

## Research Reports

# Coming to Terms With Permanent Involuntary Childlessness: A Phenomenological Analysis of Bulletin Board Postings

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## Abstract

Little is known about the role that online support communities play in the lives of women faced with permanent involuntary childlessness. To understand the experiences of these women, this study conducted a thematic analysis of messages downloaded from an online community for permanent involuntary childlessness. Four central themes were identified: Feeling like an “outsider”, A whole lifetime of loss, Coming to terms with childlessness and Finding a safe haven online. These findings show that the online community appeared to empower women to move on with their lives and discover a new sense of self-worth and identity beyond that of motherhood.

*Keywords:* infertility, online support, involuntary childlessness, social support, internet, psychosocial well-being

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Infertility defined as the inability to conceive after two years of regular unprotected sexual intercourse, is estimated to affect approximately 72.4 million people worldwide (Boivin, Buntin, Collins, & Nygren, 2007). A review of the infertility literature suggests that men and women faced with infertility will often experience a strong need for psychosocial support and guidance; a need which is not always adequately met by existing sources of support (Alesi, 2005; Malik & Coulson, 2008a; Schmidt, 2009). Recent research has explored the potential role of the Internet and in particular online support communities, in helping to address these unmet support needs (Epstein, Rosenberg, Grant, & Hemenway, 2002; Epstein & Rosenberg, 2005; Himmel, Meyer, Kochen, & Michelmann, 2005; Malik & Coulson, 2008a).

An online community can be described as a social network that is created and supported by electronic media (Wellman, 1997). Online support communities are typically facilitated through bulletin boards, which allow users to communicate with one another by posting and replying to messages on a discussion board. Some websites may include additional features such as a chat room or private messaging option. These online communities are unique in that they allow individuals to engage in either synchronous or asynchronous written communication with people from all over the world and access a dynamic source of peer and/or professional support, advice and information at virtually any time of the day (Braithwaite, Waldron, & Finn, 1999; Ferguson, 1996).

Research across a range of different health conditions has shown that online support communities can offer individuals a unique and valuable source of social support (Braithwaite et al., 1999; Bunde, Suls, Martin, & Barnett,

2006). In addition, participation in online communities has been linked to several positive psychosocial outcomes including a sense of empowerment, improved quality of life and reduced depression (Bartlett & Coulson, 2011; Evans, Donelle, & Hume-Loveland, 2012; Mo & Coulson, 2010; van Uden-Kraan et al., 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). In relation to infertility, several studies have shown that the anonymity of the Internet and online communities offers individuals a novel opportunity to express their feelings and experiences without fear of embarrassment or stigmatization (Malik & Coulson, 2008a; Malik & Coulson, 2008b). Furthermore, research reveals that online infertility support communities can offer many of the therapeutic and self-help processes that occur in face-to-face support networks and can create a strong sense of camaraderie among participants (Malik & Coulson, 2010a). The benefits of accessing online infertility support communities have been shown to be experienced by both individuals who actively post messages to online communities as well as those individuals who simply access the community to read messages posted by others (Malik & Coulson, 2011). Key psychological benefits of participation include reduced feelings of isolation, informational and emotional support, a sense of hope and positivity and tips/advice on how to cope with the effects of infertility on interpersonal relationships (Gold, Boggs, Mugisha, & Palladino, 2012; Hinton, Kurinczuk, & Ziebland, 2010; Malik & Coulson, 2008b; Malik & Coulson, 2010a; Malik & Coulson, 2011). As such it appears that online support communities offer a viable and beneficial alternative source of support for many people affected by infertility.

However, online infertility support communities are not without their disadvantages. Several studies indicate that online communities may not always fulfill the support needs of people facing permanent involuntary childlessness. Research has shown that women who had experienced treatment failure and were facing permanent childlessness, found it difficult to hear about treatment success from other members of the online community. Reading about other people's pregnancies resulted in feelings of immense grief, anger, and jealousy and appeared to heighten infertility-related stress (Malik & Coulson, 2008b; Malik & Coulson, 2010b; Malik & Coulson, 2011). Thus, it appears that while women may initially benefit from accessing a network of similar others, there is a risk that those women who do not fall pregnant will become increasingly depressed and isolated overtime, particularly if fellow members have become pregnant while they are facing the prospect of potential permanent childlessness (Verhaak, Smeenk, van Minnen, Kremer, & Kraaimaat, 2005; Verhaak, Smeenk, Nahuis, Kremer, & Braat, 2007).

Estimates suggest that around 4.2% of women wishing to conceive between the ages of 40 and 55 years remain childless due to unresolved infertility (Oakley, Doyle, & Maconochie, 2008). These women may be at risk for developing depression and long-term emotional problems (Verhaak et al., 2005, 2007). Moreover, a number of studies utilizing both qualitative and quantitative approaches; have indicated a general dissatisfaction with the level of information and support provided by clinics in relation to the decision to end treatment and alternative options such as adoption (Peddie, van Teijlingen, & Bhattacharya, 2005; Schmidt, 1998; Souter, Penney, Hopton, & Templeton, 1998). For example, a qualitative study by Peddie et al. (2005) found that women felt the information provided at their final consultation was inadequate and expressed a need for ongoing support from the IVF unit. In light of this, it is important to ensure that individuals making the transition from fertility treatment to permanent childlessness are able to access adequate support and guidance both online and offline.

To date, much of the research focusing on online support and infertility issues has been conducted in online communities that are dominated by individuals undergoing investigation or treatment for infertility. Consequently, comparatively little is known about the role that online support communities can play in the lives of women faced with permanent involuntary childlessness. More in depth research in this area may help health care professionals gain an insight into how they can create positive online and offline environments, in which women feel they can

access the support that they need. To help address the gaps in our understanding of online women's support needs at this stage of their infertility journey, we conducted a qualitative analysis of messages posted to an online community dedicated solely to individuals facing permanent childlessness. It was felt that a qualitative approach would allow for a more in-depth and richer insight into the experiences of women using the online community. Consequently, through the qualitative analysis, we sought to understand the "lived" experience of women accessing an online community for unresolved infertility and to explore the role that online support plays in the lives of these individuals. To the best of our knowledge, the current study is one of the first to focus specifically on online communication among women facing permanent involuntary childlessness.

## Methods

### Sample and Data Collection

The data for this study were messages obtained from the archive of a peer-moderated online community designed solely to support individuals dealing with permanent involuntary childlessness. The online community was identified through conducting a Google search of online support for permanent infertility and selected as it appeared to be one of the largest and most active online communities of this nature. At the point of data collection the online community consisted of one bulletin board, which contained just over 1000 messages in its archive, with new messages being posted on a regular basis (around 5-10 messages per week). To begin with, the 40 most recent discussion threads in the archive were downloaded on 15/12/10. This resulted in 224 messages for data analysis. Following the analysis of these messages, it was felt that the point of data saturation (i.e. no new themes or relevant insights coming to light) had been reached therefore no further messages were collected. The length of the messages ranged from 2-956 words (mean = 122 words). Messages identified the date and time of posting and the senders name and gender followed by the message text. From this information it appeared that all the messages were posted by women and a total of 49 unique sender names were identified. Due to the anonymous nature of an online support community, further personal/demographic data about the sample was not available.

### Data Analysis

Messages were analyzed using a thematic analysis, which drew on principles of phenomenological research to understand the "lived" experiences of the senders. Phenomenological research is concerned with gaining a deeper and richer insight into the lived experiences of individuals and understanding the meanings that individuals attach to events and phenomena (Beck, 1994). A phenomenological analysis was thus considered an appropriate and ideal method for describing and interpreting the meanings that women attach to their experiences of involuntary childlessness and accessing an online support community. The practical steps involved in the data analysis process, broadly followed the generic thematic analysis guidelines set out by Braun and Clarke (2006) and involved a collaborative process between the study authors. In the first instance, the lead author read the discussion threads several times to become familiar with the dataset. Following this, salient and interesting features of the data were coded. In the final stage, similar codes were grouped together to form overarching conceptual themes, which captured the women's experiences as expressed through their bulletin board postings. The data and thematic conceptualization was then reviewed by the second author for validity. Following discussions between the two authors, an agreement was reached around the final thematic framework.

## Ethical Considerations

Ethical approval was obtained from the University Research Ethics Committee, in accordance with the ethical guidelines for Internet research published by the British Psychological Society (BPS, 2007). For the present study, issues concerning informed consent, privacy and confidentiality were considered particularly relevant. In light of recommendations from previous authors (e.g. BPS, 2007; Eysenbach & Till, 2001), a relatively large and open access online community (i.e. one that does not require any form of registration or subscription to access and read messages) was selected for research purposes. Since the online support community could be considered “public” in nature, informed consent from individual members was not sought.

However, in accordance with the British Psychology Society ethical guidelines, to further protect the privacy and confidentiality of individuals using the online community, the name of the support community and address of the website from which data was collected has not been disclosed in any dissemination of the work. In addition, all quotations used in the reporting of the results were anonymised and entered into a search engine to ensure the quotes could not be traced directly to an individual posting. In instances where quotes were traceable to the original posting, the quote was paraphrased when reporting the results to ensure privacy and anonymity.

## Results

The results of the analysis revealed four emergent themes related to the experiences of women accessing an online support community for permanent involuntary childlessness. These themes were labeled as:

- Feeling like an “outsider”
- A whole lifetime of loss
- Coming to terms with childlessness
- Finding a safe haven online

### Feeling Like an “Outsider”

A common experience among women posting to the online bulletin board was a sense of isolation from the “fertile world” and the feeling that they were somehow “different” to other women. Many women talked about how not having children of their own meant that they were forever “on the outside looking in” on their peers becoming mothers and raising families. The knowledge that they would never be admitted into this “mum’s club” evoked a range of strong negative emotions in members of the online community. Emotions commonly expressed in the postings included intense feelings of grief and anguish at the loss of their opportunity to become biological parents, as well as anger that this role had been denied to them.

*“I constantly feel like an outsider in this world. Wherever I go or whatever I do, I feel like the odd one out. I work in a female dominated environment with either younger girls having babies or the older women becoming grandparents. There are always happy family photos being passed around, so I do feel 'different' to everyone else.”*

Several women also described how being unable to conceive a child of their own, appeared to have changed their outlook on life in general, which served to further separate them from other women around them. For example:

*“One of the things I find hardest to deal with is people with a child talking about the next or one planning their first as if they are going to order one and the universe will deliver, at particular age gap, what sex they want and that be most convenient after their holiday so they can enjoy a drink!! But the reason it*

*bothers me so much is that I've had to learn that life isn't like that when it appears others don't have that lesson taught. It can make me feel singled out for some hardship and it's so unfair."*

Hearing about other people's pregnancies appeared to be a particularly painful experience for women in the online community and served as a poignant reminder that they were unable to conceive themselves. For many women, receiving news that a friend, colleague or family member was pregnant resulted in a mixture of joy, despair and feelings of jealousy. Such news often prompted members to access the online community, in order to vent their frustration and express these conflicting emotions to people who could empathize with their experiences. In this context, the online community served as a unique environment in which women could alleviate their sense of isolation and connect with other women in similar situations.

*"I went over to see a friend yesterday to 'mourn' the breakup of my relationship and she announced that she is pregnant. I wouldn't wish this feeling of isolation and hopelessness on anyone, especially a close friend but it felt like a kick in the gut non-the-less...."*

Some women also described feelings of distress when they heard stories in the media about motherhood or attended family gatherings, where there were young children present. These experiences heightened their feeling of being "the odd one out" and once again brought home the realization that they would never experience motherhood.

*"TV personalities seem to get pregnant at the drop of a hat or they have fertility treatment and it just seems to work first time for them. Reading these stories makes me really upset and angry"*

To protect themselves against reminders of their infertility and feeling like an outsider in social situations, several women reported avoiding certain family gatherings or cutting themselves off from friends who were pregnant or had children. Although this coping strategy was effective in avoiding painful feelings in the short-term, in the long-term it appeared to create a vicious cycle with members feeling more isolated and alienated from society as time went by:

*"I have had an in built safety mechanism for years in which I distance myself from any friends/work colleagues/family of child bearing age, hence I was left with very few friends of my own age and have gradually felt more and more isolated."*

*"I always dreaded family gatherings and made excuses not to go because I hated feeling like the odd one out whilst everyone around me had children or were expecting them. I tried to protect myself because I found it all too painful but at the same time I have found the feeling of isolation really painful and difficult too"*

One environment in which the women found it more difficult to avoid pregnancies and discussions about children was within the workplace. Several members reported that they had gone to great lengths (e.g., changing jobs) to create a "safe" working environment for themselves. However, this safe haven was often short-lived, for example as one woman describes:

*"Hi folks, well here I am again after my few months away whilst I am 'coping' (haha) Its that wave again.....after moving job to escape the many pregnancies around me I find 2 of my colleagues are pregnant very unexpectedly. one being in her forties with 2 grown up children and the other on her 4th. my safe space has now crashed!"*

This posting elicited a surge of responses from other members of the online community who had also been through similar experiences:

*"I do really know what you mean about how that sinking feeling grabs you...and then stays for a length of time. It seems so unfair that you have changed jobs and thought you were in a safe place...only to have to it thrust upon you again. It happened to me last year too and I remember that blow."*

These messages were used to share common experiences and empathy, and also offer reassurance to the poster that the pain and anguish would lessen with time. In this way, members of the online community created a safe and supportive environment in which infertile women could reach out to one another, every time they felt down or experienced a new wave of negative emotions.

### **A Whole Lifetime of Loss**

Members of the online community described multiple losses as a consequence of infertility. First and foremost, there was the loss of an unborn child and the accompanying loss of their hope of becoming parents. Furthermore, for some members permanent childlessness also seemed to challenge their core identity as women; with several posters questioning their role in a society, which they perceived to be obsessed with childbearing. For example:

*"I keep thinking I am moving on as my life has changed so much since we stopped the IVF treatments but I just feel like I am slipping backwards when I want to keep looking forwards with as much of a positive way as I can. Living in a society that expect women to have children"*

As this quote illustrates, a key challenge that many women accessing the online community were faced with was the struggle to create a new identity for themselves following their lost hopes of becoming a mother. The online community provided an accessible forum in which these challenges could be shared and discussed anonymously.

Several women expressed the view that although they might learn to live with their loss, they would never fully recover from the grief that came with it. As one woman describes, unresolved infertility seemed to instigate a "whole lifetime of losses" that she would have to encounter at each stage of her life:

*"Does anyone else ever get really angry about not having children? It washes over me every so often and I get really cross and hurt, even after all this time. Not only do we miss out on the babies but it's a whole lifetime of experiences too. Sorry, just feeling a bit sorry for myself. Xx"*

A key advantage of accessing the online community for many women was receiving validation for these powerful emotions. For example, this feeling was reciprocated by other members of the online community, with another woman posting:

*"I do get where you are coming from about missing out on things: first birthdays, 18th birthdays / 21st birthdays, first day at school, learning to drive, passing exams (or not), meeting boyfriends / girlfriends for the first time, Christmases of course!, seeing them ride a bike for the first time, perhaps going to college or university, weddings of course (and hopefully), grand children of course (and hopefully), birthday parties etc, etc, etc. It is so difficult and I too try to think of the lovely husband I have and my dog, Harvey, and my home and the fact I have a car and occasionally have a lovely holiday, but sometimes that just doesn't do it does it!"*

Another life event that appeared to be particularly distressing for members was the realization that they would never become grandparents either. Several members discussed their emotional reactions to news that their peers

were becoming grandparents. These reactions seemed to parallel the pain and jealousy they had initially felt when they heard of other women falling pregnant. However, as some women described, the loss of their opportunity to become grandparents not only served as a reminder that they didn't have children but was almost like a "second wave" of infertility, where they grieved anew for their unborn grandchildren and were again pushed to seek support and consolation online, which for many women was the only forum in which they could access and communicate with other women living with permanent infertility.

*"I could not help observing the sign Grandchild on board in the rear window of a car the other day. I have noticed lots of baby/child/princess etc etc on board but never the grandchild one before. It just made me think that it does not matter what age we are or how we feel there is always something or someone to remind us that not only are we not parents but are never to be grandparents either.."*

*"Found out last night that my partners sisters daughter has just become pregnant and as I am now in the Grandmother age thought I had got past all these feelings but once again I spent all last evening feeling I should be over this by now and then feeling like crying."*

Thus it seems that for this group of women, involuntary childlessness was experienced as a major and recurring loss throughout their life course.

### Coming to Terms With Childlessness

Most of the people posting to the online community had been through the "emotional rollercoaster" of several unsuccessful cycles of infertility treatment; before they went from "trying to conceive" to facing the prospect of permanent infertility. Prior to this, these individuals had been wholly consumed with the goal of resolving their infertility crisis, but now suddenly found themselves searching for new life goals that did not involve parenthood.

*"It's funny that when things don't go according to plan, you just want to hide away and be as invisible as possible. Then it's incredibly hard to re-emerge and reinvent yourself".*

*"I have found that I really struggle to come to terms with it all ...the fact that you can do nothing to change it, is very disempowering. I have achieved many things in recent years...yet I often feel that this all is nothing because I cant have a child.."*

Many women accessing the online community expressed a strong desire to learn to "accept" their infertility and move on with their lives. However as the quotes above suggest, members generally agreed that this was a long and difficult process, particularly with the constant external reminders of their loss (e.g. seeing other women become mothers or grandmothers). There was also a distinction made between "coping" with infertility and achieving "closure". For example, several women described how they had experienced periods of "calm" where they were able to temporarily move on with their lives, only to find their emotions spiraling downwards again when they were hit with the reality of permanent childlessness.

*"I feel I have lots of stuff that I need closure with and I ache for a time when I can get on with my life without this affecting me all the time....It's that old chestnut again and I'm fed up of it. Thanks for listening".*

*"It comes out of nowhere and knocks you flat. I am currently in a calm period but I know that the wave will hit again".*

*"Really thought I'd come to terms with not having children but when I see my sisters/brother and friends with grandchildren, it hits home again. It's not easy."*

A number of women appeared to experience a sense of guilt that they were still dwelling on their infertility years later and were unable to achieve permanent closure.

*"I don't know where I am going and everything seems so pointless, my hubby is fantastic and is so supportive so I should be grateful for what I've got.."*

*"I thought I had got past all these feelings but once again I spent all last evening feeling I should be over this by now and then feeling like crying."*

Counseling was frequently discussed as one means of achieving closure. The online community was used as a forum in which to share both good and bad experiences of counseling. Members also sought advice from one another about the type of counseling they should have and shared some of their anxieties about the process:

*"It is a big step to say those inner thoughts out loud and to someone who may have children has always put me off, so I have found a counselor with experiences in this area and I can only hope that if she has children she does not tell me. Will let you know honestly how I get on. I am very positive about counseling and know it can work wonders if you get the right person at the right time so fingers crossed."*

As this quote highlights, most women posting to the online community seemed to consider seeing a counselor as a positive and cathartic process and actively encouraged other members to explore counseling. However, women also expressed the view that finding the "right" counselor and ensuring that they were ready to openly talk about their infertility issues was crucial.

*"I found the process challenging sometimes draining and exhausting, but deeply cleansing too. The therapist was very clever and found ways to push my buttons and get me in touch with my feelings because I'm soo good at pasting a big smile on and telling myself I'm doing great when I'm not".*

The use of self-help strategies was also evident within the messages. Women frequently shared inspirational quotes and poetry with one another and described using cognitive strategies to help change negative thought patterns surrounding their infertility. For example:

*"I don't know about anyone else but I have a collection of inspirational quotes which I read from time to time and find that they really help...I thought it maybe would be good if we could share some of our favorites. So here are three things I find inspirational. I hope you do too."*

*"It's easy to think that others have it easy especially with their made to order kids and feel like the grass is always greener. It's easier to say than do but I'm working on making my little patch as green as possible so that I can stop and admire it rather than looking longingly at someone else's patch. There are already times I notice theirs looking a bit rough when they are knackered and close to tears with screaming kids fighting around them".*

In addition, some women spoke of the need to "reinvent" themselves through seeking out new activities and social groups as well as finding a new sense of purpose and meaning to their life. This appeared to be a central part of the process of coming to terms with childlessness and accessing the online support community was often viewed as a first step in this process.

*"I've found it really helpful spending time with friends I'm making who are in a similar position to me and doing things I enjoy that aren't child-oriented so I give myself more of a chance to notice what's positive for me. It's more of a test faced with poster advert scenes of happy families and at those times I just have to accept it makes me feel sad".*



## Finding a Safe Haven Online

Accessing the online community appeared to play an integral role in helping this group of women cope with permanent childlessness. Through using the online community, women discovered a “safe haven” free from pregnant women and families; which was not so easy to find offline. This, coupled with the shared experiences of group members, created a unique environment in which they felt they could openly discuss their experiences and release any negative or confusing emotions surrounding infertility.

*“The online community is a life saver for me - having somewhere to ‘feel’ what I’m feeling – safely...”*

Although members of the online community were often unable to offer tangible support or advice in response to such postings, they readily provided an empathic “listening ear”. For example, women would often frame their response to messages with phrases like:

*“Wish I could say something more useful but take care and we are thinking of you” or “I’m sorry if I cannot help much but I am thinking of you. That’s the great thing about this place people really do know how hard it is.”*

The opportunity to simply vent in a supportive environment was experienced as a cathartic and empowering event. As one woman wrote:

*“I feel better already just posting and apologise for having displaced on you guys. Thank you again.”*

Receiving empathic responses from other members and reading their experiences of similar issues was also perceived as beneficial. Learning that there were others women who went through the same emotions and experiences served to validate the sometimes confusing and conflicting feelings that member’s experienced as a consequence of childlessness. Many women felt unable to talk about their infertility with friends and family, as it was felt that only people who had experienced it firsthand could fully understand their pain and anguish. Consequently, being able to connect with other women who faced permanent childlessness also helped to alleviate some of the isolation and separateness that women felt in their day-to-day lives.

*“This online community is the only place that I feel can come to where I am amongst people who truly understand and I feel able to share my difficult moments”.*

*“I have been a member of this online community for a long time and am pleased to say that time and the friendship of the members has helped heal my wounds”.*

*“I know what you mean about being on the outside looking in but with this online community I’m beginning to feel a bit more like I belong somewhere...maybe in time we can say that we are on the inside looking out”.*

As these quotes suggest, for most individuals the online community created a sense of belonging that was absent in other areas of their life. Indeed, many of the messages posted within the bulletin board conveyed a strong sense of universality and camaraderie between group members. Several members described the online community as a “family” and regularly posted messages praising one another’s coping efforts and offering words of support and encouragement.

*“I can promise you, you will get through this and live to be happy again. You’re not at all hopeless and you are a very brave lady. What I read in your post as I read in soo many of the posts on here is the human spirit kicking away under all the misery, refusing to accept the suffering and fighting to come out of the pain. Very best of luck to you and a massive hug to you”.*

*“Thank you for being brave enough to put your feelings down here. It’s true that we do feel on the outside looking in. I feel that everytime I have contact with my brother who has three children”.*

*“...here’s to all of us here. We may not be mums and das but we are aunties, uncles, step parents, doting pet parents, teachers, carers and role models to the young people in our lives...”*

The online community also appeared to play a huge part in women’s efforts to build new lives for themselves post fertility treatment. Some women actively used the online community as a way of building a new social circle for themselves. Where women were unable to meet face-to-face due to geographical distance, the bulletin board was used to strike up friendships with other regular posters. For instance, several women regularly posted off topic messages and conversed with one another about other aspects of their life.

*“I would like to meet with other members but every time there has been an event close enough for me to get to I have been working or not free to go. I live in West Essex”.*

*“I would love to exchange feelings and thoughts if you would like too. I am not living in England at the moment but can easily exchange emails and other messages”.*

*“For me it’s been really important to start building a new network of friends who are childfree...this online community is obviously a big part of that which is why as much as possible I’ve thrown myself into meeting new members and getting to know them better socially, as well knowing that I have people who understand”.*

## Discussion

The current study is one of the first to focus specifically on online communication among women facing permanent involuntary childlessness. Through a phenomenological analysis of bulletin board postings, this study provides a novel insight into the “lived” experience of individuals who access an online support community for permanent infertility. Moreover, the study demonstrates the important role that online communities can play in the lives of these individuals and in their efforts to come to terms with childlessness.

In line with previous qualitative studies with this population (Daniluk, 2001; Johansson & Berg, 2005; McCarthy, 2008; Schwerdtfeger & Shreffler, 2009; Wirtberg, Möller, Hogström, Tronstad, & Lalos, 2007), the analyzed messages show that women experienced involuntary childlessness as a major and recurring loss that pervaded all aspects of their lives; threatening their core identity and sense of self, as well as the central values and meanings that they attached to their life. One theme that was particularly strong across the messages was the sense of immense grief and loss that characterized women’s experiences of permanent involuntary childlessness. The knowledge that they would potentially never become biological mothers appeared to instigate a grief reaction akin to that of bereavement.

Kübler-Ross (1969) proposed a five stage model to describe emotional reactions to loss and the process through which individuals come to terms with the accompanying grief: Denial, Anger, Bargaining (seeking in vain for a solution), Depression, and Acceptance (adapting to the loss and planning for the future). This five-stage model has been applied to a variety of significant life events such as job loss, divorce, terminal/ chronic illness and bereavement. However, although the theory captures many of the conflicting emotions that women experience in response to infertility, as Volgsten et al. (2010) argue, the model does not adequately portray the complexities of accepting and adapting to permanent childlessness. Indeed, our findings reveal that permanent infertility was typically suffered as a recurring loss that women felt in varying intensities throughout their life. For example, some

women described times when they felt they had reached a level of acceptance, only to find the anger, grief and depression return when they were faced with an external reminder of their loss. The chronic and cyclical nature of their grief was particularly evident for women entering the “grandparent” stage of life. For these women, not becoming a grandmother like their peers was experienced as both a reminder of their infertility as well a secondary loss (i.e. that of a potential grandchild).

These findings mirror the results of an earlier qualitative study with women 20 years after unsuccessful infertility treatment (Wirtberg et al., 2007). The study found that these women were now at the age when their peers were having grandchildren and were thus having to deal with the concept of “grandchildlessness”. Taken together, these findings highlight that although permanent infertility is in many ways similar to other major life crises, there are also several marked differences in the ways in which this grief manifests itself and is experienced by women. Consequently, traditional models of grief and loss may not always be applicable when supporting women facing the prospect of permanent involuntary childlessness. In particular, it is important for counsellors and other health care professionals to be aware of the cyclic nature of women’s grief and the potential need for ongoing support throughout their lifespan.

Another dominant theme within the messages was the sense of isolation and difference that women experienced within their social networks and day-to-day lives. Unsurprisingly, the women in this study found it extremely difficult to deal with talk of pregnancy and childbearing from friends, family and colleagues and often felt the need to isolate themselves from such reminders of their own childlessness. In this context, the online community became one of the only venues in which women felt that they could “safely” communicate and connect with other women. Although similar themes have been identified in previous studies of online infertility support communities (e.g. Malik & Coulson, 2008b; Malik & Coulson, 2010a), the vast majority of people who access online infertility support communities are often pursuing some form of treatment for infertility and can thus be described as in a “not yet pregnant” state (Throsby, 2001). While some of these individuals will become pregnant and make the transition to parenthood, others will have to come to terms with permanent childlessness (Daniluk, 1997). The bonds and friendships that women form in online infertility support communities can therefore be short lived and dependent on the outcomes of their fertility treatment. Furthermore, as previous research has suggested, accessing an online infertility support community may simply serve to increase the feelings of distress and anguish that individual’s experience as they lose hope of becoming biological parents (Malik & Coulson, 2008b; Malik & Coulson, 2010b).

The findings of this study highlight the importance of also having online communities dedicated specifically to people faced with permanent infertility. As our results reveal, the ability to vent, seek support and share thoughts in a “safe” environment is perceived as a cathartic, unique and an invaluable experience, particularly for those women who are struggling to find a new sense of identity. Previous research has demonstrated that dissatisfaction with social support among individuals dealing with permanent infertility is linked to higher levels of depression, anxiety, and grief (Lechner, Bolman, & van Dalen, 2007). Consequently, being able to access an online support community to bridge gaps in offline social support can be seen as a positive coping strategy and one that should be actively encouraged by professionals involved in infertility care.

Our findings further show that moving from “trying to conceive” to permanent childlessness presents a significant threat to women’s sense of self and in particular their gender role identity. For example, through their bulletin board messages many women described instances where they had questioned their identity as a woman and the purpose of their life now that the motherhood status was denied to them. Even though these women expressed

a desire to establish a new personal identity for themselves that was distinct from motherhood, in reality many women struggled to find meaningful alternative life goals. This is perhaps unsurprising given that culturally, caring and nurturing for a child is often considered a social norm for a woman and seen as an integral part of her gender role identity (Daniluk, 1997). Hence, as evidenced in this study, the inability to conceive can carry a hidden stigma and create feelings of inferiority and being “different” (Dyer, Abrahams, Hoffman, & van der Spuy, 2002; Glover, McLellan, & Weaver, 2009; Sandelowski, 1988; Slepickova, 2009).

In a similar vein, a qualitative study by Kirkman (2003) suggested that the cultural dominance of the motherhood narrative was a significant barrier to infertile women revising their life goals. Additionally, the absence of a clear and collective narrative of the “non-mother”, further complicated women’s ability to make sense of infertility. While, our study also highlights the complex and difficult nature of women’s struggles to come to terms with childlessness, the findings suggest that the online community may go some way towards helping this group of women create a new collective narrative for themselves. The current study’s results concur with previous studies of online support, which have found that the emotional and informational support exchanged within online communities can have an empowering effect on individuals (Bartlett & Coulson, 2011; Mo & Coulson, 2010; van Uden-Kraan et al., 2008; van Uden-Kraan et al., 2009). However, the messages in this study often went beyond the exchange of simple information and support, with members actively using the forum as a venue in which they could explore new collective identities for themselves and promote one another’s self-worth and sense of purpose in life. This pattern of findings suggests that for some individuals online communities can potentially play a positive and important role in the process of coming to terms with involuntary childlessness. Further research is therefore warranted to examine the long-term outcomes of participation in an online community specifically for permanent infertility. Importantly, future research should seek to explore and compare the adjustment and journey of both women who seek support online and those women who do not.

### Limitations

The current study has a number of potential limitations that should be taken into consideration when interpreting the findings. Importantly, although the study provides rich data for understanding the challenges and issues that this particular group of women face, these findings may not be representative of how all women cope with permanent infertility. For example, very little is known about the demographic profile of members and how representative these individuals are of infertile women in the wider population. Also, it may be that those women who eventually resolve their grief discontinue their participation in the community, leaving behind those who continue to have trouble. Thus, the results may only represent the experiences of a particular subset of infertile women who are struggling to cope with infertility. In addition, the analyzed messages were only a snapshot of discussions taken from a single online community, the extent to which these messages are representative of communications in other online support communities for permanent involuntary childlessness or the same community at other times remains unclear. Future research should therefore seek to examine messages posted to multiple online support communities for permanent involuntary childlessness and over a longer period of time, in order to explore the extent to which similar patterns emerge.

It is also noteworthy that the analyzed messages were all posted by women; consequently the study does not tell us anything about the online experiences of men dealing with permanent infertility. This mirrors the results of research examining other online infertility support communities, which were also found to be dominated by women (Malik & Coulson, 2010a). However, research has shown that male partners often feel the need to take on a supportive role in the couple and suppress their own grief, both during and after unsuccessful infertility treatment

(Malik & Coulson, 2008a; Volgsten, Svanberg, & Olsson, 2010). In this context, online communities could provide a welcoming environment in which men can anonymously and safely express their grief surrounding unresolved infertility. Future research should therefore seek to understand the male partner's perceptions towards online infertility support communities, in order to identify whether anything can be done to encourage men to make use of this novel source of support.

### Practice Implications

The findings of this study highlight the potential valuable role that online communities can play in helping women come to terms with permanent involuntary childlessness. Individuals struggling to cope with the prospect of permanent infertility can therefore be encouraged to access and seek support online. Equally, given the increasing popularity and accessibility of the Internet, it is important for health care professionals to ensure that there are adequate online support resources available to cater specifically for the needs of women with permanent infertility. Women should also be made aware that not all online infertility communities will necessarily meet the support needs of women facing permanent childlessness.

More broadly, the results of this study point to the need for health care professionals to be aware of the complex and recurring nature of infertility grief. Individuals terminating fertility treatment should therefore be given details of available counseling and support services and encouraged to access these as and when they feel the need to. In particular, it is important to ensure that women are provided with the resources and support to help them deal with difficult situations (e.g., the workplace, family events, etc.) and build their self-esteem.

### Conclusions

In summary, this study provides a novel insight into communication within an online support community specifically for permanent infertility. The findings highlight the powerful and sometimes conflicting emotions experienced by women accessing the online support community and the cyclic nature of their grief. For this group of women the struggle to come to terms with their loss, find a new identity and sense of self-worth seemed to be key driving factors pushing them to seek consolation and support online. Importantly, our results suggest that the online community played a pivotal role in empowering these women to move on with their lives and come to terms with infertility, through providing them with a unique source of emotional support and a comfortable, anonymous environment in which they could make sense of their feelings free from reminders of pregnancy.

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