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Impact of Non-caregiving Related Stressors on Informal Caregiver Outcomes

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Abstract

Background—Caregivers of persons with dementia are stressed. Stressors not related to care recipients' needs impact caregiver outcomes, yet are seldom reported.

Methods—31 caregivers completed the Most Stressful Event form, Patient Health Questionnaire (PHQ-9) and the Revised Memory Behavioral Problem Checklist (R-MBPC). Fisher's exact test and two-sample t-test were used to compare Most Stressful Events between caregivers. ANOVA model tested whether the PHQ-9 and R-MBPC subscales differed by stressor.

Results—Caregivers reported no stressors 21.5%, 1–2 stressors 25%, and 3 stressors 53% of the time with 318 stressors total. Care recipient needs (30.2%), caregiver needs (26.7%), and decision-

making (16.7%) were the most frequently reported stressors. Using a mixed effects model, there were associations between Most Stressful Events and depression ($p=0.016$), mobility ($p=0.024$) and caregiver issues ($p=0.009$) subscales of R-MBPC.

Conclusion—Results can be used to develop intervention and support strategies for caregivers experiencing non-caregiving related stressors.

1. Introduction

The fact that family caregivers of persons with dementia and Alzheimer disease (AD) are stressed, burdened, and suffer high levels of depression compared with the general population has been well documented (1–3). Caregiving stress and burden have been shown to be related to the care recipient's functional characteristics (e.g., need for assistance with personal care like bathing, toileting), severity of their cognitive, behavioral or psychological symptoms (e.g., agitation, aggressive behavior), and level of depression (2). Additionally, stressors not related to directly to the care recipient's needs will also impact caregiver stress, yet these are seldom addressed, measured, or reported in the literature (4, 5).

Research assessing caregiver stress and burden has become more advanced. For example, we now know that caregivers' appraisal of the stress may be more important than objective measures of stress *per se* (6–8). Yet, methods of assessing caregiver stress tend to vary across studies and in most studies it is difficult to determine when caregivers are asked about issues of concern and if those issues change over time (8–10). Because a key feature of AD is the progressive nature of the disease, stressors can and do change and fluctuate over time, thus the timing of assessing caregiver stress may also impact the outcome. For example, what a caregiver finds stressful one day may not be what is most stressful the next day or week.

In order to examine the challenges that caregivers faced, as part of a clinical trial studying the impact of collaborative care for older adults with AD (11), we asked family caregivers participating in the psychosocial educational support group the open-ended question, *What are the three most stressful things in your life right now* as a measure of their current stressor(s). Caregivers were asked to respond to this question each time they attended the psychosocial educational support group meeting and met with the advanced practice nurse (APN). The purpose of this study was threefold:

1. To explore the most stressful events reported by intervention caregivers over a 6-month period;
2. To examine the association between the caregivers' most stressful event reported and their depressive symptoms, as measured by the Patient Health Questionnaire (PHQ-9) and the care recipient's memory and behavioral problems as measured by the Revised Memory and Behavioral Problems Checklist (R-MBPC); and
3. To examine the impact of direct caregiving stressors and non-direct caregiving stressors on caregiver's depressive symptoms (PHQ-9) and care recipient's R-MBPC scores.

2. Methods

The data for this paper were collected from caregivers participating in the monthly psychosocial educational support group meetings in the NIH-supported Collaborative Dementia Care trial which has been described in detail elsewhere (11, 12). Briefly, the intervention group received one year of care management by an interdisciplinary team led by an advanced practice nurse (APN) working with the care recipient's family caregiver and integrated within primary care. All intervention care recipients and their caregivers were also invited to participate in voluntary monthly support group sessions. During these sessions, caregivers participated in a psychosocial educational support session led by MGA that focused on education about AD and dementia, common caregiving stressors, including aspects of care that most caregivers report as stressful based on the literature and clinical experience. Caregivers were welcome to bring their care recipient with them to the support group. Following welcome and introductions, persons with dementia were taken to a nearby room for a chair based exercise class led by a health psychologist and the APN (11).

2.1. Study population

There were a total of 153 dyads of care recipients and caregivers, 84 of these dyads were in the intervention arm in of the trial. It became clear during the support group sessions that caregivers experienced a wide range of stressful events, many of which had little to do with direct care recipient issues. Indeed, some caregivers reported such complex social situations that those stressors appeared to be more challenging than issues related to directly to the care recipient.

2.2. Procedures

Following every psychosocial educational support group meeting and during face-to-face contacts, the APN asked the caregivers to complete the following measures:

Patient Health Questionnaire 9 [PHQ-9] is a nine item self report measure that was used as measure of severity of caregiver depression (13).

Revised Memory and Behavioral Problems Checklist [R-MBPC] is a 24-item, caregiver-report measure and a standard reliable measure of the frequency of cognitive, functional, behavioral and psychological symptoms of the person with AD as well as a measure of the caregiver's reaction to such symptoms (14). It is an overall assessment of specific types of behavior problems including memory, depression, and disruption subscales. The scores of the R-MBPC are computed for the presence/absence of each problem first, and then for caregiver "reaction" or the extent to which caregivers were "bothered" or "distressed" by each behavior. Reactions are assessed by asking how "upsetting" the behavior was on a Likert scale of 0 to 4. The R-MBPC has been widely used in various ethnic groups and demonstrated good reliability (with alpha of .84 for care recipient's behavior and .90 for caregiver reaction) and validity (14).

Most Stressful Events—This was measured by asking caregivers to record, in writing, their responses to the open-ended question, *What are the three most stressful things in your life right now?* The item was asked by the APN at each visit. This item was introduced

midway through the PREVENT study. A total of 318 stressors were reported from the 144 APN visits. The stressors were analyzed using qualitative content analyses (15, 16). Initially, MGA and YL worked independently to code selected session summaries and combined the findings for a preliminary list of categories, which were then entered into a database. MGA and YL met to review a few items where there was disagreement in coding. Inter-rater reliability was approximately 95%. The major discrepancy was how to code “caregiver needs”, for example “*having the hand brace and not being able to do what I need to do*” as it was not very clear whether the caregiver’s stressor was associated either directly or non-directly with care recipient’s needs, however, we decided this stressor was most likely impacting the caregiving role and therefore categorized as indirectly related to caregiving. Once MGC and YL reached consensus, the database was reviewed by MGA and HCH and based on similarities of content, the stressors were initially grouped into 9 detailed categories and then further combined to form 4 major categories: *direct caregiving stressors care, indirect caregiving stressors, non-caregiving stressors* and *no stressors* for analysis.

Direct caregiving stressors included typical care recipient issues such as:

- Dealing with behavioral symptoms—agitation and repetitive behaviors worsening, hallucinations
- Concerns about finances, e.g., care recipient recently sold stock without telling her
- Constantly having to monitor everything
- Having to repeat everything constantly
- Breaking partial dental plate
- care recipient went to jail recently
- Dealing with care recipient’s sleep problems, other health issues

The indirect caregiving stressors included issues that caused the caregiver concern, were related to caregiving, but did not include direct hands on care:

- Decision making related to care such as selecting appropriate long-term care facility, e.g., deciding when and where to move
- Emotional issues related to care, e.g., fear of losing care recipient after 62 years together
- Family relationships are strained, e.g., children are not visiting; difficult to get the family to agree on issues that need to get done
- Role transition process, e.g., being responsible for everything, doing all the driving, having to get the care repaired

Of particular interest to us was the impact that *non-caregiving stressors* might have on the caregiver’s symptoms of depression, anxiety and physical health. Typical examples of *non-caregiving stressors* included:

- Caregiver’s feelings of stress trying to manage his small business

- Other family member's health issues, e.g., daughter was diagnosed with cancer and was under treatment
- Other family member's financial and marital stress, e.g., daughter was going through a divorce
- Conflicted relationship with adult step children
- Financial concerns related to health care payments and reimbursement issues for their own health care
- Granddaughter's upcoming wedding and caregiver was asked to bake the wedding cake
- Concern about grandson's problems and legal issues, e.g., grandson currently in prison.

While caregivers were not asked to rank order the three stressors in terms of severity, for this study, we used the caregiver's first recorded stressor as the Most Stressful Event in our analyses.

2.3. Statistical Analyses

Fisher's exact test and two-sample t-tests were used to compare whether intervention spouse caregivers who completed the Most Stressful Events form were different than caregivers who never completed the form. We used an ANOVA model to test whether the PHQ-9 and subscales of the R-MBPC differed by the type of primary stressor noted. Since caregivers had multiple visits, we used a mixed effects model with a random effect model for the caregiver to account for with-in caregiver correlations. Due to the skewness of some of the scales, we performed additional analyses transforming the scales by using the log (scale+1). Since results were similar between the original scales and the transformed scales, we only report results for original scales.

3. Results

Caregiver and Care Recipient Demographics

Descriptive caregiver and care recipient demographics are included in Table 1. As indicated in Table 1, there were some significant differences between the caregivers completing the MSE form and those who did not. Caregivers completing the MSE form were on average 68.5 years old, more likely to be a spouse (80%), and had completed more years of education (13.1 years vs. 11.6 years, $p < .05$) than those caregivers not completing the MSE form. The non-attendees were more likely to be adult child caregivers and unable to attend support group meetings due to jobs and family commitments. Thus, this group of subjects is most representative of spouse caregivers of persons with dementia and AD.

There were 31 dyads that attended the intervention support group where they were administered the Most Stressful Event (MSE) form. They averaged 4.6 visits (± 3.4 visits) where they completed the MSE form and were followed for an average of 5.3 months (± 3.4 months) and a total of 144 visits. Comparison of dyads who completed the MSE form and those that did not is presented in Table 1. Caregivers completing the MSE form were on

average 68.5 years old, more likely to be a spouse (80%), and had completed more years of education (13.1 years vs. 11.6 years, $p < .05$) than those caregivers not completing the MSE form. The care recipients of the caregivers completing the MSE form were more likely to be male, white, older, and also have more years of education.

Caregivers' Most Stressful Events

Table 2 summarizes the percentage of all stressful events reported, divided into the Major and Detailed Categories, the percentage reported as the Most Stressful Event, percentage of visits where stressors were reported, regardless of order, and the percentage of visits where caregivers reported any stressor. Of the 144 visits, caregivers reported no stressors 21.5% of the time, 1 or 2 stressors 25%, and 3 stressors 53% of the time for a total of 318 stressors. For the Major Categories, direct caregiving stressors is reported most often by caregivers when using all stressors (36.5%) as the denominator and when using only the Most Stressful Event (36.1%). A majority (77.5%) of caregivers report one of the three major categories at some time in the study. For the Detailed Categories, care recipient needs (30.2%), caregiver needs (26.7%), and decision-making (16.7%) were the most frequently reported stressors. Approximately three quarters (77.5%) of caregivers reported these three categories of stressor at some point in the study. Caregivers were likely to cite different most stressful events over time. Only 10 caregivers cited the same major category as the primary stressor at all visits. Ten cited 2 different categories, 10 cited 3 different categories, and 1 caregiver cited stressors across all 4 categories at different visits.

Association between caregivers' most stressful event, depressive symptoms and the care recipient's memory and behavioral problems

In Table 3, the mean scores on the subscales of R-MBPC are compared to the caregivers' response to the overall category of the Most Stressful Event. For all subscales, there were significant differences across the 4 primary stressor categories with the exception of sleep disturbance and repetitive behavior, when using an ANOVA model. Generally, those caregivers reporting direct-patient related concerns had higher R-MBPC than those reporting other stressors. Using a mixed model to account for repeated visits by the dyads, only the patient mobility and caregiver issues subscales of the R-MBPC are significantly higher for visits where the Most Stressful Event is a direct patient-related care issue. PHQ-9 scores were also higher for caregivers reporting direct patient-related care as the Most Stressful Event but did not reach significance. When we collapsed the major categories into two categories (direct caregiving stressors ($n=52$) vs. other stressors ($n=92$)), results were similar with one exception. PHQ-9 was significantly higher ($p=0.034$) for direct caregiving stressors (*Mean 3.8 SD 3.8*) than those with other stressors (*Mean 2.5, SD 3.1*).

Impact of direct caregiving stressors and non-direct caregiving stressors on caregivers' depressive symptoms and care recipient's memory and behavior problems

Of those 52 visits where direct caregiving stressors were cited as the Most Stressful Events, specific issues included were care recipient needs ($n=39$), decision-making ($n=11$), and safety needs ($n=2$). To investigate whether care recipient needs ($n=39$) was the sole reason for differences observed above, we compared care recipient needs versus all other stressors. As seen in Table 4, the T-test results indicate 4 of the R-MPBC subscales including

depression, aggression, mobility, and caregiver issues were significantly higher when the Most Stressful Event was a direct caregiving issue. When analyses were computed using a mixed-model to account for repeated data within caregivers, only the depression, mobility and the caregiver issues subscales were significant.

4. Discussion

In this study using qualitative methods to identify the most stressful events, we found that caregivers of persons with dementia and AD reported many types of stressors, including both direct caregiving stressors and non-caregiving stressors. Four categories of stressors were identified: *direct caregiving stressors care*, *indirect caregiving stressors*, *non-caregiving stressors* and *no stressors*.

Non-caregiving stressors were almost as common as direct caregiving ones. These included dealing with concerns over other members of the family, such as adult children's health issues and marital distress and concerns about grandchildren's wellbeing. Similar results have been reported by others (17, 18). Reported stressful events also differed over time supporting our premise that stressful events do change and fluctuate constantly.

Approximately one third of the caregivers cited the same type of issue as the most stressful event at all visits; another third of the caregivers cited 2 different types of issues, and the remaining third of the sample cited 3 different issues over time. One caregiver cited stressors in all four major categories at different times. It is important therefore that clinicians, service providers and support group leaders be aware of the wide range of possible stressors that caregivers may be dealing with. It is likely that given the context of support groups for caregivers of persons with AD and dementia, unless asked directly about any and all stressors, caregivers may not offer this information freely.

Nevertheless our findings also demonstrated that direct caregiving stressors remained the most commonly cited stressor for the caregivers in this study. Of the 144 visits and the 318 stressors reported, direct caregiving stressors were reported most often by caregivers (36.5%), with care recipient needs (30.2%), caregiver needs (26.7%), and decision-making (16.7%) as the most frequently reported stressors. Similarly, our data also confirmed previous findings that addressing direct caregiving stressors, in at least three areas, is essential to caregiver education: providing care in general, dealing with the care recipient's behavioral symptoms, and providing assistance for activities of daily living (ADLs) (18, 19). Educating caregivers about direct caregiving stressors during support group meetings was especially helpful in this study as has been previously reported by others (20, 21). In fact, providing non-pharmacological interventions designed to assist caregivers in understanding dementia and AD to help them provide direct ADL care as well as addressing their own health care needs was the essential component of our collaborative care intervention (11, 12). Severity of patient symptoms in depression, aggression, mobility and caregiver issues subscales of the R-MBPC, were significantly higher in those caregivers who reported direct caregiving stressors as their Major Stressful Event. These behavioral symptoms have been associated with both caregiver depression and patient institutionalization (22–24). Behavior problems are quite common in dementia and are perhaps the most difficult stressor faced by caregivers. Findings from previous psychosocial educational support, and skill building

interventions have been shown to be effective in decreasing caregiver burden and increasing caregiver ability (8). Similar to previous studies we also found that due to the frequency of the care recipient's behavioral symptoms, most commonly depression, agitation, aggression and delusions, these behaviors were reported by caregivers as the most stressful events, increased their burden and sleeping problems, and also taxed their ability to care for their care recipient (25–27).

Caregiver depression scores were modestly correlated with stressor type. PHQ-9 scores in caregivers who reported no stressors were lower, but not significantly so, as compared to those caregivers reporting any stressor. This was likely due to the fact that the caregivers in our sample were active participants in the monthly psychosocial educational support group, which was designed to increase caregiving skills and self-management. Although depressive symptoms have been the most widely used outcome measure in caregiver intervention studies and have a significant prevalence (25 to 50%) in caregiver samples, it is by no means a universal problem for all caregivers (22, 24). These researchers report that between 50% and 80% of caregivers do not suffer from significant depressive symptoms and they might not benefit from an intervention designed to reduce depression.

It is only when a comparison was made between caregivers reporting direct caregiving stressors to those reporting non-caregiving stressors that we saw a significant difference in depression scores, which is similar to Farran's pilot study findings, where care recipient's behavioral symptoms were stable during the intervention (18). During the monthly psychosocial educational support group meetings, sharing information about their stressors in a mutually supportive environment with other caregivers, while helpful, is not likely to be an effective treatment for major depression (28). The potential benefits of support group interventions may also depend on other problems the caregiver has and whether there is a need for increased support over time (29). Aside from the monthly psychosocial educational support group meetings, a major benefit of our collaborative care intervention was the APN's involvement and her ability to tailor the intervention during one-on-one meetings with the caregivers and the immediate assistance in responding to their needs including assisting caregivers in addressing needs not necessarily related to the care recipient.

The findings of this study are similar to previous intervention studies, where caregivers have changed their behavior toward the person with dementia as a result of the intervention, because they have gained new knowledge, increased skills in assessing disruptive behaviors, learned the underlying causes of these behaviors, and improved their abilities to adapt to the change in the care recipient over time (22, 24, 30, 31). However, our findings are also unique in that we were able to identify stressors not related directly to caregiving that had an impact on caregiver coping. It is important that all issues faced by caregivers be included when addressing caregiver coping skills, self-management skills and improving their abilities to adapt to changes in any stressors over time. As reported, our caregivers' most stressful event changed over the 6-month period, therefore, clinicians and service providers should prepare caregivers for the fluctuations in care recipient needs over time, thereby caregivers will feel prepared by changes in care needs and feel less overwhelmed as the disease continues to progress. Teaching and coaching caregivers to anticipate changes in their own situations, as

well as that of the care recipient, e.g., jobs, extended family concerns, their own health, over time will help reduce the impact of non-caregiving stressors.

Limitations

While the sample of 31 caregivers may not be representative of all caregivers, it is a good representation of spouse caregivers. Other caregivers such as adult children may have a different stress profile but we were unable to measure this in this small sample. Indeed, caregivers who attend support groups may have less severe outside stressors and/or more resources and support to attend support groups. Although, in our collaborative care trial we provided transportation and additional resources as needed for the intervention dyads, not everyone took advantage of the resources available. Also, the support group attendance was voluntary rather than mandatory, as we believed making attendance mandatory would add an additional burden to these caregivers. Another limitation in this study was that we did not ask caregivers to rank order their stressors in terms of severity. For the purposes of analyses we used the first recorded stressor as the Most Stressful Event. Finally, the MSE form was introduced half way through the intervention as it became clear that caregivers were experiencing many different types of stressors. Thus, participants were already receiving what proved to be an effective intervention; introducing the MSE form at the beginning might have revealed different stressors.

Implications

Nevertheless, the results of this study can be helpful in developing targeted intervention and support strategies for caregivers experiencing various stressors in providing care. Given these findings, support services, either in clinical or community settings, could provide much needed education on understanding the progressive nature of dementia, how this will impact the care recipient and his needs over time, and how caregivers can prepare and learn strategies to manage stressful situations as they arise including both direct caregiving and non-caregiving related stressors. In addition, teaching caregivers about the long-term needs and consequences of these diagnoses can help them to pace themselves over the long haul. Equally important is the education of caregivers about their own health care, health promotion strategies and stress management techniques to reduce their level of stress and burden over time. Caregivers do not provide care in a vacuum. Caregivers come to their caregiving role experiencing both direct caregiving and non-caregiving related stressors. Open-ended interviewing techniques can be helpful in identifying all stressors that caregivers are dealing with and effective psychosocial education interventions can result in a reduction of caregiver burden, depressive symptoms and improved care. Continued coaching and teaching caregivers self-management skills, the ability to identify the source of their stressors and utilizing available resources will mitigate the impact of those stressors.

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Table 1

Caregiver and Care Recipient Characteristics

	Completed Most Stressful Event Form (n = 31)	Did not complete Most Stressful Event Form (n = 53)	P- Value
Caregivers Characteristics			
Mean Age (SD)	68.5 (14.0)	55.4 (14.2)	<0.001
Mean Years of Education (SD)	13.1 (2.8)	11.6 (2.1)	0.013
% Female	93.6	77.4	0.071
Relationship to Care Recipient	80.7	20.8	<0.001
% Spouse	6.5	52.8	
% Adult Child	12.9	26.4	
% Other			
Care Recipient Characteristics			
Mean Age (SD)	79.5 (5.5)	76.2 (5.9)	0.012
Mean Years of Education (SD)	12.1 (4.1)	8.1 (4.0)	<0.001
% African American	16.1	56.6	<0.001
% Female	12.9	66.0	<0.001

Table 2

Percentage of Categories of Stressors and Most Stressful Event Reported

	% All Stressors Cited (n = 318)	% Cited as Most Stressful Event (n = 144)
Major categories		
Direct caregiving stressors	36.5	36.1
Indirect caregiving stressors	25.5	19.4
Non-caregiving stressors	28.3	22.9
No stressors	9.8	21.5
Detailed categories		
Care recipient needs	30.2	29.2
Caregiver needs	26.7	20.1
Decision making	16.7	15.3
Dealing with housework	5.7	3.5
Role transition process	1.9	2.8
Safety needs	1.3	1.4
Health concerns	6.3	6.3
Positive perceptions	1.6	0.0
No stressors	9.8	21.5

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Table 3

The Association of Most Stressful Event with Scores on R-MBPC Subscales

R-MBPC Subscales	Non-caregiving stressors (n = 33)		Indirect caregiving stressors (n = 28)		Direct caregiving stressors (n = 52)		No Stressors (n = 31)		P-value*	P-value**
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
Depression	8.1	7.9	13.1	8.3	16.9	12.7	9.2	8.1	0.003	0.016
Aggression	3.7	6.8	5.6	6.9	8.2	7.7	3.1	4.2	0.003	0.419
Personal care	1.3	3.1	4.6	6.6	3.8	5.6	0.9	2.1	0.003	0.303
Mobility	1.3	2.0	2.9	3.0	3.9	3.1	1.3	1.6	<0.001	0.024
Sleep disturbances	0.9	2.0	1.3	2.0	1.1	2.0	0.4	1.0	0.226	0.940
Repetitive behavior	2.6	2.4	3.3	2.0	3.6	2.2	2.9	1.9	0.218	0.684
Delusions	0.4	0.9	1.4	1.6	0.9	1.7	0.5	1.4	0.047	0.124
Caregiver Issues	6.9	7.1	10.6	6.9	13.5	6.8	7.6	5.6	<0.001	0.009
PHQ-9	2.3	2.7	2.7	2.5	3.8	3.8	2.5	3.9	0.194	0.150

* p-value based on ANOVA

** p-value based from mixed-model accounting for repeated data within patients

Table 4

The Association of Most Stressful Event with Scores on R-MBPC Subscales

R-MBPC Subscales	Other Stressors (n = 105)		Care Recipient Needs (n =39)		P-value *	P-value **
	Mean	SD	Mean	SD		
Depression	11.2	9.4	15.8	12.9	0.048	0.217
Aggression	4.8	6.9	7.5	7.0	0.043	0.286
Personal care	2.4	4.7	3.7	5.6	0.176	0.499
Mobility	1.9	2.5	4.2	3.1	<0.001	0.003
Sleep disturbances	1.0	1.9	0.7	1.5	0.491	0.080
Repetitive behavior	3.0	2.2	4.1	2.0	0.230	0.842
Delusions	0.8	1.5	0.7	1.4	0.860	0.288
Caregiver Issues	8.7	6.6	14.0	7.1	<0.001	0.006
PHQ-9	2.8	3.4	3.4	3.3	0.292	0.324

* P-value from T-test

** P-value from mixed-model accounting for repeated data within care recipients