The Caregivers for Alzheimer’s disease Problems Scale (CAPS): development of a new scale within the LASER-AD study

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Abstract

Background: we developed the Caregivers for Alzheimer’s disease Problems Scale (CAPS) comprising common risk factors for anxiety and depression for family carers of people with dementia.

Objective: to calculate the sensitivity and specificity of the CAPS in order to measure its usefulness in identifying dementia caregivers at risk of anxiety and depression and therefore whether it identifies clinically relevant areas for intervention or highlights the need for support if the problem could not be changed.

Method: 153 family caregivers were interviewed as part of a larger epidemiologically representative study of people with Alzheimer’s disease and their caregivers. Caregiver anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS).

Results: the CAPS had high sensitivity and specificity in detecting caregivers with screen positive anxiety and depression. Five areas were indicated: neuropsychiatric symptoms and depression in the care-recipient, co-residence and relationships with the care-recipient, and physical health of the caregiver.

Conclusions: awareness of these problems can help clinicians identify those carers most likely to be anxious or depressed and indicate appropriate intervention and support. We recommend that this instrument be used as part of routine assessments of people with dementia and their families.

Keywords: Alzheimer’s disease, caregivers, anxiety, depression, elderly
Introduction

The number of people with Alzheimer’s disease (AD) and therefore of their family caregivers is increasing worldwide. While caregiving is often rewarding, caring for someone with dementia can be stressful, and caregivers experience high levels of psychological morbidity [1]. Several risk factors for carers developing psychological distress and morbidity have been reported [2–5]. These relate to the caregiver’s demographic profile, additional pressures in their lives or the care-recipient’s (CR) symptoms. Commonly identified carer risk factors are: being a female carer, being a spouse of the CR, living with the CR, looking after a CR who lives in the community, having a poor relationship with the CR, having dependent children, having a job and having physical health problems. While being a spouse has been commonly found to be a risk factor for caregivers’ mental health, it has been speculated that it is not the relationship itself which increases vulnerability, but the fact that spouse caregivers are likely to be older and in less good physical health [5]. Factors in the CR include having neuropsychiatric symptoms, especially depression. Several studies have examined the effect of dependency in the CR and although the results have been equivocal, generally, no direct relationship has been found [3, 4]. It would be useful to have a scale for rapidly identifying carers who are at high risk of anxiety or depression that includes the risk factors and therefore suggests a management plan. This might possibly be preventative as well as therapeutic. We have therefore compiled the Caregivers for Alzheimer’s Disease Problems Scale (CAPS) comprising the risk factors which have been shown to be important (Table 1), and tested it in a representative sample of people with AD and their carers.

Method

We conducted a large naturalistic study of people with AD and their caregivers [6, 7]. Participants in the study came from urban, suburban and rural areas of London and the South-East Region (LASER) of England. The people who took part were recruited purposefully to ensure an epidemiologically representative sample in terms of dementia severity, gender and care setting [8]. People with AD and their caregivers were approached through a variety of means. They were contacted through local psychiatric services, through the voluntary sector and through managers of nursing and residential care homes.

All CRs had a formal diagnosis of dementia according to DSM-IV [9] and fulfilled criteria for probable or possible AD [10]. CRs were aged 55 years or over and lived either at home or in institutions. An inclusion criterion for the study was that the caregiver was defined as someone spending a minimum of four hours a week caring for the person with AD.

We tested the CAPS using data collected in the LASER-AD study. A total of 153 family caregivers were included. Paid caregivers were excluded. Trained researchers collected the following information.

Caregiver

(i) Demographics: age, gender, whether or not the caregiver was married to and/or living with the CR, caregiver employment and whether or not the caregiver had dependent children.

(ii) The Hospital Anxiety and Depression Scale (HADS) [11], which measures anxiety and depression caseness. The HADS excludes somatic items (which can be misleading in older subjects) and has been validated throughout the age range and in all settings to identify clinically significant anxiety and depression [12]. It has good results for validity and reliability against clinical diagnosis. It has been shown to perform very well in measuring both caseness and severity of both anxiety and depression in general population and primary care as well as hospital cohorts [13]. The 14-item HADS assesses how the person has been feeling within the past week and generates scores for both anxiety and depression (0–21). Scores of 8–10 imply borderline cases; scores of 11 or more are considered cases. We included those who were borderline cases as screening positive in this analysis. Optimal balance between sensitivity and specificity for the HADS as a screening

Table 1. The Caregivers for Alzheimer’s disease Problems Scale (CAPS)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Score = 0</th>
<th>Score = 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver items:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Being married to the CR</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Living with the CR*</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Having children aged under 18</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Having a job</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Health*</td>
<td>Not interfering with daily life</td>
<td>Interfering with daily life</td>
</tr>
<tr>
<td>Quality of relationship with CR*</td>
<td>Good/excellent</td>
<td>Poor/fair</td>
</tr>
<tr>
<td>Care-recipient items:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressed*</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Neuropsychiatric symptoms*</td>
<td>No</td>
<td>Yes (score &gt;15 on NPI or 4 or more neuropsychiatric symptoms present)</td>
</tr>
<tr>
<td>Living situation</td>
<td>24-hour care</td>
<td>In the community</td>
</tr>
</tbody>
</table>

*Items included in the 5-item CAPS, which was generated by backward logistic regression analysis. CR = care-recipient; NPI = Neuropsychiatric Inventory.
instrument is best achieved by using a cut-off score of 8 or higher for both scales [13].

(iii) Physical health rating: caregivers rated whether or not health problems interfered with their daily life. This is the question related to the domain ‘role physical’ in the Health Status Questionnaire, which is suitable for older and younger people (HSQ-12) [14, 15].

(iv) Quality of their relationship with the CR: caregivers rated this on a four-point scale (poor, fair, good or excellent). This question is taken from the Quality of Life-Alzheimer’s Disease (Qol-AD) [16].

Care-recipient

(i) Demographics: age, gender, marital status.

(ii) Cornell Scale for Depression in Dementia (CSDD) [17]. A total score is derived by the clinician based on their judgement from carer and CR ratings of 19 depressive symptoms. Scores of 8 or more suggest significant depressive symptoms.

(iii) Mini-Mental State Examination (MMSE) [18] to measure cognitive impairment.

(iv) Neuropsychiatric Inventory (NPI) [19] to measure 12 psychiatric symptoms. These symptoms were delusions, hallucinations, dysphoria, anxiety, elevated mood, sleep, appetite, irritability, aberrant motor behaviour, aggression/agitation, apathy and disinhibition. Carers rate each symptom by frequency (score 1–4) and severity (score of 1–3) or as absent (score 0). The frequency score is then multiplied by the severity score for each symptom and the sum of these creates a global score (maximum score = 144).

(v) Medical history, physical examination and investigation results.

Analysis

We scored each carer–CR dyad on the CAPS, and performed logistic regression analyses in the first 50 caregivers to find independent predictors of screening positive for anxiety or depression, incorporating those variables with P values of <0.05. This reduced the scale from 10 to 5 items (Table 1). We then calculated sensitivity and specificity for various cutpoints using data from the remaining caregivers.

Results

The CRs had MMSE scores varying from 0 to 29 (mean = 14.6, standard deviation (SD) = 8.5). The age of CRs ranged from 55 to 98 (mean = 81.0, SD = 7.6). One hundred and four (68.0%) were female. Thirty-nine (25.5%) were living in 24-hour care settings. Seventy-six (49.7%) scored more than 15 on neuropsychiatric symptoms. Thirty-one (20.3%) were depressed. The age of carers ranged from 32 to 93 (mean = 64.0, SD = 13.3). One hundred and seven (69.9%) were female; 68 (44.4%) were married to the CR; 50 (32.7%) were employed; 27 (17.6%) had children under 18 living with them; 75 (49.0%) were living with the CR. Seventy (45.0%) and 40 (26.1%) scored (including borderline cases) as screening positive for anxiety or depression, respectively.

On the 5-item CAPS the mean score for those screened positively for anxiety was 2.0 (95% confidence intervals (CI) = 1.7–2.3), which was significantly different to the mean for those who were not anxious (mean = 1.4, CI = 1.2–1.7; t = 3.4, P < 0.001). Sensitivity and specificity at scores of 1, 2, 3 and 4 were 89% and 24%, 72% and 51%, 53% and 87%, and 13% and 96%, respectively. The mean CAPS score for those who were screened as depressed was 2.3 (CI = 2.0–2.7), which was significantly higher than those who were not depressed (mean = 1.5; CI = 1.3–1.7; t = 4.1, P < 0.0001). Sensitivity and specificity at scores of 1, 2, 3 and 4 were 100% and 24%, 82% and 49%, 41% and 84%, and 22% and 97%, respectively.

Discussion

The CAPS is the first screening tool to enable clinicians to identify rapidly those dementia caregivers at risk of having significant anxiety or depressive symptoms. Trained researchers performed the study using validated instruments in a representative sample of people with AD from within the UK. Participants were from urban, suburban and rural areas, thus it should be possible to generalise the results. The limitations are that, as in any study, the population who consent to take part may be particularly motivated. In addition, those who were most severely ill or did not speak English were excluded and this may have introduced bias. Finally, we did not measure all possible variables so there are likely to be other problems which put caregivers at risk that we have not identified using this scale.

The advantages of the scale are that it uses data that are collected as part of routine clinical practice and indicates five areas that are all potentially amenable to change. It is of interest that ‘having a job’ did not appear as a protective or a risk factor, although it was another major task the caregiver had to cope with. Despite earlier literature which had suggested it was a risk factor (as mentioned in the Introduction above), some people in our group felt strongly that it would be protective through allowing the caregiver an arena in which they would function and be rewarded. It is probable that work can act both as a stressor and a protector, with the balance varying according to individual circumstances.

The five areas identified as predictors are neuropsychiatric symptoms and depression in the CR, co-residence and relationships with the CR, and physical health of the caregiver. Awareness of these can help clinicians identify those carers most vulnerable to anxiety and depression and focus on changing risk factors as far as possible. In addition, this would highlight clinicians to the areas which cannot be changed, e.g. if caregiver’s physical health has already been maximised, or living arrangements with which the caregiver is happy. Overall, this would enable health and social services and the voluntary sector to prioritise and manage rationally these carers in most need of practical help, psychological support, or emotional support.

In conclusion, this scale adds value to current routine practice, as it enables clinicians to identify the roots of anxiety and depression for individual caregivers, thus showing exactly which problems need to be tackled for treatment.
We recommend that the CAPS be used as part of the routine assessment of people with dementia and their families.

Key points

• Several risk factors for caregiver psychological morbidity have previously been reported.
• There are scales to screen for psychological disorder but no validated scale which uses the risk factors as the screening tool.
• Such a risk factors scale would identify clinically relevant areas for intervention or highlight the need for support if the problem could not be changed.
• We present the CAPS (the Caregivers for Alzheimer’s disease Problems Scale), which is a new 5-item sensitive and specific scale to identify caregivers at risk of psychological morbidity.
• We recommend that the CAPS be used as part of the routine clinical assessment of people with dementia and their families to identify problems.

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References


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