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Evaluation of a grandparent bereavement support group in a Pediatric Palliative Care Hospice

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Abstract: This study aimed to explore grandparents' experiences of grief after the death of a grandchild, their perception of socially supportive behavior as well as their satisfaction with a bereavement support care. A six-session bereavement support group was implemented, followed by a cross-sectional survey with open-ended questions. The death happened mostly in the last 2 years (26, 90%). The findings revealed the presence of grief (mean score of 67, SD 13) and existing perception of socially supportive behaviors (mean score of 79, SD 23) after participation in the bereavement group. The thematic analysis showed three themes of 'We are feeling it; There are ways to heal and return to a different normal; We want to help our family'. This study adds to the existing literature about the experience of grandparents coping with grief, explores some of their challenges, and needs after the death of a grandchild.

Keywords: Hospice care, Bereavement, Palliative care, Grandparents, Grief

Introduction

Becoming a grandparent plays a significant role in an individual's life and the privilege to fulfill the functions associated with grandparenthood promote the wellbeing of older adults.¹ Death of a grandchild is devastating; it is the loss of grandparents' joy, their legacy, and more. Most grandparents experience complexity of pain because of their dual role of being both grandparent and parent and their efforts are mostly focused on supporting and reducing the pain of their adult children while grieving themselves.² Grief is described as the collection of internal thoughts and feelings one experiences when a loved one dies.³ When the death of a child happens, grandparent grief is often overlooked and described as 'silent or forgotten grief'.^{3,4}

Research on functioning and health outcomes of grandparents following a grandchild's death is scarce in the last 25 years.¹ Following the death of a grandchild, grandparent's grief is expressed mentally and physically,^{5,6} including experiencing crushing emotions, loss of energy, and a feeling as though their life has been permanently changed.² Additionally, grandparents who provided direct care

to their grandchild before the death are more likely to experience intense feelings of grief accompanied by clinically significant levels of depression and Post-Traumatic Stress Disorder (PTSD).¹ Grandparents reported, in different studies, that after the death of their grandchild they experienced feelings of disbelief, helplessness, depression, PTSD, more tendency towards substance use and suicidal thoughts.^{7,8}

Though the experience and effects of grief on grandparents following the death of a grandchild is significant, existing professional bereavement supports for grandparents were found to be limited, and not consistently accessible to the bereaved population encountered by the Roger Neilson House Bereavement Program. Grandparents have their own specific grief needs and to better meet their needs, the role and supporting needs of grandparents should be acknowledged.⁹

Roger Neilson House (RNH), located in Ottawa, Ontario, is an eight-bed pediatric residential hospice center which offers compassionate care in collaboration with the Children's Hospital of Eastern Ontario (CHEO)'s Palliative Care Team.¹⁰ To address the needs of grieving grandparents at RNH, a closed bereavement support group was developed

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and delivered within the context of a pediatric palliative care setting. The bereavement support group included six sessions. The themes and titles of the sessions were: (1) Telling Your Story; (2) Loss History & Secondary Losses; (3) Coping Strategies & Self-Care; (4) Impact on Relationships: spouse, children and other grandchildren (guest speaker); (5) Linking Objects and the Ongoing Connection to your Grandchild; (6) Group Graduation and Closing Transformation.

The purpose of this study was to explore grandparents' feelings of grief, their perception of socially supportive behavior after the death of a grandchild and their satisfaction with receiving bereavement support care at RNH.

Methods

Objectives

The objectives of this study were:

- (i) Evaluating the feelings of grief and the use of coping skills of grandparents after attending the bereavement support group.
- (ii) Evaluating grandparents' perception of socially supportive behaviors during the preceding month after attending the bereavement support group.
- (iii) Evaluating grandparents' satisfaction and acceptability of a bereavement support program at RNH.

Design and measures

A cross-sectional study using survey was conducted to evaluate the study outcomes of presence of grief, the perception of socially supportive behavior, and the satisfaction with bereavement support group among grandparents of deceased children at RNH. This questionnaire comprised of standardized surveys of The Texas Revised Inventory of Grief (TRIG) and The Inventory of Socially Supportive Behaviors (ISSB), accompanied by open-ended questions. The completion of the survey took 10–20 min.

The description of measures are explained as below:

- (i) *The Texas Revised Inventory of Grief (TRIG)* is a two-scale measure of the intensity of grief reactions. This self-reported scale includes three sections measuring past behavior (part I, 8 statements), present feelings (part II, 13 statements) and related facts (part III). The items in part I investigate the retrospective grief by inviting participants to recall their feeling immediately after their grandchild's death, while items on part II ask questions about the current grief feelings related to their grandchild's death. Participants are asked to rate how various statements related to their past and current feelings on a 5-point scale (Completely True, Mostly True, True & False, Mostly False and Completely False). Related Facts in part III are rated as true or false. The TRIG questionnaire also requests demographic data, such as the age, gender, religion, race and

education of the respondent. Higher scores indicate more feelings of grief. The tool has good internal consistency (alpha 0.86) and split-half reliability (r 0.88), established in the literature.^{11,12}

- (ii) The items from The Texas Revised Inventory of Grief are summed for a total score for each scale. Respondents who had high grief on both scales (Past feelings and Present feelings) are classified as having persistent grief, and those with low grief on both scales are classified as having low grief. Low grief on the Past Behavior scale and high grief on the Present Feelings scale placed the respondent in the delayed grief group. Having high grief on both scales of past and present feeling, classify respondents as having prolonged grief, and participants with low grief on both scales are classified as having absence of grief. Accordingly, low grief on the past feeling scale and high grief on the present places the participants in the delayed grief feeling, and finally high grief on the past feeling and low grief on the present scale shows an acute grief. The scores ranked below the 50th percentile are classified as low grief and above 50th percentile as high grief.¹¹
- (iii) *The Inventory of Socially Supportive Behaviors (ISSB)* is a 40-item self-report measure that was designed to assess the perception of social support, by investigating the frequencies of experiences of supportive assistance from others during the preceding month. Participants are asked to rate the frequency of each item on 5-point Likert scales (1 = not at all, 2 = once or twice, 3 = about once a week, 4 = several times a week, and 5 = about every day). This tool assesses the frequency of marital aid, behavioral assistance, intimate interactions, guidance, feedback, and positive social interactions over the past month. The total score ranged from 40 to 200, the higher the score means the person is the recipient of higher socially supportive behavior. ISSB established great reliability and validity in the literature ($\alpha = .95$).¹³
- (iv) Satisfaction with the Roger Neilson House Grandparent Bereavement Group Survey is a survey completed at the end of the six-session bereavement support group. The survey consisting of eight questions (six open ended and two multiple choice) assesses a participant's general feelings, feedback for future improvement, any challenges, and facilitators to receive quality bereavement care.

The survey was reviewed for acceptability and understandability by a group of academic researchers, health care professionals and parents beforehand. In addition, the internal consistency and reliability of the data collection tools was measured using Alpha Cronbach test in SPSS (IBM SPSS Statistics, Version 27.0. Armonk, NY). The results show a great reliability for ISSB tool (Alpha: 0.94), and good reliability for TRIG (Alpha: 0.85) in this study.

Participants

All grandparents who lost a grandchild and enrolled in the grandparent bereavement support groups offered at RNH were invited to participate in this study. Exclusion criteria were non-English speakers as the grandparent bereavement group was offered only in English, consequently the survey was only offered in English.

Data collection

All grandparents who enrolled in the grandparent bereavement support groups from October 17 to October 2017 were invited to participate in this study. They were provided with additional time to complete the surveys at the end of the bereavement support group. Further exploration of participant's grief reactions and their experience and challenges with the bereavement group was done by asking open-ended questions embedded in the surveys.

Data analysis

The quantitative data were analyzed using Microsoft Excel (2016), and SPSS (IBM SPSS Statistics, Version 27.0. Armonk, NY). Categorical variables were analyzed using frequencies and percentages. Normally distributed continuous variables were analyzed using means and standard deviations, 95% Confidence Interval (CI) and a statistical significance was set at $P \leq 0.05$. Answers to the open-ended questions were coded and entered into a spreadsheet for thematic analysis. Descriptive thematic analysis¹⁴ was used to identify common themes. The themes were extracted by the corresponding author (SM);

revisions were made to the labeling and organization of the themes and sub-themes until all authors agreed.

Ethical considerations

Ethics approval was granted from the CHEO's Research Ethics Board (REB) prior to the enrollment of any participants. Informed consent was received prior to the completion of survey questionnaires. A unique number was assigned to each participant, and the dataset contained no information that could identify participants by name. Participants were reassured prior to completing the questionnaires that they did not have to answer any questions that they were not comfortable with answering.

Results

Demographics information

Total of eligible participants approached for the study participation were 44 grandparents, out of those 31 consented to participate (70%). A total of six groups were held between October 17 to October 2017. Thirty-one number of grandparents participated in the support group and twenty-nine grandparents completed and returned the survey. The demographic information showed most participants were female (20, 74%), had college or university level education (26, 90%), with the mean age of 65 years old (SD = 8). Mean age of the child at the time of death was 2 years old, the death occurred within 2 years prior to when this study was conducted (26, 90%) and most grandparents described their experience of death and grieving as unexpected or sudden (17, 65%) (Table 1).

Presence of grief

The total number of participants who completed both past and present items of TRIG tool was 23 (79%). The evaluation of the grandparents' feelings of grief after their participation in the bereavement support group, showed a total TRIG mean score of 67 (SD = 13). Mean Sub-scores were 23 (SD = 8) for part I, and 34 (SD = 11) for part II, respectively. The means, minimum, and maximum scores of TRIG scores are listed in Table 2. In total, participants showed the presence of grief in both past and present feelings (TRIG scores, ranged from 23 to 34, higher score represent more grief). Half of the participants showed low grief feelings in both past and present timeframes. Almost half of the participants (48%) showed prolonged feelings of grief. Prolonged, acute and delated grief of participants is shown in Table 2.

Presence of social support

Receiving and accessing socially supportive behaviors among grandparents were evaluated by the ISSB tool. A total of 18 participants completed the survey (62%). The findings showed a mean score of 79 (SD 23) [Min

Table 1 Demographics information

Demographics information		N (%)
Gender	Male	7 (26)
	Female	20 (74)
Education	Missed	2
	High school	3 (10)
	College or University	26 (90)
Death time of the child	Within the past 6m	7 (24)
	6m–12m	8 (28)
	1y–2y	11 (38)
Child's age at the time of death (Days)	2y–5y	3 (10)
	Mean	875
	Min	1
	Max	4380
Grandparents age	SD	1319
	Mean	65
	Min	43
	Max	75
Description of death by grandparents	SD	8
	Expected	9 (35)
	Unexpected/Sudden	17 (65)
	Missed	3

Table 2 The Texas Revised Inventory of Grief (TRIG)

Categories	N (%)	Possible range	Observed range	Mean (SD)	Median	Low grief ^a N (%)	Prolonged grief ^a N (%)	Acute grief ^b N (%)	Delayed grief ^c N (%)	Absence of grief ^d N (%)
Part 1. Past behavior (8 items)	23	8–40	14–40	23 (8)	21	12 (52)	11 (48)	2 (9)	3 (13)	9 (39)
Part 2. Present Feelings (13 items)	28	14–55	13–55	34 (11)	34	14 (50)				

*The scores ranked below the 50th percentile
^aHigh grief on both scales of Past and Present feeling
^bHigh grief on the Past feeling and low grief on the Present scale
^cLow grief on the Past Behavior scale and high grief on the Present Feelings
^dLow grief on both scales of Past and Present feeling

47, Max 128, Median 75] which indicated the presence of socially supportive behavior among participants from their social network.

Correlational analysis and regression model

This study was not aimed at investigating the correlation or related factors influencing feelings of grief or socially support behaviors of grandparents. However, to investigate if the perception of socially supportive behavior could be predicted by feelings of grief over the course of the bereavement support group, correlational and regression analysis was

done. In the model, perceived social support was entered as a dependant variable. Feelings of grief (TRIG mean scores), and demographic information such as grandparents’ age, gender, education level, time of grandchild’s death, age of grandchild at the time of death, the circumstances of death (unexpected and expected) were entered as independent variables. The model was created with the intent to identify significant variables that can predict the perceived socially support behavior of grandparents. No single variable was found to be significant in predicting the relationship between perceived socially behavior and feelings of grief or demographic information.

Table 3 Themes emerged from written answers to open-ended questions

Themes	Codes
We are feeling it	Feeling guilty, upset, angry, exhausted with care, difficulty to relate to others, it’s different and complicated, Feeling helplessness
There is ways to heal and return to different normal	Storytelling, carry on and time heals, sharing and belonging to a group with common loss, helpful reading material, have closure, self-care, resilience, allow myself to be down, forgiveness and letting go skills, praying, remembering good memories, my feelings are normal, Sharing memories
We want to help our family	Support for siblings, engaging with our children (parents) and how to help them, be patient with our children, open communication with our children, partner, family or friends support
Suggestions for future	Better discussion facilitation, more time and less space restrictions of sessions, having a grieved grandparents as a speaker, exploring gender differences in experiencing grief, Understanding and caring facilitators, email reminder of the sessions, follow-up meetings, smoother transition from hospital to hospice care

Satisfaction with bereavement support group

Most grandparents self-reported that after participating in the RNH grandparent bereavement support group, they felt better in general (26, 90%). Over half of participants enjoyed the Impact on Relationships Session (spouse, children and other grandchildren) most and the Invited Bereaved Parent Guest Speaker session (15, 52%).

The thematic analysis of their answers showed three major themes as shown below, the list of categories and codes are listed in Table 3.

‘We are feeling it’. Grandparents described their experience of the death of a grandchild as difficult and overwhelming sad time:

All Grandparents should have access to ...
 .[support group] when going through these difficult and overwhelming sad time in their life.
 [Grandparent #17]

They added this experience is accompanied by feelings of anger and frustration.

For example: ‘I feel upset that I never got to say hello or goodbye to my grandchild. I feel cheated, angry. I am angry and frustrated’.
 [Grandparent #2]

Feelings of guilt and regret also emerged in many responses of grandparents of our study:

I wonder with everyday how she would have grown. What would be her personality? We were blaming so many things. It is like a void. [Grandparent#10]

Or

I feel that it is unfair to have somebody so young leave when we have had a full life. [Grandparent#13]

Grandparents felt helpless towards their bereaved child (parent) by adding:

“I could have done more to help our bereaved child”. [Grandparent #10]. “I was almost drowning feeling helpless, being strong for sake of my children and dying inside”. [Grandparent #12]

The next theme that emerged from the grandparents’ responses was

“We want to help our family”. Grandparents wanted to help their grieving children: “I want to be patient with my daughter and son-in-law their grief journey is very different than ours”. [Grandparent #12]

They felt the urge to step up and take care of the other siblings of the deceased child. They also felt the need for their partner be in the support sessions with them for a reciprocal family support.

... The family support works 2 ways: giving and receiving. [Grandparent #2].

Grandparents were interested in learning more about strategies on how better understand the grieving process of their children and how to help them in coping with the death and engaging them in the healing process.

We would like to understand what is the state of mind of our “kids”. [Grandparent #6]

Or

Perhaps a joint session with the “kids” i.e. our grieving children can help. [Grandparent #18]

‘There are ways to heal and return to a different normal’. Most grandparents found the feeling of belonging to a group of people with shared interests and experiences helpful:

This session was the most helpful-realized you are not alone, and experience similar emotions. [Grandparent #12]

Hearing from others during the group helped grandparents to relate to their experience as one clearly said ‘hearing X [our parent guest speaker] speak of her loss(es) and how she felt, especially in relation to her family and friends made me realize ‘how my daughter felt as a mom losing her child’. [Grandparent #22]

Just knowing how many people (families) are suffering from that one question (Why Why Why??? Did this happen to my child’s baby.). [Grandparent #20]

Participants reported different length of healing time:

I have come out of the helpless feeling, I have started keeping company of friends. Of course there are bad days. But the hopeless and helpless feeling is gone. [Grandparent #16]

While most grandparents reported positively in the responses healing from grief, some had different manifestations of grief in their healing process by stating:

I learned that grief is very differently experiencedcan be manifested very differently... - all can make a difference how our grief unfolds; and –there is no time factor (a death 20 s ago can feel like yesterday). And what helps one person may not help another. Very personal!! [Grandparent #26]

Or

The fact that it was a year since our loss I still was having issues made me feel there was something wrong with me. Your friends look at you and some make you feel “Are you still not over this?” I want to reply, “I will never be over this!” This is for life! [Grandparent #15]

Finally, participants recommended some suggestions for future improvement in the delivery of bereavement support group including having a reunion or follow up meetings and having empathic facilitators for these sessions. They also found the reading materials, email reminders of the sessions, hearing stories from others, exchanging of coping strategies, and having a support system of family and friends surrounding them helpful in supporting their healing process.

Discussion

As pediatric palliative care is moving toward family centered care, the inclusion of grandparents in the care plan is necessary.¹⁵ Pediatric palliative care teams are in unique positions to acknowledge the role of grandparents in providing holistic care addressing physical, mental, emotional and spiritual outcomes in the process of grief.¹⁵ The experience of

the grandparents in this study can be conceptualized into three main themes of feeling the emotional pain in forms of existing grief, guilt, helplessness, sadness; urge to helping their adult children, and healing by receiving social support.

The findings of this study showed the presence of feelings of grief in grandparents after participation in the bereavement support group. A study by Seecharan et al, investigating grief in parents with TRIG tool, showed that almost 2 years following their child's death parents reported an intermediate level of grief, and similar to our findings most participants showed high levels of satisfaction with the supportive care.¹⁶ However, in our study participants commonly reported feelings of sadness and helplessness because of witnessing the parent's pain. Studies showed that a major part of a grandparent's grief includes seeing their children's pain with the death, which they suppress mostly due to the fear of adding burden and worsening the situation, or feeling miserable and unfulfilled in protecting their children or being unhelpful in mitigating their pain.^{19,20} The death of a child affects the relationships between the grandparents and their adult children (the parents).¹ Grandparent's feelings of helplessness is associated with being powerless to help their child or making them feel better.¹⁷

In this regard, participants of our study felt the urge to help their children (parents) by engaging them in the support group sessions, seeking partner support, taking care of other siblings of the deceased grandchild, and reconstruct the relationship with their children. A study by Gilrane-McGarry and Ogrady showed that more than half of the parents and grandparents felt a change in their relationship with each other toward a distant or strained context upon the death of the grandchild.⁶ Effective communication and an inclusive relationship between grandparents and their children are correlated with intensity of feeling less helplessness.⁹ Grandparent grief is found to be secondary to the grief of the parents of the deceased child, and assumed that grandparents cope easier with death.²¹ While intergenerational position of grandparents causes individuals to experience emotional pain in witnessing the pain in their family.⁹ Yet, there is limited understanding of grandparents' needs⁶ with most studies showing grandparents putting their energy and efforts toward soothing their children rather than focusing on their own grief.^{5,18}

In this study, grandparents commonly described feelings of guilt toward their child's pain and not have a chance to see the life of their deceased grandchild. This feeling of guilt is accompanied by holding back to support the unity of family, this findings is also reported in Miller, Buys, and Woodbridge

(2012)'s study.²² They described the grief process of grandparents as 'feeling of cumulative pain', which includes witnessing the pain of their adult children in addition to the pain of a grandchild's death.²⁴ Leveson et al. showed that grandparents experiencing the death of a grandchild usually do not seek grief support, because they did not feel comfortable with the word 'grief'.^{15,23} Bereavement culture and legitimacy of grief feelings are not usually established for grandparents as it is well-known for parents and siblings of a deceased child.¹ That being said, bereaved grandparents have the most important supportive role in comforting their adult children, despite their own grief.²⁰

Another important aspect of grief process described by grandparents in our study was their experience with anxiety. Tatterton and Walshe identified that the lack of control over the uncertain situation adds to a grandparent's emotional feeling of pain.⁹ A better sense of control and belonging are reported as being correlated with better bereavement outcomes in grandparents. In addition, similar to our results, sharing feelings and cherishing good memories are recognized as an effective healing methods in order to cope with death of beloved ones.⁹ Nehari et al. showed that grandparents experience and report similar feelings of grief to that of parent participants after the death of a child,⁴ however they had a hard time to find someone to listen when they needed to talk and subsequently felt isolated and distant from their children. However, the grandparents in our study reported an existing perception of socially supportive behavior in their network. Perhaps, this is a surprising finding. When a child dies, it may be easier for parents to find the social support, because of receiving the attentions and meeting their needs by HCPs, families and spiritual leaders.²⁵ While grandparents' needs remained ill-recognised and their social support is driven by self-seeking behavior to their network.^{5,6} It is reported in the literature that one important aspect of receiving social support among grandparents was their employment status, unlike parents, they do not benefit from paid bereavement leave after the death of a child, which adds further stress to their existing emotional distress. Alternatively, having a job or being employed was reported as helpful to cope better and limit rumination after the death of a grandchild.²⁵

The plan of care in palliative care setting varies according to the conditions of families. Many children's death happen in infancy from prematurity or congenital complications soon after the birth, when they may need care for a few days, whereas other children may require care for years before death.^{1,2} Although the occurrence of death and grief in

palliative care context seems anticipatory to health care team, yet families may not accept the death.^{1,2} In this regard, most families of our study described their experience with death of a grandchild as ‘unexpected’. This finding highlights that families’ needs differs, when developing care plan, different expectations, and different patterns of coping and grieving in families must be considered to provide a holistic family centered care in the bereavement support care. Our findings enforced supporting the grandparents’ role in pediatric palliative care trajectory. When planning a family centered care, their dual and simultaneous roles of being a parent and grandparent must be acknowledged. Bereavement support interventions such as support groups must be concentrated on identifying unique needs and concerns of grandparents. Incorporating grandparents’ experiences, needs and concerns in the care plan is reported as contributing to better coping mechanisms with the death of their grandchildren.^{9,24}

Limitations and strengths

The experience of death of a grandchild is distressing for grandparents; however research and practice initiatives that include grandparents in the bereavement care plan are limited. This study added to the existing literature about the experience of grandparents of deceased grandchildren, their challenges, needs and role of a grandparent during the death of a grandchild. However, the small sample size may limit the generalizability of the study’s findings. In addition, participants were mainly of Caucasian decent; further research is needed to explore the experience of grandparents from minority ethnic groups to better understand how culture, beliefs and values influence grief and bereavement support in western context. In this study, differences in grief responses by gender, race, and other intersectional identity of grandparents was not explored. Future investigation into the grief bereavement of grandfathers as well as that of those grandparents who are single versus have a partner would also be of importance.

Implications

Family-centered care in pediatric palliative care setting must reflect the grandparents’ experiences of a grandchild’s death. To enhance the care quality, grandparents’ roles and positions must be recognized and available supports at the time of a grandchild’s death must be identified and be accessible to them. The findings of this study enforced the current evidence in bereavement support care for families in palliative care centers; the results can inform future policy development to be more reflexive of multigenerational need assessment of a family. Pediatric bereavement care is poised to include grandparents as integral members of the deceased child’s family

and support them when possible with bereavement services and supports. The results of this study may advise those planning for future bereavement interventions to consider and better meet the grief needs of grandparents after their grandchild’s death. HCPs needs to treat grandparents the way they do parents, and incorporate their needs into an intergenerational bereavement support care.

Conclusions

Delivery of the bereavement support group for grandparents in Roger Neilson House was received well by participant of this study. Implementation of similar programs delivering bereavement support care to multigenerational families in palliative care settings is recommended. Findings of our study reinforced that grief of grandparents is not well recognized, and their needs, roles, and positions must be incorporated fully into the bereavement support care of families to better meet the goal of family centered care. This study builds further insight into the important role of bereavement support in experience of grandparents and their reciprocal dual role (acting as both parent and grandparent) within the family at the time of a grandchild’s death.

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