Description of Dementia Caregiver Uplifts and Implications for Occupational Therapy

Mary Lou Donovan, Mary A. Corcoran

OBJECTIVE. Most occupational therapy interventions for caregivers are designed to reduce negative consequences of caregiving by building skills to manage problem behaviors and dependence. However, therapists may be missing an opportunity to provide interventions that directly help caregivers to emphasize and act on positive aspects of care. We describe care-related thinking and action processes of long-term caregivers who report positive effects related to caring for a spouse with dementia.

METHOD. We analyzed data from 15 experienced and uplifted (reporting improved well-being from caregiving) spouse caregivers to describe how they think about and carry out their care duties.

RESULTS. We describe two primary themes of caregiver thinking and action: (1) engaging in positive behaviors and (2) making adjustments in attitudes.

CONCLUSION. These findings support a new focus for occupational therapy caregiver intervention that promotes a positive approach to thinking about and enacting care tasks.


Alzheimer’s disease and related disorders (ADRD) is one of the fastest growing diseases in the United States; numbers are expected to quadruple by 2050 (Shenk, 2001). Currently, 9.9 million Americans provide unpaid caregiving for people with ADRD (Alzheimer’s Association, 2009). This level of care is provided at a high cost to caregiver physical, mental, social, and financial health (Juozapavicius & Weber, 2001). Negative consequences of caregiving have been well documented and are related to well-being, institutionalization, and survival of the care recipient and caregiver (Gilley, McCann, Bienias, & Evans, 2005; McClendon, Smyth, & Neundorfer, 2004; Schulz & Beach, 1999). As a result, negative aspects of caregiving have dominated the focus of caregiving research for many years, a trend confirmed by a 2003 meta-analysis in which Pinquart and Sörensen reported that most interventions were focused on reducing caregiver burden or depression. This overwhelming attention to the negative aspects of caregiving, however, has not resulted in conclusive evidence of these interventions’ effectiveness. By contrast, comparatively little attention has been given to the positive aspects of caregiving, or uplifts, despite recognition in the literature that some caregivers report improved feelings of well-being as a result of providing care to a loved one (Caswell et al., 2003). Pinquart and Sörensen (2004) defined uplifts as “indicators of positive, subjective well-being” (p. 438) and documented their statistical associations with improvements in stress, well-being, depression symptoms, and intervention outcomes.

This limited approach to caregiving interventions is reflected in the occupational therapy literature as well. Although many occupational therapy caregiver studies measured the effects of intervention on constructs such as quality of life and mood, no occupational therapy interventions reported in the literature actually attempted to enhance the caregivers’ positive feelings about care. Instead, the focus...
of most occupational therapy interventions was problem based, designed to teach caregivers how to compensate for cognitive decline, ease the burden of care, provide more effective supervision, or strengthen coping behaviors (Gitlin & Corcoran, 2005; Gitlin et al., 2008; Graff et al., 2007). Teri, Logsdon, Uomoto, and McCurry (1997) reported that an intervention designed to enhance caregiver uplifts, although not an occupational therapy intervention, was superior at reducing depression in both spouses compared with a problem-solving caregiver intervention. Perhaps occupational therapists have overlooked a potentially powerful tool to improve outcomes for caregivers and their family members with dementia—promoting caregivers’ positive thinking and action processes.

The Person–Environment–Occupation (PEO) theoretical model (Law et al., 1996) helps to explain the important role that uplifts can play in the transactional relationship between caregivers and care recipients, their occupations, and environments. It is well understood from the literature that a dynamic relationship exists among characteristics and occupations of both the caregiver and care recipient and attributes of the environment (Roff et al., 2004). Moreover, these dynamics influence outcomes such as well-being, function, and capacity for care provision over time (Roff et al., 2004). An occupational therapy intervention designed to promote uplifts (a caregiver characteristic) as they are translated into everyday caregiving actions should result in better health for the caregiver and care recipient. However, a knowledge gap exists about the specific thinking and action processes used by uplifted caregivers. This knowledge gap impedes occupational therapists’ ability to design strategies for modifying caregivers’ attitude (person) and actions (occupation). Therefore, the study described here fills this gap through an in-depth description of how uplifted caregivers think about and conduct care.

Method

In this study, we used a phenomenological approach to describe the caregiving-related beliefs, meanings, and actions identified by a group of uplifted, long-term spouses of people with ADRD. Data for the study described in this article were obtained from existing interviews collected as part of a larger National Institute on Aging–funded study (NIA–R29–AG13019) conducted over a 5-year period (1997–2002) by Corcoran (2003, 2004a, 2004b). The purpose of Corcoran’s study was to develop a description of caregiving style, thinking, and action processes used by spouses as they provide daily care to a husband or wife with moderate to severe symptoms of ADRD. Corcoran described three caregiving styles for spouses (habilitating, preserving, and enforcing) that were distinctive in terms of care priorities, interactions with the care recipient, self-care habits, and use of care strategies (Corcoran, 2004b).

As part of Corcoran’s (2003, 2004a, 2004b) study, the spousal caregivers provided written consent (approved by the George Washington University Institutional Review Board) and took part in 90-min interviews on three occasions over a period of 6 weeks. The interviewers (several trained occupational therapists) used probes and a topical list to gather the caregiver’s report of beliefs, meanings, and actions related to caregiving. Qualitative data, gathered through audiotaped interviews, were recorded, professionally transcribed, and imported into a qualitative data analysis program.

For the purposes of this article, we identified a subset of data from Corcoran’s (2003, 2004a, 2004b) original study. Data were included in the positive-aspects-of-care study if they originated with a caregiver who scored at or above the sample median on (1) the Caregiving Uplifts Scale (Kinney & Stephens, 1989) and (2) length of caregiving (sample median = 4 years). Of the 41 participants in the Corcoran study, 15 (36.5%) were identified who were relatively long-term caregivers and reported high uplifts related to caregiving.

The first author (Donovan) used manual and computerized coding of the narrative data from Corcoran’s (2003, 2004a, 2004b) original study. Two levels of in vivo coding were used: (1) constant comparative analysis to identify pertinent text indicators of positive aspects of caregiving and (2) groupings of statements into similar categories by their properties. As a result, 23 original themes were identified and then collapsed into two primary thematic categories with eight key subthemes. Descriptive and interpretive accuracy was established by relying on the theoretical framework identified for the study and offering clear definitions of terms used. Rigor for this study was established through exposure to the construct (approximately 1,350 hr of interview) and peer review by three impartial content experts.

Results

The sample for this study of uplifted, long-term caregivers consisted of 6 men and 9 women who were caring for a spouse with a diagnosis of Alzheimer’s disease (73.3%) or a related disorder (26.7%). The mean caregiver age was 67.8 yr (standard deviation = 11.8 yr), and the group reported an average of 15.9 yr of education. All but 1 caregiver classified their ethnicity as White. The caregivers

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were caring for spouses with moderate cognitive impairment secondary to ADRD who required daily assistance with four of eight activities of daily living. The spouses’ average Mini-Mental State Exam (Folstein, Folstein & McHugh, 1975) score was 17.4. All the caregivers reported use of paid supports (such as home health aide or adult day care); 47% reported using more than five services.

Caregivers had been providing care for an average of 5.4 yr, and all were above the sample median score of 54 on the Caregiving Uplifts Scale (modified from Kinney & Stephens, 1989). The sample was compared with 26 caregivers in the Corcoran study who scored below the sample median for number of years providing care (< 4 yr) or uplifts (frequency <54). The uplifted, long-term (ULT) caregivers were statistically less likely to live alone with the care recipient (p < .023) and reported fewer symptoms of depression (p < .041), objective burden (p < .038), and subjective burden (p < .004). Thus, non-ULT caregivers reported more symptoms of depression and burdensome behaviors by their spouses and had a greater stress response to those behaviors.

Two primary thematic categories resulted from analysis and included caregivers (1) engaging in positive behaviors and (2) making adjustments in attitudes.

Engaging in Positive Caregiver Behaviors

Caregivers displayed multiple positive behaviors in caring for themselves and the care recipients. Particularly salient for these ULT caregivers was the habit of simplifying the daily routine and making things as organized and systematic as possible to help them in their caregiving role. Specific approaches to organization ranged from tasks such as table setting or clothes sorting to financial preparation. Although this approach was beneficial to the caregiver, it also helped to reduce the care recipient’s confusion (“Because I’m sure she’s overwhelmed with what to wear … I went around and got all the tops and all the bottoms and all the colors, and organized them that way”).

ULT caregivers also talked about the benefits of taking care of themselves (eating right, getting exercise or rest, or pursuing hobbies or interests). Through good self-care habits, caregivers ensured their energy and ability to continue caring for their spouse (“I have to think of the long term here. I have got to keep my mental health together, and I am not going to become a martyr or a doormat”).

ULT caregivers actively engaged with family, friends, coworkers, and paid staff as an essential source of the support needed to continue in their role as caregivers. This support was often beneficial for both the caregiver and the spouse; as one wife explained, “He needs to be in his group, and I need to be at my work, because that’s kind of my group. It is a caregiving issue; because that’s how I give his care during the day; other people give it to him for me.”

Support was also found in faith rituals and religious communities. Although many ULT caregivers in this study considered themselves religious people who were highly involved in their faith communities, others coped more effectively with the challenges of their role through the use of quiet, solitary meditation involving prayer or listening to religious music. Support was also found in secular meetings, such as support groups. ULT caregivers found support groups helpful for learning useful suggestions and as an outlet for self-expression (“You can talk about whatever you want, in any manner you want. You can cry, you can laugh, and no one is going to look at you like you’re out of your mind or something.”).

ULT caregivers talked about the benefit of continued communication with their spouses, even if the mode of communication was different or required great effort. Some caregivers indicated that as the care recipient lost ability to speak, nonverbal messages, delivered through eye contact, facial features, or body movements, became important markers of their comfort or satisfaction (“I can talk to [her], but of course, she doesn’t answer back. Although, when she coughs, you better pay attention, because there’s something wrong, even though it’s very hard to find out what it is.”). These four types of positive behaviors conveyed by ULT caregivers were particularly notable because each was undertaken to simultaneously benefit both the caregiver and the care recipient. They are external actions that may be rooted in the more internal second theme derived from this study, making adjustments in attitudes.

Making Adjustments in Attitudes

Caregivers talked about practicing a positive approach to caregiving. Although this approach may have been related to a natural tendency, it was still apparent from the data that active work was conducted to maintain and support a positive attitude toward the caregiving role and the care recipient.

Several caregivers described the importance of dwelling on the positives and avoiding thoughts about potential negative outcomes (“You just make the best of it you can. You go on with it.” “If you don’t look for the good in the bad, you can’t make it, you really can’t.”). Caregivers regarded these perspectives as instrumental in their ability to cope and maintain their stamina through the caregiving experience (“You have to really, really take a different
approach to things.”). This perspective required active cognitive work to “constantly remind yourself that you’re not dealing with an ordinary person [who] has a logical mind that can figure things out. And, once you do that, then you can sort of work around it and keep things simple”). The extent of this attitude adjustment is illustrated in this caregiver’s story of a freezer door left open:

One night I got up and the freezer door was wide open, and everything was just pretty much defrosted, and so I went in there and I said, you know, I have been meaning to clean out this freezer part. So within 5 minutes I took all the trays out and poured them off. I took a rag and wiped it up and it was spotlessly clean. I said, thank you Lord, I got my freezer cleaned.

This positive perspective was aided through the use of humor and promotion of the care recipient’s sense of humor. Some caregivers expressed that when daily situations, at times tension filled, were negotiated with humor, things went better:

He’ll sit down, and he’ll take off the old pants, and say, ‘I have to take off my shoes too.’ And, then I’ll make fun of it, and I’ll say, ‘Awwww, you really have to take off your shoes again? Awwww,’ and then he’ll smile.

Sometimes the caregiver felt the care recipient’s sense of humor changed after a diagnosis of ADRD (“She laughs at my jokes. She has a much better sense of humor now than she used to.”).

Underlying these active attempts to sustain a positive attitude seems to be a continued commitment to the marriage and spouse, even though the care recipient’s personality and behaviors had changed significantly. ULT caregivers spoke about continuing to enjoy the daily contact with their spouse and named their marriage vows as “the glue that held things together through the difficult times.” Some caregivers even regarded their relationship with the care recipient as improved since the onset of ADRD, as illustrated in these caregivers’ statements: “Oh, [the relationship is] closer than it’s been in many years…. I’m more comfortable with [my husband]. I’m more relaxed. And, he seems to be absolutely delighted with me” and “It’s probably a better relationship than we had when we were younger. Because, as he has weakened, I have strengthened. So, that gives me more power and more control and more say and that equalizes things for me.”

The continued connections of ULT caregivers to their spouses is illustrated by one particular wife when speaking of her attitude toward her husband, whose ADRD had progressed to advanced stages: “He’s very much a part of my life, still… he’s just not an object lying in bed that needs my 24-hour attention. He is still very much a living person.” Providing care for a spouse with ADRD is an expression of love (“I’m trying very hard to keep the relationship I have with [care recipient], with the recognition that he is a person who has his own feelings, and his own will, and his own ideas for as long as possible. It’s good for him, and it’s absolutely necessary for me to do that for my own feelings about myself.”). For many caregivers, the changes in the relationship with their spouse altered the way they interacted but did not change or even strengthened their willingness to provide love and care.

Discussion

As more families take on the responsibility of caring for their loved one with ADRD, the demand will grow for information about how to promote the emotional, physical, and social health of caregivers and their care recipients. Literature from the broad field of gerontology has suggested that optimizing uplifts is associated with caregiver well-being and enhanced treatment outcomes. Consistent with the PEO model, occupational therapists possess the unique expertise to help caregivers develop and modify daily tasks to emphasize the positive aspects of care and, in doing so, promote occupational performance of the caregiver and care recipient. These unique therapeutic skills include choosing and grading activities to simultaneously benefit both spouses, helping caregivers recognize and adjust the social demands of activities (i.e., using humor to reduce care recipient anxiety), and developing needed communication and social–emotional skills and habits required to sustain long-term care for a spouse with ADRD (American Occupational Therapy Association, 2008).

Despite the potential contribution of occupational therapy to promoting caregiver uplifts, we could not find any reports of occupational therapy interventions designed specifically to enhance positive aspects of care. This lack of interventions is surprising because optimizing a person’s capabilities is consistent with the profession’s underlying philosophy and because many of the strategies used by ULT caregivers (such as organizing the environment and simplifying tasks) are familiar to occupational therapists.

The benefit of this study, therefore, may lie not in teaching a new or novel tool for helping caregivers but in providing occupational therapists with justification and direction for expanding the focus for caregiving interventions on uplifts. Occupational therapists can use the description of thinking and action processes presented in this article to create a focus on promoting caregiving uplifts.
by building on and expanding existing interventions reported in the literature. Such a focus would need to emphasize therapeutic activities that simultaneously support the well-being of the caregiver and care recipient. Occupational therapy can support this dual purpose by beginning with an activity to address the care recipient’s needs (e.g., the need for a simple, repetitive, gross-motor home chore related to a former occupation) and grading that activity so that it also addresses a caregiver need (e.g., providing an opportunity to interact as spouses while preparing a meal). Both spouses gain therapeutic benefits from a dual-purpose activity, and the caregiver is likely to seek additional opportunities for uplift. This dual purpose was consistent with the preserving caregiver style described by Corcoran (2004a, 2004b), which is characterized by a preference for strategies that maintain a balanced attention to the needs of both spouses. Perhaps this positive cycle is one explanation for Norton et al.’s (2009) findings that care recipients who had closer relationships with their caregivers showed slower declines in “cognition and functional capacity” (p. 565).

In a caregiving approach that emphasizes the positive aspects of care, a comprehensive evaluation of both the caregiver and the care recipient is crucial, much like the family-based approach used in pediatric occupational therapy. Reflecting the dynamic relationships involved in caregiving, the PEO model is a useful way of organizing evaluation data for this purpose. Given this study’s results, particular emphasis should be placed on caregiver characteristics and attitudes to reveal the thinking behind caregiver actions, not just a recitation of duties and problems. As the study suggests, evaluation should include information about the daily routine, caregiver health habits, engagement of others in care, communication and care patterns, and values underlying daily care decisions (i.e., commitment to marriage, opportunity to do the right thing, maintaining a positive attitude). By helping caregivers to focus on values and social relationships underlying care actions, the experience can be enhanced for both spouses.

This study’s results suggest the potential power of caregiver commitment to the relationship and feelings of uplift, but these feelings cannot be assumed to exist for all caregivers. Many caregivers may not feel committed to the spouse or may be exhausted from caring for someone with upsetting behavioral issues. As part of a complete assessment of relevant caregiver characteristics, we suggest incorporating use of tools to measure uplifts, such as the nine-item Positive Aspects of Caregiving measure (Tarlow et al., 2004), as part of the caregiver assessment process. When indicated by a low uplifts score, intervention should begin with helping the caregiver examine and expand his or her thinking about the purposes of caregiving. That purpose statement can then be used to guide care decisions, such as how to establish a daily routine or find supports that benefit both the care recipient and the caregiver. An occupational therapy practice model focused on promoting uplifts fosters and encourages new caregivers to develop a positive sense of direction for their roles as caregivers. In addition, caregivers who are overwhelmed, burdened, or discouraged may benefit from an occupational therapy perspective that focuses on the caregiver’s needs and prioritizes therapeutic activities that are designed to help the caregiver feel more positive about his or her efforts and outcomes.

Despite the contribution of this study to our understanding of positive caregiver thinking and actions and processes, the question of why the participating spouse caregivers chose to emphasize positive aspects of the role remains unanswered. It is likely that other important mediators of uplift exist that have important implications for future occupational therapy models. The relationship between several variables of well-being (depression symptoms, objective burden, and subjective burden) cannot be assumed. It is not possible to know whether this group of ULT caregivers reported uplifts because they were less depressed and burdened than their non-ULT counterparts or whether depression and burden interfered with feeling uplifted. The literature has reported that a positive attitude could be helpful for caregivers faced with negative care recipient behaviors, decreasing the associated risks of mental and physical health problems (Ory, Yee, Tennstedt, & Schulz, 2000). However, those caregivers who maintained a positive approach may also have personality characteristics that helped them experience positive caregiving aspects, in spite of daily challenges (Caswell et al., 2003). Either way, the relationship between well-being and individual approaches to caregiving is a potentially important one that deserves the attention of health care providers and further study.

This study investigated the experiences of one group of ULT caregivers of people with dementia who resided in the Washington, DC, area from 1997 to 2002. Limitations of this study include limited racial diversity and use of a secondary database, where information was filtered through the views of other interviewers. Even with these limitations, one can conclude that caregivers, whether new or experienced, may benefit from occupational therapy to emphasize positive aspects of taking care of a person with dementia. Sharing such information with caregivers, especially when the care recipient is in the early stages of the disease, holds the potential to ease the stresses experienced
by both caregiver and care recipient. Information about positive aspects, such as those learned through this study, expands this important arena of professional practice with caregivers and is consistent with a transactional approach to occupational therapy. As stated by Pinquart and Sörensen (2004, p. 447), if caregivers “developed and maintained sources of positive affect,” they might be able to protect their sense of well-being and mental health while at the same time offsetting the negative aspects of caregiving. The next step, therefore, is to test whether an occupational therapy intervention designed to promote a positive response to caregiving has a relationship to health outcomes and service costs. ▲

References


