



Published in final edited form as:

Qual Health Res. 2014 November ; 24(11): 1492–1500. doi:10.1177/1049732314548879.

Adapters, Strugglers, and Case Managers: A Typology of Spouse Caregivers

Linda Lindsey Davis¹, Deborah Chestnutt², Margory Molloy¹, Tess Deshefy-Longhi³, Bomim Shim⁴, and Catherine L. Gilliss¹

¹School of Nursing, Duke University, Durham, North Carolina, USA

²Charles George VA Medical Center, Asheville, North Carolina, USA

³Connecticut Community Care, Inc., Bristol, Connecticut, USA

⁴School of Health Sciences, Seattle Pacific University, Seattle, Washington, USA

Abstract

Although family home care problems are frequently described in the health care literature, the ways in which families and other informal caregivers manage those problems are not often addressed. We conducted a descriptive analysis of interviews in which spouses caring for a partner with Alzheimer's or Parkinson's disease were asked to describe difficult home care problems and how they managed those problems. Analysis of these interviews indicated three recurring management styles. Adapters told stories about applying pre-existing skills to manage home care problems. Strugglers told stories of reoccurring home care problems for which they had few or no management strategies. Case Managers' interview stories focused on the challenges of finding and coordinating home care services. These findings suggest that caregiving burden might be influenced more by the caregiver's management style than the demands of the care situation. Suggestions for tailoring support programs for the three types of caregivers are proposed.

Keywords

Alzheimer's disease; caregivers; families; caregiving; Parkinson's disease; relationships

Caregiving burden, often referred to as caregiving stress, role strain, or hassle, was originally defined by Hoening and Hamilton (1966) as the situations and tasks of caregiving (objective burden) and caregivers' distress about taking on those tasks (subjective burden). Montgomery, Gonyea, and Hooyman (1985) further differentiated between objective burden (the cognitive, physical and behavioral changes of the care recipient) and subjective burden (the worries, frustrations, anxiety, and fatigue of the caregiver associated with those

Corresponding Author: Linda Lindsey Davis, Duke University School of Nursing, 307 Trent Drive, DUMC 3322, Durham, NC, 27710, USA, davis317@mc.duke.edu.

¹Portions of this article were presented at the biennial International Family Nursing Conference, June 21, 2013, in Minneapolis, Minnesota.

Declaration of Conflicting Interests

The authors declared no potential for conflicts of interest with respect to the research, authorship, and/or publication of this article.

changes). Objective burden emanates from characteristics of the care recipient, while subjective burden is concerned with the caregiver's attitudes and responses to caregiving.

Objective caregiving burden has been attributed to issues such as the physical demands (for bathing, toileting, feeding) of home care for an increasingly dependent care recipient (Habermann, Cooper, Katona, & Livingston, 2009), who develops troubling disease-related problem behaviors such as combativeness, wandering, and hallucinations (Ornstein & Gaugler, 2012; Roland, Jenkins, & Johnson, 2010). Subjective burden is associated with issues such as the caregiver's health status (Schulz & Martire, 2004; Vitaliano, Zhang, & Scanlan, 2003) and conflicting demands of co-existing work, family, and social relationships and obligations (Ball et al., 2010; Garand et al., 2012; Garlo, O'Leary, Van Ness, & Fried, 2010; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009).

The physical, social, and psychological difficulties associated with family caregiving have generated an impressive number of burden studies. Pinqart & Sørensen (2003) reported over 400 published studies of caregiving burden for the period 1980–2000 alone. According to some researchers, family care burden is moderated by differences in caregiver gender and kin relationship: spouses often report more distress and burden in connection with the impending loss of the relationship (Croog, Burlison, Sudilovsky, & Baume, 2006; Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007; Ott, Sanders, & Kelber, 2007), while adult children often report more distress about competing work, family, and social demands (Durant & Christian, 2007; Pinqart and Sørensen, 2011).

Long-term management of caregiving and the associated burden has not been frequently addressed in the literature on caring for older adults with progressive, chronic diseases. Martire, Lustig, Schulz, Miller, and Helgeson (2004) indicated in their meta-analysis of dementia caregiving literature that including a family member in chronic care management improved patient outcomes. Vugt and colleagues (2004) reported that caregiver management strategies were important predictors of both patient outcomes and caregiver burden in a longitudinal study of dementia patients and their informal caregivers. Schulz and Martire (2004) identified aspects of caregiving that appear to be the greatest contributors to caregiving burden and suggested generic approaches for working with caregivers, but did not elaborate on how those approaches might be tailored for individual caregivers.

The purpose of this article is to explore Alzheimer's and Parkinson's disease caregiving spouses' conceptualization of their care problems and the perceived efficacy of their problem management strategies and to identify caregiver management styles that can provide a contextual frame for understanding their experiences of caregiving burden. We propose three distinct care management styles drawn from narrative analysis of stories told by these caregiving spouses, and provide direction for tailoring caregiver assistance programs to meet the needs of individual caregivers on the basis of their observed caregiving management style.

Typological Analyses

Typological analysis refers to the classification of individuals or cases on the basis of similar characteristics or variable scores, and there are existing published descriptions of caregiving

typologies. Corcoran (2011) proposed a typology of four communication styles of caregiving family members (spouses and adult children) in interactions with an older adult with dementia: facilitating, balancing, advocating, and directing strategies. However, caregivers' management styles were not linked to specific caregiving problems.

Knafl and colleagues, who conducted and published more than two decades of studies of parental perceptions of family life and functioning when a child has a chronic condition, have described and operationalized family-level management styles as thriving, accommodating, enduring, struggling, or floundering (Knafl, Deatrck, & Havill, 2012). Their Family Management Style Framework has been widely used in research on families of chronically ill children (Knafl et al., 2012), but preliminary exploration of its applicability to caregiving for a frail spouse with a progressive illness such as Alzheimer's disease and Parkinson's disease has just begun (Beeber & Zimmerman, 2012).

Alzheimer's Disease and Parkinson's Disease

Home care for a family member with Alzheimer's disease (AD) or Parkinson's disease (PD) is considered particularly burdensome. Both AD and PD are characterized by progressively downward trajectories and increased need for support and assistance over time. More than five million Americans demonstrate the cognitive losses, disruptive behaviors, and physical self-care deficits that exemplify AD (Alzheimer's Association, 2013), and the long-term course of this disease presents exceptional management challenges for family caregivers (Brodaty & Donkin, 2009; DeFries, McGuire, Andresen, Brumback, & Anderson, 2009).

PD, which affects approximately 1–2 million Americans (Van Den Eeden, et al., 2003), is initially characterized by immobility and physical self-care dependency, but cognitive deficits become more common as the disease progresses (Weintraub & Burn, 2011). Family caregivers (usually spouses and adult children) provide the majority of AD and PD care in the community (Lyons, Stewart, Archbold, & Carter, 2009; Roland, Jenkins, & Johnson, 2010).

Many researchers have attempted to identify and quantify AD and PD caregiving burdens, but few have focused on the ways in which family caregivers define and manage those burdens. In this article, we examine the conceptualization of care problems by AD and PD spouse caregivers and the efficacy of their problem management strategies, and propose a typology of caregiver management styles that can provide a contextual frame for understanding their experiences of caregiver burden.

Methods

Because the caregiving literature indicates that spouses experience greater burden than non-spouse caregivers (Pinquart & Sörensen, 2011), we focused our analyses on spouses who had participated in a multisite randomized trial of in-home caregiver skill training in four Southeastern states. Participants in the parent study were recruited from memory and movement disorder clinics, private medical practices, and caregiver support groups. A total of 187 family caregivers met eligibility criteria for the parent study: aged 18 years or older, self-identified as the primary family caregiver for an older adult with AD or PD, and

currently living with the care recipient. University institutional review boards reviewed and approved the human subjects' protection plan. All subjects provided their written consent to participate in the study and were interviewed in their homes, without the care recipient present.

Sample

We conducted a secondary analysis of audiotaped baseline interviews with 130 participants in the parent study who were spouse caregivers of a partner with either moderate-to-severe AD ($n=58$) or PD ($n=72$). Because subjective burden is considered the benchmark of stressful and difficult home care (Montgomery, Gonyea & Hooyman, 1985), we used the subjective burden subscale ("upsettedness") of the Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991) to select interviews for review. The Screen for Caregiver Burden (SCB) is a 24-item, Likert-scale measure of spousal distress associated with caregiving for a husband/wife with cognitive and behavioral issues because of a progressive disease such as dementia (Vitaliano, et al., 1991). The SCB has a possible score range of 0–96, with lower scores indicating less burden. The SCB has demonstrated adequate reliability and validity across caregiving spouse studies (Hirschman, Shea, Xie, & Karlawish, 2004). We rank ordered AD and PD spouses on the basis of whether they had high, moderate, or low SCB scores.

SCB scores of the 58 caregivers of spouses with AD were positively skewed and ranged from 0–53 ($M = 17.2$). AD spouse caregivers with SCB scores between 30 and 53 ($n = 20$) were classified as high burden; those with scores between 16 and 29 ($n = 19$) were classified as moderate burden ($n = 19$); and those with scores between 0–15 ($n = 19$) were classified as low burden.

SCB scores of the 72 caregivers of spouses with PD were positively skewed and ranged from 0–37 ($M = 12.5$). Not all PD care recipients in the parent study had memory/cognitive deficits, so the lower SCB scores of the PD spouse caregiver group were not unexpected. PD spouse caregivers with SCB scores between 27 and 37 ($n=22$) were classed as high burden; those with scores between 11 and 26 ($n=25$) were classified as moderate burden; and those with scores between 0 and 10 ($n = 25$) were classified as low burden.

Interview Selection and Analysis

In the parent study, caregivers were interviewed by trained interviewers in the privacy of their own homes without the ill spouse present. These semi-structured interviews employed a guide and ranged from 45 to 120 minutes in length ($M = 60$ minutes). The AD and PD caregivers were asked to describe the caregiving context of their most difficult caregiving problems and how they managed those problems. After each interview, the interviewer verified the content of the interview with the caregiver. Interviews were audiotaped and transcribed.

For this article, we initially drew a random sample of six AD and six PD caregiving spouses (two each from the high, moderate and low burden SCB score groups) for analysis. We used

the following steps to code these spouses' descriptions of caregiving problems and management.

First, our research team members independently read interview transcripts line by line, and coded the spouses' descriptions of their caregiving burden and management strategies. The team then met to compare and discuss their individual burden and management codes. Where there was group consensus, we condensed, abstracted, and compiled these codes. To verify reproducibility and dependability of codes, two family care experts independently applied the codes to additional samples of interviews.

To facilitate within-case analyses, matrices were constructed to cross-reference each spouse caregiver's burden and management strategies. As we coded additional samples of high, moderate, and low burden AD and PD groups, we were able to recognize consistent thematic patterns (saturation) after analyzing 20% of the interviews (12 AD spouse interviews and 15 PD spouse interviews).

Next, we combined AD and PD spouse caregiver matrices to compare burden and management strategy similarities and differences by disease group (across-case analysis). We then clustered AD cases and PD cases by similarities in burden management themes.

Results

Our analysis of the caregiving description stories suggested three types of caregiving spouses: adapters, strugglers, and case managers. Characteristics of each spouse caregiver type are described below and illustrated with representative quotes from spouses within that typology.

Adapters' Stories

Adapters focused on how they solved home care challenges. They provided details of their management strategies, frequently volunteering explanations of where and how they developed those strategies from prior life experiences: "I learned how to do this when my mother was ill." "I watched a friend care for her husband." "I read books on the topic and figured out how to make it work for me." These spouse caregivers were the ones most likely to describe collaborative relationships with family members (often the ill spouse), friends, and/or neighbors to accomplish care tasks. They were also the caregivers more likely to describe "good" days and "bad" days in caregiving. Most of them verbalized their expectations that the care situation would change over time.

A woman who had cared for her husband with AD for five years described how she managed the physical care demands for her husband:

Getting him dressed can be a real challenge. He weighs two hundred pounds and I weigh a hundred pounds. When my father had his stroke, I watched my mother. She used a sheet to roll Daddy over and to get him out of bed. I'm glad I learned how.

Despite her husband's cognitive losses, this spouse caregiver described how she enlisted him in his care:

He will not clean himself anymore ... I decided to give him a reason to help me. So now when he needs a bath, I take snacks into the bathroom. He really loves soda crackers, so I sit across from him and hand him the wash cloth and say, "Wash your face and we will have some crackers." It works every time.

A woman who had cared for her husband with severe AD for four years also described physical care as her major challenge. Her solutions also included partnering with her husband:

When I help him with a bath, I just say, "Let's get your clothes off." I say, "Take off the shirt first" and then, "Step out of the pants." I just move in and sort of start helping and then I guide him to the tub. I stand by and watch and help him whenever we can work together to get it done.

This spouse caregiver changed her management strategies as the disease progressed: "I used to write him notes to let him know what was coming up that day, but he has got to the point that he won't pay attention to notes anymore, so I quit that all together." On some occasions, she enlisted the aid of friends who were also caring for their spouse:

Watching him eat is painful because it is messy ... It helps if we go down and eat with [another married couple dealing with AD]. She and I know each other's husband's needs ... If you have other people you can talk to and you are not watching what they [the two husbands] are doing, it helps.

She also saw herself as a problem-solver:

Sometimes during the day he will have them [hallucinations]. He thinks people are outside. He has had this thing about them being out there moving the bushes and trees, and it is real to him. I have to convince him that there is no one out there. Sometimes it is hard to get that going. You can't plan your steps; I don't know if there is any way that you can. [I] just handle each thing as it comes.

A another woman who had cared for her husband with PD for seven years identified her major challenge as feeling guilty that she no longer wanted to sleep in the same bed with her husband because of his dyskinesias. She described how she solved this problem:

He's just continuously moving in his sleep and it wakes me up. I feel like I want to go to the other room and sleep but I knew he wouldn't want me to go there. So, I bought a Bed Buddy, one of those long bed things and put [it] between us. It works better. The nights are better. He still moves but I don't feel it that much. He was satisfied with it as long as I am sleeping with him.

This spouse caregiver described in detail the experiences of the wife of a friend who had died recently of PD, as forecasting what likely was ahead:

I do understand what is going to happen. It is hard to accept, because I know that it is going to be that way. We had a friend who just died and he had Parkinson's disease and the things that his wife had to go through, were hard to see. I was

seeing all of these things happening. It has helped me to realize that we are going to have to be prepared for the same kind of stuff.

Another spouse caregiver was pragmatic in her description of physical care for her incontinent husband:

I probably change him anywhere from one to three times or more per night. I have an all-over protective sheet on the mattress, on top of that is the mattress pad, then there's a rectangular piece that goes across in the rump area, and then the sheet, and then I have a pad under his rump. You just make it work.

A woman who had been caring for her husband with PD for seven years described her strategies in working with her husband around his increasing physical weakness. Because her husband was cognitively intact, she found it difficult to offer him help because that emphasized his dependency:

He gives it his all. He gives it everything. I say, "What do you need?" He'll say, "I'm getting up", and I give him my hand. If he needs help to walk, I walk along beside of him and he holds onto me. We are a team but we don't talk about it.

She reflected on her management style: "I (manage things) by attacking them head on is basically what I do. I just ... charge ahead. I just see myself as this is what I've got to do and I'm going to do it." She, like most of the adapters, expressed realistic expectations: "We have good days and we have bad days. These thirty minutes might be good, the next hour, things might have changed."

Strugglers' Stories

Strugglers focused on descriptions of situations in which they were unable or unwilling to solve recurrent and ongoing caregiving problems. Their stories described "mismatches" between problems and solutions: "When [caregiving problem] happens, I try ... but it doesn't work out." "It never changes." "It happens every time." These spouse caregivers saw themselves as the only support for the care recipient, citing numerous reasons: "My [children / friends / neighbors] are busy." "Our family has never been close." Unlike adapters, strugglers were reluctant to discuss the future: "If ... happens, I don't know what I will do." "I just don't go there." Struggling was the steady state for these spouses.

A woman who had cared for her husband with AD for the past year described her frustration:

I didn't realize I would have to watch him all the time and I wasn't prepared. I turned my back and he was gone. He wandered off again. When I try to keep the doors locked, he gets angry. He put a hole in the side door screen with his fist last week. There are days I am so angry with him; I want to pack up and leave here.

Another woman who had cared for her husband with AD for four years became tearful as she described her situation:

This is the second marriage for both of us. I married [husband] five years ago. He promised me we would travel and see the world. Then he was diagnosed with dementia ... When he wanders off and the police have to bring him home, his

daughter gets angry with me. I can't talk to her. I can't talk to him, and I am too embarrassed to tell my daughter about my situation. She didn't want me to marry him. I don't know where to turn.

The onset of troubling behavioral changes in the spouse was particularly difficult for the strugglers. One woman who had cared for her husband with AD for five years thought things were going well until he began taking money from her purse and hiding it.

He was a banker and he has always managed our money. At first, I gave him a checkbook on a closed account. When he would write checks, I would promise to 'mail' them for him. That didn't work very long. Now he is taking money from my purse. When I try to explain that this is my money, he gets angry and yells for hours. I have to figure this out by myself.

Another woman whose family had regularly stopped by to help her care for her husband throughout the six years since his AD diagnosis described losing control:

I did all right when he cut off the tops of all the shrubs, and I laughed when he threw my pot plants away, but how do you deal with a man who won't take a bath? Our children say "Don't worry Mom, just roll with it", but I can't roll with it any more.

A woman who had cared for her spouse with PD for four years could not stop talking about her concern that she might make mistakes in his care:

One thing that I worry about is something will come up and I won't be able to handle it, I won't be able to figure out what to do or think of a solution. I'm afraid I'll make the wrong decisions.

A man and his wife had both worked in accounting before they took early retirement and moved into a retirement community eight years ago. Shortly after their move, the wife was diagnosed with PD and the husband became her caregiver. He described his challenges:

I give her meds. I take care of that, which is pretty elaborate. Getting her to bed, brushing her teeth, getting her dressed is a real, real chore. I get very angry. It is the biggest, no question, it is the biggest challenge. I recognized that I needed to get home health care for her so now someone comes from seven to nine in the morning and seven to nine in the evening. She is really angry with me about this.

Case Managers' Stories

Case managers were care service brokers and coordinators who conceptualized caregiving as a job to be done. Their stories concerned their spouse's functional limitations and losses, the tasks that needed to be done, and the resources necessary to accomplish those tasks. There was little description of including the ill spouse in care. These case manager spouses often verbalized limits on how long they would continue to be a caregiver: if the care situation remained stable, they would continue; if not, they would consider terminating it and institutionalizing the ill spouse.

One man who had cared for his wife with AD for two years described why, one evening when their daughter could not stop by on her way home from work to bathe her mother, he secured home care services:

I guess my main problem is not getting help. Bathing my wife every day is not my thing. Fortunately I can pay someone else to do it. She [wife] gets a little upset when the aides try to take her clothes off of her, but I tell them just go ahead and get it done.

As time passed, this man began looking at long term care facilities:

It is getting to be too much for me, so I have picked out a couple of good homes that are reasonably priced, where I can put [wife]. I'll probably move her next month when I have some time off from work. I can visit once a week to check on the care she is getting.

After eight years of caring for his wife who has AD, another man described why he found his wife's dependency to be increasingly problematic:

Taking someone to the bathroom is something I don't like doing. So when I go to a restaurant, I take somebody with me who will take her [wife] to the bathroom. If not, I find some woman to take her. Women never turn me down. I always get good help.

He volunteered his plans for the future:

I'll take care of her as long as I can. She was a good mother to the kids and a good wife. She never complained. If it gets too difficult, there is a nursing home close to the house. One of my former business associates has his mother there and she is always clean when he goes to visit.

Case managers focused on efficient solutions to caregiving problems. A woman who had been caring for her husband with PD for four years described how she managed his increasing memory loss:

When he gets tunnel vision, I can usually divert his thinking. One day he wanted to do something and I said, "Let's not do that right now." So, I talk to him like you would do with a kid. You just treat him pretty much the way you do a child.

She described the effectiveness of her approach to care.

I keep a calendar when he goes to the bathroom. I try to think in terms of all right, on the third day if he hasn't been, then I give him some laxative that I keep that in the bathroom. A schedule is the most important thing.

Relationship of Style to Level of Burden

Following the interview analysis and categorization of the three styles, we reexamined the selected subjects' management styles in the context of their SCB scores. By design, we had selected the cases for analysis across the range of SCB scores (high, moderate, and low burden), but following the narrative analysis we observed that SCB scores were clearly related to the management styles employed by caregivers. Strugglers reported the highest

levels of burden, adapters reported moderate levels of burden, and case managers reported the lowest levels of burden.

Discussion

This secondary analysis of baseline interviews with spouses recruited into a clinical trial provided insight into how caregivers' levels of burden might be related to their management styles. Stories told by these caregiving spouses differed in the following ways.

Adapters

Adapters' stories included descriptions of collaborative partnerships with others: "We" decided to ... "We" did this." This "we" work usually was with the spouse, but often with an adult child or a neighbor. The importance of "we" work in successfully managing a chronic disease continues to be reported in family caregiving studies. Based on research with 92 healthy spouses helping a chronically-ill spouse, Badr, Acitelli and Taylor (2007) concluded that "we work" in couple interviews was a manifestation of an intact "couple" identity and served as a buffer for care strain in the healthy spouses. Rohrbaugh, Mehl, Shoham, Reilly, and Ewy (2008), who followed couples managing heart disease over time, reported that ill spouses had better cardiac outcomes in dyads where "we" work was manifested. From their longitudinal study of 116 married couples in which one spouse had dementia, Perrin, Schmid, Hermann, and Wettstein (2011) observed that the care recipient demonstrated fewer problem behaviors and the caregiving spouse reported less caregiving burden over time in dyads in which spouse caregivers continued to discuss "we" work. Adapters also were more likely than strugglers or care managers to describe home care as involving "good days" as well as "bad days", and to acknowledge that care situations would change over time.

Strugglers

Strugglers' stories were dominated by two recurrent themes: "my spouse resists/refuses care", and "I am alone in my situation". Most caregiver assistance programs focus on physical care skills [how to bathe, how to toilet, how to feed someone], but the majority of challenges described by both AD and PD strugglers were associated with the spouse's resistance to care. When confronted with the care recipient's resistance [e.g., resistance to bathing, brushing their teeth, or changing their clothes; wandering off; taking and hiding things], strugglers were unable to describe successful management strategies.

The second theme in struggler interviews was the spouse's perceived aloneness in the caregiving situation. The relational content of strugglers' stories was around care conflicts. Strugglers had various explanations for the absence of help from others ("Our children/friends/neighbors are busy with their own lives") or their own reluctance to ask for assistance from other ("It's my job; No one can do it as well as I can"). As a group, caregivers who represented the struggler style reported the highest levels of caregiving burden.

Case Managers

Case managers' stories were similar to those of strugglers in their descriptions of care recipient's behavioral deficits as problems. Their stories differed from those of other caregiver types in the absence of 'we' work and limited mention of the care relationship. Rather, case managers' stories emphasized tasks to be done (e.g., baths, toileting). Care managers' stories also were likely to equate caregiving to past experiences (e.g., "it's like taking care of a child"; "it's like running an organization".) For these spouses, caregiving challenges resulted from "mismatches" between assistance needed and assistance available (e.g., "I do not do this sort of task; I need [someone else] to do this").

Caregiver Styles and Caregiver Burden

We readily acknowledge alternative explanations for these findings. Previous studies have indicated that caregiver burden is related to caregiver mood state (Ornstein & Gaugler, 2012; Pinquart & Sörensen, 2003; Quinn, Clare & Woods, 2010), and we were curious about whether the difficulties reported by these strugglers were a manifestation of a negative mood state. A baseline assessment of caregiver mood was available for this sample, because caregivers had reported the number and frequency of depressive symptoms on Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977) when they enrolled in the parent study. We found no significant correlation between CES-D total scores (depressive symptoms) and SCB scores (burden) in the full sample of 130 caregiver spouses. However, within the struggler group (n = 42), depressive symptoms were significantly and positively correlated with level of caregiver burden. We also examined severity of disease, an objective component of burden. Although all ill spouses had moderate to severe AD or PD, the duration of caregiving experience was not related to the spouse caregiver's management style.

It is possible that the adapter spouse caregivers had personality traits (e.g., resilience, hardiness, optimism) that mediated the more difficult aspects of home care for spouses with these two progressive chronic diseases, but the caregiver personality variables were not assessed in the parent study. We recommend that future studies of caregiver spouses' management of chronic disease should explore caregiver personality factors as potential factors that could accentuate or buffer caregiving burden, as well as the role of stress in shaping management styles and levels of burden.

Finally, our typology might reflect the evolution of spousal caregiving over time for a partner whose chronic disease has a downward trajectory. That is, all caregivers are likely to struggle with problems in the early stages of home care as family roles shift, new responsibilities are taken on, and caregivers strive to find some sense of meaning in caring for a spouse with a progressively worsening disease such as AD and PD. During mid-stage disease with periods of relative disease stability, spouses might begin to gain a sense of competence and capability as they adapt to home care management. As disease progresses further, spouses may be forced to accept the reality that the scope of needed care is moving beyond the limits of home care, and now requires managing complex services that can better be provided by others.

Implications for Tailoring Caregiver Assistance Programs

“Problems” described by caregivers in the three groups were similar: AD and PD adapters, strugglers, and case managers all reported problems with care recipients’ resistance to physical care, troubling personality changes, and “unsafe” behaviors (e.g., driving), as well as increased social isolation and interpersonal conflicts with others. Spouses’ reported management strategies differentiated the groups. Management style differences might provide direction for tailoring family caregiver support programs. For example, AD and PD strugglers clearly need intensive intervention to help them sort out care problems, develop effective management strategies, and learn to ask for and accept aid and assistance on occasion. AD and PD case managers need information on finding, accessing, and evaluating appropriate community resources. AD and PD adapters who state they are managing well might best benefit from anticipatory guidance that includes information on where and how to find caregiving assistance during the “bad days”, with periodic follow-up as their spouse’s disease evolves over time.

In an age of personalized and patient-centered care, clinical research that addresses the management of chronic problems must progress beyond descriptions of the problems to development of personalized interventions designed to target both the caregiver’s management style and the evolution of the disease. We propose that creating and testing interventions for those in greatest distress (the strugglers) and matching those interventions to the caregiver’s management style present the greatest promise for delivering the right care, to the right person, at the right time. In this way, tailoring home care should improve outcomes for the care recipient with a progressive chronic disease as well as their family caregiver.

Acknowledgment

We gratefully acknowledge Elizabeth Flint for her invaluable assistance in reviewing and editing this paper.

Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article. The National Institutes of Health, National Institute of Nursing Research provided funding through grant RO1 NR 008285.

Data-based papers from this grant may be accessed through the National Center for Biotechnology Information under grant Project ASSIST for Chronic Illness Caregivers RO1 NR 008285 at <http://www.ncbi.nlm.nih.gov/>

References

- Alzheimer's Association. 2013 Alzheimer's disease facts and figures. 2013 Retrieved from Alzheimer’s Association website: http://www.alz.org/downloads/facts_figures_2013.
- Badr H, Acitelli LK, Taylor CLC. Does couple identity mediate the stress experienced by caregiving spouses? *Psychology and Health*. 2007; 22:211–229.
- Ball V, Snow AL, Steele AB, Morgan RO, Davila JA, Wilson N, Kunik ME. Quality of relationships as a predictor of psychosocial functioning in patients with dementia. *Journal of Geriatric Psychiatry and Neurology*. 2010; 23:109–114. [PubMed: 20233854]
- Beeber AS, Zimmerman S. Adapting the family management style framework for families caring for older adults with dementia. *Journal of Family Nursing*. 2012; 18:123–145. [PubMed: 2223494]

- Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*. 2009; 11:217–228. Retrieved from <http://www.dialogues-cns.org/>. [PubMed: 19585957]
- Corcoran MA. Caregiving styles: A cognitive and behavioral typology associated with dementia family caregiving. *The Gerontologist*. 2011; 51:463–472. [PubMed: 21335422]
- Croog SH, Burleson JA, Sudilovsky A, Baume RM. Spouse caregivers of Alzheimer patients: Problem responses to caregiver burden. *Aging & Mental Health*. 2006; 10:87–100. [PubMed: 16517483]
- DeFries EL, McGuire LC, Andresen EM, Brumback BA, Anderson LA. Caregivers of older adults with cognitive impairment. *Preventing Chronic Disease*. 2009; 6(2):A46. Retrieved from <http://www.cdc.gov/pcd/>. [PubMed: 19288989]
- Durant T, Christian O. Caregiving to aging parents. *Forum on Public Policy: A Journal of the Oxford Round Table*. 2007; 2007(1) Retrieved from <http://forumonpublicpolicy.com/papers.htm>.
- Garand L, Lingler JH, Deardorf KE, DeKosky ST, Schulz R, Reynolds CF III, Dew MA. Anticipatory grief in new family caregivers of persons with mild cognitive impairment and dementia. *Alzheimer Disease and Associated Disorders*. 2012; 26:159–165. [PubMed: 21946013]
- Garlo K, O'Leary JR, Van Ness PH, Fried TR. Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*. 2010; 58:2315–2322. [PubMed: 21087225]
- Habermann S, Cooper C, Katona C, Livingston G. Predictors of entering 24-h care for people with Alzheimer's disease: Results from the LASER-AD study. *International Journal of Geriatric Psychology*. 2009; 24:1291–1298.
- Hirschman KB, Shea JA, Xie SX, Karlawish JH. The development of a rapid screen for caregiver burden. *Journal of the American Geriatrics Society*. 2004; 52:1724–1729. [PubMed: 15450052]
- Hoenig J, Hamilton MW. Elderly psychiatric patients and the burden on the household. *Psychiatria et Neurologia*. 1966; 152:281–293. [PubMed: 5966211]
- Knafel KA, Deatrick JA, Havill NL. Continued development of the Family Management Style Framework. *Journal of Family Nursing*. 2012; 18:11–34. [PubMed: 22223495]
- Lyons KS, Sayer AG, Archbold PG, Hornbrook MC, Stewart BJ. The enduring and contextual effects of physical health and depression on care-dyad mutuality. *Research in Nursing and Health*. 2007; 30:84–98. [PubMed: 17243110]
- Lyons KS, Stewart BJ, Archbold PG, Carter JH. Optimism, pessimism, mutuality, and gender: Predicting 10-year role strain in Parkinson's disease spouses. *The Gerontologist*. 2009; 49:378–387. [PubMed: 19386827]
- Martire LM, Lustig AP, Schulz R, Miller GE, Helgeson VS. Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychology*. 2004; 23:599–611. [PubMed: 15546228]
- Montgomery RJV, Gonyea JG, Hooymann NR. Caregiving and the experience of subjective and objective burden. *Family Relations: An Interdisciplinary Journal of Applied Family Studies*. 1985; 34:19–26.
- Ornstein K, Gaugler JE. The problem with "problem behaviors": A systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *International Psychogeriatrics*. 2012; 24:1536–1552. [PubMed: 22612881]
- Ott CH, Sanders S, Kelber ST. Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. *The Gerontologist*. 2007; 47:798–809. [PubMed: 18192633]
- Perrin S, Schmid R, Hermann S, Wettstein A. The impact of attachment on dementia-related problem behavior and spousal caregivers' well-being. *Attachment & Human Development*. 2011; 9:163–178.
- Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*. 2003; 58(2):P112–P128.
- Pinquart M, Sörensen S. Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*. 2011; 26:1–14. [PubMed: 21417538]

- Quinn C, Clare L, Woods RT. The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: A systematic review. *International Psychogeriatrics*. 2010; 22:43–55. [PubMed: 19772684]
- Radloff LS. The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977; 1:385–401.
- Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M. A broader view of family caregiving: Effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*. 2009; 64B:788–798.
- Roland KP, Jenkins ME, Johnson AM. An exploration of the burden experienced by spousal caregivers of individuals with Parkinson's disease. *Movement Disorders*. 2010; 25:189–193. [PubMed: 20063397]
- Rohrbaugh MJ, Mehl MR, Shoham V, Reilly ES, Ewy GA. Prognostic significance of spouse *we* talk in couples coping with heart failure. *Journal of Consulting and Clinical Psychology*. 2008; 76:781–789. [PubMed: 18837595]
- 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]
- Van Den Eeden SK, Tanner CM, Bernstein AL, Fross RD, Leimpeter A, Bloch DA, Nelson LM. Incidence of Parkinson's disease: Variation by age, gender, and race/ethnicity. *American Journal of Epidemiology*. 2003; 157:1015–1022. [PubMed: 12777365]
- Vitaliano PP, Russo J, Young HM, Becker J, Maiuro RD. The Screen for Caregiver Burden. *The Gerontologist*. 1991; 31:76–83. [PubMed: 2007478]
- Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*. 2003; 129:946–972. [PubMed: 14599289]
- Vugt ME, Stevens F, Aalten P, Lousberg R, Jaspers N, Winkens I, Verhey FR. Do caregiver management strategies influence patient behaviour in dementia? *International Journal of Geriatric Psychiatry*. 2004; 19:85–92. [PubMed: 14716704]
- Weintraub D, Burn DJ. Parkinson's disease: The quintessential neuropsychiatric disorder. *Movement Disorders*. 2011; 26:1022–1031. [PubMed: 21626547]

Biographies

Linda Lindsey Davis, PhD, RN, FAAN is Ann Hinshaw Gardiner Professor Emerita at the Duke University School of Nursing, Durham, North Carolina, USA.

Deborah Chestnutt, MSN, RN is Dementia Caregiver Case Manager at the Charles George VA Medical Center, Asheville, NC, USA.

Margory Molloy, MSN, RN is Director of the Center for Nursing Discovery at the Duke University School of Nursing, Durham, North Carolina, USA.

Tess Deshefy-Longhi, DNSc, RN, is a Community Care Transitions Nurse with Connecticut Community Care, Inc., Bristol, Connecticut, USA.

Bomin Shim, PhD, RN, is an Assistant Professor in the School of Health Sciences at Seattle Pacific University, Seattle, Washington, USA.

Catherine L. Gilliss, PhD, RN, is Dean and Helene Fuld Professor at the Duke University School of Nursing, Durham, North Carolina, USA.