

1 **Title**

2 Health status of people who have provided informal care or support to an adult with chronic disease
3 in the last 5 years: results from a population-based cross-sectional survey in South Australia

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25 **Competing interests**

26 The authors declare no competing interests

27

28 **Abstract**

29 **Objective**

30 To explore health status of South Australians with recent experience of caring for an adult with
31 chronic disease, vis-à-vis non-carers.

32 **Methods**

33 The South Australian Health Omnibus is an annual, population-based, cross-sectional survey.
34 Respondents were asked whether they had provided care or support in the last 5 years to someone
35 with cancer, heart disease, respiratory disease, mental illness, neurological disease or dementia.
36 Health status was measured using SF-12 physical and mental component scale summary scores (PCS
37 and MCS), with poor health status defined as ≥ 0.5 standard deviation below the normative mean.
38 Logistic regression explored characteristics associated with poor health status.

39 **Results**

40 Of 3033 respondents analysed, 987 (32.5%) reported caring experience. Poor PCS and MCS were
41 associated with carer status, lower-than-degree education, employment status other than
42 employed, and annual household income $< \$60k$. Protective factors for PCS were being Australian-
43 born, and, for MCS, being married/defacto and ≥ 65 years.

44 **Conclusions**

45 Providing care or support in the last 5 years is independently associated with poorer health status,
46 but not to the magnitude found in studies of current carers. Future research should explore health
47 status recovery after completing the caring role, and investigate whether relationships between
48 health and socioeconomic status differ for carers versus non-carers.

49

50 **Key question summary**

51 **What is known about the topic?**

52 Population-based survey studies in Australia and overseas have consistently found that informal
53 carers have worse health status than non-carers.

54

55 **What does this paper add?**

56 Including recent as well as current carers in a population-based sample was associated with less
57 influence on health status compared with studies focused on current carers only. This finding is
58 consistent with the possibility that health status recovers during the 5 years post caring.

59

60 **What are the implications for practitioners?**

61 Support for Australian carers is warranted to ensure their continuing contributions to society and
62 return to productivity after their caring role is completed.

63 **Introduction**

64 In Australia in 2015, 2.7 million (11.6%) of the population were informal carers (1). The financial
65 value of caring to Australia includes cost savings both from reduction in the need for community
66 healthcare (estimated to equal \$60.3 billion in 2015 (2)) and decreased likelihood of care recipients
67 being admitted to long-term care (3).

68 However, the societal value of informal caring comes at a personal cost to carers themselves. In the
69 2012 National Survey of Disability, Ageing and Carers, the majority (54%) of Australian carers
70 reported negative impacts on their wellbeing as a result of caring (4). Australian research has
71 suggested that carers may be at greater risk than non-carers of poor mental and, to a lesser extent,
72 physical health (5-11). These studies have focused, respectively, on carers of elderly people living in
73 Sydney (N=208) (7), carers of people with a disability or other long-term health condition in New
74 South Wales more generally (N=222 (8) and N=153 (10)), older carers providing care to a person they
75 live with in Victoria (N=202) (5), and three national samples of people either caring for someone with
76 a disability ((N=1002) (6) and (N=424) (9)) or with unspecified needs (N=4190 (11)). All studies to
77 date have focused on people with current caring experience, so have not assessed whether health
78 and wellbeing recover after caring comes to an end. Only two of the studies (7, 9) included a
79 comparison group of non-carers drawn from the same population as the carers rather than relying
80 on normative data reported in other studies.

81 The current study aimed to explore mental and physical health status of people with recent
82 experience of caring for an adult with chronic illness, vis-à-vis non-carers from the same population-
83 based sample in South Australia.

84 **Design**

85 A cross-sectional survey was conducted from September to November 2016. The Health Omnibus
86 has been conducted annually of the South Australian population since 1991. Researchers 'buy'

87 questions to include in the survey alongside sociodemographic questions and the Short Form-12
88 version 1 (SF-12) health status measure (12). A commercial company employs trained interviewers
89 to administer the survey. Independently, the current authors conducted analysis. Ethics approval
90 was granted from the University of Adelaide Ethics Committee. Reporting has been guided by
91 Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria (13).

92 With one exception (14), carer-related data collected by the Health Omnibus over previous years
93 have focused on caring at the end of life and/or regarding specific diseases such as cancer, heart
94 failure and neurodegenerative disease (15-27).

95 **Sample**

96 Sampling used a multi-stage, systematic approach. A total of 5300 households were randomly
97 selected, 75% from the capital, Adelaide, and 25% from country centres with ≥ 1000 inhabitants in
98 each statistical area, with probability of selection being proportional to the centre's size. One person
99 aged 15 years and over was randomly selected from each household to complete the survey.

100 Weighting was applied to the final survey data by sex, five-year age groups and geographic area to
101 ensure that the sample mirrored the demographic profile of South Australia.

102 **Procedure**

103 The survey was administered in a face-to-face structured interview by a trained interviewer in
104 respondents' homes for 60-90 minutes each. Ten percent of respondents were re-contacted and
105 interviewed again on selected questions to validate original responses. Data were double-entered to
106 ensure accuracy. Prior to the main survey, a pilot study of 50 interviews were conducted to test
107 questions and procedures.

108 The survey comprised approximately 200 questions across a large range of topics, but this paper
109 focuses on a single item that asked respondents whether they had experience in the last 5 years of
110 providing care or support to an adult with one or more of the following chronic diseases: cancer,

111 heart disease (e.g. heart failure), respiratory disease (e.g. emphysema), mental illness (e.g.
112 depression, schizophrenia), neurological disease (e.g. Parkinson's, stroke) or dementia. These six
113 diseases were selected because they confer a high burden of disability that requires carer input and
114 support over an extended period across the illness trajectories.

115 Sociodemographic questions asked about respondents' gender, age, country of birth, Aboriginal
116 and/or Torres Strait Islander status, marital status, highest qualification and employment.

117 Respondents were also asked about their household's postcode, number of inhabitants and income.

118 The SF-12 includes 12 items grouped into scales measuring overall health, role functioning as a result
119 of physical and emotional health, physical functioning, mental health, social functioning, pain and
120 vitality (12). These scales are summarised into overall physical health (PCS) and mental health (MCS)
121 component summary scores. All scales refer to experience over the past 4 weeks, except general
122 health, which does not specify a recall period. The SF-12 is scored using population norms to
123 transform scores to be out of a possible 100, with 50 the mean score and a standard deviation (SD)
124 of 10. The current study used norms derived from the Australian Bureau of Statistics (ABS) 1995
125 Australian National Health Survey dataset (28). The SF-12 has been validated in general and clinical
126 populations in many countries, including Australia (29).

127 **Analysis**

128 People reporting caring experience in the last 5 years ('carers') were compared with people
129 reporting no such experience ('non-carers') for differences on sociodemographic characteristics and
130 the SF-12 PCS and MCS scales using chi-squares, Mann-Whitney or t-tests as appropriate, with
131 statistical significance set at $p < 0.05$. Because statistically significant differences may not be clinically
132 important, differences on the SF-12 were also defined in terms of minimal important difference
133 (MID) – the smallest difference likely to be perceived as beneficial or harmful (30). While MID's have
134 been estimated for some clinical conditions (e.g. (31)), we used a more generic estimate that

135 acknowledges these may not be standard across different populations, namely 0.5 standard
136 deviation (SD) (32). Following this rule of thumb, we defined 'poor' PCS and MCS as ≥ 0.5 SD lower
137 than the mean based on national normative data (28). Univariate analyses using chi-square
138 compared proportions of respondents reporting poor PCS or MCS based on age (\geq / $<$ 65 years), sex,
139 Aboriginal and/or Torres Strait Islander status, country of birth (Australia vs overseas), marital status
140 (married/defacto vs other), education level (degree or higher vs other), household income ($>$ / \leq \$60k
141 per annum), and metropolitan vs rural status. The cut-off for age was selected based on eligibility for
142 receiving an age pension from the federal government, while the cut-off for household income was
143 selected as the lower end of the Health Omnibus category containing the 2016 median income for
144 South Australians (\$62,712 per annum (33)). We retained participant characteristics associated with
145 perceived benefit at a $p < 0.25$ level as covariates in a binary logistic regression model of adjusted
146 relationships with poor PCS and MCS, calculating 95% confidence intervals (CIs) (34). Goodness of fit
147 was assessed using Pearson chi-square. Statistical significance for regression analyses was set at
148 $p < 0.05$. Data were analysed using SPSS V23.0 statistical software.

149 Results

150 Of these, 987 (32.5%) self-identified as carers. Carers were significantly older than non-
151 carers (mean age 47.82 years [SD 18.23] vs 46.43 years [SD 19.97]; $t = -1.85$, $p < 0.001$). Compared with
152 non-carers, carers were significantly more likely to be female (56.7% [560/987] vs 48.0% [982/2046];
153 chi-square=20.36; $p < 0.001$), born in Australia (78.4% [774/987] vs 68.1% [1393/2046]; chi-
154 square=34.86; $p < 0.001$), employed either full or part-time (58.5% [577/986] vs 53.1% [1086/2044];
155 chi-square=7.80; $p = 0.005$), and own their own house (72.6% [714/983] vs 68.0% [1383/2034]; chi-
156 square=6.73, $p = 0.009$) (see Table 1).

157 *Table 1 about here*

158 Mean SF-12 scores for the whole sample were 49.79 (SD 10.24) on the PCS and 50.52 (SD 9.71) on
159 the MCS. Mean scores on the SF-12 were significantly lower for carers versus non-carers both for
160 PCS (48.31 [SD 10.61] vs 50.51 (SD 9.99); $t=5.56$ [95% CI 1.42 to 2.97]; $p<0.001$) and MCS (49.22 [SD
161 10.08] vs 51.15 [SD 9.48]; $t=5.13$ [95% CI 1.19 to 2.66]; $p<0.001$), although differences between
162 means did not meet a MID magnitude in either case. Significantly higher proportions of carers versus
163 non-carers reported poor PCS (29.1% [287/987] vs 22.5% [460/2047]; $\text{chi-square}=15.66$; $p<0.001$)
164 and MCS (25.9% [256/987] vs 21.4% [437/2046]; $\text{chi-square}=7.83$; $p=0.005$).

165 In univariate analyses, all respondent characteristics were associated with poor PCS and MCS at the
166 $p<0.25$ level, with the exception of Aboriginal and/or Torres Strait Islander status, which could not
167 be analysed because of the small proportion (1.4%) self-identifying with this status.

168 In multivariate analyses, being a carer continued to be significantly associated with reporting poor
169 PCS and MCS after adjusting for other characteristics. Other characteristics retaining statistically
170 significant relationships in the regression model are summarised in Table 2. Goodness of fit for the
171 PCS and MCS models was as follows: PCS Pearson $\text{chi-square}=38.48$, $p=0.055$; MCS Pearson chi-
172 $\text{square}=69.02$, $p=0.10$).

173 *Table 2 about here*

174 **Discussion**

175 Our study is among the largest population-based study to have explored health status in Australian
176 carers of people with chronic disease, and the first to include people with recent but concluded
177 caring experience, as well as current. This difference is the most likely explanation for the
178 substantially higher prevalence of carers versus non-carers we observed compared to other
179 Australian population-based surveys (1, 11, 14). Our research joins several studies focusing on
180 current carers in finding a relationship between carer status and poor physical as well as mental
181 health, in contrast to others that have identified an association with poor mental health status alone

182 (35-38). While health status in people with caring experience was also lower than that for non-carers
183 based on mean, this difference did not reach a MID magnitude for either physical or mental
184 domains. This difference was less than that found in studies of current carers (5-11), giving hope that
185 health status may recover after people complete their caring role.

186 Our findings contribute to mixed evidence on the influence of gender on carer health status and
187 wellbeing, which a meta-analysis has concluded may be observable but 'small to very small' across
188 the literature (37). Whilst we joined some other studies in finding that women tended to report
189 poorer health status than men, this difference was not retained in multivariate analyses adjusting for
190 other characteristics. Our study joins the majority of previous research in finding a correlation
191 between age and mental health status but, unlike some studies, age was correlated with only
192 mental, not physical, health status after controlling for other variables (35, 38). Moreover, we found
193 older age protective of mental health status, which aligns more with previous studies on stress than
194 with those on depression, which have found older age to be a risk factor.

195 Our finding that being employed was protective of health status contradicts another large-scale
196 Australian carer study by Kenny et al (2014), which found this to be a risk factor, especially in the
197 context of high caring hours (9). Given that employment is associated with better health status in
198 the general population (40), this difference may be a further reflection of the fact we included past
199 as well as current carers, consistent with the relatively high employment rates we found in carers
200 versus non-carers compared to other studies (1, 11, 14). Indeed, given that some people experience
201 a loss of meaning and identity when their role as carer is completed (41), research is needed to
202 explore whether people derive additional psychological and/or physical benefits from employment
203 when returning to work after caring has ended.

204 Our study replicates consistent findings that poor health status and wellbeing in carers are
205 associated with lower education and income both in carers (35, 38) and the general population (42).

206 Further research is needed to explore whether reasons underlying relationships between

207 socioeconomic status and health status differ for carers versus non-carers. For example, lower
208 socioeconomic status correlates with poor health literacy, which may present barriers to healthy
209 lifestyles and health service access regardless of carer status (43). At the same time, these problems
210 may be compounded for carers by the additional financial burden of illness within a family and the
211 low priority carers often accord to self-care (44).

212 Two further findings from the current study consistent with research conducted in general
213 populations concerns the protective effects of being in a married/defacto relationship and of being
214 born overseas. Being married has been found to confer a health benefit across a variety of
215 measures, including mortality (45). The 'healthy migrant' effect is likely to be more nuanced and
216 depend on timing and years since migration, as well as inter-relationships with other determinants
217 of health such as socioeconomic status and healthcare access (46). As for socioeconomic status, it is
218 unclear whether relationships between health status and marital and migrant status in the current
219 study resulted from additional, carer-specific reasons.

220 It is worth noting that, due to population ageing and other societal changes, there is increasing
221 demand for carers but decreasing availability, rendering people prepared to take on the caring role a
222 precious resource (2). Ensuring the health and wellbeing of carers is important not only in enabling
223 them to continue caring, but also in promoting the role to other, would-be carers. A range of
224 approaches have been attempted to improving carer health and wellbeing, with varying evidence for
225 effectiveness (47). However, few intervention studies have targeted the period of transition from
226 carer to non-carer after the role has been completed. Indeed, support services tend to withdraw at
227 this time, especially for carers who have relinquished their role to long-term care rather than been
228 bereaved. A better understanding of the phases of caring and transitions between these is needed
229 to inform strategies that support recovery through preparation, screening and early intervention.
230 Future cost-effectiveness studies are needed that measure carers' societal contributions not only

231 during the time they are caring but also when they return to economic and societal productivity
232 afterwards (2).

233 **Limitations**

234 The cross-sectional nature of the current study means that correlations should not be interpreted as
235 evidence of causal relationships. Our survey used a sampling method and weighting to ensure
236 representativeness of the South Australian general population, and SF-12 scores were similar to
237 published 2003 estimates for this population (mean PCS 48.9 and MCS 52.4) (39). However,
238 comparability with data from other carer research is limited not only by our inclusion of past as well
239 as current carers, but also our expansion of the carer definition to include people providing
240 'support'. This was intended to acknowledge the less intensive but nonetheless important
241 contributions of extended networks who may not identify with the role of carer (48). It should also
242 be noted that this study examined relationships between self-reported health status and only a
243 relatively small range of sociodemographic variables. To enable comparability between carers and
244 non-carers, our analyses omitted variables relating to care recipients, care provided and informal
245 support that have been found associated with carer health status in previous research (35, 37, 38).
246 Given this was the first population-based study to include people with past as well as current caring
247 experience, additional questions about the timeline of this experience would have enabled further
248 analyses exploring whether health status recovers after the caring role is completed. Asking
249 respondents about the reason their caring role ended might also have been useful in distinguishing
250 people whose dependent recovered versus those who were admitted into long-term care or died.
251 Whilst it might seem intuitive that people whose dependent recovered are likely to experience the
252 most positive change in health status, research suggests that the determinants of health and
253 wellbeing for past carers following admission to long-term care or bereavement are multiple and
254 complex (49, 50).

255 Finally, the study's focus on potential negative impacts of caring does not deny that many carers
256 perceive there to be positive benefits from their experience (51) and may report average or even
257 above average health status during their time caring. Gaining a better understanding of how carers
258 maintain or recover health status would be valuable for informing interventions to support those
259 who are struggling.

260 **Conclusion**

261 This study found that South Australians with caring experience in the last 5 years are more likely
262 than non-carers to report poor health status. However, the smaller differences we observed
263 compared with research on current carers gives hope that people may recover health status after
264 their caring role is ended. More research is needed to explore this, as well as whether
265 socioeconomic determinants that influence health status in the general population interact with
266 carer-specific concerns to confer additional impact. Support for carers is warranted to ensure their
267 continued contribution to Australian society both during the time they are caring and after this role
268 has been completed.

269 **Competing Interests**

270 The authors declare no competing interests.

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Table 1. Characteristics of carers and non-carers responding to health status survey questions

Respondent characteristics	Frequency (%)	
	Carers (n=987)	Non-carers (n=2046)
Age (years)		
15-24	139 (14.1)	337 (16.5)
25-34	128 (13.0)	372 (18.2)
35-44	146 (14.8)	318 (15.5)
45-54	201 (20.4)	296 (14.5)
55-64	174 (17.6)	281 (13.7)
≥65	198 (20.1)	442 (21.6)
Female*	560 (56.7)	982 (48.0)
Aboriginal and/or Torres Strait Islander	18 (2.3)	25 (1.8)
Born in Australia*	774 (78.4)	1393 (68.1)
Marital status [#]		
Never married	224 (22.6)	516 (25.2)
Married/de facto	617 (62.4)	1239 (60.6)
Widowed/separated/divorced	147 (14.9)	291 (14.2)
Education level [#]		
Still at school	29 (2.9)	95 (4.5)
Left school at ≤15 years	93 (9.4)	194 (9.5)
Left school >15 years	187 (18.9)	407 (19.9)
Left school >15 years, still studying	59 (6.0)	120 (5.8)
Trade qualification	122 (12.3)	255 (12.4)
Certificate/diploma	274 (27.7)	453 (22.2)
Degree or above	224 (22.6)	520 (25.4)
Work status [#]		
Working full or part time*	577 (58.5)	1,086 (53.1)
Home duties	63 (6.4)	121 (5.9)
Unemployed	21 (2.1)	59 (2.9)
Retired	201 (20.4)	441 (21.6)
Student	69 (7.0)	234 (11.4)
Not working due to injury/disability	42 (4.2)	72 (3.5)
Other	13 (1.0)	30 (1.5)
Annual household income (\$) [#]		
Up to \$20,000	61 (7.8)	125 (6.1)
\$20,001 - \$40,000	154 (19.8)	284 (13.9)
\$40,001 - \$60,000	135 (17.3)	214 (10.4)
\$60,001 - \$100,000	170 (21.8)	350 (17.1)
\$100,001 - \$140,000	127 (16.3)	282 (13.8)
≥\$140,001	132 (16.9)	261 (12.8)
Housing [#]		
Owned or being purchased*	714 (72.3)	1,383 (68.0)
Rented from Housing SA	57 (5.8)	99 (4.9)
Rented privately	183 (18.5)	521 (25.6)
Community housing	15 (1.5)	13 (0.6)
Retirement village	10 (1.0)	13 (0.6)
Other	4 (0.4)	4 (0.2)
Metropolitan (versus rural)	749 (75.9)	1528 (74.7)

395 *Carers differed from non-carers at $p < 0.01$ level; # numbers do not add up to overall sample size due

396 to missing data

397 **Table 2.** Respondent characteristics found by a logistic regression to be significantly associated with
 398 poor physical or mental health status in a population-based sample of South Australian carers
 399 (n=987) and non-carers (n=2046)

Characteristic	Physical health status				Mental health status			
	P value	Exp(B)	95% CI for EXP(B)		P value	Exp(B)	95% CI for EXP(B)	
			Lower	Upper			Lower	Upper
Carer	<0.001	1.50	1.21	1.84	0.007	1.34	1.083	1.66
Graduate or above	0.003	0.67	0.51	0.87	0.019	0.73	0.56	0.95
Employed full or part time	<0.001	0.33	0.27	0.42	<0.001	0.37	0.29	0.48
≥\$60k household income	<0.001	0.51	0.41	0.64	<0.001	0.45	0.35	0.57
Born in Australia	0.002	1.44	1.14	1.82	-	-	-	-
Age ≥65 years	-	-	-	-	0.002	0.65	0.50	0.85
Married/defacto	-	-	-	-	0.020	0.77	0.62	0.96

400 *CI = confidence intervals*

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