

Short Communication

When I Die...Parents of Children with IDD

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Abstract

A brief summary of a parental bereavement research project for persons with intellectual/developmental disabilities (IDD) is provided. The author advocates for not just more research but pleas for palliative care and hospice providers to pay focused attention to family members with IDD. Recommendations are made for palliative, hospice and bereavement providers to better fulfill our obligation to these underserved family members.

Keywords

- Intellectual and developmental disabilities
- Palliative care
- Hospice care
- Bereavement
- Grief

INTRODUCTION

I have heard the ache in mothers' voices when asking "When I die, will anyone know how to support my son or daughter in grief?" Their sons and daughters have intellectual/developmental disabilities (IDD). Some have autism; Down syndrome, head trauma, fetal alcohol syndrome (FAS) or other syndromes. Their abilities vary. But my hope is that I can answer "yes" to these parents more often. Persons with IDD are in our communities, our families and on our caseloads and we need to reach out to support these individuals and families. Not that long ago, life expectancies for persons born with IDD were quite short. Adults with IDD are now living longer due to many factors, like advances in health care, social support and advocacy [1]. But now, like all of us, most persons with IDD live long enough face the inevitable loss of parents, friends, and co-workers. Eventually, they will face their own death. Research and training has been slow to respond to the need for end of life care and grief support for this population. I think, as do others, that we are missing out [2]. As an academic, my research is bereavement in adults with IDD. My part-time practice is bereavement counseling for individuals with IDD. I was inspired by pioneers in the field that brought attention to persons with IDD, like Tamar Heller, Marsha Mailik Seltzer, MaureenOswin, Sue Read, Stuart Todd, Jeffrey Kauffman and Kenneth Doka among others. I have seen disenfranchised grief as proposed by Kenneth Doka. I have witnessed the multitude of secondary losses of home and activities that challenge the surviving son or daughter with IDD [3]. I believe the losses and the disenfranchisement begins even earlier for the family members with IDD who are in the sidelines of palliative and hospice care for their parents.

In my studies on bereavement and IDD, I have gently untangled the narratives of grief woven into the fabric of living with IDD. The stories about loss are multiple, very visible strands that tie the narratives together. It is hard to overlook the recounting of losses after losses. Moves, job changes, family

changes, activity changes, and staff changes, provide repeated themes. But unheralded evidence of resilience and wisdom are offered by these individuals.

MATERIALS AND METHODS

With University Institutional Review Board approval, three adults with IDD (two female and one male ages 22-59) and four guardians (all female ages 54-72) were interviewed about parental bereavement. Recruiting was done through the local ARC and community agencies serving adults with IDD. The guardians who participated included two mothers and, two sisters. The semi-structured interview questions were based on questions used with permission from a study team headed by Marsha Mailik Seltzer at the Waisman Center, a University Center on Excellence in Disability and a social support index to address reciprocity in care used with permission from Tamar Heller.

This small focused interview project on parental bereavement led then to two unfunded online surveys on bereavement and death understanding. One survey was designed for self-advocates with IDD (adults with IDD who function without a guardian). Another survey was designed for guardians of adults with IDD. Survey response was lower than expected, despite partnering with Sib Net, reaching out to Arc's and People First groups. The number of self-advocates participating in the survey totaled 16(9 male; 2 transgender; 5 female).The number of guardians participating in survey was 37 (32 females; 4 males; 1 transgender).

RESULTS AND DISCUSSION

Despite the small numbers of participants, content analysis of the guardian interview narratives and surveys of self-advocates and guardians provided several informative themes. The first theme was the "value of and need for death education/preparation". All of the guardian interviews supported the importance of providing early death education. The survey responses strongly supported the need for educating persons

with IDD about the life cycle in childhood and having information provided about death. Guardians interviewed as well as survey participants believed strongly in early death education. Information serves to help people prepare for and cope with death.

The second theme was “spirituality”. Family and individual spiritual beliefs came into play as death is explained. Spirituality was clearly represented in the narratives of the adults with IDD, as they tried to make sense of death. In the survey responses for both guardians and self-advocates, spirituality was a frequent tool for explaining death and meaning of life. Spirituality also played a major role in coping with loss.

Because in spite of what is said there is no sadness in heaven, I mean I can conclude that he can see the good times but not the sad ones. (Participant with IDD)

She thinks her dad is in heaven, and he is with his friend and the dog is there. You know she has this picture in her mind of where her dad is and she does say, He's not coming home. (Guardian).

The third theme was “inclusion”. The interviews all reflected efforts or values about including the adult with IDD into end of life care of the dying parent when possible (if the parent lived locally). The inclusion theme was present, but due to the use of scaling, the rich narratives were absent. Of the nine respondents, six indicated some level of reciprocal care at the end of life from the son/daughter to the parent. Two adults with IDD who were interviewed provided their views on being included in the care of their dying parent:

Mom didn't like to be alone so I was with her, like Fridays and on the weekend. Mommy was diagnosed with Alzheimer's um, back at the time there were a lot of things going on. I would write my sister a letter... She was forgetting this and that. (Interview participant with IDD).

We were taking turns of taking care of him and my time was at night, and I woke up and ate my breakfast and my mom said my dad passed away. And, um that was really hard. For a long time I didn't let my mom know that... I was mad at her cuz she didn't wake me up. That she thought that he would have lasted longer than what he did. (Interview participant with IDD).

The fourth theme was “dealing with parental grief” which was present in both interviews and survey data. Adults with IDD described bonds of love and care that continue on beyond death. The adults with hard lessons learned and advice to share about grief. We need to listen.

[Advice for people who are grieving] If they know of a pastor, they might talk to a pastor. They could tell them, they lost their mom, or their dad... Maybe he could go pray with them and give them some kind of comfort. (Interview participant with IDD)

[Advice for people who are grieving] Focus their anger in a constructive manner. At least try...I know anger can overwhelm you pretty quicklyif I break something, not to

break it against someone else. (Interview participant with IDD).

In my clinical work I assist adults with IDD to reconstruct and revisit joyful memories of being with the parent to treasure and carry forward. The following participant with IDD eloquently spoke to the importance of these memories.

I came home on the weekends. After getting dressed, Mom would be in the living room with her Bible and I would sit by her. And sometimes she'd be right in the middle of a paragraph and I would stop her and say, Mom, what does this mean? Like areas I couldn't understand. And she'd stop reading and explain it. Sometimes we'd take turns reading. ..Like she'd read for a while and then she'd let me read. So when Mother's day comes that the one thing that just lifts me up... I hold onto that memory when its' Mother's day, I hold onto that (Interview participant with IDD).

In addition, a surveyed guardian also provided support for the usefulness of memories.

She has done well; she speaks to his picture or the heavens when she is missing him. It's short and to the point and then she moves on with what she is doing. (Surveyed guardian)

Survey responses from guardians on advice to help the adult child deal with grief included:

Allowing her to talk about it as much as she needed to, or whenever she needs to.

Sharing stories and memories of him with her.

I would say his routine.

She will see pictures of my mother occasionally and thinks about her.

Having me take care him.

Having fun activities to look forward to, family time with us two other sisters and cousins.

Talking to him about it.

Open communication about the death, getting her back into her school/daily routine as quickly as possible, doing activities to honor my mother (a big one for our family is to write notes on balloons and let them go in the sky). My dad always makes sure to give her a gift from my Mom on holidays she's often heard saying, "my mommy sent me this from heaven". He'll leave the gift in a common area for her to "find".

Although the findings provide some guidance for providers, this series of studies had several limitations: The small scope naturally limited generalizability. Time and funds for further interviews were not available. In an effort to expand the study without any funding, an online survey for persons with disabilities was developed, based on the interview questions. Although the online survey was less time consuming than interviews, it was limited in effectiveness. Persons with IDD and guardians, as well, may have been uncomfortable with or challenged by the online format. In addition, recruiting relied heavily on outside agencies or organizations sharing the survey. Those who were

able to respond may be very different than other guardians or persons with IDD in their beliefs or experiences. Despite the limitations, the study provided evidence of the needs of adults with IDD and their families about end of life and grief issues. There are recommendations that can be made when adding these results to the existing literature. I believe the themes from these narratives can offer insight for end of life and palliative care teams, as well. Death education needs to be provided as early as possible. Palliative care and hospice teams have access to materials and resources to help families prepare all members for inevitable death of loved ones. Palliative care, hospice workers and bereavement staff should acknowledge that family members with IDD do utilize spiritual coping. Chaplains and clinical staff should ensure access to spiritual support for all family members, including those with IDD. Inclusion is crucial. I strongly recommend that palliative and hospice teams ask how the person with IDD has contributed and be included in ideas for supporting the dying parent. Ask both the family members and the person with IDD. What is a meaningful contribution by one person may be overlooked by another. In bereavement work, I often utilize the stories clients tell about how they provided care to their loved one. I see this as helping the bereaved client recognize their contributions and strengths. The bereaved can explore how their efforts helped provide the dying with care and support in their last months, weeks and days. Team members should also ask what the concerns the sons and daughters with IDD have about the death, about grief. It is essential, if the parent was the guardian or care taker for the adult with IDD, what planning has been done to transfer care, residence or guardianship as death moves closer. Finally, grief support should be available, if needed for persons with IDD. Grief counselors can work on grief education for persons with IDD and those who support those using materials such from Books beyond Words Publishers such as *When Mum Died* Hollins & Sierling, 2014 [4] and other titles. Knowing the effects grief can have may normalize the raw and sometimes scary darkness that can overwhelm. Group support, expressive arts, and bibliotherapy are interventions being utilized with success [5]. Online resources are readily accessible such as Rutger's (2013) "End of life Resources". Books have been published on grief and persons with IDD such as [6] text, *Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers and* [7] *Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers*.

CONCLUSION

The population with IDD is aging, and parents of sons

and daughters with IDD are facing death today. They worry if palliative care and hospice providers will be willing and ready to serve their adult children with IDD. We need more researchers to provide additional evidence of what is needed and what works best for persons with various types of IDD. We also need for those who work in end of life care to receive the wisdom of those with IDD, to witness their stories, to sit with them as they prepare for the death of parents. There is not always ready evidence to guide us. I believe we need to educate ourselves, but then, at least attempt, what we might be unsure of. I believe it is worse to overlook someone who needs end of life care than to embrace the unfamiliar and do our best to support them.

Even though people with IDD have a wide range of abilities from the physical, cognitive to the emotional realms, we owe it to them, their parents, and their loved ones to puzzle out what they need and what they have to offer. They are not afraid to teach us what they know, what they need, and how to provide it. We need to ask. Individuals with IDD should receive the same consideration, the same level of care as those without disabilities. Inclusion of family members with IDD needs to expand in palliative care and hospice care. Inclusion early on may help the bereaved son or daughter with IDD prepare for and realize their contributions to a dying parent. They are facing the death of their parents today, and tomorrow, and next week. They will continue their journey with or without us. I believe the death and grief journey can be less painful and more meaningful with our support.

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