

The Longitudinal Effects of Caregiver Grief in Dementia and the Modifying Effects of Social Services: A Prospective Cohort Study

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BACKGROUND: Caregivers of persons with dementia (PWD) can experience loss and grief long before the death of the PWD, with such caregiver grief postulated to affect the well-being of the PWD-caregiver dyads. However, the longitudinal effects of caregiver grief and the moderating effects of social services are not yet clear.

OBJECTIVES: We investigated the longitudinal effects of caregiver grief on caregiver depression, caregivers' quality of life (QoL), and caregivers' perceived positive aspects of caregiving (PAC); and examined potential effect modification of social service utilization (dementia care services, caregiver programs, and paid caregivers).

DESIGN AND SETTING: A prospective cohort study with three time points of assessments (at 0, 6, and 12 months).

PARTICIPANTS: Family caregivers of community-dwelling PWD ($n = 178$).

MEASUREMENTS: At time point 1 (baseline), participants completed questionnaires that captured caregiver grief, burden, and social service utilization. Outcomes that were captured over time were: depression (time points 1–3), QoL (time point 2), and PAC (time point 3). Caregiver grief as well as interaction terms with social service utilization were included in Tobit regression to examine the association with outcomes.

RESULTS: After accounting for the effect of caregiver burden, caregiver grief remained associated with depressive symptoms ($P < .001$) and poorer QoL ($P < .001$). However, compared with burden, grief contributed to larger magnitudes of the adverse effects. Grief, not burden, was associated with less PAC ($P = .006$ and $P = .746$, respectively). In contrast,

burden, not grief, was associated with poorer physical health ($P = .010$ and $P = .110$, respectively). Dementia care services attenuated the effect of burden but not grief; caregiver programs did not affect burden but appeared to aggravate the effect of grief; and paid caregivers attenuated the effect of burden, and partially attenuated the effect of grief.

CONCLUSION: Caregiver grief has an impact on dementia caregivers, likely through a distinct mechanism from that of caregiver burden. However, prevailing social services may not be sufficient to address grief, highlighting the need to further train care workers in this respect. *J Am Geriatr Soc* 68:2348-2353, 2020.

Keywords: caregiver; dementia; grief; burden; social services; longitudinal outcomes; cohort study

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INTRODUCTION

Caregivers of persons with dementia (PWD) may begin their bereavement long before the physical death of PWD.¹ They often experience multiple losses within the context of caregiving, including the anticipation of future losses related to the physical death of PWD; and the ambiguous loss of PWD who, despite being physically present, becomes emotionally disconnected from the caregiver.² Caregivers' emotional, cognitive, and behavioral responses to the losses³ (henceforth denoted as "caregiver grief") can be overwhelming and may accentuate caregivers' unmet needs for companionship, nurture, and emotional security.⁴ In several systematic reviews,^{4,5} caregiver grief has been identified as a key challenge in dementia caregiving,⁴ as well as highlighted as the central experience of spousal caregivers.⁵

In recent literature, caregiver grief has been shown to be distinct from the well-studied construct of caregiver burden. Although caregiver grief may be common in dementia caregiving (with its prevalence range of 47%–71% as reported in a systematic review),⁶ it may not be easily

detected using a caregiver burden scale (with only modest agreement between grief and burden scales).² Although caregiver grief may share some common risk factors with caregiver burden (such as later stage of dementia, behavioral problems in PWD, and primary caregiving role), there are also several risk factors that are unique to grief and differentiate grief from burden, including younger age of PWD, lower educational attainment of caregivers, and spousal caregiver.⁷ In addition, caregiver grief has an independent effect (which is separate from that of burden) on the adverse outcome of caregiver depression.³ It also has a synergistic relationship with caregiver burden, with high grief further amplifying the effect of burden on caregiver depression.³

To date, there has only been one longitudinal study of caregiver grief,³ which demonstrated the effect of grief on caregiver depression over time. Apart from this evidence, the literature is not yet clear whether caregiver grief has longitudinal effects on other outcomes that are relevant to dementia caregiving, and whether use of currently available social services may be effective in moderating the longitudinal effects of caregiver grief. Hence, this study investigated:

1. whether caregiver grief has a longitudinal effect on outcomes of caregiver depression, caregivers' quality of life (QoL), and caregivers' perceived positive aspects of caregiving (PAC); and
2. whether utilization of social services (specifically, dementia care services, caregiver programs, and paid caregivers) may moderate the effects of caregiver grief on the outcomes.

METHODS

Participants and Procedures

This is a prospective cohort study that recruited spouses or adult children of PWD from two tertiary hospitals in Singapore. Caregivers were recruited as they accompanied PWD to dementia clinics. They were invited to self-administer

questionnaires at home over three time points (at 0, 6, and 12 months). As this study focused on the lived experience of dementia caregivers (while they were still actively involved in the care of community-dwelling PWD), we only included spousal and children caregivers who fulfilled the following criteria: (1) care recipient (PWD) resided in community throughout the study period (i.e., not admitted to residential care facilities during study period); and (2) care recipient remained alive during study period.

At time point 1, caregivers self-administered a set of questionnaires that assessed caregiver grief (Marwit-Meuser Caregiver Grief Inventory (MM-CGI)),⁸ caregiver burden (Zarit Burden Interview (ZBI)),⁹ use of dementia care services, participation in caregiver programs, and employment of paid caregivers. To capture outcomes over time, caregivers completed a depression scale (Center for Epidemiologic Studies Depression Scale (CES-D))¹⁰ at time points 1 to 3, a QoL scale (Assessment of Quality of Life Eight Dimension Scale (AQoL-8D))¹¹ at time point 2, and a scale on PAC (Gains in Alzheimer's Care Instrument (GAIN))¹² at time point 3. Of note, the various outcomes were measured across different time points to reduce participants' burden of scale administration. The study received ethical approval from local institutional review board.

Measures

MM-CGI is a caregiver grief scale that captures various aspects of caregiving losses.⁸ Its 50 items are rated on five-point Likert scales, and summed to generate total scores ranging from 50 to 250 (higher scores indicate higher levels of grief). ZBI is a widely used scale to assess perceived burden of caregivers of older persons.⁹ Its 22 items are rated on five-point Likert scales, and summed to generate total scores ranging from 0 to 88 (higher scores indicate greater burden). MM-CGI^{2,7,13-15} and ZBI^{9,16} have been shown to have good validity and reliability for use among dementia caregivers in Singapore.

Table 1. Associations Between the Predictors at Baseline (MM-CGI and ZBI) and the Various Outcomes over Time (n = 178)

Outcomes	ZBI at time point 1 ^a		MM-CGI at time point 1 ^a	
	Regression coefficient (95% CI) ^b	P value	Regression coefficient (95% CI) ^b	P value
CES-D score at time points 1, 2, and 3	1.86 (0.29 to 3.44)	.020	5.76 (4.20 to 7.32)	<.001
AQoL-8D (overall) utility score at time point 2	-0.05 (-0.09 to -0.01)	.009	-0.08 (-0.12 to -0.04)	<.001
AQoL-8D (mental health) utility score at time point 2	-0.05 (-0.08 to -0.01)	.012	-0.08 (-0.12 to -0.05)	<.001
AQoL-8D (physical health) utility score at time point 2	-0.05 (-0.09 to -0.01)	.009	-0.03 (-0.07 to 0.01)	.113
GAIN score at time point 3	0.32 (-1.62 to 2.25)	.747	-2.70 (-4.62 to -0.77)	.006

Abbreviations: AQoL-8D, Assessment of Quality of Life Eight-Dimension Scale; CES-D, Center for Epidemiologic Studies Depression Scale; CI, confidence interval; GAIN, Gains in Alzheimer's Care Instrument; MM-CGI, Marwit-Meuser Caregiver Grief Inventory; ZBI, Zarit Burden Interview.

^aTo fairly compare the results between grief and burden, we standardized MM-CGI and ZBI scores in all analyses so that their mean values were equal to zero, whereas their standard deviations were equal to one. As such, the regression coefficients indicate the changes in the outcome scores with each standard deviation increment in MM-CGI or ZBI scores.

^bModels were adjusted for baseline variables related to persons with dementia (age, sex, behavioral problems, and dementia severity), caregivers (age, sex, ethnicity, educational attainment, relationship with person with dementia, primary caregiving role, and length of time in caregiving role), as well as social service utilization (use of dementia care services, participation in caregiver programs, and employment of paid caregivers). Significant coefficients (with $P \leq .05$) are highlighted in bold.

Dementia care services in Singapore include day care facilities (where PWD attends center-based activities related to physical exercise, social interaction, and cognitive stimulation) and elder-sit program (where occupational therapists provide home-based activities for PWD). Their utilizations were identified by asking whether PWD “utilize a support service for dementia (including day care, day program for dementia, elder-sit program, and befriending service).” Caregiver programs include full-day training workshops and monthly caregiver support groups provided by Alzheimer’s Disease Association of Singapore. Their participations were identified by asking whether caregiver “attend a training program or support group for dementia caregivers.” Employment of paid caregivers is a common respite practice in our local context, where foreign domestic helpers from neighboring countries are employed by family members (on a long-term basis; supported by financial subsidy from local government) to live within the same

household as PWD to supervise their daily affairs. It was identified by asking “whether there is currently a domestic maid who helps with the care of PWD.”

Other measures in this study are further described in Supplementary Material S1.

Statistical Analyses

Tobit regression was conducted to evaluate the association with outcomes of interest, namely, CES-D (time points 1–3), AQoL-8D (time point 2), and GAIN (time point 3). MM-CGI (time point 1) was included in the regression analyses as exposure of interest. ZBI (time point 1) was concurrently included in the regression analyses, to allow comparisons of results between caregiver grief and burden. Details on the statistical analyses—including rationale of using Tobit regression and potential confounders that were adjusted for—are described in Supplementary Material S2.

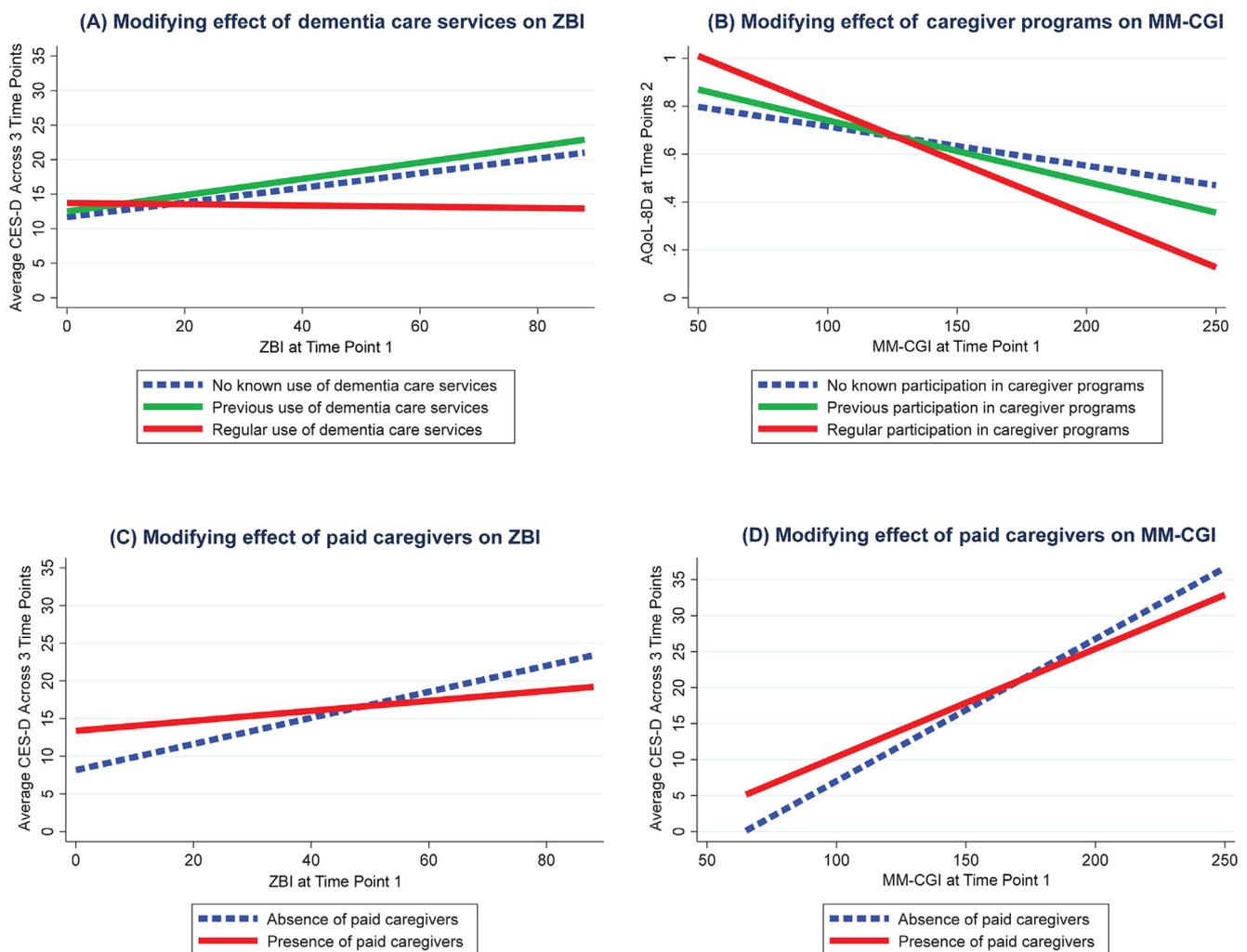


Figure 1. (A) Modifying effect of dementia care services on Zarit Burden Interview (ZBI), for the outcome of Center for Epidemiologic Studies Depression Scale (CES-D). (B) Modifying effect of caregiver programs on Marwit-Meuser Caregiver Grief Inventory (MM-CGI), for the outcome of Assessment of Quality of Life Eight-Dimension Scale (AQoL-8D). (C) Modifying effect of dementia care services on ZBI, for the outcome of CES-D. (D) Modifying effect of caregiver programs on MM-CGI, for the outcome of AQoL-8D. Among those who utilized dementia care services (A) and paid caregivers (C and D), each unit increment in ZBI or MM-CGI was associated with a smaller magnitude of adverse effect (i.e., depressive symptoms). In contrast, among those who utilized caregiver programs (B), each unit increment in MM-CGI was associated with a larger magnitude of adverse effect (i.e., poorer quality of life).

To evaluate for moderating effects of social service utilization, interactions between exposures of interest (MM-CGI and ZBI) and three types of social service utilization were evaluated in regression analyses, with significant interaction defined by $P_{\text{interaction}} \leq .10$ (a less stringent cut-off for $P_{\text{interaction}}$ was chosen to identify potentially relevant interaction effects).¹⁷ All analyses were performed using Stata (version 16).

RESULTS

Initially, 202 caregivers were recruited into the study. However, during the study period, 18 PWD died and 6 were admitted to residential care facilities, resulting in final sample of 178. Characteristics of the participants are presented in Supplementary Table S1. Included caregivers had a mean age of 56.5 years (standard deviation (SD) = 9.9 years) and mean caregiving duration of 8.7 years (SD = 6.8 years). Mostly, they were adult children (80.3%) and provided care to PWD with severe dementia (51.7%). At baseline, 25.3% of PWD were using dementia care services regularly; 5.1% of caregivers were attending caregiver programs regularly; and 62.9% of PWD had paid caregivers.

Both ZBI and MM-CGI were associated with CES-D over time (Table 1). However, each SD increment in ZBI led to a smaller magnitude of 1.86-point increase in CES-D ($P = .020$), whereas each SD increment in MM-CGI led to a larger magnitude of 5.76-point increase in CES-D ($P < .001$). Similar patterns were seen for the outcomes of AQoL-8D (overall) and AQoL-8D (mental health), with MM-CGI leading to larger declines in utility scores. Two outcomes showed differing associations with ZBI and MM-CGI: AQoL-8D (physical health) was associated with ZBI ($P = .009$) but not with MM-CGI ($P = .113$), whereas GAIN was associated with MM-CGI ($P = .006$) but not with ZBI ($P = .747$).

Dementia care services modified the effect of ZBI ($P_{\text{interaction}} = .064$), but not MM-CGI ($P_{\text{interaction}} = .206$), on the outcome of CES-D. As seen in Figure 1A, without the use of dementia care services, each SD increment in ZBI led to a 2.12-point increase in CES-D (95% confidence interval (CI) = 0.56–3.68; $P = .008$). Those with previous use of dementia care services also showed a similar, although marginally significant, increment in CES-D (regression coefficient = 2.36; 95% CI = –0.04 to 4.75; $P = .054$). In contrast, with regular use of dementia care services, ZBI was no longer associated with CES-D (regression coefficient = –0.18; 95% CI = –2.41 to 2.06; $P = .878$).

Participation in caregiver programs modified the effect of MM-CGI ($P_{\text{interaction}} = .069$), but not ZBI ($P_{\text{interaction}} = .200$), on the outcome of AQoL-8D. This interaction effect is visible in Figure 1B, with an apparent dose-response relationship. Without prior participation in caregiver programs, each SD increment in MM-CGI led to a 0.05-point decrease in AQoL-8D (95% CI = 0.01–0.10; $P = .017$). With prior participation in caregiver programs, each SD increment in MM-CGI led to a larger decrease of 0.08 points in AQoL-8D (95% CI = 0.04–0.13; $P < .001$), whereas regular participation in caregiver programs led to the largest decrease of 0.16 points in AQoL-8D (95% CI = 0.07–0.26; $P = .001$).

Paid caregivers modified the effect of both ZBI ($P_{\text{interaction}} = .067$) and MM-CGI ($P_{\text{interaction}} = .042$) on the outcome of CES-D (Figure 1C,D). In the absence of paid caregivers, each SD increment in ZBI led to a 2.95-point increase in CES-D (95% CI = 1.19–4.72; $P = .001$), whereas each SD increment in MM-CGI led to a 6.81-point increase in CES-D (95% CI = 5.12–8.50; $P < .001$). In the presence of paid caregivers, ZBI was no longer associated with CES-D (regression coefficient = 1.51; 95% CI = –0.23 to 3.25; $P = .088$), whereas each SD increment in MM-CGI led to a smaller increase of 5.21 points in CES-D (95% CI = 3.45–6.97; $P < .001$).

DISCUSSION

Both grief and burden were associated with depressive symptoms and poorer QoL; although compared with burden, grief contributed to larger magnitudes of adverse effects. Grief, not burden, was associated with less PAC. In contrast, burden, not grief, was associated with poorer physical health. Among the three social services, *dementia care services* attenuated the effect of burden but not grief; *caregiver programs* did not affect burden but appeared to aggravate the effect of grief; and *paid caregivers* attenuated the effect of burden and partially attenuated the effect of grief.

The findings put into perspective the relevance of caregiver grief in the course of dementia caregiving. Although caregiver burden is the conventional emphasis in dementia caregiving,^{18,19} the findings demonstrated the comparatively larger impact of caregiver grief, and are consistent with extant literature that highlighted grief as a key challenge in dementia caregiving.^{3-5,20} Plausibly, burden and grief may have acted through different mechanisms in leading to adverse outcomes, with the postulated framework in Figure 2 as a possible way to consolidate the findings. As seen in this study, *burden (not grief) leads to poorer physical health in caregivers*. In the course of providing care, family caregivers are faced with a myriad of physical care demands,^{7,18,21} which may result in subjective perception of burden,¹⁸ as well as manifest with the consequence of poorer physical health.²² In contrast, grief (not burden) leads to poorer perception on the PAC. It is possible that continual process of caregiving heightens caregivers' awareness of losses, in particular, ongoing ambiguous loss and anticipation of future losses. This leads some caregivers to center on losses rather than PAC.

Notwithstanding the relevance of grief in dementia caregiving, the findings highlighted the limited benefit of current social services on caregiver grief. This is understandable, given that current social services are conceptualized based on the transactional model of stress and coping^{18,23,24} and are primarily focused on addressing caregiver burden.²⁴ In particular, the finding that caregiver programs worsened the effect of grief was unexpected. It is possible that those who are motivated to participate in caregiver programs may have closer bonds with PWD, and hence may be more affected by the effects of grief. However, it is equally plausible that routine exploration of emotions in support groups, especially among caregivers with high grief and when the emotions are not properly processed, may potentially overwhelm caregivers and

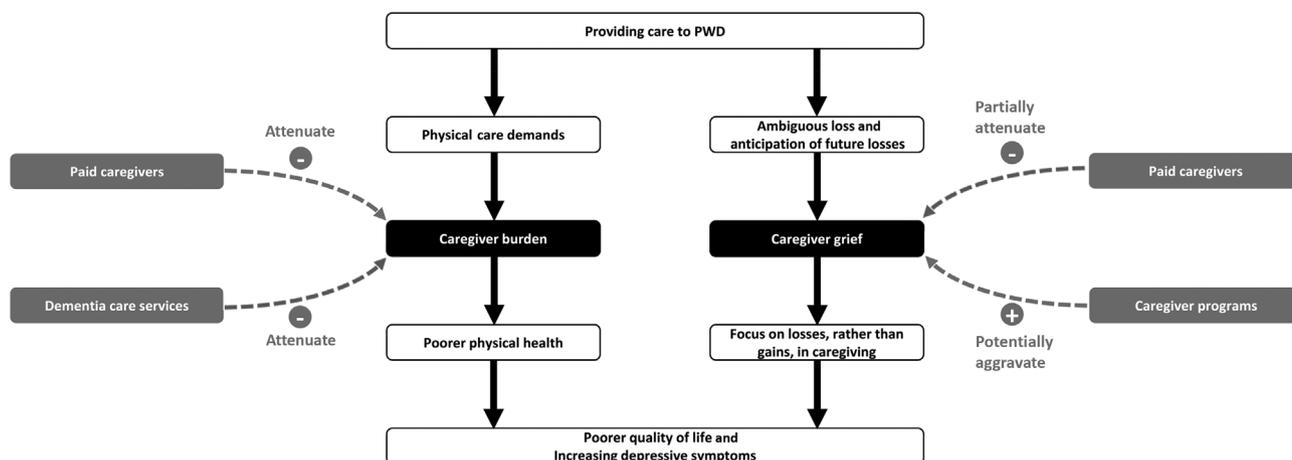


Figure 2. A postulated framework to consolidate the findings on the differential effects of caregiver burden and grief.

aggravate the effects of grief—this argument mirrors findings from a recent network meta-analysis,²⁵ where caregiver support groups, when used indiscriminately, were suggested to worsen caregiver depression.

All in all, the findings demonstrated a gap in current social services, suggesting the need to equip care workers with appropriate skills to deal with caregiver grief. Front-line workers need to be made aware of the relevance of grief in dementia caregiving, and trained to identify high grief using available grief scales.^{8,26-28} Those involved in caregiver support groups need to be familiarized with the approaches to address high grief, in accordance with prevailing dual-process model of grief,^{29,30} which emphasizes attending to emotions related to losses (by acknowledging and normalizing the presence of grief; and by involving other family members in the grieving process) as well as facilitating practical ways to live with the losses (by finding new ways to remain connected to PWD, such as through therapeutic touch, humor, life review, spiritual practices, and celebrations).^{3,7}

Several limitations should be considered. First, due to the small sample size, the findings from this study—including the postulated framework in Figure 2—will benefit from further validation in other populations as well as across different participant profiles. Second, social service utilization was recorded at baseline, and arguably may fluctuate over time. However, our local caregivers often maintain the same care arrangements over time, and are less likely to have changed their social services utilization within 1 year. Third, we only focused on live-in paid caregivers as this is the prevailing group of paid caregivers in Singapore. Although such live-in paid caregivers may not be available in other countries, the findings may still reflect the benefits of similar respite practices, such as non-live-in paid caregivers or unpaid social support provided by friends and neighbors.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Supplementary Material S1: Further descriptions on the scales that were used in this study.

Supplementary Material S2: Further descriptions on the statistical analyses that were conducted in this study.

Supplementary Table S1: Characteristics of the Caregivers and Persons with Dementia at Wave 1 (n = 178).