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Accounts of Family Conflict in Home Hospice Care: The Central Role of Autonomy for Informal Caregiver Resilience

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Abstract

End-of-life caregiving is a highly stressful experience often fraught with conflict and tension. However, little is known about the ways family conflict manifests for informal caregivers of home hospice patients (IHCs). Framed by relational dialectics theory, the purpose of this study was to provide nurses and other health care professionals with an empirical understanding of how IHCs experience family conflict and tensions associated with caregiving. A second aim was to determine what strategies IHCs use to manage these family conflicts. Data used in this qualitative secondary analysis were originally collected as part of a randomized clinical trial of an IHC support intervention. Based on thematic analysis of data from 25 IHCs who reported family conflict, a conceptual model of caregiver resilience was developed from the themes and categories that emerged during the coding stage. Autonomy was identified as a central tension. IHCs used several strategies to address family conflict including communication, formal support, and emotional self-care.

Keywords

home hospice; palliative care; informal caregivers; family conflict; resilience

Hospice care is delivered by an interdisciplinary team of professionals who provide specialized care to patients with life-limiting illnesses and their families. In the United States, this service is extended to individuals with a life expectancy of 6 months or less; approximately 1 million Medicare beneficiaries die each year while enrolled in a U.S. hospice (National Hospice and Palliative Care Organization [NHPCO], 2018). Although U.S. hospice agencies typically provide care in a variety of different settings, most patients

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receive care in a private residence or community-based facility with significant support from informal caregivers (NHPCO, 2018). Informal hospice caregivers (IHCs) are the relatives, partners, friends, and others who provide a broad range of typically unpaid care and assistance with activities of daily living for patients receiving hospice. Multiple studies have demonstrated that caregiving takes a tremendous toll on caregivers' well-being, especially for those providing care at the end of life (Chentsova-Dutton et al., 2000; Harding, Higginson, & Donaldson, 2003; Oechsle, Goerth, Bokemeyer, & Mehnert, 2013; Williams, Wang, & Kitchen, 2014). IHCs report significant challenges associated with their caregiving role, including time conflicts, emotional distress, miscommunication, and diminished self-care (Chentsova-Dutton et al., 2000; Ratowski, Washington, Craig, & Albright, 2015; Washington, Pike, Demir, & Parker Oliver, 2015). Compared with caregivers of individuals receiving disease-directed treatment, IHCs score lower on measures of quality of life and physical health (Weitzner, McMillan, & Jacobsen, 1999). Moreover, their challenges are unique to the end-of-life context, where difficult decisions about care must be made, and feelings of anxiety and ambivalence heighten as the patient's death draws near (Grande, Rowland, van den Berg, & Hanratty, 2018; Kehl, Kirchhoff, Kramer, & Hovland-Scafe, 2009; Parker Oliver, Washington, Smith, Uraizee, & Demir, 2017). The high levels of confusion, miscommunication, fear, and sadness that are experienced during this time of discomfiture and extreme stress stand to overwhelm the IHC, creating an environment ripe for tension and family conflict.

Background

Conflict within families is a natural phenomenon and can even benefit relationships when it spurs open communication and is perceived as resolvable (Wilmot & Hocker, 2011). However, family conflict can be difficult to manage, particularly when individuals face numerous stressors and powerful emotions. If new or reoccurring conflicts between family members are not successfully managed as a hospice patient nears the end of life, the consequences may be dire for the caregiver, patient, and entire family network (Hamano et al., 2018; Kissane, Bloch, Dowe, et al., 1996; Kissane, Bloch, Onghena, et al., 1996).

The purpose of hospice is to provide comfort care and support on a family wide level. Hospice care uses a team approach including nurses, physicians, home health aides, social workers, clergy, and other professionals, such as nutritionists and physical therapists. These professionals work together to meet the emotional, spiritual, and physical needs of not only the patient, but also of those closely involved in the patient's care. Medical professionals in various end-of-life contexts have reported that family conflict is a common impediment to delivering quality patient care (Bowman, 2000; Goold, Williams, & Arnold, 2000; Kramer & Yonker, 2011). In particular, nurses, patient advocates, social workers, and clergy often find themselves responsible for resolving or managing family conflict at the end of life (Boelk & Kramer, 2012; Hopeck & Harrison, 2017). We know some about the strategies these professionals utilize to manage family conflict; however, most of this work has narrowly focused on family conflict concerning advance directives or life-sustaining interventions (Breen, Abernethy, Abbott, & Tulsky, 2001; Chiarchiaro et al., 2016) and is understood from the health professional's point of view (Hart, Yates, Clinton, & Windsor, 1998; Hopeck & Harrison, 2017; Kramer, Boelk, & Auer, 2006). Although some

understanding about the process of family conflict has been gained from these studies, hospice nurses and their team members would benefit by considering the perspectives of IHCs. Understanding the ways IHCs experience and manage family conflict while caring for a hospice patient at home is not only important for improving the quality of care delivered by hospice nurses and other team members, but also affords hospice providers with important insight on how family conflict may relate to IHC resilience.

Family Conflict and Resilience

Understanding what issues give rise to family conflict for IHCs, and appreciating how IHCs react to and manage these conflicts, can inform our knowledge of resilience processes and provide us with new directions for developing resilience-building interventions for IHCs. Although many definitions of resilience exist, fundamentally, resilience refers to the ability to withstand adversity (Herrman et al., 2011). According to Hwang and colleagues (2017), resilience acts as an internal psychological intervention that eases emotional distress and maintains, or helps an individual regain, mental health. Others conceptualize resilience as a process to harness resources to sustain well-being (Panter-Brick & Leckman, 2013). Characterizing resilience as a process implies that it is not just a binary attribute or trait, considered in terms of its absence or presence (Pietrzak & Southwick, 2011). Resilience is dynamic and multifaceted, representing an individual's ability to "adjust to adversity, maintain equilibrium, retain some control over the environment, and move in a positive direction" (Pines et al., 2014, p. 86). By adjusting to adversity, a resilient individual is not necessarily resolving or evading adverse situations or pathology; instead, the individual finds ways to thrive in spite of these experiences (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). In terms of family conflict and resilience for IHCs, theoretically, resilience can be viewed as the process IHCs engage in to maintain or restore their personal well-being despite experiencing family conflict. Although resilience has been investigated in the context of family caregiving (Ross, Holliman, & Dixon, 2003), including examining ways of fostering resilience (Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2016), gaining an empirical understanding of resilience among IHCs has received minimal attention from scholars. Those who have examined resilience among IHCs typically included these caregivers in their studies as part of mixed samples, which were comprised predominantly of informal caregivers of individuals diagnosed with a terminal illness, but not receiving any hospice support (e.g., Hwang et al., 2017). Moreover, we could find no published research explicitly examining the relationship of family conflict and resilience for IHCs. In fact, little empirical evidence exists on the study of family conflict in hospice, in general (for exception, see Boelk & Kramer, 2012; Kramer et al., 2006).

Theoretical Framework

In this current investigation, a relational dialectics framework is applied to the interpretation of IHC narratives on family conflict and resilience. Relational dialectics describes a set of conceptual assumptions about the contradictory tensions, or conflicts, that exist in relationships (Baxter & Montgomery, 1996). These tensions are dealt with internally by the individual and externally between the individual and the others. Common dialectical tensions applied to the study of personal relationships and family life include autonomy

versus connection, stability versus change, and expression versus nonexpression. According to Baxter and Montgomery (1996), these tensions are an intrinsic aspect of all ongoing social relationships. Our relationships are thought to continue as individuals perpetually engage in strategies that serve to balance these tensions. In accordance with this study, relational dialectics suggests that IHCs experiencing conflict will engage in strategies to (re)establish a sense of equilibrium, personal well-being, or sense of control-in essence, this is the process of *resilience* (Panter-Brick & Leckman, 2013).

Study Purpose and Contributions

The purpose of this study was twofold: (a) to identify types, topics, and/or sources of family conflict and tensions for IHCs, and (b) to better understand how IHCs are resilient against family conflict by investigating how they manage family conflict and tensions associated with their caregiving role. The following research questions guided our analysis: “How do IHCs experience family conflict?” Next, we asked, “How do IHCs respond to-or manage-family conflict?”

In an effort to gain a comprehensive understanding of family conflict in hospice care, we defined conflict in its broadest sense. Therefore, descriptions of disagreements, conflicts of interest, verbal or physical hostility, aggression, and internal conflicts manifesting as emotional tension, worry, or ambivalence were all conceptualized as conflict. We also examined conflict within the wider family network by including disclosures of conflict experienced between the IHC and the patient, as well as with family members of the IHC and/or patient. Finally, the data we examined are firsthand narratives of IHCs reporting episodes of conflict while they were actively caregiving, which eliminates bias associated with retrospective reporting.

Method

In this secondary analysis, researchers analyzed a subset of the qualitative data originally provided by participants in the attention control arm of a randomized clinical trial (RCT) of a psychosocial support intervention for IHCs (R01NR012213; Principal Investigator: George Demiris, 2011–2015). The University of Washington Institutional Review Board (IRB) approved the original trial, and all individuals enrolled in the study provided written documentation of consent to participate in research.

IHCs in the attention control group of the original RCT received four “friendly” phone calls from a member of the research team and were asked general questions regarding their caregiving experience (see Table 1). The purpose of these calls was to provide nonjudgmental active listening without any attempt to assist with problem solving or to interfere with or intervene in IHCs’ handling of challenges and overall coping. Phone calls were designed to be 15- to 30-min long and social in nature. As part of the IRB-approved consent process, IHCs agreed to the audio-recording of these phone calls and acknowledged that the content of the calls would be used for research purposes.

Researchers conducting the “friendly” phone calls completed field memos following each call. Upon reviewing the field memos, study investigators noted the frequency with which

IHCs discussed family conflict and identified an opportunity to contribute to the knowledge base by describing the types, topics, and sources of family conflict for IHCs and illustrating how IHCs manage family conflict and tensions associated with their caregiving role. To do this, researchers analyzed a subsample of the “friendly” phone calls, purposively selecting calls with IHCs who were actively caring for a home hospice patient at the time of their participation in the original trial ($n = 52$). Because the original trial was ongoing at the time this analysis was conducted, this subsample did not include all IHCs who were ultimately enrolled in the trial. Calls with IHCs who became bereaved while they were completing the series of calls were excluded, as researchers sought to capture real-time accounts from IHCs engaged in active caregiving.

Data Analysis

We applied principles of deductive thematic analysis to analyze the data (Braun & Clarke, 2006). NVivo software was used for all data management and coding. First, audio-recordings of caregiver interviews were reviewed for accuracy and subsequently transcribed by the coders. An initial coding frame was developed by the principal investigator based on the research questions, experience of the interventionists (two of whom also served as the coders), and a review of the literature. This coding frame was designed to guide coders in assigning an initial set of codes to any excerpts from the narratives that described (a) types, topics, and sources of conflict; (b) reactions to conflict; and (c) strategies for managing conflict. The two coders jointly coded 10 interviews to develop common definitions and a shared coding perspective. The coders then separately coded another 10 interviews and compared codes for reliability. The separate coding of the same interviews resulted in intercoder agreement of only 40%. Conflicting codes were compared over and definitions were once again refined. A second set of 10 interviews were again separately coded and compared once more, resulting in 80% agreement. The remaining interviews were then split between the two coders and coded separately. The study’s principal investigator reviewed all coding, and sorted and combined categories to develop initial themes. These themes were reviewed and corroborated by the second and third authors. To further our triangulation efforts, the first author was then invited to participate in the analytic process. The first author further refined the themes, debriefing again with the remaining authors for validation. The first author then revisited the literature to theoretically triangulate the data. Relational dialectics framework was selected as the best fit for interpreting our themes and helped inform the development of a conceptual model to explain the process of IHC resilience in response to family conflict. Finally, the theoretical framework and the conceptual model were reviewed and verified by the remaining authors.

Trustworthiness in the analysis (Krefting, 1999) involved prolonged engagement (both coders served as interventionists and were involved in the setting for 4 years), peer debriefing by all authors over the course of the analysis and during interpretation, and a complex coding process involving both separate and joint coding by multiple coders to establish intercoder reliability, with consensus coding to address any questionable narrative. Moreover, an electronic audit trail was conducted using NVivo software, which included documentation of written memos about the analysis and meeting notes from the research and coding team meetings.

Results

Table 2 summarizes the demographic variables for the final sample ($n = 25$). The original sample included 52 caregivers who participated in a total of 205 phone calls for a total of nearly 58 hr. Each interview averaged 33 min and ranged from 2 to 60 min. Caregivers were an average of 62 years old, primarily female (77%), White (90%), and were most often adult children of the patient (56%).

Nearly 50% ($n = 25$) of the original sample reported episodes of conflict or tension. Caregivers most often reported family conflict with patients and siblings, although they mentioned extended family members in a few cases. Regarding the way family conflict was experienced by IHCs, the data revealed one central theme, *autonomy*, and two subthemes: *caregiver reactions* and *conflict management strategies*. Autonomy emerged as both a topic of overt conflict itself and an underlying source and consequence of other conflicts, most of which revolved around conflict with the patient or other family members about care decisions and the process of decision making. The data also revealed that feelings of resentment were tied to autonomy. Resentment appeared to surface among caregivers who perceived an unjustified imbalance of autonomy and dependence, met with a lack of compassion and trust from the patient or other family members. Despite these experiences, caregivers found ways of adapting—demonstrating marked resilience in response to the conflictual environments they often experienced in their caregiving roles. Strategies identified for managing family conflict included behavioral and cognitive approaches: *communication*, *formal support*, and *emotional self-care*. What follows next is an in-depth description of the aforementioned themes that emerged from the data. Data excerpts and rich descriptions of participant experiences provide evidence for these themes; pseudonyms are used in all cases.

Autonomy

The central theme that emerged from the data was that of *autonomy*. Autonomy refers to a quality or state of self-governance, independence, choice, and personal responsibility (Funk, 2010). Being an autonomous individual means having the power to make one's own decisions, speak, or act without the interference of others. For the caregivers in this study, tensions often arose for them when patients attempted to maintain or regain autonomy. The patient's actions toward maintaining his or her own autonomy appeared to pose a direct threat to the caregiver's own personal sense of autonomy. Struggles over who had control was a common feature in most of the conflicts and tensions the caregivers discussed. Caregivers described having trouble giving patients the authority to make decisions on their own behalf, especially when it put patients at risk or created more work for the caregiver by delaying or prolonging a task. One caregiver described how her father's "insistence on being independent [was] ... a burden." When her father's struggle to remain autonomous lessened, her caregiving burden eased. She said, "Now that he's dependent on people, it's a lot easier for me." Another caregiver shared an example regarding patient safety and autonomous decision making. She described the difficulty of addressing the topic of driving cessation with her parents:

They were both emphatic about going back down to Arizona so we had to frame it as a next step in their rehabilitation, hoping they would come to recognize their limitations and need for extra care ... If we had sent them down to Arizona they might have killed somebody, including themselves, if they had tried to drive.

Notably, some conflict over autonomy was about patients' unwillingness to assume authority in making their own care decisions or advocate for what they needed. One caregiver described this difficulty when she talked about the challenges she faced caring for her mother: "I really want my mom to tell me what she needs." However, this same caregiver also disliked that her mother was "always trying to manage things the way she wants." It was evident from several caregiver comments that the struggle for autonomy between patient and caregiver was difficult for caregivers to reconcile-patient autonomy and patient dependency were not mutually exclusive desires. One caregiver shared her keen awareness about this dialectic challenge:

Sometimes I have to remember it's not about me controlling the situation as much as it needs to be about her having control of herself ... she might get more happiness out of getting more control over her life ... so I struggle with that.

Although several caregivers indicated they struggled with patients over control, some also found their autonomy as the primary caregiver challenged by extended family. Caregivers viewed micromanagement by family members as a threat and a direct display of mistrust. Family member suspicions were often about the caregiver fully disclosing patient symptoms. One caregiver described this difficulty with her sister: "My sister is pretty critical of me and always has been ... she sometimes can be too bossy ... she'll call up for a report, I feel it's a report, on Dad." Another caregiver reported experiencing similar tensions with her care recipient's sister:

This particular sister has difficulties in accepting his disease and his decline. She's always checking with me, "has he been coughing?" and "has he been this?" and it drives me crazy. I don't need that kind of pressure; I cannot keep him alive for her sake.

Another dimension of conflict related to autonomy was a caregiver's need for self-governance over her or his personal life. "You're always on their schedule," said one caregiver, "It's never your time." A different caregiver lamented over her inability to enjoy retirement on her own terms:

I'm just wishing that ... I could do all the things that I want to do. I'm already retired and I'm not doing a life ... I wish that I didn't have to make dinner for my mom. It's work having to put it in the freezer. Every night I have to cook dinner for my dad too. If not he would only be eating T.V. dinners.

Caregivers also talked about wanting to return to activities and relationships they had put on hold or neglected while caregiving. Caregivers mentioned resuming exercise routines, attending religious services, and volunteering, as well as a strong desire to reconnect with spouses and children and have more control over their image as perceived by others-in essence, caregiving had hijacked their identities. One caregiver said, "I'm not the person I want to be ... my husband and my poor kids are seeing me just not in the manner I want to

be.” Although being perceived as someone other than a caregiver was important to many, some struggled to even recognize themselves as anything else:

It kind of opened my eyes to my role as a caregiver. I didn’t even think of myself as a caregiver ... I didn’t see myself.

Caregiver Reactions

Caregiver reactions involved the reactions caregivers expressed in an attempt to address the central issue of autonomy. We categorized these reactions as *behavioral* or *cognitive*. Behavioral reactions included caregiver descriptions of *interpersonal conflict*, or disagreements caregivers had with other family members or the patient. Cognitive reactions involved the caregivers’ feelings and emotional responses about the interpersonal conflicts they had with patients and family members: *resentment*, *negative perceptions of family support*, and *cognitive dissonance*.

Behavioral reaction.—The central issue of autonomy and the struggle for control is evidenced within the following quotes and descriptions about interpersonal family conflict, especially with regard to care decisions. Care decisions appeared to be the most common area of disagreement. These disagreements yielded many displays of overt conflict, such as arguments or voiced dissension, which often reverberated throughout the family system to include individuals beyond the caregiver/patient subsystem. Arguments or disagreements occurred about the need to hire formal helpers or enroll a patient in hospice, patient transitions to formal care settings, treatment, and decisions about who should provide care. Relationship histories, clashing personalities, and denial about the patient’s declining health appeared to play a role in exacerbating family conflict about care decisions.

One woman described a conflict she was currently experiencing with her siblings over their mother’s permanent transition to a skilled nursing community. Previous experience with the facility their father lived in before his death had led to different conclusions among siblings over where their mother should live out her final days:

My Dad died in a nursing care facility so there are mixed feelings in my family (about mom’s move from assisted living to skilled nursing) ... my siblings to this day still say that (where Dad lived) was an awful place.

Caregivers often lamented about their siblings not helping enough. These complaints were mostly about siblings’ lack of involvement in performing caregiving tasks, such as taking the patient to doctor’s appointments or administering medications. Most caregivers described their siblings as passively avoidant, while others alluded to the fact that their siblings made overt refusals to help with certain tasks. For instance, one caregiver talked about her sisters being unwilling to administer pain medication to their mother. She said, “I have a job, to give [mom] the [morphine] pill. My other three sisters refuse to do that.” Several caregivers mentioned denial as reasoning for their siblings’ lack of involvement, and this appeared to have a greater impact on caregiver strain than when caregivers gave other reasons for their siblings’ detachment (e.g., personality traits). One caregiver described how her sister’s denial about their father’s impending death was placing undue burden on her shoulders:

[My sister] has trouble accepting his death. She had an emotional reaction and said, “if we can just keep him from breathing wrong or aspirating that he’ll live forever,” or something like that. I feel pressure from her from afar to keep him from breathing wrong or aspirating. That’s been a burden ... we’re doing the best we can.

An additional woman caring for her spouse felt her husband’s brothers did not appreciate the severity of his health condition and the level of caregiving that he required. Their denial or lack of understanding caused immense frustration on her part:

The older brother doesn’t understand ... “Wally gets around fine,” he says. They don’t realize the number of times I have to help him off the toilet, that he can’t get into the kitchen ... They’re men. The reality is, in this culture, the men don’t often have to do the caretaking. They don’t get it.

Further conversation with this caregiver suggested that the brothers’ personalities served as an additional contributing factor to their lack of support: “The older and younger brother are totally different personalities than Wally ... terms that come to mind are arrogant, self-centered, obnoxious ... they act like 4 year olds. It’s ridiculous.”

Battles related to care decisions often involved outward displays of conflict. These confrontations were about the need to hire help, whether or not a patient should move to a formal care facility, the correct way to complete a caregiving task (e.g., how to bathe a patient), and patient behaviors that put the patient at risk. One caregiver shared that she often engaged in overt disputes with her stepfather about how to help her mother with the physical care she needed. She said, “There’s arguments about how to help [mom] take a shower ... our stepfather was having issues, in his mind, of my ability to help.” This caregiver also described conflict with her stepfather over pain management: “There’s been battles with our stepdad about, ‘is she in pain, or isn’t she? What does she need, what doesn’t she need?’”

Concerns about patient safety were tied to conflict about the functional capabilities of patients, both cognitively and physically, and whether or not they should be living autonomously, or independently performing certain tasks. Power struggles were a central issue when caregivers expressed concerns about patient safety. Caregivers often talked about “fighting” patients over these decisions, and having to “convince” patients to agree with them and accept their help. One caregiver who discussed issues about patient compliance, said, “When we were battling the PEG tube I’d get frustrated and I’d go ‘I don’t understand what you’re doing. I don’t think it’s in your best interest but I’m not going to fight you on it.’” A different caregiver sought legal advice about obtaining guardianship of her father so she could force him to move to a formal care facility:

Before the nurses came in ... he wasn’t able to make it to the bathroom. I was cleaning up stool from the floor. He just refuses to consider something like assisted living ... I called an attorney, “Is there anything I can do? Can I just take guardianship or force him to go?” She said it’s next to impossible to declare somebody incompetent.

Cognitive reactions.—In general, issues eliciting feelings of resentment were linked to conflict surrounding both a lack of autonomy and, as one caregiver put it, “a lack of compassion” on behalf of family members. The word *support* came up often in these caregivers’ narratives. Resentment surfaced when other family members did not provide support in the form of respite or by shouldering some of the burden of completing various caregiving tasks, such as providing the patient transportation to doctor’s appointments. Descriptions of burnout surfaced when the demands of caregiving intensified so much that major restrictions were placed on a caregiver’s time, making it impossible for them to pursue their own hobbies and interests, travel, or spend quality time with their own families. “There have been times I’ve gotten pissed,” said one caregiver, “I can’t go to the gym, I can’t really go on [vacation], or I can’t do this or that.” Another shared, “I get irritated if anything is cramping my time.” Caregivers appeared especially frustrated when caregiving demands increased at important turning points along their own life course, such as retirement. One woman discussed how she felt resentment toward her father because his increasing caregiving demands were placing limits on her ability to enjoy life at a time when her schedule was becoming less restricted: “As our schedules became freer his health became [worse] ... he became more reluctant [to be alone] to the point that we couldn’t travel. I was somewhat resentful for a while.”

Although caregivers expressed umbrage over receiving little physical support from other family members, these feelings paled in comparison with their feelings about receiving limited or no emotional support. “A little consideration for what I need, how I’m feeling, how I’m doing,” summed up one caregiver’s experience. She described a time when she finally shared these feelings with her sister-in-law:

She and I went out for lunch and I confronted her about the dinner thing. But then I also was talking about how we feel basically deserted. And what it’s like to have to deal with this alone with no help from any of the family ... I said that doesn’t mean people can’t call, or text message ... it’s not like I was asking them to come out here.

Others talked bitterly about the fact that they have received more support from “strangers” than from family. One distressed caregiver spoke about the emotional insensitivity of her family members who did not seem to recognize the hardship she was going through. She stated,

I think it’s hard for me and, I think, other caregivers. If you know someone is a caregiver, I don’t think you should throw in their face constantly that you’re having an amazing life ... it’s like you don’t even realize what I’m going through, that I have no life, and you throw a beautiful life (in my face)? I’ve had more support from strangers. I have had more support from the people in the coffee shop downstairs than from my family ... these are the people that said they would support me all the way.

Caregivers reporting resentment experienced a great deal of cognitive dissonance. Several caregivers appeared to experience psychological stress over the contradictory feelings they were having about the care they did (or did not) deliver, and about their attitudes toward

their role. Ambivalent feelings about guilt and regret were common sentiments. One caregiver demonstrated uncertainty over feelings of guilt as she discussed her desire for more personal autonomy in her day. She shared, “I felt like taking time for me, for my private enjoyment, was not acceptable ... not feeling guilty about that is the hardest part.” Another caregiver described feeling guilty that she did not make a stronger effort to carve out time in her life to be present for her mother’s back surgery: “I should have flown out to Indianapolis and been there for her surgery ... in fact, that was one of my big mistakes.” Although these caregivers wished for autonomy in terms of how they spent their time throughout a given day, it was difficult to reconcile this desire with their desire to be devoted caregivers. One caregiver had moved closer to his care recipient to better care for her. Soon after, the patient made the decision to move to another city; consequently, the caregiver struggled with feelings of guilt about the discontinuance of his role as the caregiver. He also expressed some resentment about his role loss, suggesting he felt unappreciated for the care he had provided: “The good-hearted part of me feels like a failure,” he said. “Then the selfish part of me wants to feel like, ‘wait a minute; I did this all for you.’” Other caregivers experienced mixed feelings about their role and the amount of time they were devoting to providing care. One caregiver demonstrated discomfort with what she perceived as role reversal: “It’s like I take on the [role as] mom.” For her, caring for her mother was both difficult, and not. She summed up her feelings of ambivalence when she stated, “She is not that difficult to deal with, but she is that difficult to deal with ... she would like me to be there 24 hours a day. I can’t be there for my own head 24 hours a day, every day.”

Conflict Management Strategies

Caregivers employed a number of strategies to manage the interpersonal conflicts and cognitive reactions that they experienced because of feeling a sense of imbalanced autonomy. In line with the theme *caregiver reactions*, we used consistent nomenclature to categorize these strategies as either behavioral or cognitive. In terms of caregivers’ behavioral approaches to conflict management, caregivers’ interpersonal conflict and their cognitive reactions were often addressed by *direct communication*, such as asserting one’s own needs, and seeking *formal support*, for example, enrolling the care recipient in hospice. Formal support served two purposes: (a) to assist caregivers in communicating messages with the patient or other family members and (b) to assume some of the caregiving responsibilities to alleviate caregiver stress and conflict when the topic of conflict was about the caregiver’s need for respite. *Emotional self-care* was categorized as a cognitive approach to managing interpersonal conflict, resentment, negative perceptions of family support, and cognitive dissonance. Engaging in emotional self-care included activities such as meditation or engaging in positive self-talk. In general, these activities occurred in lieu of communicating needs or concerns, or when conflict could not be resolved via communication.

Behavioral approaches: Direct communication.—Caregivers often used direct, verbal communication when they needed to be assertive with family members about their need for emotional support. For example, a caregiver quoted in the previous section shared how she met with her sister-in-law over lunch to express her feelings of desertion and ask for emotional support, even if she communicated such support in truncated ways (e.g., text

messages). Caregivers were also assertive in their communications with care recipients about care decisions:

We had a huge problem with her oxygen equipment. We have a Helio system ... it's mobile, it just kept failing on us ... I took a whole different approach to it. I said, "We have emergency tanks, let's put those in the car, let's just go, we're going to deal with this," and my mom was like, "No, I don't want to go; it's not going to work." And I was like, "We'll make it work."

Direct communication of care decisions to patients did not always involve a caregiver assertively commanding compliance. Some caregivers talked about taking a softer approach with the hope that it would help prevent or diffuse tensions and avoid an immediate response of opposition or defensiveness from the patient. Notably, this strategy was not necessarily about engaging in true negotiation, but rather *appearing* negotiable by delivering the message with tenderness, or in multiple stages, to avoid overwhelming the patient. For example, one caregiver talked about how she and her sisters conspired to figure out how they could convince their mother that it was no longer safe for her to live alone. Their plan involved together taking their mother to the doctor, hoping the visit would segue into a discussion with her about moving to assisted living. However, prior to attending the appointment, the caregiver introduced the idea to her mother so that her mother would have time to think about it: "I kind of broached the subject with her," the caregiver said, "and she was very open to it; [it was] kind of a surprise."

Behavioral approach: Involving formal support providers.—Some caregivers managed conflict by involving a formal support provider as a mediator to help caregivers communicate with other family members about "stepping up to the plate." For example, one caregiver sought a hospice staff member to communicate to her sibling that she needed additional assistance with some of the caregiving responsibilities of their mother:

[The hospice staff] just told my brother that he's got to provide someone to turn her at night; because of the bed sores, we have to have that now. I have a hard time asserting myself on things like that. It was just so nice having their support.

Formal support providers also mediated communication with patients. One caregiver employed the assistance of a hospice social worker to help explain to her mother that she needed her to communicate better: "Something that we talked to the social worker about was just my mother being able to tell me what she needs rather than asking me when something is going to happen."

Caregivers also used formal support providers to directly assume some of the responsibilities of caregiving rather than serve as mediators. Several caregivers talked about being overwhelmed with caregiving duties and engaging in ongoing arguments with family members about their need for respite or assistance with caregiving tasks. Rather than continue making requests for help only to be rejected or ignored, caregivers used formal support providers to ease some of the burden. One caregiver talked about how she ignored her father's wishes and "finally called the hospice social worker" to get help with caring for her stepmother. Her father, who was also providing care to her stepmother, kept refusing to work with the hospice staff:

My dad kept the chaplain and social worker at bay. He felt like he could do it all ... they didn't need those services ... I finally called the social worker and asked to meet her.

Another caregiver shared that she decided to hire professional caregivers when her stamina ran out and her brother was unwilling to fill in the care gap:

[I set up caregivers] through the COPES program ... my brother was not willing to help me after mom broke her hip, and with financial matters ... it was a difficult situation ... I was making sure she had everything.

Cognitive approach: Emotional self-care.—The final conflict management strategy that we identified in the data was caregiver emotional self-care. Emotional self-care strategies appeared to ease anxiety and tension for caregivers, thus helping them avoid creating new conflicts or re-engaging in unresolved conflicts. Several caregivers talked about positive self-talk or cognitive restructuring as forms of emotional self-care. For example, rather than let her sister's negative interactions bother her and lead to arguments between the two of them, one caregiver talked about how she no longer lets her sister's behavior trouble her: "It doesn't matter what she thinks," she said, "we are doing the best we can." Other caregivers found venting to friends helped them cope with conflict. The following caregiver expressed this sentiment and also talked about engaging in breathing exercises and cognitive restructuring:

I bitch to a lot of people. I vent a lot ... and I do a lot of deep breathing. I [tell myself] "come on, you know very good and well it's not hurting them any, it's only hurting you. You need to be here to take care of Wally, and let it go, let it go."

Two additional emotional self-care strategies identified in the data were self-awareness and acceptance of unresolvable conflicts. These strategies were engaged in tandem. "Learning to accept what cannot be changed" was the general sentiment among these caregivers. One said, "These are life choices. This is how he wants to live his life. I've got to accept that. I may not agree with it, but I've got to accept it." Another caregiver talked about gaining awareness about her own idiosyncrasies and that becoming aware is helping her relinquish control:

I'm a producer, so I make things ... I'm way more of a producer than a consumer and in some ways I've made my mom my next project. I'm going to produce [my mother] to death in some way ... the dress rehearsal ... sometimes I take that too much to heart ... I have to remember it's not about me controlling the situation.

Conceptual Model

Based on our collective findings, we generated a conceptual model of IHC family conflict and resilience (Figure 1). This model is not intended to serve as a staunch prescription; rather, it serves as an organizing structure for the data and is intended to stimulate innovative thinking about family conflicts and tensions as manifestations of autonomy loss or imbalance. The model depicts how IHCs' responses toward autonomy loss reflect their resilience process.

The model highlights what Soulliere, Britt, and Maines (2001) maintain as the three key elements of conceptual modeling: (a) the important concepts, (b) the nature of these concepts, and (c) the nature of the relationships among these concepts. In general, the important concepts in the model include (a) perceived autonomy, (b) the behavioral and cognitive *reactions* of perceived autonomy imbalance, and (c) the behavioral and cognitive *strategies* employed to maintain (or regain) balance in perceived autonomy. The specific strategies caregivers utilize to oppress conflicts and maintain or regain balance in perceived autonomy include *communication*, *formal support*, and *emotional self-care*. Caregivers react to a sense of imbalanced autonomy by experiencing *interpersonal conflict*, *cognitive dissonance*, *negative perceptions of family support*, and *feelings of resentment*. In our data, interpersonal family conflict generally manifested as disagreements over care decisions and the process of making those decisions. The small, bidirectional arrows illustrate how caregiver reactions are mutually influential. For example, as negative perceptions of family support intensify, feelings of resentment may become exacerbated. The large vertical arrows are included in the figure to suggest that both caregiver reactions and conflict management strategies can have an impact (positive or negative) on maintaining or regaining balance in perceived autonomy.

Discussion

This study provides an additional perspective of the ways family conflict is experienced and managed by informal home hospice caregivers. Our study is unique in that we analyzed interviews from IHCs who were actively providing care, and serving as a control group for a large randomized controlled trial. Although family conflict in hospice has been studied to some degree, prior research was frequently based on retrospective accounts of conflict (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2009), based only on the perspectives of health care professionals (Hart et al., 1998; Kramer et al., 2006), and/or focused on specific topics of dispute (Breen et al., 2001). Others limited their samples to family caregivers in high-conflict families (Boelk & Kramer, 2012). Our data extend current knowledge in this area by revealing the multifaceted ways IHCs experience conflict by including reports from caregivers undergoing intense, overt, and/or ongoing conflict *as well as* those experiencing minor, covert, and/or acute episodes of conflict. Examining conflict in the hospice environment at varying degrees of intensity is particularly important because it can provide practitioners with better understanding about the minor tensions that may precede more extreme conflict. However, longitudinal research is needed to fully understand the antecedents to such events. In our sample, respondents were asked to discuss challenges broadly as they related to family caregiving, rather than prompting them to discuss a specific topic already known to generate tension and conflict. Such an approach may generate data portending a more robust and organic accounting of the types, sources, and topics of conflict that can occur for IHCs.

The conceptual model that we developed is suggestive of what many communication and family scholars have long articulated about family conflict being both intrinsic to and supportive of close social relationships and individual well-being (Silverstein, Gans, Lowenstein, Giarrusso, & Bengtson, 2010; Simmel, 1955). In addition to relational dialectics, several frameworks and conceptual ideas in the family science discipline have

been used to discuss or explain the dynamics of conflict within the context of caring relationships. For example, according to the solidarity-conflict paradigm, conflict and affection coexist among strongly bonded family members (Bengtson, Giarrusso, Mabry, & Silverstein, 2002). Luescher and Pillemer (1998) have likewise conceptualized this idea that individuals can simultaneously exhibit both warm and hostile feelings toward one another as *ambivalence*. In general, what these models and the work of others (Boelk & Kramer, 2012; Hamano et al., 2018) highlight is the dynamic nature of family conflict. Our model supports and extends these ideas by suggesting another way to conceptualize family conflict at the end of life-as an expression and manifestation of the central tension caregivers experience when they feel their autonomy is threatened or weakened by the patient and/or other family members. Our model suggests that IHCs react to a loss of autonomy in multiple ways, one of which may be what we traditionally operationalize as conflict-disagreements, arguments, stonewalling. Interpersonal conflict is thus a reaction to an underlying tension or conflict about autonomy that caregivers are perpetually struggling to balance. Moreover, caregivers may attempt to balance this central tension by engaging in a number of conflict management strategies. To this end, our model is intended to inspire testable propositions about the ways in which an informal hospice caregiver's cognitive and behavioral responses toward family conflict operate to impact caregiver outcomes, and shed further light on what contributes to, or undermines, caregiver resilience. For example, hypotheses that could be generated from our model would be those predicting how caregiver reactions and conflict maintenance strategies are associated to influence caregiver burnout. Future research examining these associations may provide crucial information about additional ways practitioners can intervene to improve quality of life and prevent burnout among IHCs.

Implications for Practice With Families

Our findings also highlight the need for future research developing and evaluating customizable and comprehensive interventions to assist caregivers in recognizing which strategies might be more successful than others in preventing or defusing family conflict, thus contributing to their overall resilience. The caregivers in our study appeared to use cognitive strategies, such as cognitive restructuring, to help them manage conflicts and tensions that were largely perpetual and unlikely to be resolved. Whereas many conflicts or problems were addressed by problem-solving actions or behaviors, those that were ongoing or worsening appeared to necessitate a cognitive-emotional approach. For example, in the context of ongoing conflicts/tensions, caregivers reported utilizing such helpful strategies as becoming self-aware of his or her personal liabilities, distinguishing resolvable from unresolvable conflicts, positively reframing negative situations, and ignoring disparagement and disapproval from others. Although our data provide evidence that these emotional/cognitive strategies are used, most interventions developed to improve the caregiving experience predominantly focus on teaching caregivers behavioral strategies (Cagle et al., 2015; Demiris et al., 2012; Houts, Nezu, Nezu, & Bucher, 1996; McMillan & Small, 2007; McMillan et al., 2006; Parker Oliver et al., 2010). While it is important to teach caregivers behaviorally focused problem-solving skills, emotional and cognitive approaches may need emphasis as well. Ample research from marriage and family science disciplines suggests that conflict management strategies like cognitive restructuring can promote known indicators of resilience, such as positive changes in relationships and improved individual

well-being. Indeed, simply recognizing conflict as a common, potentially beneficial aspect of relationships has positive implications for romantic partners (Gottman, 1999; Peleg-Koriat, Weimann-Saks, & Ben-Ari, 2018). In general, research has shown that when family members avoid conflict and view it as nonnormative and universally unhealthy, families suffer (Koerner & Fitzpatrick, 2006; Laursen & Hafen, 2009; Meeks, Hendrick, & Hendrick, 1998; Noller, Feeney, Bonnell, & Callan, 1994; Wujtewicz, Wujtewicz, & Owczuk, 2015).

Although researchers and practitioners have recognized the benefits of conflict for decades, negative stigma about conflict remains. Notwithstanding the profound negative implications of extreme violence and gridlocked conflicts, much needs to be done to assist individuals and families in embracing the normativity and potential utility of conflict in family relationships. Based on our findings, we speculate whether conflict may be better understood and constructively managed by IHCs if nurses and other hospice staff were to help them recognize disagreements and incompatible behaviors not only as normative, but also as an outward expression of an attempt to gain or preserve a common desire among humans—autonomy. By cognitively restructuring conflict experienced with patients and other family members in this way, IHCs may be able to express greater compassion, accept influence from other family members, and view compromise as an autonomous choice rather than an act of surrender. Our strengths-based perspective also aligns with the International Family Nursing Association's (IFNA; 2017) recent position statement for advanced practice in family nursing. This statement defines the competencies for advanced family nursing practice, stipulating nurses as key figures in helping families to foster positive and healthy relationships among themselves, clinical staff, and their infirm family members. According to the IFNA (2017), a key role of an advanced practice nurse is an “ability ... to act within a collaborative, non-hierarchical relationship between families and nurses, to offer a focus on strengths rather than pathology, and to support a belief in the legitimacy of multiple realities” (p. 1).

The nature of our data limits us in making strong conclusions about whether to recommend certain conflict maintenance strategies over others. To arrive at such conclusions, comparative research focused on the examination of various strategies and conflict scenarios among IHCs, patients, and family members is needed. Still, our findings regarding conflict management strategies may be useful in guiding nurses and other clinicians in how to recognize family conflict in the home hospice setting. For example, although hospice nurses and staff may not directly witness IHCs engaged in overt conflict with their care recipients or other family members, they may witness caregiver reactions that are symptomatic of family conflict. IHCs' expressions of resentment, sadness, and longing for a return to daily routines predating their caregiving role serve as opportunities for hospice staff to intervene psychosocially. Engaging IHCs in therapeutic conversations about ways they can improve their caregiving experience by communicating their needs and concerns with other family members may be key to minimizing psychological distress or defusing conflict while caregiving, as previous studies have also implied (Hamano et al., 2018; Hudson et al., 2015).

Study Limitations

Overall, the sample of caregivers in this study were mostly female, White, and adult children of the patient. A more diverse sample might have yielded different data about family conflict at the end of life. This study was also a data-driven approach to secondary analysis of caregiver narratives that were collected as part of a control group for a RCT. A hypothesis-driven study utilizing primary data on IHCs' experiences with family conflict would have given us the opportunity to ask caregivers about specific conflicts and strategies for handling them. In light of this, the results of our study-particularly our estimation about the prevalence of family conflict-may be a conservative interpretation of the phenomenon because the caregiver interviews from which these analyses are drawn do not include direct questions about family conflict. Despite these limitations, we believe our findings are a significant contribution to nursing and other health care professionals who work with families at the end of life. Our application of the relational dialectics framework provided a new, interpretative lens for analyzing family conflict at the end of life. Rather than replace existing models that have been developed by others who studied this same phenomenon (e.g., Boelk & Kramer, 2012; Kramer et al., 2006), ours complements prior work by offering an additive approach to understanding how dialectics may influence how IHCs experience and manage family conflict to promote resilience.

Conclusion

A hallmark of qualitative findings is that they often stimulate more questions than they provide answers, and our study is no exception. Overall, our findings confirm that family conflict is a dynamic phenomenon with multifaceted origins, manifestations, and outcomes. However, more research is needed to understand how the dialectic tensions we inherently experience as human beings influence our interactions, and potential conflicts, with family members during times of stress and crisis. Conflict in a general sense is stressful, but it is also necessary and can lead to positive change. Although understanding the causes and consequences of conflict is pertinent to improving the family-centered care that hospice nurses and staff provide IHCs, patients, and families, we hope our findings inspire alternative ways to think about family conflict and caregiver resilience at the end of life.

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Figure 1.
Conceptual model of caregiver resilience.

Table 1.**Attention Control Call Script.**

Each visit lasts approximately 15 to 30 min.

It is OK to use small talk to break the ice (e.g., talk about the weather).

- Tell me more about you, your background.
 - Would you like to tell me your story? How long have you been a caregiver for your loved one?
 - What are some of the challenges or problems you face as a caregiver?/Are there things you are struggling with as a caregiver?
 - Do you have family or friends who are helping you with this role?
 - Are there any other things you want to talk about? I am here to listen.
 - Anything you need to get off your chest?
 - Are you making any plans for the summer/the holidays/(seasonal reference)?
 - How did you (and your family) learn about _____'s illness?
 - What led to your involvement with hospice?
 - How does your family support your caregiving efforts?
 - How would you describe your loved one's experience throughout this illness?
 - If you could, what would you change about the way that doctors or nurses talked to you and your family?
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Table 2.Characteristics of Caregivers and Patients ($n = 25$).

Characteristic	No. (%) ^a	
	Caregivers	Patients
Female	21 (84)	18 (72)
Age, <i>M (SD)</i>	58.3 (14.2)	79.6 (15.4)
Race/ethnicity		
White, non-Hispanic	21 (84)	21 (84)
Asian	3 (12)	3 (12)
Multiracial	1 (0.04)	1 (0.04)
Relationship to patient		
Adult child	16 (64)	
Spouse or partner	3 (12)	
Other relative	6 (24)	
Employed	12 (48)	
Caregiving >20 hr/week	13 (52)	
Caregiving >1 year	20 (80)	
Diagnosis		
Cancer		10 (40)
Dementia or related illness		6 (24)
Cardiovascular disease		3 (12)
Other		4 (16)
Unknown		2 (0.08)

^aDue to rounding, percentages might not sum to 100.