Evaluation of an Occupation-Based Retreat for Women After Pregnancy or Infant Loss

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Importance: Pregnancy loss and infant death are unexpected, traumatic, life-changing events. The role of occupational therapy practitioners in treating this population is not well defined.

Objective: To describe the outcomes of an occupation-based residential retreat for women who have experienced pregnancy or infant loss.

Design: Program evaluation.

Setting: Seven residential retreats for bereaved mothers.

Participants: One hundred forty-one women who experienced perinatal loss.

Intervention: Residential retreats that were held in natural settings and included occupation-based activities such as group discussions, yoga, meditation, crafts, and rituals to facilitate grieving and healing processes after perinatal loss.

Outcomes and Measures: The Beck Depression Inventory, PTSD Checklist–Civilian Version, Self-Compassion Scale, and Multidimensional Scale of Perceived Social Support were collected pre- and postretreat.

Results: Statistically significant improvements were seen in women's depression, trauma, self-compassion, and perceived social support from pre- to postretreat.

Conclusions and Relevance: At present, occupational therapy practitioners support this population primarily by providing referrals and information about local resources. However, as occupational therapy practice in primary care settings grows, so too do possibilities for the development of occupational therapy–related interventions to support maternal mental health.

What This Article Adds: This article provides preliminary support for occupation-based retreats as a treatment for improving maternal mental health after perinatal loss.

Pregnancy loss and infant death are unexpected, traumatic, life-changing events (Cacciatore et al., 2013; Gold et al., 2016; Kersting & Wagner, 2012). Such events include miscarriage, termination for medical reasons, stillbirth, and infant death. One in 4 mothers reports experiencing pregnancy loss or infant death, but because of unreported pregnancy loss, the number may be as high as 1 in 2 (Jaffe & Diamond, 2010). Approximately 24,000 babies are stillborn (>20 wk gestation) each year, and an additional 23,000 infants die within the first 28 days of life (MacDorman & Gregory, 2015). Pregnancy loss and infant death, often referred to as *perinatal loss,* occur 10 times more often than deaths related to sudden infant death syndrome (Centers for Disease Control and Prevention, 2017).

Although the occurrence of pregnancy and infant loss is widespread, only limited research has attempted to understand its effects on maternal mental health and wellness. Among the studies that have been conducted, some have found significantly higher levels of depression among women who experienced perinatal loss compared with those who gave birth to healthy infants (Boyle et al., 1996; Cacciatore et al., 2008; Gold et al., 2016). Gold et al. (2016) reported that perinatal loss resulted in a 4 times greater chance of screening positively for depression and a 7 times higher risk of posttraumatic stress disorder (PTSD). Women who experience pregnancy and infant loss also endure social stigma and shame, which they may subsequently internalize as self-blame. Women who blame themselves for

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their pregnancy loss are more likely to be diagnosed with other mental health conditions (Cacciatore et al., 2013). Moreover, many women who have experienced pregnancy or infant loss are not screened or diagnosed and therefore do not receive treatment. Women also often report a discrepancy between the intensity of their grief and the extent to which they are allowed to express it because of the stigma (Uren & Wastell, 2002).

Social support has been shown to buffer against negative outcomes. Cacciatore et al. (2008) reported that perceived social support from family members predicted lower levels of depression among women who had experienced perinatal loss. In a qualitative study, women reported that participation in support groups (not occupation based) with other bereaved parents was most helpful and comforting because they connected with others and their experiences were validated, both of which resolved the sense of isolation they experienced in the aftermath of their loss (Cacciatore & Bushfield, 2007).

Relationship to Occupational Therapy

The death of a baby impairs a mother's day-to-day functioning (Jaffe, 2014; Kersting & Wagner, 2012). Mothers who experience perinatal loss report changed appetite and sleep patterns, decreased social participation, decreased marital satisfaction, and increased isolation (Cacciatore, 2013; Cacciatore et al., 2008; Kersting & Wagner, 2012). In addition, perinatal loss frequently affects a woman's professional career and relationships with colleagues (Cacciatore et al., 2013; Jaffe, 2014). After perinatal loss, a woman's domestic and professional habits and routines can be interrupted because she must care for her recovering postpartum body, grieve, and potentially make plans for a funeral or memorial service.

Although grief and loss can clearly disrupt occupational engagement, occupational therapy research on this topic is scant. Hoppes and Segal's (2010) grounded theory study of occupational adaptation to the death of a close family member found that individuals used two primary occupational responses: occupational adaptation and occupational assimilation. In addition to this study, Hoppes (2005) published an autoethnography about his family's response to the death of his 13-yr-old nephew from complications of a chronic illness. Forhan (2010) wrote the only occupational therapy or occupational science publication to address infant loss. Like Hoppes, she wrote an autoethnography in which she reflected on the period after the stillbirth of her son Quinn. It provides an intimate portrait of her experience and occupational changes. Nonetheless, more literature is necessary to determine a clear direction or role for occupational therapy professionals in the care of women who experience pregnancy or infant loss.

The first author of this article, Kiley Krekorian Hanish, an occupational therapist, experienced the stillbirth of her first child. In an effort to bring greater awareness of perinatal loss, break the silence of the stigma accompanying pregnancy and infant loss, decrease the social isolation that families experience, and promote her own family's healing process, she and her husband created the feature film *Return to Zero* (Jaconi-Biery & Hanish, 2014), which dramatizes their experience. The strong grassroots response to the film inspired Hanish and her husband to establish Return to Zero: HOPE (originally called the Return to Zero Center for Healing). Hanish then collaborated with the second author, Ivy Margulies, a clinical psychologist, to create seven occupation-based residential retreats for women who have experienced pregnancy or infant loss. The retreats were designed to provide activities and interactions that build a supportive community for bereaved mothers to reduce their long-term distressing symptoms of grief, depression, trauma, isolation, and self-blame. This article presents a program evaluation of retreats that focus on maternal mental health.

Method

The purpose of this program evaluation study was to assess the impact of an occupation-based residential retreat on the mental health outcomes of women who have experienced perinatal loss. Data were collected from participants

1–2 wk before they attended one of seven 4- or 5-day occupation-based residential retreats and again on the last day of the retreat. Participants completed assessments that included some or all of the four following measures:

- The Beck Depression Inventory (BDI; Beck et al., 1988) was used to evaluate depression. The BDI is a psychometrically sound assessment that has demonstrated a high correlation with clinical ratings of depression across various populations.
- The PTSD Checklist–Civilian Version (PCL–C; Ruggiero et al., 2003) was used to measure trauma among retreat participants. This measure has high internal consistency, test–retest reliability, and convergent and discriminant validity.
- The Self-Compassion Scale (SCS; Neff, 2003; Raes et al., 2011) was administered to better understand how retreat participants typically feel about themselves in difficult situations.
- The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1990) was used to measure subjective social support.

The PCL–C, SCS, and MSPSS scales were not administered to the first two retreat groups. Participants could decline to complete the assessments, and this decision did not affect their retreat participation. Those who chose to complete the assessments also signed a consent form indicating that the information they provided would be made available for program evaluation. Pre- and postretreat data were analyzed using Wilcoxon signed-rank tests to compare pre- and postretreat scores.

Description of the Retreats

Data were drawn from seven occupation-based residential retreats held between 2014 and 2016. Five of these retreats were held in the United States, and two were held in Australia. Authors Hanish and Margulies designed and led the retreats, each of which was structured similarly, lasted 4 or 5 days, and was held in a natural setting reserved exclusively by the Return to Zero: HOPE group. Retreat activities emphasized ritual and social participation and included candle lighting, guided meditation, storytelling, large and small group discussion, crafts, yoga, and free time. All activities aimed to help each participant forge a connection with her child and build a supportive community. Various additional activities, such as horseback riding, swimming, hiking, and spa services, were offered, depending on what was available at each retreat location.

Participants

The retreats were open to women who had experienced pregnancy and infant loss. The fee to attend a retreat was approximately $1,200–$1,400, and approximately one-third of the participants used crowdfunding to attend or received a scholarship. Participants were also responsible for their own transportation to and from the retreat locations.

Results

Data from 127 retreat participants were analyzed. Fourteen participants chose not to complete all of the surveys. The attendees' average age was 34.5 yr (range = 21–47). Types of loss included miscarriage, termination for medical reasons, stillbirth, and infant death. Table 1 reports gestational age at loss. The time since the loss occurred averaged 33 mo (range = 1–202). Among the 49% of women (n = 69) who reported more than one loss, half (n = 34) had experienced three or more losses. Of the 118 participants questioned, 64% (n = 76) had at least one living child, 89% (n = 105) had a spouse or partner, and 78% (n = 92) were employed. Participants were not asked questions about ethnicity or other demographic factors because such data were not necessary for this article or for retreat participation.

Table 1. Gestational Age of Child at the Time of Death

Age	Frequency (%)
<20 wk	14 (9.93)
20–32 wk	31 (21.99)
33–36 wk	22 (15.60)
≥37 wk	41 (29.08)
Infant death	33 (23.40)
Total	141 (100.00)

Participants showed significant improvements in scores on all four assessments from pre- to postretreat (Table 2). Because assessment scores did not differ significantly among retreat locations at either time point, the data represent the full cohort. We found no significant differences on the basis of gestational age at infant death. Individuals with incomplete assessments were excluded from the analysis of change scores.

Table 2. Change in Summary Scores

	Preretreat		Postretreat		Change		
Measure	*n*	*M* (*SD*)	*n*	*M* (*SD*)	*n*	*M* (*SD*)	*p*[a]
BDI	127	21.46 (11.86)	121	11.60 (8.44)	112	−9.29 (9.42)	<.0001
PCL–C	59	42.81 (13.11)	62	33.82 (11.24)	57	−8.75 (11.57)	<.0001
SCS	60	26.73 (8.44)	63	32.52 (9.75)	58	5.78 (9.00)	<.0001
MSPSS	57	64.60 (14.41)	62	68.31 (11.77)	55	4.65 (12.99)	.003

Note. BDI = Beck Depression Inventory; MSPSS = Multidimensional Scale of Perceived Social Support; PCL–C: Posttraumatic Stress Disorder Checklist–Civilian Version; SCS = Self-Compassion Scale.
[a]Wilcoxon signed-rank test. All *p* values were statistically significant.

Older participant age was associated with lower scores on the MSPSS both pre- and postretreat. However, participant age was not correlated with overall change score ($r_s = -.33$, $p = .01$). Women with a longer time since loss were likely to have a lower BDI score at both pre- and postretreat ($r_s = -.18$, $p = .04$) and were likely to have a greater increase in their MSPSS score ($r_s = -.32$, $p = .01$). No other differences were detected among groups on the basis of participant age, gestational age of the child at death, or time since loss.

Discussion

Women who participated in retreats for mothers who had experienced pregnancy or infant loss demonstrated improvements in depression level, posttraumatic stress, self-compassion, and perceived social support. These findings provide preliminary evidence that an occupation-based residential retreat can help to facilitate improvements in maternal mental health in the aftermath of losing a pregnancy or young infant.

The retreat activities were intended to foster positive change in depression, perceived social support, self-compassion, and trauma. Spending time in a natural physical environment has been shown to improve mood in individuals with depression (Berman et al., 2012). Large and small group discussions have been shown to encourage social participation and create a supportive community (Cacciatore, 2007). Meditation and yoga have been shown to encourage the development of self-compassion (Gard et al., 2012), and a recent meta-review supported yoga's positive effect for those who have suffered trauma (Macy et al., 2015). Rituals involving candle lighting and craft activities helped retreat participants forge a connection with the child and make sense of the loss experience, thereby reducing trauma and depression (Uren & Wastell, 2002). The retreats provided women with the opportunity to participate in a physical temporal context that was separate from their everyday lives, thereby allowing them to focus on their own grieving process.

Health providers frequently overlook maternal mental health, particularly with women who have experienced pregnancy or infant loss. Occupational therapists are most likely to encounter such women in primary care, pediatric, and possibly mental health practice settings. One of the simplest ways that occupational therapists can identify women who may need support is to engage them in whatever occupational therapy setting they work in and take the women's pregnancy histories. Occupational therapists can then direct women who have experienced loss to the appropriate community resources, many of which Return to Zero: HOPE has compiled on its Web site (available at http://rtzhope.org/). Occupational therapists can also share with women findings from the literature that show the importance of social support and occupational engagement in coping with pregnancy and infant loss and encourage women to seek out community or other support networks.

It is important for health providers to be educated about the mental health implications of pregnancy and infant loss. By being knowledgeable about this topic, clinicians can provide women with informational brochures, refer them to other resources such as mental health services, and give them contact information for a local support group. It is key that, when encountering a woman who has experienced perinatal loss, health care providers keep in mind that (1) pregnancy

loss and infant death are traumatic events; (2) each loss affects a woman's ability to live a meaningful, productive life; and (3) such a loss affects not only how a woman parents and bonds with her future children but also her children's social and emotional development.

Limitations

This article presents a program evaluation, not a formal research study. Consequently, the participants may not be representative of the overall population of women who have experienced pregnancy or infant loss. In addition, the participants self-selected attendance at a retreat; therefore, we did not have a control group for comparison. Although approximately 25% of participants used crowdfunding to raise money to attend a retreat, the socioeconomic diversity of the sample is limited because the majority of participants could afford the cost of the retreat and transportation. Some participants also received partial scholarships from Return to Zero: HOPE.

Identification of which specific or combination of retreat activities or features actively caused the changes that occurred in assessment scores is not possible. Nevertheless, social support appears to be an important factor. We also do not know whether improvements in depression, PTSD, self-compassion, and perceived social support were sustained after women left the retreats and returned to their daily lives. A private Facebook group was created for each retreat so that participants could stay in contact with one another, which may facilitate continued contact. Last, spouses, partners, and other family members were not invited to participate in the retreats, primarily because of the accommodations available at the selected locations.

Implications for Occupational Therapy Practice

This research has the following implications for occupational therapy practice:

- Pregnancy loss and infant death are traumatic events. Each loss affects a woman's ability to live a meaningful, productive life, how she parents and bonds with her future children, and her children's social and emotional development.
- When working with women in any practice setting, it is important to identify those who may need mental health support by taking a women's pregnancy history.
- Bereaved mothers should be educated on the mental health impact of pregnancy and infant loss and the importance of social support and occupational engagement, and they should be encouraged to seek out community or other support networks.
- Practitioners should direct women who have experienced loss to the appropriate community resources, many of which Return to Zero: HOPE has compiled on its website (https://rtzhope.org/).

Conclusion

Health care providers need to be aware of the consequences of pregnancy and infant loss and knowledgeable about resources available to support women and their families in their communities. The Return to Zero Center: HOPE model has demonstrated improvements in women's depression, trauma, self-compassion, and perceived social support after pregnancy loss and infant death. As occupational therapy practice in primary care settings grows, opportunities to develop occupation-based interventions to support maternal mental health will increase. Therefore, further research on the role of occupations in the grieving process of both mothers and fathers will be beneficial.

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