Caregiver distress in dementia in rural Victoria

Primary Healthcare
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Dubai

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Aim of the study

The aim of the study was to explore the levels of stress, anxiety and depression of informal carers, caring for someone with dementia. A secondary aim was to determine the types of services they were utilising in their caring role and particular sources of stress.

Background

- Recent figures show long term care has decreased in Australia in the last decade(1).
- Seventy to 80% of people with dementia are now cared for at home (2).
- Carers of people with dementia are reported to have poorer health, than carers of people without a cognitive deficit (3, 4).
- Anecdotal evidence showed that carers were increasingly stressed.

1. Australian Institute of Health and Welfare (AIHW). Patterns in use of aged care. Data linkage series Number 18. 2014.
2. Livingston G. Alzheimers Association International Conference (AAIC). . Abstract p4-345. 2014;Presented July 16th.
3. Chene B. Dementia and residential placement: A view from the carer's perspective. Qualitative Social Work. 2006;5(2):187-215.
4. Wilks S, Croom, B., . Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of support. . Aging and Mental Health. 2008;12:357-65.

Methods

- Carers of people with dementia were recruited through a variety of community services and primary health care settings.
- Staff identified carers and invited them to complete a survey that incorporated the Depression, Anxiety and Stress Scale (DASS) to measure emotional wellbeing.
- The survey also included the Neuropsychiatric Inventory Questionnaire (NPI-Q) which assesses the prevalence and severity of behavioural and psychological symptoms of dementia of care recipients and their effect on the carer.
- The survey also asked about utilisation of community services.

Results

A total of 39 carers completed the survey.

CARERS

- Most of the carers were female (77%) and identified as wives (28%) or daughters (33%) of the care recipient.
- The median age of carers was 66.5 years (ranged from 43 - 87 years)
- Years spent as a carer averaged 4 years (ranged from 1 – 15 years)

Results

CARE RECIPIENTS

- Even mix of males (46%) and females (54%).
- Forty three percent did not know the type of dementia, 46% were diagnosed with Alzheimer’s Disease .
- Median age was 82 years (ranged from 70 – 98 years).
- Median duration of symptoms was 4.6 years (ranged from 1 – 15 years).

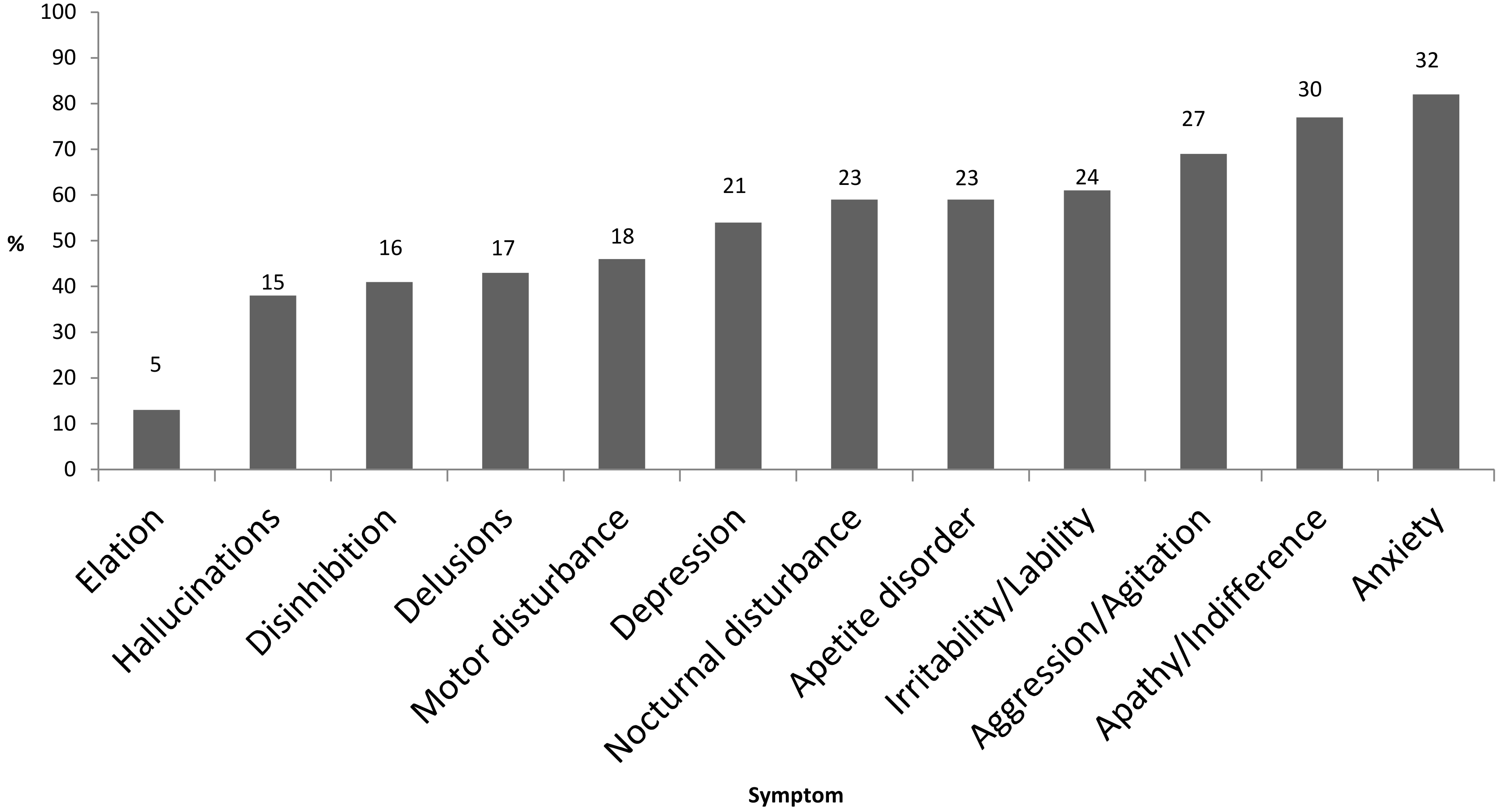
Results of the DASS

Scores on the DASS-21 subscales for carers

Depression			Anxiety			Stress		
Clinical classification			Clinical classification			Clinical classification		
	n	%		n	%		n	%
Normal (0-9)	20	51	Normal (0-7)	29	74	Normal (0-14)	20	51
Mild (10-13)	4	10	Mild (8-9)	0	0	Mild (15-18)	0	0
Moderate (14-20)	6	15	Moderate (10-14)	7	18	Moderate (19-25)	4	10
Severe (21-27)	6	15	Severe (15-19)	1	3	Severe (26-33)	9	23
Extremely Severe (28+)	3	8	Extremely Severe (20+)	2	5	Extremely Severe (34+)	6	15
Median Score (IQR)	6 (2,20)		Median Score (IQR)	2 (0,10)		Median Score (IQR)	14 (6,28)	
Range	0-36		Range	0-28		Range	0-42	

Results of the NPI-Q

Prevalence of behavioural and psychological symptoms of dementia in care recipients



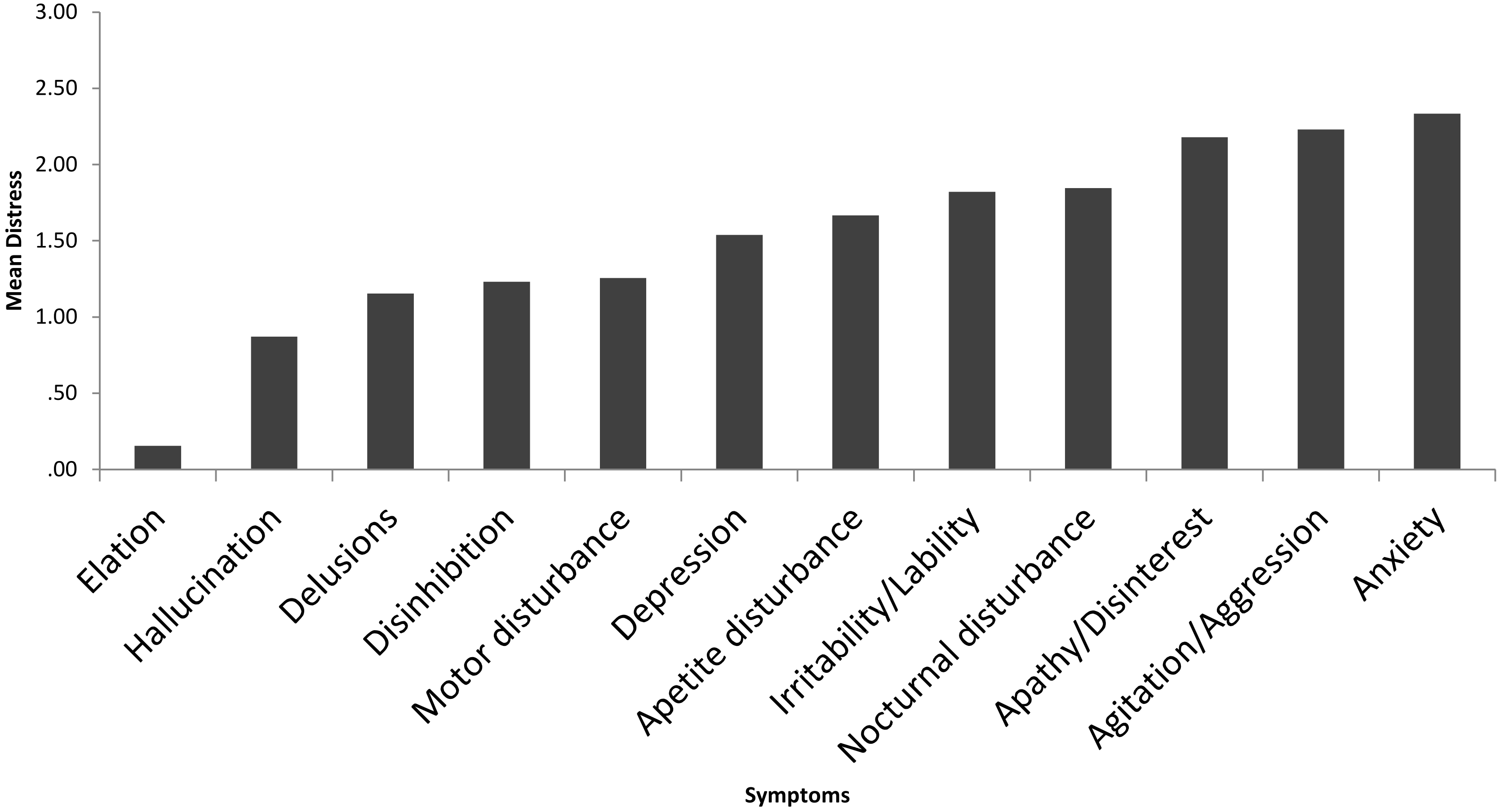
Results of the NPI-Q

Severity of care recipient's symptoms

Symptom	Total n (%)	Mild n (%)	Moderate n (%)	Severe n (%)
Anxiety	32 (82)	8 (25)	9 (28)	15 (46.8)
Apathy/Indifference	30 (76.9)	5 (16.6)	9 (30)	16 (53.3)
Aggression/Agitation	27 (69.2)	6 (22.2)	13 (48.1)	8 (29.6)
Irritability/Lability	24 (61.5)	6 (25)	9 (37.5)	9 (37.5)
Nocturnal disturbance	23 (58.9)	3 (13)	5 (21.7)	15 (65.2)
Appetite disturbance	23 (58.9)	4 (17.3)	10 (43.4)	9 (39.1)
Depression	21 (53.8)	5 (23.5)	7 (33.3)	9 (42.8)
Motor disturbance	18 (46.1)	5 (27.7)	4 (22.2)	9 (50)
Delusions	17 (43.5)	3 (17.6)	11 (64.7)	3 (17.6)
Disinhibition	16 (41)	3 (18.7)	7 (43.7)	6 (37.5)
Hallucinations	15 (38.4)	8 (53.3)	3 (20)	4 (26.6)
Elation	5 (12.8)	3 (60)	1 (20)	1 (20)

Results of the NPI – Q

The mean level of distress of carers in relation to the symptoms exhibited by the care recipient



Key points

- Rural carers of people with dementia report high levels of stress and depression

- Some BPSD, such as agitation/aggression and anxiety, are highly prevalent and cause the highest levels of distress for carers.

Reported utilisation of services by carers of people with dementia

Service	N (%)	Service	N (%)
Personal Counselling	9 (23.1)	District/Community Nursing	19 (48.7)
Counselling and emotional support guided by a trained professional (such as carers support group)	10 (25.6)	Holidays together with the person in a specialised setting	2 (5.1)
Printed information on dementia or the services available	24 (61.5)	Community transport (taxi's and community cars free of charge)	10 (25.6)
Social worker	10 (25.6)	General assistance with household chores (Home Help)	20 (51.3)
Financial compensation (such as carers pension)	18 (46.2)	Telephone hotline information, where the carer can get help or advice in a crisis (such as Dementia Behaviour Advisory Service)	4 (10.3)
Respite care in the home	15 (38.5)	Aged Psychiatry Mental Health Service	5 (12.8)
Respite care in a nursing home or hostel	16 (41)	Aged Care Assessment Service	33 (84.6)
Alzheimers Australia	10 (25.6)	Meals on Wheels	8 (20.5)

Supportive services used by participants with moderate to severe depression, anxiety and stress

	Moderate-severe depression N = 15 (38.5%)	Moderate – severe anxiety N = 10 (25.6%)	Moderate-severe stress N = 19 (48.7%)
	N (%)	N (%)	N (%)
Personal counselling	4 (26.7)	3 (30)	4 (21.1)
Support group	7 (46.7)	4 (40)	7 (36.8)
Respite in the home	5 (33.3)	2 (20)	6 (31.6)
Respite in an aged care facility	6 (40)	3 (30)	8 (42.1)

The most prevalently reported BPSD utilising services that may assist them

	Anxiety N= 32 (82%)	Aggression/ Agitation N = 27 (69%)	Irritability / Lability N = 24 (61.5%)	Nocturnal disturbance N = 23 (58.9%)	Depression N = 21 (53.8%)	Hallucinations N = 15 (38%)
Service	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Aged Psychiatry Mental Health Service	4 (12.5)	4 (14.8)	3 12.5)	3 (13)	2 (9.5)	4 (26)
Dementia Behaviour Advisory Service	4 (12.5)	3 (11)	2 (8.3)	3 (13)	2 (9.5)	3 (20)

Key points

- Rural carers of people with dementia report poor utilisation of commonly available community and dementia-specific services.

- Services that may assist carers who report stress and depression and those that could assist with managing BPSD in care recipients are poorly utilised

Is there anything at all you find particularly stressful in your role as a carer?

Thematic analysis conducted by 3 researchers

- Carrying the load
- The impact of BPSD on the carer
- Carers feelings of powerlessness and inadequacy in their caring role
- Grief and loss of the care recipients character and his/her previous relationship

Carrying the load

‘There are no breaks or holidays….being a carer is the loneliest job in the world’

‘I am unable to get time to myself, mum is demanding more and more attention’

‘I am not able to go anywhere or do very much, I don’t feel part of the real world’

The impact of BPSD on the carer

‘When he can’t get his own way – like he wants to go out, and I don’t, he gets very angry’

‘Having to deal with the aggression shown by my mother, at times towards me, for no reason’

‘Constant repetitive questions about the time and the day’

Carers feelings of powerlessness and inadequacy in their caring role

‘ I don’t know how to ease her symptoms’

‘I don’t get to spend as much time as I would like with my father’

‘I don’t like watching my husband suffer’

Grief and loss

‘The gradual change in the person’s character, especially losing them to have clear conversations’

‘I have found it hard sometimes because of the closeness of the person you are caring for. I am so sorry for her as she was such an outgoing person’

‘Changes in personality’

Key recommendations

- Services need to be tailored to carers dependent on their source of stress.
- Increased referral to services for carers and care recipients are required.
- Periodic screening of carers to detect stress and depression to enable early introduction of timely interventions to assist them in their caring role.

Keep in mind……

- Recent studies show that there are many positive aspects to the caring role.

Publications from this study;

Ervin, K. Reid, C, Moore, S. (2015).What do dementia caregivers find stressful? *Open Journal of Nursing. (5).* 370-375

Ervin, K., Reid, C. Service utilisation by carers of people with dementia in rural Victoria. *Australasian Journal on Ageing.*

Ervin, K., Reid, C., Pallant, J. Caregiver distress in dementia in rural Victoria. *Australasian Journal on Ageing.*