Anxiety and depression in family caregivers of
people with Alzheimer's disease
- the LASER-AD study.

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Abstract.

Background: There are high rates of stress, distress and psychological illness in family caregivers of people with dementia. Female caregivers and those caring for people with neuropsychiatric symptoms are particularly at risk. No study has focused on distinguishing states of anxiety and depression and their determinants in a representative community sample of family caregivers.

Objective: To report the prevalence of anxiety and depression in a representative sample of family caregivers of people with Alzheimer's disease (AD) and to compare the characteristics of those that did or did not have those conditions.

Method: 153 people with AD and their caregivers were interviewed as part of a larger representative study of AD.

Results: 23.5% of caregivers scored at or above caseness level for anxiety and 10.5% for depression. Care-recipient (CR) activities of daily living (ADL) impairment, being a caregiver living with the CR, being a female caregiver, reporting a poorer quality of relationship with the CR and caregivers reporting their health as being poor all predicted anxiety disorder. CR irritability, caregivers reporting poor health and a poorer quality of relationship with the CR predicted depression.

Conclusions: Clinicians should be aware of the high rates of anxiety as well as depressive symptoms in family caregivers of people with AD**,** especially in female caregivers. CRs' and Caregivers' impaired physical health are at risk of psychological morbidity and should be treated energetically. A poor quality relationship between the caregiver and the CR predicts both caregiver depression and anxiety and there is potential for intervention. Caregivers living with the CR are much more likely to be anxious rather than depressed.

Introduction

The number of people with Alzheimer's disease (AD) and therefore the number of caregivers is increasing as the population ages[1]. Family caregivers provide the majority of care for people with dementia[2] and experience significantly higher levels of psychological morbidity, depression, stress and burden than their counterparts who are not caregivers or who are caring for the physically ill[3,4,5,6,7].

The words 'burden', 'strain' and 'stress' are used interchangeably in research about caregivers[8]. 'Caregiver burden' may be divided into the physical, psychological, social and financial demands of caring for someone or, alternatively, into 'subjective' and 'objective' burden, with subjective burden referring to the emotional consequences of caregiving[7,9]. For caregivers in general, various factors are associated with caregiver 'burden' and 'stress', such as being female, having a poor relationship with the care-recipient (CR), lack of social support and the CR having dementia[7,10,11,12,13]. The sources of stress may vary according to the caregiver's own situation: spouses, being older, may experience strain due to physical or financial problems, whereas adult children may have conflicting responsibilities, such as work or children[13].

Most studies that have looked at distress in caregivers have focused on psychological symptoms rather than on diagnosis. They have found that depressive and anxiety symptoms in caregivers of people with dementia are strongly associated with CRs' neuropsychiatric symptoms, particularly, depression[2,8,14,15,16,17] but not usually to level of cognitive impairment[4,8,18]. Although most studies have found no relationship between caregiver 'burden' and limitations of activities of daily living (ADL), it has

been associated specifically with caregiver depressive symptoms[8.19].

Overall, caregivers of people with dementia are often burdened and distressed but no study has yet investigated the prevalence and determinants of anxiety and depression in a representative community sample of family caregivers of people with AD with a range of severity representative of that found in the general population.

Aims

We investigated the prevalence of anxiety and depression and compared the previously reported characteristics of those who did or did not have those conditions, namely:

1. For the caregiver: the type of relationship with the CR and its quality; age, gender and physical health; whether the caregiver has other responsibilities (work and children at home).

2. For the care-recipient: demographic factors, severity of neuropsychiatric symptoms, depression, cognitive impairment and ADL impairment.

Methods

This is part of a larger naturalistic study of people with Alzheimer's disease and their caregivers (London and South-East Region Alzheimer's disease Study, LASER-AD[20]). The people who took part were recruited purposefully to ensure a representative community sample that was representative in terms of dementia severity. People with AD and their caregivers were approached through a variety of means. They were contacted though local psychiatric services, through the voluntary sector and through managers of nursing and residential care homes.

Participants

CRs had a diagnosis of dementia and Alzheimer's disease[21.22]. CRs were chosen to be epidemiologically representative of the wider community of people with AD in terms of gender, severity of illness and living settings. In terms of severity, this involved selecting people with AD so that those classified as mild, moderate and severe on the MMSE made up approximately 30, 40 and 30% of the total sample respectively[23]. They all lived in the London and South-East Region (LASER) of England (inner-city, suburban, semi-rural and new town areas), either at home or in institutions. A caregiver was defined as someone spending a minimum of four hours a week caring for the person with AD. For this study, only informal caregivers (family and friends) were included.

Procedure

The relevant local research ethics committees granted approval. CRs were interviewed at their place of residence. Both caregivers and CRs were asked for their written informed consent to participate. If the CRs were unable to give informed consent they were asked for assent and written agreement from caregivers. The interview was stopped if the CR asked to withdraw or showed distress. Trained researchers from a range of disciplines (medicine, nursing and psychology) conducted all the interviews.

The interview

1. Demographic data

- CR: age, gender, ethnicity and domicile.

- Caregiver: age, gender, relationship to CR, employment status, marital status and number of children under 18 years living with them.

2. Caregiver anxiety and depression was assessed using the Hospital Anxiety and Depression Scale (HADS[24]). This does not include somatic items (which can be misleading in older subjects). It has good results for validity and reliability against clinical diagnosis[24], and has been validated throughout the age range and in all settings to identify clinically significant anxiety and depression[25]. The 14-item HADS assesses how the person has been feeling within the past week and generates scores for two subscales: anxiety and depression (0-21 for each). A score of 8-10 implies borderline cases; and scores of ¤11 are considered cases. We used scores of ¤11 to define 'caseness' for both anxiety and depression in our analysis.

3. Caregivers' physical health was assessed using the relevant domains of the Health Status Questionnaire (HSQ-12[26,27]): health perception, physical functioning and role physical (whether health interferes with daily living).

4. Caregivers were asked to rate the quality of their relationship with the CR on a 4-point scale, where 1= poor, 2= fair, 3= good, and 4= excellent. This is an item from the Quality of Life for patients with Alzheimer's disease (Qol-AD[28]).

5. CR cognitive functioning was measured with the Mini-Mental State Examination (MMSE[29]).

6. Neuropsychiatric symptoms displayed by CRs were assessed using the Neuropsychiatric Inventory (NPI[30]). This scale assesses 12 different psychiatric symptoms by asking the caregiver to rate each one by frequency (score 1-4) and severity (score of 1-3) or as absent (score 0), with a maximum global score of 144.

7. Depressive illness in CRs was rated using the Cornell Scale for Depression in Dementia (CSDD[31]). A score of ⌐ 8 indicates depression.

8. Activities of daily living (ADL) was assessed using the Alzheimer's Disease Co-operative Study Inventory- Activities of Daily Living (ADCS-ADL[32]). This 23-item questionnaire is completed by the caregiver and scores range between 0 and 78. Higher scores indicate less impaired functioning.

9. CRs' current medications were also recorded.

Statistics

SPSS 11.5 was used for data entry and analysis. As the data were not normally distributed, Mann Whitney-U or Chi-square analyses were used to identify factors associated with anxiety and depression in caregivers and only the significant findings are reported. Though we have reported the individual bivariate comparisons for completeness we regard the multivariate analyses as the indicative ones. It should be noted that individual bivariate significance values are NOT adjusted for multiple comparisons.

The independent predictors of anxiety and depression caseness (including odds ratios, OR and 95% confidence intervals, CI) were identified by forward logistic regression analysis. Dependent variables entered into the analysis were: CR at home or in 24-hour care, CR gender, cognition (MMSE), each neuropsychiatric symptom and total NPI score, ADL functioning, CR depression (CSDD), psychotropic medications (antidepressants, antipsychotics, cholinesterase inhibitors), and caregiver characteristics (gender, marital status, caregiver living with the CR, relationship to the CR, perceived quality of the relationship to the CR, employment, presence of children, physical health). This regression analysis was also rerun after removing the

quality of the relationship to the CR to further examine the model. We were interested in whether this might be a proxy measure for the severity of caregiver rated neuropsychiatric symptoms, and in particular, irritability.

Results

Participants

153 informal caregiver and CR dyads were interviewed for this study.

Care-recipients

CRs had a mean age of 81 years (standard deviation; SD=7.6, range=55-98 years) and 104 (68.0%) were female. 126 (82.4%) of them were of white British origin, 20 (13.1%) were white Irish or white other and 7 (4.5%) were from non-white ethnic backgrounds. 39 (25.5%) lived alone, 54 (35.3%) with spouses/partners, 18 (11.8%) with other relatives, 3 (2.0%) with others at home and 39 (25.5%) with others in 24-hour care. Of those living in care, 13 (33.3%) were living in hospital, 17 (43.6%) were living in residential homes and 9 (23.1%) were living in nursing homes. On the MMSE, 44 (28.8%) were mildly impaired (MMSE=21+), 63 (41.2%) were moderately impaired (MMSE=10-20), and 46 (30.1%) were severely impaired (MMSE=0-9).

Caregivers

Caregivers had a mean age of 64 years (SD=3.3, range=32-93 years). 72 (47.1%) were over 65 years of age. 107 (69.9%) were female. 40 (26.1%) were wives/female partners, 28 (18.3%) were husbands/male partners, 68 (44.4%) were daughters/sons,

10 (6.5%) were other relatives and 7 (4.6%) were friends of the CR. 75 (49.0%) were living with the CR. 118 (79.8%) caregivers were married/living as married, 15 (9.8%) were single, 9 (5.9%) were separated/divorced, and 6 (3.9%) were widowed. 50 (32.7%) caregivers were employed and 27 (17.6%) had children under 18 living with them.

Caregiver anxiety and depression (see table 1)

The mean anxiety score on the HADS was 7.4 (SD=4.4) and the mean depression score was 5.1 (SD=4.0). 36 (23.5%) were anxious and 16 (10.5%) depressed at caseness level; 13 (36.1% of anxiety cases and 81.3% of depression cases) were both. 31 (86.1%) and 11 (68.8%) of anxiety and depression cases, respectively, were female.

Anxiety caseness in caregivers was more frequent when the CR was male, and the CRs' had greater ADL impairment and total NPI score. Irritability was the only individual neuropsychiatric symptom correlated with caregiver anxiety. Male CRs were significantly more likely to have a female caregiver (94%) than a male caregiver (6%; χ^2=19.7, p<0.001). With regard to the characteristics of the caregiver, the caregiver being female, living with the CR, having poor health, health interfering with daily living and a poorer rating by carers of the quality of their relationship with the CR were related to anxiety caseness. Caregiver depression caseness was correlated with their health interfering with daily living, poor health and physical functioning and with CR irritability.

Regression analyses (see figure 1)

The caregiver being female, living with the CR, rating the quality of relationship with the CR as less good, having poor perceived health and the CR's ADL impairment were all significant independent predictors of anxiety caseness. The significant independent predictors of depression caseness were higher NPI irritability scores, the caregiver's perception of poor health and a poorer quality of relationship with the CR.

When the quality of the relationship with the CR was removed from the analysis, anxiety caseness was found to be predicted by the CR living in the community as opposed to in 24-hour care (Wald=9.22; df=1; OR=5.56, CI=1.84-16.95, p<0.01), greater ADL impairment (Wald=13.54; df=1; OR=1.04, CI=1.02-1.06, p<0.001), being a female caregiver (Wald=8.22; df=1; OR=4.03, CI=1.55-10.44, p<0.01), higher NPI irritability scores (Wald=5.28; df=1; OR= 1.18, CI= 1.03-1.36, p<0.05) and caregivers' physical health interfering with daily living (Wald =7.39; df =1; OR=1.01, CI=1.00-1.02, p<0.01). With depression caseness as the dependent variable, the significant predictors were: the CR living in the community (Wald=4.08; df=1; OR= 4.35, CI=1.04-18.18, p<0.05), greater ADL impairment (Wald=7.89; df=1; OR=1.03, CI=1.01-1.05, p<0.01), higher NPI irritability score (Wald=10.44; df=1; OR=1.33, CI=1.12-1.59, p<0.001) and caregivers' perception of poor health (Wald=13.67; df=1; OR=1.04, CI=1.02-1.05, p<0.001).

Discussion

We found that nearly a quarter of caregivers of people with AD screened positive for anxiety and 10% for depression. In caregiver anxiety, the caregivers' rating of a poorer quality of the relationship with the CR was found to be a significant predictor. CR irritability emerges as an independent predictor of caregiver anxiety when the

quality of the relationship is removed from the analysis. Three possible explanations for this exist: firstly, that CRs' irritability or aggression may lead to a worse relationship with the caregiver; secondly that relationship problems may result in the CR being more irritable; and finally that caregivers with a poor relationship may perceive neuropsychiatric symptoms as more severe.

Impairment of ADL in the CR but not cognitive impairment itself was related to caregiver anxiety. This is a powerful relationship as the odds ratio was significant for every one point increase in the scale. This suggests that it is the additional burden of physical impairment in the CR related to other comorbidity rather than cognitive impairment, that constitutes a risk to the caregiver's mental health. Poorer physical health in caregivers (including their perception of it as a problem) and poorer relationships with the CR predicted anxiety and depression. These findings suggest that it is not only being a caregiver of someone with dementia but also having additional stresses which compounds the likelihood of the caregiver having psychiatric problems[13]. It is at first sight surprising that both living in the community and greater ADL impairment predicted caregiver anxiety caseness. This is however explained by the fact that the results are from a regression analysis and indicates that caring for a person with high ADL and caring for someone with dementia in their home are independent predictors of caregiver anxiety.

Most of our caregivers are older therefore depression and anxiety levels in this sample can be compared to those in general populations of older people though it should be noted that most of these studies used instruments other than the HADS.. Depression is not higher than in similar aged general population whereas anxiety is higher than in

the general population, which has a prevalence rate of around 3-6% [5]. Our results in terms of mean scores (depression 5.1 vs 4.0; anxiety 7.4 vs 7.4) and caseness prevalence for both anxiety and for depression are very similar to those reported by Clare et al[33] who used the HADS in a sample of caregivers of memory clinic attenders. Both depression and anxiety caseness levels are however higher (as might be expected) than general population norms for the HADS subscales[34]. There are various reasons that might account for levels of anxiety caseness being higher than those for depression in the present study. Clinicians may now be effectively targeting caregivers' depression, thus lowering the rates. In addition, previous studies have tended to use scales measuring psychological symptoms[3,4], or non-validated scales[14,16] and therefore psychological morbidity that has previously been attributed to depression may be due to anxiety.

Caregivers' poor perceived health rather than physical functioning predict both anxiety and depression. Poorly perceived health is closely related to physical health but also has a subjective element. We would expect caregivers to evaluate their health as worse if they also had affective symptoms. We have not found an association between carer anxiety or depression and being a spouse caregiver. Previous studies' findings of spouse caregivers being more vulnerable may be a reflection of the fact that as spouses are often older they are more likely to have impaired physical health.

We did not find as other studies have that depression in the person with dementia predicts caregiver psychological morbidity[17]. It maybe that irritability (either as part of or separate from depression) is a more important influence on the quality of the relationship between patient and caregiver than patient depression per se.

Trained researchers from a variety of disciplines conducted this study using validated instruments in a representative sample of people with AD from within the UK that was representative in terms of dementia severity. Participants were from urban, suburban and rural areas thus it should be possible to generalise the results. The limitations are that 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. Another limitation of this study is that anxiety and depression were assessed using a screening instrument, which although has good validity and reliability for detecting these states, is not a diagnostic tool based on gold-standard criteria. The HADS has however 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[35]. Future research should use a clinical interview to measure diagnostic levels of anxiety and depression disorders. Finally, we did not collect information on caregiver past psychiatric history or current use of psychotropic medication; these variables should also be included in further research in this area.

There are important clinical implications that can be drawn from the findings of the present study. Clinicians should be aware of the high rates of anxiety caseness in family caregivers of people with AD, particularly in female caregivers and caregivers living with the person. In addition, we should be alert for risk factors for anxiety and depression, specifically additional difficulties, such as caregiver poor health, the quality of the relationship between the caregiver and the CR, and irritability in the CR as these are potentially alterable. Similarly, the CR's physical health as well as the

mental health is important.

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Table 1. Associations with caregiver anxiety and depression caseness using Chi-

Squared (X^2) or Mann-Whitney (U) Tests.

Variable	HADS anxiety caseness			HADS
depression caseness				
	Mean (SD) or percentage	Critical value	P value	
	Mean (SD) or percentage	Critical value	p value	
ADL impairment	28.6 (18.9) vs 37.1 (23.5)	U= 1649.0	p<0.05	
	26.6 (17.7) vs 36.1 (23.1)	U= 816.5	NS	
NPI total score	25.1 (18.3) vs 17.1 (15.1)	U= 1473.5	p<0.01	
	26.4 (23.6) vs 18.1 (15.0)	U= 893.0	NS	
NPI irritability	2.6 (3.5) vs 1.4 (2.6)	U= 1625.5	p<0.05	
	3.8 (4.1) vs 1.4 (2.6)	U= 718.5	p<0.01	
Patient gender (male vs female)	34.7% vs 18.3%	X^2=5.0	p<0.05	10.2% vs
10.6%	X^2= 0.01	NS		
Caregiver gender (female vs male)	86.1% vs 13.9%	X^2=5.9	p<0.05	68.8% vs
31.2%	X^2= 0.01	NS		
Caregiver living with the patient (vs not living with them)	30.7% vs 16.7%	X^2=4.2	p<0.05	
	10.7% vs 10.3%	X^2= 0.01	NS	
Caregiver's perception of poor health	48.5 (32.4) vs 62.5 (31.1)	U= 1581.0	p<0.05	
	33.4 (35.2) vs 62.2 (30.2)	U= 322.5	p<0.001	
Caregiver's poor physical functioning	67.6 (32.6) vs 73.1 (34.0)	U= 1842.0	NS 51.0	
(38.2) vs 74.2 (32.4)	U= 691.5	p<0.05		
Caregiver's health interfering with daily living		61.4 (38.4) vs 77.4 (35.4)	U= 1579.0	

P<0.01   44.7 (38.9) vs 77.0 (35.0)   U= 597.5
P<0.001

Caregiver rating of a poor quality of relationship with the patient		2.9 (1.0) vs 3.3 (0.8) U=	
1494.5	p<0.05 NS	2.9 (1.0) vs 3.2 (0.8) U= 840.0	