

“HONOUR THY FATHER AND THY MOTHER”: GIVING CARE AND GRIEVING FOR DYING PARENTS IN FRAGMENTED FAMILIES

By John M. Mulder

Abstract: The situation is uncomfortably familiar. A woman died. As is customary, her husband and children were present at the funeral home. But so were a variety of other family members: her first husband, the children by her first and second marriages, her step-children through both husbands, grandchildren from each marriage, and various aunts, uncles, and cousins—all reflecting the complexity of a family in modern America.

Leading up to her death was a process filled with loving caretaking but also fraught with difficulties that often led to misunderstandings, tension, and conflict. After the woman had been diagnosed with cancer, questions arose as to who would provide care for her during her last months. She had been taking care of her husband, who had Parkinson’s, and he too now needed care. Which family members would become responsible for both of them? What support could be provided by organizations outside the family, including and especially the church?



Rev. Amy Zietlow

This situation lies at the heart of a new study by Amy E. Zietlow, Elizabeth Marquardt, and Naomi Cahn, sponsored by the Institute for American Values and funded by Lilly Endowment, Inc. Zietlow is an ordained minister in the Evangelical Lutheran Church and served as Chief Operating Officer of the Hospice of Baton Rouge in Baton Rouge, LA. Cahn is professor of elder and family law at George Washington University.

The project investigates “how young and mid-life adults who came of age in an era of high family fragmentation are experiencing the aging and dying of their parents and parent figures, including how the church might be uniquely equipped to lead the way for a culture grappling with end of life issues in a changed family landscape.”

“Right now,” the research proposal states, “the literature on death and dying has a large and glaring gap. It largely assumes an intact family experience—that is, an experience in which persons grow up with and raise their own children in

families with a married mother and father—and that persons confront the aging, death, and dying of family members within those settings.”

The researchers focused “on the point of view of the generations who came of age amidst the precipitous rise in divorce rates that begin in the late 1960s, followed by more recent and dramatic increases in unwed childbearing, as they now confront the aging and loss of their parents and parent-figures. Parents and parent-figures might include divorced or unmarried mothers and fathers, step parents, parents’ current or former live-in partners, ex-step parents, and others.”

On the basis of their research, Zietlow, Marquardt, and Cahn identified four different care giving paradigms based on the parent or stepparent in need of care:

- the married parent where the healthy parent serves as next of kin;
- the divorced and/or single parent where the grown child serves as next of kin;
- the remarried parent where the stepparent to the grown child serves as next of kin;
- the remarried parent’s new spouse, also known as a stepparent, where the grown child’s biological parent serves as next of kin.

The paradigms reflect the complexity of family reality, but in the midst of these different families and their relationships, Zietlow and Cahn have discovered insights on how families can care for one another, even unto death, and how churches might support them during the last pilgrimage of life.

Zietlow and Cahn have written several articles on the research: “Honor Your Father, Mother, Stepmother, Stepfather, Mother’s Partner . . .: Reciprocity and Gender in 21st Century Elder Care and Law,” which was presented at a Religion, Feminism, and Law conference at St. Thomas University; “Digital Planning,” published in the May/June 2014 volume of *Probate and Property Magazine*, and “‘Making things fair’: An Empirical Study of How People Actually Approach the Wealth Transmission System,” presented at the May 2014 Law and Society Conference. They continue to write about their research for popular audiences as well, including *Slate*, *Huffington Post*, and *The Atlantic*.

In an interview, Zietlow described this intriguing and ambitious research project and what they have learned. The text has been edited and abridged for publication.

Q: This project must have been difficult because the subject(s) are so multi-faceted. Whom are you studying, and how did you go about your work?

Zietlow: Through our project, we wanted to study how the shape of your family shapes your care-giving and grief experience. Although many Baby Boomers are currently caring for their own parents in the “greatest generation,” the Baby Boomers were the first generation to see wide-spread divorce, decreased family size, increased geographic mobility, and increased single parenthood. How would this impact the care they receive from their children?

We interviewed mid-life adults, aged 28-50, often called Generation X. Their mom, dad, or stepparent who died a year prior to our interview was 70 years old or younger, i.e., a member of the Baby Boom generation. The deceased had an obituary published in the Baton Rouge, Louisiana newspaper, but the grown children of the deceased hailed from across the country.

We spoke to 38 females, 24 males; 3 Hispanics, 24 African Americans, and 35 Caucasians. In terms of birth order, 20 were the oldest child, 13 the middle child, 13 the youngest child, 5 were the only child, and one was adopted. Our sample reflected current Baby Boomer family demographics: one-third from first and only married parent families, one-third from single parent families (many divorced and now single), and one-third from remarried parent families.

After obtaining informed consent, we used a semi-structured interview of open-ended questions that included:

- creating a drawing of their family when they were a child,
- describing their home and family rituals as a child,
- the story of divorce/remarriage/cohabitation, if applicable,
- describing their church/faith home growing up,
- the time before, during, and immediately after the death of their parent or parent figure,
- describing the funeral and burial,
- sorting through the belongings of their parent and the inheritance,
- and lastly, coping in the past year, how private and public rituals have changed, what spiritual beliefs have been helpful, and their reflections on the commandment, “Honor your father and mother.”

Q: What are your conclusions about each of the four groups you studied? What actually is the impact of family fragmentation on the aging, death, and dying process?

Zietlow: Our interviews gave us a rich description of four distinctly different experiences of the serious illness and death of a parent or stepparent and we are convinced that these differences stem from the structure of the family itself.

1. *A grown child of married parents.* These children experience the death of their mom or dad within a web of support. They experience the illness and death of a parent with a surviving parent who serves as next of kin, a role which carries the full burden of decision-making and hands-on, day-to-day care. This surviving parent relies on the grown child to help make those decisions, but the grown child is spared carrying the full burden alone. The surviving parent also tends to be an active source of support and comfort for the grown child.

2. *A grown child of a single parent.* The parent might be widowed or divorced. These children experience the death of their mom or dad as a confrontation with loneliness. The grown child who assumes responsibility as next-of-kin carries the full burden of decision-making and providing hands-on care. That child must often mediate the conflicting opinions of siblings as well as the extended family of their parent, and frequently did not feel supported by other family members.

A poignant example can be seen in the conflicts over cremation. In Louisiana, if a person dies without a will or an advanced plan that authorizes cremation, then the surviving spouse must agree, and in lieu of a spouse, *all* children of the deceased must authorize cremation. Despite knowing the wishes of a deceased parent as well as the potential cost savings (at least half of our families would be considered lower middle or poverty class), several groups of siblings of single parents could not agree on cremation.

Thus, the mourning process began in a conflicted and difficult place. The grieving grown child must settle the estate of the parent alone and often cares for other members of the family in the midst of their own grief.

3. *A grown child who cares for a remarried parent.* The grown child’s stepparent serves as next of kin for the dying parent. This experience is filled with conflict. Throughout the journey of care and grief, two different stories of the family exist—one of the families before the arrival of the stepparent and one of the families after the arrival of the stepparent.

The remarried parent has often established new family rituals and values that now differ and often conflict with the rituals and values of the previous rituals of the family. Simple as well as heated misunderstandings break out between the stepparent and the grown children of the dying parent. The grown child often unwittingly competes for the attention of the dying parent and many times disagrees with the health care proxy decisions made by the stepparent.

The conflicts can rise into high relief at a funeral where the grown child becomes hyper-sensitive as to where everyone sits. Grown children can be pushed to a second row instead of sitting in the front row, a place of honor, where the stepparent and his or her family would be seated.

Most of our interviewees note that they have had very little contact with the widowed stepparent in the past year now after their connective parent is gone.

4. *A grown child who cares for a step-parent.* This is the other side of the coin for the remarried parent family. In terms of the dying stepparent, the grown step child is markedly distant and objective. If they participate in the care of the dying, it tends to be directed toward supporting their biological parent in their role as next of kin. If they reach out to the step parents’ family, support comes in more cursory forms such as sending an email or reaching out on social media. They often see the conflicts their parent is going through with their stepsiblings, usually over inheritance, and they side with their parent.

So, our overall conclusion is this: The care of the dying, the experience of death, and grieving a family member is overwhelmingly affected by family structure.

Q: What surprised you in your findings?

Zietlow: Nine out of the 40 deaths of single parents involved the support of the ex-spouse. The grown child still acted as the next of kin for the dying parent in terms of making medical decisions, meeting with clergy to plan the funeral, and assuming all financial responsibility for the care and burial of their dying parent.

However, the ex-spouse supported their grown child by sitting with the ill parent during the day so that the grown child could work or by coming to the hospital or being available by phone as a sounding board for the grown child. Many attended the funeral, although few sat next to their grown child.

We were surprised to learn that social media accounts are valuable narratives left behind after death. They are similar to treasured photo albums or sentimental keepsakes.

Social media can be a lovely community of support for those grieving; it can connect us to people from every stage of our lives and those at a great geographic distance. These interviews were conducted in 2011, before the huge rise in Facebook, Instagram, and Twitter and thus we heard people wrestling with these questions for the first time.

The location of death did not surprise us since, based on the age of the deceased (ages 50-70), most died from sudden accidents, complications from surgery, heart attack, or cancer.

Eleven died at home, surrounded by at least one family member; 5 died at the home of the child who was caring for them; 25 died at the hospital with at least one family member with them; 5 died in a hospice inpatient unit with at least one family member; and 9 died alone in their home.

We were saddened to see that of those who died alone, all were single or estranged from their spouse and grown children. All were struggling with drug or alcohol addiction. One was incarcerated.

The commandment to honor your father and mother inspires the impetus to care for a parent, even when a parent has been emotionally volatile or abandoned the child for brief periods of time in his or her childhood.

Our interviewees found creative and wise ways to protect their own personal boundaries, refusing to be victimized by a parent, while still living their belief in this ethic. Many cared for a hurtful or dysfunctional parent as an expression of their own faith and belief in showing loving kindness or grace to the vulnerable.

It was interesting that many of our interviewees were very mystical. They experienced the presence of their mom or dad in different moments, or they would hear a song at just the right time, or they would have a dream where they would be with their mom and their dad.

In the last analysis, I found these interviews to be kind of a moment of beauty. They were tremendously sacred time, sitting with people and receiving the story of their family and their parents. All of the stories that we heard had moments of deep, deep pain and brokenness, from incarceration to verbal abuse to alcohol abuse to the scars of having served in war. Every single family had challenges that they were carrying with them.

Sometimes people think that there is a perfect family or only one way to talk about family life. I believe that these people found out: Your family is normal. And they found the process of talking to me therapeutic, one of the important lessons for clergy we learned from the study.

Q: You started out with a sample of about 1,500 people, but only 63 agreed to be interviewed. What do you make of this high level of resistance to talking about the death of a relative?

Zietlow: There are two reasons, one related to the methodology of our research and one to the topic itself.

First, the response rate is typical for qualitative studies that require a two-hour time commitment. On a practical level, many potential participants simply cannot budget that much time. Invitees also had no connection to us, and we were inviting them to entrust us with the sacred story of their family and their grief.

Many participants came after they researched the Institute for American Values. Some came because they knew about the particular church where we were conducting interviews. Some agreed to be interviewed because they were able to read our work on the internet and see that we are legitimate researchers.

In addition, few people talk to *anyone* for two hours about *anything*, let alone about something as vulnerable as death. Most interviewees admitted that they had not talked to anyone about the death of their parent since it had occurred a year ago. But remember: these were 63 people who made time to come and talk to me for two hours!

Many were fearful of crying or “losing it,” but all expressed value for “talk therapy.” Many were encouraged to come by a spouse or parent who read the letter and told them that they should “go talk to someone.” The process of being interviewed was an opportunity for the participant to reflect on how he or she had adapted to the loss.

Based on the gap of support we observed, as well as the positive impact of telling one’s story at this turning point in grief, we are developing a Bereavement Interview Tool inspired by the questions we used in the study. It can be used by pastors or elders of a congregation with someone who is grieving a loss around the one-year anniversary of the death.

We realized that many of those we interviewed were longing to tell their story and simply needed an invitation and someone willing to give their time to listen. Clergy and church members often struggle with how best to support someone grieving, and this tool seeks to fill that need.

Q: Let’s assume you are speaking to an audience of pastors. What are the three most important things they should know about ministering to the dying and their families?

Zietlow:

1. *Pastoral care:* Your pastoral visits in the hospital, the ER, the home, etc. are remembered in vivid detail and are much appreciated. Your spiritual role in that stressful time gives stability to the moment. People appreciate that you care deeply about them and their loved one but are not emotionally impacted in the same way as they are by the crisis. You are a safe person to break down with and cry with. They can ask you to act as their advocate with medical or funeral home professionals.

2. *Funerals:* Funerals can bring out all kinds of tensions, ranging from choice of music to choice of pallbearers. Where people sit at the funeral is far more important than we may realize. People remember almost nothing of the funeral beyond snapshot memories. They remember faces of people who attended, photos, flowers, who said a poem or eulogy, and most importantly where they sat.

For families where the deceased was remarried, you should intentionally talk through with the widow and the grown children where they plan to sit. If the grown children feel dishonored by where they sit, this memory will dominate their remembrance and cause a rift between them and the widowed stepparent.

In addition to seating arrangements, a funeral is filled with many different props from flowers, to pall, to candles, to pall bearers, etc. Because our memories of the funeral are so visual, our interviewees remembered all these pieces and parts but did not understand their full meaning. They simply assumed “this is what you do for a funeral.”

We recommend having education materials that could be shared with families or using a part of the funeral service as a teaching moment to walk through the meaning of these symbols.

3. *The Grieving:* A year after a loss, the grieving person feels ready to revisit their “identity narrative” or their life story, and reflect on their experience in the light of the death of their parent. We would recommend intentionally making a pastoral visit at the year anniversary of a loss. Also, because very little is remembered about the content of the funeral service, sharing a copy of the sermon from the funeral and even the aforementioned educational material about the elements and symbols used at a funeral would find a receptive audience at the year anniversary.

Q: You did your research in Baton Rouge, Louisiana. Did you find there were differences in the caring/grieving experience between Protestants and Catholics and those with no church involvement?

Zietlow: There are no significant differences for those within faith communities (Protestant, Catholic, etc.). Clergy and the church are a source of support (practical, emotional, and spiritual). When a death happens, there is a protocol that kicks in that will carry the grieving family individuals through the immediate days after the loss.

The year following a death is often marked by profound existential doubts, and those within faith communities have a spiritual vocabulary that can be questioned, challenged, and learned anew through the lens of loss. Spiritual practices such as worship attendance, Bible study, and prayer are both familiar and comforting but also can change as individuals live with loss. God often speaks to them through visions, dreams, art work, and music.

Very few of our interviewees would be considered “nones,” except one who confessed he was an atheist at the start of our interview. But his atheist beliefs actually led to dramatic changes in his life after the death of his father. He, like his dad, was overweight, smoked, and suffered from heart disease. As he watched his dad die, he realized, “Oh my. That will be me soon.”

Because he believed that this is the only life we get, he knew that he wanted to live life as fully as possible. In the year since the death, he had lost over 100 pounds, had trained for and run a half marathon, and was preparing to move out West in order to “have an adventure.”

Q: Finally, what are the most important things you want religious leaders to know about your project?

Zietlow: Grown children who care for and grieve a single or remarried parent need a higher level of support from congregations and clergy as well as from society as a whole.

The likelihood that the majority of the 30-50 year olds in your congregation fit into this category of dealing with dying and grief is very high. It will only increase as the baby boomers enter into their 80’s and 90’s.

My co-author, Naomi Cahn, is a professor of elder law, and we have strong suggestions concerning Family Medical Leave and filial responsibility laws. We found that most grown adults are making sacrifices of time, energy, and money

(willingly) on behalf of the myriad of parent and parent figures in their life. Filial responsibility laws that punish the failure to care would not have made them do more than what they had already done. Good news!

However, few knew that they could potentially access a benefit like the Family and Medical Leave Act, which would provide protection for their job and up to 12 weeks of unpaid leave. Several reforms to FMLA would be beneficial as well. It needs to be *paid* leave, and the list of eligible kin needs to be expanded to include grandparents, stepparents, and ex-stepparents.

Also, much can be done by parents to plan in advance for when they can no longer make healthcare decisions for themselves and for their death and burial. Grown children experienced tremendous relief and peace of mind when they realized that their mom or dad had made arrangements for the funeral and burial. For single and remarried parishioners, completing these advanced care documents is all the more critical and could be something clergy propose during preparation for the marriage ceremony.

We highly recommend that clergy and congregations use *5 Wishes*, an advanced health care planning document, which can be downloaded at the website: www.aqingwithdignity.org.

Those are practical steps, but I think overall what we saw across the board is just this: Everything is going to be all right, and how you get there is unique and very different. Your family is different, and how you deal with dying and death and grief are going to be your own.

Almost everyone has some regret: “I wish things had gone this way or I wish I had known this or I wish things had been different.” Even in that moment, they are able to look back and make sense of it within the light of the love they have known and who they are in this world. Overall, there was a general sense of peace with the person who died.