

# BMJ Open

## Self-reported physical and mental health of Australian carers

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-011417
Article Type:	Research
Date Submitted by the Author:	08-Feb-2016
Complete List of Authors:	Hussain, Rafat; Australian National University, ANU School of Medicine & Research, School of Population Health,; University of New England, School of Rural Medicine Wark, Stuart; University of New England, School of Rural Medicine Dillon, Gina; University of New England, School of Rural Medicine Ryan, Peta; University of New England, School of Rural Medicine
<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Public health
Keywords:	informal care, physical health, carer health

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**Title**

Self-reported physical and mental health of Australian carers

**Authors**

Rafat Hussain, ANU School of Medicine & Research School of Population Health, Australian National University, Canberra, ACT, Australia.

Stuart Wark (corresponding author), School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia. Email: swark5@une.edu.au Phone: 612 6773 2204

Gina Dillon, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia

Peta Ryan, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia

**Word Count**

3531

## ABSTRACT

**Objective:** To report on self-reported physical and mental health of informal carers in non-metropolitan areas of New South Wales, Australia.

**Methods:** A community based sample (n=222) of carers completed a questionnaire incorporating self-reported measures of health from the SF-36, CES-D and K10 instruments. Results from this study were compared to Australian population normative data.

**Results:** Rural carers' self-reported health was significantly below Australian age-matched population norms. This was evident on the SF-36 Physical and Mental Health component scales as well as each individual domain of the SF-36. Results from the CES-D and K10 scales indicated very high rates of depressive symptoms and psychological distress. Over 70% of carers within the current study had CES-D scores indicative of depressive symptoms. Scores on the K10 indicate almost half the carers were experiencing high levels of psychological distress, which is over 4 times the rate reported in the general Australian population.

**Conclusions & Implications:** These findings illustrate the poor health profile of informal carers relative to the general Australian population, especially in terms of depressive symptoms and psychological distress. This highlights the need for additional support for carers in order to ease the accumulated mental and physical health burdens of this group.

### Strengths and Limitations

- This study specifically focusses on the self-reported health of carers in non-metropolitan Australia
- It was found that the health of rurally-located carers' was significantly below Australian age-matched population norms, with over 70% of carers showing depressive symptomology
- Almost half the carers were found to be experiencing high levels of psychological distress
- This study methodology contains the risk of self-selection bias, and problems associated in the self-reporting of health conditions.
- There was a significant gender bias towards female respondents, so any sex-based comparisons must be viewed with caution.

## INTRODUCTION

The Australian Government has a stated commitment to supporting individuals with various health needs, such as a disability, ageing-related impairment, and physical or mental health issue, to be assisted to remain within their local community.<sup>1,2</sup> However, the support provided by the Government is not always comprehensive, and often requires significant assistance from informal carers. Informal care is a support model where a person provides unpaid assistance to another individual with respect to general activities of daily living such as physical, emotional, financial and personal care.<sup>3</sup> The support of the informal carer is often vital, playing a significant role in increasing the individual's access to health and rehabilitation services.<sup>4</sup>

The 'burden' of providing informal care is considered to be the reduction in personal opportunities or actual health of an individual as a direct result of having to provide this unpaid support.<sup>5</sup> It has been previously identified that informal carers are likely to experience high levels of psychological distress,<sup>6</sup> and a decline in both physical health<sup>7</sup> and quality of life.<sup>8</sup> The need to provide informal care, particularly personal care,<sup>9</sup> has an impact on the carer's ability to both seek and maintain external paid employment.<sup>10</sup> It was estimated in 2015 that 2.86 million people in Australia provide informal care support to another person.<sup>11</sup> This figure represents approximately 12.5% of the nation's population and an increase of around 260,000 carers from 2012.<sup>12</sup> However, it is concerning to note that there are now perceived to be fewer carers, relative to demand, than in 2010, and the demand for informal care is predicted to considerably exceed its supply within the next decade.<sup>11</sup>

In rural areas of Australia, the issues faced by informal carers may be amplified compared to those in metropolitan locations.<sup>13</sup> Rural carers are often geographically isolated, and struggle to access relevant health care support services for both themselves and the person for whom they provide care.<sup>14,15</sup> A failure to receive appropriate and timely treatment magnifies the issues for carers, as the existing health condition then worsens progressively over time,<sup>16</sup> which then places additional stress onto the carer.<sup>17</sup> Individuals in rural areas are less likely to receive formal carer training to cope with these concerns<sup>18</sup> and this in turn can lead to issues with poor self-esteem.<sup>19</sup>

In spite of these issues, there remains only limited research that specifically examines the issues and care-giver burden facing individuals in rural areas of Australia.<sup>20</sup> The current paper is part of a larger study focussing on the experiences of informal carers in non-metropolitan

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3 areas of New South Wales, Australia. The goal of this research is to establish an initial profile  
4 of self-reported health in rurally-based informal carers to facilitate future comparative studies  
5 with metropolitan based peers. Formal ethical approval for this project was granted by the  
6 Institution's Human Research Ethics Committee (details to be provided after blind peer  
7 review).  
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## 10 11 **METHOD**

### 12 13 **Recruitment**

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15 Potential participants for this project were defined as being any individual over the age of 18  
16 who self-identifies as providing informal care and support for a person with either a disability  
17 or other long-term health condition. The geographic catchment was specified as being areas  
18 in the state of New South Wales (NSW), Australia that are outside of the Australian Standard  
19 Geographic Classification (ASGC) remoteness category of 'major cities'. The ASGC is a  
20 nationally standardised measure of geographic remoteness which incorporates aspects of  
21 distance and access to services in order to define five remoteness categories, namely: major  
22 cities, inner regional, outer regional, remote and very remote areas.<sup>21</sup>  
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26 A variety of community-based recruitment strategies were used to distribute information  
27 about the project and enrol participants. These included social media, community-group and  
28 carer organisation newsletters, posters in community facilities, and a combination of  
29 electronic and traditional media sources such as radio and newspaper interviews. A \$5  
30 grocery voucher incentive was provided for all respondents. Potential participants were given  
31 the option of receiving a hard copy of the information package and associated questionnaire,  
32 or to access the survey via a purpose-developed web-site that contained all relevant  
33 documentation and an online version of the survey questionnaire.  
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### 36 37 **Measures of self-reported health**

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39 Self-reported health was evaluated by the Medical Outcomes Short-Form (SF-36) which  
40 measures health across eight domains of physical and mental health, namely: general health,  
41 physical functioning, role physical, bodily pain, vitality, social functioning, mental health,  
42 and role emotional. These eight subscales are also used to calculate two summary or  
43 component scales: the Physical Component Score (PCS), reporting on physical health, and  
44 the Mental Component Score (MCS), reporting on mental health. Imputation of missing  
45 values and computation of the domain and component scores were performed according to  
46 the procedures outlined in the *SF-36 Manual and Interpretation Guide*<sup>22</sup>. Scores on each of  
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3 the SF-36 domain and component scores can range from 0 – 100 and higher scores indicate  
4 better health. Australian population normative data for SF-36 scores were accessed from the  
5 Australian Bureau of Statistics.<sup>23</sup>  
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9 Self-reported mental health was additionally assessed via the Centre for Epidemiologic  
10 Studies-Depression (CES-D) Scale and the Kessler (K10) Psychological Distress Scale. The  
11 CES-D is a validated and widely used scale designed to measure current levels of depressive  
12 symptoms within the general population.<sup>24</sup> CES-D scores have a possible range of 0 – 60 and  
13 higher scores indicate worse mental health. A score of 16 points or more is generally  
14 accepted as an indicator of depression symptoms<sup>25</sup> and scores of 24 and over are suggestive  
15 of severe depressive symptoms.<sup>26</sup> Normative CES-D data for the Australian population was  
16 derived by entering the cut points for depressive and severe depressive symptoms (16 and 24  
17 respectively) into the *MoodScore* computer programme of Crawford & Cayley<sup>27</sup> which has  
18 been developed as a means of quickly referencing Australian normative data on a range of  
19 self-reported mood scales.  
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27 The K10 questionnaire provides a measure of non-specific psychological distress based on  
28 questions about negative emotional states experienced in the past four week period.<sup>24</sup> Scores  
29 on the K10 range from 10 – 50 with higher scores indicating higher levels of psychological  
30 distress. The designated cut-off scores for low (10-15), moderate (16-21), high (22-29), and  
31 very high (30-50) levels of psychological distress, plus Australian population norms were  
32 drawn from Australian Bureau of Statistics data.<sup>28</sup>  
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### 38 **Socio-demographic and caring-role characteristics**

39 Information was collected on a range of socio-demographic and caring role characteristics of  
40 participants including: sex, age, employment status, whether they are in a primary care-giving  
41 role, their relationship to the person they provide care for (spouse/parent/child/other),  
42 whether they are aware of, or members of, any carer support groups, whether they are a live-  
43 in carer and the medical condition/s of the care recipient. The medical conditions were  
44 classified into four broad categories of:  
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- 50 • Cognitive: including autism spectrum disorders, Alzheimer's disease, Down's  
51 syndrome and acquired brain injury
- 52 • Physical: including cancer, stroke, post-operative recovery, Parkinson's disease,  
53 cerebral palsy, quadriplegia, blind, deaf, diabetes, heart and lung conditions and frail  
54 aging.  
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- Mental health: including schizophrenia, ADHD, bipolar disorder, alcohol and drug addiction, depression and anxiety disorders.
- Multiple: this category involves the simultaneous occurrence of conditions across more than one of the Cognitive, Physical or Mental health categories.

### Statistical methods

Analysis was performed using SPSS V22 (2013 release). ANOVA with post hoc comparison via Dunnett's C, with  $p \leq 0.05$  as the critical value, were used to test for differences between mean SF-36 scores of participants across age and sex. Graphical representation and comparison of SE error bars were used to gauge significant difference between mean SF-36 scores of participants from the current study and Australian population norms. In order to age-match data from the current study with ABS data for the SF-36 population norms, the average age of participants was calculated for each age grouping in the current study. This average age was then compared to the ABS data age categories, and the normative data for the relevant category was used as a comparison to the current study.

### RESULTS

The demographic characteristics of the study sample are summarised in Table 1 below. The majority of participants were female (85%), live in carers (75%), involved in the primary care role (80%). Ages ranged from 21 to 86 years, with more participants being from the older age groups. Approximately 45% of the carers were also working in paid employment. Just over one third of the participants (38%) were caring for someone with a physical condition and 27% of carers were caring for people with multiple conditions.

**Table 1** Demographic and caregiving characteristics of participants (n=222)

	n (%)
Sex	
Female	191 (84.9)
Male	31 (13.8)
Age	
Range	21-86 yrs
Mean	52.7 yrs
Std Dev	14.4 yrs
Age (grouped)	
40 yrs and under	47 (21.2)
41 – 50 yrs	53 (23.9)
51 – 60 yrs	58 (25.8)
61 yrs and over	64 (28.4)
Currently working	
Yes	98 (45.2)

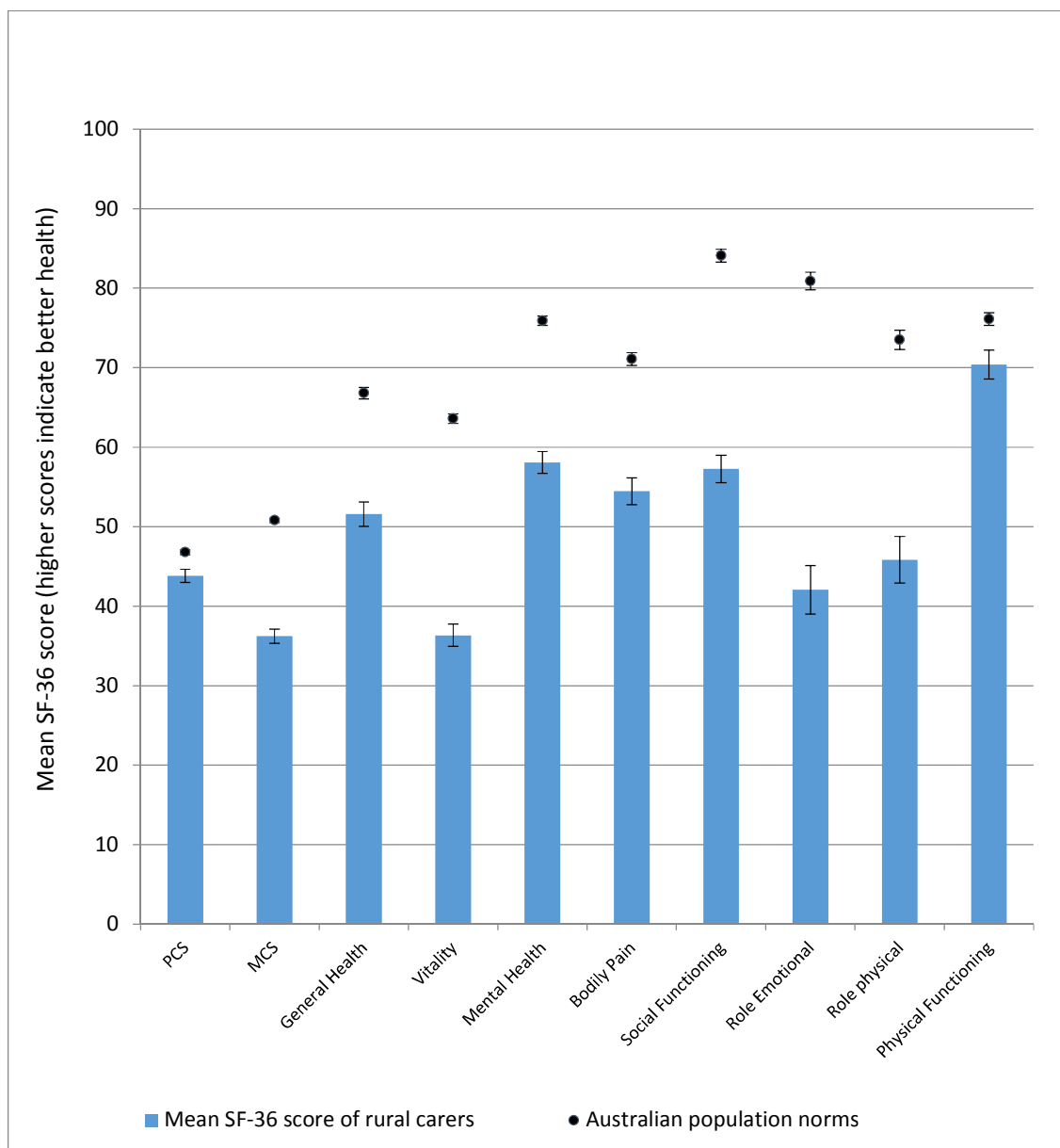
No	119 (54.8)
Care giver role	
Primary	180 (80.0)
Secondary	19 (8.4)
Caring relationship	
Caring for a parent	27 (12.0)
Caring for a child	92 (40.9)
Caring for spouse	77 (34.2)
Other	17 (7.6)
Live in carer	
Yes	142 (75.5)
No	46 (24.4)
Condition cared for	
Physical	81 (37.7)
Cognitive	48 (22.3)
Mental Health	27 (12.6)
Multiple categories	59 (27.4)
Aware of any carer support groups	
Yes	152 (67.6)
Member of a carer support group	
Yes	61 (27.1)

### Self-reported health

Carers in the study had self-reported physical and mental health that was significantly below Australian age-matched population norms. This was evident on the SF-36 Physical (PCS) and Mental (MCS) component scales as well as within each individual domain of the SF-36 (see Figure 1 below). Carers showed particularly lower comparative scores in the domains of social functioning, role emotional role physical and vitality.



Figure 1 Mean SF-36 scores\* for rural carers compared to Australian population norms<sup>23</sup>

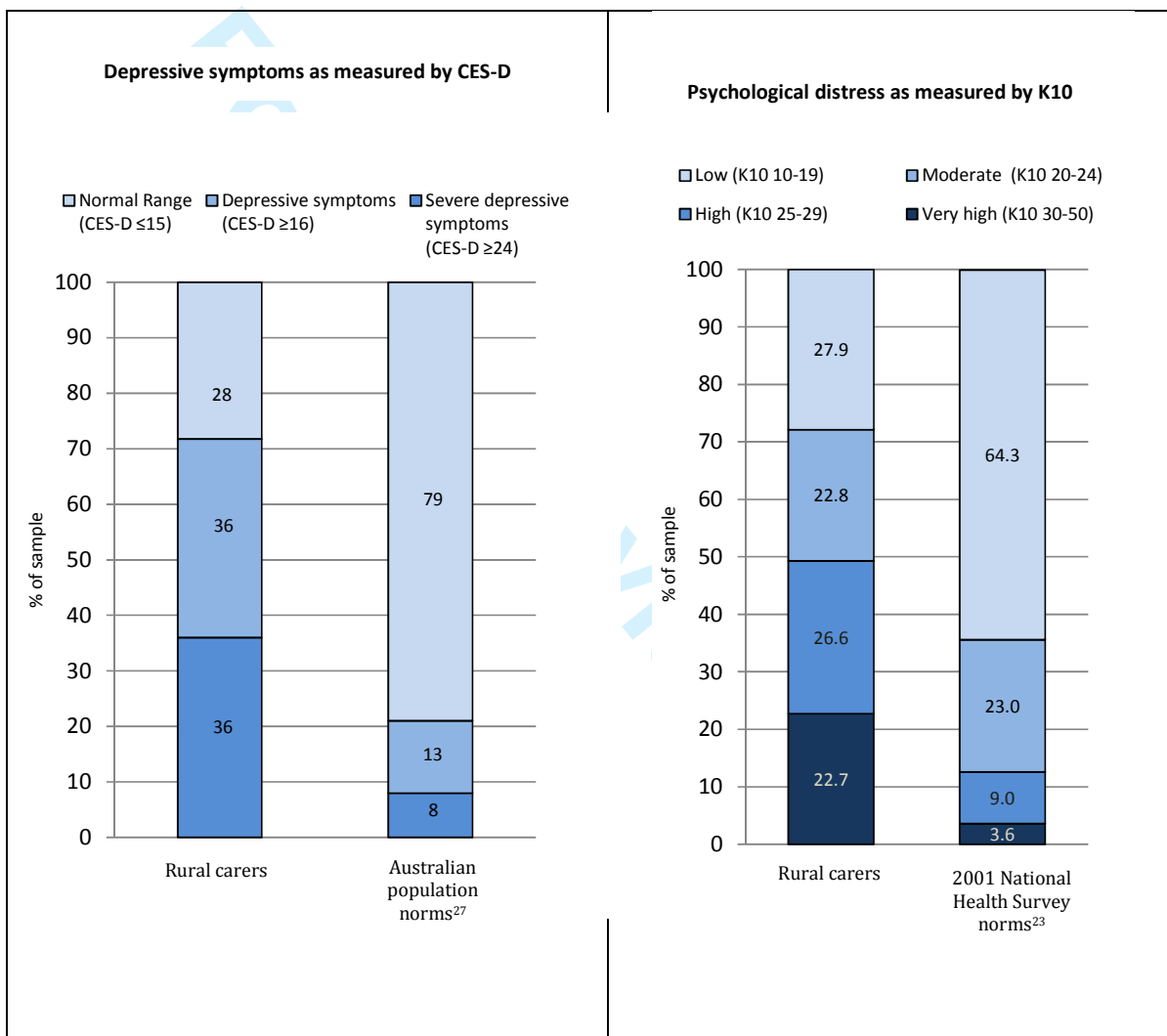


\* Error bars indicate SE of mean scores

Results from the CES-D and K10 scales indicate very high rates of depressive symptoms and psychological distress amongst the rural carers sample compared to the wider Australian population (Figure 2 below). Over 70% of carers within the current study had results on the CES-D that indicated the presence of depressive symptoms, with 36% meeting the criteria for severe depressive symptoms. Within the Australian population only 21% meet the criteria for depressive symptoms and only 8% of people would be considered as experiencing severe

depressive symptoms. Scores on the K10 indicate almost half the carers (49.3%) were experiencing high and very high levels of psychological distress, which is over 4 times the rates expected in the general Australian population (12.6%). Furthermore, only 28% of carers had low levels of psychological distress compared to 64.3% of the general population.

**Figure 2** Percentage of rural carers reporting depressive symptoms as defined by CES-D scores, or psychological distress as measured by K10 scores compared to Australian



population norms

### Factors associated with self-reported health in rural carers

Self-reported health was associated with both age and sex in the survey sample (Table 2), although given the relatively small number of male participants, differences by sex should be interpreted with caution. Significant differences in the self-reported health of male versus female carers were in the areas of SF-36 MCS, role emotional, vitality, and bodily pain. In all of these domains males had higher mean scores than females indicating better self-reported health in male compared to female carers.

Significant age differences were found in the SF-36 measures of PCS and MCS as well as the vitality, mental health, social functioning and physical functioning domains. Additionally there were also significant age associations with scores on both the CES-D and the K10 scales as seen in Table 2.

**Table 2** Mean self-reported health scores for the SF-36, CES-D and K10 scales, divided by sex and age

	n	SF-36 (higher scores indicate better health)										Lower scores indicate better health		
		PCS	MCS	General Health	Vitality	Mental Health	Bodily Pain	Social Functioning	Role Emotional	Role physical	Physical Functioning	CES-D	K10	
<b>Sex</b>														
Male	30	46.07 <sup>a</sup>	41.46 <sup>a</sup>	55.43 <sup>a</sup>	47.00 <sup>a</sup>	63.77 <sup>a</sup>	63.10 <sup>a</sup>	59.17 <sup>a</sup>	63.22 <sup>a</sup>	58.89 <sup>a</sup>	74.97 <sup>a</sup>	19.62 <sup>a</sup>	20.79 <sup>a</sup>	
Female	186	43.44 <sup>a</sup>	35.40 <sup>b</sup>	50.96 <sup>a</sup>	34.61 <sup>b</sup>	57.15 <sup>a</sup>	53.10 <sup>b</sup>	56.96 <sup>a</sup>	38.71 <sup>b</sup>	43.72 <sup>a</sup>	69.65 <sup>a</sup>	21.77 <sup>a</sup>	22.81 <sup>a</sup>	
<b>Age (years)</b>														
40 and under	46	44.98 <sup>cd</sup>	33.09 <sup>c</sup>	47.33 <sup>c</sup>	30.00 <sup>c</sup>	55.30 <sup>c</sup>	57.04 <sup>c</sup>	54.08 <sup>cd</sup>	36.59 <sup>c</sup>	38.04 <sup>c</sup>	77.31 <sup>c</sup>	23.27 <sup>c</sup>	24.46 <sup>c</sup>	
41-50	51	47.37 <sup>c</sup>	33.82 <sup>c</sup>	52.19 <sup>c</sup>	33.20 <sup>c</sup>	55.14 <sup>c</sup>	58.90 <sup>c</sup>	56.37 <sup>cd</sup>	43.79 <sup>c</sup>	56.70 <sup>c</sup>	77.00 <sup>cd</sup>	21.38 <sup>cd</sup>	22.42 <sup>cd</sup>	
51-60	57	42.37 <sup>cd</sup>	34.30 <sup>c</sup>	47.99 <sup>c</sup>	34.91 <sup>c</sup>	53.44 <sup>c</sup>	49.81 <sup>c</sup>	51.97 <sup>d</sup>	38.10 <sup>c</sup>	43.75 <sup>c</sup>	66.16 <sup>cd</sup>	23.24 <sup>c</sup>	24.28 <sup>c</sup>	
61>	62	40.75 <sup>d</sup>	43.40 <sup>d</sup>	57.53 <sup>c</sup>	45.08 <sup>d</sup>	66.95 <sup>d</sup>	53.12 <sup>c</sup>	65.37 <sup>c</sup>	48.59 <sup>c</sup>	44.58 <sup>c</sup>	63.51 <sup>d</sup>	18.46 <sup>d</sup>	19.46 <sup>d</sup>	
<b>Total</b>	<b>216</b>	<b>43.80</b>	<b>36.24</b>	<b>51.58</b>	<b>36.34</b>	<b>58.07</b>	<b>54.46</b>	<b>57.27</b>	<b>42.06</b>	<b>45.85</b>	<b>70.40</b>	<b>21.47</b>	<b>22.54</b>	

Age related differences on the physical functioning domain of the SF-36 followed population norms of declining scores with age and could be considered to be a normal function of ageing. Age related scores for the vitality domain within the current study show a trend towards increasing vitality scores with older age. This is in contrast to the age related trend in the population norm data which showed a decline in vitality scores in older age groups.<sup>23</sup> Furthermore, there was no significant difference between the PCS scores of younger carers (40 years and under) compared to carers who were 61 years and above. This again is contrary to the population norm trend and could be interpreted as indicating that the burden

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3 of caring on physical health may be more prominent in young carers compared to older carers  
4 within the current study.  
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7 There are also several age related associations within measures of mental health. Scores on  
8 the SF-36 MCS, mental health and social functioning domains all increased with age  
9 indicating better aspects of mental health in older carers compared to younger age groups. In  
10 the normative data from the Australian population there is a decline in social functioning with  
11 age which is contrary to the data from the current study. Normative data indicates an  
12 increase in the MCS and mental health scores of older participants, so the current data is in  
13 line with this trend. However the score increases within the current study are larger than those  
14 seen in the normative data set, with an increase of over 11 points on the mental health scores  
15 in the older group compared to the youngest group of carers, whereas a comparative age  
16 difference in the normative data is associated with only a 0.5 point difference in mean mental  
17 health scores. Scores on the CES-D and K10 measures also indicated better mental health for  
18 older carers compared to their younger counterparts. These results, along with the findings  
19 from the SF-36 domains, can be interpreted as indicating a relatively larger mental health  
20 burden on young carers compared to older carer age groups.  
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23 Several other associations were investigated and it was found that there were no significant  
24 differences in the mean self-reported health scores of primary versus non-primary carers  
25 across any of the eight domains or two component scores of the SF-36, or total scores on  
26 CESD or K10. Also there were no significant differences in the mean self-reported health  
27 scores of carers from any of the relationship categories of caring for a  
28 parent/child/spouse/other. There were no significant differences in any of the mean health  
29 scores of carers categorized by the condition that they were caring for (physical, cognitive,  
30 mental health or multiple conditions).  
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32  
33 When categorised by their working status (Working Yes/No), it was found that carers who  
34 were working had better self-reported health on both the SF-36 PCS and physical functioning  
35 domains. There were no other significant associations of working status with health on any  
36 of the other SF-36 domains or on the K10 or CES-D. Better physical functioning amongst  
37 those carers who were working was interpreted as indicating that any additional stress of  
38 working in addition to caring was not impacting negatively on the physical health of carers.  
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40 The only significant difference in self-reported health between members and non-members of  
41 support groups was on the physical functioning domain of the SF-36. It was found that non-  
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members of support groups had significantly higher scores (better health) in the domain of physical functioning compared to non-members.

### **Associations between caring relationship, condition cared for and age of carer**

There was no significant association between age of carer and the type of condition being cared for. There was however a significant relationship between the condition being cared for and the relationship between carer and recipient of care. People caring for a parent were most likely to report caring for a physical condition (66.7%) compared to caring for a mental health or cognitive condition or multiple conditions. People caring for a child were most likely to report caring for a cognitive condition (33%) or for multiple conditions (33%). Although only 16.5% of people caring for a child reported caring for a mental health condition, this was the most common caring relationship in the mental health category.

There was also a significant association between the age of the carer and the relationship with the care recipient. This would logically be related to the care of elderly parents or spouses, with 50% of carers in the 51-60 years age group reporting that they were caring for a parent and 55% of carers in the 61+ years age group reporting that they were caring for a spouse.

### **DISCUSSION**

The need to support another individual in basic activities of daily living is becoming an increasingly important issue in Australia. It is estimated that one in eight people provide informal and unpaid support to another person, and the demand for this type of care is predicted to increase substantially over the next ten years.<sup>11</sup> It is known that the provision of informal care is associated with health decline in several areas including psychological distress,<sup>6</sup> physical manifestations<sup>7</sup> and general quality of life.<sup>8</sup> It is further understood that that there is a higher proportion of informal carers in rural localities compared to metropolitan locations<sup>11</sup>, and it is recognised that health-care issues are potentially worse in country areas where access to health care services may be compromised.<sup>17</sup>

The current study aimed to establish an initial self-reported health profile of rurally-based informal carers to facilitate future comparative studies with city resident peers. It was found that the self-reported physical and psychological health of carers within this study was significantly worse than the Australian population norms across all eight domains and the two summary component scores of the SF-36. Additionally, almost half of the carers reported high or very high level of psychological distress on the K10 scale. This is indicative of a major health burden related to the role of informal caregiving.

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3 The current study had a majority of female participants, which is in line with the gendered  
4 nature of informal caregiving in Australia. The nationally-based Disability, Ageing and  
5 Carers Survey<sup>29</sup> reports that, within Australia, females represent 70% of primary carers and  
6 56% of carers overall. In the current study male carers had significantly higher levels of self-  
7 reported health, than female carers, in the SF-36 Mental Health Component (MCS) score as  
8 well as the health domains of vitality, role emotional, and bodily pain. The additional  
9 caregiving burden for female carers has been highlighted by several previous studies and  
10 factors related to this additional burden have been identified as including: the multiple caring  
11 roles of women, especially related to childrearing and household duties,<sup>30</sup> spending more time  
12 with care recipients than male caregivers<sup>31</sup> and seeking less social and tangible support than  
13 male carers.<sup>32</sup> The current study provides additional data to indicate a trend towards a higher  
14 health-related burden for female compared to male carers.

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24 There were also age-related differences in self-reported health of carers that went against  
25 expected trends. For example, the Physical Health Component (PCS) score of younger carers  
26 (40 years and under) was not significantly different to the PCS score of carers aged 61 years  
27 and over. This is contrary to the expected decline in self-reported health with increasing age,  
28 as evidenced in the Australian normative SF-36 data. Furthermore, scores in the SF-36  
29 domain of vitality showed a significant increase with age which is also against the trend from  
30 the Australian normative data. These trends indicate a greater health burden for younger  
31 carers compared to older carers. The additional care burden experienced by younger carers  
32 may be attributed to the fact that carers in the under 40 age group may be raising a family in  
33 addition to meeting the responsibilities of a caring role. The life stage prior to 60 years of age  
34 represents the key time for engagement in career and employment, and being a carer in this  
35 age group may contribute significant additional life stress, as dual responsibilities of work  
36 and caring roles compete for time and priority.<sup>33</sup> Decisions to work in a part-time capacity, or  
37 to withdraw from the paid workforce due to caring commitments, carry significant financial  
38 consequences both in the short-term and for future employment prospects and long-term  
39 financial security. The perceived financial cost of caregiving has been found to be a  
40 significant contributor to the overall caregiving burden of informal carers,<sup>34</sup> and this  
41 perceived financial loss may be greater for younger carers compared to older carers.

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The high levels of psychological distress and depressive symptoms among the carers in this  
sample is a worrying result, with over 70% of the carers indicating depressive symptoms and  
almost half of the sample reporting high or very high levels of psychological distress. This

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2  
3 alarmingly high rate of mental distress highlights an urgent need for additional support for  
4 informal carers in rural areas of New South Wales. A meta-analysis of factors contributing to  
5 physical health of informal caregivers<sup>32</sup> reported that depressive symptoms of caregivers had  
6 a higher association with declines in physical health than objective care related stressors such  
7 as hours of care provision, behavioural problems of the care recipient and medical condition  
8 of the care recipient and access to support. It then follows that measures to increase the  
9 mental health and well-being of carers will also have flow on benefits for physical well-  
10 being.  
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### 16 **Limitations**

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18 This study had a number of limitations that need to be considered. It is acknowledged that the  
19 Australian population normative data for the SF-36, collected in 1995, may now be dated  
20 given changes in population health over the past 20 years. However, this data was the most  
21 recent, of suitable format, that could be found. More recent Australian health surveys (for  
22 example 45 and Up Study<sup>35</sup>) have included some aspects of the SF-36 in their reporting, but  
23 there was no alternative source found that reported gender specific, age-based, Australian  
24 population means for the full eight domains and two component scores of the SF-36. The  
25 limited number of male respondents in the current study meant that sex-based comparisons  
26 need to be viewed with caution. It is recommended that in future carer studies active  
27 recruitment of male participants may be needed in order to gain a sex ratio that is in line with  
28 the Australian overall ratio of male to female carers.  
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### 37 **CONCLUSIONS**

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39 Despite the noted limitations, the current study has contributed to the health-related data of  
40 Australian carers by providing a profile of self-reported health for carers in non-metropolitan  
41 areas of New South Wales, Australia. These findings indicate the poor health profile of this  
42 group relative to the general Australian population, especially in terms of high levels of  
43 psychological distress, and highlight the need for additional support for carers in order to ease  
44 the accumulated mental and physical health burdens of this group.  
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### 52 **CONTRIBUTIONSHIP STATEMENT**

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54  
55 RH was the chief investigator of the study. RH and SW designed the study. RH, SW and PR  
56 were responsible for data collection, while RH, SW and GD were responsible for data  
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2  
3 analysis and interpretation. All the authors helped to draft the manuscript and approved the  
4 final version.  
5  
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### 7 **COMPETING INTERESTS**

8  
9 There are no competing interests to declare.  
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### 12 **FUNDING**

13  
14 The authors would like to acknowledge the [institutional details to be provided after blind  
15 review] Research Seed Grants that supported this project.  
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### 18 **DATA SHARING STATEMENT**

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20 No additional data are available.  
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# BMJ Open

## Self-reported physical and mental health of Australian carers: A cross-sectional study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-011417.R1
Article Type:	Research
Date Submitted by the Author:	02-Jun-2016
Complete List of Authors:	Hussain, Rafat; Australian National University, ANU School of Medicine & Research, School of Population Health,; University of New England, School of Rural Medicine Wark, Stuart; University of New England, School of Rural Medicine Dillon, Gina; University of New England, School of Rural Medicine Ryan, Peta; University of New England, School of Rural Medicine
<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Public health
Keywords:	rural, carer, MENTAL HEALTH, Physical Health

SCHOLARONE™  
Manuscripts

**Title**

Self-reported physical and mental health of Australian carers: A cross-sectional study

**Authors**

Rafat Hussain, (corresponding author), ANU School of Medicine & Research School of Population Health, Australian National University, Canberra, ACT 0200, Australia.

Email: [Rafat.Hussain@anu.edu.au](mailto:Rafat.Hussain@anu.edu.au); Tel 612 6125 9758

Stuart Wark, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia.

Gina Dillon, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia

Peta Ryan, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia

**Word Count**

4664

## ABSTRACT

**Objective:** To report on self-reported physical and mental health of informal carers in rural regions of New South Wales, Australia.

**Methods:** A cross-sectional community-based sample (n=222) of carers completed a questionnaire incorporating self-reported measures of health from validated international instruments including Medical Outcomes Study scale (SF-36), the Centre for Epidemiology-Depression (CES-D) and Kessler-10 (K10) Psychological Distress scales, along with information on participant demographics and other key caregiving characteristics such as health condition of care recipient.

**Results:** Rural carers' self-reported health was poor as evident on the SF-36 Physical and Mental Health component scales as well as each individual domain of the SF-36. Results from the CES-D and K-10 scales indicated very high rates of depressive symptoms and psychological distress. Over 70% of carers within the current study had CES-D scores indicative of depressive symptoms. Scores on the K-10 indicate almost half the carers were experiencing high levels of psychological distress, which is over 4 times the rate reported in the general Australian population.

**Conclusions & Implications:** Results from this study were compared to Australian population normative data and were found to be significantly below Australian age-matched population norms for SF-36, CES-D and K-10. These findings illustrate the poor health profile of informal carers relative to the general Australian population, especially in terms of depressive symptoms and psychological distress. This highlights the need for additional support for rural carers in order to ease the accumulated mental and physical health burdens of this group.

### Strengths and Limitations

- This study specifically focuses on the self-reported health of carers in non-metropolitan Australia
- It was found that the health of rurally-located carers' was significantly below Australian age-matched population norms, with over 70% of carers showing depressive symptomology

- Almost half the carers were found to be experiencing high levels of psychological distress
- This study methodology contains the risk of self-selection bias, and problems associated in the self-reporting of health conditions.
- There was a significant gender bias towards female respondents, so any sex-based comparisons must be viewed with caution.

For peer review only

## INTRODUCTION

The Australian Government has a stated commitment to supporting individuals with various health needs, such as a disability, ageing-related impairment, physical or mental health issue, to be assisted to remain within their local community.<sup>1-2</sup> However, the support provided by the Government is not always comprehensive, and often requires significant assistance from informal carers. Informal care is a support model where a person provides unpaid assistance to another individual with respect to general activities of daily living such as physical, emotional, financial and personal care.<sup>3</sup> The support of the informal carer is often vital, playing a significant role in increasing the individual's access to health and rehabilitation services.<sup>4</sup>

The 'burden' of providing informal care is considered to be the reduction in personal opportunities or actual health of an individual as a direct result of having to provide this unpaid support.<sup>5</sup> It has been previously identified that informal carers are likely to experience high levels of psychological distress,<sup>6</sup> and a decline in both physical health<sup>7</sup> and quality of life.<sup>8</sup> The need to provide informal care, particularly personal care,<sup>9</sup> has an impact on the carer's ability to both seek and maintain external paid employment.<sup>10</sup> It was estimated in 2015 that 2.86 million people in Australia provide informal care support to another person.<sup>11</sup> This figure represents approximately 12.5% of the nation's population and an increase of around 260,000 carers from 2012.<sup>12</sup> However, it is concerning to note that there are now perceived to be fewer carers, relative to demand, than in 2010, and the demand for informal care is predicted to considerably exceed its supply within the next decade.<sup>11</sup>

Although there are a number of Australian studies on caregiving, many have either looked at specific health issues such as chronic heart conditions,<sup>13</sup> motor neurone and other similar degenerative diseases,<sup>14-15</sup> Alzheimer's or dementia<sup>16-18</sup>, specific cancers<sup>19</sup> and palliative care and/or end-of-life care issues.<sup>20-21</sup> Almost all studies on carers' health with the exception of a recent qualitative study<sup>22</sup> have been conducted in large cities and metropolitan areas. It is well established that people living in rural regions in Australia face significant challenges in relation to health and social services, and this background merits specific focused investigations.<sup>23</sup>

In rural areas of Australia, the issues faced by informal carers may be amplified compared to those in metropolitan locations.<sup>24</sup> Rural carers are often geographically isolated, and struggle to access relevant health care support services for both themselves and the person for whom they

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2  
3 provide care.<sup>25 26</sup> A failure to receive appropriate and timely treatment magnifies the issues for  
4 carers, as the existing health condition then worsens progressively over time,<sup>27</sup> which then places  
5 additional stress onto the carer.<sup>28</sup> Individuals in rural areas are less likely to receive formal carer  
6 training to cope with these concerns<sup>29</sup> and this in turn can lead to issues with poor self-esteem.<sup>30</sup>  
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9  
10 In spite of these issues, there remains only limited research that specifically examines the issues  
11 and care-giver burden facing individuals in rural areas of Australia.<sup>15,31</sup> The current paper is part  
12 of a larger study focussing on the experiences of informal carers in non-metropolitan areas of  
13 New South Wales, Australia. The aim of this research is to establish an initial profile of self-  
14 reported physical and mental health of rurally-based informal carers using validated international  
15 health scales. A secondary aim is to assess these self-reported measures against Australian  
16 normative data and facilitate future comparative studies with metropolitan-based peers. Formal  
17 ethical approval for this project was granted by the University of New England's Human  
18 Research Ethics Committee (HREC approval number HE13/130).  
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## 27 **METHOD**

### 28 **Study design, setting and Participants**

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30 A cross-sectional community-based survey was undertaken in rural areas of New South Wales  
31 (NSW). NSW is the most populous state in Australia (total 23m) comprising 7.1m individuals of  
32 which nearly 20% live in rural and regional areas.<sup>32</sup> The rural or non-metropolitan cohort of the  
33 population, as defined by the Australian Standard Geographic Classification (ASGC) system, is  
34 dispersed over a large geographic footprint comprising populations resident in very diverse  
35 regional towns and a small proportion in rural and very remote regions.<sup>32-33</sup> The ASGC is a  
36 nationally standardised measure of geographic remoteness which incorporates aspects of distance  
37 and access to services in order to define five remoteness categories, namely: major cities, inner  
38 regional, outer regional, remote and very remote areas.<sup>34</sup>  
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48 Potential participants for this project were defined as being any individual over the age of 18  
49 who self-identifies as providing informal care and support for a person with either a disability or  
50 other long-term health condition. The geographic catchment was specified as being areas of  
51 NSW that are outside of the ASGC remoteness category of 'major cities'. In order to overcome  
52 the challenge associated with the wide geographical dispersal of carers, a survey tool was  
53 developed. A cross-sectional survey questionnaire was designed and piloted both in print and  
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3 online format with 10 people, with expert knowledge of rural health and carer health issues.  
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5 Minor modifications were made to some of the items in the survey form based on feedback from  
6  
7 the pilot study.  
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9  
10 A variety of community-based recruitment strategies were used to distribute information about  
11 the project and enrol participants. These included social media, community-group and carer  
12 organisation newsletters, posters in community facilities, and a combination of electronic and  
13 traditional media sources such as radio and newspaper interviews. A \$5 grocery voucher  
14 incentive was provided for all respondents. Potential participants were given the option of  
15 receiving a hard copy of the information package and associated questionnaire, or to access the  
16 survey via a purpose-developed web-site that contained all relevant documentation and an online  
17 version of the survey questionnaire. A total of 237 participants completed the survey of which  
18 222 were considered valid responses from rural areas of NSW.  
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### 25 **Data measurement**

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28 The outcome variables included self-reported health using three validated scales: the Medical  
29 Outcomes Short-Form (SF-36) which measures health across eight domains of physical and  
30 mental health; the Centre for Epidemiologic Studies-Depression scale (CES-D) and the Kessler-  
31 10 (K-10) Psychological Distress scale. Each of these scales is briefly discussed below.  
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36 The SF-36 comprises of 36 questions which focus on general health, physical functioning, role  
37 physical, bodily pain, vitality, social functioning, mental health, and role emotional. These eight  
38 subscales are also used to calculate two summary or component scales: the Physical Component  
39 Score (PCS), reporting on physical health, and the Mental Component Score (MCS), reporting  
40 on mental health.<sup>35</sup> Scores on each of the SF-36 domain and component scores can range from 0  
41 – 100 and higher scores indicate better health. Australian population normative data for SF-36  
42 scores were accessed from the Australian Bureau of Statistics.<sup>36</sup> Imputation of missing values  
43 and computation of the domain and component scores were performed according to the  
44 procedures outlined in the *SF-36 Manual and Interpretation Guide*.<sup>35</sup> Australian population  
45 normative data for SF-36 scores were accessed from the Australian Bureau of Statistics.<sup>36</sup>  
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54 Self-reported mental health was additionally assessed via the Centre for Epidemiologic Studies-  
55 Depression (CES-D) Scale and the Kessler (K-0) Psychological Distress scale. The CES-D is a  
56 validated and widely used scale designed to measure current levels of depressive symptoms  
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3 within the general population.<sup>37</sup> CES-D scores have a possible range of 0 – 60 and higher scores  
4 indicate worse mental health. A score of 16 points or more is generally accepted as an indicator  
5 of depression symptoms<sup>38</sup> and scores of 24 and over are suggestive of severe depressive  
6 symptoms.<sup>39</sup> Normative CES-D data for the Australian population was derived by entering the  
7 cut points for depressive and severe depressive symptoms (16 and 24 respectively) into the  
8 *MoodScore* computer programme of Crawford & Cayley<sup>40</sup> which has been developed as a means  
9 of quickly referencing Australian normative data on a range of self-reported mood scales.  
10

11  
12 The K-10 scale provides a measure of non-specific psychological distress based on questions  
13 about negative emotional states experienced in the past four week period.<sup>24</sup> Scores on the K-10  
14 range from 10 – 50 with higher scores indicating higher levels of psychological distress. The  
15 designated cut-off scores for low (10-15), moderate (16-21), high (22-29), and very high (30-50)  
16 levels of psychological distress. Australian population norms were drawn from Australian  
17 Bureau of Statistics data.<sup>41</sup>  
18

19  
20 Information was collected on a range of explanatory variables including socio-demographic and  
21 caring role characteristics of participants including: sex, age, employment status, whether they  
22 are in a primary care-giving role, their relationship to the person they provide care for  
23 (spouse/parent/child/other), whether they are aware of, or members of, any carer support groups,  
24 whether they are a live-in carer and the medical condition/s of the care recipient. The medical  
25 conditions were classified into four broad categories of:  
26

- 27 • Cognitive: including autism spectrum disorders, Alzheimer's disease and other  
28 dementias, intellectual disability, Down syndrome and acquired brain injury.
- 29 • Physical: including cancer, stroke, post-operative recovery, Parkinson's disease, cerebral  
30 palsy, quadriplegia, blind, deaf, diabetes, heart and lung conditions and frail aging.
- 31 • Mental health: including schizophrenia, ADHD, bipolar disorder, alcohol and drug  
32 addiction, depression and anxiety disorders.
- 33 • Multiple: this category involves the co-existence of conditions across more than one of  
34 the Cognitive, Physical or Mental health categories.  
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36  
37 Issues relating to potential bias including selection and measurement bias are discussed in the  
38 limitations section of the paper.  
39

## Statistical methods

Analysis was performed using SPSS V22 (2013 release) for univariate and multivariable analyses. ANOVA with posthoc comparison via Dunnett's C, with  $p \leq 0.05$  as the critical value, were used to test for differences between mean SF-36 scores of participants. Graphical representation and comparison of SE error bars were used to gauge significant difference between mean SF-36 scores of participants from the current study and Australian population norms. In order to age-match data from the current study with ABS data for the SF-36 population norms, the average age of participants was calculated for each age grouping in the current study. This average age was then compared to the ABS data age categories, and the normative data for the relevant category was used as a comparison to the current study.

Multiple linear regression technique was used for multivariable analyses for two of the four dependent variables namely - PCS and MCS to estimate the proportion of variance in PCS and MCS scores that could be accounted for by age, gender, employment status, type of condition that care is being provided for, and membership of a carer support group. Key assumptions were evaluated prior to interpreting the results of the multiple linear regression analyses. A visual inspection of the normal probability plot of standardised residuals and of the scatterplot of standardised residuals against standardised predicted values was undertaken. These both indicated that assumptions of normality, linearity and homoscedasticity of residuals were met. Multivariate outliers were not of concern; for all cases in the data file the Cook's distance value was  $<1$  and Mahalanobis distance did not exceed the critical  $\chi^2$  for  $df = 8$  (at  $\alpha = 0.001$ ) of 26.125. Logistic regression analysis was used individually for the remaining two dependent variables – CES-D and K-10 using stepwise technique for inclusion of explanatory variables (spin  $<0.05$ ; spout  $>0.10$ ). The explanatory variables included in both regression models were age (categorical), gender, work status, type of condition that care is being provided for and membership of a carer support group.

## RESULTS

The findings are based on responses from 222 participants from rural NSW. The demographic characteristics of the study sample are summarised in Table 1 below. The majority of participants were female (85%), live in carers (75%), involved in the primary care role (80%). Ages ranged from 21 to 86 years, with more participants being from the older age groups.

Approximately 45% of the carers were also working in paid employment. Just over one third of the participants (38%) were caring for someone with a physical condition and 27% of carers were caring for people with multiple conditions.

**Table 1: Demographic and caregiving characteristics of participants (n=222)**

	n (%)
<b>Sex</b>	
Female	191 (84.9)
Male	31 (13.8)
<b>Age (years)</b>	
Range	21-8
Mean	52.7
Std Dev	14.4
<b>Age (grouped – years)</b>	
40 and under	47 (21.2)
41 – 50	53 (23.9)
51 – 60	58 (25.8)
61+	64 (28.4)
<b>Currently working</b>	
Yes	98 (45.2)
No	119 (54.8)
<b>Caregiver role</b>	
Primary	180 (80.0)
Secondary	19 (8.4)
<b>Caring relationship</b>	
Caring for a parent	27 (12.0)
Caring for a child	92 (40.9)
Caring for spouse	77 (34.2)
Other	17 (7.6)
<b>Live in carer</b>	
Yes	142 (75.5)
No	46 (24.4)
<b>Condition cared for</b>	
Physical	81 (37.7)
Cognitive	48 (22.3)
Mental Health	27 (12.6)
Multiple categories	59 (27.4)
<b>Aware of any carer support groups</b>	
Yes	152 (67.6)
<b>Member of a carer support group</b>	
Yes	61 (27.1)

## Self-reported health

Carers in the study had self-reported physical and mental health that was significantly below Australian age-matched population norms. This was evident on the SF-36 Physical Component Scale (PCS) and Mental Component Scale (MCS), as well as within each individual domain of the SF-36 (see Figure 1). Carers showed particularly lower comparative scores in the domains of social functioning, role emotional role physical and vitality. The comparison between findings of the present study and the Australian normative data for summary measures of SF-36, namely PCS and MCS as well as the scores for each of the eight individual domains, is outlined in the Discussion section of the paper.

Results from the CES-D and K-10 scales indicate very high rates of depressive symptoms and psychological distress amongst the rural carers sample (see Figure 2). Over 70% of carers within the current study had results on the CES-D that indicated the presence of depressive symptoms, with 36% meeting the criteria for severe depressive symptoms. Scores on the K-10 indicate almost half the carers (49.3%) were experiencing high and very high levels of psychological distress. Comparison with normative data for SF-36 in Australian population is provided in the Discussion section of the paper. Additional information comparing the depressive symptoms reported by rural carers to Australian national data has been placed in Supplementary Materials section.

## Factors associated with self-reported health in rural carers

In Table 2 we present the bivariate results for SF-36 summary scores as well as the eight individual domains along with scores for CES-D and K-10. Self-reported health was associated with both age and sex in the survey sample (Table 2), although given the relatively small number of male participants (13%), differences by sex should be interpreted with caution. Significant differences in the self-reported health of male versus female carers were in the areas of SF-36 MCS, role emotional, vitality, and bodily pain. In all of these domains males had higher mean scores than females indicating better self-reported health in male compared to female carers. Significant age differences were found in the SF-36 measures of PCS and MCS as well as the vitality, mental health, social functioning and physical functioning domains. Additionally there were also significant age associations with scores on both the CES-D and the K-10 scales as seen in Table 2.

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3 Age-related differences on the physical functioning domain of the SF-36 followed population  
4 norms of declining scores with age and could be considered to be a normal function of ageing.  
5 Age-related scores for the vitality domain within the current study show a trend towards  
6 increasing vitality scores with older age. Furthermore, there was no significant difference  
7 between the PCS scores of younger carers (40 years and under) compared to carers who were 61  
8 years and above.  
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14 There are also several age-related associations within measures of mental health. Scores on the  
15 SF-36 MCS, mental health and social functioning domains generally increased with age  
16 indicating better aspects of mental health in older carers compared to younger age groups. Scores  
17 on the CES-D and K10 measures also indicated better mental health for older carers compared to  
18 their younger counterparts. These results, along with the findings from the SF-36 domains, can  
19 be interpreted as indicating a relatively larger mental health burden on young carers compared to  
20 older carer age groups.  
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28 Several other associations were investigated and it was found that there were no significant  
29 differences in the mean self-reported health scores of primary versus non-primary carers across  
30 any of the eight domains or two component scores of the SF-36, or total scores on CES-D or K-  
31 10. Also there were no significant differences in the mean self-reported health scores of carers  
32 from any of the relationship categories of caring for a parent/child/spouse/other. There were no  
33 significant differences in any of the mean health scores of carers for SF-36 categorised by the  
34 condition that they were caring for (physical, cognitive, mental health or multiple conditions).  
35 However, there were significantly lower scores for CES-D and K-10 of carers for physical health  
36 conditions of care recipients (Table 2).  
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**Table 2: Mean self-reported health scores for the SF-36, CES-D and K-10 scales stratified by caregiving characteristics**

	SF-36 (higher scores indicate better health)											Lower scores indicate better health	
	n	PCS	MCS	General Health	Vitality	Mental Health	Bodily Pain	Social Functioning	Role Emotional	Role Physical	Physical Functioning	CES-D	K10
<b>Sex</b>													
Male	30	46.07 <sup>a</sup>	41.46 <sup>a</sup>	55.43 <sup>a</sup>	47.00 <sup>a</sup>	63.77 <sup>a</sup>	63.10 <sup>a</sup>	59.17 <sup>a</sup>	63.22 <sup>a</sup>	58.89 <sup>a</sup>	74.97 <sup>a</sup>	19.62 <sup>a</sup>	20.79 <sup>a</sup>
Female	186	43.44 <sup>a</sup>	35.40 <sup>b</sup>	50.96 <sup>a</sup>	34.61 <sup>b</sup>	57.15 <sup>a</sup>	53.10 <sup>b</sup>	56.96 <sup>a</sup>	38.71 <sup>b</sup>	43.72 <sup>a</sup>	69.65 <sup>a</sup>	21.77 <sup>a</sup>	22.81 <sup>a</sup>
<b>Age (years)</b>													
40 and under	46	44.98	33.09 <sup>c</sup>	47.33 <sup>a</sup>	30.00 <sup>a</sup>	55.30 <sup>b</sup>	57.04 <sup>a</sup>	54.08 <sup>a</sup>	36.59 <sup>a</sup>	38.04 <sup>a</sup>	77.31 <sup>a</sup>	23.27 <sup>a</sup>	24.46 <sup>a</sup>
41-50	51	47.37 <sup>a</sup>	33.82 <sup>c</sup>	52.19 <sup>a</sup>	33.20 <sup>a</sup>	55.14 <sup>b</sup>	58.90 <sup>b</sup>	56.37	43.79 <sup>a</sup>	56.70 <sup>a</sup>	77.00	21.38 <sup>a</sup>	22.42
51-60	57	42.37	34.30 <sup>c</sup>	47.99 <sup>b</sup>	34.91 <sup>a</sup>	53.44 <sup>b</sup>	49.81 <sup>a</sup>	51.97	38.10 <sup>a</sup>	43.75 <sup>a</sup>	66.16	23.24 <sup>a</sup>	24.28 <sup>a</sup>
61+	62	40.75	43.40 <sup>c</sup>	57.53 <sup>b</sup>	45.08 <sup>b</sup>	66.95 <sup>b</sup>	53.12 <sup>a</sup>	65.37	48.59 <sup>a</sup>	44.58 <sup>a</sup>	63.51	18.46 <sup>b</sup>	19.46 <sup>b</sup>
<b>Currently working</b>													
Yes	95	46.04	34.52	50.86	34.56	56.47	57.78	55.53	42.55	49.73	76.33 <sup>a</sup>	21.89	22.95
No	117	46.02	37.85	52.62	37.89	59.53	52.43	59.05	42.54	43.41	65.56 <sup>a</sup>	21.17	22.16
<b>Condition</b>													
Cognitive	42	46.45	34.71	49.83	35.43	54.57	59.43	57.45	42.39	48.37	75.17	23.77	24.93
Physical	76	44.25	37.46	54.35	38.48	58.88	54.14	59.53	46.41	48.73	70.16	19.58 <sup>a</sup>	20.81 <sup>a</sup>
Mental Health	24	44.92	32.04	49.28	34.00	57.12	55.76	48.00	29.17	44.00	74.55	22.33	24.56
Multiple Categories	57	41.82	37.21	49.46	35.00	59.79	50.42	58.62	40.80	39.51	68.97	21.89	22.05
<b>Support Group</b>													
Yes	60	41.89	36.31	48.77	36.58	58.22	50.51	56.25	36.26	43.75	63.22 <sup>a</sup>	19.98	22.47
No	112	44.64	36.65	53.31	37.77	58.79	56.65	57.48	42.86	45.00	74.00 <sup>a</sup>	22.01	22.17
<b>Total</b>	<b>216</b>	<b>43.80</b>	<b>36.24</b>	<b>51.58</b>	<b>36.34</b>	<b>58.07</b>	<b>54.46</b>	<b>57.27</b>	<b>42.06</b>	<b>45.85</b>	<b>70.40</b>	<b>21.47</b>	<b>22.54</b>

Note: a = p < 0.05, b = p < 0.01

1 When categorised by their employment status (Working: Yes/No), it was found that carers  
2 who were working had better self-reported health on both the SF-36 PCS and physical  
3 functioning domains. There were no other significant associations of working status with  
4 health on any of the other SF-36 domains or on the K-10 or CES-D. Better physical  
5 functioning amongst those carers who were working was interpreted as indicating that any  
6 additional stress of working in addition to caring was not impacting negatively on the  
7 physical health of carers. The only significant difference in self-reported health between  
8 members and non-members of support groups was on the physical functioning domain of the  
9 SF-36. It was found that members of support groups had significantly lower scores (better  
10 health) in the domain of physical functioning compared to non-members (see Table 2).

### 11 **Associations between caring relationship, condition cared for and age of carer**

12 There was no significant association between age of carer and the type of condition being  
13 cared for. There was however a significant relationship between the condition being cared for  
14 and the relationship between carer and recipient of care. People caring for a parent were most  
15 likely to report caring for a physical condition (66.7%) compared to caring for a mental  
16 health or cognitive condition or multiple conditions. People caring for a child were most  
17 likely to report caring for a cognitive condition (33%) or for multiple conditions (33%).  
18 Although only 16.5% of people caring for a child reported caring for a mental health  
19 condition, this was the most common caring relationship in the mental health category. There  
20 was also a significant association between the age of the carer and the relationship with the  
21 care recipient. This would logically be related to the care of elderly parents or spouses, with  
22 50% of carers in the 51-60 years age group reporting that they were caring for a parent and  
23 55% of carers in the 61+ years age group reporting that they were caring for a spouse.

24 In Table 3, we outline the results of the multivariable regression analyses for each of the four  
25 outcome variables. As mentioned in the Methods section, we used multiple linear regression  
26 for regression models for the two summary component scores of SF-36, namely PCS and  
27 MCS; and binary logistic regression for CES-D and K-10. After adjusting for an explanatory  
28 variables such as gender, work status, condition cared for and membership of carer support  
29 group, the only statistically significant category for PCS was the age group 51-60 years. On  
30 the other hand, for MCS all age categories were significantly associated with poor mental  
31 health when compared to the 60+ age group. The results for CES-D were somewhat  
32 anomalous, with three times higher odds of high CES-D scores indicating depression, though  
33 the results were marginally significant ( $p=0.06$ ). For K-10, there were three times higher odds  
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of poor mental health across all age groups and results for all the age categories were statistically significant (see Table 3).

**Table 3: Multivariable analysis for predictors of self-rated health in rural caregivers**

	PCS Beta(Sig)	MCS Beta(Sig)	CES-D exp(B)(Sig)	K-10 exp(B)(Sig)
<b>Age</b>				
40 and under	0.187 (0.061)	<b>-0.339 (0.001)</b>	3.492 (0.057)	<b>3.767 (0.010)</b>
41-50	<b>0.265 (0.010)</b>	<b>-0.348 (0.001)</b>	0.866 (0.791)	<b>3.416 (0.017)</b>
51-60	0.124 (0.205)	<b>-0.330 (0.001)</b>	2.052 (0.163)	<b>3.584 (0.006)</b>
61+ - reference				
<b>Gender</b>				
Female	-0.107 (0.185)	-0.114 (0.145)	0.967 (0.955)	1.020 (0.971)
Male - reference				
<b>Currently working</b>				
No	-0.097 (0.259)	0.040 (0.631)	0.547 (0.157)	1.468 (0.292)
Yes - reference				
<b>Condition cared for</b>				
Physical	0.052 (0.611)	-0.013 (0.894)	0.748 (0.562)	0.870 (0.753)
Mental Health	0.021 (0.818)	-0.046 (0.602)	0.717 (0.629)	1.788 (0.340)
Multiple	-0.036 (0.711)	0.049 (0.605)	1.387 (0.575)	0.784 (0.605)
Cognitive - reference				
<b>Support group</b>				
No	0.031 (0.701)	0.438 (0.662)	2.222 (0.051)	0.998 (0.996)
Yes -reference				

## DISCUSSION

The need to support another individual in basic activities of daily living is becoming an increasingly important issue in Australia. It is estimated that one in eight people provide informal and unpaid support to another person, and the demand for this type of care is predicted to increase substantially over the next ten years.<sup>11</sup> It is known that the provision of informal care is associated with health decline in several areas including psychological distress,<sup>6</sup> physical manifestations<sup>7</sup> and general quality of life.<sup>8</sup> It is further understood that that there is a higher proportion of informal carers in rural localities compared to metropolitan locations,<sup>11</sup> and it is recognised that health-care issues are potentially worse in country areas where access to health care services may be compromised.<sup>28</sup> The SF-36 scale has been used in some Australian longitudinal studies such as the Household Income and Labour Dynamics Australia (HILDA), using a panel survey design,<sup>42</sup> and the Women's Health Australia (WHA) study.<sup>43</sup> However the HILDA survey does not have a specific focus on information about caregiving issues and its impact on health, while the WHA is limited to women participants in specific age cohorts.

1 The aim of the present study was to establish an initial self-reported health profile, both  
2 physical and mental health, of rurally-based informal carers with a secondary objective of  
3 comparing the results to Australian normative data. It was found that the self-reported  
4 physical and psychological health of carers within this study was significantly worse than the  
5 Australian population norms across all eight domains and the two summary component  
6 scores of the SF-36. Additionally, almost half of the carers reported high or very high level  
7 of psychological distress on the K-10 scale. This is indicative of a major health burden related  
8 to the role of informal caregiving.  
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10 The current study had a majority of female participants, which is in line with the gendered  
11 nature of informal caregiving in Australia. The nationally-based Disability, Ageing and  
12 Carers Survey<sup>44</sup> reports that, within Australia, females represent 70% of primary carers and  
13 56% of carers overall. In the current study male carers had significantly higher levels of self-  
14 reported health, than female carers, in the SF-36 MCS score as well as the health domains of  
15 vitality, role emotional, and bodily pain. The additional caregiving burden for female carers  
16 has been highlighted by several previous studies and factors related to this additional burden  
17 have been identified as including: the multiple caring roles of women, especially related to  
18 childrearing and household duties,<sup>45</sup> spending more time with care recipients than male  
19 caregivers<sup>46</sup> and seeking less social and tangible support than male carers.<sup>47</sup> The current study  
20 provides additional data to indicate a trend towards a higher health-related burden for female  
21 compared to male carers.  
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23 There were also age-related differences in self-reported health of carers that went against  
24 expected trends. For example, the Physical Health Component (PCS) score of younger carers  
25 (40 years and under) was not significantly different to the PCS score of carers aged 61 years  
26 and over. This is contrary to the expected decline in self-reported health with increasing age,  
27 as evidenced in the Australian normative SF-36 data. Furthermore, scores in the SF-36  
28 domain of vitality showed a significant increase with age. This is in contrast to the age  
29 related trend in the population norm data which showed a decline in vitality scores in older  
30 age groups.<sup>36</sup> These contrary findings to the population norm trend could be interpreted as  
31 indicating that the burden of caring on physical health may be more prominent in young  
32 carers compared to older carers within the current study. In the normative data from the  
33 Australian population there is a decline in social functioning with age which also is contrary  
34 to the data from the current study.  
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1 These trends indicate a greater health burden for younger carers compared to older carers.  
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3 The additional care burden experienced by younger carers may be attributed to the fact that  
4 carers in the under 40 age group may be raising a family in addition to meeting the  
5 responsibilities of a caring role. The life stage prior to 60 years of age represents the key time  
6 for engagement in career and employment, and being a carer in this age group may contribute  
7 significant additional life stress, as dual responsibilities of work and caring roles compete for  
8 time and priority.<sup>17</sup> Decisions to work in a part-time capacity, or to withdraw from the paid  
9 workforce due to caring commitments, carry significant financial consequences both in the  
10 short-term and for future employment prospects and long-term financial security. The  
11 perceived financial cost of caregiving has been found to be a significant contributor to the  
12 overall caregiving burden of informal carers,<sup>48</sup> and this perceived financial loss may be  
13 greater for younger carers compared to older carers.  
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16 Normative data indicates an increase in the MCS and mental health scores of older  
17 participants, so the current data is in line with this trend. However the score increases within  
18 the current study are larger than those seen in the normative data set, with an increase of over  
19 11 points on the mental health scores in the older group compared to the youngest group of  
20 carers, whereas a comparative age difference in the normative data is associated with only a  
21 0.5 point difference in mean mental health scores. Considerably higher psychological  
22 distress scores were found in the present study which were over 4 times the rates expected in  
23 the general Australian population (12.6%) with only 28% of study carers indicating low  
24 levels of psychological distress compared to 64.3% of the general population.<sup>36</sup>  
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27 The high levels of psychological distress and depressive symptoms among the carers in this  
28 sample is a worrying result, with over 70% of the carers indicating depressive symptoms and  
29 almost half of the sample reporting high or very high levels of psychological distress. This  
30 alarmingly high rate of mental distress highlights an urgent need for additional support for  
31 informal carers in rural areas of New South Wales. A meta-analysis of factors contributing to  
32 physical health of informal caregivers<sup>47</sup> reported that depressive symptoms of caregivers had  
33 a higher association with declines in physical health than objective care related stressors such  
34 as hours of care provision, behavioural problems of the care recipient and medical condition  
35 of the care recipient and access to support. It then follows that measures to increase the  
36 mental health and well-being of carers will also have flow on benefits for physical well-  
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## Limitations

This study had a number of limitations that need to be considered. Any community-based study seeking participants study cannot eliminate selection bias as a risk. It is considered unlikely that carers with more significant burdens of ill-health would have opted to participate in the survey. As such, the results reported for the present study may be an under-representation of mental health issues given the significant challenges of caregiving for rural carers, and with the potential of more distressed carers not being able to find the time and/or energy to participate in the study. Measurement bias is largely eliminated by using validated scales for outcome variables such as SF-36, CES-D and K-10. However, for any self-report scales it is acknowledged that recall bias may be operative in the reporting of health conditions, such as bodily pain and physical functioning. It is noted that the Australian population normative data for the SF-36, collected in 1995, may now be dated given changes in population health over the past 20 years. However, this data was the most recent, of suitable format, that could be found. More recent Australian health surveys (for example 45 and Up Study<sup>49</sup>) have included some aspects of the SF-36 in their reporting, but there was no alternative source found that reported gender specific, age-based, Australian population means for the full eight domains and two component scores of the SF-36. The limited number of male respondents in the current study meant that sex-based comparisons need to be viewed with caution. It is recommended that in future carer studies active recruitment of male participants may be needed in order to gain a sex ratio that is in line with the Australian overall ratio of male-to-female carers.

## CONCLUSIONS

Despite the noted limitations, the current study has contributed to the health-related data of Australian carers by providing a profile of self-reported health for carers in non-metropolitan areas of New South Wales, Australia. These findings indicate the poor health profile of this group relative to the general Australian population, especially in terms of high levels of psychological distress, and highlight the need for additional support for rural carers in order to ease the accumulated mental and physical health burdens of this group.

## CONTRIBUTIONSHIP STATEMENT

RH was the chief investigator of the study. RH and SW designed the study. RH, SW and PR were responsible for data collection, while all authors were responsible for data analysis and interpretation. All the authors helped to draft the manuscript and approved the final version.

## COMPETING INTERESTS

There are no competing interests to declare.

## FUNDING

The authors would like to acknowledge the support provided by University of New England through the University Research Seed (URS) grant scheme. The authors further acknowledge the contribution made by the Collaborative Research Network on Mental Health and Well-being in Rural Communities, supported by the Department of Industry, Innovation, Science, Research and Tertiary Education, Commonwealth Government of Australia.

## DATA SHARING STATEMENT

No additional data are available.

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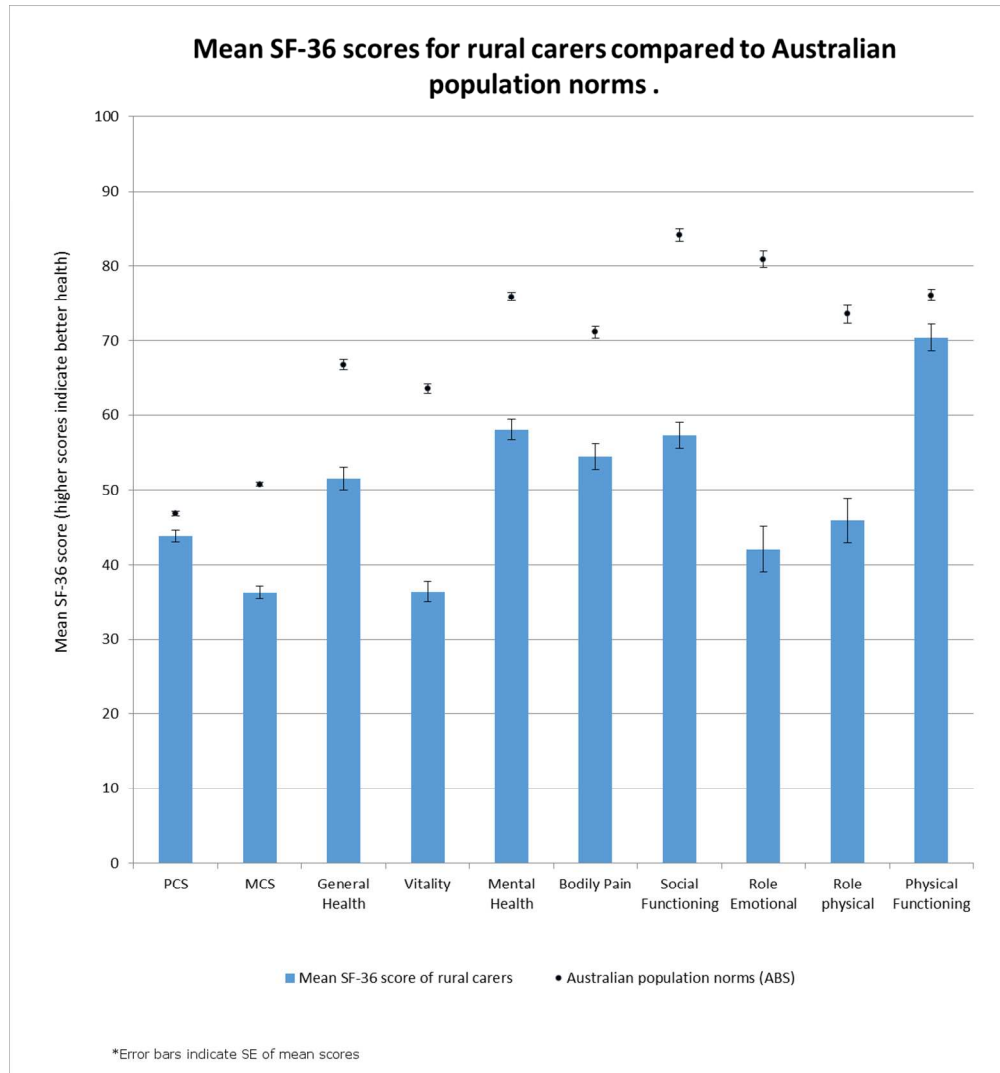


Figure 1: Mean SF-36 scores for rural carers compared to Australian population norms

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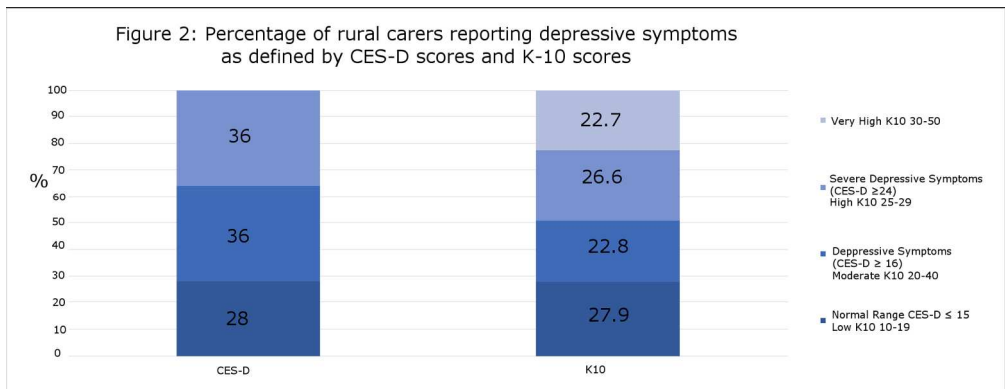
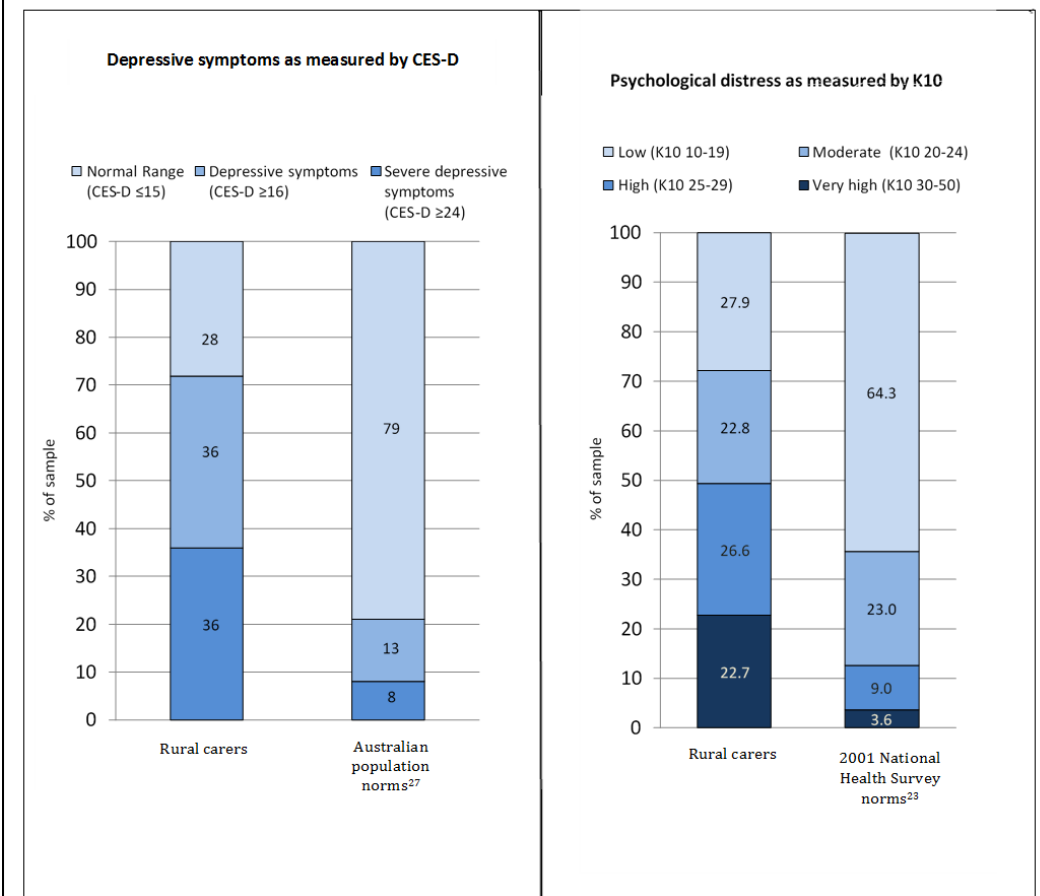


Figure 2: Percentage of rural carers reporting depressive symptoms as defined by CES-D scores and K-10 scores

166x63mm (300 x 300 DPI)

Peer review only

Figure 3: Comparison between depressive symptoms reported by rural carers compared to data from Australian national survey



Review only

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
<b>Title and abstract</b>	1√	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
<b>Introduction</b>		
Background/rationale	2√	Explain the scientific background and rationale for the investigation being reported
Objectives	3√	State specific objectives, including any prespecified hypotheses
<b>Methods</b>		
Study design	4√	Present key elements of study design early in the paper
Setting	5√	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6√	(a) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7√	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*√	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9√	Describe any efforts to address potential sources of bias
Study size	10√	Explain how the study size was arrived at
Quantitative variables	11√	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12√	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses
<b>Results</b>		
Participants	13*√	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage – Not applicable (c) Consider use of a flow diagram - Not applicable
Descriptive data	14*√	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*√	Report numbers of outcome events or summary measures
Main results	16√	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17√	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

<b>Discussion</b>		
Key results	18✓	Summarise key results with reference to study objectives
Limitations	19✓	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20✓	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21✓	Discuss the generalisability (external validity) of the study results
<b>Other information</b>		
Funding	22✓	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

# BMJ Open

## Self-reported physical and mental health of Australian carers: A cross-sectional study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-011417.R2
Article Type:	Research
Date Submitted by the Author:	01-Aug-2016
Complete List of Authors:	Hussain, Rafat; Australian National University, ANU School of Medicine & Research, School of Population Health,; University of New England, School of Rural Medicine Wark, Stuart; University of New England, School of Rural Medicine Dillon, Gina; University of New England, School of Rural Medicine Ryan, Peta; University of New England, School of Rural Medicine
<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Public health
Keywords:	rural, carer, MENTAL HEALTH, Physical Health

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**Title**

Self-reported physical and mental health of Australian carers: A cross-sectional study

**Authors**

Rafat Hussain, (corresponding author), ANU School of Medicine & Research School of Population Health, Australian National University, Canberra, ACT 0200, Australia.

Email: [Rafat.Hussain@anu.edu.au](mailto:Rafat.Hussain@anu.edu.au); Tel 612 6125 9758

Stuart Wark, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia.

Gina Dillon, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia

Peta Ryan, School of Rural Medicine, University of New England, Armidale, NSW 2351, Australia

**Word Count**

5181

## ABSTRACT

**Objective:** To report on self-reported physical and mental health of informal carers in rural regions of New South Wales, Australia.

**Methods:** A cross-sectional community-based sample (n=222) of carers completed a questionnaire incorporating self-reported measures of health from validated international instruments including Medical Outcomes Study scale (SF-36), the Centre for Epidemiology-Depression (CES-D) and Kessler-10 (K-10) Psychological Distress scales, along with information on participant demographics and other key caregiving characteristics such as health condition of care recipient.

**Results:** Rural carers' self-reported health was poor as evident on the SF-36 Physical and Mental Health component scales as well as each individual domain of the SF-36. Results from the CES-D and K-10 scales indicated very high rates of depressive symptoms and psychological distress. Over 70% of carers within the current study had CES-D scores indicative of depressive symptoms. Scores on the K-10 indicate almost half the carers were experiencing high levels of psychological distress, which is over four times the rate reported in the general Australian population.

**Conclusions & Implications:** Results from this study were compared to Australian population normative data and were found to be significantly below Australian age-matched population norms for SF-36, CES-D and K-10. These findings illustrate the poor health profile of informal carers relative to the general Australian population, especially in terms of depressive symptoms and psychological distress. This highlights the need for additional support for rural carers in order to ease the accumulated mental and physical health burdens of this group.

### Strengths and Limitations

- This study specifically focuses on the self-reported health of carers in non-metropolitan Australia
- It was found that the health of rurally-located carers' was significantly below Australian age-matched population norms, with over 70% of carers showing depressive symptomology
- Almost half the carers were found to be experiencing high levels of psychological distress



- This study methodology contains the risk of self-selection bias, and problems associated in the self-reporting of health conditions.
- There was a significant gender bias towards female respondents, so any sex-based comparisons must be viewed with caution.

For peer review only

## INTRODUCTION

The Australian Government has a stated commitment to supporting individuals with various health needs, such as a disability, ageing-related impairment, physical or mental health issue, to be assisted to remain within their local community.<sup>1-2</sup> However, the support provided by the Government is not always comprehensive, and often requires significant assistance from informal carers. Informal care is a support model where a person provides unpaid assistance to another individual with respect to general activities of daily living such as physical, emotional, financial and personal care.<sup>3</sup> The support of the informal carer is often vital, playing a significant role in increasing the individual's access to health and rehabilitation services.<sup>4</sup>

The 'burden' of providing informal care is considered to be the reduction in personal opportunities or actual health of an individual as a direct result of having to provide this unpaid support.<sup>5</sup> It has been previously identified that informal carers are likely to experience high levels of psychological distress,<sup>6</sup> and a decline in both physical health<sup>7</sup> and quality of life.<sup>8</sup> The need to provide informal care, particularly personal care,<sup>9</sup> has an impact on the carer's ability to both seek and maintain external paid employment.<sup>10</sup> It was estimated in 2015 that 2.86 million people in Australia provide informal care support to another person.<sup>11</sup> This figure represents approximately 12.5% of the nation's population and an increase of around 260,000 carers from 2012.<sup>12</sup> However, it is concerning to note that there are now perceived to be fewer carers, relative to demand, than in 2010, and the demand for informal care is predicted to considerably exceed its supply within the next decade.<sup>11</sup>

Although there are a number of Australian studies on caregiving, many have either looked at specific health issues such as chronic heart conditions,<sup>13</sup> motor neurone and other similar degenerative diseases,<sup>14-15</sup> Alzheimer's or dementia<sup>16-18</sup>, specific cancers<sup>19</sup> and palliative care and/or end-of-life care issues.<sup>20-21</sup> Almost all studies on carers' health with the exception of a recent qualitative study<sup>22</sup> have been conducted in large cities and metropolitan areas. It is well established that people living in rural regions in Australia face significant challenges in relation to health and social services, and this background merits specific focused investigations.<sup>23</sup>

In rural areas of Australia, the issues faced by informal carers may be amplified compared to those in metropolitan locations.<sup>24</sup> Rural carers are often geographically isolated, and struggle to access relevant health care support services for both themselves and the person for whom they provide care.<sup>25 26</sup> A failure to receive appropriate and timely treatment magnifies the issues for carers, as the existing health condition then worsens progressively over time,<sup>27</sup>

1 which then places additional stress onto the carer.<sup>28</sup> Individuals in rural areas are less likely to  
2 receive formal carer training to cope with these concerns<sup>29</sup> and this in turn can lead to issues  
3 with poor self-esteem.<sup>30</sup>  
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6 In spite of these issues, there remains only limited research that specifically examines the  
7 issues and care-giver burden facing individuals in rural areas of Australia.<sup>15,31</sup> The current  
8 paper is part of a larger study focussing on the experiences of informal carers in non-  
9 metropolitan areas of New South Wales, Australia. The aim of this research is to establish an  
10 initial profile of self-reported physical and mental health of rurally-based informal carers  
11 using validated international health scales. A secondary aim is to assess these self-reported  
12 measures against Australian normative data and facilitate future comparative studies with  
13 metropolitan-based peers. Formal ethical approval for this project was granted by the  
14 University of New England's Human Research Ethics Committee (HREC approval number  
15 HE13/130).  
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## 26 **METHOD**

### 27 **Study design, setting and Participants**

28 A cross-sectional community-based survey was undertaken in rural areas of New South  
29 Wales (NSW). NSW is the most populous state in Australia (total 23m) comprising 7.1m  
30 individuals of which nearly 20% live in rural and regional areas.<sup>32</sup> The rural or non-  
31 metropolitan cohort of the population, as defined by the Australian Standard Geographic  
32 Classification (ASGC) system, is dispersed over a large geographic footprint comprising  
33 populations resident in very diverse regional towns and a small proportion in rural and very  
34 remote regions.<sup>32-33</sup> The ASGC is a nationally standardised measure of geographic  
35 remoteness which incorporates aspects of distance and access to services in order to define  
36 five remoteness categories, namely: major cities, inner regional, outer regional, remote and  
37 very remote areas.<sup>34</sup>  
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47 Potential participants for this project were defined as being any individual over the age of 18  
48 who self-identifies as providing informal care and support for a person with either a disability  
49 or other long-term health condition. The geographic catchment was specified as being areas  
50 of NSW that are outside of the ASGC remoteness category of 'major cities'. In order to  
51 overcome the challenge associated with the wide geographical dispersal of carers, a survey  
52 tool was developed. A cross-sectional survey questionnaire was designed and piloted both in  
53 print and online format with 10 people, with expert knowledge of rural health and carer  
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1 health issues. Minor modifications were made to some of the items in the survey form based  
2 on feedback from the pilot study.  
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4 A variety of community-based recruitment strategies were used to distribute information  
5 about the project and enrol participants. These included social media, community-group and  
6 carer organisation newsletters, posters in community facilities, and a combination of  
7 electronic and traditional media sources such as radio and newspaper interviews. A \$5  
8 grocery voucher incentive was provided for all respondents. Potential participants were given  
9 the option of receiving a hard copy of the information package and associated questionnaire,  
10 or to access the survey via a purpose-developed web-site that contained all relevant  
11 documentation and an online version of the survey questionnaire.  
12

13 A total of 237 participants completed the survey of which 222 were considered valid  
14 responses from rural areas of NSW. The majority of the surveys (nearly 90%) across the state  
15 were completed online. As most of the survey responses were on-line and recruitment was  
16 undertaken through a variety of community-based strategies, an overall response rate could  
17 not be determined. Participation was both voluntary and anonymous. This also meant that  
18 there was no capacity to refer individuals potentially at risk for support, however, the  
19 information sheet outlining details of the study provided to all potential participants, preceded  
20 the beginning of the survey questionnaire, and included specific details to facilitate access to  
21 free counselling support if required through Lifeline Telephone Support Service, and the  
22 relevant toll-free telephone number was provided. Lifeline counsellors do suggest callers to  
23 contact their preferred doctor or a psychologist if symptoms have been ongoing. This strategy  
24 was approved by the Human Research Ethics Committee as a viable option to maintain  
25 anonymity of participants whilst also providing information on how to access counselling  
26 support for those experiencing distress associated with their caregiving role.  
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#### 45 **Data measurement**

46 The outcome variables included self-reported health using three validated scales: the Medical  
47 Outcomes Short-Form (SF-36) which measures health across eight domains of physical and  
48 mental health; the Centre for Epidemiologic Studies-Depression scale (CES-D) and the  
49 Kessler-10 (K-10) Psychological Distress scale. Each of these scales is briefly discussed  
50 below.  
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55 The SF-36 comprises of 36 questions which focus on general health, physical functioning,  
56 role physical, bodily pain, vitality, social functioning, mental health, and role emotional.  
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1 These eight subscales are also used to calculate two summary or component scales: the  
2 Physical Component Score (PCS), reporting on physical health, and the Mental Component  
3 Score (MCS), reporting on mental health.<sup>35</sup> Scores on each of the SF-36 domain are  
4 standardized and component scores can range from 0 – 100 and higher scores indicate better  
5 health. The SF-36 imputation was undertaken by CR&DITSS (Clinical Research Design IT  
6 and Statistical Support), which is the statistical consulting arm of the Centre for Clinical  
7 Epidemiology and Biostatistics (CCEB) at the Hunter Medical Research Institute affiliated  
8 with University of Newcastle, Australia. CCEB have an established algorithm for missing  
9 values, which has been used by numerous research projects across Australia. Imputation of  
10 missing values and computation of the domain and component scores were performed  
11 according to the procedures outlined in the SF-36 *Manual and Interpretation Guide*.<sup>35</sup> The  
12 SF-36 domain generation was done using the SAS software. The SAS codes contained in the  
13 document [www.sascommunity.org/sugi/SUGI94/Sugi-94-168%20Newvine.pdf](http://www.sascommunity.org/sugi/SUGI94/Sugi-94-168%20Newvine.pdf) was used to  
14 create the 9 domains (eight original and the summary component scores for PCS & MCS)  
15 using the SF36 variables. For missing data imputation, it was assumed missing data were  
16 completely at random and used person-mean imputation for subjects with missing values.  
17 Missing values on an item were replaced with the mean of all the individual's completed  
18 items. Person-mean imputation has been shown to be reliable when the numbers of  
19 respondents with missing items are 20% or less.<sup>36</sup> The imputed data variables were then  
20 exported and reinserted in the SPSS data file before undertaking analyses for the present  
21 paper. Australian population normative data for SF-36 scores were accessed from the  
22 Australian Bureau of Statistics.<sup>37</sup>

23 Self-reported mental health was additionally assessed via the Centre for Epidemiologic  
24 Studies-Depression (CES-D) Scale and the Kessler (K-0) Psychological Distress scale. The  
25 CES-D is a validated and widely used scale designed to measure current levels of depressive  
26 symptoms within the general population.<sup>38</sup> CES-D scores have a possible range of 0 – 60 and  
27 higher scores indicate worse mental health. A score of 16 points or more is generally  
28 accepted as an indicator of depression symptoms<sup>39</sup> and scores of 24 and over are suggestive  
29 of severe depressive symptoms.<sup>40</sup> Normative CES-D data for the Australian population was  
30 derived by entering the cut points for depressive and severe depressive symptoms (16 and 24  
31 respectively) into the *MoodScore* computer programme of Crawford & Cayley<sup>41</sup> which has  
32 been developed as a means of quickly referencing Australian normative data on a range of  
33 self-reported mood scales.

1 The K-10 scale provides a measure of non-specific psychological distress based on questions  
2 about negative emotional states experienced in the past four week period.<sup>24</sup> Scores on the K-  
3 10 range from 10 – 50 with higher scores indicating higher levels of psychological distress.  
4 The designated cut-off scores for low (10-15), moderate (16-21), high (22-29), and very high  
5 (30-50) levels of psychological distress. Australian population norms were drawn from  
6 Australian Bureau of Statistics data.<sup>42</sup>

7 Information was collected on a range of explanatory variables including socio-demographic  
8 and caring role characteristics of participants including: sex, age, employment status, whether  
9 they are in a primary care-giving role, their relationship to the person they provide care for  
10 (spouse/parent/child/other), whether they are aware of, or members of, any carer support  
11 groups, whether they are a live-in carer and the medical condition/s of the care recipient. The  
12 medical conditions were classified into four broad categories of:

- 13 • Cognitive: including autism spectrum disorders, Alzheimer’s disease and other  
14 dementias, intellectual disability, Down syndrome and acquired brain injury.
- 15 • Physical: including cancer, stroke, post-operative recovery, Parkinson’s disease,  
16 cerebral palsy, quadriplegia, blind, deaf, diabetes, heart and lung conditions and frail  
17 aging.
- 18 • Mental health: including schizophrenia, ADHD, bipolar disorder, alcohol and drug  
19 addiction, depression and anxiety disorders.
- 20 • Multiple: this category involves the co-existence of conditions across more than one  
21 of the Cognitive, Physical or Mental health categories.

22 Issues relating to potential bias including selection and measurement bias are discussed in the  
23 limitations section of the paper.

### 24 **Statistical methods**

25 Analysis was performed using SPSS V22 (2013 release) for univariate and multivariable  
26 analyses. ANOVA with posthoc comparison via Dunnett’s C, with  $p \leq 0.05$  as the critical  
27 value, were used to test for differences between mean SF-36 scores of participants. Dunnett’s  
28 C was recommended for use with SF-36 data as it provides very tight Type 1 error control  
29 and performs well when the group sizes are different, when population variances are different  
30 or when data is not normally distributed.<sup>43</sup> Graphical representation and comparison of SE  
31 error bars were used to gauge significant difference between mean SF-36 scores of  
32 participants from the current study and Australian population norms. In order to age-match  
33 data from the current study with ABS data for the SF-36 population norms, the average age  
34

1 of participants was calculated for each age grouping in the current study. This average age  
2 was then compared to the ABS data age categories, and the normative data for the relevant  
3 category was used as a comparison to the current study.  
4

5  
6 Multiple linear regression technique was used for multivariable analyses for two of the four  
7 dependent variables namely - PCS and MCS to estimate the proportion of variance in PCS  
8 and MCS scores that could be accounted for by age, gender, employment status, type of  
9 condition that care is being provided for, and membership of a carer support group. Key  
10 assumptions were evaluated prior to interpreting the results of the multiple linear regression  
11 analyses. A visual inspection of the normal probability plot of standardised residuals and of  
12 the scatterplot of standardised residuals against standardised predicted values was  
13 undertaken. These both indicated that assumptions of normality, linearity and  
14 homoscedasticity of residuals were met. Multivariate outliers were not of concern; for all  
15 cases in the data file the Cook's distance value was <1 and Mahalanobis distance did not  
16 exceed the critical  $\chi^2$  for  $df=8$  (at  $\alpha=0.001$ ) of 26.125.  
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19  
20 Logistic regression analysis was used individually for the remaining two dependent variables  
21 – CES-D and K-10 using enter technique for inclusion of explanatory variables (spin <0.05;  
22 spout >0.10). The explanatory variables included in both regression models were age  
23 (categorical), gender, work status, type of condition that care is being provided for and  
24 membership of a carer support group.  
25

## 26 RESULTS

27  
28 The findings are based on responses from 222 participants from rural NSW. The  
29 demographic characteristics of the study sample are summarised in Table 1 below. Raw  
30 percentages rather than cumulative percentages are reported; as there are missing values the  
31 final totals do not necessarily tally to 100%. The majority of participants were female (85%),  
32 live in carers (75%), involved in the primary care role (80%). Ages ranged from 21 to 86  
33 years, with more participants being from the older age groups. Approximately 45% of the  
34 carers were also working in paid employment. Just over one third of the participants (38%)  
35 were caring for someone with a physical condition and 27% of carers were caring for people  
36 with multiple conditions.  
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**Table 1: Demographic and caregiving characteristics of participants (n=222)**

Participant Characteristics	n (%)
<b>Sex</b>	
Female	191 (84.9)
Male	31 (13.8)
<b>Age (years)</b>	
Range	21-8
Mean	52.7
Std Dev	14.4
<b>Age (grouped – years)</b>	
40 and under	47 (21.2)
41 – 50	53 (23.9)
51 – 60	58 (25.8)
61+	64 (28.4)
<b>Currently working</b>	
Yes	98 (45.2)
No	119 (54.8)
<b>Caregiver role</b>	
Primary	180 (80.0)
Secondary	19 (8.4)
<b>Caring relationship</b>	
Caring for a parent	27 (12.0)
Caring for a child	92 (40.9)
Caring for spouse	77 (34.2)
Other	17 (7.6)
<b>Live in carer</b>	
Yes	142 (75.5)
No	46 (24.4)
<b>Condition cared for</b>	
Physical	81 (37.7)
Cognitive	48 (22.3)
Mental Health	27 (12.6)
Multiple categories	59 (27.4)
<b>Aware of any carer support groups</b>	
Yes	152 (67.6)
<b>Member of a carer support group</b>	
Yes	61 (27.1)

### Self-reported health

Carers in the study had self-reported physical and mental health that was significantly below Australian age-matched population norms. This was evident on the SF-36 Physical Component Scale (PCS) and Mental Component Scale (MCS), as well as within each individual domain of the SF-36 (see Figure 1). Carers showed particularly lower comparative scores in the domains of social functioning, role emotional role physical and vitality. The comparison between findings of the present study and the Australian normative data for



summary measures of SF-36, namely PCS and MCS as well as the scores for each of the 8 individual domains, is outlined in the Discussion section of the paper.

Results from the CES-D and K-10 scales indicate very high rates of depressive symptoms and psychological distress amongst the rural carers sample (Figure 2 and Supplementary Figure 1). Over 70% of carers within the current study had results on the CES-D that indicated the presence of depressive symptoms, with 36% meeting the criteria for severe depressive symptoms. Scores on the K-10 indicate almost half the carers (49.3%) were experiencing high and very high levels of psychological distress. Comparison with normative data for SF-36 in Australian population is provided in the Discussion section of the paper.

### **Factors associated with self-reported health in rural carers**

In table 2 we present the bivariate results for SF-36 summary scores as well as the eight individual domains along with scores for CES-D and K-10. Self-reported health was associated with both age and sex in the survey sample (Table 2), although given the relatively small number of male participants (13%), differences by sex should be interpreted with caution. Significant differences in the self-reported health of male versus female carers were in the areas of SF-36 MCS, vitality, mental health, bodily pain, role emotional and role physical. In all of these domains males had higher mean scores than females indicating better self-reported health in male compared to female carers. Significant age differences were found in the SF-36 measures of PCS and MCS as well as the general health, vitality, mental health, role emotional, role physical social functioning and physical functioning domains. Additionally there were also significant age associations with scores on both the CES-D and the K-10 scales as seen in Table 2.

Age-related differences on the physical functioning domain of the SF-36 followed population norms of declining scores with age and could be considered to be a normal function of ageing. Age-related scores for the vitality domain within the current study show a trend towards increasing vitality scores with older age. Furthermore, there was no significant difference between the PCS scores of younger carers (40 years and under) compared to carers who were 61 years and above.

There are also several age-related associations within measures of mental health. Scores on the SF-36 MCS, mental health and social functioning domains generally increased with age indicating better aspects of mental health in older carers compared to younger age groups. Scores on the CES-D and K10 measures also indicated better mental health for older carers

1 compared to their younger counterparts. These results, along with the findings from the SF-  
2 36 domains, can be interpreted as indicating a relatively larger mental health burden on  
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4 young carers compared to older carer age groups.  
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7 Several other associations were investigated and it was found that there were no significant  
8 differences in the mean self-reported health scores of primary versus non-primary carers  
9 across any of the eight domains or two component scores of the SF-36, or total scores on  
10 CES-D or K-10. Also there were no significant differences in the mean self-reported health  
11 scores of carers from any of the relationship categories of caring for a  
12 parent/child/spouse/other. There were no significant differences in any of the mean health  
13 scores of carers for SF-36 categorised by the condition that they were caring for (physical,  
14 cognitive, mental health or multiple conditions). However, there were significantly lower  
15 scores for CES-D and K-10 of carers for physical health conditions of care recipients.  
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19 When categorised by their employment status (Working Yes/No), it was found that carers  
20 who were working had better self-reported health on both the SF-36 PCS and physical  
21 functioning domains. There were no other significant associations of working status with  
22 health on any of the other SF-36 domains or on the K-10 or CES-D. Better physical  
23 functioning amongst those carers who were working was interpreted as indicating that any  
24 additional stress of working in addition to caring was not impacting negatively on the  
25 physical health of carers. The only significant difference in self-reported health between  
26 members and non-members of support groups was on the physical functioning domain of the  
27 SF-36. It was found that non-members of support groups had significantly lower scores  
28 (better health) in the domain of physical functioning compared to non-members (see table 2).  
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**Table 2** Mean self-reported health scores for the SF-36, CES-D and K10 scales, divided by sex and age

	n	SF-36 (higher scores indicate better health)										Lower scores indicate better health	
		PCS	MCS	General Health	Vitality	Mental Health	Bodily Pain	Social Functioning	Role Emotional	Role Physical	Physical Functioning	CES-D	K10
<b>Sex</b>													
Male	30	46.07	41.46	55.43	47.00	63.77	63.10	59.17	63.22	58.89	74.97	19.62	20.79
Female	186	43.44*	35.40*	50.96	34.61*	57.15*	53.10*	56.96	38.71*	43.72*	69.65*	21.77*	22.81*
<b>Age (years)</b>													
≤40	46	44.98	33.09*	47.33*	30.00*	55.30	57.04	54.08	36.59*	38.04*	77.31*	23.27*	24.46*
41-50	51	47.37*	33.82*	52.19*	33.20*	55.14	58.90	56.37	43.79*	56.70*	77.00	21.38*	22.42*
51-60	57	42.37	34.30*	47.99*	34.91	53.44*	49.81	51.97*	38.10*	43.75*	66.16	23.24	24.28
61>	62	40.75*	43.40*	57.53*	45.08*	66.95*	53.12	65.37*	48.59*	44.58*	63.51*	18.46*	19.46*
<b>Total</b>	<b>216</b>	<b>43.80</b>	<b>36.24</b>	<b>51.58</b>	<b>36.34</b>	<b>58.07</b>	<b>54.46</b>	<b>57.27</b>	<b>42.06</b>	<b>45.85</b>	<b>70.40</b>	<b>21.47</b>	<b>22.54</b>

\* p <0.05

### Associations between caring relationship, condition cared for and age of carer

There was no significant association between age of carer and the type of condition being cared for. There was however a significant relationship between the condition being cared for and the relationship between carer and recipient of care. People caring for a parent were most likely to report caring for a physical condition (66.7%) compared to caring for a mental health or cognitive condition or multiple conditions. People caring for a child were most likely to report caring for a cognitive condition (33%) or for multiple conditions (33%). Although only 16.5% of people caring for a child reported caring for a mental health condition, this was the most common caring relationship in the mental health category. There was also a significant association between the age of the carer and the relationship with the care recipient. This would logically be related to the care of elderly parents or spouses, with 50% of carers in the 51-60 years age group reporting that they were caring for a parent and 55% of carers in the 61+ years age group reporting that they were caring for a spouse.

In table 3, we outline the results of the multivariable regression analyses for each of the four outcome variables. As mentioned in the Methods section, we used multiple linear regression for regression models for the two summary component scores of SF-36, namely PCS and MCS; and binary logistic regression for CES-D and K-10. After adjusting for an explanatory variables such as gender, work status, condition cared for and membership of carer support group, the only statistically significant category for PCS was the age group 51-60 years. On the other hand, for MCS all age categories were significantly associated with poor mental

1 health when compared to the 60+ age group. The results for CES-D were somewhat  
2 anomalous, with three times higher odds of high CES-D scores indicating depression, though  
3 the results were marginally significant ( $p=0.06$ ). For K-10, there were three times higher odds  
4 of poor mental health across all age groups and results for all the age categories were  
5 statistically significant (see table 3).  
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Table 3: Multivariable analysis for predictors of self-rated health in rural caregivers

	PCS Beta (Sig) & 95%CI		MCS Beta(Sig) & 95%CI		CES-D exp(B)(Sig) & 95%CI		K-10 exp(B)(Sig) & 95%CI	
<b>Age</b>								
40 and under	0.187 (0.06)	-(0.24-10.69)	<b>-0.339 (0.00)</b>	-(15.95- -4.56)	3.492 (0.06)	(0.96-12.62)	<b>3.767 (0.01)</b>	(0.35-2.93)
41-50	<b>0.265 (0.01)</b>	(1.73-12.83) -	<b>-0.348 (0.00)</b>	-(16.09- -4.54)	0.866 (0.79)	(0.29-2.52)	<b>3.416 (0.02)</b>	(0.35-2.93)
51-60	0.124 (0.20)	(1.83-8.47)	<b>-0.330 (0.00)</b>	-(14.99- -4.18)	2.052 (0.16)	(0.75-5.63)	<b>3.584 (0.00)</b>	(0.35-2.93)
61+ - reference								
<b>Gender</b>								
Female	-0.107 (0.18)	-(9.73-1.89)	-0.114 (0.14)	-(10.54-1.56)	0.967 (0.95)	(0.29-3.13)	1.020 (0.97)	(0.35-2.93)
Male - reference								
<b>Currently working</b>								
No	-0.097 (0.26)	-(6.24-1.69)	0.040 (0.63)	-(3.12-5.14)	0.547 (0.16)	(0.24-1.26)	1.468 (0.29)	(0.72-3.00)
Yes - reference								
<b>Condition cared for</b>								
Physical	0.052 (0.61)	-(3.60-6.10) -	-0.013 (0.89)	-(5.39-4.71)	0.748 (0.56)	(0.28-1.99)	0.870 (0.75)	(0.36-2.07)
Mental Health	0.021 (0.82)	(5.79-7.32) -	-0.046 (0.60)	-(8.63-5.02)	0.717 (0.63)	(0.18-2.77)	1.788 (0.34)	(0.54-5.90)
Multiple	-0.036 (0.71)	(6.09-4.16)	0.049 (0.60)	-(3.94-6.74)	1.387 (0.57)	(0.44-4.35)	0.784 (0.60)	(0.31-1.97)
Cognitive - reference								
<b>Support group</b>								
No	0.031 (0.70)	-(3.22-4.77)	0.035 (0.66)	-(3.24-5.01)	2.222 (0.05)	(0.99-4.96)	0.998 (0.99)	(0.49-2.02)
Yes -reference								

## DISCUSSION

The need to support another individual in basic activities of daily living is becoming an increasingly important issue in Australia. It is estimated that one in eight people provide informal and unpaid support to another person, and the demand for this type of care is predicted to increase substantially over the next ten years.<sup>11</sup> It is known that the provision of informal care is associated with health decline in several areas including psychological distress,<sup>6</sup> physical manifestations<sup>7</sup> and general quality of life.<sup>8</sup> It is further understood that that there is a higher proportion of informal carers in rural localities compared to metropolitan locations,<sup>11</sup> and it is recognised that health-care issues are potentially worse in country areas where access to health care services may be compromised.<sup>28</sup> The SF-36 scale has been used in some Australian longitudinal studies such as the Household Income and Labour Dynamics Australia (HILDA), using a panel survey design,<sup>44</sup> and the Women's Health Australia (WHA) study.<sup>45</sup> However the HILDA survey does not have a specific focus on information about caregiving issues and its impact on health, while the WHA is limited to women participants in specific age cohorts.

The aim of the present study was to establish an initial self-reported health profile, both physical and mental health, of rurally-based informal carers with a secondary objective of comparing the results to Australian normative data. It was found that the self-reported physical and psychological health of carers within this study was significantly worse than the Australian population norms across all eight domains and the two summary component scores of the SF-36. Additionally, almost half of the carers reported high or very high level of psychological distress on the K-10 scale. This is indicative of a major health burden related to the role of informal caregiving. It is acknowledged that, as an initial study, not all key demographic data was able to be captured. In particular, it is recommended that future research specifically examine two additional factors, the length of time the individual had been providing care, and whether the care recipient was receiving palliative or end-of-life care, as it is acknowledged that these issues may have a further impact upon carers' health.

The current study had a majority of female participants, which is in line with the gendered nature of informal caregiving in Australia. The nationally-based Disability, Ageing and Carers Survey<sup>46</sup> reports that, within Australia, females represent 70% of primary carers and 56% of carers overall. In the current study male carers had significantly higher levels of self-reported health, than female carers, in the SF-36 MCS score as well as the health domains of vitality, role emotional, and bodily pain. The additional caregiving burden for female carers

1 has been highlighted by several previous studies and factors related to this additional burden  
2 have been identified as including: the multiple caring roles of women, especially related to  
3 childrearing and household duties,<sup>47</sup> spending more time with care recipients than male  
4 caregivers<sup>48</sup> and seeking less social and tangible support than male carers.<sup>49</sup> The current study  
5 provides additional data to indicate a trend towards a higher health-related burden for female  
6 compared to male carers.  
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11 There were also age-related differences in self-reported health of carers that went against  
12 expected trends. For example, the Physical Health Component (PCS) score of younger carers  
13 (40 years and under) was not significantly different to the PCS score of carers aged 61 years  
14 and over. This is contrary to the expected decline in self-reported health with increasing age,  
15 as evidenced in the Australian normative SF-36 data. Furthermore, scores in the SF-36  
16 domain of vitality showed a significant increase with age. This is in contrast to the age  
17 related trend in the population norm data which showed a decline in vitality scores in older  
18 age groups.<sup>37</sup> These contrary findings to the population norm trend could be interpreted as  
19 indicating that the burden of caring on physical health may be more prominent in young  
20 carers compared to older carers within the current study. In the normative data from the  
21 Australian population there is a decline in social functioning with age which also is contrary  
22 to the data from the current study.  
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34 These trends indicate a greater health burden for younger carers compared to older carers.  
35 The additional care burden experienced by younger carers may be attributed to the fact that  
36 carers in the under 40 age group may be raising a family in addition to meeting the  
37 responsibilities of a caring role. The life stage prior to 60 years of age represents the key time  
38 for engagement in career and employment, and being a carer in this age group may contribute  
39 significant additional life stress, as dual responsibilities of work and caring roles compete for  
40 time and priority.<sup>17</sup> Decisions to work in a part-time capacity, or to withdraw from the paid  
41 workforce due to caring commitments, carry significant financial consequences both in the  
42 short-term and for future employment prospects and long-term financial security. The  
43 perceived financial cost of caregiving has been found to be a significant contributor to the  
44 overall caregiving burden of informal carers,<sup>50</sup> and this perceived financial loss may be  
45 greater for younger carers compared to older carers.  
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55 Normative data indicates an increase in the MCS and mental health scores of older  
56 participants, so the current data is in line with this trend. However the score increases within  
57 the current study are larger than those seen in the normative data set, with an increase of over  
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1 11 points on the mental health scores in the older group compared to the youngest group of  
2 carers, whereas a comparative age difference in the normative data is associated with only a  
3 0.5 point difference in mean mental health scores. Considerably higher psychological  
4 distress scores were found in the present study which were over 4 times the rates expected in  
5 the general Australian population (12.6%) with only 28% of study carers indicating low  
6 levels of psychological distress compared to 64.3% of the general population.<sup>37</sup>  
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11 The high levels of psychological distress and depressive symptoms among the carers in this  
12 sample is a worrying result, with over 70% of the carers indicating depressive symptoms and  
13 almost half of the sample reporting high or very high levels of psychological distress. This  
14 alarmingly high rate of mental distress highlights an urgent need for additional support for  
15 informal carers in rural areas of New South Wales. A meta-analysis of factors contributing to  
16 physical health of informal caregivers<sup>49</sup> reported that depressive symptoms of caregivers had  
17 a higher association with declines in physical health than objective care related stressors such  
18 as hours of care provision, behavioural problems of the care recipient and medical condition  
19 of the care recipient and access to support. It then follows that measures to increase the  
20 mental health and well-being of carers will also have flow on benefits for physical well-  
21 being.  
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### 32 **Limitations**

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34 This study had a number of limitations that need to be considered. Any community-based  
35 study seeking participants study cannot eliminate selection bias as a risk. It is considered  
36 unlikely that carers with more significant burdens of ill-health would have opted to  
37 participate in the survey. As such, the results reported for the present study may be an under-  
38 representation of mental health issues given the significant challenges of caregiving for rural  
39 carers, and with the potential of more distressed carers not being able to find the time and/or  
40 energy to participate in the study. As noted in the discussion, there were two factors that  
41 were not captured in the data, the length of time the individual had been providing care and  
42 the care recipients' stage of illness. It is acknowledged that these issues may have  
43 consequences for carers' health, but it is not believed that the failure to gain these data  
44 invalidates the reported outcomes. Nonetheless, it is recommended that future research  
45 consider stratifying the results by these variables to measure if there is any impact.  
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55 Measurement bias is largely eliminated by using validated scales for outcome variables such  
56 as SF-36, CES-D and K-10. However, for any self-report scales it is acknowledged that recall  
57 bias may be operative in the reporting of health conditions, such as bodily pain and physical  
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1 functioning. It is noted that the Australian population normative data for the SF-36, collected  
2 in 1995, may now be dated given changes in population health over the past 20 years.  
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4 However, this data was the most recent, of suitable format, that could be found. More recent  
5 Australian health surveys (for example 45 and Up Study<sup>51</sup>) have included some aspects of the  
6 SF-36 in their reporting, but there was no alternative source found that reported gender  
7 specific, age-based, Australian population means for the full eight domains and two  
8 component scores of the SF-36. The limited number of male respondents in the current study  
9 meant that sex-based comparisons need to be viewed with caution. It is recommended that in  
10 future carer studies active recruitment of male participants may be needed in order to gain a  
11 sex ratio that is in line with the Australian overall ratio of male-to-female carers.  
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## 20 CONCLUSIONS

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22 Despite the noted limitations, the current study has contributed to the health-related data of  
23 Australian carers by providing a profile of self-reported health for carers in non-metropolitan  
24 areas of New South Wales, Australia. These findings indicate the poor health profile of this  
25 group relative to the general Australian population, especially in terms of high levels of  
26 psychological distress, and highlight the need for additional support for rural carers in order  
27 to ease the accumulated mental and physical health burdens of this group. The need for  
28 access to specifically targeted psychological interventions for individuals at risk is clear.  
29 Recommendations for future research to build upon these findings include examination of the  
30 previously identified factors of length of time the individual had been providing care and the  
31 care recipients' stage of illness, as well as undertaking a comprehensive study that  
32 comparatively examines carers residing in a variety of rural settings against metropolitan-  
33 based peers in order to recognise difference and disparity in health status.  
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## CONTRIBUTIONSHIP STATEMENT

RH was the chief investigator of the study. RH and SW designed the study. RH, SW and PR were responsible for data collection, while all authors were responsible for data analysis and interpretation. All the authors helped to draft the manuscript and approved the final version.

## COMPETING INTERESTS

There are no competing interests to declare.

## FUNDING

The authors would like to acknowledge the support provided by University of New England through the University Research Seed (URS) grant scheme. The authors further acknowledge the contribution made by the Collaborative Research Network on Mental Health and Well-being in Rural Communities, supported by the Department of Industry, Innovation, Science, Research and Tertiary Education, Commonwealth Government of Australia. The authors would like to thank the CR&DITSS team at CCEB, Hunter Medical Research Institute, University of Newcastle for their statistical advice, data management of SF-36 data domains and imputing of missing values across SF-36, CES-D and K-10 validated scales as per established algorithms. Further statistical advice provided by Methuen Morgan, Harley Macnamara and Stuart Fisher from the University of New England is also gratefully acknowledged.

## DATA SHARING STATEMENT

No additional data are available.

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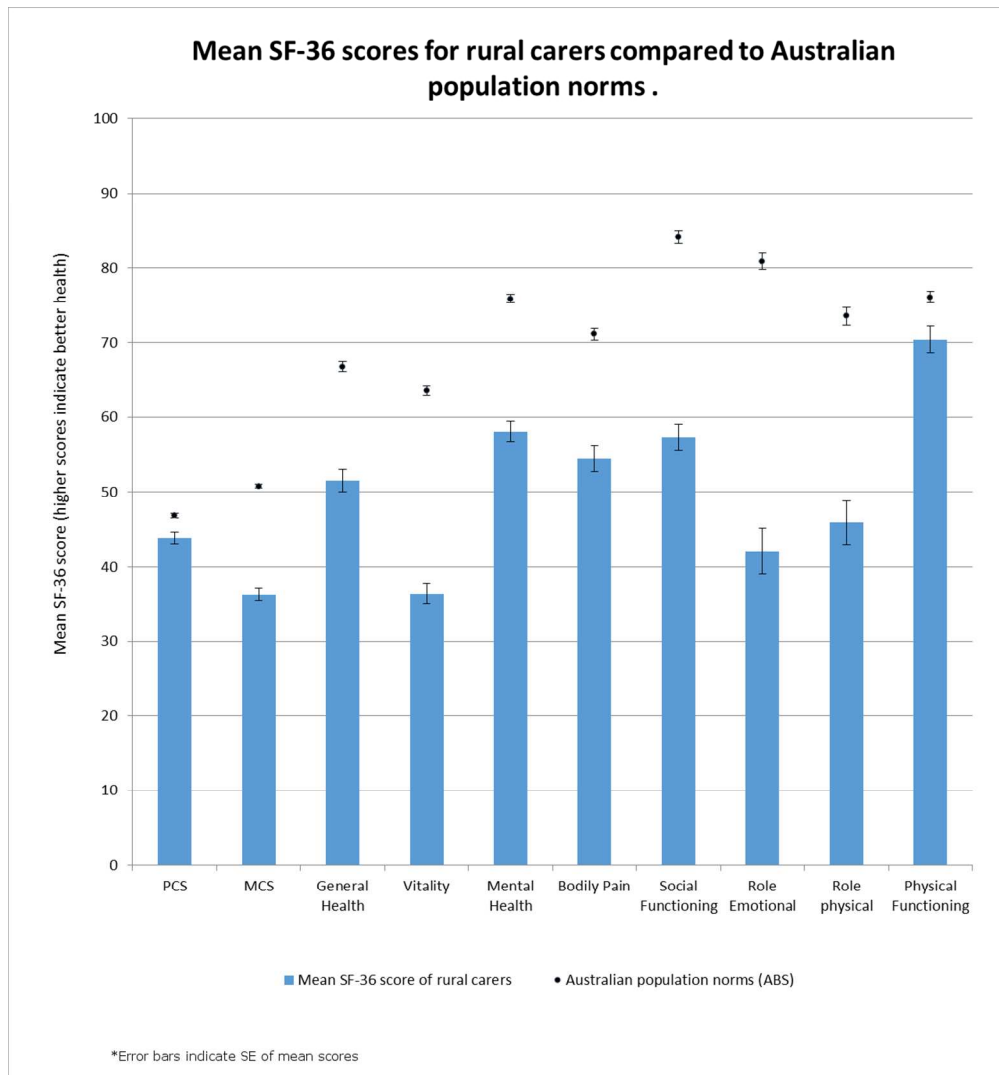


Figure 1: Mean SF-36 scores for rural carers compared to Australian population norms

108x116mm (300 x 300 DPI)



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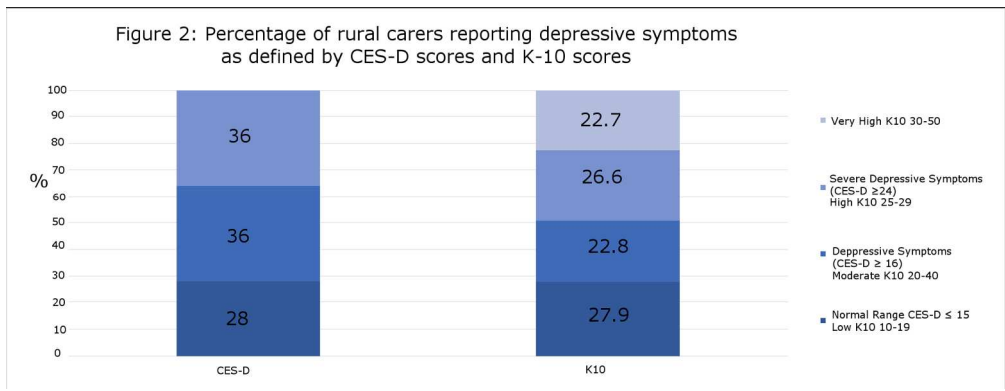
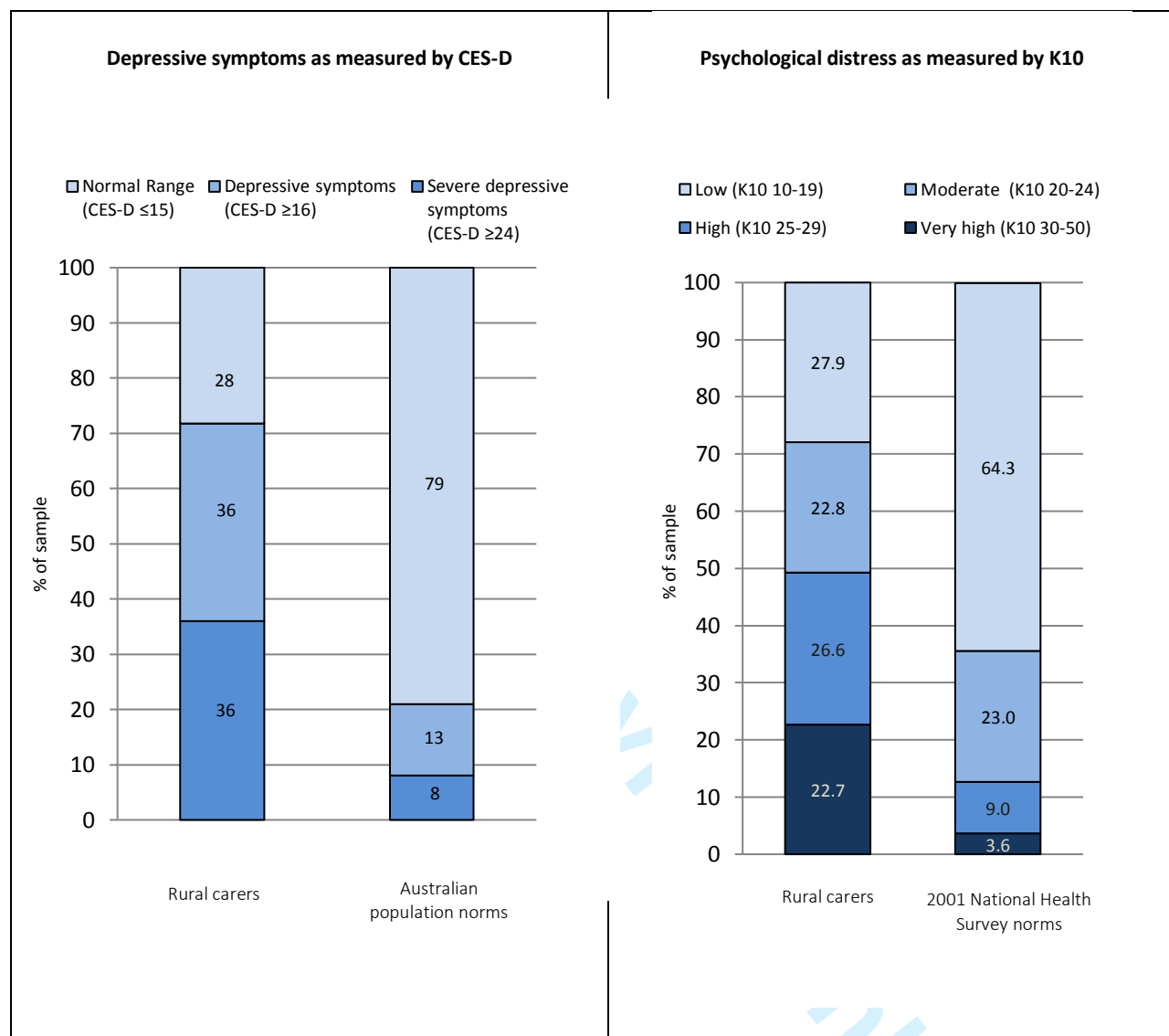


Figure 2: Percentage of rural carers reporting depressive symptoms as defined by CES-D scores and K-10 scores

166x63mm (300 x 300 DPI)

Peer review only

**Supplementary Figure 1 Comparison between depressive symptoms reported by rural carers compared to data from Australian National Survey**



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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
<b>Title and abstract</b>	1✓	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
<b>Introduction</b>		
Background/rationale	2✓	Explain the scientific background and rationale for the investigation being reported
Objectives	3✓	State specific objectives, including any prespecified hypotheses
<b>Methods</b>		
Study design	4✓	Present key elements of study design early in the paper
Setting	5✓	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6✓	(a) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7✓	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*✓	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9✓	Describe any efforts to address potential sources of bias
Study size	10✓	Explain how the study size was arrived at
Quantitative variables	11✓	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12✓	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses
<b>Results</b>		
Participants	13*✓	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage – Not applicable (c) Consider use of a flow diagram - Not applicable
Descriptive data	14*✓	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*✓	Report numbers of outcome events or summary measures
Main results	16✓	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17✓	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

<b>Discussion</b>		
Key results	18✓	Summarise key results with reference to study objectives
Limitations	19✓	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20✓	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21✓	Discuss the generalisability (external validity) of the study results
<b>Other information</b>		
Funding	22✓	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).