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End-of-Life Caregiving: Challenges Faced by Older Adult Women

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Abstract

In the United States the number of people over 60 is expected to triple over the next 50 years and as the population ages so do family caregivers. Increased levels of depression and low ratings of subjective well-being in caregivers are consistently associated with older age, the spousal relationship, and the female caregiver gender. Less well known is how care delivery models in which the family caregiver provides care affects the older adult as their spouse approaches the end of life. The purpose of this study was to explore the challenges faced by older adult spousal caregivers providing end-of-life care across different life-limiting illness trajectories in distinctive care delivery models. An instrumental case study using purposive sampling identified the following themes for older spousal caregivers: balancing multiple morbidities; feeling overwhelmed and exhausted; dealing with personal health issues; feeling isolated; and coordinating care. Implications for healthcare providers are also examined.

“There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers” (Roslyn Carter as cited in National Family Caregivers Association, 2011).

According to the National Alliance for Caregiving (2011), 65.7 million caregivers make up 29% of the United States adult population and are found in 31% of all the households. Of these, almost 49 million are caring for an adult or older adult patient, with 20–25% of caregivers estimated to be 65 or older (National Alliance for Caregiving, 2011). Age related changes can bring numerous challenges, among them the likelihood of chronic illness and/or disability. For many older adults this means witnessing the illness or disability of a loved one, such as a spouse, and the potential to transition into the role of caregiver that can be a threat to their well-being (Poulin, Brown, Ubel, Smith, Jankovis, & Langa, 2010). Older adult caregivers face a double jeopardy: while they provide supportive care to their declining loved one, they too often suffer multiple chronic conditions and decline.

Increased levels of depression and stress and low ratings of subjective well-being in caregivers are consistently associated with older caregiver age, the spousal relationship between the patient and the caregiver as opposed to parent/child or sibling, and caregivers of the female gender (Schulz & Sherwood, 2008). When compared to male caregivers, female caregivers are more likely to not only have decreased well-being but are also more likely to suffer from anxiety, depression, and other symptoms related to the emotional stress of the caregiving role (Family Caregiver Alliance, 2011). Pinquart and Sorensen (2011) found that spousal caregivers are older than other family caregivers and suffer from more health problems, which lead to greater perceived stress when providing care. Support for family caregivers has long been advocated, yet there is a shortage of evidence-based strategies to assess and respond to the caregivers' needs (Hudson et al., 2010). Clinical assessment tools generally focus on the patient, despite family caregivers' experiences of personal distress, burden, impaired self-care, increased psychological and physical morbidity, and even mortality (Christakis & Allison, 2006; Monin & Schulz, 2009). Feelings of being overburdened physically, emotionally, and financially may ensue as they provide care for a loved one (Parker, Teel, Hobbs Lennerts, & Macan, 2011). Therefore, the purpose of this study was to explore the challenges faced by older adult spousal caregivers providing end-of-life care across different life-limiting illness trajectories in distinctive care delivery models.

Significance

Changes in health status across life-limiting illness trajectories require a range of strategies to address shifting emotional needs, physical needs, and symptoms (Blum & Sherman, 2010). As the patient traverses an illness trajectory, changes in health and functional status result in transitional periods of instability that produce significant changes in the lives of both the patient and the family caregiver. Such transitions, marked by instability, are associated with important implications for well-being and health for the caregiver dyad (Schumacher & Meleis, 1994). Penrod and colleagues studied transitions among family members caring for a loved one with life-limiting, chronic conditions from pre-diagnosis through bereavement (Penrod, Hupcey, Shipley, Loeb, & Baney, 2011). The resultant model of Caregiving Through the End of Life demonstrated common phases and critical transitions experienced by all informal caregivers, regardless of life-limiting illness trajectory.

Transitioning across these trajectories is a difficult task. Those caregivers who experience the heaviest caregiving demands exhibit more symptoms of depression and poorer self-reported health and health behaviors (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). Other negative consequences of caregiving, particularly spousal caregiving, on the physical and mental health and mortality of the caregiver have been well documented (Garlo, O'Leary, Van Ness, & Fried, 2010; Pressler et al., 2009; Schulz et al., 1997; Schulz & Beach, 1999). Previous studies have explored the impact of patient's cognitive and physical impairment on caregiver burden and quality of life (Tooth et al., 2008), the effects of the suffering of a patient and its influence on caregiver emotional experiences (Monin & Schulz, 2009), and the role of pain in caregiver well-being (Blyth, Cumming, Brnabic, & Cousins, 2008).

Adding to the complexity of understanding end-of-life caregiving are the varying models of care delivery in which informal caregivers interact with health care providers. These interactions are a gateway to supportive care for the family caregiver; however, that gateway is not always open. Models of care delivery vary greatly in the integration of caregivers as co-providers (i.e., an extension of the health care team) as well as co-recipients of care (i.e., an extension of the patient system) (Penrod, Baney, Loeb, McGhan, & Shipley, 2012). While the role of caregiving has been well-documented, all care delivery models are not equal in recognizing and supporting the caregivers' needs, especially from their perspective. The care delivery model may enhance or delimit the health care providers' perspectives of the family caregivers' roles and the inclusion of informal caregivers as co-recipients of care.

In their study of the formal/informal caregiver interface, Penrod and colleagues described three care delivery models, including the Interdisciplinary Team, the Provider Dominant and the Cooperative Network (Penrod et al., 2012). In the Interdisciplinary Team model, various disciplines such as nursing, medicine, social work, and physical therapy share power and authority to provide holistic care. This holistic perspective potentiates the providers' viewing the family caregiver as a co-recipient of care (Penrod et al., 2012); that is, the providers' focus on the caregivers' needs in tandem with the needs of the patients. In the Provider Dominant model of care delivery, the medical specialist acts within a solo practice style, retaining primary responsibility for the ongoing care of the patient. In this model, the focus of the visits is on managing the patient's condition and the family caregiver is considered a co-provider of care without considerations of his/her needs (Penrod et al., 2012). In contrast, in the Cooperative Network model, care is directed at disease progression and symptom management. Typically, the lead provider in this model retains responsibility for care, augmented by support from other disciplines (primarily nursing), referrals, or consultations to other services. Family caregivers may or may not be integrated into the focus of care, depending on their finding a voice and bringing their needs to the provider's attention.

The body of literature surrounding older adult spousal caregivers is further limited by the use of cross-sectional designs (Lavela & Ather, 2010). A longitudinal design with an extended follow-up period will add to the understanding of the challenges faced by older caregivers that transition across trajectories and thus provide valuable information for this potentially vulnerable group of caregivers. Considering the potential negative effects health status, age, gender, and relationship to the patient (Doorenbos et al., 2007; Pinquart & Sorensen, 2011; Schulz & Sherwood, 2008) may have on caregivers, and that “most caregivers of older relatives are spouses, also aging and in need of help” (Salin & Astedt-Kurki, 2007, p. 39) a longitudinal exploration of older female spousal caregivers providing end-of-life care is needed. Additionally, the current focus in the caregiving literature is dominated by examination of caregivers providing care to patients with dementia and to a lesser extent by studies of caring for patients with other life-limiting illnesses (Schulz, Martire, & Klinger, 2005; Stetz & Brown, 2004). In their systematic review on psychological health in older spousal caregivers of older adults, Lavela and Ather (2010) found only one study that examined a patient population other than dementia. This study addresses these gaps by studying spousal caregivers' experiences longitudinally across varied life-limiting illness trajectories.

Method

As part of a larger ethnographic study, an instrumental case study was completed to explore the phenomenon of providing care at the end of life, in the Interdisciplinary Team, Provider Dominant, and Cooperative Network care delivery models from the perspective of older female spousal caregivers. According to Stake (1995), an instrumental case study is used to gain a general understanding and insight into a phenomenon. An instrumental case study approach was conducted as it allowed for the in-depth collection of complex and contextual data from different perspectives (Fitzsimons et al., 2007). The case study method was also used for its ability to examine small datasets to provide a deep description, and in this instance illustrated the demands older adult women face in the spousal caregiving role. In this study, within and across case analysis was used to examine the older adult's perception of caring for a spouse with one of three life-limiting illnesses.

The researchers took a number of steps to safeguard the participants. Approval was obtained through the Institutional Review Board and Human Protections Office before commencing the study. Each participant provided signed, informed consent before the study. Data for this study were part of a longitudinal ethnographic study that explored the interface between formal and informal caregivers across three caregiving trajectories (NIH/NINR 5R01NR0102703). Participant recruitment was focused in a large academic medical center. This medical center houses a number of specialized outpatient settings including the three settings from which the current sample was drawn: an amyotrophic lateral sclerosis (ALS) clinic; a cancer clinic; and a cardiology clinic. Beyond dramatic differences in the life-limiting illness trajectories, each of these clinics portrayed unique care delivery models identified in the parent study with ALS representing the Interdisciplinary Team, the cancer clinic representing the Cooperative Network, and the cardiology clinic representing the Provider Dominant (Penrod et al., 2012). Inclusion criteria for the informal caregivers from the original study were: providing care to a patient with ALS, lung cancer, or heart failure; aged 18 or older; proficient in English; not diagnosed with the condition for which the care recipient is being treated; and no neurological or cognitive impairments that would preclude participation in the study. A total of forty-five informal caregivers participated in the caregiver arm of the ethnographic study.

In the parent study, data were collected using qualitative semi-structured interviews with older female caregivers providing care to a spouse. The interviews were 60-90 minutes and completed monthly for a period of 12 months to reveal changes in condition/caregiving role; times of distress; and types of support received during healthcare interactions. For those caring for a spouse who did not survive 12 months, interviews were continued for two months after the death of the care-recipient. Researchers attended all regularly scheduled clinic visits for the patient's life-limiting condition and collected observational data during the office visit. Data from the interviews and observations were digitally-recorded, transcribed verbatim, and then cleaned of all identifying information during verification.

Subjects and Setting

Purposive sampling was used to determine an adequate and appropriate dataset for this instrumental case study. The research team collaborated to select the cases that would

maximize variation in the life-limiting illness trajectory and care delivery model while providing deep, rich descriptive data. The cases discussed in this paper were selected because they illustrate the challenges faced by older female caregivers. One participant from each clinic in the parent study (i.e., ALS, heart failure, lung cancer) was selected, producing a total of three cases used in this study. In addition to the inclusion criteria cited above for the parent study, all participants in the case study were female, in a spousal relationship with the patient, and over 65 years of age.

Data Collection and Analysis

Data were collected as part of the parent study. The sampling plan for the case study resulted in a dataset consisting of longitudinal individual interviews with the three selected female caregivers. The final data set included 26 in-depth interviews conducted over a range of 9-13 months. Using principles described by Yin (1994) as a framework for the analysis, cases were analyzed independently (i.e., within case analysis) prior to cross-case analysis. Analysis began with categorical aggregation to establish categories and instances to reveal meaning in the context and link the data to the propositions. As insights were clarified, categories were further analyzed to establish common themes related to the phenomenon of older adult women providing end-of-life care to their spouse in one of three care delivery models.

Results

In this section, a brief overview of each caregiver is presented followed by a description of the identified themes. Mrs. A. is a 78-year-old woman providing care to her spouse who suffers a life-limiting illness. His care progressed from a curative focus into comfort care. Care was provided in a Cooperative Network care delivery model. Mrs. A. has been married for over 40 years and has three children who live within a close proximity and provide a supportive network. Mrs. A. has a history of stroke, depression, vision and hearing impairments, and has had bilateral knee replacements. Mrs. S. is a 73-year-old woman providing care to her spouse with terminal illness being treated within the Interdisciplinary Team care delivery model. Mrs. S. has been married for almost 20 years and has four children who are supportive but live at a distance and are busy with their own lives. Mrs. S. has a history of stroke and cardiovascular disease. Mrs. M. is an 80-year-old woman providing care to her spouse with a life-limiting condition that is demarcated by a series of exacerbations that may end in an unanticipated or very late acknowledgement of the probability of death. Mrs. M.'s spouse is being treated within the Provider Dominant care delivery model. Mrs. M. has been married for over 50 years, with no children. Mrs. M. has a limited, informal support network of friends and neighbors and has a history of cardiovascular disease, arthritis, and vision impairment. The following five themes emerged from the instrumental case study: balancing multiple morbidities; feeling overwhelmed and exhausted; dealing with personal health issues; feeling isolated; and coordinating care.

Balancing Multiple Morbidities: “I don't know how this treatment is affecting his other problems”—As the older adult patients in this case study all had multiple morbidities in addition to their life-limiting illness, this added to the complexity of the caregiving role. The older adult caregivers faced difficulty in balancing not just the life-

limiting condition but also the patient's multiple morbidities. Feelings of frustration were expressed when the caregivers perceived only the life-limiting condition was being treated without attention to the other co-morbidities. In discussing her frustration over the health care professionals' failure to treat the whole patient, Mrs. A. reported that "...it just seems like they only want to take care of the cancer and this bothers us... I think they need to deal more with the big picture and not just part of the picture." Focusing on the treatment response to a particular disease is common in the Cooperative Network care delivery model (Penrod et al., 2012) in which Mrs. A. was providing care.

This frustration was also evident when discussing difficult care routines due to pre-existing multiple morbidities in addition to the life-limiting illness. Mrs. M. voiced concern over the pain and disability her husband was experiencing from a shoulder injury which prevented him from dressing and showering himself. Due to his multiple morbidities, surgery was not an option. "The doctor said...his shoulder should be operated on, but he said they couldn't operate because of his kidneys..., the doctor said he's too old to operate, his kidneys wouldn't take it." She attributed increased caregiving demands due to this shoulder injury including activities of daily living (ADL) assistance as well as taking on household responsibilities that he was no longer able to complete such as raking leaves. The patient's co-morbidities (which increase with age) impacted the care required by his caregiver.

In addition to expressing frustration about managing the patient's multiple morbidities, the challenge of dealing with different specialists intensified feelings of uncertainty in the caregiving role. Uncertainty is a condition of doubt in a situation as to its outcome or meaning with states of uncertainty being influenced by one's perception of confidence and control (Penrod, 2007). In this case, uncertainty was manifested by a lack of confidence and control regarding how the pre-existing multiple morbidities would affect the treatment for the life-limiting condition. Mrs. A. described a situation in which the patient had been released from the hospital and within one day of being home had fallen and broken his foot. Even before breaking his foot, the patient was having a great deal of trouble walking. Mrs. A. expressed the following "...something just wasn't right. We went to the neurologist just the other day and they had done an MRI and so they think he has a form of hydrocephalus." Mrs. A. stated many times that she was uncertain how her spouse's chemotherapy treatments were affecting the hydrocephalus. Mrs. A. went on to further explain the situation of going back and forth between the neurologist and oncologist to determine what was happening with the patient and how difficult and unsettling it was:

We're gonna talk to [the oncologist] about...what his prognosis is and then we're considering, the family, having a neurologist do a spinal tap to drain some of the fluid to see if in fact it helps his walking. If it does, then we're gonna go that route... It's trial and error kind of thing.

In contrast, when balancing the multiple morbidities of her spouse, Mrs. S. received support from the Interdisciplinary Team, the care delivery model in which she was providing care. Mrs. S.'s spouse was becoming more and more debilitated to the point he was no longer able to sit up. The clinic nurse was contacted and he was seen by a specialist the next day for what turned out to be a cardiac issue and a pacemaker was inserted. Mrs. S. expressed confidence in the interdisciplinary team's ability to help her manage her spouse's care "...

we're working with a good team here and I think they're going to be very helpful and I know they will get us some help”.

Feeling overwhelmed and exhausted: “I can’t do what I did when I was 50!”—

The second theme the older female spousal caregivers in the study discussed was feeling overwhelmed and exhausted. The difficulty of always having to be responsible was exemplified in the following quote: “I think the hardest part is being on call 24/7.” In addition to being responsible for the patient on a 24/7 basis, the caregivers were also faced with expanded individual demands to maintain the household. These themes are not unique to the older caregiver however, they are intensified as described by Mrs. M., “I want to wash windows but I get tired, I get tired. I'm 80 years old! I'm going to get tired.” Mrs. S. expressed this as: “Everything overwhelms me. Everything. From the house, everything is up to me. But before, it was he and I, now I have to take care of everything. I just feel like I don't have control anymore.”

Being overwhelmed and exhausted is not unique to the older caregiver however older caregivers' attributed much of their exhaustion to their age and to their own health issues. As part of the exhaustion felt by the caregivers, simple chores became overwhelming. “I am 73 years old. I get tired and last night I was exhausted. I guess maybe I have to realize that I can't do what I did when I was 50.” Mrs. M. related her concern about only having the endurance to look after the patient and not having any energy left to deal with household responsibilities:

All I do is take care of him. I don't have any strength, energy, mentally or physically to do anything. I'm lucky to get the dishwasher unloaded...that's very distressing to me...That's what is very bothersome to me... I just can't stand it. It wears me out.

Dealing with personal health issues: “I've come up against my own mortality”

—The older adult caregivers in this case study had their own aging health issues to attend to that escalated due to the physical and emotional demands of the caregiving role and in turn impacted their ability to provide care. The caregivers were facing age-related changes and experiencing a decrease in their physical and psychological reserves as noted by Mrs. S. when discussing her cardiac issues: “So it's this valve problem that I guess I have to work around. We age... these things start to happen, you know, and something is going to get us sometime. So I guess maybe that's my thing.” In fact, when dealing with her own heart health issues, a result of radiation for breast cancer over 30 years ago, Mrs. M. stated that she had to “fit” insertion of a pacemaker between the admission of her husband to the hospital and his discharge so that he would be cared for during her procedure.

The caregivers were philosophical about growing older but still faced their own multiple morbidities, which affected their caregiving role and made simple daily activities more difficult. Although the primary caregiver for her husband, Mrs. A. had several of her own age-related health issues:

Not only do I have arthritis, but I have breathing problems. So they finally diagnosed it as the right side of my diaphragm is paralyzed. So I can only breathe

from this one side. And going up and down steps and carrying things, walking to the bathroom, I can't do it.

As well, caregivers put the patient's needs and health ahead of their own well-being. The caregivers viewed themselves as co-providers of the patient's care; the focus was on caring for their spouse in the midst of struggling with their age-related health issues sometimes at the expense of their own health. Mrs. M. shared a story of taking her husband to a doctor's visit the day following cataract surgery, "The next day, I had to push [patient] in wheelchair first to the 2nd floor and then 4th floor." Rather than focusing on her own health, Mrs. M. was determined the patient attend his appointment. In this scenario it was the nurse who expressed concern for Mrs. M. as captured in the following: "I said I just got my cataracts removed and the nurse said you're pushing him? I said, yes, and the nurse said, well you're not going to push him out of here, I'm getting someone to push him out." As a result Mrs. M.'s needs as a co-recipient of care were acknowledged and acted upon.

Mrs. A. also put her husband's health first when discussing the possibility of having her husband placed in an assisted living facility: "I'm determined to give him the best care he can have and I'm keeping him here. It might do me in, but I don't want to go that other route." Caring for the patients at the cost of their own health was compounded by the caregivers dealing with issues of their own mortality as they saw changes in the patients and themselves. Mrs. S. articulated it this way:

I am aware that I'm 73 years old and I had a stroke... I was in the hospital for 10 days so I've come up against my own mortality... So, I guess I'm feeling like... I have a need to do things for myself, fun things... but there are so many things that need to be done just to maintain the house and keep [spouse] going. I've had to give up some of my outside activities. How healthy it is for me to do that, I don't know...

The well-being of these older adult caregivers was already compromised with age-related health issues but became even more at risk because they placed their health second to the needs and health of their care recipient spouses. As the caregivers focused their efforts on caring for their spouses, outside activities and relationships were curtailed which increased feelings of isolation.

Feeling isolated: "I'm not a gad about, but I do need social interaction"—The theme of feeling isolated was a concern for the older female caregivers. As with other caregivers, caring occupied so much time and energy that opportunities for social interaction outside of the caregiving role were limited. The extent of feeling isolated became pronounced for the older caregiver especially when their social support consists of individuals of similar age. Mrs. M. revealed that she would talk to a friend about her "troubles." However, this social support was now limited due to the fact that the friend moved to an assisted living facility and she has "old-timers." Social support is lessening for these older caregivers due to the health issues of their older friends and family. Mrs. S. conveyed the impact that aging has when discussing her waning social interaction and entertaining:

I guess that's one of my fears is becoming isolated. I'm not a "gad about", but I do need social interaction...I mean I don't entertain the way I used to and part of that is because I'm a lot older than I used to be...it's hard when you have to do it all by yourself. I guess 30 years ago, I wouldn't have thought much about it but now...we don't entertain the way we used to.

With the encompassing nature of the caregiving role, making plans outside the realm of the patient was difficult. Participating in outside activities necessitated finding alternative care for the patient. As this was not always possible or overwhelming to arrange, the caregivers were often forced to change their plans or put them on hold which added to feeling isolated. This is exemplified by Mrs. A. who wanted to be with her daughter when she was to have surgery:

I'd really like to be with her when she has her surgery. So I'll have to find somebody that might be able to come and hang out with [spouse]. I'm hoping it will be outpatient. I would like to be with her. So it's been hard to make any kind of plans for anything, but again, you deal with what you gotta deal with.

Interactions with family and friends became more limited as the patient's condition progressed and demands in the caregiving role escalated. This is illustrated by the following "...we don't go out the way we used to, you know I'm not getting any younger so I can't organize the way I used to so we're [staying] in more." This sense of being alone and isolated was also affected by the changing relationship with the patient as a result of the progression of the life-limiting illness. Mrs. S. was able to express her sense of isolation with a counselor who was part of the Interdisciplinary Team care model and highlighted this sense of isolation within the changing relationship when discussing communication issues with her husband: "Our relationship...we don't have the kinds of conversations we used to have and the kinds of interactions we used to have. We don't do the things we used to do. All that has changed." In this environment of feeling isolated, what little time and energy that was left was at times consumed by hands-on care and the effort required to coordinate the patient's care.

Coordinating Care for Patient and Caregiver: "They said they'd call, but they haven't yet"—In this case study, the older caregivers faced complex coordination of formal care for multiple age-related morbidities. This complexity required the older adult caregivers to traverse and coordinate care across multiple specialists (e.g., neurology, cardiology, and oncology), multiple care systems (e.g., private offices, different hospitals, distinctive care agencies) and various care routines (e.g., heart failure, diabetes). Coordinating care became a complex juggling act across different care systems and medical specialists. Mrs. M. expressed that a typical week for her often included many office visits.

He saw a kidney doctor and they took x-rays and he has a doctor in [town] and then he had to go to this nose doctor yesterday... he goes for blood shots every 3 weeks [17 miles away]. Now on Monday, we had 2 office visits at [medical center 1]... Then Tuesday we go to the [medical center 2] to get blood work and then he has to

see the kidney doctor...but, then we went up to the emergency room twice. My calendar is full.

The model of care delivery significantly influenced the caregivers' attempts to coordinate care. The older adult female caregiver interfacing with the healthcare providers in the Interdisciplinary Team model felt supported. In this environment, both the patient and family caregiver had access to support groups and members of the healthcare team. Mrs. S. was enthusiastic about the support she and her husband received during their clinic visits: "we were really pleased, as we always are...I think the session with the social worker and nurse counselor...was excellent. We got some things out on the table that needed to be addressed...so it was a good session." As well in this care delivery model, different members of the team, assisted in coordinating care and providing needed assistance as described by Mrs. S. "...the social worker told us that they'd be checking in with us every month so I think that we're more likely to get the kinds of help that we need, she's already signed [the patient] up for the skilled care facility...that we want to be in." To sum up the support that the Interdisciplinary Team provided to her and her spouse, the caregiver expressed "I'm not sure how we would get through it without [the team].I mean I don't know what we would have done. Of course we would go through it, but I don't know how we would have done it."

In contrast to the experiences of the caregiver in the Interdisciplinary Team model, in the Provider Dominant model, coordinating care and juggling appointments were largely the responsibility of the older adult caregiver with little assistance from the healthcare professionals unless that care or appointment was directly related to the life-limiting illness. Depending on their area of expertise, the various specialists proposed different medical regimes. Considering that the Provider Dominant model of care delivery is characterized by a single provider without interdisciplinary support, these multiple regimes were narrowly focused on one disease leaving the caregiver to manage the multiple care systems further complicating the caregiving role. The older patient with multiple co-morbidities is challenged with communicating between many specialists, care systems, and care routines as captured by Mrs. M. in the following:

...he changed doctors. His neurology doctor is now at the [medical center 1] because we can't get the medication if he goes to [medical center 2]. So we have to go to the doctor at the [medical center 1] and now they want to do his blood shots there too. I was there last week and they said they hadn't received anything from [medical center 2] yet. I talked to the nurse, she thinks they did receive the information but it hasn't been put in the computer yet. But they haven't called us, they said they'd call, but they haven't yet. He needs to have another shot on [date]. The nurse from [medical center 1] said she sent the information to the [medical center 2]. But the neurologist didn't have it, then I spoke with the other doctor's nurse and she thought they had the information but it wasn't in the computer yet.

This occurrence is similar to that experienced by the older adult providing care in the Cooperative Network model, in which the lead provider makes treatment and referral decisions. Treatment and referral plans are prescribed by the lead provider and clarified during debriefing sessions with interdisciplinary staff; however, the family caregiver is

largely responsible for coordinating this care for the patient. This is extremely complex to coordinate. Mrs. A. expressed her difficulties in coordinating care as she attempted to juggle care between different medical specialists and various agencies including the Office of Aging:

...I've got to call the Office of Aging to get some respite care...Everything is an effort, nothing is simple...I don't want to be bothered, yet I need the help. Nothing makes sense...they know I'm asking for respite care, so maybe it won't be such a hassle the next time I want somebody. It's a hassle, that's the word I want. I'm tired of everything being a hassle.

Summary—In this instrumental case study, the themes that emerged illustrate the complexity of the caregiving role for the older women. Balancing multiple morbidities and coordinating care across various specialists, care systems and care regimes affected the perceived level of control and confidence contributing to the uncertainty of the caregivers and ultimately states of distressed caregiving. These themes were most influenced by the care delivery model in which the family caregiver was providing care. The type of care delivery model mattered and influenced the caregivers' experiences in balancing and coordinating care for their spouse. Dealing with personal health issues, feeling exhausted and isolated were also themes that added to the complexity for older adult women caring for a spouse at the end of life.

Discussion

Family caregivers are getting older. During the 20 year period extending from 2011 – 2031, 10,000 people per day will turn 65 in the United States (Alliance for Aging Research, 2011). This will result in an aging population in which *both* patients *and* their family caregivers are older. Currently, nearly one-quarter of caregivers who themselves are 65 or older are caring for a spouse (Family Caregiver Alliance, 2011). As part of the normal aging process, 88 % of adults over the age of 65 have at least one chronic health condition with the most prevalent ones being arthritis, cardiovascular disease, cancer, and diabetes (Centers for Disease Control and Prevention, 2011). Compounding these threats, older adult spousal caregivers tend to develop illnesses and disabilities around the same time as the patient. Patients at the end of life will have problems that require a caregiver, but chances are the older adult caregiver also has health problems (Schulz & Sherwood, 2008). The caregivers in the current study were all older than 70. Despite having their own health issues these older adult caregivers continued to provide care at the expense of their health. Other studies have also found an increase in psychological and physical morbidity and even mortality for caregivers (Christakis & Allison, 2006; Schulz & Beach, 1999).

Previous efforts to improve outcomes for caregivers have often not been successful (Schulz & Martire, 2004). In the three care delivery models (Interdisciplinary Team, Provider Dominant and Cooperative Network) support for the caregiver varied. According to Penrod and colleagues (2011) caregivers often do not see themselves as recipients of care and for most their interactions with the formal healthcare system reinforce this perception. As demonstrated in the *balancing multiple morbidities* and *coordinating care* themes, these

older female spousal caregivers were often viewed as an extension of the healthcare system. Typically, family caregivers are responsible for providing both emotional and physical care to the patient as well as organizing and coordinating health services on behalf of their dying loved one (Stajduhar, Martin, Barwich, & Fyles, 2008).

For family caregivers to provide the best care possible and engage in adequate self-care, it is important for health care providers to view them as co-providers and co-recipients of care (Penrod et al., 2011). In addition to highlighting areas of need, viewing caregivers as co-recipients of care allows them to express concerns about their caregiving role and presents the opportunity to raise questions and be provided with helpful resources (Next Step in Care, 2011). The responsibility for managing multiple specialists, care systems and complex care regimes fell to the caregivers and this contributed to their being overwhelmed, exhausted and isolated. Although this study highlighted the challenges faced by older adult women caregivers, the study does have limitations. The generalizability of the findings is limited by several factors including the small sample size and the heterogeneity of the sample. The study's participants were Caucasian women over the age of 70, from the same rural area with their spouses receiving care from the same medical center. To select the participants, purposive sampling was used which enabled the identification of participants who would contribute to the richness of the data but this type of sampling also limits the generalizability of the results to other caregiver populations. As a result, we do not know how the experiences of older women caregivers compare to the experiences of younger caregivers, male caregivers or non-spouse caregivers across the three care delivery models.

Summary and Implications

There is little debate that family caregivers experience a significant amount of distress as a result of their caregiver roles (Jones, Hadjistavropoulos, Janzen, & Hadjistavropoulos, 2011; Tooth et al., 2008; Torres, McCabe, & Nowson, 2010; Zarit, 2004) and reduced quality of life (Tooth et al., 2008). The older adult caregivers in this study identified several challenges of caregiving, namely: balancing multiple morbidities, feeling overwhelmed and exhausted, dealing with personal health issues, feeling isolated and coordinating care. They discussed the importance of comprehensive care; specifically treating the whole person rather than just the life-limiting condition. Unfortunately, at times care was fragmented and necessitated the caregivers navigate uncoordinated services, which contributed to their distress. Recognition by healthcare providers of the challenges faced by older adult caregivers providing care to a spouse with a life-limiting illness is essential as is an understanding of how the care delivery model can also impact the caregiving experience. Cues of caregiver distress must be assessed and addressed. A greater understanding of how the care delivery model impacts older adults in their caregiving role as well as the caregivers' perspective of caregiver distress are areas for future research. Additional areas of potential research include comparing the experience of younger and older adult caregivers across the different care delivery models as well as female vs. male experiences of caregiving.

Another important aspect is viewing the older adult caregiver as a co-recipient of care (Penrod et al., 2011). Caregivers put the needs of the patient first, often at the expense of their own health. To address the needs of the caregivers, flexibility on the part of the

healthcare providers is important. Interventions tailored to meet the needs of older adults will allow the adjustment of care to the resources and preferences of the patient and the family caregiver (Lynn & Adamson, 2003). For examples of resources for both older adults and healthcare providers see Table 1.

Finally, the results of this instrumental case study highlight the complexity of providing care at the end of life. The family caregivers expressed their frustration in having to provide and coordinate care in a system that was at times fragmented. This suggests that continuity of care, regardless of the type of disease, may help to address issues in the caregiving role and facilitate the transition across the life-limiting illness trajectory for both the patient and their family caregiver.

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References

- Alliance for Aging Research. 2011. Retrieved from: <http://www.agingresearch.org/content/article/detail/826>
- Blum K, Sherman DW. Understanding the experience of caregivers: A focus on transitions. *Seminars in Oncology Nursing*. 2010; 26(4):243–258. [PubMed: 20971405]
- Blyth FM, Cumming RG, Brnabic AJ, Cousins MJ. Caregiving in the presence of chronic pain. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*. 2008; 63(4):399–407.
- Burton LC, Zdaniuk B, Schulz R, Jackson S, Hirsch C. Transitions in spousal caregiving. *The Gerontologist*. 2003; 43(2):230–241. [PubMed: 12677080]
- Centers for Disease Control and Prevention. 2011. Retrieved from: <http://www.cdc.gov/>
- Christakis N, Allison PD. Mortality after the hospitalization of a spouse. *New England Journal of Medicine*. 2006; 354:719–730. [PubMed: 16481639]
- Doorenbos AZ, Given B, Given CW, Wyatt G, Gift A, Rahbar M, Sangchoon J. The influence of end-of-life cancer care on caregivers. *Research in Nursing & Health*. 2007; 30:270–281. [PubMed: 17514724]
- Family Caregiver Alliance. 2011. Retrieved from: http://www.circlecenterads.info/documents/FCAPrint_SelectedCaregiv...pdf
- Fitzsimons D, Mullan D, Wilson JS, Conway B, Corcoran B, Dempster M, et al. The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliative Medicine*. 2007; 21:313–322. [PubMed: 17656408]
- Garlo K, O'Leary JR, Van Ness PH, Fried T. Burden in caregivers of older adults with advanced illness. *Journal of American Geriatrics Society*. 2010; 58(12):2315–2322.
- Glaser, B.; Strauss, A. *Time for dying*. Chicago: Aldine; 1968.
- Hudson PL, Trauer T, Graham S, Grande G, Ewing G, Payne S, et al. A systematic review of instruments related to family caregivers of palliative care patients. *Palliative Medicine*. 2010; 10.1177/02692216310373167

- Jones SL, Hadjistavropoulos HD, Janzen JA, Hadjistavropoulos T. The relation of pain and caregiver burden in informal older adult caregivers. *Pain Medicine*. 2011; 12(1):51–58. [PubMed: 21143758]
- Lavela S, Ather N. Psychological health in older adult spousal caregivers of older adults. *Chronic Illness*. 2010; 6:67–80. [PubMed: 20308352]
- Lynn, J.; Adamson, DM. Living well at the end of life: Adapting health care to serious chronic illness in old age. Santa Monica, CA: RAND Publications; 2003.
- Monin JK, Schulz R. Interpersonal effects of suffering in older adult caregiving relationships. *Psychology and Aging*. 2009; 24(3):681–695. [PubMed: 19739924]
- National Alliance for Caregiving. 2011. Retrieved from: <http://www.caregiving.org/>
- National Family Caregivers Association. 2011. Retrieved from: http://www.nfcacares.org/who_are_family_caregivers/
- Next Step in Care. 2011. Retrieved from: <http://www.nextstepincare.org/>
- Parker C, Teel C, Hobbs Lennerts M, Macan A. A theory-based self-care talk intervention for family caregiver-nurse partnerships. *The Journal of Gerontological Nursing*. 2011; 37(1):30–35.
- Penrod J. Living with uncertainty: concept advancement. *Journal of Advanced Nursing*. 2007; 57(6): 658–667. [PubMed: 17346325]
- Penrod J, Baney B, Loeb S, McGhan G, Shipley PZ. The influence of the culture of care on informal caregivers's experiences. *Advances in Nursing Science*. 2012; 35(1):64–76. [PubMed: 22293611]
- Penrod J, Hupcey JE, Baney BL, Loeb S. End-of-Life Caregiving Trajectories. *Clinical Nursing Research*. 2011; 20(1):7–24. [PubMed: 20876553]
- Penrod J, Hupcey JE, Shipley PZ, Loeb S, Baney B. A model of caregiving through the end of life: Seeking normal. *Western Journal of Nursing*. 2011 Published online before print March 14, 2011. 10.1177/0193945911400920
- Pinquart M, Sorensen S. Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*. 2011; 26(1):1–14. [PubMed: 21417538]
- Poulin MJ, Brown SL, Ubel PA, Smith DM, Jankovis A, Langa KM. Does a helping hand mean a heavy heart? Helping behavior and well-being among spouse caregivers. *Psychology and Aging*. 2010; 25(1):108–117. [PubMed: 20230132]
- Pressler SJ, Gradus-Pizlo I, Chubinski SD, Smith G, Wheeler S, Wu J, et al. Family caregiver outcomes in heart failure. *American Journal of Critical Care*. 2009; 18(2):149–159. [PubMed: 19255105]
- Salin S, Astedt-Kurki P. Women's views of caring for family members: use of respite care. *Journal of Gerontological Nursing*. 2007; 33(9):37–45. [PubMed: 17899999]
- Schumacher KL, Meleis AI. Transitions: a central concept in nursing. *IMAGE: Journal of Nursing Scholarship*. 1994; 26(2):119–127.
- Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregivers Health Effects Study. *Journal of the American Medical Association*. 1999; 282:2215–2219. [PubMed: 10605972]
- Schulz R, Martire LM. Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*. 2004; 12:240–249. [PubMed: 15126224]
- Schultz R, Martire LM, Klinger JN. Evidence-based caregiver interventions in geriatric psychiatry. *Psychiatric Clinics of North America*. 2005; 28:1007–1038. [PubMed: 16325738]
- Schulz R, Newsom JT, Mittlemark M, Burton LC, Hirsch CH, Jackson S. Health effects of caregiving: The Caregiver Health Effects Study. *Annals of Behavioral Medicine*. 1997; 19:110–116. [PubMed: 9603685]
- Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *American Journal of Nursing*. 2008; 108(9 Suppl):23–27. [PubMed: 18797217]
- Stake, R. The art of case research. Thousand Oaks, CA: Sage Publications; 1995.
- Stajduhar KI, Martin WL, Barwich D, Fyles G. Factors influencing family caregivers'ability to cope with providing end-of-life cancer care at home. *Cancer Nursing*. 2008; 31(1):77–85. [PubMed: 18176135]

- Stetz KM, Brown MA. Physical and psychological health in family caregiving: A comparison of AIDS and cancer caregivers. *Public Health Nursing*. 2004; 21(6):533–540. [PubMed: 15566558]
- Tooth L, Russell A, Lucke J, Byrne G, Lee C, Wilson A, et al. Impact of cognitive and physical impairment on carer burden and quality of life. *Quality of Life Research*. 2008; 17:267–273. [PubMed: 18157616]
- Torres SJ, McCabe M, Nowson CA. Depression, nutritional risk and eating behavior in older caregivers. *The Journal of Nutrition, Health & Aging*. 2010; 14(6):442–448.
- Yin, R. *Case study research: Design and methods*. 2nd. Beverly Hills, CA: Sage Publications; 1994.
- Zarit SH. Family care and burden at the end of life. *Canadian Medical Association Journal*. 2004; 170(12):1811–1812. [PubMed: 15184336]

Table 1
Website Resources for Older Adult Caregivers and Healthcare Providers

<p>Administration on Aging</p> <ul style="list-style-type: none"> Website maintained by the Federal Government to provide healthcare providers and consumers with information about health and social issues facing older adults. Includes “The Savvy Caregiver” which is a 12 hour training program. www.aoa.gov <p>ConsultGeriRN.org</p> <ul style="list-style-type: none"> Evidence-based geriatric clinical nursing website of The Hartford Institute for Geriatric Nursing. Includes the Try This Assessment series that includes 30 nationally recommended instruments for use with older adults. www.consultgerirn.org <p>Hospice and Palliative Nurses Association</p> <ul style="list-style-type: none"> Organization for nurses specializing in end-of-life and palliative care. Website contains documents specific to geriatric end-of-life care as well as patient/family “Tips” teaching sheets. www.hpna.org <p>John A. Hartford Foundation Institute for Geriatric Nursing</p> <ul style="list-style-type: none"> Includes resources on palliative care for older adults, resources for nurses to initiate hospital competencies, develop nursing protocols, and gerontologic review courses. www.hartfordign.org <p>The End-of-Life Nursing Education Consortium (ELNEC)</p> <ul style="list-style-type: none"> National education initiative to improve palliative care. Provides nurses with training in palliative care so they can teach the information to nursing students and practicing nurses. The core content is divided into eight modules: Nursing Care at the End of Life; Pain Management; Symptom Management; Ethical/Legal Issues; Cultural Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement; and Preparation for and Care at the Time of Death. www.aacn.nche.edu/elneec
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