

Recurrent Depressive Symptomatology and Physical Health: A 10-Year Study of Informal Caregivers of Persons With Dementia

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Objective: To examine the degree to which recurrent depressive symptomatology predicts the decline in the health status of a randomly derived national sample of caregivers of persons with dementia.

Method: Individuals with dementia and their caregivers were recruited from each Canadian province as part of a national epidemiologic study of dementia prevalence and the health and welfare of care providers. Both patients and caregivers were assessed at 3 points over a 10-year period. Cohabiting family members who shared the same residence as care recipients were selected for the current study ($n = 96$ pairs). We computed a repeated measures analysis of variance to compare the health of caregivers who were consistently asymptomatic for depression, of those symptomatic at 1 of 3 points of measurement, and of those symptomatic at 2 of 3 points.

Results: As hypothesized, caregivers presenting with elevated depressive symptomatology at multiple points of measurement reported poorer and worsening physical health over time.

Conclusions: The results of this study support the assertion that depressive symptomatology significantly predicts the decline in health status of caregivers of persons with dementia. Concerted effort to treat depression in this population is warranted to forestall this trajectory of decline and premature patient institutionalization.

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Clinical Implications

- Persistent depressive symptomatology is a significant predictor of caregivers' physical health decline.
- Elevated levels of depressive symptomatology among caregivers are evident at each point of measurement.
- Assessment of caregiver mood should be an ongoing component of dementia patient management.

Limitations

- The cohabiting patient–caregiver sample selected for this study represents a minority of the CSHA participant dyads.
- Depressive symptoms were measured by self-report as opposed to structured diagnostic interviews.
- Change occurred in the measurement of caregiver health at Time 3, and an abridged version of the CES-D was used.

Key Words: caregivers, dementia, depression, health

Those who provide care to persons with dementia, most often immediate family members, are known to be at elevated risk for depression.¹⁻³ Whereas the depression prevalence among community-dwelling older adults is believed to be less than 7%,⁴ estimates of clinical depression among caregivers of persons with dementia range up to 83%.⁵ This disparity has generally been explained in relation to the diathesis–stress model of psychopathology because the pronounced and unrelenting demands of care (such as wandering, sleep disturbances, repeated questioning, and behavioural disinhibition) are believed to be sufficient to trigger the onset of depression among caregivers predisposed to this condition.⁶

The physical well-being of caregivers can also be significantly compromised as a function of role demands.⁷ Research that has examined the relation between depression and physical health in later life has found a significant association.^{8,9} Of further note, both clinical and subclinical, or minor, depression are associated with increased risk of death.^{10,11} For instance, depression among older adults may be as great a mortality risk as cardiovascular disease and diabetes.¹² Since a sizable proportion of caregivers of persons with dementia are themselves elderly,¹³ these factors make caregivers an ideal population in which to study the association between health and depression in later life.⁷

Despite advances in recent years, debate remains regarding the nature and direction of the association between physical illness and depression. Longitudinal studies have shown that, after controlling for initial depressive symptomatology, ill health at baseline (both objectively and subjectively assessed) significantly predicts depressive symptoms at intervals extending up to 8 years.¹⁴⁻¹⁸ Conversely, however, depression has not emerged consistently as a significant and meaningful predictor of future health status.¹⁵⁻¹⁷ The absence of a relation in this direction has been explained by the transitory nature of depressive symptoms. The argument has been made that depression must be persistent to exert a noticeable effect on health.¹⁷ Participants in studies with only briefly elevated depressive symptomatology (lasting less than 14 days, for example) likely did not have a bona fide depressive disorder but, rather, an adjustment reaction with depressive mood or

other cause of transitory elevation in depressive symptomatology. Indeed, Meeks and colleagues¹⁶ found a link, albeit weak, between depression and poorer health when depressive symptoms persisted over time (manifest at both points of assessment, separated by 2.5 years). In a similar vein, Lenze and colleagues¹⁹ recently reported that older adults with persistently elevated depressive symptomatology (for more than 4 years) had a significantly greater increase in functional disability ratings when compared with those having only temporarily elevated symptoms. To advance our understanding, it is thus clear that we need longitudinal research that examines the impact on health of both temporary and persistent depressive symptomatology.¹⁹

The present study examines change in physical well-being in relation to depression status in a randomly derived group of caregivers of persons with dementia assessed 3 times over a decade. Although differences between groups may not be observed at baseline, we hypothesize that persistent depressive symptomatology will predict decline in health status over time. Conversely, we assume that caregivers who are asymptomatic at each point of measurement will provide consistent health ratings over time vis-à-vis those symptomatic at multiple points. The number of points at which caregivers appear symptomatic for depression is assumed to predict worsening physical health status.

Methods

Participants

Care Recipients. Older adults were recruited as part of the CSHA,²⁰ a national epidemiologic study of dementia prevalence in Canada. Individuals aged over 64 years were randomly identified from government health records in all provinces except Ontario, where enumeration records were used. A total of 9008 community-dwelling older adults underwent clinical screening with the 3MS.²¹ As compared with Folstein's original Mini-Mental State Examination, the 3MS provides greater gradation of scores and covers a broader range of cognitive abilities (such as abstract reasoning and generative naming). Scores on the 3MS range from 0 to 100, with lower totals indicating cognitive impairment.²²

Individuals unable to complete the 3MS or scoring below 78/100 were invited to undergo clinical examination ($n = 2339$). On the basis of all clinically relevant information, consensus diagnoses were reached by interdisciplinary teams comprising a physician, a neuropsychologist, and a nurse or a psychometrician.²³

Caregivers. Patients and (or) their families identified a primary caregiver as the individual most responsible for day-to-day decisions. During the initial wave of data collection, a primary caregiver was identified in all but 7 cases.¹³ Of

Abbreviations used in this article

CES-D	Center for Epidemiologic Studies Depression Scale
CSHA	Canadian Study of Health and Aging
NHRDP	National Health Research and Development Program
SF-12	Short-Form Health Survey
3MS	Modified Mini-Mental State Examination

the identified caregivers, 32 (2.8%) could not be contacted and 38 (3.4%) declined participation.

Follow-up data were collected at 2 subsequent time points to examine patterns of change in the cognition of persons with dementia and in the health and welfare of their caregivers.²⁴ The initial data collection occurred between February 1991 and May 1992,²⁰ with follow-up data collection occurring at roughly equal intervals of about 4.5 years. For participants selected for this study, the average (SD) duration between initial participation and Time 3 data collection was 9 years, 5 months, (3 months, 5 days).

For the current study, we restricted inclusion to dyads where the care recipients lived in the community with their caregivers at each point of measurement. We based this criterion on previous research indicating that the nature and severity of caregiving demands are distinct for this population, compared with the demands for caregivers who do not reside with care recipients or for caregivers of institutionalized patients.²⁵ Given estimates suggesting that the duration between the onset of dementia symptoms and death is about 10 to 15 years,²⁶ this sample likely represents CSHA participants followed for most of their caregiving careers.

Of the original CSHA sample of 406 caregiver–care recipient dyads cohabiting in the community, only 96 met the inclusion criteria for the current study (most patients either had died or had been institutionalized over this period). This sample comprised 37 men and 59 women with dementia. Consistent with previous research,⁷ the distribution by sex of the caregiver sample was less proportionate (21 men and 75 women). A slight majority of caregivers were adult children of the care recipients (49/96 or 51%), a sizable portion were spouses (42/96 or 43.2%), with 2 sisters and 3 daughters-in-law.

Ethics

Ethical approval was obtained from the institutional review boards of the 18 CSHA study centres. Written informed consent for participation was obtained from each index subject or proxy as well as from his or her caregiver.

Measures

Patient Illness Characteristics

Multidisciplinary teams arrived at consensus diagnoses after the clinical examination of index subjects. Consistent with criteria of the National Institute of Neurological and Communicative Diseases and Stroke–Alzheimer’s Disease and Related Disorders Association,²⁷ care recipients received specific diagnoses, such as probable or possible Alzheimer disease and vascular dementia. They were also grouped within 1 of 5 categories to reflect their overall illness severity on the basis of DSM-III²⁸ criteria (specifically, normal, cognitively impaired–no dementia, mild dementia, moderate dementia, or

severe dementia). Given that inclusion in the current study was restricted to those with a dementia diagnosis, the selected patients were categorized as having mild, moderate, or severe impairment.

Caregiver Variables

Demographic information was obtained from caregivers at each time point. At Time 1 (baseline), this information included age of both patient and caregiver, years of formal education (caregiver), marital status, and relationship to the index subject.

Center for Epidemiologic Studies Depression Scale. The 20-item CES-D²⁹ was also administered at both baseline and Time 2. A brief 10-item version of this scale was administered at Time 3. According to Radloff and Teri,³⁰ scores greater than 15/60 on the 20-item CES-D suggest clinically significant depressive symptomatology^{31,32}; similarly, scores greater than 9/30 on the abridged CES-D are deemed to be clinically significant.³³

The CES-D asks respondents to rate the frequency of various depressive symptoms over the past week (for example, “I thought my life had been a failure” and “I felt lonely”). Responses are provided along a 4-point Likert-type scale ranging from 0 = “rarely or none of the time” to 3 = “most or all of the time.” Within the full CSHA sample, the internal consistency of responses to the 20-item scale was calculated as $\alpha = 0.88$ at Time 1.¹³ At Time 3, the calculation was $\alpha = 0.80$ for responses to the abridged version of the CES-D.

Lewinsohn and colleagues³⁴ contend that the utility of the CES-D is not compromised by age, sex, physical disease, or cognitive or physical impairment. Although developed and first validated with general adult populations, the CES-D appears appropriate for use with older adults.^{30,34}

Caregiver Health Status

At Time 1 and Time 2, caregivers were asked to indicate whether they had experienced a series of health problems over the past year (specifically, allergies, chest problems, heart condition, kidney disease, cancer, diabetes, high blood pressure, arthritis or rheumatism, digestive troubles, nervousness, stroke, and insomnia). Caregivers were also asked 3 subjective health questions (“How would you say your health is these days?” “Is your health now better, about the same, or worse than it was one year ago?” and “How much do your health troubles stand in the way of your doing the things you want to do?”) Responses were recorded along Likert-type scales with 5 response alternatives for the first question (1 = “very good” to 5 = “very poor”) and 3 for the remaining 2 questions (1 = “better” to 3 = “worse”). A cumulative health variable was created on the basis of responses to both health

problems and perceived health questions at Time 1 and Time 2.

At Time 3, the SF-12³⁵ was administered to caregivers. This brief health status survey is scored on 2 summary scales (physical and mental components) with a mean of 50, SD 10, based on transformed distributions of adult population norms. The physical health component selected for the current study measures physical wellness, role function, pain, and health perceptions. It is somewhat more heavily weighted toward perceived health, compared with the health measure computed at Time 1 and Time 2, which is more heavily weighted toward diagnosed health conditions.

The overall sample mean (SD) for the SF-12 health component was 47.89 (10.76) (range 38.11 to 59.47). Although approaching population norms, this physical health score is similar to levels previously reported with caregiver samples.³⁶ Unlike the composite variable created for the Time 1 and Time 2 health variable, higher SF-12 scores reflect superior health status; thus, we reverse-coded the CSHA I and II scores prior to analyses for consistency of measurement. We standardized both SF-12 (Time 3) and composite health scores (Time 1 and Time 2) to allow comparisons between groups over time.

Results

Participant Groupings

Caregivers were first categorized on the basis of responses above or below cut-off for the CES-D. At each of the 3 measurement points, caregivers were classified as either symptomatic (CES-D scores > 15/60 at Time 1 and Time 2 or Brief CES-D score > 9/30 at Time 3) or asymptomatic (CES-D scores < 16/60 at Time 1 and Time 2 or Brief CES-D score < 10/30 at Time 3). Thus caregivers could fall into 1 of 3 groups: consistently symptomatic, consistently asymptomatic, or variably symptomatic. The variably symptomatic grouping was further subdivided into those scoring above cut-off at 1 or at 2 points of measurement. Lenze and colleagues¹⁹ used a similar categorization strategy in their recent longitudinal study of depression and functional disability.

Notable percentages of caregivers provided responses to the CES-D that were suggestive of significant depressive symptomatology at each point of measurement (34.4%, 31.3%, and 26% at Time 1, Time 2, and Time 3, respectively). None of the identified caregivers, however, fell within symptomatic range at all 3 points. As previously reported by O'Rourke,³⁷ chronic depressive symptomatology among caregivers is a significant predictor of patient institutionalization; thus, it is unlikely that community care would endure over this extended period if caregivers suffered persistently from depression.

We identified 3 distinct groupings on the basis of caregiver responses to the CES-D. The largest group (42/96 or 43.8%) presented as symptomatic at 1 of 3 measurement points (or, conversely, asymptomatic at 2 of 3 points), the next largest group (31/96 or 32.3%) was consistently asymptomatic (asymptomatic at 3 of 3 points), and the smallest group (23/96 or 24%) was symptomatic at 2 of 3 points of measurement (asymptomatic at 1 of 3 points).

Apart from CES-D responses, we observed few caregiver differences between groups. For instance, we found no caregiver age differences ($F_{2,93} = 1.224, P = 0.299$) or differences in levels of educational attainment ($F_{2,93} = 0.687, P = 0.506$). However, a smaller percentage of female caregivers were in the consistently asymptomatic group relative to their male peers ($\chi^2 = 5.894, df 2, P = 0.053$). This finding is consistent with previous research indicating higher levels of depression among female caregivers³⁸ and among women, more generally.³⁹

Further, we noted few care recipient differences across groups. For instance, the age of care recipients did not differ significantly ($F_{2,93} = 0.978, P = 0.380$) nor did sex ($\chi^2 = 0.590, df 2, P = 0.745$) or socioeconomic status based on work performed prior to retirement ($\chi^2 = 7.253, df 12, P = 0.840$). More noteworthy still, care recipients did not differ on the basis of disease severity measured at either Time 1 ($\chi^2 = 12.828, df 8, P = 0.118$) or Time 3 ($\chi^2 = 6.000, df 2, P = 0.199$). It therefore does not appear that patient demographics or dementia-related factors are related to caregivers' depression group membership.

Comparative Analyses

We first plotted mean standardized health scores to visually compare health status by group over time. As seen in Figure 1, the health of caregivers who were consistently asymptomatic for depression was reported to be better than the health of both other groups at each point of measurement. At Time 1 and Time 2, the health of those who were asymptomatic at 2 measurement points was superior to those asymptomatic for depression at only 1 point (symptomatic at 2 points). The health of all 3 caregiver groups appeared to decline at Time 3. These observations suggest that caregiving takes its toll over the course of caregivers' careers, which is consistent with previous reports, and that depressive symptomatology is associated with reduced health status at each point of measurement.

We computed the following analyses to ascertain whether differences between groups were statistically significant. As previously stated, we hypothesized that the physical health of caregivers who were symptomatic for depression would be reduced relative to their asymptomatic peers and that this discrepancy would increase over time.

Figure 1 Physical health over time of informal caregivers of persons with dementia

Note: Caregiver health was measured as a composite of perceived health and identified conditions at Time 1 and Time 2 (reverse keyed) and the SF-12 at Time 3. Scores were standardized prior to statistical analyses to enable comparison across time points.

We compared the physical health of the 3 groups (divided on the basis of depressive symptomatology), using a 2-way analysis of variance with repeated measures. As hypothesized, the group \times time interaction was statistically significant ($F_{4,184} = 5.80$, Pillai's Trace = 0.222, $P < 0.001$). Tests for simple effects indicated no significant change in health status over time for the consistently asymptomatic group ($F_{2,29} = 1.07$, $P = 0.356$). In contrast, the health of caregivers who were symptomatic for depression at both 1 ($F_{2,40} = 12.90$, $P < 0.001$) and 2 points in time ($F_{2,21} = 7.12$, $P = 0.004$) appeared to decline significantly. (To avoid overstating observed changes over time, we are not reporting post hoc comparisons between time points because of the variability in the measurement of health status, that is, use of the composite SF-12 at Time 3.)

We also observed simple effects across groups at Time 1 ($F_{2,93} = 7.19$, $P = 0.001$), Time 2 ($F_{2,93} = 6.16$, $P = 0.003$), and Time 3 ($F_{2,93} = 13.94$, $P < 0.001$). Post hoc analyses (using the least significant difference method) indicated that all groups differed significantly at Time 1 (Bonferroni corrected $\alpha = 0.05/3$ or $\alpha = 0.017$). At Time 2, the health of consistently asymptomatic caregivers was superior to that of both other groups, whereas the latter 2 groups were statistically indistinguishable. At Time 3, caregivers who were asymptomatic at 2 of 3 points appeared to have the most compromised health status, and these caregivers differed significantly from those in both other groups.

The overall results of this study support the hypothesis that depressive symptomatology is associated with reduced physical well-being among informal caregivers of persons with dementia. The number of points at which caregivers are in the clinical range for depressive symptomatology is significantly

associated with initial health status, which appears to further decline over time. In addition to reflecting the emotional distress of caregivers, these results suggest that recurrent depressive symptomatology is also predictive of reduced physical wellness. This finding may further explain why depressive symptomatology is associated with the institutionalization of individuals with dementia.³⁷

Discussion

Our study results support the assertion that depressive symptomatology is significantly associated with reduced physical well-being among family or unpaid caregivers of persons with dementia. Although we had assumed that caregiver groups would appear similar at the time of recruitment, depressive symptomatology as measured over time appears to be significantly associated with reports of poorer health status at all points of measurement. In addition to previous research indicating that reduced physical wellness among caregivers predicts future depression,¹⁷ the results of this study indicate that the reverse may also be true. This finding is in accord with an earlier report demonstrating that both anxiety and depressive components of psychological distress predict negative perceived health about 1 year later in a large representative sample of older adults living independently in the community.¹⁴

Several possible mechanisms may explain the influence of depression on physical health. For example, individuals with depression are less likely to engage in consistent self-care. Also, depression is accompanied by declines in activities of daily living, such as toileting and meal preparation, which are known to negatively affect health.¹⁹ In addition, lack of motivation and interest as well as social withdrawal may impede

the willingness and capacity of individuals with depression to engage in health-enhancing behaviours (such as physical activity, social contact, and treatment adherence) that help to manage the illness. The pronounced frailty of older adults with depression may itself lead to increased risk for poor health as a function of reduced appetite and sleep. Depressive symptoms may also exacerbate the immunologic declines that accompany the aging process.⁴⁰

One strength of this study is that participants were followed over an extended period of about 10 years. Unlike the bulk of correlational caregiving research using single-point measurement, causal assertions can be made here with greater confidence, given the longitudinal nature of this study design. Further, with repeated measures analyses, participants act as their own control subjects, allowing for greater sensitivity to change over time (that is, less extraneous error).

CSHA index subjects and their caregivers (by association) were randomly derived as part of a nationwide epidemiologic study of dementia prevalence and informal care; this, too, enhances our ability to generalize findings. In the study of caregiving, reliance on region-specific convenience samples has been identified as a significant limitation of most research.^{41,42} The limitations of this data set must also be acknowledged, however. For instance, owing to our inclusion criteria (cohabitation at each point of measurement), dyads selected for the current study represent but a minority of those initially recruited for the CSHA. Although this decision limited our sample size, the resulting number of participants was sufficient for repeated measures analyses and enabled us to examine a relatively homogeneous cohort of caregivers known to be at elevated risk for depression.

Although the CSHA sample is a particular strength of this study, some measurement limitations must be acknowledged. The most notable (and inexplicable) limitations were decisions to alter the measurement of both depressive symptomatology and health at Time 3. The decision to use the SF-12 in place of the health measures administered at Time 1 and Time 2 meant that the physical health variable at Time 3 was more heavily weighted toward perceived health than toward chronic health conditions. Although previous research with CSHA caregivers suggests that these aspects of physical wellness are strongly correlated (for example, $r = 0.56$ and $r = 0.53$),¹⁷ they are not synonymous constructs. Therefore, health changes between Time 2 and Time 3 should be interpreted more cautiously than those between Time 1 and Time 2.

Further, the fact that our measure of health combined both objective and subjective aspects makes it difficult to reconcile our findings with studies that have examined only perceived health. One such study recently reported that depressive

symptoms had little effect on self-assessed health at lagged intervals ranging up to 8 years.¹⁵ The sample of that study, however, comprised healthy and relatively young participants (aged 51 to 61 years at baseline). More important, as Kosloski and colleagues¹⁵ acknowledged, health ratings by participants remained stable over the course of their study, providing little observed variance to be explained by depressive symptoms or any other variable.

At first glance, the results of the present study seem to contradict those we previously reported involving CSHA caregivers (first 2 waves of data collection only).¹⁷ In our earlier study testing for reciprocal effects between depressive symptomatology and physical health, CES-D response levels did not appear to predict decline in physical well-being after controlling for health as measured at baseline. Notably, however, the caregivers selected for the current study were a subset of the earlier study and were examined over a period that was twice as long. Also of note, depressive symptomatology was analyzed as a continuous measure and not dichotomized as we have done here. According to Meeks and colleagues,¹⁶ differences in results suggest that depression may best be examined categorically in terms of its effects on physical health over time.

It should also be noted that no objective corroboration of physical health reports was obtained for CSHA caregivers. Therefore, it is possible that some caregivers may have under- or overreported their physical health concerns or conditions at baseline or at subsequent points of measurement. This observation is more germane given that dysphoric individuals are more likely to recall negative information, compared with their euthymic counterparts.⁴³ In other words, persistent depressive symptomatology may be associated with a tendency to negatively skew reports of physical health information.

Also unfortunate was the decision to use an abridged version of the CES-D for the first time at Time 3. Although some researchers suggested no loss of accuracy with shortened versions of the scale,^{33,44} O'Rourke⁴⁵ concluded in a more recent metaanalysis that the original 20-item version should be used whenever possible because of a significant decline in the reliability of responses to briefer versions of this scale. This measurement decision also prevented examination of the factor structure of responses to the CES-D previously reported with Time 1 and Time 2 caregiver data.¹⁷ We also point out that a depression screening measure is not equivalent to a structured diagnostic interview such as the Structured Clinical Interview for DSM-IV Axis I Disorders.⁴⁶ Some caregivers falling within clinical range might not have had a depressive disorder, whereas some of those identified as euthymic might have met diagnostic criteria.

Conclusion

Census data suggest that individuals aged over 84 years represent the fastest growing segment of the populations in most Western nations.⁴⁷ Because advancing age remains the single strongest risk factor for illnesses such as Alzheimer disease,²⁰ prevalence rates of all dementias are expected to increase substantially in coming years. This awareness underscores the need to more fully understand factors associated with declining health among family caregivers, such as recurrent depressive symptomatology. Concerted efforts at treating depression in this population are warranted to prevent this trajectory of decline and premature patient institutionalization.

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Résumé : La symptomatologie dépressive récurrente et la santé physique : une étude de 10 ans sur les soignants naturels des personnes souffrant de démence

Objectif : Examiner le degré auquel la symptomatologie dépressive récurrente prédit le déclin de l'état de santé d'un échantillon national aléatoire dérivé de soignants de personnes souffrant de démence.

Méthode : Les personnes souffrant de démence et leurs soignants ont été recrutés dans chaque province canadienne dans le cadre d'une étude épidémiologique nationale de la prévalence de la démence ainsi que de la santé et du bien-être des soignants. Tant les patients que les soignants ont été évalués à 3 points d'une période de 10 ans. Les membres de la famille cohabitant avec les destinataires des soins ont été sélectionnés pour l'étude courante ($n = 96$ paires). Nous avons comptabilisé une analyse de variance de mesures répétées pour comparer la santé des soignants qui étaient toujours asymptomatiques pour la dépression, de ceux qui étaient symptomatiques à 1 des 3 points de mesure, et de ceux qui étaient symptomatiques à 2 des 3 points.

Résultats : Conformément à l'hypothèse, les soignants présentant une symptomatologie dépressive élevée à plusieurs points de mesure ont déclaré une mauvaise santé physique qui s'aggravait avec le temps.

Conclusions : Les résultats de cette étude confirment l'hypothèse que la symptomatologie dépressive prédit de façon significative le déclin de l'état de santé des soignants de personnes souffrant de démence. Il faut un effort concerté pour traiter la dépression chez cette population afin de prévenir la trajectoire du déclin et l'institutionnalisation prématurée des patients.