Is caring a health hazard? The mental health and vitality of carers of a person with a disability in Australia

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ABSTRACT

Objective: To compare the mental health and vitality of people caring for a family member with a disability with those of the general population. Second, to identify factors experienced by carers that put them at risk of poor mental health and vitality.

Design: Cross-sectional design where logistic and multiple regression analyses were used to compare rates of mental health problems and vitality between carers and the general population while controlling for demographic characteristics. In addition, logistic and multiple regression using data from the survey of carers were used to identify risk factors for poor mental health and vitality that were particular to caregiving.

Participants and setting: A randomly selected representative survey of 1002 carers from the Australian Centrelink administrative database (June 2006) who received government payments to care for a person with a disability or severe medical condition, or a person who was frail aged. A sample of 10 223 non-carers was drawn from the fourth wave of the Household, Income and Labour Dynamics in Australia Survey, a nationally representative household panel survey (August 2004 to February 2005).

Main outcome measures: Mental health and vitality as measured by the Medical Outcomes Study 36-item Short-Form Health Survey.

Results: Compared with the general population, carers were at significantly greater risk of having a mental health problem and lower levels of vitality, even after controlling for demographic characteristics. For carers, the risk factors for poor mental health and lower levels of vitality were caring for a person with a disability with higher care needs, experiencing greater levels of financial stress, lower levels of support and worse family functioning.

Conclusion: Carers are at greater risk of mental health problems and lower energy levels than the general population.

MJA 2009; 190: S61–S65

Studies of people who care for others with a disability or severe medical condition, or who are frail aged, have indicated that carers have higher levels of depression and stress than non-carers.[1-3] In Australia, it is estimated that there were 474 600 primary carers for people because of their disability or age in 2003.[4] The issue is of particular importance because the number of Australians who have caring responsibilities is growing. The number of people receiving government payments that support carers is substantial. In June 2007, there were 116 614 people receiving the Carer Payment and 393 263 receiving the Carer Allowance, representing an increase since June 2000 of 145% and 102%, respectively.[5,6] Given that many disabling conditions require medical care,[7] it is likely that many carers would be in frequent contact with a general practitioner as part of their care role. If caring is a mental health risk, then this frequent contact with GPs suggests a possible avenue for screening and treatment.

The Victorian Carers Program[3] and Carer Health and Wellbeing[1] survey have been the only large Australian studies to use standardised measures to assess the mental health of carers. In the Victorian Carers Program, 761 female carers reported significantly higher levels of negative mood compared with 219 female non-carers, but no comparisons were made between male carers and males in the general population. Other limitations of that study were that the sample of carers was limited to the state of Victoria, and that data were collected in 1993. While more recent, the Carer Health and Wellbeing survey only surveyed carers who were members of the state carer associations. Only 37% of these members completed the survey, and no evidence was reported about the representativeness of the sample of 4107 carers.[1] When depression was considered, 19% of carers had "extremely severe" levels of depression, with a further 18% showing "severe" and 19% showing "moderate" levels of depression according to the clinical cut-offs (but comparisons were not made with a sample from the general population).

Our aim was to compare the mental health and vitality of a nationally representative sample of carers of a person with a disability with those of another nationally representative sample of the general population while controlling for factors that may predispose someone to provide care. Our second aim was to identify risk factors for poor mental health and vitality particular to caregiving based on data from the nationally representative sample of carers only.

METHODS

The nationally representative sample of carers of a person with a disability or severe medical condition, or a person who was frail aged, was obtained through the Families Caring for a Person with a Disability Study (FCPDS).[8] The sample for the FCPDS consisted of 1002 primary carers receiving the Carer Payment or Carer Allowance in June 2006 who were randomly selected from the Centrelink administrative database. An initial random sample of 5000 carers (that was proportional to the total population at 19 May 2006) was drawn from the Centrelink database. The following records were excluded from the initial selection: silent telephone numbers, Centrelink customers who do not wish to participate in surveys, deceased customers, imprisoned customers or customers who were overseas. Eligible Centrelink customers were sent a brochure outlining the study's aims and advising them they could be contacted to participate, and giving them a free-call number to ring if they did not want to be contacted; 65 carers opted out of the survey at this point, leaving 4935 potential respondents.

The Australian Institute of Family Studies' ethics committee approved the study, and all participants gave their informed consent before participating.

Computer-assisted telephone interviews (CATIs) were conducted, with the contact details of random samples of potential respondents being progressively released to the CATI operators until 1002 primary carers were interviewed. Further details of the design of the survey, sampling issues, the conduct of the fieldwork, response rates and representativeness of the sample have previously been reported.[9] Importantly, 73% of the 1372 carers who were contactable by telephone and who were eligible to be interviewed agreed to participate and completed the interview. The profile of the FCPDS sample was very similar to that of carers who receive government assistance, with no significant differences with respect to the proportion of male and female carers, their state or territory of origin, and the proportion receiving different government payments to care. The FCPDS sample was slightly older than the population of payment recipients.[9]

The nationally representative sample of the general population used for the study was the Household, Income and Labour Dynamics in Australia (HILDA) Survey. This was a household-based panel study, representative of the Australian population, that began in 2001.[10] In our study, we used data from the fourth wave of this survey (August 2004 to February 2005), the most recently available at the time of analysis. The analyses were based on a sample of 10 223 non-carers from the general population.

Measures

- ***Mental health*:** the 5-item Mental Health Inventory from the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) was used to assess the mental health status of carers in the past 4 weeks.[11] Scores ranged from zero to 100, with higher scores indicating better mental health status. People who score less than 52 have been found to satisfy the clinical diagnostic criteria for depression and related disorders with high sensitivity and specificity.[12] We used this cut-off as an indicator of carers at risk of a mental health problem.
- ***Vitality:*** the vitality or energy levels of carers were assessed by the vitality subscale of the SF-36. Scores ranged from zero to 100, with higher scores indicating more vitality or energy.[11]
- ***Family functioning:*** this was assessed by five items; three adapted from the Family

1 Odds of carers being at risk of a mental health problem

Variable	Odds ratio (95% CI)	Variable (continued)	Odds ratio (95% CI)
Age (18–35 years)	1.00	Care need (low)	1.00
36–50 years	0.90 (0.46–1.75)	Medium	1.87* (1.08–3.22)
51–65 years	0.70 (0.32–1.54)	High	2.55† (1.32–4.96)
⩾66 years	0.61 (0.23–1.66)	Hours of caring a week (0–20)	1.00
Sex (male)	1.00	21–39	0.53 (0.18–1.55)
Female	0.75 (0.40–1.40)	40–59	0.94 (0.33–2.69)
Employment status (not in the labour force)	1.00	60–100	0.84 (0.31–2.30)
Employed	0.74 (0.43–1.28)	⩾101	0.90 (0.39–2.06)
Unemployed	0.55 (0.21–1.47)	Additional care roles (none)	1.00
Carer (had no partner)	1.00	One	0.53* (0.31–0.90)
Carer had a partner	0.63 (0.38–1.04)	Two or more	0.94 (0.28–3.19)
Carer's education (trade, workplace training, certificate)	1.00	Type of disability (intellectual/learning)	1.00
Diploma	1.22 (0.58–2.58)	Physical	1.41 (0.73–2.75)
University	0.66 (0.31–1.43)	Psychiatric	1.88 (0.85–4.16)
School only	0.68 (0.40–1.16)	Sensory/speech	3.26 (1.06–10.05)
Other/don't know/refused to answer	1.09 (0.32–3.66)	Multiple	1.22 (0.54–2.77)
Household income (> $600 per week)	1.00	Unassigned	4.26 (0.95–19.08)
Refused to disclose or didn't know	1.60 (0.69–3.73)	Acquired brain injury	4.10* (1.14–14.74)
$0–$100	1.17 (0.33–4.12)	Years caring (0–1)	1.00
$101–$200	0.95 (0.39–2.31)	2–3	0.61 (0.25–1.50)
$201–$300	0.36* (0.14–0.93)	4–6	1.47 (0.67–3.21)
$301–$400	1.10 (0.42–2.87)	7–12	0.66 (0.29–1.48)
$401–$500	0.53 (0.19–1.53)	⩾13	0.54 (0.23–1.30)
$501–$600	1.07 (0.37–3.12)	Family functioning (no problems)	1.00
Financial stress (no financial hardship events)	1.00	One problem	4.84‡ (2.89–8.11)
One	2.22† (1.22–4.05)	Two or more	5.92‡ (3.24–10.79)
Two or more	3.15‡ (1.78–5.57)	Social support (about right)	1.00
Number of people with a disability (one)	1.00	A little more support	1.55 (0.89–2.68)
Two	1.24 (0.67–2.30)	A lot more support	2.33‡ (1.28–4.24)
Three	2.24 (0.45–11.25)		

* $P < 0.05$. † $P < 0.01$. ‡ $P < 0.001$.

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2 Results from a multiple regression analysis for vitality of carers

Variables	B*	SE†	*t*	*P*
Intercept	76.77	9.43	8.14	0
Carer's age	–0.03	0.07	–0.45	0.65
Sex (female)	–7.00	1.88	–3.73	< 0.001
Carer had a partner	–0.08	1.76	–0.05	0.96
Financial stress	–4.13	0.79	–5.24	< 0.001
Years caring	–0.05	0.10	–0.54	0.59
Hours of caring a week	0	0.01	–0.02	0.99
Care need	–0.77	0.27	–2.87	< 0.001
Additional care roles	0.06	1.47	0.04	0.97
Employment status (Reference: Not in the labour force)				
Employed	0.20	1.79	0.11	0.91
Unemployed	2.44	3.40	0.72	0.47
Household income (Reference: $201–$300)				
Refused to disclose or didn't know	–2.62	2.49	–1.05	0.29
$0–$100	–5.63	4.05	–1.39	0.17
$101–$200	–3.75	2.32	–1.61	0.11
$301–400	–3.65	2.88	–1.27	0.21
$401–$500	–5.71	3.38	–1.69	0.09
$501–$600	–6.57	3.62	–1.82	0.07
⩾ $601	–5.25	2.94	–1.79	0.08
Type of disability (Reference: Intellectual/learning)				
Psychiatric	2.65	2.18	1.22	0.22
Sensory/speech	–1.9	2.34	–0.81	0.42
Multiple	1.27	3.71	0.34	0.73
Unassigned	0.12	2.13	0.06	0.96
Acquired brain injury	2.80	4.90	0.57	0.57
Carer's education (Reference: Less than Year 11)				
University	0.28	8.01	0.03	0.97
Trade, workplace training, certificate	–0.75	7.77	–0.10	0.92
Year 12	–0.49	7.75	–0.06	0.95
Refused to answer	–7.64	8.75	–0.87	0.38
Family functioning problems	–8.97	1.06	–8.51	< 0.001
Social support (Reference: About right)				
Needs a lot more support	–8.33	2.03	–4.10	< 0.001
Needs a little more support	–6.86	1.78	–3.86	< 0.001

* Unstandardised multiple regression coefficient. † Standard error.

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Relationship Inventory, one from the Family Adaptability and Cohesion Evaluation Scales IV, and one developed by the first author.[9] Carers were asked whether they strongly agreed, agreed, disagreed or strongly disagreed with each of the five items. As previous studies of family functioning have indicated that problems in just one dimension of family functioning can have implications for mental health,[13] we summed carers' responses to the five items to indicate the number of the five different dimensions of family functioning on which problems occurred.

- ***Support needs of the carer*****:** these were assessed by the question, "Now thinking about the support you receive in providing care for [name of person with a disability] overall, do you feel that YOU need: a lot more support, a little more support or is the support you are getting now about right?" (adapted from the Arizona Social Support Interview Schedule[14]).
- ***Level of care need of the person with the disability*****:** this was assessed through a series of age-specific questions that were used in the Australian Bureau of Statistics Survey of Disability, Ageing and Carers and the 2006 Australian Census.[8] Scores ranged from zero to 12, and responses to the six questions were summed. As 120 carers were caring for more than one person with a disability, we used the highest level of care needs reported for anyone under their care. To ease interpretation in the statistical analyses, the scores on the level of care needs were divided into three groups: low (0–4), medium (5–8) and high (9–12).
- ***Type of disability:*** this was derived from a question to the carer about the primary medical diagnosis or disability of the person with the disability. The five major categories used by the National Community Services Data Dictionary were used, along with a category for multiple medical or disabling conditions and an unassigned category (where carers' responses did not provide sufficient information to be categorised).[15]
- ***Other caregiving characteristics:*** these included the number of people with a disability (one, two or three), hours of caring per week, years of caring, and whether carers also played a role caring for people who were not disabled (eg, children or ageing parents). As some carers were caring for more than one person with a disability, we used the highest number of hours caring per week and the years caring reported for any one of the people with a disability being cared for.
- ***Financial hardship:*** this was measured by asking participants whether their family had experienced any of four financial hardship events this year because of a shortage of money. These hardships were: "Could not pay electricity or the telephone bills on time"; "Could not pay the mortgage or rent on time"; "Pawned or sold something"; and "Asked for financial help from friends or family". These financial hardships were also included in the HILDA Survey. The internal consistency for the scale of financial stress was 0.73 for the FCPDS and 0.70 for the HILDA Survey.
- ***Other sociodemographic variables:*** these included carer's sex, whether he or she had a partner, age, employment status (employed, unemployed, not in the labour force), education status and household income. The number of adults and children in the household was taken into account when calculating household income. This is referred to as "equivalised household income", as it

attempts to take into account the costs of living of households with different family sizes. Household income was equivalised using the Organisation for Economic Co-operation and Development equivalence scale.[16]

Statistical analysis

One of the limitations of unadjusted measures of mental health and vitality of carers and people in the general population is that carers may be systematically different to the general population on a range of other variables that may, in turn, be associated with their mental health and vitality. To control for this selection bias, we used logistic regression to examine risk of depression, and multiple regression to model vitality (because it is a continuous measure). Data common to the FCPDS and HILDA Survey were integrated into a single dataset so that carers' risk of depression and levels of vitality could be compared with those of the general population while controlling for age, sex, employment status (not in the labour force, employed, unemployed), whether the person had a partner, household income and the experience of financial hardship events. In the second set of regression models, we used FCPDS data so that we could include additional risk factors in the model that are specific to the caregiving experience. These additional risk factors are included in Box 1.

RESULTS

Carers were 1.95 times more likely to be at risk of clinical levels of depression (odds ratio [OR], 1.95; 95% CI, 1.64–2.30; 17.5% v 9.9%; $P > 0.001$) and vitality was significantly lower (14 points) than for non-carers in the general population (B [unstandardised multiple regression coefficient] = –14.55; SE [standard error], 0.09; $t = -12.27$; $P < 0.001$). After controlling for demographic characteristics, carers were still 1.42 times more likely to be at risk of clinical levels of depression (OR, 1.42; 95% CI, 1.15–1.76; $P < 0.001$) and vitality was still significantly lower (by 6 points) than for non-carers (B = –6.01; SE, 0.76; $t = -7.86$; $P < 0.001$).

The risk factors that were associated with poorer mental health within the group of carers were the same as those for vitality (see Box 1 and Box 2). Carers who cared for a person with a disability with high care needs were more likely to have a mental health problem and lower levels of vitality than people caring for someone with low or moderate care needs. Carers were more likely to have a mental health problem and have lower levels of vitality if they reported problems in family functioning, lack of support and financial hardship.

DISCUSSION

Carers of a person with a disability had an increased risk of mental health problems and lower levels of vitality compared with the general population, even after adjusting for factors that may be associated with becoming a carer. These differences are consistent with evidence from international reviews and population-based studies from overseas,[17,18] and major large-scale Australian studies on this issue.[1,3]

The rate of mental health problems in the previous 4-week period was 17.5% for carers, while for the general population it was 9.9%. Although these estimates of clinical levels of depression may appear high, the Carer Health and Wellbeing Survey reported that when carers reported on how they were feeling over the past week, 56% had clinical levels of depression (19% extremely severe, 18% severe, 19% moderate).[1] We attribute our lower estimates to differences in the sampling frames. The FCPDS had a 73% response rate from a representative sample of carers receiving government payments, whereas in the Carer Health and Wellbeing Survey, members of the state- or territory-based carer associations were invited to participate, and a lower proportion (37%) of this target population participated. Given the lower response rate, the Carer Health and Wellbeing Survey may have been more open to self-selection bias. Nevertheless, the rates of mental health problems in both studies are very high, and the mental health of carers is clearly a concern.

The risk factors associated with increased risk of mental health problems and lower levels of vitality are also consistent with previous research in this area. For instance, family functioning has also been reported to be an important correlate of mental health in Australian studies of carers of cancer patients and their families.[13,19] The importance of informal social support by friends or relatives has also been well documented.[2] Moreover, a variety of studies show that high care needs of people with a disability are associated with lower energy levels and worse mental health for carers.[2]

Financial hardship was also a risk factor for mental health problems and lower levels of vitality. It was recently reported that a higher proportion of families in this sample of carers (from the FCPDS) experienced greater financial hardship than families from the general population, which is consistent with other Australian research showing that financial hardship is more prevalent where there is someone in the household with a disability.[20] Referring carers and their families to free or low-cost community support resources available in the area may be one way that medical practitioners can help.

These findings are particularly important for GPs and other doctors who may come in contact with people with a disability — and their carers (see Box 3). As part of the overall plan for ensuring the care needs of people with a disability are met, it would be beneficial for doctors to consider the mental health and vitality of their carers, particularly those who are caring for someone with high care needs. Suggesting ways for carers to look after their own health and wellbeing, sharing the burden of caring, and seeking support for themselves are all useful strategies that are supported by research evidence on the impact of caring on carers. If GPs and other doctors are aware of the risks that carers face, they may be able to offer other assessments and, where necessary, referral for appropriate treatment and support. Because the needs of people with a disability — and the needs of family members providing care to them — are intricately linked, family-based interventions may be useful.[21]

Although our sample was representative of carers receiving government payments, it may not have been representative of the more general population of carers in Australia. However, some 504 000 carers receive government payments and our results are

3 Key issues for practice

- Consider the mental health and vitality of the carer in the overall plan for ensuring the care needs of the person with a disability are met, particularly for a patient with high care needs.
- Suggest ways carers can look after their own health and wellbeing, such as sharing the caring with other relatives and seeking support for themselves.
- Offer to provide other assessments and, where necessary, referral for appropriate treatment and support.
- Family-based interventions may be useful, as the needs of people with a disability and the needs of family members providing care are linked.

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consistent with other studies of carers in the general population.[1,3]

Because of the ageing of the population, the number of people requiring care is likely to increase.[7] Given that carers are at greater risk of mental health problems than other people, medical practitioners need to be aware of this and the consequences, not only for carers, but also for their continued availability and quality of care for the person with a disability.

ACKNOWLEDGEMENTS

The Australian Government Department of Families, Housing, Community Services and Indigenous Affairs funded the data collection for the Families Caring for a Person with a Disability Project. However, the findings and views reported here are those of the authors and should not be attributed to either the Department or the Australian Institute of Family Studies. We thank the carers who were generous enough with their time to be interviewed. We also thank Matthew Gray, Norbert Zmijewski and Marcia Kingston for their comments on an earlier version of this manuscript, and a range of experts who were consulted when developing the interview schedule.

COMPETING INTERESTS

None identified.

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REFERENCES

1 Cummins RA, Hughes J, Tomyn A, et al. Australian Unity Wellbeing Index Survey 17.1. The wellbeing of Australians — carer health and wellbeing. Melbourne: Deakin University, Carers Australia and Australian Unity, 2007. http://acqol.deakin.edu.au/index_wellbeing/Survey_17.1.pdf (accessed Feb 2009).

2 Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003; 18: 250-267.

3 Schofield H, Bloch S, Herrman H, et al, editors. Family caregivers: disability, illness and ageing. Melbourne: Allen and Unwin, 1998.

4 Australian Bureau of Statistics. Disability, ageing and carers, Australia: summary of findings 2003. Canberra: ABS, 2004. (ABS Cat. No. 4430.0.) http://www.abs.gov.au/ausstats/ABS@.nsf/7d12b0f6763c78caca257061001cc588/c258c88a7aa5a87eca2568a9001393e8!OpenDocument (accessed Feb 2009).

5 Australian Government Department of Family and Community Services. Annual report 1999–2000. Canberra: FaCS, 2000.

6 Australian Government Department of Families, Community Services and Indigenous Affairs. FaCSIA annual report 2006–2007. Canberra: FaCSIA, 2007. http://www.facsia.gov.au/annualreport/2007/default.htm (accessed Feb 2009).

7 Australian Institute of Health and Welfare. Carers in Australia. Assisting frail older people and people with a disability. Aged Care Series No. 8. Canberra: Australian Institute of Health and Welfare, 2004. (AIHW Cat. No. AGE 41). http://www.aihw.gov.au/publications/age/cia/cia.pdf (accessed Feb 2009).

8 Edwards B, Higgins DJ, Zmijewski N. The Families Caring for a Person with a Disability Study and the social lives of carers. *Fam Matters* 2007; 76: 8-17.

9 Edwards B, Higgins DJ, Gray M, et al. The nature and impact of caring for family members with a disability in Australia. Research Report 16. Canberra: Australian Institute of Family Studies, 2008. http://www.aifs.gov.au/institute/pubs/resreport16/main.html (accessed Feb 2009).

10 Watson N, Wooden M. Assessing the quality of the HILDA Survey wave 2 data HILDA Project Technical Paper Series 5/04. Melbourne: Melbourne Institute of Applied Economic and Social Policy, University of Melbourne, 2004. http://www.melbourneinstitute.com/hilda/hdps/htec504.pdf (accessed Feb 2009).

11 Ware JE, Kosinski M, Gandek B. SF-36 health survey: manual and interpretation guide. Lincoln, RI: QualityMetric Incorporated, 2002.

12 Berwick DM, Murphy JM, Goldman PA, et al. Performance of a five-item mental health screening test. *Med Care* 1991; 29: 169-176.

13 Edwards B, Clarke V. The validity of the family relationships index as a screening tool for psychological risk in families of cancer patients. *Psychooncology* 2005; 14: 546-554.

14 Barrera MJ. Social support in the adjustment of pregnant adolescents. In: Gottlieb BH, editor. Social networks and social support. Beverly Hills, Calif: Sage Publications, 1981: 69-96.

15 National Community Services Data Dictionary Committee. National community services data dictionary, version 4. Canberra: Australian Institute of Health and Welfare, 2006. (AIHW Cat. No. HWI 91.) http://www.aihw.gov.au/publications/index.cfm/title/10243 (accessed Feb 2009).

16 De Vos K, Zaidi MA. Equivalence scale sensitivity of poverty statistics for the member states of the European Community. *Rev Income Wealth* 1997; 43: 319-333.

17 Cochrane J, Goering PN, Rogers JM. The mental health of informal caregivers in Ontario: an epidemiological survey. *Am J Public Health* 1997; 87: 2002-2007.

18 Hirst M. Carer distress: a prospective, population-based study. *Soc Sci Med* 2005; 61: 697-708.

19 Kissane DW, Bloch S, Burns WI, et al. Psychological morbidity in the families of patients with cancer. *Psychooncology* 1994; 3: 47-56.

20 Saunders P. The costs of disability and the incidence of poverty, Social Policy Research Centre Discussion Paper 147. Sydney: SPRC, 2006. http://www.sprc.unsw.edu.au/dp/DP147.pdf (accessed Feb 2009).

21 Wade SL, Carey J, Wolfe CR. An online family intervention to reduce parental distress following pediatric brain injury. *J Consult Clin Psychol* 2006; 74: 445-454.

(Received 29 Jul 2008, accepted 19 Dec 2008) ❏