Forgotten Mourners: Grandparents & Adult Siblings
Joann O’Leary, PhD, MPH, MS

How Many?
• 160,000 grandparents experience the death of a grandchild each year
• 34,000 are child and infant death
• 72% under one year of age (Youngblut, Brooten, et al, 2015)
• Currently little information on adult siblings
Experience Multiple Losses

- Loss of grandchild/niece or nephew
- Cannot fix adult child’s/siblings pain
- Still carry their own grief

What does the literature tell us?

- Is their grief legitimate?
  - Disenfranchised
  - Silenced
- Forgotten by others
- Helpless in supporting the bereaved parents
- Expressing their own grief may be a burden
- Grandparents risk for health issues (Youngblut, et al., 2015)

The Bereaved Parents Perception

- Can feel responsible for their parents sadness
- May hold back information
- Conflict in grandparents not talking about the deceased baby

Bereaved Parents Request

- Acknowledge the deceased child as part of the family
- Keep pictures of deceased child visible in the home just as other grandchildren
- Appreciate the deceased child as a continued family member in the pregnancy that follows

Sibling Grief

Pilot Focus Group

O’Leary, Parker, & Wimmer, (in press). Bereaved Grandparents: We didn’t know our Part. Journal of Community Medicine & Public Health Care
Focus Group Questions

• How did you hear about the death of your grandchild?
• What things were you able to do to support your adult child?
• Who did you call for support when you heard the news?
• What was helpful to deal with your own grief?
• How has this loss changed your family dynamics?
• Did you feel you had adequate support from your community of family and friends?
• As we finish can you share any suggestions of what you would tell another grandparent who also has suffered the loss of a grandchild?

Hearing The News

• Except for one family all “normal pregnancies”
• I was just like screaming in the bedroom, what do you mean you lost the baby? She’s 39 weeks!
• 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.
• It was devastating; still is.

Supporting Adult Child

• We didn’t know our part
• What are the boundaries?
• I lost a grandchild so all I can do is support them...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.
Coping With Milestones

• We didn’t know how to handle her first Mother’s Day.

• We changed our tradition too – just made it less – like any other day. I did buy myself the grandbaby’s first ornament because I wanted one that was dated. But I was careful that she [daughter-on-law] didn’t know that.

Changed Relationships

• 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. It’s so hard.

• Seems like it happened yesterday and [our daughter] has never been the same since. We used to be quite close. We talk but it isn’t the same. She is so withdrawn now.

• I feel alienated because 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?”

Grandparents Grief

• 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.

• 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.
Finding Support

- We live isolated, in communities where they probably talk a lot less. There is nothing – I’ve made calls to [larger hospitals in their state] and it’s horrible. 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.
- There are a few online resources for parents but not enough of those either – but for grandparents there isn’t anything. Searching online you can find blogs but that isn’t the same kind of connections.

Remembering the Life...

- Lighting a candle at family gatherings
- Memorial walks
- Donations:
  - Toys for Tots
  - Volunteering at Ronald McDonald
- Starting a non-profit
  - To help pay medical expenses
  - To help pay mortgage

Wisdom of Grandparents