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Examining What Caregivers Do During Respite Time to Make Respite More Effective

Dale A. Lund
Rebecca Utz
Michael S. Caserta
Scott D. Wright

University of Utah Gerontology Center and Center on Aging, Salt Lake City

Research on respite services for caregivers has been extensive over the past 25 years; however, findings regarding the effectiveness for improving their well-being have shown only moderate or mixed support. Missing from this research has been an examination of what caregivers do during their respite time. We studied 52 family caregivers who used adult day services and examined the consistency between their desired and actual respite activities and its relation to well-being outcomes. We concluded that (a) caregivers pursued a wide range of respite activities; (b) 46% were only somewhat or not very satisfied with how they spent their time; (c) those who were inconsistent in their desired versus actual respite activities and also dissatisfied with their use of time were more depressed, more negative in dimensions of burden, and less satisfied with caregiving; and (d) facilitators should be used to work individually with caregivers to identify activities and goals for respite time that are most likely to improve their well-being.

Keywords: adult day care; intervention; caregiver activities; burden and satisfaction

There are four primary purposes of this investigation. First, we summarize some of the most important research findings regarding the effectiveness of respite services for family caregivers. Second, because previous research on respite services and caregiver outcomes has neglected to pay sufficient attention to potentially one of the most important features of respite, we

Authors’ Note: This study was funded by a targeted research grant from the Alzheimer’s Association. Please address correspondence to Dale A. Lund at dale.lund@nurs.utah.edu.
examine what caregivers do when they have respite time. Third, we present results of a study that examined caregivers’ desired and actual use of respite time and the degree of consistency between them, their satisfaction with their activities, and how these factors relate to selected caregiver outcomes. Fourth, we provide suggestions for future research and practice to enhance caregivers’ use of respite time and improve their well-being outcomes.

Summary of Past Research

Family and Informal Caregiving Research

Research on family caregiving in the United States has steadily increased since the early 1980s (Family Caregiver Alliance, 2006; Zarit, 1989) and will likely continue to do so over the next few decades, as approximately 8,000 baby boomers turn age 60 every day (U.S. Census Bureau, 2006). Particularly common have been descriptive studies of caregiver profiles (Smyth, Rose, McClendon, & Lambrix, 2007; Wolff & Kasper, 2006), including investigations of racially, ethnically, and geographically diverse caregivers (Dilworth-Anderson, Williams, & Gibson, 2002; Mahoney, Cloutterbuck, Neary, & Zhan, 2005); studies that examine strains, burdens, sacrifices, and satisfactions associated with caregiving (Johnson & Wiener, 2006; Kinney & Stephens, 1989; Lawton, Kleban, Moss, Rovin, & Glicksman, 1989); and research that focuses on needs, resources, coping strategies, and use of services (Dal Santo, Scharlach, Nielsen, & Fox, 2007; Fortinsky, 1998; Link, Dize, Folkemer, & Curran, 2006). Also included have been correlational studies examining factors associated with caregiver burden and well-being (Gitlin, Reever, Dennis, Mathieu, & Hauck, 2006; Harper & Lund, 1990). In addition, we know that the value of unpaid caregiving in the United States exceeds $257 billion annually, which is greater than the combined costs of nursing home care and home health care (Feinberg, Wolkwitz, & Goldstein, 2006). Also, formal paid care declined between 1994 and 1999 while sole reliance on family caregivers increased (Spillman & Black, 2005). There is a potential caregiving crisis growing in the United States because there are too few caregivers, both paid and unpaid, and too many people who need care (International Longevity Center, 2006).

Only recently has research shifted toward an examination of the effectiveness of services and interventions expected to enhance caregivers’ well-being and reduce financial costs of expensive institutional care (Gallagher-Thompson & Coon, 2007; Sorenson, Pinquart, & Duberstein, 2002). Perhaps the most significant intervention research effort to date to improve the quality of lives of family caregivers was the six-site REACH I studies. These studies
were designed to examine the feasibility and effectiveness of nine intervention approaches to reduce caregiver stress and improve positive outcomes (Schulz et al., 2003). REACH I studies (1996-2000) were followed by REACH II, another multisite intervention with multiple components to improve caregivers’ safety, self-care, social support, and emotional well-being and to help them better manage problem behaviors (Belle et al., 2006; Schulz et al., 2003). The REACH interventions for caregivers included behavioral and environmental skill training, telephone-based support, behavioral modification, family systems therapy, computerized telephone communication, coping classes, community support groups, and minimal support. From these studies we learned that a one-size-fits-all approach is likely to be ineffective and that more-successful interventions are those that are responsive to individual risk profiles (Schulz et al., 2003) and each caregiver’s unique needs (Beauchamp, Irvine, Seeley, & Johnson, 2005; Kelly & Williams, 2007). Each of the REACH interventions produced modest benefits for some caregivers, but, surprisingly, none examined the effectiveness of respite services.

**Importance of Respite and Respite Research**

Respite, or temporary planned or emergency relief (time away) from the daily obligations of providing care to a loved one, has been identified by family caregivers and professionals who work with them as the most needed and desired service (Caserta, Lund, Wright, & Redburn, 1987; Shope, Holmes, Sharpe, Goodman, & Izenson, 1993). Respite care usually refers to services provided in the home or at adult day care centers or in institutional settings that offer overnight or multiday extended care (Lund, Wright, & Caserta, 2005). Respite services usually have dual purposes as they are intended to provide care to a physically or cognitively impaired person while simultaneously giving the caregiver opportunities for having time away from the caregiving situation. During the past 20 years, respite services have grown to include more than 20,000 providers in the United States (Kirk, 2002). Despite the increase in respite providers, a national study (1998-1999) of 1,247 family caregivers found that the most frequently mentioned (35%) unmet caregiver need was “finding time for myself,” which is the primary purpose of respite (National Alliance for Caregiving & AARP, 2004). Similarly, another national study of more than 1,000 caregivers to chronically ill persons found that 39% said they needed respite, yet only half of them had received the service in the year prior to the survey (Foundation for Accountability & Robert Wood Johnson Foundation, 2001).
Further recognition of the importance of respite services is the establishment of the National Family Caregiver Support Program (NFCSP) in the Older Americans Act Amendments of 2000 (Pub. L. No. 106-501), which provides funds to states to increase knowledge and access of caregivers to support services, counseling, training, and respite care (Feinberg et al., 2006; Link et al., 2006). The NFCSP requires all State Units on Aging and Area Agencies on Aging to provide caregivers a minimum set of services, including respite. And even more recently, Congress passed the Lifespan Respite Care Act of 2006 to expand and enhance respite care services to family caregivers, “thereby reducing family caregiver strain” (Pub. L. No. 109-442, December 21, 2006). Respite care is on the national agenda and will likely remain there for many years.

Respite services have received growing research attention since the late 1980s (Lawton, Brody, & Saperstein, 1989). The primary focus has been on examining the effectiveness of respite services on reducing caregiver strain, burden, and depression, improving the ability of caregivers to maintain their own physical health, and keeping the patient independent in community settings rather than using more-costly institutional care (Pinquart & Sorensen, 2003, 2007; Zarit, Stephens, Townsend, & Greene, 1998). This research could be characterized as somewhat inconsistent and only moderately positive. Some examples of the inconsistent findings are found in the following studies: Kosloski and Montgomery (1993) found that caregivers who used respite (compared with nonusers) had lower subjective burden, higher morale, but no differences in objective burden. Theis, Moss, and Pearson (1994) found positive qualitative evidence for respite effectiveness but very limited evidence of support through quantitative measures. Lawton, Brody, et al. (1989) found that families using respite maintained their impaired relative longer in the community than those not using respite, but the service was reported to be ineffective in reducing caregiver burden. In our national study of nearly 900 informal caregivers, we found that 36% of those who were using respite services did not have lower burden levels than nonrespite users did (Caserta et al., 1987). Some of the others who reported mixed or no dramatic positive results for respite services include Chappell, Reid, and Dow (2001), Graham (1989), Kirwin (1991), and Zarit, Gaugler, and Jarrott (1999).

On the other hand, several studies have concluded that respite is at least moderately effective in reducing caregiver burden and improving well-being, health, and confidence in caregiving (ARCH National Respite Network, 2007; Cox, 1998; Curran, 1995; Gitlin et al., 2006; Knight, Lutzky, & Macofsky-Urban, 1993). Respite is most likely to be effective in
reducing stress, role overload, and depression for caregivers if they use it consistently and for longer periods of time (Gaugler, Zarit, Townsend, Stephens, & Greene, 2003; Grasel, 1997). Perhaps one of the most important studies examining the effectiveness of respite services to date concluded that caregivers needed to use respite at least 2 days per week, on a regular schedule, and in sufficient blocks of time that are uninterrupted and planned in advance (Zarit et al., 1998). No specific type or form of respite is most effective as it needs to match the caregiver’s profile, culture, and caregiving circumstances (Bourgeois, Schulz, & Burgio, 1996; Whitlatch & Feinberg, 2006). Respite needs to be used earlier in the caregiving career (Cox, 1997, 1998; Whitlatch, Feinberg, & Sebesta, 1997), in conjunction with other types of services, such as support groups, education, home health, senior centers, skill training, transportation, nutritional assistance, care management, and Internet programs (Acton & Kang, 2001; Beauchamp, et al., 2005; Belle et al., 2006; Gitlin et al., 2006), and needs to be individually tailored to meet the specific needs of each caregiver (Feinberg et al., 2006; Gaugler, Kane, & Newcomer, 2007).

Focus on Use of Respite Time

Rather than assuming that respite, or time away from caregiving responsibilities, is automatically and equally effective for all caregivers, we need to know what caregivers do with their respite time. Not all caregivers use their time for the same purposes and activities, so diverse outcomes should be expected. For example, caregivers who use some portion of their respite time for rest, exercise, and social activities might experience more favorable outcomes than those who spend their time being a caregiver for an additional person, taking on other stressful responsibilities, or engaging in less satisfying unplanned activities.

The few studies that have reported on caregivers’ use of time during respite have provided primarily descriptive accounts of respite activities and have not included an investigation into the relationship between types of activities pursued and caregiver well-being. Scharlach and Frenzel (1986) examined an institution-based (Veterans Administration; VA) respite care program and reported that the majority of caregivers used it for emotional and physical rest, followed by making visits to family and friends, meeting medical needs, doing household chores, doing church activities, and simply having solitude. In another study of VA respite care, Berman, Delaney, Gallagher, Atkins, and Graeber (1987) reported similar uses of time by caregivers. These researchers identified three categories of activities, (a) personal care, which included rest, vacations, and visiting others;
(b) patient care, which involved learning new caregiving skills; and (c) development of formal and informal support systems to help with caregiving. Berry et al. (1991) found that caregivers used home care and day care services more often to work, run errands, and perform chores and less often to engage in social and leisure activities. Employed caregivers usually rely on adult day services in order to retain their job-related responsibilities (Jarrott, Zarit, Parris Stephens, Townsend, & Greene, 2000; Levine, Reinhard, Feinberg, Albert, & Hart, 2004). Most investigators agree that respite allows caregivers to spend less time on stressful care responsibilities and provides increased opportunities to engage in other fulfilling activities, such as leisure, time alone, work (Jarrott et al., 2000), or socially connected activities (Chappell et al., 2001) that enhance support networks (Nicoll, Ashworth, McNally, & Newman, 2002), but none of them reported on the relationships between specific activities and caregiver outcomes. In a recent national study of more than 3,700 caregivers in Australia, however, respite was rated as the most important service for caregivers, and it was found that the single best way to improve caregivers’ well-being is to improve their satisfaction with leisure time (Cummins & Hughes, 2007).

We suggest that one of the most important missing pieces in respite research is an examination of the relationship between the caregiver’s specific uses of respite time and their well-being outcomes. Although she did not study caregivers, Seleen, (1982) found that older adults who had congruency between their actual and desired use of time had higher satisfaction with their time use and higher life satisfaction. With respect to family caregivers in this study (Lund et al., 2005), 46% of them said that they were only “somewhat” or “not very” satisfied with how they had used their respite time. Their qualitative comments indicated that many did not plan in advance for their respite time, nor were they successful in spending their respite time according to their plans. It is quite possible that this high degree of caregiver dissatisfaction with and inconsistent use of respite time might help explain why so many previous studies found little or no apparent benefits of respite care.

Specifically, we addressed the following research questions:

What activities do caregivers report as desired for their respite time, what do they actually do with their time, and what is the degree of consistency or inconsistency between their desired and actual use of time?

What are the relationships among caregivers’ consistency in desired and actual use of respite time, satisfaction with respite time use, and selected caregiver outcomes (i.e., dimensions of burden, depression, and satisfaction with caregiving)?
Method

Procedure

We focused this study exclusively on caregivers’ use of adult day respite because (a) it has been identified by caregivers and others as one of the most seriously needed caregiver services and likely to be one of the most widely available and used respite services in the future (Caserta et al., 1987; Gottlieb & Johnson, 2000; Kirk, 2002); (b) it provides opportunities to reduce negative impacts on families and caregivers by restructuring caregiving time (Gaugler, Jarrott, et al., 2003; Gottlieb & Johnson, 2000); (c) it provides relatively large segments of time, which allows for variability in the types of activities and amount of time spent on those activities during respite; and (d) it allows for a fairly regular (Zarit, et al., 1998) schedule of respite so that caregivers can engage in activities inside and outside the home.

After obtaining institutional review board approval from the University of Utah, we recruited caregivers from client lists of three adult day centers in two moderately sized cities (including the outlying rural areas) in the western United States. These facilities were selected because their administrators had participated in previous caregiver research and were known to be interested in helping with this project. The staff members at each facility reviewed their client files and identified caregivers who spoke English, had used their services for a minimum of 1 month, and were known to be the primary caregiver to someone age 50 or older. Being a primary caregiver meant that the caregiver performed the majority of caregiving tasks for the client and spent more time doing those tasks for the client than anyone else did (Lund, 1993). Caregivers first received a letter, then a follow-up phone call, inviting them to be part of the study. We confirmed eligibility with preliminary screening questions during the phone call. Of the 91 eligible caregivers contacted, 52 (57%) agreed to participate. The most common reasons for refusal were “too busy” ($n = 17$) or “not interested” ($n = 12$); six caregivers cited health problems as a reason not to participate. For those who agreed to participate, a trained interviewer made a home visit, completed the informed consent procedures, and then left with the caregiver a time-use form (time log) to keep track of the caregiver’s desired and actual use of respite time during the next week. The interviewer then scheduled a 90-min in-home interview with the caregiver 1 week later to obtain the time-use form and complete the questionnaire.
Respondent Characteristics

Women, with an average age of 58 years ($SD = 15.3$), constituted 77% ($n = 40$) of the respondents. More than half (56%) were providing care to a parent, and 36% were providing care to a spouse. The average age of the care recipient was 78.9 ($SD = 8.9$). Almost half (48%) were diagnosed with some type of dementia. Most caregivers were high school graduates (91%), were employed outside the home (53%), and would be considered middle class. They had been the primary caregiver for an average of 3.6 years ($SD = 2.9$) and had been using day care for an average of 1.8 years at almost 33 hr per week.

Other than their reported reasons for refusal, it is not known how the non-participants might differ from those who agreed. Caregivers’ reporting themselves too busy to participate in a study is a reasonable and common problem in gaining high participation rates. Our initial invitation emphasized that their participation would be helpful primarily to us and to future caregivers rather than to them because we offered no intervention service or financial incentive. Therefore, those who did participate might have greater altruistic motivations and more favorable views about research than those who declined.

Measures

In addition to demographic data, we obtained detailed information on how the caregivers used their respite time and how satisfied they were with their respite time, as well as standardized measures of caregiver burden, depression, and caregiving satisfaction.

Respite time use. First, caregivers reviewed a list of 23 activities and indicated the amount of time (to the nearest half hour) that they wanted to spend doing each one during their respite time in the upcoming week (7-day period). As the week progressed, caregivers kept track of their actual use of respite time for each of the 23 activities listed. When the interviewer visited again at the end of the week, interviewer and caregiver reviewed the time-use form and updated any incomplete or missing information. We used the caregivers’ time-log responses to provide a measure of total respite time for that week and to facilitate comparisons of desired and actual use of respite time. Most of the activities listed came from the Yesterday Interview (Moss & Lawton, 1982), an instrument that was originally used to document time use among elders in the community. Three activities on the original list (job hunting, running errands, and volunteer work) were dropped from the
analyses because they were not endorsed by any of the respondents as ways they spent or wanted to spend their respite time. Employment was also dropped because not all caregivers were employed, and among those who were not, only one endorsed employment as a desired activity during respite. Therefore, this article reports findings pertaining to the remaining 19 activities.

By comparing the desired versus actual time use for each activity, we calculated a consistency scale where a value of “1” was assigned to each activity in which the actual and desired time use were equal. These items were then summed to create an overall consistency score ranging from 0 to 19, with an alpha coefficient of .90. A score of zero indicates complete inconsistency between the desired and actual use of respite time, whereas a score of 19 indicates that a caregiver spent the exact amount of time he or she desired on each activity (perfect consistency).

**Respite satisfaction.** Caregivers were asked to rate their satisfaction with how they used their respite time (1 = not very, 2 = somewhat, and 3 = very satisfied). Three additional, open-ended questions provided qualitative information about their positive, negative, and ideal experiences with respite time use. These comments were used to identify explanations and examples that could clarify the statistical findings.

**Caregiver burden.** The Multidimensional Caregiver Burden Inventory (CBI) is a 24-item Likert-format scale that measures five dimensions of caregiver burden: time dependence, developmental, physical, social, and emotional burden (Novak & Guest, 1989). Each subscale ranges from 0 (low) to 20 (high). The CBI was selected over other possible measures because it provides a multidimensional assessment of burden. Acton and Kang (2001) conducted a meta-analysis on 27 intervention studies for caregivers and concluded that overall or total burden was too global an outcome measure and not sufficiently sensitive to detected intervention effects.

**Depression.** Depression was measured using the Center for Epidemiological Studies Depression scale (CES-D; Radloff, 1977). This is a 20-item Likert-format scale in which scores range from 20 (low) to 80 (high). Many caregiver studies use this scale as an outcome indicator (Schulz et al., 2003).

**Satisfaction.** Satisfaction with caregiving was measured by a subscale of the Caregiving Appraisal Instrument developed by Lawton, Kleban, et al. (1989). This scale, ranging from 9 (low) to 45 (high), consists of nine
Likert-type items that measure the positive aspects of caregiving. It is important to include assessments of potentially positive caregiver outcomes in studies of caregiving so that there is a broad range of effects.

**Analysis**

The analyses were done in three steps. First, we made a frequency distribution for each of the 19 respite activities so that we could identify which ones were most commonly desired and accomplished and also note the amount of time that caregivers wanted to spend and actually spent on each activity. The second step focused on examining the relationships that degree of consistency in respite time use and satisfaction with time use had with the selected caregiver outcomes (e.g., depression, burden measures, and satisfaction with caregiving). These analyses included correlations and t tests, with the consistency in and satisfaction with respite time use dichotomized into high and low categories. The third step examined differences on outcome measures among groups formed by combinations of low or high time-use satisfaction and low or high consistency in respite time use. We wanted to know whether consistency in time use (i.e., desired vs. actual time use) interacts with satisfaction with time use to indicate desirable caregiver outcomes. Or is it possible that simply being consistent with the use of respite time will be associated with more-favorable outcomes without caregivers actually feeling satisfied with how they had spent their time? This is an important assessment because it could affect how we intervene in the future to help caregivers. Should we focus primarily on helping caregivers make certain that they do as intended with their respite time, or do we also need to help them feel satisfied with their respite activities? In these analyses we combined the two independent variables (consistency in time use and satisfaction with time use) into four categories, ranging from low consistency and low satisfaction to high consistency and high satisfaction. We then compared the outcome measures of the caregivers in each of the four categories using mean scores, percentages when appropriate, and ANOVA analyses. During the third step, we also added to the analyses the caregiver’s age, gender, employment status, duration of caregiving, and amount of respite time to see what impact or associations they might have on the caregiver outcomes. Collectively, these analyses led to several clear and specific recommendations for helping caregivers make more effective use of their respite time.
Results

The first research question explores whether caregivers used their respite time to do the activities they had wanted to do. As shown in Table 1, caregivers engaged in a wide variety of activities during respite time, including attending to personal needs, taking care of the house, and spending time with friends and family. The three most-desired activities included time with family, housework, and rest and relaxation. On average, caregivers wanted to spend 2 to 3 of their respite hours per week on each of these three activities ($M = 3.0, 2.4, \text{and } 2.0 \text{ hr, respectively}$). Similarly, the top-two actual activities included time with family and doing housework, with caregivers spending approximately 3 hr of their respite time each week visiting with family members and nearly 3.5 hr doing housework.

The data presented in the right-hand three columns of Table 1 show that the caregivers were moderately successful in doing the types and amounts of activities they had wanted to do during their weekly respite time. The mean score on the consistency scale was 13.7 ($SD = 4.9$), indicating that the caregivers spent on average the same amount of time they had desired in nearly 14 of the 19 activities assessed on the time log. Although consistency was fairly high across the sample, the degree of inconsistency between desired and actual time use was noteworthy. For example, one third of the caregivers spent more time doing housework than they had wanted. Similarly, we found that 25%, 38%, and 27% of caregivers spent more time cooking, eating, and shopping, respectively, than they had wanted to during their respite time. Two different caregiving daughters made comments that illustrate their disappointment. One of them said, “I am somewhat annoyed with having to spend so much time on housework.” The other one reported, “It is my only time to do errands, and I’m satisfied to do these, but I want more time to spend at home alone.”

Conversely, some caregivers spent less respite time than they had wanted doing potentially restorative activities such as resting or exercising or diversionary activities such as listening to the radio or visiting friends and family. For example, approximately one in three caregivers (29%) reported spending less respite time reading or writing than they had wanted, and nearly one in four (23%) spent less time with friends. One daughter said, “I need to organize my time better to do hobbies,” whereas a wife who lived in a rural setting said, “I would love to take my horse for a long exhausting ride and not worry about what might go wrong.”
Overall, these data suggest that (a) the types of activities that caregivers desired and actually performed during respite were quite diverse, (b) there was a moderate amount of consistency in desired and actual time use, and (c) the inconsistency between desired and actual time use varied across activities considered restorative, diversionary, and even potentially enjoyable versus those activities necessary for daily household function or personal care.

Table 1
Description of and Consistency Between Desired and Actual Respite Time Use

<table>
<thead>
<tr>
<th>Activities and Consistency</th>
<th>Desired Time Use (hr)</th>
<th>Actual Time Use (hr)</th>
<th>% Whose Actual Time-Use Was</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$ ($SD$)</td>
<td>$M$ ($SD$)</td>
<td>Less Than</td>
</tr>
<tr>
<td>Respite activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Time with family</td>
<td>3.0 (5.8)</td>
<td>3.1 (6.2)</td>
<td>17</td>
</tr>
<tr>
<td>2. Housework</td>
<td>2.4 (4.0)</td>
<td>3.3 (3.6)</td>
<td>17</td>
</tr>
<tr>
<td>3. Rest and relaxation</td>
<td>2.0 (4.8)</td>
<td>1.3 (3.2)</td>
<td>20</td>
</tr>
<tr>
<td>4. Read or write</td>
<td>1.8 (2.5)</td>
<td>2.1 (4.4)</td>
<td>29</td>
</tr>
<tr>
<td>5. Help others</td>
<td>1.7 (3.3)</td>
<td>1.7 (3.5)</td>
<td>15</td>
</tr>
<tr>
<td>6. Watch TV</td>
<td>1.6 (3.5)</td>
<td>1.8 (4.0)</td>
<td>4</td>
</tr>
<tr>
<td>7. Sleep or nap</td>
<td>1.5 (6.2)</td>
<td>0.7 (1.6)</td>
<td>10</td>
</tr>
<tr>
<td>8. Cook</td>
<td>1.5 (2.2)</td>
<td>1.8 (2.2)</td>
<td>13</td>
</tr>
<tr>
<td>9. Eat</td>
<td>1.4 (1.9)</td>
<td>1.8 (1.8)</td>
<td>13</td>
</tr>
<tr>
<td>10. Shop</td>
<td>1.4 (2.2)</td>
<td>1.6 (1.8)</td>
<td>15</td>
</tr>
<tr>
<td>11. Time with friends</td>
<td>1.2 (1.9)</td>
<td>0.7 (1.3)</td>
<td>23</td>
</tr>
<tr>
<td>12. Hobby</td>
<td>0.9 (2.4)</td>
<td>0.5 (1.5)</td>
<td>15</td>
</tr>
<tr>
<td>13. Exercise</td>
<td>0.8 (2.0)</td>
<td>0.8 (2.0)</td>
<td>13</td>
</tr>
<tr>
<td>14. Personal or medical care</td>
<td>0.7 (1.3)</td>
<td>1.0 (1.6)</td>
<td>10</td>
</tr>
<tr>
<td>15. Listen to radio</td>
<td>0.6 (1.3)</td>
<td>0.6 (1.0)</td>
<td>8</td>
</tr>
<tr>
<td>16. Religious activity</td>
<td>0.5 (1.3)</td>
<td>0.4 (1.1)</td>
<td>6</td>
</tr>
<tr>
<td>17. Travel</td>
<td>0.5 (1.1)</td>
<td>0.6 (1.2)</td>
<td>4</td>
</tr>
<tr>
<td>18. Recreation</td>
<td>0.4 (1.1)</td>
<td>0.3 (1.0)</td>
<td>10</td>
</tr>
<tr>
<td>19. Attend support group</td>
<td>0.2 (0.7)</td>
<td>0.1 (0.4)</td>
<td>8</td>
</tr>
</tbody>
</table>

Consistency scale: $M = 13.7; SD = 4.9; range = 0-19

Note: $N = 48$ for these analyses because of missing data. The consistency scale measures whether caregivers used their respite time doing the types and amount of activity they desired (i.e., actual time use = desired time use). A value of 0 indicates that someone did not spend the desired amount of time in any of the 19 activity domains; a value of 19 means that someone spent exactly the amount of time they desired in all 19 activity domains. Thus, higher scores represent higher levels of consistency between desired and actual respite time use.

Overall, these data suggest that (a) the types of activities that caregivers desired and actually performed during respite were quite diverse, (b) there was a moderate amount of consistency in desired and actual time use, and (c) the inconsistency between desired and actual time use varied across activities considered restorative, diversionary, and even potentially enjoyable versus those activities necessary for daily household function or personal care.
<table>
<thead>
<tr>
<th>Caregiver-Related Outcomes</th>
<th>Respite Satisfaction</th>
<th>Consistency in Time Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving satisfaction (9-45)</td>
<td>33.3 (4.5)</td>
<td>36.1 (6.7)</td>
</tr>
<tr>
<td>Depression (20-80)</td>
<td>35.7 (9.3)</td>
<td>27.3 (7.7)</td>
</tr>
<tr>
<td>Time dependence burden (0-20)</td>
<td>15.7 (3.0)</td>
<td>13.9 (5.1)</td>
</tr>
<tr>
<td>Developmental burden (0-20)</td>
<td>12.4 (4.3)</td>
<td>8.9 (5.5)</td>
</tr>
<tr>
<td>Physical burden (0-20)</td>
<td>8.8 (4.7)</td>
<td>7.2 (5.5)</td>
</tr>
<tr>
<td>Social burden (0-20)</td>
<td>5.9 (5.3)</td>
<td>5.5 (5.8)</td>
</tr>
<tr>
<td>Emotional burden (0-20)</td>
<td>4.8 (2.6)</td>
<td>4.2 (4.0)</td>
</tr>
<tr>
<td>Consistency in respite time use (0-19)</td>
<td>12.7 (4.7)</td>
<td>14.5 (4.8)</td>
</tr>
<tr>
<td>Very satisfied with respite time use (yes)</td>
<td>43%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Note: The sample size varied from 44 to 48 in these analyses because of missing data; t tests were used to determine statistical mean differences between those who report being “very” versus “not very” satisfied with respite time use, and those who had “higher” (above median) versus “lower” (below median) consistency in respite time-use. Zero-order correlation was used to test the association between the consistency scale and other caregiver-related outcome scales.

*p < .10, *p < .05, **p < .01.
Our second research question asked whether this degree of consistency or inconsistency is associated with caregivers’ well-being and satisfaction with respite. In other words, if caregivers do not do the type of activity they wanted to do during respite, are they more likely to report dissatisfaction with how they used their respite time? Does this lack of consistency between desired and actual time use influence caregiver-related outcomes such as depression and dimensions of burden, as well as satisfaction with caregiving? The data presented in Tables 2 and 3 provide some answers to these questions.

As already mentioned, nearly half (46%) of the caregivers reported that they were only somewhat or not very satisfied with how they used their

### Table 3

The Interaction Between Respite Satisfaction and Consistency in Respite Time Use: Demographic Profile and Relationship With Caregiver-Related Outcomes

<table>
<thead>
<tr>
<th>Respite Satisfaction Versus Consistency in Time Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Demographics and Outcome Measures</td>
</tr>
<tr>
<td>Demographic profile</td>
</tr>
<tr>
<td>% of sample</td>
</tr>
<tr>
<td>Average age</td>
</tr>
<tr>
<td>Female (%)</td>
</tr>
<tr>
<td>Use respite for employment (%)</td>
</tr>
<tr>
<td>Average duration of caregiving (in months)</td>
</tr>
<tr>
<td>Average amount of respite (in days per week)</td>
</tr>
<tr>
<td>Caregiver-related outcomes</td>
</tr>
<tr>
<td>Caregiving satisfaction (9-45)</td>
</tr>
<tr>
<td>Depression (20-80)</td>
</tr>
<tr>
<td>Time dependence burden (0-20)</td>
</tr>
<tr>
<td>Developmental burden (0-20)</td>
</tr>
<tr>
<td>Physical burden (0-20)</td>
</tr>
<tr>
<td>Social burden (0-20)</td>
</tr>
<tr>
<td>Emotional burden (0-20)</td>
</tr>
</tbody>
</table>

Note: N = 48 for these analyses because of missing data.

a. Categories that are different (p < .05) with Bonferroni and Scheffe post hoc tests.

**p < .01.
respite time (Lund et al., 2005). Surprisingly, this dissatisfaction was not dependent on how long they had been a caregiver ($r = .12$, n.s.) or on the amount of respite time they received ($r = .10$, n.s.). However, as expected, respite satisfaction was strongly associated with how consistent they were in doing the types of activities they wanted during respite time. The average consistency score for the persons who were very satisfied with how they spent their respite time was 14.5 ($SD = 4.8$), compared with 12.7 ($SD = 4.7$) for the not very satisfied group. Similarly, 43% of the caregivers who had lower consistency values (as measured by being below the median on the consistency scale) were not very satisfied with respite time use, whereas 67% of the high-consistency group (as measured by being above the median on the consistency scale) were very satisfied with how they spent their respite time.

The following statements from caregivers who were consistent in doing as they desired help explain why they might have higher satisfaction with their respite time. A husband said, “I get done all that I need to do.” A son indicated, “No waste of time. I did what I wanted to do most.” And, a wife described one of her respite breaks by saying, “I was able to go to the store and find a few books by my favorite author. I am an avid reader. I was alone, with no one looking over my shoulder. I was able to take all the time I wanted. I had a great time going through those books. Having time to read means a lot to me.” At the other end of the continuum were two caregivers who were not able to do as they wanted with their respite time and indicated that they were not very satisfied with their respite activities. A daughter-in-law said, “We all get along OK on what time we have, but I could use more time alone with my children.” A wife simply said, “I could improve on it. For now I am hanging on.”

As expected, our data show that caregiver-related outcomes, especially depression, were associated with both (a) how satisfied the caregivers were with how they spent their respite time and (b) how consistent they were in doing the types and amount of activities they desired to do during respite. Caregivers who were very satisfied with their respite time had significantly lower depression scores than those who were not very satisfied with how they spent their respite time ($M = 27.3$ and 35.7, respectively, $p < .01$). Likewise, those who did the types and amount of activities they desired during respite (i.e., the high-consistency group) had lower depression scores compared to those who were not as consistent in their time use during respite ($M = 27.3$ and 35.0, respectively, $p < .01$). The measure of caregiving satisfaction and the five subscales of the CBI showed similar associations in the expected direction, although not significant given the small sample size.
Table 3 further explores the relationship between respite consistency, respite satisfaction, and caregiver-related outcomes by creating a four-category typology of caregivers: those who were not very satisfied and had low consistency (least desirable situation), those who were very satisfied but had low consistency, those who were not very satisfied but had high consistency, and those who were both very satisfied and had high consistency (most favorable situation). Again, as expected, depression scores were lowest among those in the most favorable situation (i.e., high consistency and high satisfaction with respite time), and depression was highest among those with lower consistency and lower satisfaction with respite time ($M = 25.4$ and $38.5$, respectively, $p < .01$).

Table 3 also presents a comparison of the demographic characteristics among those in each of the four categories of high and low levels of respite consistency and respite satisfaction. We did not find any statistically significant findings regarding caregivers’ age or gender. However, caregivers who used respite to work were significantly more likely to report satisfaction with their respite time. Nationally, it is estimated that 59% of family caregivers are employed (National Alliance for Caregiving & AARP, 2004). The employed caregivers in our study also were more likely to exhibit higher levels of consistency in their respite activities. As expected, the 25 caregivers who were employed (48% of the sample) had fewer opportunities to use their respite time for activities other than paid employment. Additional analyses are planned to further examine the role of employment in how respite time is spent and caregiver outcomes.

Conclusions and Discussion

Several limitations of this study should be noted. First, the sample is relatively small and homogeneous in terms of socioeconomic status and race and ethnicity. Second, we included only primary caregivers to adults age 50 and older. Third, we focused exclusively on those who used adult day services for respite, and we did not examine caregivers who use other forms of formal and informal respite. Fourth, we only assessed 1 week of respite activities and were unable to capture the dynamic aspects of caregiving circumstances and experiences. Fifth, we do not know how the study participants differ from those who declined to participate. Because of these limitations, caution is warranted in making generalizations to the millions of family and informal caregivers who have widely varied characteristics and circumstances.
While recognizing these limitations, we believe that our findings still provide justification for paying greater attention to caregivers’ activities during their respite time and how specific activities relate to caregiver outcomes. Our findings can be useful in identifying some promising ways to make respite services more effective for family caregivers.

First, caregivers reported a wide range of desired activities to pursue during their respite time. They identified 19 categories of desired activities, with nearly all the caregivers reporting that they wanted to do several of them. The most-desired activity was spending time with family, followed by doing housework and then resting and relaxing. These three activities obviously cover a wide range of preferences, including solitary time for rest or necessary household chores and social time to be shared with friends and family. Therefore, we should not assume that any one specific activity is the most important for all caregivers because their own unique circumstances, resources, and needs are likely to vary (Gaugler, Jarrott, et al., 2003; Gaugler et al., 2007; Guberman, 2006). Our data also showed that examining only a caregiver’s desired respite activities is not sufficient because caregivers are not equally effective in actually doing the things that they desired.

Our second and third conclusions pertain to the 46% of the caregivers who were only somewhat or not very satisfied with how they had spent their respite time. This is perhaps best explained by the inconsistencies that some caregivers experience when they are not able to do what they desired during their respite time. Second, those who had the greatest degree of inconsistency in desired and actual use of time were also more likely to be the ones who were most dissatisfied with how their time was spent. Both the quantitative and qualitative data in our study support this conclusion. Third, those who were the most inconsistent and also experienced the most dissatisfaction with their use of respite time were significantly more depressed, somewhat less satisfied with caregiving, and more negatively affected in each of the five dimensions of burden. These results are somewhat similar to the findings reported many years ago by Seleen (1982), when she found that older adults had higher overall life satisfaction when they had greater congruence between their desired and actual use of time. Regarding the association between depression and lower satisfaction with respite time, it is important to note that it is also possible that those who are depressed to begin with may be less able to optimize their respite time. In other words, the relationship could be reciprocal in nature.

Given these results, we believe that it is important not only to find ways to help caregivers identify more satisfying respite activities but also to help them become more successful in actually doing those satisfying activities.
during their available respite time. If our interventions can accomplish both these goals, we may have better opportunities to improve their well-being (e.g., through lower depression, lower caregiver burden, and greater satisfaction with caregiving). Therefore, we suggest that providers and researchers should offer assistance to respite users to (a) assess their situations, resources, and needs (Guberman, 2006; Zarit, 2006); (b) determine what types and amounts of respite activities might be most beneficial to them given their preferences and areas in which their lives are being most negatively affected by caregiving; (c) set specific goals for how to use their upcoming respite time; (d) develop a plan to make their goals achievable so that obstacles are minimized and desired activities are realistic and likely to occur; (e) evaluate the effectiveness of the outcomes in terms of enjoyment, satisfaction, and other indicators of well-being; and (f) make goal setting and evaluation ongoing activities to adjust to the dynamic nature of caregivers’ changing life circumstances, needs, and preferences. We believe that these six features are essential to making respite time and respite services more effective. Rather than focusing our efforts on increasing the numbers and percentages of caregivers who use respite, we ought to first improve the effectiveness of respite so that caregivers who choose to use the service will have a much greater likelihood that it will enhance their daily lives. We believe that many caregivers could benefit from recognizing that respite provides a unique opportunity but that the potential benefits may not occur without careful assessment and plans to use their time wisely.

Some caregivers may need assistance with broadly assessing their situations and needs so that they carefully identify respite activities that are likely to maximize their benefits. We believe that “continuity theory” may be useful to help guide caregivers as they consider worthwhile activities for their respite time. According to continuity theory (Atchley, 1989, 1999), most people find satisfaction in being able to maintain specific personal traits, interests, and activities throughout their life course. Caregiving tasks and responsibilities can easily become obstacles to doing so. A national survey of family caregivers found that 51% of them had given up time for family and friends; 44% gave up vacations, hobbies, and social activities; and 26% were exercising less than before they became caregivers (National Alliance for Caregiving & AARP, 2004). If caregivers are experiencing considerable stress from the disruption of desired continuity in specific aspects of their lives and identities, then their respite time is perhaps one of the single best opportunities for reestablishing continuity. Therefore, when caregivers are selecting respite activities, continuity theory may encourage them to use their respite time to do things they always enjoyed, especially those activities they did prior to becoming a caregiver.
We suggest that consultants, facilitators, or existing respite staff could be trained to help make respite service much more individualized and effective. In addition to helping caregivers identify activities they sacrificed to become caregivers, the facilitators could also help assess specific types of burden that are most problematic for individual caregivers and then help identify goals to alleviate specific difficulties. For example, if a caregiver has a high social burden score, he or she might be encouraged to set a goal to engage in a specific activity with a friend or relative, whereas another caregiver experiencing high physical burden might want to set goals to obtain more rest, exercise, and an improved diet during respite time.

Future research should continue to place an emphasis on theoretically based interventions (Pillemer, Suitor, & Wethington, 2003) and longitudinal designs that are tailored to the individual needs of each caregiver (Beauchamp et al., 2005; Dal Santo et al., 2007). We suggest that this individual focus include assessments of specific subtypes of burden rather than viewing burden as a unidimensional outcome. Interventions can and should be tailored to address the specific types of burden unique to each caregiver. Also needed are studies that assess diverse forms of formal and informal respite services. Future research also needs to include more diverse populations and provide appropriate cultural sensitivity to ethnic and racial differences among caregivers (Belle et al., 2006; Dilworth-Anderson et al., 2002; Mahoney et al., 2005). And finally, we strongly agree with Pillemer et al. (2003) that future intervention research for caregivers be done in collaboration with clinicians, practitioners, and community partners so that we have more-creative designs and better translational research. In short, if we want to make one of the most needed and wanted services for caregivers, namely respite, more effective, there is considerable promise in better understanding the important role that caregivers’ use of respite time most likely plays in the process.

References


Dale A. Lund, PhD, is a professor of gerontology and sociology in the University of Utah Gerontology Interdisciplinary Program and Center on Aging and serves as the associate director for research, Hartford Center for Geriatric Nursing Excellence, College of Nursing. His research has examined the longitudinal coping processes and interventions for older adults experiencing later life transitions, particularly family and informal caregiving, spousal bereavement, and widowhood. He is a past president of the Utah Chapter of the Alzheimer’s Association, recipient of the outstanding researcher award from the international Association for Death Education and Counseling, and the book series editor for *Death, Value and Meaning* for Baywood Publishing.

Rebecca Utz, PhD, is an assistant professor in the Department of Sociology and a faculty associate with the Center on Aging at the University of Utah, where she teaches courses in research methods, epidemiology, and medical sociology. She has published in the areas of bereavement, aging families, and obesity.

Michael S. Caserta, PhD, is a professor in the University of Utah Gerontology Interdisciplinary Program and Center on Aging, where he teaches courses in research design and health promotion and coordinates the student practicum experiences. He has published widely in the areas of spousal bereavement, family caregiving, and health promotion and self-care. He is a fellow of the Gerontological Society of America and is a founding member of the Utah Gerontological Society, serving as its president in 2000.

Scott D. Wright, PhD, is associate professor and director of the University of Utah Gerontology Interdisciplinary Program and faculty associate with the Center on Aging. He is a fellow of the Association of Gerontology in Higher Education and has research interests in caregiving and respite and environmental impact, environmental vulnerability, and risk in aging populations using geographic information system mapping and analysis. He is also actively involved in technological delivery systems for curriculum materials related to aging.