


# The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives

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## Abstract

Family members with a relative with dementia often experience what has been called the “unexpected career of caregiver” and face multifaceted, complex, and stressful life situations that can have important consequences. This exploratory study was designed to address this major public health challenge through the lens of caregiver resilience and caregiver respite programming. While many caregivers report that they derive significant emotional and spiritual rewards from their caregiving role, many also experience physical and emotional problems directly related to the stress and demands of daily care. One way to alleviate these demands is the growing respite care field, providing services in a variety of settings for caregiver. Through qualitative analysis from face-to-face interviews with 33 family caregivers of individuals with dementia, several themes emerged describing the path to caregiver resilience which include family dynamics, isolation, financial struggles, seeking respite, and acceptance. While much research focuses on a caregiving burden perspective, the innovation of the present study is applying the resilience framework to outcomes from respite programming.

## Keywords

dementia, resilience, respite care, family caregivers, qualitative inquiry

## Background

Family members with a relative with dementia often experience what has been called the “unexpected career of caregiver” and face multifaceted, complex, and stressful life situations that can have important consequences. Multiple factors make the adjustment to the caregiving role particularly hard, as the caregiver balances this role with other demands, including child rearing, careers, and relationships.<sup>1</sup> While motivated to provide care out of a sense of love or reciprocity, spiritual fulfillment, or a sense of duty, the impact of dementia on the family member in its advanced stages resembles having lost a spouse or parent.<sup>2,3</sup>

Despite this confluence of factors, making the decision to relinquish the caregiving role to health care providers can also be a very difficult and stressful event.<sup>4</sup> Many family caregivers have made significant personal sacrifices to keep their family members at home, often developing important patterns of coping, mastery, and hardiness over the course of their family caregiving role.<sup>5,6</sup> Therefore, the concepts of self-efficacy, hopefulness, and stress resistance become necessary components of coping capabilities, a complex construct which is often referred to as resilience. Caregiver

resilience may be termed as the use of successful coping strategies used by informal and formal caregivers, shifting from the burden perspective to a resilience perspective.<sup>7</sup>

Educating caregivers about the benefits of caring for themselves is vital for their success and resiliency. Caregiver respite can be one way that family caregivers can take time for themselves and possibly avoid the need to relinquish their caregiving role. Respite care takes many forms in the United States and is often used as a generic description for a diverse range of services and supports.<sup>8</sup> Recent evidence suggests that respite has tangible benefits for caregivers, care receivers, and their families, yet research findings over the years about the effects of respite have been limited and inconsistent.<sup>9,10</sup> In findings from their 2013 study, Black, Johnston, Rabins, Morrison, Lyketos, and Samus reported

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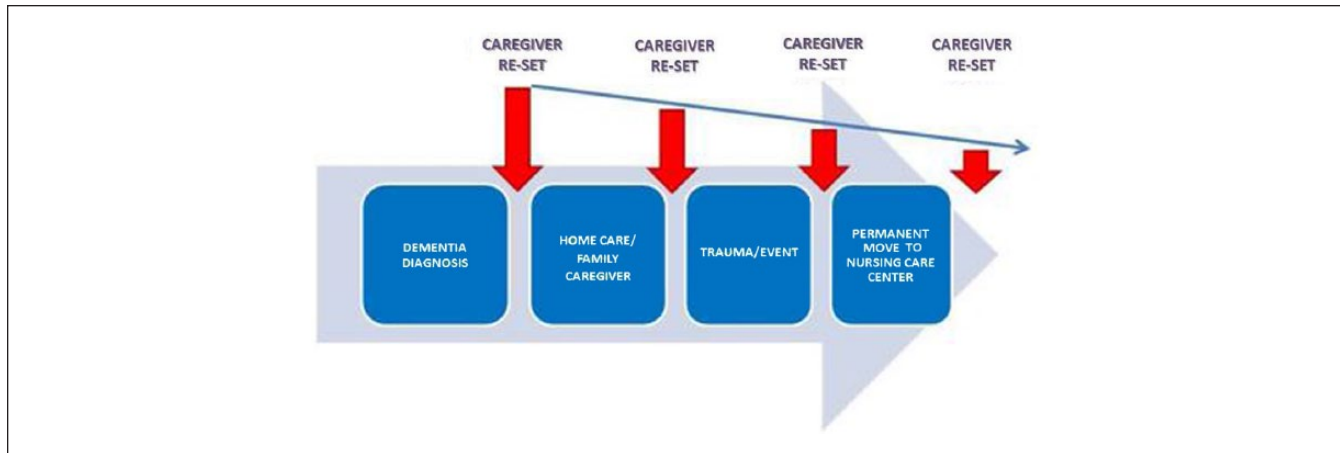
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**Figure 1.** Trajectory of resilience without support through the continuum of care.

that 85% of caregivers had unmet needs for referrals to community resources (eg, Alzheimer's Association) and caregiver education.<sup>11</sup> Almost half (45%) of caregivers had unmet needs in the area of mental health, most of whom needed emotional support or respite care.

Family caregivers represent the bridge between the time and place that have been left behind and the present day; therefore, the long-term nature of dementia caregiving requires long-term support strategies that are oriented around the various transitions that merge in the context of the caregiver career.<sup>12,13</sup> Individuals in stressful situations such as caregiving can benefit from social support networks as they can provide the resources that help them manage their situation.<sup>14</sup> Without these supportive services at each transition in the continuum of care, family caregivers risk poor health outcomes as their resilience and stamina may wear down, making it harder to bounce back with each new set of caregiving responsibilities and circumstances (Figure 1). This article addresses the importance of caregiver respite as one factor in sustained resilience over the continuum of care for family members caring for an individual with dementia.

## Family Caregivers of Individuals With Dementia

There are currently an estimated 30 million people with dementia worldwide, and this figure is likely to double every 20 years as medical technology lengthens life spans. In the United States, it is estimated that 70% to 80% of people with dementia are living at home. Sixteen million Americans are caring for a person with dementia, with 75% of this care is being provided at home without pay by family and friends.<sup>15</sup>

Families of persons with dementia face unique challenges that many other caregivers do not.<sup>9</sup> The behavioral and psychological symptoms that are core features of dementia include a cluster of neuropsychiatric symptoms such as depression, apathy, sleep disorders, agitation, and psychosis.

Individuals with dementia may have multiple psychological, biological, and interpersonal unmet needs, losing grasp of their understanding of their circumstances and relying heavily on their family for all aspects of their physical and emotional support, as well as activities of daily living.<sup>16</sup> This level of care can be intense and physically demanding, and challenges are exacerbated if caregivers are in poor health themselves.<sup>17</sup>

## Caregiver Resilience

The nature of the dementia care challenge is varied and individualized, calling attention to the need to address each circumstance within the broader life context. Because of the long-term trajectory of dementia, the role changes for family caregivers are subtle and at times insidious with varying degrees of physical and emotional impact.<sup>18</sup> A consistent theme in dementia caregiving research is the diversity of responses to care demands and one potentially predictive factor in caregiver adaptation to the role is resilience.<sup>6</sup> Resilience as a psychological conceptualization is the ability to maintain normal or enhanced functioning during times of adversity and consists of two components: The first is thriving and succeeding, and the second is exhibiting the competence in difficult situations or a situation where others often do not succeed.<sup>19</sup>

Studying resilience provides an opportunity to understand how family caregivers may function as well as or better than before caregiving began.<sup>20</sup> Gaugler, Kane, and Newcomer find that those caregivers who indicate less stress resistance, or low resilience (high burden, low care demands), would be more likely to exit at-home caregiving roles than would caregivers who report high resilience (low burden, high care demands).<sup>6</sup> Their 2007 study goes on to point out that resilience is influenced by 3 constellations of variables: context of care; status of the care recipient; and individual, family, and community resources.

## Caregiver Respite Programming

American caregiving policy has seen a shift in the past several decades from institutionalization to aging in place initiatives through the promotion of community-based care.<sup>21</sup> Funded and distributed through state grants and voucher programs, federal and state programs for caregivers include the National Family Caregivers Support Program, the Lifespan Respite Program, the Alzheimer's Disease Supportive Services Program, and most recently the National Alzheimer's Project Act.<sup>9</sup>

The National Academies of Sciences, Engineering, and Medicine define respite interventions broadly to represent therapeutic strategies, care delivery models, programs, and services intended to support family caregivers of older adults.<sup>22</sup> Respite may take the form of adult day center-based programming, group or individual counseling services, as well as respite voucher programs that allow for help with household chores as well as short-term and long-term care. While respite may provide help with the day-to-day responsibilities of living with a family member with dementia, the varying options often create confusion about what services provide what outcome. Respite care research, therefore, requires clarity and consistency of terms that allow researchers to examine which of the specific aspects of the respite service, and the way it is delivered or used, lead to immediate, short-term, or long-lasting benefits.<sup>8</sup>

## Significance

This study examines family caregiver perspectives on how respite programming impacts their resilience and ability to better handle the demands of their responsibilities. This is an important area of study, because while there is a large focus on stress and burden in family caregiving research, few studies have examined caregiving from a resilience perspective, particularly through the lens of respite programming. Using interviews about participant use of respite programming to address the factors which contribute to resilience in caregiving, the research questions for the study include the following:

**Research Question 1:** What was the determining factor in the transition to the role of family caregiver?

**Research Question 2:** In what ways do awareness of respite programming and actual utilization of respite impact resilience outcomes?

**Research Question 3:** If the use of respite programming has impacted resilience for the caregiver, how has this translated to improved outcomes for the care recipient?

## Study Design

This research is part of a larger mixed-method study. Quantitative data from Phase 1 of the study were collected through an online survey directed toward current family caregivers who are using respite programming. At the end of

the survey, Phase 1 participants were invited to take part in Phase 2 of the study, where qualitative data were gathered through face-to-face interviews with a focus on the longitudinal implications of respite programming on informal long-term care. This article addresses the Phase 2 qualitative interview portion of the larger study. Institutional review board approval was obtained prior to sample recruitment, and all participants completed consent documents prior to the study.

## Sample Population and Data Collection

Inclusionary criteria for this study required participants to be unpaid family caregivers age 18 years or older, caring for someone with any type of dementia. Participants were to be using or have used in the past some form of respite such as voucher programs, adult day care, overnight respite for the family member or support groups, or counseling for the caregiver. The sample was drawn from respondents to an information letter sent from respite providers which included a request for participation in an online survey, a description of consent, and the online survey link. At the conclusion of the survey, participants were given the option to go to a separate survey page which asked for their contact information, so that a member of the research team could reach them to set up an interview. A total of 101 individuals responded to the initial survey link, with 77 respondents fitting the inclusionary criteria and 54 requesting contact for a follow-up interview. Within 6 months of the initial response to the online survey, a research team member made an attempt to contact all respondents interested in a follow-up interview, with ultimately a total of 33 of this sample agreeing to an interview.

## Interview Protocol

Interviews were prescheduled and took place in a predetermined location, and if circumstances warranted, phone interviews were offered as an alternative. Each interview lasted approximately 45 minutes and was audio recorded. A semistructured interview protocol was used as a guide to foster conversations, so that the family caregivers could describe their experiences in their own words. Questions included caregiver's perspectives about (1) their specific needs, strengths, and resources; (2) emotional and physical functioning in the caregiving dyad; (3) the caregiver's ability to help meet the needs of the care recipient; and (4) caregiver interactions or relationships with health care teams and/or long-term care systems.<sup>22</sup> The protocol also addressed general questions around changes in the caregivers' motivation and ability to use respite programming in the time frame since their responses to the initial survey. How does the respite help and how does it fall short? In addition, the interviewees were asked to describe their personal attitudes about resilience as stress resistance. All names in the transcriptions were changed to pseudonyms to protect the participants' anonymity.

**Table 1.** The Impact of Caregiver Respite Programming on Caregiver Resilience.

Theme	Definition	Example
Family Dynamics	Discussion relating to the dynamics when coming to terms with a family member with dementia	<ul style="list-style-type: none"> <li>• I said, “you guys can make it work too”—but they don’t want to help.</li> <li>• We’ll keep her as long as we can, as long as you want to.</li> </ul>
Isolation	Discussion relating to the circumstances surrounding loss of support from family and friends when caring for a family member with dementia	<ul style="list-style-type: none"> <li>• I asked my neighbor next door, “How come you never come over anymore?” She said, “Because it’s depressing.” I’m like, “Well son-of-a-bitch.”</li> <li>• There’s times I would love to have Jack taken care of by someone else, so I could just go have a good time and not always have him in the front of my mind worrying about him.</li> </ul>
Financial Struggles	Discussion relating to the problems relating to the costs associated with caring for someone with dementia at home	<ul style="list-style-type: none"> <li>• We cannot use Adult Day Care because of finances. The VA is helping some but I don’t know how long that will last and I am still fighting them for money that is due.</li> </ul>
Seeking Respite	Discussion of types of respite programming that is available and how each best fits caregiver needs	<ul style="list-style-type: none"> <li>• I recommend it (adult day care) to people. I tell them that they need to use that facility. It just gives them an opportunity to get out and when you’re taking care of everything, all the business and things need to be done for the house, the phone calls, the insurance, you’re doing everything. You have to have something like this.</li> </ul>
Acceptance	Discussion of the ability to step back from a caregiving situation to assess the entirety of the situation	<ul style="list-style-type: none"> <li>• So this is the way that it is and I’m learning to deal with it. I have fought for a long time, “Why me?” I have come to the conclusion that I’ve really been feeling sorry for myself for a long time.</li> </ul>

### Data Analysis

To explore the individual experiences and real-life situations which family caregivers face on a day-to-day basis, a phenomenological approach was used for this article. This inductive approach is based on allowing research findings to emerge from the dominant themes found in the raw data. Three broad tasks are required for qualitative data analysis: data reduction, data display, and conclusion drawing.<sup>23</sup>

With respect to the caregiver interviews in this study, a researcher initially transcribed the audio recordings, followed by each member of the 3 person research team rereading the transcripts several times to determine what is happening within the text. This was done by each researcher independently, and then discussed and outcomes compared within the research team, resulting in the data being broken down into a series of categories to aid in the development of a theoretical concepts. Similarities and differences in the emerging themes were explored to code the data in a way to assign meaning.<sup>23</sup>

A detailed analysis of themes and interpretations were then developed and reoccurring themes interconnected into a theoretical model. These overarching themes included family dynamics, isolation, financial struggles, seeking respite, and acceptance (Table 1). The following section will discuss these themes within a framework of the continuum of care, beginning with the landscape of family dynamics in which the caregiving role began.

### Study Findings

#### Family Dynamics

The median age of the interviewees was 61 years, with a range of 39 to 83 years. Of the 33 respondents, 29 of the respondents were female. Sixteen of the respondents were caring for their mother or mother-in-law, 12 were caring for a husband, 2 were caring for their wife, 2 were caring for their father, and 1 was caring for a sister. While these caregivers made clear their strong desire to continue to help the care recipient, the strain of caregiving often left them with a range of negative emotions. Many reported feelings of guilt for wanting relief from their caregiving duties and several described the circumstances around the initiation of their caregiving role. In many cases, the role was relegated to them by other family members, as it had been taken for granted that they would be best in the role due to their proximity or relationship with the care recipient. Rachel took on the role of principal caregiver for her father after he was widowed and had received a dementia diagnosis. She explains that her 6 siblings had no desire to take on the role of caregiver: “We had seven children in our family. I obviously tried to get the other siblings on board to help, we’d all take turns. Their response was to put him in a nursing home.” When she tried to make the case to create a team of caregivers with her siblings, she recalls that their response was that her relationship with their father was better than theirs:

My brother and sister's excuse is, "Well, you can talk to Dad like we can't, he'll listen to you." I'm like no, I work a full-time job, my husband is getting ready to have his second hip surgery. You guys can make this work too. But they don't want to help.

Other interviewees took on the role of caregiver to help out in-laws. LeAnn explains that she was concerned that her mother-in-law was not getting the attention she needed at her brother-in-law's home:

My brother-in-law moved her (mother-in-law) in with him to start with, but he worked during the day and I was concerned about her well-being during the day. I was afraid she was just eating Twinkies and things, not being able to prepare meals. I work from home, so I thought I could take care of her and work from home, so we brought her to our house.

Very quickly LeAnn realized the depth of the issues that she was going to be facing as the primary caregiver for her husband's mother:

My husband and I probably have the best marriage of any couple I know, but I was starting to feel a little resentful because he could drive off every day to work. I feel sorry for him that his mom having to go through this and I feel sorry for her because she has the disease and I don't, but after a while it just wasn't enough. All of sudden, I'd find myself feeling angry at everybody.

LeAnn continued in her role, because as she put it, "I didn't ever want to be the wife that quit. I said, 'We'll keep her as long as we can, as long as you want us to.' Thought I was tougher than I am, I guess."

*Nontraditional familial structures.* Other complex family structures are impacted by dementia care, as divorce rates remain high, leading to nontraditional caregiving dyads due to late-life marriage. This change has important implications for family caregiving, because adult stepchildren may have weaker feelings of obligation and provide less care to their aging stepparents than their parents, and late-life marriage may impact a sense of duty in spouses.<sup>24,25</sup> A number of the study participants described their own complex family structures. Carol returned to care for her ex-husband Richard 20 years after their divorce. She initially saw herself as part of a care team with their 2 adult daughters and moved in to Richard's apartment to help him. As she explains, the current situation is far from what she would have ever expected or planned for:

Ours is the strangest situation, ours is different than most peoples. I came back to town 4 years ago from a bad marriage to be a part of his care team. I just knew, right or wrong, it was my place, I needed to be there. My goal is just to keep him going.

Within a year of moving in with her ex-husband, they decided to remarry. Their daughters have not been supportive

of the marriage, and as Carol puts it, the family dynamics have suffered due to the stress of the unknowns of Richard's dementia and Carol's new role in his life:

One daughter says I enable him, our other daughter quit her job and tries to help out, but there is now a wedge between them. I've told them, I need help, I need a team. I don't care if you take him to your house for dinner for an hour, just give me a moment. I was gone for twenty years, I should have stayed gone, I told them, I should have never come back.

Similar tensions can be found in step-families formed through late-life marriages. Doris married her current husband of 8 years after losing her first husband to cancer. Ted had been a family friend, and a little over a year after they married, Ted began to show signs of dementia and quit his job. Ted's adult children did not approve of his marriage to Doris and have been hands off in their care and understanding of their father's Alzheimer's disease.

For Doris, there are unspoken questions about her decision to remarry, as she recounts her current circumstances:

I have been getting very depressed about this and very angry, the whole gamut that this wasn't what I wanted my life to be like. I wanted to spend my golden years with someone who is fun to do things with, we could go places.

Despite asking for her adult stepchildren's assistance, Doris remains Ted's sole caregiver. As she explains, "I asked his daughter in April if she could give me one Saturday a month, give me six hours. She said, 'No, because I work.' That really irritated me, I mean really, six hours." This lack of support from both Carol's and Doris's families is indicative of boundary ambiguity described earlier, as adult children resist renegotiating definitions of family relationships.<sup>25</sup> Family dynamics such as these lay the groundwork for what lies ahead in the trajectory of care for primary caregivers.

### *Isolation*

The study respondents were unanimous in reporting that their feelings of isolation were amplified with the increase in their caregiving responsibilities. As reported earlier, family members check in occasionally but do not have an understanding of the care recipient's needs, and often it is too difficult to convey caregiving demands to family and friends. For Doris, it was just easier to let go of these relationships. She recalls the last conversation that she had with her neighbor who had been a close friend:

I asked my neighbor next door, "How come you never come over anymore?" She said, "Because it's depressing." I'm like, "Well son-of-a-bitch, big deal. How do you think I feel?" But I didn't say that. I thought OK, you're off my list.

Francis is another spouse caring for her husband Charlie. She had tried to have her adult daughter come sit with him

occasionally, but her daughter had trouble focusing on caregiving because she had to bring her small children with her. Although Francis wanted to get out for a bit, she says that it became easier for her daughter to just run errands for her instead: “It was just easier, but I never have a chance to get a break, and be by myself. It was always me right there with Charlie.”

Other caregivers reported that while at home, the care recipient was not comfortable being alone in a room, even if they, the caregiver, was close by. Monica describes having her mother with her almost all time when they are in the house:

She’s glued to me, she’s just glued to me. She’s not able to go anywhere and she doesn’t want to go anywhere. She just gets mean if you make her go anywhere she doesn’t want to go. So I just used to stay home. That house bound feeling is awful.

This long-term isolation leads to self-doubt for the caregivers. If they leave and there is an emergency, they will feel responsible, so many choose to maintain the full caregiving duties, rather than let go for just a little bit. As Monica puts it, “Right now, wherever I go, she goes. It’s just hard, it’s very, very, hard, I didn’t think it would be.”

### Financial Struggles

Research consistently shows that family caregivers of older adults with dementia are at the greatest risk of economic harm, due to the extreme care and supervision that these older adults need.<sup>22</sup> Caregivers incur an average of about \$5500 annually in out-of-pocket expenses related to providing care and losing some or all of their salaries from paid employment and future Social Security benefits due to reduced hours in the workforce.<sup>26</sup> Tina explains her family’s financial situation due to her husband’s dementia:

Our main burden is financial. I have quit my job and my salary has been cut to my Social Security, which is only half of my past salary. Our daughter quit her job 2 years ago to help with her dad and now she has to go back to work. We have tried to help her but we are in a money crisis.

For many interviewees caring for their husbands, this is the first time that they have taken responsibility for the family assets. Often they have had to wade through years of financial paperwork or, as Carol explained, had to come to terms with the poor decisions that were made as their husbands’ dementia became more severe:

Richard had \$100,000 for each of our daughters, and he reduced it or wiped it out by about 75% after he turned 65. He doesn’t even know he cashed out, you try to explain it, but he doesn’t know why or how he would have done it.

Doris, too, explains that the family finances were the hardest thing to grapple in her new role as caregiver:

I think that the biggest hurdle that I have had to get over, emotionally, was how I was going to pay for the logistics of this? For the first time Ted is in financial trouble, he sees me fighting every day. I’ve got to get the money right.

For many, the financial impact of caring for someone with dementia was the thing that kept them up at night searching for answers, at a time when their ability to rest was critical for the next day’s caregiving responsibilities.

### Seeking Respite

Research shows respite options that maximize flexible scheduling and affordability may prove especially useful in helping caregivers recapture or substitute activities during respite that have been lost because of caregiving.<sup>9</sup> The goal for respite providers is to have services function as a bridge for building relationships with family caregivers, enabling them to continue in the caregiving role, yet often caregivers will not have received information about respite far in to their caregiving role.<sup>10</sup> The interviewees in this study learned about respite through a variety of sources, many discovering information about respite options by chance while researching the progression of their family member’s dementia.

**Adult Day Programming.** Adult Day Programming allows the caregiver personal time while the individual with dementia has opportunities for socialization and meals. Day centers are open during traditional business hours (ie, M-F 9-5), and participants and their families can create their own schedule and number of days/hours per week that they will attend. Those caregivers who are using the adult day programming are generally positive about the ability to leave the care recipient for several hours in a trustworthy setting to continue working or to get important house work and errands done. LeAnn is grateful to have found a place for her mother-in-law, so that she can have a few uninterrupted hours at home to get her work done. As she recalls, she learned about day care by chance:

I’m trying to remember who told me about the daycare. Oh, my sister-in-law, she’s the one who kept my mother-in-law before she got really bad. Otherwise, I don’t think the doctor’s office mentioned it and not very many people know about it. I looked in the phonebook and found the center and called them.

Adult day care options can be an important source of help with activities of daily living for care recipients. Linda is grateful her father has help with bathing and showering at the center, because she does not have a safe shower at home. As she reports,

The daycare center gives him a shower twice a week, which is wonderful. I don’t know what I’d do if I didn’t have that. I was going out to his house, driving back and forth just to give him his showers. But his shower doesn’t have anything for him to hang onto when he gets in, it wasn’t safe.

Linda goes on to discuss the importance of the center in her life as it allows her a block of time to get errands done:

I recommend it (adult day care) to people. I tell them that they need to use that facility. It just gives them an opportunity to get out and when you're taking care of everything, all the business and things need to be done for the house, the phone calls, the insurance, you're doing everything. You have to have something like this.

Though the caregivers had high regard for the programming, the care recipients did not necessarily look forward to attending. Tina's husband John does not enjoy the day programming. As she puts it, "He doesn't like going to the program because he says he's smarter than all the rest of them. He says it's boring for him to sit there while the lady is talking to other people." Tina tries to communicate to her husband that having the time for herself is just as important for him as it is for her. She describes her conversations with her husband:

The only way I get my husband to go is to say to him, "John, don't you want me to have some time, would you do this for me?" Then he'll say, "Oh well, I guess I can then, if it's important for you." So I have him there at 8 o'clock in the morning. I pick him up around 3:30, it has just been a life saver for me.

While many receive vouchers for the day care, others are fighting for funding while they continue to self-pay. Mary discusses how her fight for funding adds to the burden that she is feeling with her husband's early on-set Alzheimer disease: "We cannot use Adult Day Care much because of finances. The VA is helping some but I don't know how long that will last and I am still fighting them for money that is due." If full funding is not made available, Mary will likely lose her opportunity for the respite that she currently needs and uses.

**Support groups and counseling.** Other factors to consider in respite programming are the heterogeneity of the caregiving experience and the longitudinal trajectory of providing care. In particular, in the case of support groups, different intervention approaches may be warranted for different caregivers, older adult populations and stages in the caregiving career and stages in the life course of caregivers. For example, young adult caregivers may require different types and levels of support than older adults caring for spouses.

Several study participants spoke of being introduced to group counseling through the Alzheimer's Association or their family member's adult day centers. Some attended a session just once, while others found a group that they felt comfortable with and continue to visit several times a month. These group settings create an opportunity for a caregiver to share experiences and advice with like-minded individuals living with similar circumstances. Study participants describe a setting where there is no judgment, whether they are angry,

fed-up, or feeling stressed. Ginger has high regard for her support group, which meets twice a month at her church. As she puts it, "It's like we come in and we can say whatever we want. We know it doesn't go out the door, it's just, 'Help', you know? 'Help me, I have guilt', there's guilt everywhere." Carol discussed similar feelings for her support group:

The caregiver group is a godsend, because sometimes you've just got to dump and you can do it there. It makes me feel better because I know I'm not alone. Every other one of those wives is going through what I'm going through, it's the neatest, tiredst looking group of women I've seen. We have days when we laugh and cry, it's like this little amount of light. Without the groups, I wouldn't have made it.

While many interviewees had positive experiences with their counseling options, others found it more difficult to relate in a group setting, particularly if their family circumstances are not similar to the rest of the group. Tina describes her situation due to her husband's early on-set Alzheimer disease:

My husband just turned 60. That was my problem, I wasn't finding support groups that had the same problems. I went to three support groups and I couldn't relate to them. That's the problem that I'm having. I want someone to relate to.

Others expressed not feeling comfortable in a group setting and have attended private counseling. Monica did attend such a session but explains that she was not free to express her feelings about caring for her mother, because the counselor spent most of the session referring her to other providers:

I didn't really like it because the person that was talking to me, every time I would say something regarding my mother or myself, she would just give me a different referral and phone number and tell me to call. The main thing is to listen to the caregiver. Just listen, that's all we want. Not to be referred to someone else.

Monica did not return to the counselor and to date has not found any other outlets to discuss her caregiving concerns.

**Respite vouchers.** The purpose of the respite voucher program is to provide temporary help in the home for full-time caregivers. Most state voucher programs provide services in vouchers of \$200 to \$400 once every 3 months, based on available funding. Caregivers can hire a person of their choice as the respite provider, as long as the person is 18 years or older, has a social security card, and lives outside the caregiver and care recipient's home.<sup>27</sup> Respite services can be provided in the caregiver's home or someone else's home.

Becky is taking care of her husband and says that the vouchers are a little push to do something for herself: "Getting the vouchers makes me make a conscious effort to try to do stuff for myself, I'm really bad about that." She describes the work that is done for her husband Paul:

I have an aide that comes in and helps me with the bathing and some of the light housework. She does his laundry and changes his bed which kind of relieves me a little bit. She sits with him a couple of hours which gives me enough time to mess with my horse or do something outside away from him. Like I said, she's great.

While the vouchers are a relief, Becky admits she still has reservations just doing something to help herself: "It does feel really good to just get a break, I just feel guilty, I'm not gonna lie."

Study participants were often funding outside help on their own prior to finding out about vouchers, and while the opportunity to get financial help with the services was seen as a benefit, that quickly became complicated and time-consuming for many. Vouchers are released quarterly, and even if caregivers get their paperwork in on time, there is a chance that the program will already have run out of funds due to high demand and small quarterly state allocations. Despite these hold-ups, family caregivers appreciate the opportunities that vouchers provide. Tom is 82 and is a full-time caregiver for his wife and had used vouchers for a few months until the program ran out of funds. He recalls the relief it brought him:

What I got were vouchers to pay a sitter. That helped me get caught up, like I'd been wanting to get to the VA and get established there for my medical needs. Money is scarce, and you take what they give you, I'm just tickled to get anything that helps.

## Acceptance

Due to the unknowns of dementia, and with finances and familial struggles always in the back of their mind, caregivers come to a point when they have to find it within themselves to make a choice, fight their situation, or accept it and move forward. For many, respite provides a little time or a place to step back and assess their situation. Doris had been squarely planted in anger regarding her relationship with Ted. She explains the road to acceptance of her situation began after taking time in the afternoons to leave Ted with a home aide:

I have fought for a long time, "Why me?" I have come to the conclusion that I've really been feeling sorry for myself for a long time. Looking at this . . . my life is really the cup half full. I have so much to be thankful for, Ted isn't abusive, he's kind, and he's gentle. So this is the way it is, I'm learning to deal with it.

Ginger describes gaining understanding and acceptance of her husband's dementia through her support group:

The main thing I miss most is that I no longer have that man that was my husband. That lack of companionship is kind of a difficult situation for me and that's where the support group came in for me. They (support group) help me be aware of the fact that that's just the way it is. I don't blame my husband in any way for this, it wasn't his fault.

Carol, too, has come to terms with the fact that she is the glue that allows the family relationships to work, and her attitude will make or break the time that she shares with her husband: "I need to be more understanding and I need to find another way to do things, that's the place to be. I don't want him to feel like he's a burden."

## Caregiver Resilience

The road to acceptance became a critical factor in the development of resilience for the participants. Having the ability to assess their situation helped build their confidence in their ability to face the ups and downs that each day can bring. Ginger explains that she can now use this perspective to understand the importance of her work in keeping her husband safe at home:

You worry that you're not doing a good enough job, at the same time you're thinking that you'll do a better job than some stranger would . . . yeah, I feel like he's in a better place with me. We live out in the country, we have cows, he'll go out there and spend time with them, he enjoys doing stuff like that. I mean I feel like I'm doing something, trying to do something. There are lots of days when you're not doing a good job, but at least you're trying.

Others have learned it's OK to let go with their emotions more frequently. Francis knows that her feelings of sadness will come and go, but as she puts it, "You weep through it, and then you're OK. It's just the cleansing of your emotions and your mind." Most of the respondents felt that with continued use of respite services, they would be able to continue in their caregiving role, but not indefinitely. Brenda is pragmatic about her role in her father's life:

I guess when you have to do it, you find it in yourself to do it (caregiving). It's made me a lot more patient, but I've also learned that I had limits. All the warnings I got about how hard it was going to be were right, there's going to be a breaking point.

That strength to continue until the time comes to let go was shared by Doris, though in her case, the knowledge that there had been help available during her struggle, made her angry as well:

It (respite) has made me stronger, but it has also made me madder, because there should be more help out there for caregivers. There should be more programs and more money, where I can get out in the afternoons to get the shopping done, get the medicine, do what I need and come back. There should be more opportunities for help.

This perspective may well push Doris and others like her to advocate for stronger funding streams and to fight for others to receive pertinent information about the diversity and specifics of respite opportunities at the beginning of their caregiving journey, rather than by chance or when it may be too late to have a significant impact on their resilience.



## Discussion

The deeply rooted, long-term relationship between the caregiver and his or her family member, whether it be positive or negative, is fundamental to understanding the caregiver experience through the continuum of care after an initial dementia diagnosis.<sup>28</sup> The interviews in this study were windows into the experiences of family caregivers through the lens of the caregiving trajectory. The first research question focused on the determining factors in the transition to the role of family caregiver. Many of the participants took on their role by default, as other family members were not available, or not interested in taking on the responsibilities of family caregiver. And, due to this ad hoc introduction to their duties as a caregiver, many were not given the appropriate information about what to expect, how to handle difficult situations, and where to reach out for help. As a result of this lack of education, prior to their introduction to respite programming, many participants felt that by reaching out for help, they were in essence acknowledging some kind of failure and continued to wear down their resilience through the day-to-day minutia of their caregiving role. This calls to attention the need for primary doctors and specialists who diagnose dementia to include the entire family in the initial decision-making about the best next steps, providing access to information about services and program which are available for whoever takes on the family caregiving role.

The second research question probed the relationships between awareness of respite programming versus the actual use for caregiver resilience. Determining the influences of respite services on caregiver resilience has several long-term implications for the funding of social services, therefore, ease and frequency of use become critical factors in the planning for future programming. While some study participants used respite programming frequently, others had only used respite once or twice. For some, just knowing that help was available should they need it, allowed some relief. This is due to the push and pull of emotions for caregivers, as often there is a sense of guilt in asking for help, and the fact that the programs are available can be seen as a validation of the larger need. Finally, those participants who found out about the programming late in their caregiving journey actually talked about renewed anger that the systems were not in place to educate caregivers about respite options earlier in the caregiving trajectory. This was an unexpected outcome, and speaks to the need for better systems for educating caregivers about their respite options in the early stages of their caregiving role.

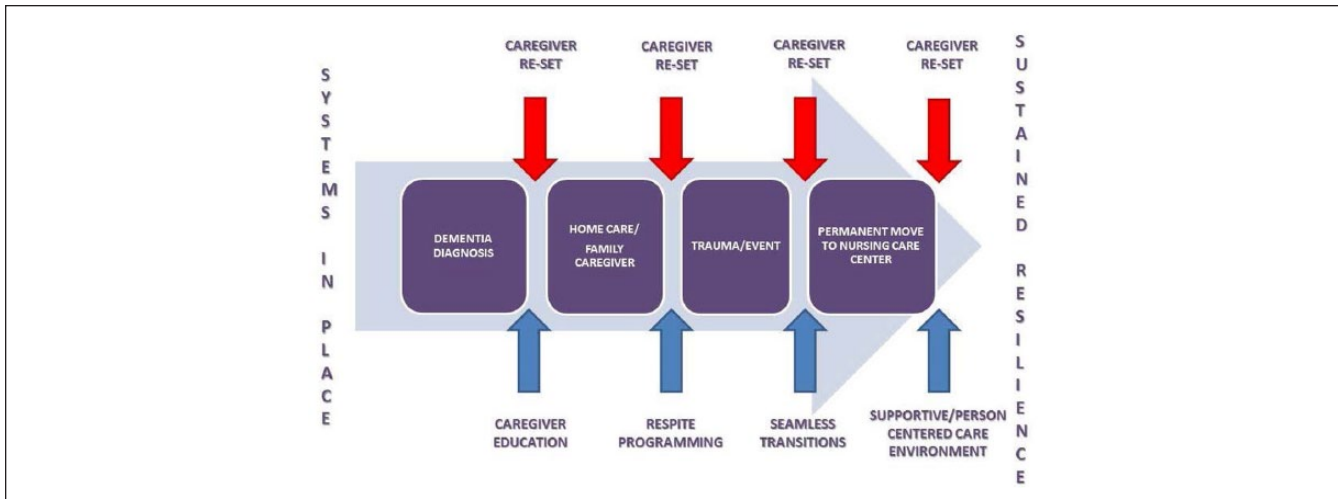
The final research question concentrated on the impact of respite on well-being for the care recipients. The majority of the study participants had come to understand how respite opportunities impacted their resilience and ultimately the well-being of the care recipient. While caregivers in this study were vigilant in their role as advocates for the well-being of the care recipient throughout the trajectory of care, they continued to expend both emotional and physical

resources along the way. The services provided by adult day care allowed for time to take care of a multitude of responsibilities, in-home help gave caregivers a needed break or extra hand around the house, and support/counseling opportunities helped mitigate feelings of isolation by creating a new community of mutual understanding. Many participants reported that when given time to negotiate the demands of caregiving with the aid of respite programming, they were able to develop a clearer understanding of the importance of their role in the care recipient's dementia journey. They were able to accept that they were doing their best, and their best was OK, despite the particular outcomes in a specific day. This perspective also gave the caregivers permission to feel, rather than fight, the emotions of their circumstances and was an important hurdle, allowing for greater empathy for the care recipient's circumstances. Feeling rather than fighting their conflicted emotions allowed many participants the needed "recharge" to take on their daily caregiving role with renewed emotional and physical vigor.

In addition to the unknowns and isolation of dementia care, other factors emerged in the research relating to participants having to juggle finances and red tape to secure respite funding due to income guidelines, deadlines, and fiscal shortages. This calls attention to the need to restructure and augment the funding streams for respite so that once approved for services, there will be no need for wait times or reapplication for services for caregivers. Other important highlighted issues included the need to create opportunities for individualized, rather than one-size-fit-all support programming. Walsh (2003) describes a family resilience model of adaptation which includes making meaning out of adversity, having a positive outlook, flexibility, and connectedness with each other and the community.<sup>29</sup> Optimal results may be found in counseling settings where individuals share similar circumstances, in terms of age of the care recipient and the progression and type of dementia. In addition, with respect to one-on-one counseling options, service providers should be reminded to give caregivers ample opportunity to voice to their frustrations and concerns. If it is necessary to provide referrals to other programs or providers, these should occur at the end of a session, in order for the caregiver to feel that they have been fully heard and validated in a supportive setting. Upfront screening opportunities for counseling services may help mitigate mismatches in programming and allow for more timely response to caregiver needs for support.

## Conclusions and Future Study

The long-term nature of dementia caregiving requires long-term support strategies that are oriented around the various transitions that merge in the context of the caregiver career.<sup>13</sup> Individuals in stressful situations such as caregiving can benefit from social support networks, as they can provide the resources that help them manage their situation.<sup>14</sup> Without these supportive services at each transition in the continuum



**Figure 2.** Caregiver resilience through systems in place.

of care, family caregivers risk poor health outcomes as their resilience and stamina may wear down, making it harder to bounce back with each new set of caregiving responsibilities and circumstances. This article addresses the importance of caregiver respite as one factor in sustained resilience over the continuum of care for family members caring for an individual with dementia.

A cohesive framework of social systems in place is therefore necessary for a well-integrated care plan to give caregivers the opportunity to retain resilience across the trajectory of care (Figure 2). This is important because while the psychological conceptualization of resilience is the ability to maintain normal or enhanced functioning during times of adversity, an individual's ability to transition to a new and similarly complex set of challenges may test this resilience. Consequently, rather than of an "on/off" conceptualization of resilience, the policy focus instead should be the continuum of support for the caregiver throughout the course of their family member's dementia, as each care transition leads to a different set of needs and interpersonal tools for resilience.

At the time of a dementia diagnosis, easy-to-access educational resources are necessary for caregivers to gain a full understanding of the breadth of the role that they are taking on, and during the months and/or years of caregiving, respite programming which allows for the flexibility of the needs of the changing caregiving role should be easily accessible. Another critical juncture in the caregiving journey is if/when it is determined that the caregiver may need to relinquish their care responsibilities with the care recipient moving into a long-term care setting. Caregivers want their family member to be treated with the same care that they had had at home and have a desire to retain some measure of control in their loved one's life to ensure that they are treated with dignity and respect in a care facility.<sup>28</sup> This speaks to the need for supportive, person-centered care environment in which family members are welcomed and respected.

It is hoped that the outcomes in this study may inform policy makers of the significant role that respite support programs and services play in building policy frameworks for sustained resilience in caregiving, though due to the exploratory status of this research and small sample size, the outcomes may not generalizable to other state programs. The research team intends to use these findings to develop a more rigorous multistate longitudinal study, and future analysis will be required to determine the relationships of each of the respite program types to caregiver resilience. Further study into specific demographic groups of caregivers (ie, disease progression, age, etc) may prove beneficial to better address the individuality of caregiving needs. In addition, further research is also needed to fully understand how family structures affect the care of aging adults, in particular dementia caregiving for a spouse in late-life marriage.

Unger et al. (2011) argue that context plays a crucial role in facilitating resilience, and may, in fact, be where efforts should be first concentrated.<sup>30</sup> An individual's resources for resilience may not be activated unless their environment facilitates the opportunities to negotiate, manage, and adapt.<sup>14</sup> Respite programming is one in a number of systems in place to counterbalance the depletion of resources when caring for a family member with dementia at home, and this study demonstrates that respite programming has the potential to help caregivers emotionally and physically reset through the transitions resulting from their family member's dementia. This focus on respite programming for caregiver resilience is appropriate and timely, in light of current fiscal challenges and potential funding cuts at the state and national levels. Any research that can illuminate what is working well, and why, enables policy and program professionals to serve families more effectively, informing future program implementation and service delivery, while at the same time defining structural and institutional solutions for familial resilience in dementia caregiving.

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