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# Journey Interrupted: A Phenomenological Exploration of Miscarriage

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# Journey Interrupted: A Phenomenological Exploration of Miscarriage

#### Abstract

Background: Miscarriage is a significant life event that impacts occupational performance, identity, and competence and that influences perceptions of motherhood. Because of the lack of social rituals often attributed to the death of a loved one, miscarriages may result in disenfranchised grief, which impedes coping.

Methods: This phenomenological study explored the impact of miscarriage on relationships, perceptions of motherhood, and the meaning of occupation in the context of grief. Data was collected through semi-structured interviews (N = 4) and completion of a brief demographic questionnaire. The interviews were digitally recorded, transcribed verbatim, and reviewed to ensure accuracy. Using inductive thematic analysis, the first author identified initial codes, collated the codes into preliminary themes, and then reviewed, further analyzed, and refined the themes.

Results: Three overarching themes were identified: (a) the journey: ambiguity, vulnerability, and the trauma of a miscarriage; (b) seeking acknowledgement and validation of loss: impact on relationships; and (c) occupational engagement: evolving roles and perspectives.

Conclusion: The findings of this study illustrated the complexity of the lived experience of miscarriage and highlighted the significant impact of miscarriage on self-identify, relationships, and the complex role of occupation in the context of bereavement.

#### Comments

Disclosure Statement: The authors report no conflict of interest. The authors presented the findings from this study at the 2017 American Occupational Therapy Association Annual Conference in Philadelphia, PA. The authors alone are responsible for the content and writing of this manuscript.

# Keywords

motherhood, occupation, pregnancy complications, grief, bereavement, qualitative studies

## **Cover Page Footnote**

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## Credentials Display

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Maternity is a state of being. Expanding stomachs signify outwardly to the world the enormity of the physical and emotional transitions women experience as pregnancy progresses. In a sense, changes in outward appearance serve as an illustration of the journey toward motherhood. However, for many women, the journey toward motherhood is tragically and inexplicably interrupted by a miscarriage. An unexpected loss during pregnancy creates an occupational void (Harvey, Moyle, & Creedy, 2001). A miscarriage is often incorrectly believed to be a solitary moment of loss. However, the physical, emotional, and psychological ramifications of a miscarriage may extend across a lifetime (Cahill, 2015).

Miscarriage is defined as the unexpected uterine loss of a fetus weighing less than 500 g or prior to the 20th week of gestation (Davidson, London, & Ladewig, 2016). Globally, an estimated one in four pregnant women experiences the inexplicable loss of a child through a miscarriage (Nikčević, 2003; Nikčević, Kuczmiercyzk, & Nicolaides, 2007; Séjourné, Callahan, & Chabrol, 2010). Of those women, an estimated 50% experience psychological morbidity in the weeks and months after a pregnancy loss (Lok & Neugebauer, 2007). Psychological morbidity may include symptoms of depression, anxiety, and grief (Frost, Bradley, Levitas, Smith, & Garcia, 2007; Nikčević, 2003; Nikčević et al., 2007; Robinson, 2014; Séjourné et al., 2010), or expressions of anger, guilt, and self-blame (Nikčević, 2003). Feelings of self-betrayal (Miller, 2015), isolation, loneliness, fear, panic, lack of understanding (Harvey et al., 2001), and failure (Ockhuijsen, van den Hoogen, Boivin, Macklon, & de Boer, 2014) are prevalent.

A miscarriage is a significant life event that dramatically impacts one's self-identity, sense of competence, and sense of fulfillment (Frost et al., 2007). For women without children, the often eagerly anticipated identity and occupation of "mother" is lost during a miscarriage. In fact, women reported that they often felt forgotten as mothers and "abandoned between the world of motherhood and non-motherhood" (Harvey et al., 2001, p.11). A miscarriage represents multiple losses: loss of control, loss of self-esteem, loss of a child (perceived to be real or potential); and the loss of hopes, dreams, and expectations for the future (Adolfsson, Larsson, Wijma, & Bertero, 2004; McCreight, 2008). A lack of understanding and support of the invisible loss from a miscarriage contributes to feelings of social isolation and self-blame, and a sense of spoiled identity (Frost et al., 2007; McCreight, 2008).

The innocence of childbearing is forever altered, leaving women to face a newfound vulnerability and feelings of failure (Harvey et al., 2001). Miller (2015) reported that women often lacked confidence in their ability to have children after a miscarriage or pregnancy loss. A preoccupation with achieving motherhood (Frost et al., 2007) or feelings of jealousy and guilt when interacting with pregnant women or with babies also occurred (Ockhuijsen et al., 2014). Furthermore, the impact on subsequent pregnancies is worth noting. The attribution of personhood to a previous loss may negatively influence emotional attachment and increase anxiety in a subsequent pregnancy due to fear of recurrence (Wood & Quenby, 2010). Gaudet, Séjourné, Camborieux, Rogers, and Chabrol (2010) discussed the fear, insecurity, hypervigilance, anxiety, and need for control that often occurs with pregnancy after loss. Challenges also occurred in the emotional investment and intensity of attachment to a new baby due to fear of facing another loss (Gaudet et al., 2010). A miscarriage creates an emptiness that is not alleviated by another pregnancy or the presence of another living child (Adolfsson et al., 2004).

Lok and Neugebauer (2007) reported that "studies show that early pregnancy loss can produce a grief reaction as substantial as that to loss of any loved one" (p. 231). However, the ambiguity of miscarriage contributes to disenfranchised grief as the lack of societal recognition and support does not

correspond to the intensity of the emotional response to the physical and emotional loss (Lang et al., 2011; Mulvihill & Walsh, 2014; Rowlands & Lee, 2010). Women often have difficulty moving through the bereavement process and engaging in typical coping behaviors after a miscarriage (Broquet, 1999; Lang et al., 2011; Mulvihill & Walsh, 2014). Expectations of unconditional support by loved ones are often not met and negatively impact the grieving process (Rowlands & Lee, 2010). Difficulties coping with the mental, physical, psychological, and societal ramifications of a miscarriage may impact activities or daily living and engagement in meaningful activities (Lok & Neugebauer, 2007).

Rather than considering the uniquely individual implications that occur during the loss of a baby, many people often view miscarriage simply as an unfortunate outcome of pregnancy (Frost et al., 2007) or as a medical event (McCreight, 2008). Findings illustrate medical management of physical and emotional needs are inadequate during and after a miscarriage due to insensitive comments by medical staff, a lack of empathy, and poor educational resources, all of which may intensify parental grief (Lang et al., 2011; Rowlands & Lee, 2010). Factors leading to inadequacies in medical care include a lack of training, time constraints, and perceived discrepancies between medical staff in regard to the significance of loss (Olson, 2013). Women's feelings of vulnerability may also amplify perceptions of negative experiences, impede efforts to cope, and put health and well-being in jeopardy (Lang et al., 2011). As a result, women are often left attempting to navigate the tragic experience of a miscarriage while simultaneously wondering why there is a lack of support and acknowledgement from loved ones and health care providers (Harvey et al., 2001).

To promote and sustain the well-being of women who have experienced a miscarriage, health care professionals, families, and community members must view miscarriage as a personal and significant experience that requires compassionate and timely support (McCreight, 2008; Olson, 2013). Parents who have experienced a miscarriage should be considered a vulnerable population with specific needs for improved physical, psychosocial, emotional, and spiritual resources (Olson, 2013; Slootjes, McKinstry, & Kenny, 2016).

Occupation may be viewed as an intermingling of our desire to "do" (occupational performance); our ability to "be" (occupational identity); and the lived experiences, skills, and talents that shape what we "become" (occupational competence) to address our social, mental, physical, and spiritual needs successfully (Bar & Jarus, 2015; Wilcock, 1999, 2005). The occupation of "mother," held by 81% of American women, is a dynamic and ever-evolving occupation that is both personally and socially constructed (Bar & Jarus, 2015; Cronin, 2004). The transition to "mother" is a significant event with physiological, emotional, spiritual, and psychosocial changes (Slootjes et al., 2016). Planning for the future roles and responsibilities of motherhood is an exciting aspect of early pregnancy and influences transformation in self-identity and competence (Adolfsson et al., 2004; Horne, Corr, & Earle, 2005). Psychosocial and emotional challenges during this perinatal transformation may result in anxiety, depression, and posttraumatic stress disorder, and it may negatively impact self-identity and self-efficacy (Pizur-Barnekow & Erickson, 2011; Slootjes et al., 2016).

Occupation is also all-encompassing and often underappreciated, with focused consideration of those little moments that may seem mundane, but which are the underlying foundation to a life well-lived. Engagement in meaningful and purposeful activities, or occupations, strengthens our hold on life and positively impacts health and well-being (American Occupational Therapy Association, 2014; Bar & Jarus, 2015; Hoppes, 2005).

However, grief and loss disrupt our participation in normal routines and may influence our perception of self-identity and self-worth (Frost et al., 2007; Hoppes, 2005). In their autoenthnographic research, Forhan (2010) and Hoppes (2005) discussed the occupational responses to loss (occupational maintenance, occupational dissolution, occupational ambivalence, and occupational resolution) and the subsequent implications for occupation in the context of bereavement.

A unique power lies in the study of occupation to understand the significance of the complex and/or mundane activities that contribute to our health and happiness (Wilcock, 2005). Despite the focus on the mental health ramifications of a miscarriage, there is a paucity of research examining the influence of a miscarriage on relationships, perceptions of motherhood, and the role of occupation during this complex event of bereavement. This phenomenological study sought to understand the lived experience of women who are coping with an unexpected pregnancy loss in order to fill gaps in current insights and studies related to the influence of a miscarriage on relationships, perceptions of motherhood, and the meaning of occupation in the context of grief.

Encouraged by the autoethnographic research conducted by Forhan (2010) and Hoppes (2005) on the context of occupation in the event of bereavement, this study also sought to study more closely occupational responses to loss and identify potential implications for occupational therapists to proactively facilitate navigation of grief across the continuum of age or diagnoses. Further examination of a miscarriage as a life-shaping event has the potential to influence program development with more comprehensive and occupation-focused resources for women navigating pregnancy loss. Therefore, this study addressed the following research questions:

- 1. What is the lived experience of women who are coping with a miscarriage?
- 2. In what way does a miscarriage impact relationships with friends and family?
- 3. How does a miscarriage impact perceptions of motherhood?
- 4. In what way does a miscarriage influence occupational roles and routines?

### Method

This qualitative study used a phenomenological approach to provide an intimate exploration of the lived experience of a miscarriage. The Institutional Review Board of Creighton University approved this study, and all of the informants provided informed consent.

## **Informants**

To be considered for inclusion in this preliminary study, women were required to be between 25 and 45 years of age, to be proficient in the English language, and to have a personal history of at least one miscarriage prior to 20 weeks' gestation in the past 5 years. Criteria for exclusion included women whose miscarriage occurred while under a physician's care after an assisted reproductive procedure, such as intrauterine insemination or in vitro fertilization, and women who were diagnosed with a chronic mental health disorder or a chronic illness prior to the miscarriage. The selection criteria of this study were purposely designed to realistically narrow recruitment criteria while still providing an opportunity to recognize the individuality in each loss or journey toward motherhood. The authors did not intend for this research study to place a greater importance on a specific time frame of loss or method of conception.

## **Interview Guide**

The first and second authors developed the interview guide to further investigate and analyze points of reflection on miscarriage (Patton, 2015). A literature review directed the initial draft of the interview guide. An expert panel of two occupational therapy researchers and one bioethicist reviewed

the interview guide and provided feedback to ensure content validity. To acknowledge the individuality inherent in each miscarriage experience and to ensure the direct correlation of the interview questions to the research inquiry, the interview guide was further reviewed by a panel of three women with personal experiences of miscarriage. The first author provided each woman with a copy of the research purpose statement, the research questions, and the interview guide and sought feedback on the clarity and relevance of the interview questions. This panel of three women provided insight into the validity and relevance of the questions in the interview guide and generated possible probing questions to acknowledge and validate the individuality of each informant's experience with miscarriage (see Appendix).

# **Procedures**

Due to the intimate nature of miscarriage, the researchers used snowball sampling to allow for recruitment of informants with greater sensitivity and respect (Portney & Watkins, 2015). To mitigate the risk of coercion, the researchers posted a recruitment letter describing the study on social media forums and sent the recruitment email to individuals in personal and professional networks. These networks included family, friends, clergy, local miscarriage and pregnancy loss support groups, internet miscarriage support forums, and referrals from health care providers, such as mental health professionals, obstetricians, gynecologists, and midwives. Women interested in participating or learning more about the study contacted the first author for additional information. A small cohort of four women was selected as the target enrollment for this study. All of the informants had a history of multiple miscarriages and three of the four informants had at least one living child at the time of the interview.

Interviews were conducted via telephone by the first author and ranged in time from 49 to 73 min. The informants completed a brief demographic questionnaire (see Table 1). Semi-structured interviews were the primary source of data collection and were digitally recorded. The interviews used a conversational approach to build rapport as well as a set of open-ended questions to guide the interview flow. The informants discussed each miscarriage experience chronologically and offered reflections on loss, pregnancy after loss, and relationships with living children as relevant to their personal journey toward motherhood. Additional probing questions were asked during the interview to clarify topics and to ensure the interview accurately captured each informant's personal miscarriage experience.

# **Data Analysis**

Braun and Clarke's six phases of thematic analysis guided the data analysis process (2006). The first author transcribed each interview transcript, thus allowing an opportunity to gain greater familiarity with the interview data. The transcripts were then read and reread with comparison to the original interview digital recording to ensure accuracy (Phase 1). Initial thoughts and reflections on each interview were documented during this time of immersive reflexivity. Compelling quotes and data extracts were marked for further reflection and analysis.

Phase 2 involved coding line-by-line to generate initial codes in the data item (individual interview) and then across the data set (all four interviews) (Braun & Clarke, 2006). Care was taken to identify significant statements regarding nuance and meaningful implications. Initial codes included frequently used words, such as journey, trauma and traumatic, vulnerability, validation, failure, fertility, taboo, anxiety, waiting, miscarriage, self-identity, motherhood, disconnect, education, and relationships. The first author then reviewed the entire data set, searching for patterned commonalities and differences.

Codes were collated into potential themes, such as miscarriage experience, relationships, perceptions of motherhood, occupation, trauma, validation of loss, and self-identity (Phase 3). These potential themes were then reviewed and refined to assess accurate reflection of data and thematic analysis in relation to coded extracts and the entire data set (Phase 4) (Braun & Clarke, 2006). After further analysis and review, three overarching themes were identified and considered for inclusion in the research manuscript, which accurately portrayed the overall story and combined lived experience of the four women interviewed (Phase 5). Phase 6 included writing this report.

#### **Trustworthiness**

To establish trustworthiness, the authors employed member checking, reflexivity, and a thick description of the research process (Curtin & Fossey, 2007). The first and second author kept a journal throughout the research process to document decisions made during the analysis process to support researcher reflexivity. Member checking of the completed transcripts and the final manuscript occurred via email with all four of the informants to ensure thematic consistency of the results with shared interview perspectives. Finally, the authors provided a detailed description of the process in this report and in the journals.

Table 1 provides relevant demographic data about the relationship status and pregnancy experiences of the four informants. All of the informants were assigned pseudonyms to ensure confidentiality of personal narrative used in the final research manuscript.

**Table 1**Demographics of Women Interviewed

Pseudonyms	Location	Relationship Status	Pregnancy History
Margaret	Oregon	Engaged	Miscarriage
			Miscarriage
			Pregnant
Elizabeth	Illinois	Married	Miscarriage
			Miscarriage
			First Living Child
Josephine	Maryland	Married	Miscarriage
			First Living Child
			Miscarriage
			Second Living Child
Abigail	New Jersey	Married	First Living Child
			Miscarriage
			Miscarriage
			Second Living Child
			Miscarriage
			Miscarriage*
			Miscarriage
			Miscarriage*

Note. \*Miscarriages occurred in the second trimester.

#### Results

The interviews yielded thought-provoking testimony of intimately personal experiences with miscarriage. The following three themes emerged during the data analysis: (a) the journey: ambiguity, vulnerability and the trauma of a miscarriage; (b) seeking acknowledgement and validation of loss: impact on relationships; and (c) occupational engagement: evolving roles and perspectives.

# The Journey: Ambiguity, Vulnerability, and the Trauma of a Miscarriage

A miscarriage is more than a moment in time. Rather, it is a journey that begins prior to conception and shapes perspectives throughout a lifetime. A certain ambiguity, however, surrounds the phenomenon that leads to common misconceptions regarding the physical and emotional impact of a miscarriage. Margaret, Josephine, and Elizabeth discussed the uncertainty in the unknown.

**Margaret.** When I thought of miscarriage before, it seemed like this day, you know, it just happens one moment and then it is over with, which was not my experience at all.

**Josephine.** That's something that I didn't expect and I didn't feel like it could be so hard . . . the way I approach life is I just go into it and I just assume that it will be okay and it will work out. I'll get what I want right away. But it's more of a journey than I ever expected it to be. So, I didn't think that I was going to have to go through that to get what I have. But it does make what I have neater, I think.

**Elizabeth.** I was about six weeks along. This one resolved on its own. In hindsight, I'd say almost a non-event. I mean, I know these things happen all the time. For me, it was pretty devastating just because I had never . . . that did not cross my mind as something that would have happened to me.

Although the experiences that the informants shared were all very diverse, some commonalities emerged when discussing their miscarriages. Discussion of hopes and dreams for the future and concerns surrounding fertility and the vulnerability in the waiting process, the lack of control, and the visceral and traumatic nature of loss were prevalent.

**Elizabeth.** I only have my experiences, but I would garner to guess that if you're 6 weeks along, 11 weeks along, 20 weeks along or later, it still hurts. I think the minute you pee on that stick, you have so many hopes and dreams for this little baby. You know, I feel really sorry for women who confide in me that they got the positive pregnancy test at home and then they went to the doctor and the ultrasound showed they miscarried. So, they are like, "Well, but we barely knew it was there, so I feel bad about being upset about it." I don't think we should feel bad. It's still real. They all count.

**Margaret.** The first time was just like a bad period. The second time was much more than that. It was more physically traumatic. I went through it at home. So that was quite an experience. That was just a very visceral experience.

**Josephine.** Until it's final, there's always this glimmer of hope. Like, "Well, maybe this is not going to happen. Maybe this blood work is wrong or maybe . . . maybe this is going to be okay." And then, no.

**Elizabeth.** At the D&C [dilation and curettage], which was at the crack of dawn, I remember through tears, begging my doctor, "Can you please just check me one more time?" I don't know, holding out hope, I guess. And he didn't. I guess in the back of my mind, I just felt awful thinking, "What if this is a mistake?"

**Abigail.** I wanted to deliver the first [second trimester] loss. I didn't want to have a D&C, and so the doctor, when my water broke, the doctor just left the hospital and was like, "Oh, I'll be back." So she left and was gone when I actually labored. She came back and was like, "Okay, so we're ready to do this?" and I was like, "Well, no." It had already happened, the nurse was so kind and took care of

everything. She [the doctor] actually applauded and started jumping up and down and was like, "Yay!" But I was like, "This isn't a happy place for me, in what world are you applauding and saying, 'Yay'? This was a terrible thing that just happened. I don't understand your reaction at all."

Miscarriage may be statistically common, but each loss is unique. The informants highlighted the importance of recognizing the individuality in each situation and providing comprehensive access to medical and educational resources by medical practitioners.

**Josephine.** You know, it's your own unique experience. But I just wish it were more out in the open so you didn't have to feel like it was some sort of underground miscarriage trade of information.

**Elizabeth.** It [miscarriage] is something couples are dealing with and it's not a female problem. It's not a girl who is upset because she miscarried, there's more to it than that. There is a family involved. . . . Follow your instincts. Just don't be afraid to inconvenience your doctor because you are the one who has to deal with the aftermath.

The medical care provided during their initial loss and recovery positively or negatively influenced the miscarriage experience with lasting perceptions evident in subsequent pregnancy and/or loss.

**Margaret.** I really like my doctor who I had at the time, too. She was really supportive. Just like, I could email her at any time, that sort of thing. And she was just really, kind of emotionally there, too. Which was nice. She was great!

**Josephine.** With the first one [miscarriage], I was probably a little more clueless as to what was happening. I was not a very good advocate for myself. They said, "This happens all the time. It'll be fine, whatever." They really blew me off. They didn't track my levels going down. They just told me to wait for a period. They didn't examine me. They didn't want anything to do with me.

Abigail. The whole process was just not good at the first hospital we were at. We went out on our own and did the funeral home and we had a cremation, which is nice for us, because we, on our own, have the urn and stuff. So, we have that. And then with our second loss we were at a different hospital and it was a little more religious-based and so maybe that is, it was a Catholic hospital so they view things a little bit differently. And they offered to, you know, a burial and they have two separate masses every year for infant loss or miscarriage and that sort of thing, which is nice. We didn't. We opted out of that because we had done one thing for our first son. We wanted to do the same thing for both of them. So we have urns for both of them. But the support level was very different. They also gave out pamphlets and had counseling support groups. We didn't participate in any of them but it was there. So, you know, it was just a different level of understanding or appreciation for what had happened.

## Seeking Acknowledgement and Validation of Loss: Impact on Relationships

Acknowledgement and validation of the emotional and physical components of loss are beneficial to recovery and moving through loss. The informants discussed the importance of being able to share and talk through their experiences without feeling like it was a shameful secret.

**Margaret.** I was just sort of in this phase . . . people need to talk about this, these things. It shouldn't be this weird, shameful, you can't talk about it, taboo subject.

The positive or negative impact on relationships with friends and family members were also discussed in regard to responses to a miscarriage. In some situations, sharing their experience with a miscarriage became an opportunity to connect; in other circumstances, sharing created distance in the relationship as people struggled to understand.

**Elizabeth.** Or, they'd say, "Oh, this happens. This is so much more common than you think." And it's like, "Well, yeah, it's true. But I mean, it's happening to me. Right now."

**Margaret.** It's not like I really needed a lot of support, but I wanted some acknowledgement that it happened because it was really traumatic.

**Abigail.** My mother-in-law called to tell me that it was probably because I was a vegetarian that I miscarried the baby. So, that impacted us in a negative way because it's obviously not that and she was real adamant.

The influence on relationships with spouses or significant others were also discussed. For Margaret and Abigail, miscarriage created closeness in their partnership. For Elizabeth and Josephine, it was a source of tension and self-doubt.

**Elizabeth.** I did end up feeling a little bit like I was struggling more than him [husband]. Sometimes I wondered, "Are you as upset about this as I am? And shouldn't you be?"

**Josephine.** I think miscarriage opens a little bit of the gap of experience of parenthood and for the female versus the male. Because physically, like in childbirth, you are still going through this thing that they cannot touch and experience. And they're going through something that you cannot experience. So, it's definitely a test of commitment.

# Occupational Engagement: Evolving Roles and Perspectives

Miscarriage impacts occupational engagement, as routines are disrupted. The informants discussed how they coped with the loss of work or attempts to schedule around the physical and emotional recovery. The informants described the return to their normal routines as "surreal."

**Margaret.** I was trying to time things, you know? I have these meetings or this stuff to do for work. Like, when will I [miscarry]? When will this actually happen? And, when can I do things? And, trying to schedule around it was weird because I didn't feel like thinking about any of that.

Careers or hobbies were frequently viewed as a distraction from loss and bereavement. For Josephine, engagement in occupation away from the home helped to alleviate marital tension, while Abigail reported being more hesitant to engage in activities alone or away from her family. Social media engagement was indicated to be an area of sensitivity and often viewed as a continued reminder of loss.

**Elizabeth.** I think [miscarriage] probably drew me into work a little bit as a distraction.

**Josephine.** After the miscarriage . . . I was already kind of busy, and I just kind of threw myself, even busier into everything. I was into everything. So, it made me just try to get away from the household for a while, and relationships. Just kind of wanted to be busy and do theater and go drink tequila and not be worried about it. So, that was what happened with that one [first miscarriage].

**Abigail.** I started doing acupuncture, which helps. Um, every now and then I'll go for a massage or something. I don't do a lot out on my own right now, just because when my husband's home, I want us to all be together. He's always like, "Go and do something on your own." But, I don't want to. I keep saying I want to, but really when it comes down to it, then I miss everyone when I'm gone. So I don't do a ton now.

**Elizabeth.** Well, Facebook got kind of hard because I felt like Facebook was just one baby announcement after the next. And I was just like, "I don't know if I should be on this anymore, I feel like I'm just an alcoholic walking into a bar." It was just . . . tough.

Self-identity may be shaped by the experience of a miscarriage. The knowledge that a miscarriage was a common phenomenon was a source of comfort and strength for Margaret. However,

most of the informants shared that they had struggled with feelings of failure, guilt, self-doubt, and lack of trust in their bodies.

**Margaret.** I think if anything identity wise, it sort of brought me closer to that kind of universal human experience thing. This [miscarriage] is something that no matter what the culture you are in, no matter what time, women have had to deal with and families have had to deal with. So, I think if anything, it sort of strengthened that.

**Josephine.** The first miscarriage that I had, that affected my self-identity the most because I immediately was like, "I'm never going to be able to have children and I'm not a woman and I'm broken." I kind of laugh at it now but it wasn't ridiculous at the time to be thinking that. And that's how I felt deep down. The other one [second miscarriage] probably didn't really affect my self-identity that much only because I already had my daughter and I knew that my body could do it. So, I trusted myself a lot more with that one. It was still sad and affected me but it didn't change how I felt about myself at all.

**Abigail.** I guess in some ways you feel guilty. Or, in every way I feel guilty. Like, I feel like, "What thing did I do that caused all of this?" There must be something that I've done in my past or now that's causing this to happen. So, I think, you feel the guilt and then you feel like you're maybe not the best mom because you're not doing everything right that you're supposed to do to make these kids there. You know, at least taking care of them the way you're supposed to. And that's not really a way that I'd see myself before because my kids are my life. And so, to feel like I've failed some of them feels terrible.

**Elizabeth.** That one [2nd miscarriage with D&C] was a little more invasive and a lot more impactful psychologically, too. Because at this point [after two miscarriages], I really started to doubt myself, like, "Am I even able? It was frustrating to get pregnant and now I don't even know if I can carry a baby."

Abigail and Elizabeth discussed how achieving pregnancy may become consuming and that fears of recurrent loss are difficult to reconcile. Interactions with pregnant women may also be a source of discomfort or resentment.

**Abigail.** Well, in the last year we've been really consumed with this whole process. I mean, I keep getting pregnant and I keep losing. And it's sort of like, we just said, if we even get pregnant again, like the pregnancy doesn't even really mean anything. You know? That sounds terrible, but if we get a positive pregnancy test it almost feels like, "Well, great." Like, you know? It doesn't feel like it's ever . . . it feels like this never-ending race. That we just keep trying and trying and trying and it just keeps failing. It's something that I still really want and so I'm not ready to throw in the towel. But, I'm also not super hopeful that it is going to happen for us again.

**Elizabeth.** It's funny, because I do the timeline math in my head and I almost add in a loss. Because a loss isn't a blip on the calendar. A loss is about a 6-month time frame, in my opinion, because you get pregnant and you keep it for a little bit, you lose it, and then it takes time for the body to heal. And then, for me, it took time for, just [to be] emotionally ready again.

**Abigail.** And women, who, you know, complain about stretch marks as if that's the worse thing about pregnancy and I want to strangle them a little bit. But if you don't know, you don't know any different . . . you don't know how to appreciate things if you haven't been through loss.

The informants also reported that miscarriages influenced or reinforced personal views on the roles and routines of motherhood, abortion, and religion or spirituality.

**Abigail.** Well, and [this] may be kind of counter to what I was saying earlier about how much you appreciate your kids. But, when people are like, "Well, at least you have these two." I'm like, "Yeah, I have these two and I love them and I appreciate them so much now, but, those, those were also my children. You know, they were also my sons and, you know, it doesn't make it less sad because I have two other ones."

**Elizabeth.** I am much more pro-life than I ever use to be in the past. I do think, now, some of that might be motherhood in general because I've experienced, you know, the birth of a child and the gift that it is. But, I also think about that D&C and I see these clips. I don't want to get too political, I don't know where you fall on the whole spectrum. You hear about people standing up for things that I just so wholeheartedly disagree with and wonder if they've ever been in shoes like mine. Would they feel differently?

Josephine. I've kind of worked those experiences into my religious beliefs. Like, it's not like I thought, um, like that miscarriage that I had before my youngest daughter. I really do feel like it was biology. I don't think there was like a little soul in there yet. I think that it was like, her. She was trying to be born and like, because that body wasn't like the right body, it wasn't working out, she was like, "I have to wait for the next one . . . that one is not going to work out." So, I kind of have adapted my beliefs to accept, like fit miscarriage into it, which makes it more okay for me in my mind, I guess. Because, I didn't feel like I was giving up, like a soul to the porcelain in the toilet. Jesus, that's horrible. Oh, my God. I'm like, "I'm going to flush this little, little soul down the toilet." So, yeah. I still believe that, not that I believed that before but it kind of reaffirmed and made me think about things I probably never would have considered. Which is something that people think about abortion all the time. I already kind of had my beliefs that way. This just actually tested it. Made me re-examine it, I guess. So.

**Elizabeth.** I started going to church. Not because I thought that it would be my golden ticket or anything. But, it was just, I don't know what else to do, I guess. And you're just clinging to the fact that maybe somebody up there could be helping us out.

Elizabeth discussed the void she felt when unable to fulfill the life role of "mother" despite occupational competence at work and her decision to leave a successful career when given the opportunity to engage in the occupation of mothering. Abigail expressed gratefulness for her living children and the opportunity of motherhood.

Elizabeth. Sometimes, I kind of feel I was going through the motions [at work] because this other huge part of my life wasn't in motion yet. It was a weird time because again, everything was perfectly in place except for this one big gaping hole [motherhood] and I couldn't seem to fix it. And then it left me questioning, "What if this never happens for me?" It's only my perspective, because I can't undo the past, but I really think it has made me extremely grateful for [child] and for the opportunity. Because I got to the point where I was really doubtful that I would ever have that opportunity. I mean, we started thinking, "Well, do we even consider adoption?" We're getting a little bit older and I know some countries close you out at a certain age and so all these things started weighing on us. And, that's another reason I quit my job. I mean, I had thirteen years with the firm and I was up for partner at one of the world's largest accounting firms and I walked away from that because I didn't want to miss a minute of [child's] life. I'm not saying it is a walk in the park and that sometimes I don't miss the old job and the paychecks and all the things that came along with it, but, I just, I couldn't stomach it. I was like, "No, I've worked really hard for this kid!" and I also think it made me

think this is all, or he may be all we get. Which is, you know, more than enough because some days I still am in awe of this kid and I'm not even sure I deserve this one. I just want to soak him up.

**Abigail.** I feel like I appreciate my kids so much now. You know, I find myself really taking them in and just not taking it for granted as much as I did before. If I did before.

Margaret and Josephine also referenced their experiences with miscarriage as preparation for the challenges and uncertainties in motherhood or parenting.

**Margaret.** You know, the world has a lot of randomness. Especially when it comes to fertility. You know, it seems like a miracle it ever works out. So, I think that experience sort of reinforced the randomness of life. I think that is an important thing to go into motherhood with. You know, knowing it's not going to necessarily go according to script.

**Josephine.** It kind of prepares you to be, if you have to go through that, it kind of prepares you to be a parent. It's not like you have to be flexible, but you get really hard thinking life is so unexpected and you have to roll with the punches.

Miscarriage influenced perspectives on subsequent pregnancy. The informants who experienced miscarriages prior to having children or who experienced recurrent miscarriages described diminished attachment, increased anxiety, and challenges with embracing subsequent pregnancies without fear.

**Elizabeth.** It is a very sensitive pregnancy when you have a history of loss. I really refused to let myself get too attached. And I had a really hard time celebrating.

**Abigail.** With this last pregnancy, which was the second, second trimester loss; I think I didn't attach at all. I woke up the next morning after we found out and I was like, "I actually feel a little relieved," which sounds so stinking twisted because I obviously wanted it more than anything, but there was this component of, "Oh, okay. It happened. At least I don't have to worry anymore. I'm not waking up worrying." Your brain goes to, "Well, what's worse than this?" Now I'm ready for a second trimester loss. What would be worse? And it would be a third [trimester loss] or SIDS or something like that.

The phenomenon of miscarriage is more than a simple physical experience or a medical procedure. It is a life changing experience that influences relationships and self-identity and shapes perspectives of life roles and occupational engagement on a lifetime continuum. When the informants were asked to share advice for other women experiencing miscarriage, they noted that their desire to help other women navigate miscarriage motivated them to participate in this study and offer these words of wisdom.

Margaret. I think the advice I have is to be patient with yourself and give your body some space to process that experience before you draw any, you know, monumental conclusions about it, give yourself some space to process. And don't be afraid to lean on others for support, no matter what that support is. Whether that's more like people just being there or talking through it.

**Elizabeth.** I know they may not want to hear it, but time does do wondrous things. You won't necessarily forget but it will get easier as time goes on. And, until you are told otherwise, don't give up on your body because it's working really hard for you. You never know.

**Josephine.** I wish, in a perfect world, that it [miscarriage] wasn't a thing that you really needed guidance for. I wish it was just out in the open more. I didn't like the way it was said to me in [town], but I do like the idea that it can, it can be normal. But also, even though it happens to a lot of women, it's your own experience and it's horrible for you; if it's horrible and if it's not horrible, that's okay, too.

#### **Discussion**

This phenomenological study sought to facilitate an intimate exploration of miscarriage with consideration of the lived experiences of the informants. The interviews elicited detailed accounts of the personal experiences with miscarriage and focused dialogue on the impact of miscarriage on relationships, evolving perceptions of motherhood, and the influence of loss on occupational roles and routines. The findings illustrated the commonalities and diversity found in the lived experience of miscarriage and provided meaningful insight into the ambiguous and traumatic nature of loss; the significance of societal acknowledgement and validation of loss; the subsequent impact on relationships with friends, loved ones, and medical professionals; and the influence of occupational engagement on evolving roles and perspectives.

The ambiguity of miscarriage contributed to the traumatic experience of the loss for each of the informants and contributed to disenfranchised grief. Acknowledgement of the visceral physical process of a miscarriage was noted to be an important consideration in the healing process. This is congruent with the research by Nikčević (2003), who highlighted the importance of validating miscarriage to facilitate "closure" and moving forward through loss. This finding was significant as the physicality of a miscarriage varied among the informants: from navigating the process relatively alone at home, to having a dilation and curettage procedure in a hospital or outpatient clinic, to delivering a still baby on the labor and delivery unit. In some instances, the emotional upheaval of a miscarriage created distance between partners, friends, loved ones, and medical practitioners as the informants struggled to move through grief. In other instances, speaking openly and with candor about the experience of miscarriage also created opportunities to forge new connections and strengthen existing relationships.

Furthermore, the findings of this study suggest that the statistical frequency of miscarriage contributed to an apathetic atmosphere when women sought support and understanding of the traumatic nature of the event. Interactions with medical practitioners negatively or positively shaped the overall miscarriage experience and influenced the informants' perceptions of subsequent pregnancies. Overall, resources for education and support were not found to be readily accessible, which aligns with previous research (Harvey et al., 2001; Nikčević, 2003; Nikčević et al., 2007; Robinson, 2014; Séjourné et al., 2010).

The role of occupation is twofold in the event of a miscarriage. A miscarriage may be viewed as the loss or postponement of roles and routines attributed to the occupation of motherhood. However, occupation is also a means of coping with an event of bereavement through engagement in meaningful activities. The occupational responses to loss (occupational maintenance, occupational dissolution, occupational ambivalence, and occupational restoration) as described in the autoethnographic research by Forhan (2010) and Hoppes (2005) were evident in the findings of this study. The informants described engagement in occupation as they struggled with the emerging reality of miscarriage, the influence of grief, the postponement of motherhood on the meaning of everyday roles and routines, and then the adaptation to a new reality after loss (Forhan, 2010; Hoppes, 2005). These occupational responses to loss are not mutually exclusive but rather interwoven throughout the experience of miscarriage and beyond. Reactions to miscarriage may be ever evolving and shaped by perceptions of fertility, recurrent miscarriages, subsequent pregnancy, and the achievement of motherhood. The concept that a miscarriage is not a moment but rather an event that influences and shapes a lifetime has been well documented in the research (Frost et al., 2007; Gaudet et al., 2010; Harvey et al., 2001; & Ockhuijsen et al., 2014).

#### Limitations

Due to the small size of this preliminary study, the findings may not be generalizable to the public. However, the informants provided an in-depth and diverse picture of the phenomenon of miscarriage and that produced meaningful results. In addition, the use of a single researcher to conduct and code the interviews was of special consideration during the design and implementation of this study. Due to the intensely personal nature of miscarriage, the use of a single researcher with a personal history of miscarriage facilitated an open and intimate dialogue in regard to the nuances of the lived experiences of miscarriage. To mitigate the effects of a single data analyst, member checking occurred of both the completed interview transcripts and the final research manuscript to ensure congruency of data. Furthermore, reflexivity provided a mindful dialogue throughout the course of this research study.

# **Future Research and Implications for Practice**

The role of occupation in the context of bereavement after a miscarriage has specific implications for occupational therapy research, education, and practice. Not only is the occupation of motherhood impacted as a result of loss, but occupational engagement also plays a significant role in coping with and moving forward through grief, thus underscoring the distinct need for occupational therapy services for this unique population. Potential research implications include the (a) development and testing of occupation-based assessment tools to screen and assess risk for occupational disengagement throughout the perinatal period and (b) the development of efficacious intervention approaches to address both emotional and physical well-being, such as in occupation-based support groups, mindfulness-based stress reduction approaches, or supporting women's physical recovery needs after a miscarriage. Occupational therapy educational programs could incorporate content related to miscarriage and bereavement during learning modules related to occupational roles of motherhood and to coursework focused on the promotion of emotional and physical health. In addition, a more thorough exploration of motherhood as an occupation and the perceptions of occupational performance, identity, and competency in motherhood in circumstances of miscarriage, adoption, or infertility is also warranted and may have broader implications for the role of occupation in the context of evolving life roles and routines. Research questions that emerged from this study include:

- 1. How does a miscarriage impact co-occupational engagement with a child born after loss (rainbow baby)?
- 2. How does a miscarriage impact co-occupational engagement with a child adopted after experiences with infertility or recurrent pregnancy loss?
- 3. What decision-making factors influence families with living children to continue to strive for pregnancy despite recurrent miscarriage?

## **Conclusion**

This preliminary qualitative study used a phenomenological design in a personal exploration of the lived experience of miscarriage and the subsequent impact on relationships, perceptions of motherhood, and the influence on occupational roles and routines. Despite a small sample size, this study yielded rich insight into the phenomenon of miscarriage as experienced by four women. The findings illustrated the ambiguity and vulnerability in pregnancy loss and the subsequent impact on relationships as women seek validation and acknowledgement of the physical and emotional trauma of a miscarriage. The findings further suggested that the experience of miscarriage may be negatively or positively influenced by the quality and continuity of care provided by health care practitioners. The lack of satisfaction with medical care highlighted the relevance of individualized and compassionate

care by medical professionals and a general need for increased societal awareness in regard to miscarriage as a unique event of bereavement. The findings further revealed the dual role of occupation as both an evolving role in regard to achievement of anticipated motherhood roles and routines and as a means of coping through occupational engagement in meaningful activities.

What emerged from this study is a greater appreciation of the complexity of the lived experience of miscarriage. Findings highlight an increased awareness of the significance of miscarriage on self-identity, relationships, and the role of occupation in the context of bereavement. A miscarriage is understood to be a significant event that warrants further research and exploration of program development, advocacy, and improved resources to allow women to more easily navigate the interrupted journey toward motherhood.

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# **Appendix**

# **Interview Guide**

- 1. Please describe your experience with miscarriage. (If applicable, additional experiences with miscarriage may also be shared).
- 2. In what way did you receive support or guidance following your miscarriage?
- 3. How has your experience with miscarriage shaped your perception of motherhood?
- 4. Please describe the impact of miscarriage on your self-identity.
- 5. How has your experience with miscarriage influenced your outlook on childbearing?
- 6. Please describe your experience of sharing your loss with others.
- 7. In what way was your loss validated?
- 8. Please describe the impact of miscarriage on your relationship with your spouse or partner.
- 9. In what way has your experience with miscarriage impacted relationships with friends or loved ones? (This may include relationships with living children, if applicable).
- 10. How has your experience with miscarriage influenced your faith or religious beliefs?
- 11. Please describe the impact of miscarriage on your engagement in meaningful activities or routines.
- 12. What guidance would you like to offer other women experiencing miscarriage?
- 13. What additional thoughts would you like people to know about miscarriage?