



Research Article

Bereaved Grandparents-We Didn't Know Our Part

Joann M O'Leary^{1*}, Lynnnda Parker² and Lindsey J Wimmer³

¹Department of Thanatology, Marian University, Wisconsin, USA

²School of Nursing, University of Northwestern St. Paul, Minnesota, USA

³Star Legacy Foundation, Minnesota, USA

Abstract

This article presents information on the grief of grandparents whose adult son or daughter experienced a perinatal loss. Data is drawn from two focus groups of grandmothers (11) and grandfathers (9) in a Midwestern area of the US using a qualitative method. Finding addresses their changed family dynamics, the dual pain of losing their grandchild, watching their adult child's grief and not knowing how to support their adult child. Grandparents also speak to their own disenfranchised grief from their peers. Recommendations for those working with bereaved grandparents in the medical and community settings are offered to help support their needs.

Keywords: Bereavement; Family issues; Grandparents; Perinatal loss

Introduction

It is estimated that approximately 160,000 grandparents experience the death of a grandchild each year. 34,000 of those are child and infant deaths; and within this number, 72% were under one year of age [1]. This a permanent, irrevocable loss that changes bereaved parents and grandparents' relationships [2,3]. Both enter uncharted territory in how to make sense of the changed family dynamics [4]. Just as a bereaved parent needs to express their grief, so do grandparents. There are few structures in place for grandparents [5] nor do we know what they need. This article presents information from two focus groups with the goal of exploring the needs of grandparents whose adult children experience a perinatal loss (death of a baby during pregnancy or shortly after birth).

Literature Review

It has been said that the most difficult experience a grandparent may endure is having a grandchild die before them [4]. A perinatal loss can be more difficult when no one is prepared for it [6]. The loss represents what the grandchild might have been and loss of a portion of their own legacy [1]. Yet grandparents' grief has been characterized as "disenfranchised grief" [7]. Some suggest they are forgotten

mourners, not unlike fathers in the past [5]. They often feel silent, unheard [8] and forgotten by others [9-11]. They have difficulty finding a place of support and solace for themselves [1], feel their grief is "not legitimate", and describe their relationship with their adult children as "pained" [9,10]. They carry a double loss of grieving for their grandchild and witnessing the intensive grief of their adult child [1,4,8,11-14]. They can feel helpless in not being able to make it better for their adult child [3,15,16]. They have also been found to experience: clinical depression, hospitalizations, new chronic health conditions (mental disorders, hypertension, angina, cancer), and medication changes [1].

Essential tasks of grief resolution are recognition of the loss, and acknowledgement of the unique grief experienced by each family member [17-19], as well the family's relatives and friends [3]. How each generation copes with a baby's physical absence but psychological presence [20] can be uniquely different in each bereaved parent's family of origin. Grandparents may worry that expressing their grief with their adult child might increase the adult child's burden, making things even worse [21]. Asynchronous grief can occur between generations where there is a difference in how a bereaved parent and grandparent respond to the loss of a baby [14]. Thus, grief can either be inhibited or facilitated by those around them [3,9]. One study of intergenerational family support following infant loss found that more than half of the participants reported that kin relationships changed, although whether this change was for the better or worse was not identified [12].

Method

The goal of this study is to gain insight into the needs of bereaved grandparents. Understanding that humans are social beings influenced by those around them and that groups can capitalize on interactions [22], the methodology chosen was qualitative using focus groups. This effort fulfilled a request for proposals by star legacy foundation, a non-profit organization¹ that provides research and education around stillbirth prevention. While the literature addresses grandparent grief that includes pregnancy and infant loss among other kinds of loss our goal was to bring together a group of grandparents who had all experienced the loss during pregnancy or shortly after birth.

Recruitment and sample

Grandparents, whose adult children had experienced a perinatal loss and sought support from star legacy, were also seeking support in how to navigate helping their adult child. These interactions prompted development of this project to explore what this organization might provide to grandparents. The grandchildren had all died near term within the preceding 12 months except for two families, one whose grandchild had died eleven years previously and another who had lost triple grandchildren three years earlier. One baby had died in the first minutes after birth, one was a premature baby who died ten days postpartum, and all the other babies were stillborn. Within the two groups there were (11) grandmothers and (9) grandfathers. All were Caucasian, low to middle income. The first focus group was held in a private room of a library after another event that drew grandparents from out

*Corresponding author: Joann M O'Leary, Department of Thanatology, Marian University, Wisconsin, USA, Tel: +1 913732177; E-mail: jmoleary06@marianuniversity.edu

Citation: O'Leary JM, Parker L, Wimmer LJ (2017) Bereaved Grandparents-We Didn't Know Our Part. J Community Med Public Health Care 4: 029.

Received: April 17, 2017; Accepted: June 06, 2017; Published: June 20, 2017

1 - Starlegacyfoundation.org

of town. The second group was held a month later in the home of the first author.

Procedure

An invitation to participate in a focus group with other grandparents who had suffered the loss of a grandchild was posted on the star legacy foundation website. Individuals who responded were sent a letter giving information on the date, location and time of day. A consent form was developed by star legacy foundation following standard ethical procedures for the participants to understand the purpose of the group and that they volunteered to participate. In both groups at each location, parents were greeted at the door, asked to sign the consent form, provided light refreshment, and gathered around a table where they could all see each other. Before the discussion began, the moderator (second author) was introduced as someone with a background in working with bereaved parents. The facilitator (first author) led the discussion, making sure everyone had an opportunity to share their feelings.

Ethical considerations

Participants were told they were not required to answer any questions that made them uncomfortable and that they were welcome to leave at any time. They were also informed the discussion would be audio recorded with an assistant moderator in the background to take notes and that their names would not be identified in any writing or presentation of findings. Aware this could be a sensitive topic Kleenexes' were on the table. Additionally, all the authors present were experienced with bereaved families and familiar with community resources for referral. Participants that had difficult family issues and asked for more help were given referral resources in their communities after the focus groups were completed.

Data collection

The focus group question was "how do grandparents who have suffered the loss of a grandchild cope with the complex role of supporting their bereaved adult child and finding a place to express their own feelings around the experience?" These followed pre-set questions (Table 1) were used to open the dialogue for participants to share their experience. These questions helped lead the discussion and share interactions. When a grandparent shared frustration over family conflict, a follow-up comment would be offered such as "did anyone else have that experience and would like to share how they coped?"

S. No.	Focus Group Questions
1	How did you hear about the death of your grandchild?
2	What things were you able to do to support your adult child?
3	Who did you call for support when you heard the news?
4	What was helpful to deal with your own grief?
5	How has this loss changed your family dynamics?
5	Did you feel you had adequate support from your community of family and friends?
7	As we finish can you share any suggestions of what you would tell another grandparent who also has suffered the loss of a grandchild?

Table 1: Focus Group Questions.

Analysis

As procedural in using focus group research [23], the assistant moderator (second author) took notes throughout. A summary of the first focus group was debriefed and processed between the facilitator

and assistant moderator immediately after and later transcribed verbatim. This transcription was reviewed together before the second focus group was held to explore how to improve discussion. Once both groups were transcribed, the first two authors met again to analyze and review original questions, categorizing them into themes. Themes were identified through inductive analysis to gain insight to their lived experience, not to test a set of hypotheses. The findings below demonstrate the themes derived from the participants in both groups who found common ground in their feelings of grief and frustration in how to help their bereaved adult child while coping with their own grief.

Findings

Hearing the news: The discord of hearing grave news when anticipating the birth of a healthy grandchild was shocking to grandparents. Rather than the joy of birth, they heard "we lost the baby." except for one baby who had a genetic diagnosis; all the grandparents described "text book pregnancies" and were unaware that anything like this could happen.

I was just like screaming in the bedroom, what do you mean you lost the baby? She's 39 weeks!

No signs of anything during the entire pregnancy except she is overdue at 41 weeks and scheduled to be induced. He texted me at 7 am saying we're checking in. At 8 am he called and I thought-wow that's fast. An hour later and no heartbeat. He was perfect, beautiful and they never found what went wrong.

My daughter found out at her 20 week US that he had potter syndrome-no amniotic fluid. He was born at 33 weeks. Beautiful, he lived for 48 minutes and we didn't expect that. We heard him cry and thought that (crying).

Other grandparents were miles away when they heard the news and rushed to get to their adult child. One grandmother describes the drive as "the longest six hours of my life."

Our son called said "they can't find his heartbeat. Please come as quickly as you can. "To hear your son in a situation of wailing is first child for them, our first grandson.

Knowing their adult child tried to get help and was dismissed by the health care provider added anger alongside the grief. For example, one daughter had called her mother concerned about her baby's activities.

She called the doctor and they said 'oh it's fine-lay on your right side and count. Later that night she called and said, "I just feel like there is something wrong. The next morning, she woke up and there was no movement. She went to the hospital and they took the child C-section-it was devastating. It still is.

Another grandmother was told the baby was a "healthy preemie" and had gone home after seeing her when she received the news of the death.

I'll never forget it. The hell they must have gone through by themselves. I just crashed-what the heck do I do? That was just the most horrible day of our life.

Supporting their adult child: Grandparents lose their grandchild but then feel helpless as they watch their grieving adult child. They tried to let the bereaved parents lead, which was difficult for some.

You want to be supportive but you worry someone will be offended.

I don't feel that I miss my grandchild as much as I hurt because my daughter is in so much pain and I just can't do anything for her.

I am having a difficult time. When I bring up the baby she cries and wants to change the subject. So, I don't know how to comfort her.

Watching the look in your own child's eyes and know the pain they are feeling and there's not anything you can do. You can't comprehend how they are feeling. I'm just always on edge and trying to find a balance. How much do I say and how much is too much? I want to keep his memory alive and I didn't want to intrude on their grief and what they were doing.

[The parents] are so private that they dealt with it themselves so we really had to dig to be involved.

Coping with milestones: The discussion around how to cope with holidays, first birthdays and family events was another theme shared by all the grandparents. They didn't know what to do because nothing made sense anymore. Some went away for Christmas while others decided not to do Christmas and changed family traditions. Some bought ornaments in honor of their grandchild but did not share that information with the adult child, fearing their response. We didn't know how to handle her first Mother's Day. We went to the Dominican Republic for Christmas and didn't celebrate at all.

I give her cards signed from the kids. I think it really helps her. The next thing was Mother's Day and I said what do you want to do with the holidays this year? The kids were cremated she said I would like to take the kids to the zoo. So, we packed them up in blankets, put them in baskets and she carried the basket the entire day. It made her feel good. I'm sure people wondered what we were doing but I didn't really care.

I did buy myself the grand babies first ornament because I wanted one that was dated. But I was careful that she [daughter-on-law] didn't know that.

The tears are just below the surface. I say his name all the time. Somebody suggested a candle to bring out whenever we have a family even-just something there to remind us that he would be here. Others donated to organizations that support children or did benefit walks to honor their grandchild. Some people buy gifts for babies that would be the age he would be and donate to the Ronald McDonald house. And I put a note in there about him.

We do a benefit walk once a year and get together. It's a small group-it's so sacred and private. They just don't want anyone else involved because the reactions they get are either no reaction or unresponsive.

The grandparent's grief: Finding a place to tell their story and process their own grief while not being a burden to their adult bereaved child was difficult for all of them. Universally, they discussed "the double pain" of their grandchild's loss, witnessing their adult child's grief and trying to understand the best way to support them.

Being a parent and a grandparent we double grieve. I think I grieved almost more. I was just doing everything I could to hold it together-basically go to work and then sob all the way home. God, the pain just never goes away.

It's different being the dad's mom too because it's all about the mom. A part of me feels private and I'm whining about not getting any support as a grandparent. But I feel like they got a lot. To a certain extent, they came through it better than I did-they had a group they

went to. I was online and I found nothing. It's the daughter-in-law and I feel like she looks at me like-"why are you like this? It isn't about you". I don't want to make it about me- but it is.

I don't know if anyone else can relate, but I've lost a part of me. I'm not the same person-I react differently to situations, my temper is different, I'm much more outward, straightforward. So, as a mom they lost a part of a mom too. We lose a part of our kids. The whole dynamic changes and you feel so helpless.

My coworker's wife is having their second and I didn't realize how resentful I was until Wednesday of this week but I got resentful with him.

We can't grieve more than they do. It's hard for them to see us grieve and you want to be strong for your kids. Would it be better for them to see you sad or appear as though you've gone on? That balance is really hard.

Changed relationships

As noted in the literature, the changed dynamics in the grandparent's relationship with their adult children was a strong theme in both focus groups. Some of the grandparents had trouble knowing how to help because of the privacy issues with the bereaved parents not wanting to share. Others acknowledge things have never been the same and were grieving the relationship they had before the loss.

They were very private through all of it. They didn't tell people about the diagnosis until she was born. To plan to lose a baby at birth-they just didn't know so they kind of went underground. Even now they get very little support. His name is hardly ever mentioned by his family.

If you have a child that is willing to talk you are lucky. Our son is great and is open but he can't even get his wife to express to him what is going on-It's difficult because you're back to this 'what to do' and so you withdraw because you don't want to step on a landmine. It's difficult from an in-law perspective-if it had been our daughter it might be different. There just are so many dynamics here that are hard to get your arms around.

I didn't just lose my grandson I lost my son. We were always so close. He would tell me everything. It's been three years and we hardly ever talk anymore.

Seems like it happened yesterday and [our daughter] has never been the same since. We used to be quite close. Our little girl isn't our little girl any more-she is very different. We talk but it isn't the same.

Family dynamics also change when other family members are pregnant. Now aware babies can die grandparents struggle with how to celebrate another adult child's pregnancy. Some also felt frustrated with their other children who were not understanding of their bereaved sibling.

The rest of the family members really stunk [siblings to bereaved father]. In general I believe they don't know what to say so they just don't say anything. We have another grandbaby coming in another few weeks. I want to be happy for her and buy things for the baby but on the other hand it's so hard to count your chickens before they are hatched. I'm scared to death-bitter sweetly happy. Every time I see an infant I have a flashback to that incubator [deceased granddaughter].

Anticipation of a subsequent pregnancy was also addressed as being changed. There would not be baby showers before knowing a

healthy child would be the product. It's pretty-well been decided that if there is another child there will be no purchasing there will be no showers; that will all happen after the birth of the child so they won't have to go through that once again.

Like the bereaved parents, the grandparents were also aware of changed behaviors in family gatherings and with friends. This was difficult for the bereaved grandparent observing painful encounters. They struggle with not knowing how to help their adult child.

She came home for [nephews] baptism last weekend and it was tough for me to watch her. She didn't know if she could come home for Thanksgiving and see two infants at mom and dad's house and [her daughter] not be there.

There are triggers that are unexpected. I always think of him as a baby so when I see babies its hard. But she thinks of him as the age he should be.

Our daughter's sister-in-law just gave birth. There was some tension between them anyway. She won't say anything but we know that it's so painful knowing that at family gatherings there are supposed to be two babies not just one. I can't help but think she is resentful.

Recognition that a grandchild in the family is missing can be as difficult for the grandparents as it is for the bereaved parent. They need to talk about their missing grandchild too yet their grief was disenfranchised by others. This added another layer of grief not understood by others. The following quotes illustrate the lack of understanding that society has around perinatal loss and that, no matter how small, a deceased baby matters. Some quotes also speak to society not understanding such a loss impacts more than the mother/parents.

There's no one else to talk to. I don't know if you've noticed too that friends you had before this child was born; if they had a grandchild that was born even a year either direction of this. After a while the friendships kind of slip away and they're thinking, "They're still talking about that baby?"

Sometimes people are just totally oblivious. One night we went to a restaurant [after the loss and birth of subsequent baby] and one of our very best friends made some comment like-oh now you can sit at the grandparents table. My heart just exploded because I've been a grandparent for 3 years.

Friends and family have been cautious about talking about their grandkids but I've told them they are proud of their grandkids and I don't want to stop them talking. I just try to grin and bear it – it's their joy.

They don't mean to be cruel and insensitive but they don't understand. I think it is both men and women-I've had ladies say-"that happens- she'll have another one". Some people are ignorant and all you can do is blow it off.

You want to be supportive that they didn't do anything wrong but no baby will replace him. I had a male coworker whose wife had a miscarriage some time ago. He said yeah, my heart goes out to your daughter because this really affects the women. I thought-whatever, jerk.

Lack of identity and recognition as a grandparent can be especially painful when it was someone from their immediate family.

Last weekend I was a group of people that I went to high school with and they were all talking about their grandchildren. They said how about you two? My sister said we don't have any grandchildren

and I said-well I have one in heaven. She gave me the look and I'm like-really? I think she realized after she said it that she totally screwed up.

I only have one sister who is the only one that has not been there for me. Every time I would talk about the kids she would not say anything. Finally, I said I am really hurt that you don't acknowledge the kids. She blew up at me-"I just knew this was coming. I was there at the funeral, we sent flowers." She thought that was all she needed to do. I didn't talk to her for a year. You would think your flesh and blood should be more compassionate than anyone else.

Finding support

Despite most hospitals having protocols at the time of loss and offering literature and referrals to community programs for bereaved parents, resources for the extended family are lacking.

We were so lost in all of it- we didn't know what our part was.

The hospital was very useless-all they did was bring us a book "when a baby dies" Thank you-that's not helpful. We're not religious so I didn't want a pastor or priest. The hospital had no clue. They don't understand from a personal perspective what the families are going through.

We live isolated, farmers in the communities where they probably talk a lot less. There is nothing-it's very difficult-nobody to talk to.

There really isn't much information available to grandparents-we've done some reading to try to figure that out.

Something that really isn't talked about. If I say we lost a granddaughter I'm amazed at how many stillbirths happens but not talked about.

Grandparents are usually the first person called by parents. Many are at the hospital when the baby is born but are equally lost in knowing what to do for their grieving adult child. One suggestion by the grandparents in the groups to help and not burden their adult child was to provide resources just for grandparents.

In both focus groups, the need for someone to just be there and listen to them was important, yet lacking for most. I think just having that ear on the other end of the phone of someone that understands what you are going through.

There are a few online resources for parents, but for grandparents there isn't anything. Searching online you can find blogs but that isn't the same kind of connections.

Something [the hospital] can say; here is a list you can call in any time zone. We thought if we could get a phone tree going-it doesn't matter where they are-it just matters that you can talk to someone who understands.

One hospital did provide an outside resource; a loss doula for the bereaved parent and a bereaved grandmother to support the grandparents².

She came to the hospital and spoke to us as grandparents and really, really helped us a lot in terms of what to expect and how people would react and not to judge people because people just do not understand. I think that would have been amazing to have a grandparent's perspective at the hospital.

The 11 Angels³ were there right away helping them. She said right away-I know someone you need to talk to. She called and came the morning (my daughter) was induced.

2 - Starlegacyfoundation.org

3 - Starlegacyfoundation.org

Shortly after I was just a basket case and looking to reach out to someone-anyone that got it. I called the March of Dimes and started to explain-and she stopped me and said I know an organization that can help you more than I can. I'll never forget it. We talked for two hours and it was wonderful.

Such a loss can also be a strain on the grandparents' relationship when they may be grieving very differently. My husband majored in psychology so wanted to talk and I didn't. One night he totally blew up at me and walked out and said we need to go somewhere. He was up all night and found compassionate friends-so we went to a meeting. Wouldn't you know the first meeting was people who had lost an 18-year-old and older? The [topic] was about don't let death define them-remember the good times. So, we were like-this is totally not helpful. Death is the only thing that defines our grandson. It wasn't for us.

Other grandparents found helpful resources; one on Facebook with a woman she had never met.

I messaged her and said I know we've never met but I'm in the hospital with my daughter and my grandson died and he's not born yet. She stayed up with me all night long, was an absolute light to me and saved my life that night. I went through all the anger, not knowing what to do and I had to make all the phone calls [telling others]. I called her when I was on the way to get my hair cut for the funeral screaming into the phone. She was wonderful-a complete and total stranger but we had a complete and deeper understanding.

Universally the grandparents found the focus group extremely helpful and wanted more such gatherings. They found commonality, realizing there were other people out there who were also hurting for a deceased grandchild and experiencing a different, sometimes strained relationship with their adult children.

Groups like these-other grandparents. Sometimes it's good to tell the story over and over because eventually you can tell it without crying quite so much.

Discussion

The purpose of this study was to explore the needs of grandparents whose adult children had experienced a perinatal loss. Focus groups are planned groups that share a specific topic to gather information from participants to "express their views with greater clarity because of the social processes that occur in conversation around a topic" [22]. This was the first time most of the participants had met with other bereaved grandparents, who had also lost a grandchild before birth or in the first few minutes of life thus the dialogue was rich and purposeful.

The grandparents in both groups reported feeling alone and isolated in finding support for their grief, confirming what others have found [1,8]. They also felt they could not burden their adult child [21]. One grandparent was told by her daughter-in-law that it was not "even her grief". Rather than facilitating discussion and sharing the loss [9] this grandmother was inhibited in processing her feelings. This quote can be a helpful guide for those working in the hospital or community setting with bereaved families and brings up the question who cares for the caregiver and helps them in their isolation [5]. Grandparents are often the one who cares for older siblings at home, or, as a grandmother in one of the groups did, stayed with the bereaved family for two weeks cooking meals and monitoring (at the request of the parents) who could come into the home. At the time of perinatal loss, it is common for health care providers to remind parent's men and

women can grief differently. An added message to offer might also be to acknowledge the difficulty for extended family members to support the bereaved parents.

It was not just the trauma of losing their grandchild, but watching their adult child grieving and the transformed relationships with their son and daughter that was difficult. This has been described by others as a 'cumulative pain' [9] causing confusion as to what to say and how much to say without interfering with the bereaved parents' grief. The conflict in how much support to offer or not offer between the bereaved parents and grandparents has been found by others [3], Grandparents described a changed relationship [12] in not knowing how to give support, some unsure how to help and worried that they might say the wrong thing. This caused some to hold back things they were doing to honor their deceased grandchild, not letting the bereaved parents know, fearing their reaction may not be positive. Two of the grandparents expressed anger similar to that of bereaved parents who were dismissed by their health care provider and the baby died. Unlike what was found by other bereaved parents who wanted to hear their baby's name [3], three grandparents reported not feeling comfortable using the deceased baby's name in conversation. This was perceived as too painful for the bereaved parent.

Holiday gatherings were also shared by the grandparents as painfully changed. As found by others [5], some reported the bereaved parents distanced themselves from family and friends. Only one family felt the loss strengthened a relationship between siblings of one of the bereaved couples. These grandparents felt it would be helpful for social and health care workers interacting with these families to provide suggestions for ways to change family gatherings, especially in families who are uncomfortable talking about a deceased baby. For example, simply having a candle burning at the table for a missing family member can be a powerful message.

Lack of acknowledgement of their continued role as a grandparent and the inability to express their grief around families and friends was discussed at length. As reported by others [24], some grandparents found their social networks unwilling or unable to let them talk about the loss. Like bereaved parents, they were expected to "be over" their grief in a certain amount of time [25] and perceived they should no longer be talking about their grandchild [26]. This confirmed to the grandparents the lack of recognition by society that a deceased baby in the family matters and their grief was disenfranchised [7], unrecognized as a family tragedy [27]. That said, some of the grandparents reported family and friends participating in fundraising events for deceased babies and others donated toys in memory of the deceased baby. This is a message that can be offered to grandparents, co-workers, and relatives to honor someone who has suffered a perinatal loss.

Although one grandmother spoke of "death defining her relationship" with her grandson, building on the current research and knowledge of an unborn baby's competencies it can be helpful for professionals working with both the bereaved parents and grandparents to help them build memories. This can be done by sharing memories of the time the baby was alive during pregnancy. For example; sharing that an unborn baby can hear by 16 weeks' gestation means the baby knew the voices of family members. Like the grandmother that took her deceased triple grandchildren to the Zoo on mother's day, grandparents can also share places they were together as a family during the pregnancy, reaffirming that the baby was already part of the family [28]. The deceased grandchild will always be missed but also always remembered. For bereaved parents who are not open to this, as might

happen, grandparents can do this on their own and keep it until the bereaved adult child is ready to share more.

Limitations

The primary limitations to this study are related to the recruitment of participants. These grandparents were all individuals who had sought out support and involvement through a non-profit organization. Replication of this study with grandparents who had not actively sought support may identify other needs. The lack of racial and financial diversity may also affect the findings. Finally, the participants in the current study did not have their own experiences with perinatal loss, which may be affecting how they are processing this grandparenting event and relating to their adult children.

Summary

This study provides insight into the needs of grandparents and confirms that such a loss affects more than just the parents. Perinatal loss specific to bereaved grandparents was identified. Just as bereaved parents feel isolated after a perinatal loss, so do the grandparents. Now in this study, it is the exploration of what would be helpful to grandparents whose adult children experience a perinatal loss and are struggling with these challenges. While the phenomenon occurs in the medical setting, it is when people move back into the community that support becomes most important for all family members, not just the bereaved parents. Grandparents reported having a lack of information on how to help their adult child, being silenced by family and friends, and feeling isolated in what to do with their grief. Such resources are lacking in the communities represented by these families. The need to educate the public in community settings such as churches and professional organizations around perinatal loss is also lacking. In addition, with research suggesting grandparents can experience health issues after the loss of a grandchild, the medical community also needs awareness of this when treating grandparent age patients. Both the bereaved parents and their extended family struggle in their adjustment to who they are in their changed relationships. Life is never the same again.

References

- Youngblut J, Brooten D, Blais K, Kilgore C, Yoo C (2015) Health and functioning in Grandparents after a young grandchild's death. *J Community Health* 40: 956-966.
- Detmer CM, Lamberti JW (1991) Family grief. *Death Studies* 15: 363-374.
- O'Leary J, Warland J, Parker L (2011) Bereaved parents' perception of the grandparents' reactions to perinatal loss and the pregnancy that follows. *J Fam Nurs* 17: 330-356.
- White DL, Walker AJ, Richards L (2008) Intergenerational family support following infant death. *Int J Aging Hum Dev* 67: 187-208.
- Murphy S, Jones KS (2014) By way knowledge: Grandparents, stillbirth and neonatal death. *Hum Fertil (Camb)* 17: 210-213.
- Walsh F, McGoldrick M (2013) Bereavement: A family life cycle perspective. *Family Science* 4: 20-27.
- Doka KJ (1989) *Disenfranchised grief: recognizing hidden sorrow*. Lexington Books, Lexington, England.
- Reed M (2003) Grandparent's grief – who is listening? The forum: Association for death education and counselling 29: 1-3.
- Gilrane-McGarry U, O'Grady T (2011) Forgotten grievers: an exploration of the grief experiences of bereaved grandparents. *Int J Palliat Nurs* 17: 170-176.
- Nehair M, Grebler D, Toren A (2007) A voice unheard: grandparents' grief over children who died of cancer. *Mortality* 12: 66-78.
- Ponzetti J, Johnson M (1991) The forgotten grievers: Grandparents' reactions to the death of grandchildren. *Death Studies* 15: 157-167.
- Ponzetti J (1992) Bereaved Families: A Comparison of Parents' and Grandparents' Reactions to the Death of a Child. *Omega* 25: 63-71.
- Oikoneen J, Brownlee K (2002) Family therapy following perinatal bereavement. *Family Therapy* 29: 125-140.
- Rando T (1986) *Parental Loss of a Child*. Research Press Company, Champaign, USA.
- Fry P (1997) Grandparents' Reactions to the Death of a Grandchild: An Exploratory Factor Analytic Study. *Omega* 35: 119-140.
- Hayslip B, White D (2008) The grief of grandparents. In: Storebe M, Hannsson R, Schut H, Storebe W (eds.). *Handbook of bereavement, research and practice*. American Psychological Association, Washington, D.C., USA.
- Jordan J (1990) Loss and family development: Clinical implications. Paper presented at the 98th annual convention of the American Psychological Association, Boston, USA.
- Laakso H, Paunonen-Ilmonen M (2002) Mothers' experience of social support following the death of a child. *J Clin Nurs* 11: 176-185.
- Walsh F, McGoldrick M (1991) *Living Beyond Loss: Death in the family*. Norton, New York, USA.
- Boss P (2006) Ambiguous Loss Theory: Challenges for Scholars and Practitioners. *Family Relations* 56: 105-111.
- De Frain JD, Jakuls DK, Mendoza BL (1992) The psychological effects of sudden infant death on Grandmothers and Grandfathers. *Omega* 24: 165-182.
- Côté-Arsenault D (2013) Focus groups. *Routledge International Handbook of Qualitative Research*. Routledge, Abingdon, UK. Pg no: 307-318.
- Krueger RA, Casey MA (2015) *Focus Groups: A Practical Guide for Applied Research*. Sage, Thousand Oaks, USA.
- Jones K (2013) *Parental Perspectives on Grief and Loss Following Perinatal Death*. Saarbrücken, Germany: Lambert Academic Press.
- Umphrey LR, Cacciatori J (2011) Coping with the ultimate deprivation: Narrative themes in a parental bereavement support group. *Omega (Westport)* 63: 141-160.
- Carlson R (2012) Helping Families Create Keepsakes When a Baby Dies. *International Journal of Childbirth Education* 27: 86-91.
- Fernandez R, Harris D, Leschied A (2011) Understanding Grief following Pregnancy Loss: A Retrospective Analysis regarding Women's Coping Responses. *Illness, Crisis & Loss* 19: 143-163.
- O'Leary J, Warland J (2016) *Meeting the needs of parents pregnant and parenting after perinatal loss*. Routledge Publishing, London/New York, USA.