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Taking Care of a Dying Grandparent: Case Studies of Grandchildren in the Hospice Caregiver Role

Jaime R. Boquet, BA¹, Debra Parker Oliver, MSW, PhD², Elaine Wittenberg-Lyles, PhD³, Ardith Z. Doorenbos, PhD¹, and George Demiris, PhD¹

¹School of Nursing, University of Washington, Seattle, WA, USA

²Family and Community Medicine, University of Missouri, Columbia, MO, USA

³Department of Communication Studies, University of North Texas, Denton, TX, USA

Abstract

This study aims to provide insight into the role of grandchildren as informal hospice caregivers. It presents 4 cases that highlight the challenges and perceptions of grandchildren who care for a grandparent at the end of life. A researcher met regularly with family caregivers to discuss the problems or challenges during hospice caregiving. Although each caregiver presented unique individual experiences, several themes are common among the family caregivers including fatigue, stress, guilt, and loss of the “grandchild” identity. Grandchildren caregivers often take care of 3 generations (grandparents, parents, and children) and in many cases need additional assistance to help them overcome the challenges associated with managing a household, career, family, and caregiving roles.

Keywords

hospice; caregiving; grandchildren; coping; caregiver burden; family relationships

Introduction

As the United States faces a significant increase in its aging population, greater attention is being given to care of the elderly and its impact on family. Although the effect of aging family members on family caregivers has been explored extensively in the literature, the majority of research has focused on the caregiving experience of adult children. Few studies have explored the caregiving experience of grandchildren who care for their grandparents. Meanwhile there is a growing social phenomenon of grandparents who raise their grandchildren,¹ and thus there is likely to be an increase in grandchildren who serve as primary caregiver for their aging and/or dying grandparents. Given the aging demographic

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Corresponding Author: George Demiris, School of Nursing, University of Washington, BNHS-Box 357266, Seattle, WA 98195, USA
gdemiris@uw.edu.

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trends, an increased number of adult grandchildren will be called to assume the caregiving role for both their grandparents and parents. The caregiving role is essential to the delivery of hospice services where the patient–caregiver dyad is at the core of the hospice philosophy.

There are not many studies in scientific literature highlighting the challenges associated with the caregiving role for grandchildren. Tompkins qualitatively explored the relationship between grandchildren and their grandparents within the context of a caregiving role.¹ Through structured interviews, Tompkins found that grandchildren who are currently being raised by their grandparents feel that they have a responsibility and must “pay back” what their grandparents have done for them. Similarly, Dellman-Jenkins et al found that grandchildren who care for their grandparents do so out of feelings of attachment, and adult children were more likely to report feelings of obligation.²

A qualitative study by Waldrop et al³ explored the decision-making processes of caregivers who make the transition to an end-stage caregiving role for their family members. The study included only 1 grandchild as a primary caregiver, however, the qualitative data gathered during the semi-structured interviews suggest that end-stage caregiving can have varying characteristics and significant stressors on caregivers, including family role conflict, work conflict, and financial strain. The grandchild in this study accounted for less than 5% of the sample, and thus emphasizes the need for the caregiving experience of grandchildren to be further explored.³ Perhaps one of the most remarkable qualitative studies to date was completed by Fruhauf⁴ in which face-to-face semi-structured interviews were conducted with 17 grandchildren caregivers. The grandchildren reported that “family values, making grandparents happy, and preparing for the future were how they made sense of their role.”⁴ Fruhauf found that grandchildren experienced benefits and drawbacks as a primary caregiver, and that their parents served as mediators and distracters to their role.⁴ Furthermore, the grandchildren seemed to have an ability to adapt to caregiving situations and were able to cope in a way that allowed them to be successful caregivers. Fruhauf emphasizes that health care professionals should consider grandchildren as primary caregivers when establishing support groups, programs, and resources.⁴

The purpose of this study is to provide further insight into the role of grandchildren as caregivers in the hospice setting. The study aims to increase understanding of the challenges and perceptions of grandchildren that assume the hospice informal caregiving role for a grandparent at the end of life.

Methods

To describe the caregiving role of grandchildren in the hospice setting, we focused on 4 case studies. These case studies are part of a larger study that examined a problem-solving intervention for hospice caregivers described elsewhere.⁵ As part of the intervention, a member of the research team met regularly with family caregivers to discuss the problems or challenges during hospice caregiving. Family caregiver eligibility criteria included being primary caregiver of a hospice patient in one of our participating hospice agencies in the Pacific Northwest of the United States, being mentally able to provide consent, read and

write English, and have a telephone line. For this study, we extracted data sets of family caregivers who were taking care of a grandparent receiving hospice services.

We pursued a phenomenological approach focusing primarily on in-depth interviews and sessions where members of the research team worked with grandchildren caregivers through problem-solving interventions. These sessions were audio-taped and transcribed. Additional quantitative data included psychometric assessments to capture family caregiver quality of life, problem-solving skills, anxiety levels, and demographic data. Assessments were completed at the baseline and at study completion. The actual study intervention involved 3 to 4 interactions with the research team members (approximately 1 hour long per session) over a period of a month.

Audio-tapes and transcripts were reviewed by 2 members of the research team. The analysis focused on perceived challenges, advantages, and concerns associated with the caregiver role for grandchildren. Thematic coding provided us with a list of emerging themes. The themes generated by the 2 coders independently were merged and the resulting set of themes was confirmed with a second round of coding for a subset of all transcripts/audio-tapes. Furthermore, in order to provide the context and details for each of the grandchildren cases, notes taken by the researchers during the intervention, demographic, and psychometric data were compiled to establish background information for each case.

Results

Four grandchildren caregivers were recruited in the study and the detailed cases are described below. Names were altered and details regarding age, occupation, and educational background were eliminated to prevent recognition. Two of the cases involved grandchildren caregivers for patients living in an adult family home. Adult family homes are licensed private residences that provide room and board for up to 6 adults and deliver personal and social care and supervision.⁶

Mildred

Mildred was a Caucasian female in her 40s employed as a health care provider. She cared for her grandmother diagnosed with Alzheimer disease, who resided in an adult family home. The most difficult challenge identified by Mildred was dealing with the perceived responsibility of serving as the “communication hub” for her grandmother. Mildred stated that she was functioning as a buffer for her mother and aunt regarding her grandmother's status. Due to her clinical expertise, her mother and aunt preferred that she would take on the role of primary caregiver even if this role was originally assumed by her aunt. An additional reason for the family to prefer Mildred as the primary caregiver was her geographic proximity to her grandmother. Mildred found it very difficult to carry out the caregiving roles in a way that would please everyone involved; however, she felt she needed to aim for that as she called herself a “perfectionist.”

Although hospice had provided some relief, when asked by the researcher how she was responding to situations, Mildred stated, “Capably, but reluctantly ... [I must choose] key language [and] key phrases.” She expressed anxiety and fatigue trying to take care of her

grandmother and also satisfy the expectations of her mother and aunt who were relieved not to have the caregiving responsibilities but wanted to be informed and updated on the grandmother's status. Specifically, communicating updates on the grandmother's status became really difficult for Mildred as her mother wanted to receive information the same timeframe as her aunt. A conference call was not practical because of the busy schedules of all family members, which resulted in Mildred spending additional time trying to keep everyone updated. She reported that she felt "being squeezed" by her family members and having to prove she could manage her caregiving duties well.

During the intervention, Mildred worked on coping strategies such as maintaining a guestbook in the grandmother's room. The guestbook included updates for all the family members as a way to reduce phone calls and individual meetings. Mildred did schedule a face-to-face meeting with her mother and aunt to discuss details of the memorial service. As Mildred stated, she made an effort to "tune into my negative emotions around communication with family members, to explore what those feelings might be telling me, and how to create positive experiences."

The main themes identified in all interview sessions with Mildred included feelings of guilt and fear of underperforming as a caregiver, challenges in communication with family members, and frustration/anger resulting from lack of recognition of one's contributions. An additional theme pertaining specifically to the caregiver being a grandchild was that of a perception that the caregiving demands will never cease (as Mildred expressed concerns that soon she would be repeating the same tasks and facing the same challenges as her mother's caregiver).

Martha Jane

Martha Jane was a Caucasian female in her 50s employed by a private company. She cared for her grandmother with congestive heart failure and dementia, who resided in an adult family home. Martha Jane's most significant challenge was trying to find time to visit her grandmother more regularly and attend to her caregiving role in spite of her very busy work schedule. Martha Jane's mother and aunt were recently deceased, and she did not have additional next-of-kin to take on responsibility for visiting with her grandmother. She tried to stay positive stating, "[It's better to] deal with problems rather than be upset about it." In addition to making time to visit her grandmother, she was dealing with personal issues regarding her son, a recently born grandbaby, and a demanding job. Martha Jane emphasized that the decision to place her grandmother in a home was the most challenging care decision. She repeatedly expressed her anxiety that so many people (including her husband, son, daughter-in-law, and grandson) depended on her and reduced any available time she had for her grandmother. Martha Jane explained, "[I'm] trying not to use up my energy on negative things." However, she did experience physical symptoms including fatigue and stomach problems. She realized the increased demands on her scheduling explaining that she "can't be everything to everyone."

When she visited her grandmother, she found these interactions challenging, explaining that her grandmother "never wants me to leave." Over time she found that she had less time to visit her grandmother: "[I will] try to get there during the week if I can, I am more

comfortable winging it, [it] stresses me out if I plan it, and I can't make it.” One of the highlights for Martha Jane during the study was bringing her grandmother to a family function, when another relative helped with the logistics which was unexpected but appreciated. She continued to struggle with the challenge of the visit schedule, “I'm not letting it affect me if I can't get over there more than once a week ... but [I] have to get there once a week, unless I'm sick or something.”

The main themes identified in sessions with Martha Jane included feelings of guilt about missed visits, decreased time spent with her grandmother, and competing demands on time and attention from other family members.

Charlie

Charlie was a Caucasian male in his late 40s, who cared for his grandmother diagnosed with debility. He was unemployed and resided with his grandmother in her private residence. Charlie's biggest concern in caring for his grandmother was her safety, specifically her risk for falls. He reported a somewhat low quality of life for himself acknowledging poor health habits. He believed that his grandmother was well taken care of, “She's a lucky woman. [She is] financially secure, [and receives] lots of support” but he felt that he had to face his own unemployment, recent divorce, financial strains, and other family issues that made the hospice experience more challenging for him. He explained, “[It is] discouraging beyond what you can imagine.” When asked how he would address problems, he stated, “[I will] avoid it until it's in my face.” His concerns regarding his grandmother's safety were addressed when hospice installed bedside rails for his grandmother; after the second visit Charlie decided to withdraw from the study citing he did not have the desire to work on a plan for problem solving. The research staff referred him to his hospice agency social worker for further consultation and notified hospice staff of the low self-reported quality of life scores. The main themes identified in the limited sessions with Charlie included competing demands on time while facing other stressful life events (which in this case were exacerbated by his problem-solving style characterized by avoidance of resolving issues until they became critical).

Nancy

Nancy was a Caucasian female in her mid-30s employed by a private company. She resided with her grandmother in her private residence. The patient was suffering from debility, and Nancy's biggest concern was determining how to have meaningful conversations with her grandmother, and to be a granddaughter, rather than just a caregiver. Nancy had experienced significant bereavement during the prior 4 years. She lost her mother 4 years ago, and her grandfather died just 2 months prior. She moved in with both grandparents when her grandfather was ill with pancreatic cancer and had remained with her grandmother while still maintaining her own residence. Nancy's grandmother lost her will to live after her husband passed away, and although she was on antidepressants, she did not leave her bedroom. Nancy and her sibling hired home health assistance to help relieve some of the caregiver burden.

The patient had a history of over-the-counter drug abuse, and Nancy was beginning to feel overwhelmed and resentful. She was having difficulty juggling her job and her relationship with her partner, along with caring for her grandmother. The patient recently accused Nancy's partner of stealing her medication. When asked how she was handling caring for her grandmother, Nancy said she kept her spouse "out of sight" and she kept "her head down, [and her] mouth shut." She said that as a caregiver she always thinks, "How do I want to be treated when I'm her age?" However, she expressed distress that "[she didn't] get to be her granddaughter anymore."

Nancy believes that her grandmother sees her caregiving as a replacement for her husband (Nancy's grandfather). She has many confusing and broken conversations with her grandmother; however, some conversations are "crystal clear." She was able to have a very meaningful visit with her grandmother when Nancy's cousin came for a visit. During this visit, Nancy discovered that her grandmother had some unresolved issues from her past. Nancy explained that the experience was fulfilling and was a nice change from focusing on caregiving tasks. She recalled several joyful moments including one where she sat next to her grandmother and together they looked at pictures.

Despite these tender moments, Nancy felt that she was carrying a heavy burden and had resentment toward siblings who were not assisting with any of the caregiving responsibilities. She felt guilt for feeling frustrated as a caregiver and obligated to care for her grandmother, explaining that she promised her grandfather and her parents that she would make sure her grandmother was well cared for. Although Nancy's goal was to periodically be "just a granddaughter" it was very difficult for her. The caregiving demands increased when her grandmother developed an eye infection and a bladder infection. Additionally, her grandmother started having frequent episodes of urinary incontinence and not realizing what had happened. After some time, Nancy decided that it would be best for her grandmother to be in an adult family home receiving professional care, so she can move back to her own residence, spend meaningful time with her grandmother, and allow others to carry the caregiving role. She came to the conclusion that her own parents and grandfather would not want her to feel so unhappy and burdened, and she stated that this conclusion allowed her to process her feelings of guilt and failure as a caregiver.

The main identified themes included feelings of guilt, challenges in communication with family members, frustration resulting from lack of recognition of one's contributions, and perceptions of one's identity as caregiver which may be in conflict with that of a grandchild.

Discussion

Although each caregiver in this study presented unique individual experiences, several themes are common among the family caregivers. Fatigue is a common factor for Mildred, Martha Jane, and Nancy. Exhaustion due to family and work that is a significant component of middle age makes their caregiving role even more challenging. This may perhaps be a distinguishing factor among grandchildren caregivers who are often middle aged and focused on career and family, as opposed to older caregivers who may be caring for their spouses or parents. Literature has focused on the challenges of the so-called sand-which

generation, namely people who provide care at the same time to children and parents.⁷ Our participants were in an even more challenging situation where they in many cases provided care to children, their parents, and grandparents, assuming a caregiving role for 3 generations. Stress was also a common theme for all 4 participants and seems to be a result of trying to manage multiple roles—mother/father, spouse, worker, caregiver, and so on. The participants in this study are managing these multiple roles without significant support from other family members, which leads to significant stress, and even physiological symptoms, as exemplified by Martha Jane.

Guilt is also described by Mildred, Martha Jane, and Nancy. Although the source of guilt is somewhat different for all 3 caregivers, guilt may be a unique experience for grandchildren caregivers. For example, Mildred experienced guilt when she could not be the perfect communication hub for her grandmother, Martha Jane experienced guilt when she could not find adequate time for her grandmother, and Nancy experienced guilt for being the “dictator” rather than a caring granddaughter to her grandmother. In all of these instances, guilt appears to evolve from an obligation to fulfill a family role. This suggests that commitment to family roles may be stronger for grandchildren caregivers compared to other family caregivers. This aligns with previously reported findings that attachment and reciprocity are primary motivators for providing care to grandparents.² Future research should address the relational history between grandparent and grandchild caregivers, as family commitment may be stronger for grandchildren reared by the grandparent receiving care.

It has been reported that the impact of the grandparent's decline does not predict satisfaction, contact, or investment in the grandparent–grandchild relationship.⁸ In this study, grandchildren were aware of the loss of their “grandchild” identity as they took on the caregiver role. Caregiving responsibilities decreased the opportunity and time to fulfill the grandchild identity. Findings from these case studies suggest that grandchildren are additionally burdened as caregivers due to a perceived lack of recognition or assistance by other family members which is consistent with other research.⁹

Although this is a study of individual cases, the case studies presented mirror similar research documenting that the majority of caregivers are granddaughters.² Still, there are several implications highlighted that can be considered when addressing the needs of grandchildren caregivers. The results of this study suggest that these caregivers could benefit from interventions that address the challenges of dealing with multiple roles that lead to feelings of fatigue, stress, and guilt. Grandchildren caregivers may need additional assistance to help them overcome the challenges associated with managing a household, career, family, and caregiving roles. It is plausible that they also need to be encouraged to reach out to other family members, friends, and community programs to help them manage their caregiving role. Grandchildren caregivers may also benefit from support groups specifically designed for addressing the unique needs and challenges of grandchildren who see themselves taking care of parents and grandparents. In summary, the caregiving experience of grandchildren presents unique challenges, and further studies must address this emerging issue as our country continues to face a significant increase in its aging population.

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