Exploring Bereaved Mothers' Perceptions of Grief Support

Groups After Child Loss: Perspectives for Enhanced Support

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Abstract

Aim: This study explores mothers' perceptions of grief support groups following child loss and provide implications for future support. Methods: Mothers attending grief support meetings since 2017 completed online surveys after each meeting from 2020. Survey completion indicated consent. Content analysis identified from the 6th to 13th meetings to identify codes and categories from open-ended comments. Results: Thirty-seven (64.9%) out of 58 participants responded. Eight categories emerged from 106 codes: "space to talk about the deceased child," "listening and being listened to," "empathy and shared experiences," "expressing suppressed emotions," "realizing they are not alone," "emotional relief," "a place to remember the deceased child," and "facing grief." Conclusions: Mothers reported benefits from support groups, while persistent nature of

grief emphasizes the need for ongoing, individualized support.

Keywords: bereavement, child, grief support, mother

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Introduction

The death of a child is considered as a profound and devastating experience (Davies, 2004; Price, 2015). It is associated with grief-related distress, which reportedly persists longer than that of other types of loss, occasionally enduring throughout the parent's lifetime (Pohlkamp et al., 2019) Several studies have demonstrated that the death of a child has a more significant adverse impact on bereaved families' mortality and psychosocial outcomes compared with other types of loss (Li et al., 2005; Li et al., 2003; Pudrovska, 2009) (Rosenberg et al., 2012). Furthermore, it has a profound effect on parents' mental health, interpersonal relationships, and fundamental beliefs about the meaning of life (Cacciatore et al., 2014).

The presence of an appropriate support system is crucial when faced with such a severe loss. After the loss of a child, the interaction between individual grief and changes in family members' daily lives can significantly affect family relationships (Dias et al., 2017) (Gilmer et al., 2012). Consequently, all family members find themselves in a situation where they must grieve the loss of the child individually and collectively. Therefore, support from family, friends, and professionals becomes an essential element in navigating the grieving process (Klass, 2006).

In particular, grief support groups provide a valuable space for individuals with similar experiences to come together and share their experiences, feelings, and coping strategies (Umphrey & Cacciatore, 2011). They play an important role in supporting the grieving process by reducing participants' sense of isolation and creating opportunities for information sharing and mutual support (Aho et al., 2012). Previous studies have emphasized the importance of social support for bereaved parents who have lost a child (Kreicbergs et al., 2007) (Laakso & Paunonen-Ilmonen, 2002).

However, our understanding of the experiences of mothers who have lost children in grief support groups remains insufficient. Moreover, there is limited research on the quality and effectiveness of support provided by these groups, as well as their alignment with participants' needs (Lichtenthal et al., 2015). It is important to gain a deeper understanding of how mothers following child loss perceive and experience of grief support groups from multiple perspectives as it allows for the identification of strengths and weaknesses in existing support groups, revealing opportunities for improvement (Dyregrov et al., 2013). In addition, uncovering the specific needs and challenges of mothers who have experienced child loss may lead to the development of more effective and individualized interventions (Cacciatore & Flint, 2012).

Moreover, healthcare professionals and mental health specialists can use the insights

gained from the experiences of grief support groups to provide more appropriate support to the bereaved (Keesee et al., 2008). This will enable them to gain a deeper understanding of group dynamics and the needs of individual participants, thereby facilitating a more effective provision of support.

Our research team has been conducting group meetings for families who have lost a child as part of grief support. This study aims to analyze the open-ended responses from a survey administered to participants of these grief support meetings to elucidate their perceptions after participation. Through this research, we expect to gain deeper insights into the effectiveness and areas for improvement of grief support groups and the specific needs of participants. The findings are anticipated to provide valuable information for designing and implementing future grief support programs, ultimately contributing to the realization of more effective support for parents who have lost a child.

Aim

This study aims to explore mothers' perceptions and reflections on the significance of attending grief support group meetings following the loss of a child and provide implications for future support strategies.

Grief Support Group: "A Ladder to the Sky" (Overview)

"A Ladder to the Sky" is a grief support group for bereaved parents who have lost children that has been operating since 2017. It provides a safe space for members to share their experiences and feelings. Meetings are held three to four times a year, either online or in person. Aside from the adult group, a separate group for bereaved siblings, primarily children, was established in 2023.

In adult group meetings, participants begin with brief self-introductions, followed by a review of the group's guidelines, including maintaining confidentiality regarding shared experiences, allowing for the flexible entry and exit from the meeting, respecting individual comfort levels in sharing, and refraining from criticizing or judging others' contributions. Once the guidelines are established, participants are given the opportunity to share their stories openly.

During the meetings, staff members serve as facilitators, ensuring that participants feel heard and respected. They take a non-interruptive approach while actively listening to the narratives that are being shared. They also encourage dialogue and interaction by prompting questions and fostering a supportive environment for participants to connect with one another.

At the end of each session, the participants are invited to provide feedback through an

optional questionnaire. This feedback, which encompasses opinions on the group's operations and overall experience, is valuable in guiding future improvements and ensuring that the group continues to meet the needs of its members.

Methods

Participants: The participants were attendees of grief support meetings for families who have lost a child.

Study Period: April to May 2024

Data Collection: Data were collected through online surveys conducted after each meeting since 2020. After each session, the participants were invited to complete a voluntary questionnaire, and survey submission was considered as consent to participate in the study.

Questionnaire Content: Aside from five-point Likert scale evaluations of the overall experience and operational aspects of the grief support group, the questionnaire includes open-ended sections for feedback and suggestions regarding the group and personal reflections on participation. The present analysis focuses on the qualitative data collected from these open-ended sections.

Analysis: Free-text responses from questionnaires administered from the 6th to the 13th meetings were analyzed using content analysis, focusing on participants' perceptions and reflections on the significance of attending the meetings. Textual data were coded according to contextual units. Subsequently, these codes were classified and organized into categories based on similarities in their descriptive content. To ensure analytical rigor, the primary researcher maintained consistency in the coding and categorization processes and conducted member checking with co-researchers. Collaborative dialogue on uncertain classifications helped minimize subjective biases, enhancing the reliability of the analysis.

Ethical Considerations: This study was approved by the research ethics committee at the researchers' affiliated institution (Approval Number: 2408-1023) and that it conforms to the provisions of the Declaration of Helsinki.

Results

Out of 58 participants, all of whom were mothers, 37 (64.9%) provided responses. Eight categories emerged from 106 codes (Table 1).

Table 1: Categories of Mothers' Perceptions of Grief Support Groups

Category	Sub-category	Code Count
Space to Talk About the Deceased Child	Speaking comfortably among those with shared experiences	8
	Talking with people in similar situations	5
Listening and Being Listened To	Listening to diverse perspectives	7
	Having one's story heard	2
	Experiencing unique sharing confined to grief support groups	3
Empathy and Shared Experiences	Receiving empathy for one's feelings	3
	Empathizing with others' experiences and situations	7
	Sharing feelings and experiences	6
Expressing Suppressed Emotions	Venting emotions freely	8
	Expressing grief through tears	9
Realizing They Are Not Alone	Realizing one is not alone	4
	Recognizing previous isolation before joining	1
Emotional Relief	Experiencing emotional relief	5
	Feeling unburdened through talking	6
A Place to Remember the Deceased Child	Maintaining unchanging feelings towards the deceased child	4
	Preserving memories and emotions of the deceased child	3
Facing Grief	Gaining new insights	5
	Recognizing the individuality of grief	3
	Suppressing emotions in daily life	13
	Experiencing occasional tearful moments	2
	Encountering periods of distress	2

Categorical Descriptions

1. Space to Talk About the Deceased Child

This category highlights the role of the grief support group as a safe space for mothers to discuss their deceased children. This category comprised two subcategories: Speaking comfortably among those with shared experiences and Talking with people in similar situations. The first subcategory revealed that mothers found comfort in sharing their experiences with others who understood their loss, as exemplified by the code: "I felt comfortable talking to people in the same situation," The second subcategory emphasized the value of connecting with others in similar circumstances, illustrated by the code: "Although the circumstances of our children's deaths were different, we shared the common experience of losing a child." These findings demonstrate that the group provided a space where bereaved mothers could openly discuss their deceased children with others who truly understood their experience

2. Listening and Being Listened To

This category highlights the significance of participants listening to others and having their own experiences heard. The category comprised three subcategories: Listening to diverse perspectives, Having one's story heard, and Experiencing unique sharing confined to grief support groups. The first subcategory demonstrated how mothers valued hearing various experiences, as shown by the code: "I was able to listen to stories from people in different situations." The second subcategory highlighted the importance of having their own experiences acknowledged, exemplified by the code: "They listened to my story." The third subcategory revealed the unique nature of discussions possible only in these groups, as illustrated by the code: "There are things that can only be said and heard in this space." These findings indicate that the group provided mothers with a space where they could both have their experiences heard and listen to others' experiences, fostering mutual support through this reciprocal relationship.

3. Empathy and Shared Experiences

This category emphasizes the importance of emotional connections through shared experiences and mutual understanding. The category comprised three subcategories: Receiving empathy for one's feelings, Empathizing with others' experiences and situations, and Sharing feelings and experiences. The first subcategory highlighted how mothers felt understood by others, as illustrated by the code: "There were people who empathized with my feelings." The second subcategory demonstrated how mothers could

relate to others' situations, exemplified by the code: "There were many aspects of others' stories that I could identify with, as if they were expressing my own feelings." The third subcategory revealed the depth of emotional sharing, as shown by the code: "We could share our feelings because we had the same experience."

4. Expressing Suppressed Emotions

This category reveals how emotions that are usually difficult to express were freely shared within the group. The category comprised two subcategories: Venting emotions freely and Expressing grief through tears. The first subcategory demonstrated how mothers could release their suppressed emotions, as shown by the code: "I was able to release my accumulated emotions." The second subcategory revealed how mothers found comfort in expressing their emotions through tears, exemplified by the code: "I was glad I could cry here." These findings indicate that the meetings provided mothers with a space where they could express deep emotions through both words and tears that might be difficult to show in their daily lives

5. Realizing They Are Not Alone

This category illustrates how mothers found comfort in discovering they were not alone in their grief experiences. The category comprised two subcategories: Realizing one is not alone and Recognizing previous isolation before joining. The first subcategory demonstrated how mothers found solace in meeting others with similar experiences, as shown by the code: "I felt reassured that I wasn't alone." The second subcategory revealed their previous sense of isolation, exemplified by the code: "Before participating, I had been carrying the burden alone." These findings indicate that the group helped mothers transition from feelings of isolation to a sense of connection with others who shared similar experiences.

6. Emotional Relief

This category illustrates how participants found emotional relief through sharing their experiences. The category comprised two subcategories: Experiencing emotional relief and Feeling unburdened through talking. The first subcategory demonstrated how mothers felt emotional clarity after participation, as shown by the code: "I was able to sort out some of the emotions I had been keeping inside." The second subcategory revealed the therapeutic effect of verbalization, exemplified by the code: "My heart felt lighter through talking." These findings indicate that expressing grief within the group

helped mothers process their emotions and achieve a sense of emotional release.

7. A Place to Remember the Deceased Child

This category illustrates how the grief support group provided a space for mothers to honor and remember their deceased children. The category comprised two subcategories: Maintaining unchanging feelings towards the deceased child and Preserving memories and emotions of the deceased child. The first subcategory demonstrated the enduring nature of maternal feelings, as shown by the code: "No matter how much time passes since losing my child, my thoughts and feelings remain the same." The second subcategory revealed mothers' concerns about preserving memories, exemplified by the code: "I'm afraid of forgetting the memories of my child." These findings indicate that the group served as a valuable space where mothers could acknowledge their unchanging bonds with their children and actively maintain their memories.

8. Facing Grief

This category illustrates how mothers encountered and processed their grief experiences within the group. The category comprised five subcategories: Gaining new insights, Recognizing the individuality of grief, Suppressing emotions in daily life, Experiencing occasional tearful moments, and Encountering periods of distress. The first subcategory revealed mothers' development of new perspectives, as shown by the code: "Listening to mothers who have been through this longer, I realized it's okay not to force myself to move on." The second subcategory demonstrated the understanding of grief's unique nature, exemplified by the code: "Everyone's experience is different." The third subcategory highlighted the challenges of daily life, illustrated by the code: "In daily life, I usually keep my feelings about my child locked away." The fourth and fifth subcategories revealed the ongoing nature of grief, as shown by codes: "Sometimes my heart reacts with tears before I can even process my thoughts" and "In some situations, it becomes particularly difficult." These findings indicate that the group enabled mothers to face their grief while recognizing both the universality and individuality of their experiences.

Discussion

This study explored perceptions of mothers following child loss regarding their participation in a grief support group and identified eight primary categories. These

findings offer valuable insights into the effectiveness of grief support groups and the specific needs of mothers who have lost children.

Categories such as "expressing suppressed emotions" and "realizing they are not alone" emerged from this study, corroborating the established role of grief support groups in providing emotional support for the bereaved. According to Umphrey and Cacciatore (Umphrey & Cacciatore, 2011), grief support groups provide a crucial space for empathy and support during the grieving process, a finding mirrored in the present study.

Notably, the finding that shared empathy reduces feelings of isolation is consistent with Aho et al.'s (Aho et al., 2012) study, which posited that sharing experiences within a group fosters a sense of connection among participants. Moreover, the emergence of categories such as "space to talk about the deceased child," "empathy and shared experiences," and "listening and being listened to" in this study further reinforces that dialogue and emotional sharing are crucial elements in alleviating feelings of isolation. However, the quality and effectiveness of support in grief support groups may not be universally applicable. Klass (Klass, 2006) emphasized that grief processes are individualistic, and bereaved individuals may have diverse emotional needs. The findings of the present study, particularly the diverse needs emerging from participants' open-ended responses, support this assertion. Consequently, future group operations should prioritize providing individualized support. Similarly, Cacciatore and Flint (Cacciatore & Flint, 2012) emphasized that grief support groups should provide flexible support tailored to individual circumstances, considering each participant's unique grieving process.

The emergence of the category "expressing suppressed emotions" as a significant result in the present study further suggests that mothers may have different preferences and needs in emotional expression during grief, requiring varied approaches in emotional support strategies. In the study of Laakso and Paunonen-Ilmonen (LAAKSO & PAUNONEN-ILMONEN, 2002), which described the diversity of emotions and reactions to grief among bereaved parents, they highlight the possibility that necessary support and approaches may differ on a case-by-case basis. Therefore, it is important to develop tailored approaches (e.g., adopting diverse support techniques and providing support based on individual needs) in the future.

Cultural background often influences coping with loss experiences. Previous studies have discussed how cultural differences may shape the grieving process. In their study on the positive effect of robust social support on bereaved individuals' outcomes, Kreicbergs et al. (Kreicbergs et al., 2007) underscored the importance of considering

cultural context. For example, in certain cultures, internalizing grief rather than expressing it outwardly may be considered virtuous (Goss, 1999), potentially leading to resistance to group dialogue. Thus, culturally sensitive support is essential for mothers from such backgrounds.

The present study suggests the need for ongoing support as evidenced by the emergence of categories such as "a place to remember the deceased child" and "facing grief" from mothers' open-ended responses. This implies that the grieving process is not transient, highlighting the importance of long-term support. Malkinson and Bar-Tur (Malkinson & Bar-Tur, 2005) noted that grief, particularly the profound grief associated with losing a child, can persist for extended periods. While long-term support is emphasized globally (Malkinson & Bar-Tur, 2005) (Gilmer et al., 2012), efforts in Japan, such as those noted by Shimazono (Shimazono, 2022), similarly highlight the need for sustained and culturally sensitive support. However, as Okaku (Okaku, 2024) warns, evaluation frameworks for such initiatives remain underdeveloped. Therefore, while providing continuous support for the entire family, it is essential to develop higher-quality support based on participant feedback.

Gilmer et al. (Gilmer et al., 2012) emphasized the pervasive impact of bereavement on daily life and advocated for the provision of continuous support for the entire family. Beyond individual support, Kim et al. (Kim et al., 2023) highlighted the importance of addressing family system dynamics, as grief affects and transforms family relationships as a whole.

Limitations of the Study

This study has several limitations. First, the sample size was small (responses from 37 out of 58 individuals [64.9%]). Therefore, the results should be interpreted with caution. Moreover, the survey method might have resulted in varying depths and details of responses among participants, and self-selection bias might exist, potentially reflecting more opinions from mothers actively seeking support. Furthermore, relying on openended responses meant that the level of detail in answers may vary depending on the expressive abilities of participants. This may result in important information not being fully elicited. Thus, future studies should perform deeper data collection by combining interviews with surveys.

This study has several limitations. First, the sample size was relatively small, with responses collected from 37 out of 58 individuals (64.9%), which limits the generalizability of the findings and warrants cautious interpretation. Second, the survey

method may have led to variations in the depth and detail of responses among participants. Additionally, self-selection bias may have influenced the results, as mothers who were more actively seeking support might have been more likely to participate. Third, the reliance on open-ended responses introduced variability in the level of detail provided, potentially reflecting differences in participants' expressive abilities. This could have resulted in some important information not being fully captured. Furthermore, as the survey was conducted anonymously across sessions 6-13, it was not possible to distinguish unique participants from repeat attendees. Consequently, some perspectives may be overrepresented, which should be taken into account when interpreting the findings. To address these limitations, future studies should employ a more robust data collection strategy, such as combining anonymous surveys with in-depth interviews, to gain richer and more comprehensive insights.

Clinical Applications

The results of this study provide important implications for healthcare professionals and mental health specialists. In particular, categories such as "space to talk about the deceased child" and "expressing suppressed emotions" indicate aspects that professionals should pay special attention to when engaging in dialogue with the bereaved. Moreover, the importance of "empathy and shared experiences" emphasizes the value of peer support and providing opportunities for peer support alongside professional-led support. We can expect to realize more effective and comprehensive support for bereaved parents by integrating these insights into clinical practice.

Conclusions

Mothers who have lost children largely perceive grief support groups positively, reporting benefits such as increased awareness and improved management of their grief. However, the findings also highlight the ongoing challenges that these mothers face in their daily lives, underscoring the persistent and fluctuating nature of grief. The study's identification of diverse needs and the potential influence of cultural backgrounds further emphasizes the importance of providing individualized and culturally sensitive support. Therefore, grief support programs should not be limited to one-time interventions, but should offer sustained and regular support that caters to the unique and evolving needs of mothers following child loss. Incorporating flexible program structures, long-term support plans, and opportunities for peer interaction

alongside professional guidance can contribute to more effective and comprehensive support for parents navigating the complex and enduring journey of child loss grief.

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