Factors associated with being an older rather than younger informal carer of adults with a chronic health condition: results from a population-based cross-sectional survey in South Australia

#### Abstract

# Objective

To examine sociodemographic characteristics and caring experiences associated with being an older rather than younger carer of an adult with a chronic health condition.

# Methods

The population-based cross-sectional South Australian Health Omnibus survey was administered in 2016. Multiple logistic regression was used to identify sociodemographic characteristics and caring experiences associated with being an older (≥65 years) versus younger (<65 years) carer of one or more adult(s) with a chronic health condition.

Of 988 survey respondents who self-identified as carers, 198(20%) were 65 years or over.

#### Results

Characteristics associated with being an older carer included having a partner, having poor physical health, being born outside Australia, have no formal qualification, living in a household of 1-2 people, have an annual household income ≤\$60,000, and owning one's home. Carer experiences associated with older carer status included providing ≥40 hours of care per week, perceived control over caring, and caring for someone with a neurological condition, whereas caring for someone with a mental illness, reporting poor mental health of their own, and providing personal care were

# Discussion

inversely associated.

Interventions directed at older carers should consider the increased likelihood that they may be investing large amounts of time in caring for someone with a neurological condition, and be culturally and linguistically diverse.

# **MESH Compatible Keywords**

Carer, ageing, chronic disease, survey

# **Conflict of interest**

The authors declare that they have no conflicts of interest.

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#### Introduction

Unpaid caring is increasingly recognised as an emerging public health issue in light of population ageing and pressure on healthcare systems. Unpaid support and assistance provided by caregivers ('carers') to family members and/or friends living with a disability, health condition or who are ageing ('care recipients'), generates significant financial savings for the health and social care system. In Australia in 2020, there were 2.68 million (10.8%) carers providing an estimated 2.2 billion hours of unpaid care reflecting an economic saving of \$77.9 billion.<sup>2</sup>

Unpaid carers provide essential support such as assisting with treatment adherence, continuity of care, and social support to ensure optimal health for care recipients.<sup>3</sup> While caring can create a feeling of self-pride, fulfilment, and deepened levels of intimacy with the care recipient, it can also be quite challenging. Studies have reported carers are more likely to experience depressive symptoms and have poorer physical and mental health outcomes when compared with non-carers.<sup>4</sup> Carers often experience competing domands on their social and financial situation and health and wellbeing<sup>5</sup> as a result of caring responsibilities.

In 2017, Australians aged over 65 years comprised 15% of the population, and by 2057, this will rise to 22%. A consequence of this increased longevity is rising demand for care of our ageing population, much of which will be provided by older carers. Currently, over 22% of carers in Australia are aged 65 and over. Although the majority of older carers provide care for their spouses and partners, there is recognition of the growing number of 'multigenerational carers, the are providing informal care to their parents as well as to adult children with disabilities.

Despite the number of older carers and the significance of their role, they are under-represented in research, particularly in the Australian population. Numerous studies have suggested that caring activities can be very demanding and can adversely affect carer health especially in older carers who may face challenges involving their own chronic condition management, disability and even frailty alongside the often complex and multiple health needs of their care recipients. Older carers are commonly in retirement, with a decrease in multiple role demands and fewer time constraints. As a consequence of retiring from the workforce, they may have less income and reduced opportunity to engage in activity outside of caring that may have fostered socialisation and self-esteem. Previous research has been inconclusive regarding whether older carers face greater challenges with carer responsibilities than younger carers and need additional support. Qualitative research has suggested that older carers are emotionally more equipped than younger carers to provide care, yet there is little research that explicitly compares older and younger carers. The current exploratory study seeks to determine correlates of being an older versus younger carer among sociodemographic characteristics and caring experiences.

# Methods

The South Australia Health Omnibus Study (HOS) is an annual population-based, cross-sectional survey study. Using multistage, systematic, clustered area sampling, a random sample of 5,300 households from Australian Bureau of Statistics (ABS) census collector district across metropolitan and non-metropolitan towns with a population ≥1000 were selected. From selected households, one person aged 15 years and older who most recently had a birthday was selected for a face-to-face interview from September to December 2016. The final survey data were weighted by 5-year age groups, sex, household size and rurality estimates from the ABS 2011 Estimated Residential Population for South Australia, to ensure the sample represented demographic characteristics of South Australia. Comprehensive details of the survey and the data used in this study have been described previously. Sociodemographic data collected included gender, age, country of birth,

Aboriginal and/or Torres Strait Islander status, marital status, formal qualification, number of inhabitants in the household and household income. Health related quality of life (HRQoL) was investigated using the Medical Outcomes Study Short Form 12 (SF-12). The 12 questions in this instrument evaluated HRQoL in the past four weeks, generating two different 0-100 component scores (physical (PCS) and mental (MCS)).

Unpaid carers were asked to self-identify by answering a question about having provided care or support to an adult with one or more of the following chronic conditions at some time in the past five years: cancer, heart disease (e.g. heart failure), respiratory disease (e.g. emphysema), mental illness (e.g. depression, schizophrenia), neurological disease (e.g. Parkinson's disease, stroke), or dementia. Additional information was sought from those who responded that they had provided care. Caring characteristics reflected types of caring activities provided (e.g. medication management, transport) and hours spent caring each week.

Carer Experience Survey (CES)<sup>19</sup> asked carers about their ability to engage in activities outside caring, support received from family and friends, assistance received from organisations or government, fulfilment from caring, control over caring, and getting along with the care recipient.

Each item has three levels of responses (mostly, sometimes, rarely). This measure was developed using a meta-ethnography process to derive the appropriate items that were important to carers.<sup>19</sup>

Ethics approval was granted by the University of South Australia Human Research Ethics Committee (approval number: H-097-2010). All participants provided written informed consent. This article complies with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria.<sup>20</sup>

# **Analysis**

Older carers were defined as participants 65 years and older, and younger carers as those younger than 65 years of age. We used 65 as the age cut-off because it is the age at which a person became eligible to receive an Age Pension from the federal government at the time of the study. The cut off for household income was set at \$60k because this was the lower limit of a response category that was closest to the 2016 median income for South Australians (\$62,712 per annum) (ABS 2016). We classified anyone with a trade qualification/apprenticeship, certificate/diploma, or Bachelor degree or higher as having formal qualification. All others were classified (still at school, left school before 15, left school after 15, left school at 15 but still studying) as having no formal qualification. We classified the SF-12 PCS and MCS as poor physical and mental health that are ≥0.5 standard deviations lower than the mean<sup>21</sup> from the norm derived from the Australian Bureau of Statistics (ABS) 1995 Australian National Health Survey dataset. <sup>22</sup> Independent t-tests for continuous variables and chi-square tests for categorical variables were used to compare sociodemographic variables, caring characteristics and attributes of CES between younger and older carers. The multiple logistic regression was used to build a model to include all the significant covariates simultaneously. This was to ensure the impact of each significant covariate with being an older carer is assessed after controlling for all other covariates in the model. Demographic and caring characteristics associated with older carers in bivariate analysis were included in the model (p<0.1). Backward, step-wise multiple logistic regression was then performed to determine the independent correlates of being an older carer. Goodness of fit was assessed using the Hosmer-Lemeshow test. The analysis was performed using the Statistical Package for the Social Sciences (SPSS) software Version 24.0 (Armonk, NY: IBM Corporation). A p-value < 0.05 was considered statistically significant.

# **Results**

There were 3,047 respondents to the survey. Overall, 32.4% (n=988) of respondents self-identified as carers and 20.0% of these people (n=198) were aged 65 or older. The average age for older carers was 73.2 (SD=6.3) years and younger carers was 41.4 (SD=14.3) years.

# **Bivariate Analysis**

# Sociodemographic Characteristics

Comparisons between older and younger carers in terms of demographic factors are presented in Table 1. Older carers were more likely than younger to have a partner (68.7% vs 60.8%, p=0.04), live in a household with fewer people (ie. 1-2 persons vs. 3 or more persons) (93.4% vs 57.1%; p<0.001) and less likely to have formal qualification (50.5% vs 65.8%; p<0.001). A greater percentage of older carers had a household income ≤\$60,000 than younger carers (81.5% vs 35.4%; p<0.001), but a higher percentage also owned or were purchasing the home in which they lived (84.9% vs 69.4%; p<0.001). A higher percentage of older carers compared to younger were born outside of Australia (32.8% vs 18.8%; p<0.001). Older carers were more likely than younger to report poor physical (41.4% vs 26.1%; p<0.001) and mental (30.8% vs 24.7%; p<0.001) health.

Insert Table 1.

# Caring characteristics

The most common conditions cared for by both the older and younger carers was cancer (41.4% and 37.6%), followed by dementia (26.8%) for the older carers and mental illness (37.3%) for the younger carers (Table 2). Compared to younger carers, a significantly higher proportion of older carers provided care for those with heart disease (23.6% vs. 15.7%; p=0.008) and neurological conditions (18.1% vs. 11.4%; p=0.012), whereas a significantly lower proportion of older carers cared for those with mental illness (21.7% vs. 37.3%; p<0.001).

Emotional support is the most common caring activity performed by both the older and younger carers (93.4% vs 92.4%) followed by household tasks (62.1% vs 57.3%). Older carers were significantly more likely to participate in medication management (38.2% vs 24.1%; p<0.001), transport assistance (59.3% vs 49.0%; p=0.01) and acting on behalf of the care recipient (51.3% vs 32.3%; p=0.001) than younger carers. A higher proportion of older carers were also providing 40 hours of care or more per week than younger carers (38.3% vs 13.4%; p<0.001).

Insert Table 2.

# Caring experience

Older carers reported that they were less likely to be able to participate in activities outside of caring (p=0.01) (Table 3) than younger carers. However, older carers had a greater sense of perceived control over caring (p<0.001) than younger carers.

Insert Table 3.

# **Multiple Logistic Regression**

Results from the multiple logistic regression performed to model independent correlates of being an older versus younger carer are presented in Table 4. Having a partner (odds ratio (OR)=1.66, 95% confidence intervals (CI)=(1.00, 2.75)), having an annual household income ≤\$60,000 (OR=9.55,95%CI=(5.44,16.77)) and owning one's home (OR=4.35, 95%CI=(2.45,7.72)) were positively associated with being an older carer, whereas being Australian-born (OR=0.44; 95%CI=(0.26, 0.75)), having a formal qualification (OR=0.63; 95%CI=(0.39, 1.00)) and living in a household of three or more people over 15 years of age (OR=0.09; 95%CI=(0.04, 0.21)) were inversely associated with being an older carer. Among caring characteristics, spending 40 or more hours per week caring (OR=2.36, 95%CI=(1.33,4.18)) and caring for a person with a neurological condition (OR=2.04,

95%CI=(1.09, 3.83)) were independently associated with being an older carer. However, caring for care recipient with mental illness (OR=0.53; 95%CI=(0.32,0.88)) or providing personal care (OR=0.42; 95%CI=(0.23, 0.78)) were inversely associated with being an older carer. Reporting poor physical health (OR=2.92; 95%CI=(1.49, 5.71)) was positively associated with being an older carer. Whereas reporting poor mental health (OR=0.36; 95%CI=(0.18,0.74)) was negatively associated with being an older carer. Amongst CES items, both of those who reported perceived control over few (OR=0.51; 95%CI=(0.27, 0.96)) and some aspects of care (OR=0.57; 95%CI=(0.33, 0.98)) were less likely to be associated with being an older carer compared to those who perceived control over most aspects of care..

The final model was statistically significant, ( $X^2(14)=272.7$ , p<0.001), explaining 47.2% (Nagelkerke  $R^2$ ) of the variance. The Hosmer-Lemeshow goodness of fit test also confirmed the adequacy of the model (p=0.93).

Insert Table 4.

# Discussion

This study found that older carers differ from younger carers across a number of sociodemographic characteristics and caring experience. While the design of our study means interpretation must remain largely speculative, our findings are suggestive of differences in the support needs of older versus younger carers.

Notably, we found that being an older versus younger carer was associated with being born overseas. Australia has seen an increase in the number of people aged 65 and over born overseas over the past decades, <sup>23</sup> particularly from countries other than UK, Ireland and Europe. Older carers from culturally and linguistically diverse (CALD) backgrounds have been identified as a group at risk

of isolation and poor health due to the strain of their care responsibilities and underuse of support services. <sup>24</sup> To some extent, the underuse of services by older people from CALD backgrounds can be attributed to a greater reliance on family members to provide care, which indicate there may be a number of different people involved in caring. <sup>24</sup> However, carers in CALD communities may also have limited knowledge of how to access support services in comparison to other carers. For example, a recent study found that significantly fewer older Australians who were born overseas had advance care directives. <sup>25</sup> This highlights the importance of facilitating access to interpreters, if needed, and ensuring sensitivity to diverse preferences for planning future medical arrangements. <sup>25</sup> Studies also suggest there may be barriers created by implicit and explicit racism and prejudice that compound the underuse of services through lack of cultural safety. <sup>26</sup> Although support needs vary across cultural groups and the condition of the care recipient, there is a need to ensure appropriate supportive services for care recipients and carers that reflect different cultural and social expectations and assumptions. <sup>24</sup>

Another notable finding concerned the types of conditions for which older carers are more and less likely to be providing care. They were more likely to be providing care for care recipients who have diseases related to ageing including Parkinson's disease and stroke. A significant proportion of unpaid carers for neurological conditions experience distress as these can be complex and time-consuming to manage.<sup>27</sup> Perhaps a reason why dementia was not included in the groups is that they are more likely to be cared for in residential aged care. In Australia, over half (52%) of people living in residential aged care in 2016, had dementia.<sup>28</sup> Being less likely to provide care for mental health issues may reflect generational attitudes of stigma and being less likely to discuss, seek diagnosis, or perceive depression and anxiety as health conditions.<sup>29</sup> While this does not imply that the carer makes a choice about this caring, there may be less awareness or willingness to disclose. Providing care for someone with a mental illness has been described as inherently different<sup>30</sup> and more

stressful than caring for other conditions. Older carers may be less exposed to this type of caring and thus feel more in control of caring.

A compelling finding, yet inconsistent with previous research, <sup>13</sup> was that the perceived control over caring, defined as one's ability to influence the overall care of the person cared for, was significantly associated with being an older carer. From previous studies we know that feelings of insufficient control over caring are associated with poorer physical and psychological health outcomes of carers. <sup>31</sup> Despite the higher proportion of older carers caring for 40 hours and longer per week, older carers in our sample tended to have a greater feeling of being able to manage and influence care, rather than feeling a loss of control, which is particularly important for carers who live alone with care recipients. <sup>19</sup> Feeling more in control might have been related to the likely-retired status of most older participants, given that full-time employment has been found to inversely correlate with carer's physical and mental health in previous research. <sup>32</sup> There has also been a suggestion that perceived good relationship quality buffers against negative ramifications for quality of life, respective to the caring charcateristics. <sup>29</sup> Caregiving intensity and care recipient's health situation have been found to affect caregiver outcomes negatively. <sup>1,33</sup> It is likely, therefore, that family carers in this study whose experience was found to be negatively affected were confronted with higher care needs, or tasks that they felt ill-prepared to manage.

The experience gained through caring and ageing, in fact, may contribute to a sense of mastery. Mastery is a psychosocial factor that refers to understanding one's ability to control the forces that affect one's life<sup>34</sup> and can buffer the negative effects of the impact of caring on wellbeing.<sup>35</sup> Feeling in control of a situation is associated with positive mental health outcomes.<sup>36</sup> Carter et al.'s (2010) investigation of negative aspects of strain in older and younger (middle-aged) spousal carers of people with Parkinson's disease found the younger group to be at greater risk for negative consequences of the care situation, reporting significantly more strain, they were more likely to be employed and caring for children in the home, yet were in better physical health than older spousal

carers. This suggests that being in better physical health does not mitigate the perception of strain in carers with multiple competing responsibilities such as management of young children or families while maintaining employment.<sup>37</sup> Indeed, poorer physical health but better mental health for older as compared to younger carers in the current analysis likewise reflects the benefit of mastery that may mitigate perceptions of strain.

It may also be that older people expect and accept caring responsibilities at their time of life, especially for a spouse, whereas younger people expect to be focused on developing careers and raising children. A study that examined only older carers<sup>38</sup> found that despite having their own agerelated health issues, only 22.9% of older spousal carers experienced high levels of strain caring for their similarly-aged care recipients. Although physical health was not assessed in this sample of older carers in Hong Kong, findings were discussed in relation to cultural values that reflect norms of obligations and reponsibilities that influence the meaning of caring in this group. This finding points to the importance of building younger carers' perceptions of the ability to manage and influence care. However, these findings may reflect societal values that caring is an age-appropriate task for older people but not something for which young people should be responsible.

# Limitations

There were several limitations to this study. The cross-sectional design negated our ability to infer causal relationships between variables found to have statistical relationships. Our study is not directly comparable to most previous research on carers for two reasons. The self-report and retrospective nature of the data collected differs from most previous studies which have asked people receiving care to identify their carers. Also, we asked respondents to recall caring over the past five years rather than focus on current carers as nearly all previous research has done. We used 65 years as the cut-off for age because this was the age at which people accessed the *Age Pension* at the time of the study; analyses using other age cut-offs would likely have yielded different results.

Data such as health problems of the carers and characteristics of the care recipients such as age, gender, health status, and whether they were cohabiting with the carer were not available. We also did not collect information on duration of caring, whether the person was the primary carer, the relationship between carer and care recipient, number of care recipients that the carer supported, current versus past status of caring, and whether carers were also caring for children as well as an adult with a chronic condition.

# Conclusion

The current population-based study reflects that older Australian carers may have different support needs as compared to younger carers. In our study, older carers were more likely to be born overseas, live in small households, spend more than 40 hours per week caring, care for someone with a neurological condition, and perceive control over caring. Further research is needed to explore the implications of these findings for health and social services that support older carers.

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