagement with the forum, a positive relationship between perceived stress and change in PE was marginally significant ($\beta = 7.055$, $p = .062$), suggesting that people who are highly stressed at the start of the study and who engage with the forum on the app were more likely to report a greater increase in PE post-intervention.

Table 9. The conditional effect of perceived stress on change in patient empowerment at different values of the moderator

Engagement with the *Connect* forum	*β*	*SE*	*p*
One *SD* below mean	-4.578	4.564	.316
At the mean	1.239	3.229	.701
One *SD* above mean	7.055	3.783	.062

Discussion

This study was part of a larger project aiming to evaluate the benefit of the mHealth intervention *Infotility* providing targeted information and peer support to men and women undergoing fertility treatment. The present study focused on PE in relation to patient characteristics, mental well-being and engagement with the mHealth app. In addition, changes in PE during the app trial period were investigated and engagement with the app was considered as a potential factor influencing PE. Since the aim of the study was to understand the different factors associated to PE and app use in men and women, findings will be discussed separately for each gender.

I. Women

Results revealed few associations between participant characteristics and PE, with the most important being age and seeking psychological counselling during fertility treatment. First, younger woman had lower overall levels of PE. This result is somewhat contrary to the literature which shows that patients' desire to participate in their health care and to ascertain control over their treatment decision-making decreases as they become older (Arora & McHorney, 2000; Beaver et al., 1996; Degner et al., 1997). However, these studies included women who were on average 20 years older than the women seeking fertility care in this study, whose average age was 35 years. Given that PE tends to be studied in relation to chronic illnesses such as cancer and diabetes, older samples are common. It is possible that younger female patients in this study reported lower levels of PE compared to older patients because of their lack of experience with illness. As noted by many authors, competence and knowledge are central components of PE (Bravo et al., 2015; Castro et al., 2016; Fumagalli et al., 2015; van Uden-Kraan et al., 2009). Older women are likely to be more mature and to have had the time and opportunities to gather more knowledge about their health and acquire more skills and ability to navigate treatment and cope with the psychosocial issues surrounding infertility. For these reasons, older women may feel more confident with their fertility care providers and more confident about their treatment. Given that it is well-established that women's fertility decreases with age and that most Canadian women are aware of it (Bretherick, Fairbrother, Avila, Harbord, & Robinson, 2010), it is also possible that the realization of one’s infertility was more of a shock for younger women compared to older women, thereby having a greater impact on their self-esteem and perceptions of control.

Second, women who had sought psychological counselling during their treatment process reported lower levels of PE. Given that low PE is associated to high stress and low quality of life, it is likely that less empowered women may have felt a greater need to seek psychological counselling. The present findings also show that, whereas there was no overall change in PE throughout the study period, women who reported having sought counselling during fertility treatment at Time 1 experienced a greater increase in PE during the study. It is possible that these people continued to receive counselling during the study period, and that counselling was found to be empowering. While PE has often been discussed in patient-physician and in patient-patient relationships, it has been much less addressed in the context of psychological counselling. However, given that patient-centeredness and communication are central aspects of counselling and have been identified as antecedents of PE (Bravo et al., 2015; Castro et al., 2016), it is reasonable to expect that counselling may effectively promote PE. However, the present results do not allow causal interpretation; it could also be that women who gained PE were then more likely to seek psychological counselling. Further research is needed to understand the direction of this relationship and the potential of psychological counselling as a strategy to empower those with low levels of PE.

Although other patient characteristics, including being white, using social media to connect with peers, having had a shorter treatment duration, having spent less time trying to conceive and not being affiliated to a particular religion, were found to be related to PE or components of PE, these results were not considered robust enough to draw any conclusion. Moreover, contrary to expectations, education and socioeconomic status variables were not found to be related to levels of PE. Further investigation of the relationship between individual characteristics and PE may help to identify who is likely to benefit from access to empowering interventions as part of fertility care.

A major finding from the present study is that initial levels of PE influenced subsequent engagement with the app. Women who reported lower PE at Time 1 were significantly more likely to use the *Infotility* app during their 8-week study period. In particular, less empowered women were more likely to be engaged with the informational content of the app, but not the *Connect* forum. While previous studies have established the role of information provision and access to information for empowering patients (Jørgensen et al., 2018), the current study suggests that low

PE can also encourage information seeking in women when provided with the resources. Because women with lower PE are likely to be less knowledgeable, skilled and confident when it comes to understanding their condition, taking part in decision-making about their treatment and managing the psychological burden of infertility, they may have been more inclined to visit the informational sections of the app compared to women with greater PE who already feel informed and competent. That women with initially lower PE were more engaged with the app during the study indicates that *Infotility* may be a helpful resource to these patients as it provides accessible tools to better understand infertility, navigate treatment, cope and feel supported.

No relationship was found between change in PE and engagement with the app, meaning that women's levels of PE were not influenced by how much they used the app over the 8-week trial period. It is possible that the brief period of app use was not sufficient to significantly improve women's scores of PE, and that women require a larger dose of app usage and information given that they are more knowledgeable about fertility and health issues in general. It is also possible that women used other sources of information and social support. A number of studies have shown that female fertility patients often use the internet to gather information about infertility and its treatment as well as to connect with other women going through a similar situation through the use of online discussion boards (Malik & Coulson, 2008a; Zelkowitz et al., 2016).

II. Men

Since the present study included a sample of 30 male fertility patients only, the results for men should be considered exploratory and interpreted with caution. Nonetheless, the obtained results provide promising preliminary evidence for the use of mHealth interventions for empowering men undergoing fertility treatment.

First, results indicate that younger men reported lower levels of PE at Time 1 compared to older men, suggesting that age is an important factor associated to PE for men as well. Similarly to younger female patients, younger male patients are likely to be new to fertility care and have less experience with illness, and therefore be less competent and less knowledgeable about infertility and its treatment compared to older male patients. In fact, there is evidence that young men in the general population have a lack of knowledge and awareness regarding their own fertility and associated risk factors (Daumler, Chan, Lo, Takefman, & Zelkowitz, 2016). In addition, receiving an infertility diagnosis can be a devastating and disempowering event for young men as it can affect their identity, sense of control and social relationships, which are core components of PE. Indeed, infertility is a stigmatized condition often associated with sexual dysfunction and a lack of masculinity, it involves uncertainty regarding men's future fatherhood, and it is often accompanied by relationship problems (Esmée Hanna & Gough, 2015; Esmee Hanna & Gough, 2017). On the other hand, there has been little research investigating the role of age in men's experience of both infertility and PE.

Importantly, this study identified a significant negative relationship between initial levels of PE and subsequent engagement with the forum *Connect* during the 8-week trial period, indicating that men with lower levels of PE engaged more with the forum. While only a small number of men visited *Connect* ($N = 11$), this result suggests that less empowered men may have found the forum of the app useful. As shown by Malik & Coulson (2008), forums can be a helpful venue for men with fertility concerns who seek support, validation and experiential information (Malik & Coulson, 2008b). In contrast, men's levels of PE were not related to engagement with the overall app and with the informational section. This result may be related to the fact that previous studies have shown that women are more commonly involved in information gathering in the context of infertility compared to men (Zelkowitz et al., 2016).

Lastly, while reported levels of PE did not change between Time 1 and Time 2 for the overall sample of men, the present findings indicate a significant moderation effect of engagement with the forum on the relationship between perceived stress and change in PE, such that highly stressed men who used the *Connect* forum experienced a greater increase in PE. Keeping in mind that this analysis was based on a sample of 11 men only, this result highlights the possible empowering effect of access to peer support through an mHealth app such as *Infotility* for groups of men who are struggling the most to cope with infertility. Stressed men may be especially empowered by mobile access to peers as it offers a safe and anonymous place to express their feelings, and obtain validation, emotional support and experiential knowledge from others who understand what they are going through. Future research is needed to explore this moderation effect on a larger sample of men.

Implications & Limitations

Findings of the current study demonstrate that PE is closely related to perceived stress and fertility-related quality of life in both women and men, such that empowered individuals report less stress and better quality of life. This result is consistent with previous reports stating that improved quality of life, better coping and stress management are direct consequences of PE (Barr et al., 2015; Bravo et al., 2015; Castro et al., 2016; Kaal et al., 2017) as well as studies showing that empowering interventions can be effective at reducing stress (Etemadifar, Heidari, Jivad, & Masoudi, 2018). On the other hand, results of the present study differ considerably from those obtained by Nelson (2012), the only previous study investigating the relationship between PE and fertility-related quality of life in fertility patients using the PEQ and the FertiQoL. Nelson (2012) had found a significant negative relationship between the PE subscale "social well-being" and quality of life, and no relationship between other aspects of PE and quality of life. Nelson (2012) proposed two possible explanations for this result: (1) quality of life may be impacted by negative experiences on online forums following the sharing of infertility experiences and seeking of social well-being, and (2) people who experience poorer quality of life may be more motivated to seek social connections on online forums. The present results provide support for Nelson's second explanation, in that women who were less empowered and whose quality of life was more impaired at Time 1 were more engaged with the app's informational section and men who were less empowered were more engaged with the forum. The fact that this study found a positive association between PE and fertility-related quality of life, unlike Nelson (2012), may be due to fundamental differences in the sample, with this study including men (19.7%) and fertility patients actively seeking treatment in comparison to Nelson's sample of exclusively women using fertility forums. Future research is needed to further clarify the association between PE and quality of life. Importantly, the present result emphasizes the potential of PE to improve the well-being of fertility patients. A PE approach may be especially relevant to the context of infertility given that the experience of infertility has repeatedly been linked to increased psychological stress and reduced quality of life (Chachamovich et al., 2010; Arthur L. Greil et al., 2010; J. M. Ussher & Perz, 2019).

While empowering patients through technology is becoming more and more widespread (Calvillo, Román, & Roa, 2015), conducting research that evaluates eHealth and mHealth interventions' influence on PE involves challenges. The lack of consensus over the definition and measurement of PE and the breadth of strategies employed by interventions meant to empower patients creates confusion as to what PE exactly is and how it differs from similar constructs such as patient participation and patient activation. It is essential to clearly define the nature of PE and to clarify the best strategies for assessing and enhancing people's sense of empowerment. The present study contributes to the current literature concerning empowering interventions by evaluating a novel mHealth intervention amongst the fertility patient population. Indeed, this study provides some preliminary evidence in support of mHealth as a tool to empower fertility patients and suggests that those with lower PE could benefit from access to informational and social support. This is important as PE may serve to alleviate the psychological burden of those who experience the most difficulties facing fertility concerns and undergoing fertility treatment. In addition, these findings can serve to inform the future development of mHealth resources for fertility patients. Such studies are particularly needed as there exist few mHealth apps supported by empirical evidence of good quality, especially in the field of mental health (Fiordelli, Diviani, & Schulz, 2013; Marcolino et al., 2018; Price et al., 2014).

Nevertheless, the current study has certain limitations with regards to sampling and retention of participants. Recruitment of participants relied on convenience sampling, which can induce bias in the analysis as those who agreed to participate may differ from those who refused. Unfortunately, there is no way to determine how these groups of patients might differ and to what extent. Furthermore, although a large number of women were recruited and successfully completed the study, a much smaller sample of men entered and completed the study, affecting the power of analysis and limiting the interpretation of results. Consequently, the present results regarding male fertility patients should be considered exploratory and warrant future research. The main reasons for the fewer numbers of men in this study were: (1) men were less likely to be present in fertility clinics compared to women, (2) men preferred that their female partner participate, and (3) men were more likely to not use the app during the study period which led to their exclusion from the final sample. While the number of people who explicitly stated that they wished to stop their participation in the study was relatively low, the dropout rates went up substantially when counting the non-users of the app and non-completers of the surveys as dropouts. Attrition and low rates of engagement are common issues in eHealth and mHealth research (Cajita, Gleason, & Han, 2016; Melville, Casey, & Kavanagh, 2010). Lastly, although efforts were made to obtain a diverse group of participants in terms of sociodemographic characteristics, the current study was primarily comprised of non-immigrant, white, anglophone, wealthy and educated individuals. These sample characteristics are consistent with those reported in other studies involving fertility patient populations (Jain & Hornstein, 2005; Tulandi et al., 2013) and are likely to be due to the expensive costs of fertility treatment. Similarly, most studies investigating eHealth technologies are conducted in western developed countries (Iribarren, Cato, Falzon, & Stone, 2017), thereby involving mostly well-educated, wealthy and white individuals. Future research should pay particular attention to the experience of PE in sociodemographically diverse populations undergoing fertility treatment and using mHealth.

The current study also involves limitations regarding design and data collection. A pre-post study design was employed for the pilot testing of the *Infotility* app. While this type of design has the advantage of temporality, allowing to associate changes in the outcome to the intervention, and that information about key treatment-related events that could occur over the study period (pregnancy, pregnancy loss and stopping treatment) was collected, it is possible that other factors of influence that were not considered during data collection affected the outcome. Future work should involve randomization and comparison groups. For example, one could include a no-intervention group (i.e. group with no access to the app) which would act as a control and would allow to better identify the discrete effect of the app. Another limitation with regards to design is that, while app usage monitoring was limited to an 8-week trial period, participants were allowed to keep using the app after this period ended. Therefore, our measurement of app engagement may not be an entirely accurate measure of exposure to the app as it did not cover usage past 8 weeks. Moreover, while online post-surveys were sent to participants at the 8-week mark, many people did not complete the questionnaires right away. Their response to post-questionnaires may have been affected by response delay and prolonged exposure to the app.

Lastly, this study has limitations with regard to data analysis. While the use of a complex measure of user engagement represents a strength of the current study, the skewness and lack of variability of the engagement indices represent a limitation. Few studies have attempted to measure engagement and considered its impact when testing eHealth and mHealth interventions (Taki et al., 2017). Further investigation is needed to evaluate the best ways to engage participants in mHealth research and to capture the complexity of user engagement. For example, a different combination of KPIs, such as scroll depth or session length, might have been better suited to represent user engagement.

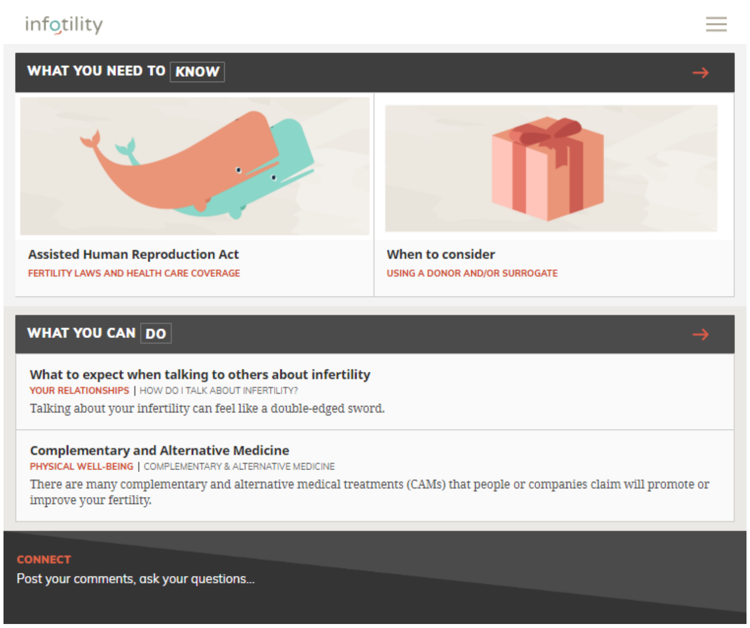
Conclusion

Empowering patients is becoming increasingly recognized as an important aspect of patient-centered care and patient well-being in various sectors of health care. The present study described how characteristics of fertility patients are related to PE, which can help identify groups of people who are less empowered and therefore at greater risk of experiencing high perceived stress and low quality of life. It is important to find strategies to empower those who are likely to feel isolated, less informed about their health condition, less able to navigate treatment and less in control of their health and their future. Overall, this study indicates that, in fertility care, PE can potentially be enhanced by the use of mobile technologies such as mobile apps which can offer easy access to informational and emotional support. Those with lower levels of PE may especially engage and benefit from an intervention that allows them to better understand their condition and their treatment process and to feel better supported. Further research is needed to grasp the potential of mHealth to empower patients. Future studies should attempt to replicate and extend the present study by involving a larger sample of men and people of diverse cultural and socioeconomic backgrounds.

This study further provides useful insight into the relationship between PE and engagement with mHealth. Given that engagement is a widespread concern in mHealth research, it is important to understand who is likely to be less engaged and to find solutions to better engage people through apps that are targeted to patients' needs, patient-centered, interactive and user-friendly. Because so few mHealth apps are evidence-based and empirically tested, the present research may serve to inform the development and evaluation of future mHealth interventions.

APPENDIX A

Figure 1. Screen capture of the *Infotility* dashboard.



WHAT YOU NEED TO KNOW

Assisted Human Reproduction Act
FERTILITY LAWS AND HEALTH CARE COVERAGE

When to consider
USING A DONOR AND/OR SURROGATE

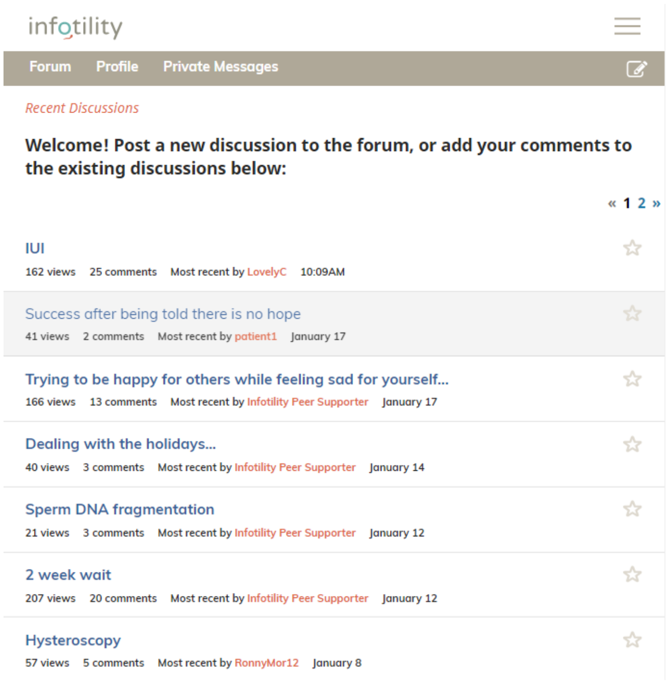
WHAT YOU CAN DO

What to expect when talking to others about infertility
YOUR RELATIONSHIPS | HOW DO I TALK ABOUT INFERTILITY?
Talking about your infertility can feel like a double-edged sword.

Complementary and Alternative Medicine
PHYSICAL WELL-BEING | COMPLEMENTARY & ALTERNATIVE MEDICINE
There are many complementary and alternative medical treatments (CAMs) that people or companies claim will promote or improve your fertility.

CONNECT
Post your comments, ask your questions...

Figure 2. Screen capture of the *Infotility Connect* forum.



Recent Discussions

Welcome! Post a new discussion to the forum, or add your comments to the existing discussions below:

IUI
162 views 25 comments Most recent by LovelyC 10:09AM

Success after being told there is no hope
41 views 2 comments Most recent by patient1 January 17

Trying to be happy for others while feeling sad for yourself...
166 views 13 comments Most recent by Infotility Peer Supporter January 17

Dealing with the holidays...
40 views 3 comments Most recent by Infotility Peer Supporter January 14

Sperm DNA fragmentation
21 views 3 comments Most recent by Infotility Peer Supporter January 12

2 week wait
207 views 20 comments Most recent by Infotility Peer Supporter January 12

Hysteroscopy
57 views 5 comments Most recent by RonnyMor12 January 8

APPENDIX B

The 34 items of the adapted version of the Patient Empowerment Questionnaire used in the pre-post survey are presented below, followed by the results of the reliability analysis, including Cronbach's alphas and inter-correlations of the seven subscales and the total scale.

I. Being informed

_ . . . I feel informed as a patient.
_ . . . I understand my fertility problems.
_ . . . I have a clear picture about my fertility problems.
_ . . . I feel like I have (correct) knowledge at my disposal to deal with my fertility problems.

II. Feeling confident in the relationship with my physician

_ . . . I feel prepared for a doctor's appointment.
_ . . . I am knowledgeable about which questions to ask my physician.
_ . . . I can explain my needs to my physician.
_ . . . I have courage to raise matters with my physician.
_ . . . I am able to oppose my physician.
_ . . . I understand the information provided by my physician.
_ . . . the relationship with my physician is good.
_ . . . I am able to judge when I really need the help of my physician.
_ . . . I feel dependent on my physician. *(score has to be reversed)*
_ . . . I am able to discuss my treatment with my physician

III. Acceptance of the fertility problems

_ . . . I am able to be open about my own fertility problems.
_ . . . I can tell others easily when I am no longer able to do something.
_ . . . I can ask others for help quickly.
_ . . . I can accept my fertility problems.

IV. Feeling confident about the treatment

_ . . . I can stick to my treatment regimen.

_ . . . I am able to follow the medical guidelines and advice of my physician.

_ . . . I know where to go with questions about my treatment.

_ . . . I feel I am skilled at dealing well with my treatment.

_ . . . I feel able to make the right decisions with regard to my treatment.

V. **Optimism and control over the future**

_ . . . I feel in charge of the course of my treatment.

_ . . . I feel I can influence my treatment myself.

_ . . . I feel in control over what is happening to me.

_ . . . I feel that what happens to me in the future is to a large degree dependent on me.

_ . . . I am positive.

_ . . . I have faith in the future.

VI. Self-esteem

_ . . . I have a great sense of worth.

_ . . . I have a positive attitude towards myself.

_ . . . I am content with myself.

VI. Social well-being

_ . . . I feel lonely. *(score has to be reversed)*

_ . . . I have social contacts.

Table 1. Cronbach's alpha of the pre and post patient empowerment questionnaire (PEQ) using the final sample of fertility patients participating in this study (*N* = 152).

	PEQ Scale	**Cronbach's alpha**
Time 1	Being better informed	0.893
	Feeling confident with physician	0.823
	Improved acceptance of illness	0.813
	Feeling confident about treatment	0.773
	Increased optimism and control over the future	0.804
	Enhanced self-esteem	0.902
	Enhanced social well-being	0.505
	Total scale	**0.922**
Time 2	Being better informed	0.897
	Feeling confident with physician	0.843
	Improved acceptance of illness	0.809
	Feeling confident about treatment	0.783
	Increased optimism and control over the future	0.759
	Enhanced self-esteem	0.915
	Enhanced social well-being	0.513
	Total scale	**0.912**

Table 2. Inter-correlations between PE subscales and total scale at Time 1 and 2.

	Subscales	1	2	3	4	5	6	7	8
Time 1	1. Being better informed	1	0.583	0.434	0.396	0.475	0.196	0.184	0.725
	2. Feeling confident with my physician	0.583	1	0.324	0.665	0.524	0.47	0.296	0.851
	3. Improved acceptance of illness	0.434	0.324	1	0.277	0.407	0.239	0.336	0.62
	4. Feeling confident about treatment	0.396	0.665	0.277	1	0.37	0.373	0.296	0.704
	5. Increased optimism and control over the future	0.475	0.524	0.407	0.37	1	0.47	0.307	0.763
	6. Enhanced self-esteem	0.196	0.47	0.239	0.373	0.47	1	0.411	0.604
	7. Enhanced social well-being	0.184	0.296	0.336	0.296	0.307	0.411	1	0.481
	8. Total sum score	0.725	0.851	0.62	0.704	0.763	0.604	0.481	1
Time 2	1. Being better informed	1	0.542	0.198	0.398	0.334	0.159	0.093	0.661
	2. Feeling confident with my physician	0.542	1	0.143	0.695	0.501	0.485	0.292	0.855
	3. Improved acceptance of illness	0.198	0.143	1	0.203	0.287	0.176	0.171	0.463
	4. Feeling confident about treatment	0.398	0.695	0.203	1	0.38	0.347	0.24	0.726
	5. Increased optimism and control over the future	0.334	0.501	0.287	0.38	1	0.518	0.394	0.735
	6. Enhanced self-esteem	0.159	0.485	0.176	0.347	0.518	1	0.465	0.623
	7. Enhanced social well-being	0.093	0.292	0.171	0.24	0.394	0.465	1	0.461
	8. Total sum score	0.661	0.855	0.463	0.726	0.735	0.623	0.461	1

APPENDIX C

Table 1 describes the missing data in our dataset prior to multiple imputation. The table presents the amount of missing data in each of the imputed questionnaires in terms of: number and percentage of items with missing values within that questionnaire, number and percentage of participants who have missing values in that questionnaire, and number and percentage of discrete missing values in that questionnaire. The following table lists the technical details of the multiple imputation process which was applied to our dataset as a first step in our analytical procedure (see Table 2).

Table 1. Amount of missing data in each of the imputed questionnaires.

	N (%) of incomplete data		
Measure	**Items**	**Participants**	**Values**
Pre-questionnaires			
eHeals	12 (100)	4 (2.367)	22 (1.085)
FertiQoL	36 (100)	34 (20.12)	121 (1.989)
GAD	7 (100)	6 (3.550)	14 (1.183)
PEQ	33 (97.06)	27 (15.98)	123 (2.141)
PHQ	9 (100)	7 (4.142)	25 (1.644)
PSS4	1 (25)	1 (0.592)	1 (0.148)
6-week mark			
uMARS	20 (100)	24 (14.20)	272 (8.047)
Post-questionnaires			
eHeals	12 (100)	11 (6.509)	88 (4.339)
FertiQoL	36 (100)	26 (15.38)	155 (2.548)
GAD	7 (100)	15 (8.876)	57 (4.818)
PEQ	34 (100)	39 (23.08)	351 (6.109)
PHQ	9 (100)	17 (10.06)	77 (5.062)
PSS4	4 (100)	8 (4.734)	26 (3.846)

Table 2. Details of the multiple imputation.

Software used:	• SPSS Statistics 25 Premium
Key settings:	• Automatic method option • 5 imputed datasets (default option) • Maximum percentage of missing values of 100% • Minimum and maximum constraints set to respect the range of possible values in the Likert type scales of each variable • Values rounded to integers
Imputation model:	• Fully Conditional Specification • 10 iterations • Linear regression model • No interactions
Order of imputations:	• Same as order of variables in the surveys
Imputed variables:	• eHeals, FertiQoL, GAD, PEQ, PHQ, PSS4, uMARS • Mostly used as outcomes

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