Title

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

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Competing interests

The authors declare no competing interests
Abstract

Objective

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

Methods

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

Results

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

Conclusions

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

What is known about the topic?

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

What does this paper add?

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

What are the implications for practitioners?

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

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

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

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

Design

A cross-sectional survey was conducted from September to November 2016. The Health Omnibus has been conducted annually of the South Australian population since 1991. Researchers ‘buy’
questions to include in the survey alongside sociodemographic questions and the Short Form-12 version 1 (SF-12) health status measure (12). A commercial company employs trained interviewers to administer the survey. Independently, the current authors conducted analysis. Ethics approval was granted from the University of Adelaide Ethics Committee. Reporting has been guided by Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria (13).

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

Sample

Sampling used a multi-stage, systematic approach. A total of 5300 households were randomly selected, 75% from the capital, Adelaide, and 25% from country centres with ≥1000 inhabitants in each statistical area, with probability of selection being proportional to the centre’s size. One person aged 15 years and over was randomly selected from each household to complete the survey. Weighting was applied to the final survey data by sex, five-year age groups and geographic area to ensure that the sample mirrored the demographic profile of South Australia.

Procedure

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

The survey comprised approximately 200 questions across a large range of topics, but this paper focuses on a single item that asked respondents whether they had experience in the last 5 years of providing care or support to an adult with one or more of the following chronic diseases: cancer,
heart disease (e.g. heart failure), respiratory disease (e.g. emphysema), mental illness (e.g. depression, schizophrenia), neurological disease (e.g. Parkinson’s, stroke) or dementia. These six diseases were selected because they confer a high burden of disability that requires carer input and support over an extended period across the illness trajectories.

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

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

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

**Analysis**

People reporting caring experience in the last 5 years (‘carers’) were compared with people reporting no such experience (‘non-carers’) for differences on sociodemographic characteristics and the SF-12 PCS and MCS scales using chi-squares, Mann-Whitney or t-tests as appropriate, with statistical significance set at p<0.05. Because statistically significant differences may not be clinically important, differences on the SF-12 were also defined in terms of minimal important difference (MID) – the smallest difference likely to be perceived as beneficial or harmful (30). While MIDs have been estimated for some clinical conditions (e.g. (31)), we used a more generic estimate that
acknowledges these may not be standard across different populations, namely 0.5 standard deviation (SD) (32). Following this rule of thumb, we defined ‘poor’ PCS and MCS as ≥0.5 SD lower than the mean based on national normative data (28). Univariate analyses using chi-square compared proportions of respondents reporting poor PCS or MCS based on age (≥/< 65 years), sex, Aboriginal and/or Torres Strait Islander status, country of birth (Australia vs overseas), marital status (married/defacto vs other), education level (degree or higher vs other), household income (>/$60k per annum), and metropolitan vs rural status. The cut-off for age was selected based on eligibility for receiving an age pension from the federal government, while the cut-off for household income was selected as the lower end of the Health Omnibus category containing the 2016 median income for South Australians ($62,712 per annum (33)). We retained participant characteristics associated with perceived benefit at a p<0.25 level as covariates in a binary logistic regression model of adjusted relationships with poor PCS and MCS, calculating 95% confidence intervals (CIs) (34). Goodness of fit was assessed using Pearson chi-square. Statistical significance for regression analyses was set at p<0.05. Data were analysed using SPSS V23.0 statistical software.

Results

Of these, 987 (32.5%) self-identified as carers. Carers were significantly older than non-carers (mean age 47.82 years [SD 18.23] vs 46.43 years [SD 19.97]; t=−1.85, p<0.001). Compared with non-carers, carers were significantly more likely to be female (56.7% [560/987] vs 48.0% [982/2046]; chi-square=20.36; p<0.001), born in Australia (78.4% [774/987] vs 68.1% [1393/2046]; chi-square=34.86; p<0.001), employed either full or part-time (58.5% [577/986] vs 53.1% [1086/2044]; chi-square=7.80; p=0.005), and own their own house (72.6% [714/983] vs 68.0% [1383/2034]; chi-square=6.73, p=0.009) (see Table 1).
Mean SF-12 scores for the whole sample were 49.79 (SD 10.24) on the PCS and 50.52 (SD 9.71) on the MCS. Mean scores on the SF-12 were significantly lower for carers versus non-carers both for 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 10.08] vs 51.15 [SD 9.48]; t=5.13 [95% CI 1.19 to 2.66]; p<0.001), although differences between means did not meet a MID magnitude in either case. Significantly higher proportions of carers versus non-carers reported poor PCS (29.1% [987/287] vs 22.5% [460/2047]; chi-square=15.66; p<0.001) and MCS (25.9% [256/987] vs 21.4% [437/2046]; chi-square=7.83; p=0.005).

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

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

Table 2 about here

Discussion

Our study is among the largest population-based study to have explored health status in Australian carers of people with chronic disease, and the first to include people with recent but concluded caring experience, as well as current. This difference is the most likely explanation for the substantially higher prevalence of carers versus non-carers we observed compared to other Australian population-based surveys (1, 11, 14). Our research joins several studies focusing on current carers in finding a relationship between carer status and poor physical as well as mental health, in contrast to others that have identified an association with poor mental health status alone.
(35–38). While health status in people with caring experience was also lower than that for non-carers based on mean, this difference did not reach a MID magnitude for either physical or mental domains. This difference was less than that found in studies of current carers (5–11), giving hope that health status may recover after people complete their caring role.

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

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

Our study replicates consistent findings that poor health status and wellbeing in carers are associated with lower education and income both in carers (35, 38) and the general population (42). Further research is needed to explore whether reasons underlying relationships between
socioeconomic status and health status differ for carers versus non-carers. For example, lower socioeconomic status correlates with poor health literacy, which may present barriers to healthy lifestyles and health service access regardless of carer status (43). At the same time, these problems may be compounded for carers by the additional financial burden of illness within a family and the low priority carers often accord to self-care (44).

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

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

Future cost-effectiveness studies are needed that measure carers’ societal contributions not only
during the time they are caring but also when they return to economic and societal productivity afterwards (2).

**Limitations**

The cross-sectional nature of the current study means that correlations should not be interpreted as evidence of causal relationships. Our survey used a sampling method and weighting to ensure representativeness of the South Australian general population, and SF-12 scores were similar to published 2003 estimates for this population (mean PCS 48.9 and MCS 52.4) (39). However, comparability with data from other carer research is limited not only by our inclusion of past as well as current carers, but also our expansion of the carer definition to include people providing ‘support’. This was intended to acknowledge the less intensive but nonetheless important contributions of extended networks who may not identify with the role of carer (48). It should also be noted that this study examined relationships between self-reported health status and only a relatively small range of sociodemographic variables. To enable comparability between carers and non-carers, our analyses omitted variables relating to care recipients, care provided and informal support that have been found associated with carer health status in previous research (35, 37, 38). Given this was the first population-based study to include people with past as well as current caring experience, additional questions about the timeline of this experience would have enabled further analyses exploring whether health status recovers after the caring role is completed. Asking respondents about the reason their caring role ended might also have been useful in distinguishing people whose dependent recovered versus those who were admitted into long-term care or died. Whilst it might seem intuitive that people whose dependent recovered are likely to experience the most positive change in health status, research suggests that the determinants of health and wellbeing for past carers following admission to long-term care or bereavement are multiple and complex (49, 50).
Finally, the study's focus on potential negative impacts of caring does not deny that many carers perceive there to be positive benefits from their experience (51) and may report average or even above average health status during their time caring. Gaining a better understanding of how carers maintain or recover health status would be valuable for informing interventions to support those who are struggling.

Conclusion

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

Competing Interests

The authors declare no competing interests.

References

2. Contract No.: 4430.0.


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

<table>
<thead>
<tr>
<th>Respondent characteristics</th>
<th>Carers (n=987)</th>
<th>Non-carers (n=2046)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-24</td>
<td>139 (14.1)</td>
<td>337 (16.5)</td>
</tr>
<tr>
<td>25-34</td>
<td>128 (13.0)</td>
<td>372 (18.2)</td>
</tr>
<tr>
<td>35-44</td>
<td>146 (14.8)</td>
<td>318 (15.5)</td>
</tr>
<tr>
<td>45-54</td>
<td>201 (20.4)</td>
<td>296 (14.5)</td>
</tr>
<tr>
<td>55-64</td>
<td>174 (17.6)</td>
<td>281 (13.7)</td>
</tr>
<tr>
<td>≥65</td>
<td>198 (20.1)</td>
<td>442 (21.6)</td>
</tr>
<tr>
<td><strong>Female</strong>*</td>
<td>560 (56.7)</td>
<td>982 (48.0)</td>
</tr>
<tr>
<td>Aboriginal and/or Torres Strait Islander</td>
<td>18 (2.3)</td>
<td>25 (1.8)</td>
</tr>
<tr>
<td>Born in Australia**</td>
<td>774 (78.4)</td>
<td>1393 (68.1)</td>
</tr>
<tr>
<td><strong>Marital status</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>224 (22.6)</td>
<td>516 (25.2)</td>
</tr>
<tr>
<td>Married/de facto</td>
<td>617 (62.4)</td>
<td>1393 (69.0)</td>
</tr>
<tr>
<td>Widowed/separated/divorced</td>
<td>147 (14.9)</td>
<td>291 (14.2)</td>
</tr>
<tr>
<td><strong>Education level</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Still at school</td>
<td>29 (2.9)</td>
<td>95 (4.5)</td>
</tr>
<tr>
<td>Left school at ≤15 years</td>
<td>93 (9.4)</td>
<td>194 (9.5)</td>
</tr>
<tr>
<td>Left school &gt;15 years</td>
<td>187 (18.9)</td>
<td>407 (19.9)</td>
</tr>
<tr>
<td>Left school &gt;15 years, still studying</td>
<td>59 (6.0)</td>
<td>120 (5.8)</td>
</tr>
<tr>
<td>Trade qualification</td>
<td>122 (12.3)</td>
<td>255 (12.4)</td>
</tr>
<tr>
<td>Certificate/diploma</td>
<td>274 (27.7)</td>
<td>453 (22.2)</td>
</tr>
<tr>
<td>Degree or above</td>
<td>224 (22.6)</td>
<td>520 (25.4)</td>
</tr>
<tr>
<td><strong>Work status</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full or part time***</td>
<td>577 (58.5)</td>
<td>1,086 (53.1)</td>
</tr>
<tr>
<td>Home duties</td>
<td>63 (6.4)</td>
<td>121 (5.9)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>21 (2.1)</td>
<td>59 (2.9)</td>
</tr>
<tr>
<td>Retired</td>
<td>201 (20.4)</td>
<td>441 (21.6)</td>
</tr>
<tr>
<td>Student</td>
<td>69 (7.0)</td>
<td>234 (11.4)</td>
</tr>
<tr>
<td>Not working due to injury/disability</td>
<td>42 (4.2)</td>
<td>72 (3.5)</td>
</tr>
<tr>
<td>Other</td>
<td>13 (1.0)</td>
<td>30 (1.5)</td>
</tr>
<tr>
<td><strong>Annual household income ($)</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to $20,000</td>
<td>61 (7.8)</td>
<td>125 (6.1)</td>
</tr>
<tr>
<td>$20,001 - $40,000</td>
<td>154 (19.8)</td>
<td>284 (13.9)</td>
</tr>
<tr>
<td>$40,001 - $60,000</td>
<td>135 (17.3)</td>
<td>214 (10.4)</td>
</tr>
<tr>
<td>$60,001 - $100,000</td>
<td>170 (21.8)</td>
<td>350 (17.1)</td>
</tr>
<tr>
<td>$100,001 - $140,000</td>
<td>127 (16.3)</td>
<td>282 (13.8)</td>
</tr>
<tr>
<td>≥$140,001</td>
<td>132 (16.9)</td>
<td>261 (12.8)</td>
</tr>
<tr>
<td><strong>Housing</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Owned or being purchased***</td>
<td>714 (72.3)</td>
<td>1,383 (68.0)</td>
</tr>
<tr>
<td>Rented from Housing SA</td>
<td>57 (5.8)</td>
<td>99 (4.9)</td>
</tr>
<tr>
<td>Rented privately</td>
<td>183 (18.5)</td>
<td>521 (25.6)</td>
</tr>
<tr>
<td>Community housing</td>
<td>15 (1.5)</td>
<td>13 (0.6)</td>
</tr>
<tr>
<td>Retirement village</td>
<td>10 (1.0)</td>
<td>13 (0.6)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (0.4)</td>
<td>4 (0.2)</td>
</tr>
<tr>
<td>Metropolitan (versus rural)</td>
<td>749 (75.9)</td>
<td>1528 (74.7)</td>
</tr>
</tbody>
</table>

*Carers differed from non-carers at p<0.01 level; #numbers do not add up to overall sample size due to missing data
Table 2. Respondent characteristics found by a logistic regression to be significantly associated with poor physical or mental health status in a population-based sample of South Australian carers (n=987) and non-carers (n=2046)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Physical health status</th>
<th></th>
<th></th>
<th>Mental health status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>P value</td>
<td>Exp(B)</td>
<td>95% CI for EXP(B)</td>
<td>P value</td>
<td>Exp(B)</td>
<td>95% CI for EXP(B)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lower</td>
<td>Upper</td>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Carer</td>
<td>&lt;0.001</td>
<td>1.50</td>
<td>1.21</td>
<td>1.84</td>
<td>0.007</td>
<td>1.34</td>
</tr>
<tr>
<td>Graduate or above</td>
<td>0.003</td>
<td>0.67</td>
<td>0.51</td>
<td>0.87</td>
<td>0.019</td>
<td>0.73</td>
</tr>
<tr>
<td>Employed full or part time</td>
<td>&lt;0.001</td>
<td>0.33</td>
<td>0.27</td>
<td>0.42</td>
<td>&lt;0.001</td>
<td>0.37</td>
</tr>
<tr>
<td>≥$60k household income</td>
<td>&lt;0.001</td>
<td>0.51</td>
<td>0.41</td>
<td>0.64</td>
<td>&lt;0.001</td>
<td>0.45</td>
</tr>
<tr>
<td>Born in Australia</td>
<td>0.002</td>
<td>1.44</td>
<td>1.14</td>
<td>1.82</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Age ≥65 years</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.002</td>
<td>0.65</td>
</tr>
<tr>
<td>Married/defacto</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.020</td>
<td>0.77</td>
</tr>
</tbody>
</table>

CI = confidence intervals