The experience of spontaneous pregnancy loss for infertile women who have conceived through assisted reproduction technology

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BACKGROUND: The purpose of this qualitative, phenomenological study was to explore the subjective experiences of infertile women who conceived through the use of assisted reproduction technology—ovarian stimulation, intrauterine insemination or IVF—only to lose their pregnancy at 2–16 weeks gestation.

METHODS: Ten women participated in in-depth, tape-recorded interviews. After initial content analysis, a phenomenological analysis was undertaken to identify common themes in the participants’ stories.

RESULTS: Nine common themes were identified. These included: a sense of profound loss and grief; diminished control; a sense of shared loss with their partners; injustice or lack of fairness; ongoing reminders of the loss; social awkwardness; fear of re-investing in the treatment process or a subsequent pregnancy; the need to make sense of their experience; and feelings of personal responsibility for what had happened.

CONCLUSIONS: Participants’ experiences of pregnancy loss were embedded within their experiences of infertility and medical treatment, and shaped by their significant investment in having a child. A significant feature was their marked ambivalence regarding future reproductive options after their pregnancy loss, reflecting a unique overlay of prominent anxiety in their grief experience.

Key words: assisted reproduction technology / grief / miscarriage / spontaneous pregnancy loss / infertility

Background

The experience of miscarriage after conception through assisted reproduction technology (ART) is an area of research that has yet to be explored in depth. Two distinct bodies of literature inform our current understanding of this complex experience—research examining the psychosocial effects of infertility and medical treatment (Covington and Burns, 2006) and research focused on understanding the experience of unintentional pregnancy loss (Peppers and Knapp, 1980; Glazer, 1997; Gray and Lassance, 2003; Adolfsson et al., 2004; Bennett et al., 2005; Keefe-Cooperman, 2005). Infertility and unintentional pregnancy loss on their own are associated with considerable grief, loss and intra- and interpersonal distress. What has yet to be determined is the impact of pregnancy loss for infertile women following conception through ART.

The experience of miscarriage is seen to be moderated by several factors, including the degree of prenatal attachment, investment in the role of mother and previous pregnancy loss history (Klaus and Kennel, 1976; Goulet et al., 1998; O’Leary, 2004; Bergner et al., 2008). Of key relevance to this topic is the process that infertile patients go through in their attempts to become pregnant, many of which may magnify these factors. For example, it has been suggested that ultrasound monitoring during fertility treatments can enhance early prenatal attachment (Seibel and Levin, 1987; Sandelowski et al., 1990; Glazer, 1997; Bateman-Cass, 2000; Pretorius et al., 2005). Medical treatments and monitoring disrupt women’s daily lives and routines as they become focused on their bodies and on securing a viable pregnancy. Their desire to become mothers often increases with repeated treatment failures, further intensifying their investment in having a child (Sandelowski et al., 1990; Daniluk, 1997). In addition, many infertile women experience ongoing, chronic grief, related to a long history of inability to conceive after attempting to do so for months and often years (Zucker, 1999; Kirkman, 2003; Johansson and Berg, 2005). Entering repeated treatment cycles leads to a recurring
pattern of expectation, anxiety, and grief that accompanies the loss of hopes and dreams when treatment cycles fail (Glazer, 1997).

This study was undertaken to explore the combined impact for infertile women of experiencing the loss of a pregnancy following conception through ART. The question that guided this inquiry was: ‘What is the meaning and lived experience of miscarriage for infertile women who have conceived with the assistance of medical intervention?’.

Materials and Methods

Both Leedy and Ormrod (2005) and Patton (2002) recommend the use of qualitative methodology in areas of inquiry where there is little prior research available, and where there is a need for an initial systematic and explorative description, interpretation and evaluation of a phenomenon. Because of the lack of research on the phenomenon of miscarriage following ART, this study employed a qualitative, phenomenological approach.

Ethical approval of the research protocol was received from King’s University College, London, ON, Canada. Participants were recruited through the staff members of a privately-operated Canadian infertility clinic, and through notices posted by fertility service providers, self-help organizations and on Web-based infertility bulletin boards. Twenty-seven women replied to the announcement. Women who met the inclusion criteria of having experienced a miscarriage following ART treatment and being fluent in English were waitlisted for participation in the study. Data saturations were achieved after 10 interviews at which point no new themes or issues arose in the interviews. Interviews took place over a 3-month period of time in the spring of 2008. The age range of the participants was between 28 and 38 years old (mean of 32.2 years). The length of time in active infertility treatment for the participants varied from 2 to 7 years (mean of 3.8 years) (Table I). The time of gestation prior to the loss ranged from 2 to 16 weeks. Four participants had multiple losses, with one participant having two pregnancy losses, two participants experiencing three losses and one participant having four losses. The time from the interview to the last loss varied from 3 months to almost 3 years.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age (years)</th>
<th>Length of treatment</th>
<th>Type of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>34</td>
<td>5 years</td>
<td>IUI, IVF</td>
</tr>
<tr>
<td>02</td>
<td>30</td>
<td>4 years</td>
<td>IUI, IVF, FET</td>
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<tr>
<td>03</td>
<td>33</td>
<td>5 years</td>
<td>Medication², IUI</td>
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<tr>
<td>04</td>
<td>30</td>
<td>7 years</td>
<td>Medication, IUI</td>
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<tr>
<td>05</td>
<td>30</td>
<td>3 years</td>
<td>Medication, IUI</td>
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<tr>
<td>06</td>
<td>33</td>
<td>2 years</td>
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<td>07</td>
<td>31</td>
<td>2 years</td>
<td>IUI</td>
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<tr>
<td>08</td>
<td>38</td>
<td>4 years</td>
<td>Medication, IUI</td>
</tr>
<tr>
<td>09</td>
<td>35</td>
<td>3 years</td>
<td>IUI, IVF</td>
</tr>
<tr>
<td>10</td>
<td>28</td>
<td>3 years</td>
<td>Medication</td>
</tr>
</tbody>
</table>

IUI, intrauterine insemination; FET, frozen embryo transfer.

¹Length of treatment indicates time in active treatment for infertility, through medication alone or in combination with procedures.

²Use of any medications to assist with ovulation or infertility treatments.

Results

Cross-analysis: what did and did not help

Participants found talking with others who had been through the experience of infertility and/or miscarriage to be particularly helpful in normalizing their feelings and reactions. Supportive friends and family members were valued for their presence and willingness to listen and provide tangible forms of support (e.g. accompanying them to clinic appointments), and for not providing advice. The women were grateful when medical staff demonstrated their care and concern, responding quickly to phone messages, keeping them...
informed of the process and supporting their choices. Some participants found rituals helpful in coping with their pregnancy loss(es), underscoring how naming and speaking about their unborn child served to make their loss more tangible and validate their grief. Several of the women talked about the importance of having a plan for what they would do next as a way to cope with treatment and maintain hope.

Things that added to their distress included insensitive comments that diminished the extent of the participants’ losses and distress (e.g. being told that they were ‘barely pregnant’), and being labeled as a difficult or demanding patient when they expressed their dissatisfaction with their medical treatment. Participants also reported that pressure from family members to get on with trying to conceive again, probing questions from individuals not in their close circle of friends or family, and social pressures regarding the importance of being a mother, added to their distress.

Emergent themes

Nine common themes in the participant’s experiences of miscarriage following medical treatments were identified through the process of phenomenological reduction. They are discussed in detail below, in no particular order, supplemented by quotes from participants.

**Sense of profound loss and grief**

The women described feeling overjoyed when they learned that they were pregnant and shock, disbelief and a profound sense of despair and sadness when they subsequently lost the pregnancy. The women described feeling ‘completely broken’, ‘devastated’, ‘hitting rock bottom’ and ‘emotionally bankrupt’—given what they had to go through to get pregnant and the possibility that they may never realize their dreams of becoming a mother. The participants reported being highly invested in their pregnancy, the loss of which resulted in profound grief irrespective of the gestational age of the baby when it was lost. For some, the grief was compounded by multiple pregnancy losses. On top of all the losses associated with being infertile, for some of these women their miscarriage was a ‘breaking point’ in their efforts to conceive, resulting in some abandoning their medical treatment efforts.

**Sense of having no, or very limited, control**

The participants frequently reported their distress at being powerless to ensure that they would be able to realize their dream of carrying a viable pregnancy to term. Given their fertility difficulties and the need for medical intervention to become pregnant, by the time they finally conceived many of the participants already had considerable anxiety about their bodies and their inability to control outcomes. Experiencing a miscarriage compounded their sense of powerlessness, of ‘doing absolutely everything’ and still ‘having no control over the outcome, whether that outcome is getting pregnant or staying pregnant’. To their further dismay the participants learned that adoption, their only other path to mothering, involved a highly bureaucratic and intrusive process whereby they would once again have little control over the outcome.

**Sense of shared loss with their partners**

All of the participants spoke about their partner’s experience of infertility treatment and/or the loss of the pregnancy. Most participants identified their partner as their main and most significant source of support throughout their infertility and pregnancy loss ordeals, with great appreciation being expressed for the fact that they were ‘in this together’. Reflecting the sense of shared loss, the participants used the word ‘we’ when referring to being pregnant and experiencing a miscarriage. The participants recognized that their partner ‘went through a grieving period as well’ whereas also acknowledging gender differences in their partner’s expression of grief. The women also realized that they could not expect their partners to be their sole source of support, given that they too were grieving the loss of their hoped-for child.

**A sense of injustice and lack of fairness**

For many participants, this experience was the first time that they came to a realization that their lives were not unfolding as they had planned and expected. They could not comprehend the injustice of having to deal first with infertility, and then subsequent pregnancy loss. As reflected in the words of one participant: ‘loss is terrible when it happens to people who have tried so hard’. Some participants described feeling that they were being tested either by God or by

<table>
<thead>
<tr>
<th>Participant</th>
<th>Treatment resulting in pregnancy</th>
<th>Gestation (weeks)</th>
<th>Number of pregnancy losses</th>
<th>Most recent loss (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>IVF</td>
<td>16</td>
<td>1</td>
<td>24</td>
</tr>
<tr>
<td>02</td>
<td>IVF</td>
<td>7</td>
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<tr>
<td>03</td>
<td>IUI</td>
<td>12,6,2</td>
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<tr>
<td>04</td>
<td>IUI</td>
<td>2</td>
<td>1</td>
<td>14</td>
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<tr>
<td>05</td>
<td>Medication; spontaneous</td>
<td>13, 4</td>
<td>2</td>
<td>8</td>
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<tr>
<td>06</td>
<td>IUI</td>
<td>2</td>
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<tr>
<td>07</td>
<td>IUI</td>
<td>9</td>
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<td>10</td>
<td>Medication</td>
<td>8</td>
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1Pregnancy loss at 2 weeks indicates positive pregnancy test via serum beta-HCG 2 weeks after insemination, but drop in level afterwards to zero, indicating early pregnancy loss.
some force in the universe to see if they were really worthy of having children. Others expressed frustration and anger at those who claimed to understand their feelings even though they had never experienced infertility treatments and pregnancy loss. Many reflected on the sad irony of their situation when compared with women who chose to end an unplanned and unwanted pregnancy. In struggling to accept this apparent lack of justice and fairness, the participants had to reconcile themselves to the inexplicability of their multiple losses.

Ongoing reminders of their loss
All participants were acutely aware of when their child would have been born, had they not miscarried. Even those who had gone on to become mothers described feeling ongoing sadness and loss around the anniversary of their due date, being acutely aware of how old the baby they had lost would have been had they not miscarried. During these times they largely grieved in silence and isolation, feeling that others expected them to have put the loss behind them and gotten over it by now.

Feelings of social awkwardness
The social isolation that participants experienced although undergoing infertility treatments was even more pronounced after their pregnancy loss. The women felt that friends and family members ‘felt awkward’ around them or ‘avoided them altogether’ because they did not know what to say following the miscarriage. Participants also found being around children or pregnant friends even more difficult following their pregnancy loss and, as a result, they avoided social situations that included young children that served to exacerbate their sense of loss. They also became less tolerant when faced with intrusive comments and questions about their childless parental status.

Fear of investing in the treatment process or the pregnancy
Having struggled with infertility, participants had come to the realization that bad things can and do happen, and with that the possibility of more pain always loomed on the horizon, even as they tried to maintain the hope of a day becoming mothers. The women talked about the need to emotionally ‘pull back’ and not get too invested in the process or outcome of treatments. Frequently in the interviews, participants would mention that they were ‘hedging’ against further disappointment and negative outcomes. On the basis of their experience of pregnancy loss, the participants felt they could not fully invest themselves emotionally in a positive pregnancy test result and potential motherhood, until they were through the pregnancy and had their baby in their arms. Some spoke of actually experiencing some relief after a negative pregnancy test, in that they would not have to live through nine months of fear and uncertainty.

Do I even want it to come back positive? Then I’d have to deal with the next nine months wondering if I’m going to miscarry again—do I just want not to be pregnant? When it came back that we weren’t pregnant, it was almost a big relief.

The need to make sense of their experience
Many of the women shared at length the ways they attempted to draw some meaning from having lived through infertility treatments and subsequent pregnancy loss. Some reached out to help others who were going through something similar, although others indicated that their decision to participate in the study was based on their hope that in sharing their stories others might be helped. Several participants described writing in journals, scrapbooking and one wrote a book about her experience. There were numerous ways that they talked about how their experiences left them with the realization that although they had indeed been through an awful ordeal, some gains had been realized. These included an increased capacity for empathy, greater sensitivity towards others who experience challenging life situations, and a sense that they are a better person as a result of what they have been through. Many concluded that their experiences of infertility and pregnancy loss have left them better prepared and more able to cope with unexpected and painful life experiences in the future.

A sense of responsibility
Paradoxically, although participants acknowledged that they had little control over their fertility and ability to carry a pregnancy to term, at some level they also felt responsible for not being able to prevent the loss of their pregnancy. For example, one participant attributed her miscarriage to the stress that she and her husband were enduring at that time, although another blamed herself for being too active during the time she was pregnant. In the words of one participant: ‘I really felt like it was my fault. So it was this fleeting kind of ungraspable feeling that somehow I was responsible’. Even in cases where there was no medical explanation to account for their infertility or pregnancy loss, several participants questioned whether their thoughts or actions inadvertently caused or contributed to their ‘inability to conceive’ and subsequent miscarriage(s).

Discussion
Feelings of grief, injustice, loss of control, personal accountability and the questioning of beliefs are widely cited in the infertility literature (Daniluk, 1997; Zucker, 1999; Eriksen, 2001; Gerrity, 2001; Wischmann et al., 2001; Hart, 2002; Merari et al., 2002) and in the literature on women who miscarry (Lee and Slade, 1996; Swanson, 1999; Klier et al., 2002; Brier, 2004; Bennett et al., 2005). These feelings and themes were also very prominent in the stories of the women in this study. The losses already associated with infertility seemed to be compounded for these women by their experience of miscarriage. For most of the participants, the loss of their pregnancy was the culmination of many losses that had been encountered during their journey through infertility treatment. They experienced considerable anxiety when faced with the prospect of re-entering treatment only to potentially face another miscarriage. Consequently, for some participants the miscarriage marked the end of their pursuit of medical treatment and an investment in pursuing adoption.

Anxiety is a commonly reported emotional response in the infertility literature, related to managing the effects of the treatments and the uncertainty of the outcome of the treatments (Zucker, 1999; Beaurepaire et al., 1994; Gerrity, 2001; Chen et al., 2004). Anxiety is also a common response during pregnancy for fertile women who have experienced a miscarriage, with the anxiety described in subsequent pregnancies being associated with the fear that another pregnancy loss might occur (Cordell and Thomas, 1997; Cote-Arsenault, 2001; Brier, 2004; O’Leary, 2004; Bennett et al., 2005). Consistent with the literature on pregnancy following perinatal loss (Cote-Arsenault, 2003; O’Leary, 2004; Bergner et al., 2008), anxiety was compounded
for the women in this study during subsequent treatment cycles, leading to a desire to shield themselves from the potential pain of subsequent losses. Even the participants who were pregnant at the time of the interviews had not allowed themselves to do the things associated with prenatal attachment, such as decorating the nursery, for fear that they might lose the pregnancy.

It is important to note that women in this study who miscarried in their first trimester reported similar reactions of women with second and third trimester losses (Lumley, 1980; Stanton and Golombok, 1993; McMahon et al., 1997; Hjelmstedt et al., 2006; Sedgmen et al., 2006). It is possible that the constant cycle monitoring and repeated ultrasound testing heightens the significance of a pregnancy and subsequent pregnancy loss even at the earliest stage of gestation for women who have endured infertility and medical treatment. Also, the chronic sorrow accompanying the multiple losses and failures associated with infertility may leave women particularly vulnerable to extreme grief when a pregnancy is lost. In addition, the descriptions of grief and the emotionality during the interviews did not vary between the participants whose loss was a few years prior to the interview versus those whose losses were more recent. Of significance is that most of the participants referred to the loss of their baby, and not the loss of a fetus or the loss of a pregnancy—reflecting a particularly high level of investment in the pregnancy and early prenatal attachment (Cranley, 1981). Further underscoring the significance of their loss, some participants held rituals or services marking the loss of their child and acknowledging the significance of their loss.

**Implications for practice**

Consistent with findings of a recent Dutch study of 1499 infertile women (Mourad et al., 2009), the participants in this study emphasized the important role of the compassionate and supportive treatment they received from the members of their health care team in their efforts to cope with their infertility and their pregnancy loss. This finding underscores the need for, and importance of support from health care practitioners, throughout the treatment process and following even a very early pregnancy loss.

Another aspect of this study that is applicable to clinical practice is the description by the participants of the important role of their partner’s support in coping with infertility, medical treatment and the loss of their pregnancy—despite dealing with their own feelings of disappointment and loss. Consistent with this finding and with the literature (Daniluk, 1991, 1997; Gilbert and Smart, 1992; Huttu, 1992; Epstein and Rosenberg, 1997; Conway and Graeme, 2000; Lang et al., 2003; Newton, 2006) it is important in clinical practice that male partners are invited to participate in all aspects of medical treatment and decision-making, validated in their experience of loss and provided with psychosocial support following the loss of a pregnancy.

Participants repeatedly described the additional pain they experienced when individuals minimized or failed to recognize the significance of the many losses they had endured as a result of the treatments and the miscarriage. ‘It is important to name and validate the many layers of loss experienced by infertile women who miscarry after ART treatment’. Validation of the loss(es) is cited by Doka (1989) as the first step in offering support to individuals who have experienced grief which is disenfranchised, or not recognized socially for its significance. Couples can be ‘encouraged to create a ritual to validate their loss and begin to find some meaning in the experience’ (Bowlby, 1980; Parkes and Weiss, 1983; Stroebe, 2002).

During the interviews, it became clear that participants needed the mental health professionals with whom they worked to ‘have a good working understanding of fertility treatments and procedures, common medications and their side effects and the terminology used within this medical specialization’. It is also important for counselors to be aware of the various interventions that may be offered to women when they are told that their pregnancy is not viable. A list of qualification guidelines for mental health professionals in reproductive medicine can be found in Covington and Burns (2006).

In comparison to grief with other types of losses, the participants in this study struggled with both the chronic, ongoing nature of their losses related to their infertility, as well as the loss of their pregnancy, leading to an ongoing overlay of significant anxiety and sorrow for most of these women. Their pregnancy loss represented not just an ending but the start of the treatment process if they wanted to try to become pregnant again at a time when their emotional reserves were severely depleted. Helping professionals need to be ‘cognizant of this overlay of chronic sorrow and acute grief’ and of the toll this takes on infertile women who experience miscarriage following medical treatment. In general, grieving individuals improve over time after a loss. However, this may not be true for women who, although grieving the loss of a pregnancy, must undergo further fertility treatments in their efforts to continue to pursue their dream of bearing a child.

The women in this study also emphasized the need to have a concrete plan of action in place to ensure that they would become mothers, whether through adoption or further medical treatments. These plans appeared to help channel their anxiety into action, and served to enable a sense of agency. Consistent with recent literature on couples who face reproductive losses (Applegarth, 2006; Burns and Covington, 2006; Kraaij et al., 2008), it is important to ‘adopt a flexible approach, allowing the expression of emotions although helping clients build a plan for treatment and parenthood decisions that will help ensure an acceptable future’.

**Study limitations**

Given that 8 of the 10 participants in this study received care in the same fertility clinic some aspects of the findings may not apply to women whose treatment experiences differ based on their medical care providers. Also, given the sample size and demographics, more research is required to determine the empathic generalizability of these findings—the extent to which the findings resonate with, and reflect, the experience of miscarriage for women following ART treatment. This study points to the potential significance of infertility and medical treatment as a moderator of both prenatal attachment and profound grief for women who miscarry following fertility treatments. Comparative studies of infertile women who experience pregnancy loss after conceiving using ART versus their fertile counterparts who miscarry may add important insight into if, and how, the experience of pregnancy loss differs for infertile women who have already had to cope with multiple losses throughout their experience of infertility. Given that the majority of the women in this study went on to become mothers, future research could add to and extend our understanding of the experience of miscarriage following infertility treatment, for women who ultimately are unable to make the transition to motherhood.
Authors’ Roles

D.L.H. was the primary researcher for this study which was her doctoral dissertation. J.C.D. was the methodologist on this dissertation and contributed substantively to the study design, analysis and infertility content. She also was involved in the preparation of this manuscript.

References


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