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Caring for Parents with Neurodegenerative Disease: A Qualitative Description

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Abstract

Purpose/Objective—To explore the positive aspects experienced by adult children in providing care to their parent who either has Parkinson’s or Alzheimer’s disease.

Design—A qualitative descriptive approach was used to analyze audio-taped in-depth semi-structured interviews that were conducted with thirty four adult children who were primary caregivers as part of a larger randomized clinical trial.

Setting—Individual interviews were conducted by trained research assistants in the caregiver’s home.

Sample—Thirty four adult children caregivers who were primary caregiver for their respective thirty four parents. Seventy-six percent (n=26) of the caregivers were caring for a parent with Alzheimer’s disease. Twenty-four percent (n= 8) were caring for a parent with Parkinson’s disease. Eighty two percent were adult daughters. Mean age of the caregiver was 52 years and the mean age of the parent was 81 years. Fifty three percent of caregivers were Caucasian and 47% were Black.

Data Analysis—A conventional content analysis was performed to summarize themes.

Findings—Results indicated that most caregivers had positive experiences. Three relationship-centered themes were identified: Spending and enjoying time together, appreciating each other and becoming closer, and giving back care. A small number of caregivers (n=6) could not identify positive experiences.

Conclusion/Implications—Caregivers who had positive experiences in caregiving expressed fewer feelings of being overwhelmed or distressed by their situations. Caregivers who do not experience positive aspects in caring for a parent need further study and potentially may be a group that warrants further intervention by advanced practice nurses.

Keywords

Caregivers; Qualitative research; Aged

Introduction

Adult children providing care to an elderly parent are a growing segment of our United States (US) population. A recent national survey revealed that 36% of adult children in the U.S. are primary caregivers for a parent¹. A similar survey conducted in 2004 revealed an increase in the number of parents moving into their adult children's household in order to receive caregiving². In some cases, parents are moving into homes where, in addition to being a caregiver, the adult child manages multiple competing roles, such as caring for their own children and working outside the home. Regarding the economic impact of caregiving for a parent, over 70% of working adult caregivers report needing to decrease working hours, take a leave of absence, or cease work³. The growing numbers of adult children needing to balance being a caregiver to their parent, possibly being a caregiver to children and also working outside the home, suggests this group warrants attention. Adult children as caregivers have either been excluded in research studies, or have been included as part of a sample that is largely comprised of spouses and non-relative caregivers. The effect of caregiver-type on the care-recipient relationship has not been examined. Thus, in this paper we will report on analysis of data specific to adult children caring for a parent with either Alzheimer's disease (AD) or Parkinson's disease (PD). In line with an emerging call for a shift away from caregiver burden and the negative effects of being a caregiver this paper will focus on the positive experiences in being a caregiver to a parent with either AD or PD^{4,5}. These two older adult populations were selected because earlier research demonstrated caregivers needs to be similar across the two diseases⁶. The diseases are the two most common chronic, progressive neurodegenerative illnesses. Though initially thought of as two very distinct diseases, evidence over the last decade has raised the question of as to whether the diseases may be connected. Brain changes on autopsy, along with findings that up to 50–80% of people with Parkinson's disease developing dementia as the disease progresses have led basic scientists to explore the overlaps and congruencies between the two diseases⁷.

Literature Review

Although there is a well-developed body of literature related to AD caregiving, the PD caregiving literature and the literature specific to adult children as caregivers in either disease is less developed. Some of the studies related to adult children as caregivers are dated; however they are included in this discussion due to the limited number of relevant studies.

Though the majority of caregiving studies have focused on the stressful aspect of the caregiver role, a limited number of studies have started to explore the rewarding aspects as well. For example, in a study to examine the perceptions of the care giving role by son's caring for a parent with AD, improved interpersonal skills, greater patience, and compassion were expressed as some of the positive outcomes of providing care⁸. Finding meaning and joy in providing care for a parent with AD has also been noted⁹. These experiences have been further described by the adult child as a chance to cherish the relationship with their parent, form a bond that would not be there if it were not for the disease, create joyful memories, and develop a sense of commitment that reflects the quality of their relationship with their parent during earlier times⁹. Positive outcomes such as enhanced personal growth among adult child givers of persons with AD have also been reported and are thought to be

influenced by situational factors such as level of social support, coping through reframing and coping through religion¹⁰.

A study by Rashchick & Ingersoll-Dayton compared caregiver experiences between spouses and adult children. Findings from this study indicated that adult children were more likely to report their experiences as rewarding¹¹. These results were thought to be directly tied to how adult children viewed their primary role within the relationship with their parent. For example, spouses in this same study reported feeling as if their role as a caregiver was one that was socially expected of them and that it was their social responsibility to care for their spouse¹¹. On the other hand, adult children, whose primary role is often associated with being a child, and not a spouse, viewed their parental care giving responsibilities as over and above what was socially expected of them and therefore more rewarding¹¹. These data suggest the importance of societal expectations in framing how adult children define their caregiver responsibilities and how their role identity within their parental relationship influences their perceptions of the caregiver role. Other positive care giving experiences were noted in Sanders' study of reflections on strain and gain in caregivers of individuals with AD¹². Caregivers in this study reported that as a result of their caregiving role, their spirituality and relationship with God were strengthened and, they experienced personal growth and internal changes such as becoming more patient, caring, and less self-centered. They also felt a sense of accomplishment and mastery relative to their ability to perform the tasks necessary to provide care¹².

Studies that have compared the caregiving experiences of Caucasians and African Americans (AA) dementia caregivers have reported that AA tend to perceive their caregiving experiences as more positive, more satisfying, and less burdensome^{13,14}. These differences are thought to be attributed to religious beliefs, traditions, and social support that add to the meaning and reward of the care giving experience^{13,14}. Other factors such as lower levels of caregiver anxiety and depression, perceiving the care recipient's problem behaviors (memory, depression and disruptive behaviors) as less bothersome, and interpreting the parents cognitive or behavioral problems as a normal part of the aging process have been shown to partially contribute to AA more positive perceptions of care giving,^{13,14}. These findings suggest the need to not only examine race/ethnicity as a factor that can influence how adult children perceive their care giving experiences, but to also explore other contextual variables that protect adult child caregivers from the stress, burden, and negative experiences that are often associated with the care giving role.

This study addresses key gaps in the literature because it focuses solely on the experiences of adult children of parents with AD and PD. To our knowledge, most other studies including adult children either have not addressed this as a unique group of caregivers or have been limited to caring for a person with AD only.

Methods

The larger study was a mixed method longitudinal randomized clinical trial (RCT) with the primary aim of increasing caregiving skills in AD and PD caregivers. Embedded in the larger study as a second major aim was to describe caregiving appraisal and coping strategies and whether these strategies changed longitudinally as a result of either time or experience as a caregiver or as a result of the skill-building intervention. In order to achieve this aim, a qualitative descriptive design utilizing in-depth semi-structured interviews was integrated into the mixed-method design. Prior to randomization, baseline measures for all study quantitative variables were collected in conjunction with the qualitative interview by trained research assistants. The interview focused on the challenges experienced as a caregiver along with the positive aspects or the satisfying experiences of being a caregiver.

Though the questions related to positive aspects or satisfying experiences as a caregiver were not part of the study's primary aims, the investigators made a conscious decision to include them in the interviews. We believed this was congruent with the call for a shift away from solely studying caregiver burden and negative aspects of caregiving. The investigators also believed these data had the potential to lead to development of caregiver intervention that would be innovative and different from existing interventions. Since positive or satisfying experiences as a caregiver for a parent with either AD or PD were not part of the primary aim of the larger study, they are reported separately in this article.

Although interviews were conducted on three occasions during the larger study, only data from the baseline will be reported given the potential effect of the intervention on appraisal of positive experiences. Thus, baseline interviews prior to randomization of the consecutively enrolled adult children caregivers at the primary site in the Southeastern United States served as the focus of this analysis. Semi-structured interviews were conducted in the caregiver's home by two research assistants who were trained and randomly monitored by the first author. A semi-structured interview guide was utilized. Interviews averaged 30–60 minutes in length. Interviews were taped, transcribed verbatim, and reviewed for accuracy. Data were analyzed using a qualitative descriptive approach as defined by Sandelowski and more specifically a conventional content analysis approach as described by Hsieh and Shannon^{15,16}. The goal of the conventional content analysis was to summarize the informational contents of the data which is consistent with qualitative descriptive design and with the underlying research question¹⁶. Themes or codes were data-derived and driven by the research questions rather than by a theoretical framework.

NVIVO software was utilized to facilitate retrieval and management of the qualitative data. Memoing and documentation of analytic decisions were maintained in NVIVO, version 10¹⁷.

Sample

Of the first consecutive 135 caregivers consented and enrolled in the larger study, 34 were adult children. The sample being reported on is these 34 adult children caregivers. After gaining Institutional Review Board approval, caregivers were recruited from a variety of neurology and geriatric practices, community agencies, senior communities, and support groups in the Southeastern United States. The inclusion criteria for caregivers were: at least 19 years of age; live with the care recipient; provide a minimum of three hours of care to the recipient each day; have been providing informal care for a minimum of six months; able to read and speak English; be oriented to person, place and time; have access to a telephone; and the self-identified primary caregiver of a person with AD or PD. The AD care recipient inclusion criteria were to: age 60 or older; have a physician-determined clinical diagnosis of AD; have a Mini-Mental Status Exam¹⁸ Score of 23 or less; have four or more behavior problems, as evidenced by a score on the problem occurrence scale of the Revised Memory and Behavior Problem Checklist¹⁹; and not be bed-bound. Whereas PD care recipients inclusion criteria were age 60 or older; have a physician determined clinical diagnosis of PD; at least a stage 2.5 (bilateral disease with some postural instability) on the Hoehn & Yahr PD Severity Scale²⁰; on prescribed medication for the disease, and not be bed-bound. Exclusion criteria included having a clinical diagnosis of vascular dementia, frontotemporal dementia or a Parkinson's-Plus syndrome

Results

Participant characteristics

The majority of the caregivers were caring for a parent with AD (n=26, 76%) whereas 24% (n=8) were caring for a parent with PD. Daughter caregivers were the majority (n=28, 82%) of the adult children sample. The mean age of the caregiver was 52 years (SD ± 8.5 years) with the mean age of the parent being 81 years (SD ± 8.5 years). The majority (53%) of the caregivers were Caucasian (n=18) and the remaining caregivers were Black (n=16, 47%). The AD and PD caregivers did not differ significantly on any demographic variable; the only difference was in the overall numbers in each group.

Relationship-Centered Themes

The majority of participants described in one manner or another positive experience that were grounded in their relationship with their parent. Three different categories emerged relative to the relationship: Spending and Enjoying Time Together; Appreciating Each Other and Becoming Closer; and Returning and Giving Back Care. All but six participants' narratives fit into at least one of the relationship-centered categories. These six participants were unable to identify positive experiences in caring for their parent. This will be elaborated upon after the discussion of the relationship centered categories. Most caregivers' narratives fit into one of the three categories, however, some participants' descriptions of positive experiences fit into two categories. A description of each of the three categories follows.

Spending and Enjoying Time Together—The majority of caregivers discussed how much they enjoyed spending time with their parent and seeing their parent enjoying that time also. Often the time was spent doing routine activities such as having a meal together, going for a drive, or simply sitting and talking. The nature of the activity was not the focus but rather that they were together, and they were interacting and enjoying. A daughter who had moved in with her mother with AD:

I enjoy the time with my mother.I love to hear her laugh.....We talk all the time in the car; we pray together, watch TV.

Another daughter of a mother with PD:

We do things together. We go shopping or we watch a movie on the weekend. We enjoy each other. I am glad she depends on me. She enjoys it.

Appreciating Each Other and Becoming Closer—Appreciation or being grateful was often expressed by care recipients to their caregiver. This in turn resulted in caregivers appreciating the opportunity to be living with and caring for their parent. A daughter caring for her mother with AD:

I like it when her nails are done and...and when...uh...people tell her that she looks wonderful, and it makes her smile and it makes me smile. It makes me feel like I've been a part of something that's a worthy thing. And she's a very grateful...verbally grateful person. And when she said "Thank you for making me look pretty," or she says "This looks delicious," it makes me want to do even more, because she's very grateful.

A son who had quit his job and moved into his father's house and cared for his father with PD five days a week (he would return to see his wife on weekends) said:

He came up to me in the kitchen one day and he said uh "Can you button my shirt for me?" He said "My hands are shaking today." And I said okay and I buttoned it

and...he stood there for a minute, and he started to say something and...he just kept standing there and he tried to say something again and...finally he just said "Thank you." And I told him he was welcome. And we went on about what we were doing.

When questioned about whether leaving his job or living apart from his wife was difficult, this son responded "I chose to do this" and that he had his wife's full support. When contrasting the stress of his previous corporate job to his current situation he concluded that he was doing what he wanted to do and summarized: "...and I get to tuck him in and kiss him good night every night. That's cool."

Some of the caregivers who expressed appreciation also expressed either a deepening of their relationship with their parent or a deepening of the nuclear family relationship with the parent. As a result of being a caregiver to their parent, relationships grew deeper and families got closer. A daughter who had moved her mother with AD into her home and had several children still at home:

One thing, my children love to talk to my mother about things in the past, and she goes back to situations in time before even I came. ... And that's just like a family get-together. It seems like it's getting my family closer together.

Another daughter who had returned home to care for both of her parents with dementia had described a difficult relationship with her parents in earlier years partially due to her father's mental health problems and "nervous breakdowns" over the years. Her father now requires significant care, with the mother being higher functioning but frail.

I just got to know them in a different way that I never got to know and I really got to experience...and still do...unconditional love.....my relationship with them since I've been back has...freed me, just as I think it's freed them...of whatever it is that happens between parents and kids sometimes that kind of estranged them or something. And so coming back and being with them, that's really been awesome.

Returning and Giving Back Care—Many of the adult children described willingness and a joy in being able to provide care for their parent. A daughter caring for her mother with AD:

I guess the fact that I am able to do something for my mother that she did for me and return the favor....the times she took care of me. Now it's my time, so the joy of knowing that I'm doing something that's rewarding towards what was done for me when I couldn't do for myself.

Another daughter caring for her mother with AD:

It gives me great joy to give back to my mom and...I tease her...uh...on a good day, and I say "Aren't you glad you took good care of me, because you set that example?" And she'll laugh and I'll laugh and...and it gives me great joy, because she...uh...was/is a great mother. And uh...and...and now, it's my turn to be a great daughter.

Caregivers expressed the importance of being with their parent, taking care of their parent, and continuing to do for as long as needed. They clearly were with their parent for the duration, doing what they believed to be "best" and ensuring the parent wasn't "giving up."

Positive Experiences Lacking—As mentioned earlier, six participants were unable to describe any positive experiences in being a caregiver for their parent. All six caregivers were caring for a parent with AD and all were adult daughters. These caregivers described their situations as "doing what needs to be done" and were often motivated to continue as a caregiver in order to avoid nursing home placement of their parent.

I say knowing that she is my mother and...I know that she need...you know, need care. And know I don't want to put her in a nursing home.

Their narratives centered heavily on the difficulties, often identifying multiple difficulties. They found the caregiving to be "every minute of the day" and often spoke of feeling all alone. These caregivers, despite interviewers probing, could not express satisfying experiences or any joy in caregiving. Narrative regarding the parent and adult child's relationship was lacking.

Sometimes I feel like I just want to scream. You feel like you are in all by yourself.

Another caregiver:

And here I am again. Right back to ground zero, is what I feel like. I don't feel any joy in this. I don't see how I could.

Adult daughter participants, who could not express positive experiences while caring for a parent with AD, did not differ significantly by demographics from caregivers of a parent with AD who were experiencing positive aspects. There were also no differences when compared to the entire sample of adult daughters.

Discussion

The goal of this study was to explore the positive caregiving experiences of adult children providing care to a parent with either AD or PD, the two most common neurodegenerative diseases in older adults. From our analysis three categories emerged: Spending and Enjoying Time Together; Appreciating Each Other and Becoming Closer; and Returning and Giving Back Care. These themes illustrate the various ways through which relationships between adult children and their parents are strengthened (time, appreciation, and giving back) during the caregiving process and the benefits that adult children derive from providing care to their parents during their illness. In addition, these themes underscore the underlying quality and nature of the relationship between the adult child and the parent with AD or PD, and they suggest that the history of the relationship between the adult child and their parent prior to their impairment may partially determine the quality of the current care giving experiences^{21,22}. The quality and nature of the relationship between the adult child and parent have been shown to affect the overall perception of the caregiving experience²³. In their study on the correlates of care relationship mutuality among caregivers of people with AD and PD, Shim, Landerman, and Davis, found that mutuality, the perceived quality of a caregiver-care recipient relationship, was higher if the care recipient had better functional ability and if the caregiver was female, not depressed, and had been providing care for a shorter time²³.

Based on our results, spending time with the parent who has AD or PD, mutual appreciation of being cared for and being able to provide care, and the feeling of being able to return and give back may enhance care giving experiences among adult children. On the other hand, feeling obligated to provide care because there are no other options, exacerbates the negative aspects of the care giving experience and potentially obscures aspects to the experience.

Caregivers who do not experience positive aspects in caring for a parent need further study. Our findings were similar to those reported by Sanders & McFarland. In their study on the perceptions of sons providing care to a parent with AD, sons expressed an obligation to provide care for their parent in order to prevent placement in a long-term care facility⁸. These decisions to avoid nursing home placement were also influenced by the sons' desire to avoid people thinking that they were not good sons and to avoid the stigma associated with having a parent in a nursing home⁸. Given the large percentage of adult daughter

caregivers in our study (82%), our findings were limited to adult daughters expressing a need to provide care in order to avoid placement. Though this might offer an explanation for the lack of findings in sons, our results are consistent with those of Mui who reported that, when compared to sons, daughters caring for frail, elderly parents experienced higher levels of strain, poorer self-rated health, less respite support, and greater disruption in personal and social life²².

The results from our study also support findings cited from previous studies on adult children who provide care to a parent with AD. For example, several participants in Sanders's study were only able to recall the strains associated with being a caregiver and were providing care without a great deal of assistance and support¹². Similar outcomes were reported by Mui. Both daughter and son caregivers in this study cited lack of respite care, having few secondary helpers, and having a parent with disruptive behaviors as triggers of emotional strain²².

Providing care to elderly parents with dementia is often discussed in terms of the increased burden, emotional and psychological distress, and decline in mental health and wellbeing of the caregiver²⁴. As such, implications for clinical practice have historically been framed in response to these negative caregiver experiences. In light of the recently changing focus from negative to positive experiences of being an adult child caregiver to a parent with Parkinson's or Alzheimer's disease, clinical implications for nursing practice must be revised.

Our findings underscore the need for ongoing support of adult children who are providing care to their parents. In addition, they shed light on the often overlooked benefits of providing care to parents with AD or PD. Clinical Nurse Specialists (CNS) are in a position to provide encouragement and support to adult child caregivers and to reinforce the positive experiences they have as a result of providing care to their parents. In addition, CNS can help adult children recognize the signs and symptoms of caregiver strain and implement early interventions to minimize caregiver fatigue and strain. Assessment of caregiver functioning, including inventorying positive and negative experiences associated with caregiving, as well as optimizing the positive experiences is an ideal intervention to alleviate negative stress associated with caregiving.

Conclusion

Adult children as caregivers are a growing segment in the US population. Studies that continue to examine the challenges and rewards of being a caregiver to a parent will help identify which caregivers may need intervention. This study explored the perceived positive experiences in caring for a parent with either PD or AD. Although the study had a large percentage of daughter caregivers, it contributes useful information that can be used to develop interventions for both daughters and sons who are providing care to a parent with PD or AD.

The study limitations need acknowledgement. The sample was primarily adult daughters. However, adult daughters do comprise the largest segment in the adult children caregiving population. The sample was limited to Caucasians and Blacks with no other ethnic or racial groups represented.

In summary, caregivers who had positive experiences in caregiving expressed fewer feelings of being overwhelmed or distressed by their situations. Caregivers who do not experience positive aspects in caring for a parent need further study and may be a group that warrants intervention by advanced practice nurses.

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Biographies

Barbara Habermann, PhD, RN served as Co-Investigator and Site PI on the reported study. She has extensive experience doing caregiver research particularly in the area of Parkinson's disease. On this study, she was also responsible for the qualitative data and analysis.

Dana Hines, MSN, RN is a PhD student at Indiana University School of Nursing. She is being mentored by Dr. Habermann. Her involvement in the manuscript included literature review and interpretation of findings.

Linda Davis, PhD, RN, FAAN was PI on the reported study. She has extensive experience in clinical trial research and has a program of research focused on interventions to improve Alzheimer's caregivers health outcomes.