

Carers in regional Australia

2016 Regional Wellbeing Survey report

July 2017

Jacki Schirmer

Health Research Institute & Institute for Applied Ecology, University of Canberra

regionalwellbeing@canberra.edu.au

Contents

Acknowledgments.....	1
Key points.....	2
Introduction	5
The Regional Wellbeing Survey.....	7
Analysis presented in this report	7
Data weighting	7
Confidence intervals	7
How many regional Australians are carers?	9
Caring responsibilities.....	13
Number of people cared for	13
Type of people cared for.....	13
Caring needs.....	15
Hours spent caring	16
Motivations for being a carer	17
Experience of caring.....	19
Recognition of contributions	19
Experience of isolation.....	20
Experience of financial stress.....	21
Stopping or reducing work.....	22
Ability to socialise	23
Access to support.....	24
Overall access to support.....	24
Access to different forms of support	25
Access to breaks from caring	26
Access to respite care services.....	27
Access to a supportive GP	28
Access to counselling for carers.....	29
Access to practical home support.....	30
Access to carer advice and information.....	31
Access to financial support	32
Access to support from family and friends	33
Income and household finances	34
Household income	34
Household financial wellbeing.....	35
Financial stress events	36
Wellbeing of regional carers	38
Wellbeing – Global Life Satisfaction	38
Wellbeing – Feeling life is worthwhile	39
Illbeing – Psychological distress.....	40
Wellbeing – Personal Wellbeing Index	41
Caring obligations and wellbeing.....	46
Discussion and conclusions.....	50
References	53

Figures

Figure 1 Interpreting confidence intervals (source: Schirmer et al. 2016)	8
Figure 2 Percentage of adult population of who reported being carers – regional Australia and States	9
Figure 3 Percentage of adult population of who reported being carers – by gender and age	10
Figure 4 Remoteness regions of Australia (data source: ABS 2013)	11
Figure 5 Percentage of adult population of who reported being carers – by remoteness region	12
Figure 6 Number of people cared for	13
Figure 7 Types of people cared for	14
Figure 8 Needs of people being cared for.....	15
Figure 9 Average hours spent on caring responsibilities each week by carers	16
Figure 10 Reasons for being a carer instead of seeking others to take on caring responsibilities.....	18
Figure 11 Experiences of caring: recognition by the broader community	19
Figure 12 Experiences of caring: feeling isolated	20
Figure 13 Experiences of caring: financial stress	21
Figure 14 Experiences of caring: stopping or reducing work.....	22
Figure 15 Experiences of caring: effects on ability to socialise.....	23
Figure 16 Overall access of carers to help	24
Figure 17 Access to different types of support reported by carers living in regional, rural and remote Australia	25
Figure 18 Access to support: regular breaks from caring	26
Figure 19 Access to support: respite care services	27
Figure 20 Access to support: Supportive and understanding GP	28
Figure 21 Access to support: counselling for carers	29
Figure 22 Access to support: home support	30
Figure 23 Access to support: Advice and information for carers.....	31
Figure 24 Access to support: financial support for carers	32
Figure 25 Access to support: supportive family or friends	33
Figure 26 Annual household income in 2015-16, reported by carers and non-carers	34
Figure 27 Self-rated household financial wellbeing.....	35
Figure 28 Financial stress events experienced in the last year.....	37
Figure 29 Wellbeing: Comparison of Global life satisfaction scores of carers and non-carers	39
Figure 30 Wellbeing: Comparison of ‘Feeling life is worthwhile’ scores of carers and non-carers.....	40
Figure 31 Illbeing: Comparison of psychological distress scores of carers and non-carers.....	41
Figure 32 Wellbeing: Comparison of Personal Wellbeing Index scores of carers and non-carers	42
Figure 33 Comparison of scores for individual components of the Personal Wellbeing Index – all regional Australian carers and non-carers.....	43
Figure 34 Comparison of scores for individual components of the PWI – by group (i).....	44
Figure 35 Comparison of scores for individual components of the PWI – by group (ii)	45
Figure 36 Wellbeing of carers who had no, little and good access to help in their caring role (Global Life Satisfaction).....	46
Figure 37 Wellbeing of carers by weekly hours spent caring (Global Life Satisfaction)	47
Figure 38 Wellbeing of carers by type of caring responsibility (Global Life Satisfaction).....	47
Figure 39 Wellbeing of carers by access to different types of support (Global Life Satisfaction)	48
Figure 40 Wellbeing of carers by experience of caring (Global Life Satisfaction)	49

Acknowledgments

First and foremost, I would like to acknowledge the many thousands of people across Australia who give their time and energy to care for others. The significant contributions carers make to the lives of others is impossible to place a value on and make a substantial difference to the lives of many Australians. This report provides a snapshot of the experience of carers in regional Australia that highlights just how important, rewarding and also often challenging, the role of a carer can be.

The Regional Wellbeing Survey is a project that relies on the input and contributions of many different individuals, groups and organisations. In particular, it relies on rural and regional Australians choosing to take part in the survey. I thank the 13,300 people who took the time to complete the survey in 2016, particularly the 11,450 who answered questions about their caring responsibilities.

The survey relies on the support of the large number of rural and regional organisations who provide funding and in-kind support, including promoting the survey through their networks, providing advice and feedback on survey content, and helping guide the survey's future. The time these organisations invest in collaborating with the Regional Wellbeing Survey team ensures the survey results assists regional and rural organisations in fostering and improving wellbeing in rural and regional communities. In particular, I would like to thank the staff of the NSW Department of Primary Industries *Rural Women's Network*, who supported inclusion of questions about caring responsibilities in the 2016 Regional Wellbeing Survey.

I also thank the Regional Wellbeing Survey team – Brigitta Yabsley, Melinda Mylek, Kimberly Brown, Vincent Learnihan, Ivan Hanigan, and Dominic Peel – for their contributions to the survey. I thank in particular Dominic for his contribution of data tables for analysis in this report.

ISBN number 978-1-74088-462-4

Title: Carers in regional Australia: 2016 Regional Wellbeing Survey report

Authors: Schirmer, Jacki

Publication date: July 2017

Preferred citation: Schirmer, J. 2017. Carers in regional Australia: 2016 Regional Wellbeing Survey report. Health Research Institute, University of Canberra, Canberra.

Key points

- Multiple studies have identified that despite valuing their caring role, carers often report poorer quality of life and wellbeing compared to non-carers, and lack access to support and services
- Few studies have compared the experiences of carers living in urban, rural and remote parts of Australia
- Just under 11,000 participants in the 2016 Regional Wellbeing Survey answered questions about whether they were a carer for someone who had a disability, was sick or had age-related frailty
- 15% of adult regional Australians reported being carers, including 17% of women and 12% of men; the proportion of carers was highest in the 50-64 age group (19%), and lowest in the 18-29 year age group (7%)
- Most carers (68%) cared for one person, 20% for two people, and 12% for more than two; 44% of carers aged 30-49 cared for more than one person, and only 13% of those aged 65 or older
- Caring obligations changed substantially through the life course: those aged 30-49 were more likely to be carers for children with disability or illness (53%), those aged 50-64 to be caring for ageing parents (49%), and those aged 65 and over to be caring for a spouse or partner (56%)
- 36% of carers were caring for someone with a medical condition such as a long term illness; 34% were caring for someone with old-age related health problems, 33% were caring for a person with a permanent disability other than mental illness or dementia; 27% were caring for someone with a mental illness; 12% were caring for a person with dementia, and 7% cared for a person with drug or alcohol addiction/dependency
- 33% of carers aged 30 to 49 spent 30 hours or more a week on their caring responsibilities, as did 32% of those living in remote and very remote areas, compared to 24% of all carers
- 61% of carers felt that caring was the responsibility of family members; 52% that they had an obligation to be a care; 25% that they had no other options but to care for the person/people they had responsibility for; and 25% that they could provide better care than others
- 44% of carers felt the contributions carers make are not recognised by the broader community, rising to 53% for carers aged under 50, and falling to 31% for carers aged 65 and over
- 29% of carers felt isolated due to their carer role, including 40% of those aged 30-49; 19% of those aged 65 and older; 32% of women; 24% of men; and 44% of those living in remote areas
- 42% of carers had experienced financial stress due to their role as a carer, particularly those aged 30-49 (56%), living in remote regions (54%) and women (44% compared to 37% of men); carers aged 65 and older were least likely to experience financial stress (25%)
- 35% of carers had stopped or reduced work due to their role as a carer, particularly those aged 30-49 (48%), and women (37% compared to 30% of men)
- 42% of carers were unable to socialise as much as they wished to, including 54% of those aged 30-49, 45% of women, 36% of men, and 31% of those aged 65 and older
- 41% of carers could easily find someone to help with their caring responsibilities if they were ill or needed a break, 22% could not access any help and 36% could find help only with difficulty; 49% of carers aged 65 and over could easily access assistance compared to only 36% of those aged 30-49, and 33% of those living in remote areas
- Only 42% of carers had access to regular breaks from caring, including 47% of those aged older than 50, 35% of those aged 30-49, and only 25% of those living in remote regions
- 23% of carers had good access to respite care and 38% had no access; 42% of carers aged 30-49 had no access compared to only 31% of those aged 65 and older

- Access to respite care was worse the more remote the region a carer lived in: 32% of those living in major cities had good access to respite care, compared to 23% of those in inner regional areas, 22% in outer regional areas, and 14% of those living in remote and very remote regions
- 53% of carers reported they had access to a supportive and understanding GP, and only 15% did not; while 66% of carers aged 65 and older had access to a supportive GP, this dropped to 54% for those aged 50-64, 45% for those aged 30-49, and 36% for those aged under 30
- 30% of carers had good access to counselling; the poorest access was reported by those living in remote and very remote regions, with 52% reporting no access and only 21% having good access
- 36% of carers had no access to practical home support such as help with domestic chores or physical aspects of caring and 29% had good access; only 18% of those living in remote regions and 19% of those aged 30-49 had good access, compared to 43% of carers aged 65 and over
- 37% of carers had good access to advice and information for carers; only 26% of those aged 30-49 and 28% of those living in remote regions had good access, compared to 44% of those aged 50-64 and 47% of those aged 65 and older
- 50% of carers had no access to financial support for their caring role and only 16% had good access; 62% of carers in remote regions had no access
- While 44% of carers had good support from family or friends, 30% had limited support, and 21% had no support; the groups most likely to have no support were carers in remote regions (36%) and those aged 30-49 (25%), while only 19% of carers aged 65 and over had no support
- On average, carers reported lower household income than non-carers: 28% of carers had a household income of less than \$31,200 in 2015-16, compared to only 22% of non-carers; only 41% of carers had household income above \$62,400 compared to 55% of non-carers
- 49% of carers reported they were poor or 'just getting along', compared to only 35% of non-carers; this included 64% of those aged 30-49 but only 33% of those aged 65 and older
- Carers aged 65 and older were more likely than other carers to report being financially comfortable or prosperous (55% compared to only 29% of those aged 30-49)
- 48% of carers had delayed or cancelled non-essential purchases in the last year, compared to 36% of non-carers
- 29% of carers had not been able to pay one or more bills on time in the last year, compared to 18% of non-carers
- 18% of carers had asked for financial help from friends or family, compared to 13% of non-carers
- 13% of carers had gone without meals or been unable to heat or cool their home in the last year, compared to 7% of non-carers
- Carers aged under 50 were more than twice as likely as older carers to have been unable to pay bills on time (51% of those aged 30-49 compared to 8% of those aged 65 and older), gone without meals or been unable to heat or cool their home (20% compared to 6%), or asked for financial help from friends and family (28% compared to 6%)
- Female carers reported higher incidence of all types of financial stress than male carers: for example, 33% of female carers had been unable to pay some bills on time in the last year, compared to 20% of male carers
- The incidence of financial stress reported by carers increased with remoteness
- Carers had consistently and significantly poorer wellbeing than non-carers when measured using four different measures of overall wellbeing, quality of life, and psychological distress

- The wellbeing 'gap' between carers and non-carers was most significant for carers aged under 50, particularly the 30-49 age group: this group of carers both reported the lowest overall wellbeing of all the groups of carers analysed, and had the largest wellbeing 'gap' between carers and non-carers
- 14% of carers reported psychological distress levels above the threshold considered to indicate probable serious mental illness, compared to 9% of non-carers; the carers reporting highest distress were those aged 30-49, with 23% having high distress levels, compared to 12% of non-carers in this age group
- The 'wellbeing gap' between carers and non-carers was largest for their satisfaction with their (i) health (carers had a score on average 6.6 points lower than non-carers), (ii) confidence in their future security (difference of 5.9 points), (iii) satisfaction with their standard of living (5.7 points), and (iv) satisfaction with what they were achieving in life (5.7 points).
- Carers living in remote and very remote regions had lower satisfaction with their standard of living than those in other regions, and satisfaction with future security decreased with remoteness, being poorer the more remote a region a carer lived in.
- Carers who had good access to help reported significantly higher levels of wellbeing compared to those who had no access to help, or who could find help only with difficulty: those with no access to help had an average wellbeing score of 63 (scored from 0 to 100), compared to 77 for those with good access to help
- The wellbeing of carers was significantly poorer if they spent more than 30 hours a week engaged in caring: average wellbeing scores of 76 were reported by those who spent less than 15 hours a week caring, 69 by those engaged in caring 30-44 hours per week, and 66 by those engaged in caring for 45 hours or more per week
- The poorest wellbeing was reported by those who were caring for people with drug or alcohol addiction or dependency (average wellbeing score of 60), followed by those caring for people with mental illness (67)
- Carers who had good access to breaks from caring, respite care, a supportive GP, counselling, home support, advice, financial support and support from family and friends, all reported significantly better wellbeing compared to those with no/limited access to these supports
- Carers also reported better wellbeing if they felt their contributions were recognised by others, did not feel isolated or experience financial stress, and were able to socialise as much as they wished to
- Overall, carers living in remote regions and those aged 30-49 reported the greatest level of stress related to caring (including financial stress, isolation, and lack of access to support), and those living in large regions towns and cities, and aged 65 and over, reported the most positive experiences of being a carer
- Providing support for carers in the form of breaks from caring, support from others in the community including GPs, friends and family, and opportunities for social interaction, is likely to significantly improve quality of life for carers and support them to have a more rewarding experience as a carer
- While improved access to services and support can assist all types of carers, it is particularly important for those aged under 50, those living in remote regions, and for those caring for people with mental illness or drug and alcohol addiction/dependency, who report poorer wellbeing and less access to support than other groups of carers.

Introduction

A large number of Australians provide what is often called ‘informal’ care for others: they care for a family member or friend who has a disability, is sick, or who has age-related frailty. In 2015, the ABS estimated that 11.6% of all Australians were carers; this included 14.0% of all Australians aged 15 and older (ABS 2016). The support these carers provide is essential to the lives of those they care for, and in 2015 was estimated to involve 1.9 billion hours of care, with a value of \$60.3 billion if the same care was to be undertaken by formal paid carers (Deloitte Access Economics 2015).

Caring for others is often rewarding, but also challenging. Several studies have found that carers often report poorer health and wellbeing compared to non-carers, but that they also often describe caring as having important positive impacts on their lives (see for example Cummins et al. 2007; Gill et al. 2007; Nepal et al. 2008; NSW Carers 2016). They have also identified that many carers lack access to support services such as respite care and home support, feel the work they do is undervalued, and experience financial hardship due to their role as a carer (see for example Holland 2008; Nepal et al. 2008; NSW Carers 2016).

Despite the recognition of the important and essential role carers play in Australia, only a small number of studies have examined whether carers living in regional, rural and remote areas face different challenges in their caring role compared to those living in urban areas. This is noted as a gap in the literature, with an identified need for more work examining the experiences of rural carers, and whether caring for people outside an urban setting has more or different challenges when compared to carers living in major cities (Arksey and Glendinning 2008; McKenzie et al. 2010). Some studies have identified that rural carers may be more likely than their urban counterparts to lack access to carer support services, and have proposed actions such as investing in online support services to assist in overcoming the impacts of isolation and lack of access to services on wellbeing of carers (Dow et al. 2008). To help address this gap, the 2016 Regional Wellbeing Survey included a special section of questions for carers, asking them about their experiences. Because the Regional Wellbeing Survey includes a large sample of people living across regional, rural and remote areas, as well as a sample of people living in major urban centres, it is possible to compare the experiences of carers living in regions from densely population urban regions to the most remote communities.

This report summarises key findings from the survey, focusing on understanding:

- Which types of regional Australians are engaged in caring for others?
- What types of caring responsibilities do they have?
- What types of support do they have access to?
- How does their financial wellbeing compare to that of other regional Australians?
- How does their wellbeing and quality of life compare to that of other regional Australians?
- What types of support most strongly predict better wellbeing for carers?

Previous studies have emphasised that it is not necessarily the rurality of an area that contributes to different caring experiences, but rather the differences in things such as access to services and support (McKenzie et al. 2010). This is an important distinction, as it ensures the focus is on understanding how best to support carers, irrespective of where they live. Previous studies have also identified that carers strongly value their role as a carer, even when it may have negative impacts on their health and wellbeing. Given this, the focus throughout this report is on providing insight into

what factors help make a 'positive carer experience'. In other words, what characteristics and types of support do carers with higher wellbeing have which those with lower wellbeing do not? What can this tell us about the types of intervention that may support carers to undertake the caring role they value, while ensuring they can also maintain a positive quality of life?

This report has several sections, which examine

1. The proportion of regional Australians who reported being carers is identified and the types of caring responsibilities they have
2. The motivations for caring and experience of being a carer
3. The extent to which carers have access to different forms of support
4. The financial wellbeing of carers
5. The wellbeing and quality of life of carers, including how this changes depending on the type of caring they do and their access to different forms of support
6. Implications of the findings for supporting carers to have a high quality of life.

The Regional Wellbeing Survey

The Regional Wellbeing Survey is a large survey of 13,000 Australians, conducted every year since 2013. The survey is unique in that it focuses on the experiences of Australians living in regional, rural and remote areas of Australia, while also including a small sample of residents living in Australia's capital cities. The survey is described in detail in reports available at www.regionalwellbeing.org.au.

Each wave of the survey examines some special topics. In 2016, one of the special topics examined was the experience of rural carers. Of 13,300 respondents, 11,450 were asked to answer questions about whether they were a carer for a person who had a disability, mental illness, drug or alcohol dependency, chronic condition, terminal or serious illness, or frailty (as farmers were deliberately oversampled, questions about their caring responsibilities were not asked of all farmers, and this is why only 11,450 or the 13,300 were asked these questions).

Analysis presented in this report

The data presented in this report are drawn from a survey conducted at a single point in time. This means that while it is possible to identify statistical *associations* (for example, whether a person is significantly more or less likely to have access to a particular form of support, or to have good or poor wellbeing), it is not possible to identify the *causal direction* of the association. For example, if carers with access to support have poorer wellbeing and those with more support have higher wellbeing, it is possible that:

- Better wellbeing enables the carer to more easily access support
- Better access to support helps support wellbeing.

In many cases, both these 'causal stories' are likely to be true, with each factor influencing the other. When discussing findings in the report, the discussion focuses on identifying the forms of carer support associated with better wellbeing, as it is highly likely that any association involves, at least in part, a causal link in which the level of access to support has an influence on wellbeing.

Data weighting

The dataset analysed in this report has been weighted to be representative of the adult population living in regional Australia. 'Weighting' refers to a statistical process in which known biases in the responses received are corrected for. Weighting was used to correct for both intentional over-sampling (of farmers and some regions), and non-intentional biases (a bias towards female and older respondents). The weighting of responses involves adjusting the relative contribution each survey respondent makes to the whole when analysing survey results, so analysis of the sample more accurately represents the population from which it was drawn (in this case, people living in rural and regional Australia). Weighting doesn't change the answers people gave to survey items. Data were weighted using GREGWT, a generalised regression weighting procedure developed by the Australian Bureau of Statistics. Weighting has been applied to all analyses in this report, unless otherwise specified. The weighting procedure used was the same as that described in Schirmer et al. (2016).

Confidence intervals

Throughout this report, 95% confidence intervals are shown as part of the results. A confidence interval, put simply, is a measure of how confident you can be in the results. More accurately, it tells you the boundaries between which, statistically, the mean value of a given variable would be 95%

likely to fall if the survey was repeated multiple times with a similar sample. In general, confidence is higher if there is a large sample size and little deviation in responses (for example, almost all people answered '4' on a scale of 1 to 7). Confidence is lower if there is a small sample size and high deviation (for example, equal numbers of people answered 1, 2, 3, 4, 5, 6 and 7 on the 7-point scale). Figure 1 provides an example to assist in interpreting confidence intervals. The specific methods used to calculate confidence intervals are the same methods described in in Schirmer et al. (2016).

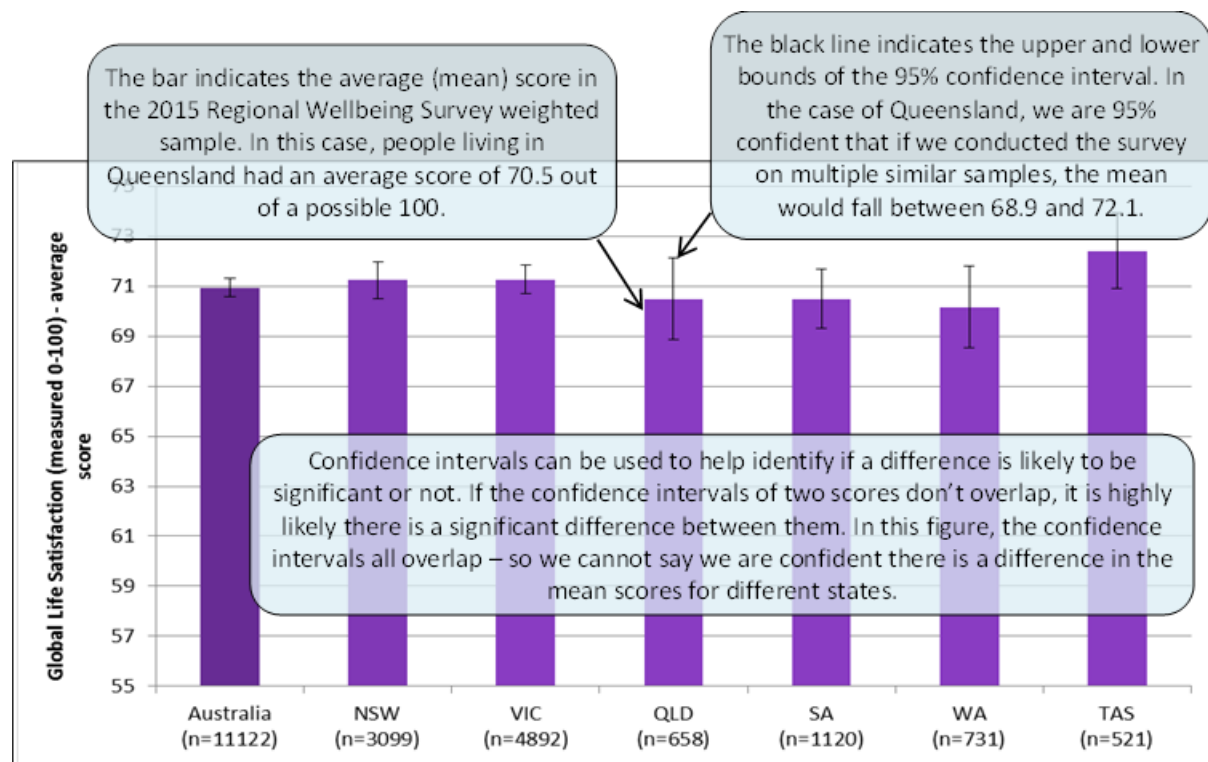


Figure 1 Interpreting confidence intervals (source: Schirmer et al. 2016)

How many regional Australians are carers?

Across Australia, 15.0% of adult regional Australians reported being carers in 2016 (n=10,946). 'Regional Australia' here includes all areas outside the capital cities of Sydney, Melbourne, Brisbane, Adelaide, Perth and Canberra. Regional Australia includes Hobart and Darwin.

This figure is very similar to the 14% of Australians aged over 15 who are carers (ABS 2016), indicating that the proportion of people who are carers in regional Australia is similar to that in urban Australia. The proportion of people caring for others was very similar in different States, ranging from 14% in Victoria and Queensland to 16% in New South Wales and South Australia, 17% in Tasmania and 18% in Western Australia¹ (Figure 2).

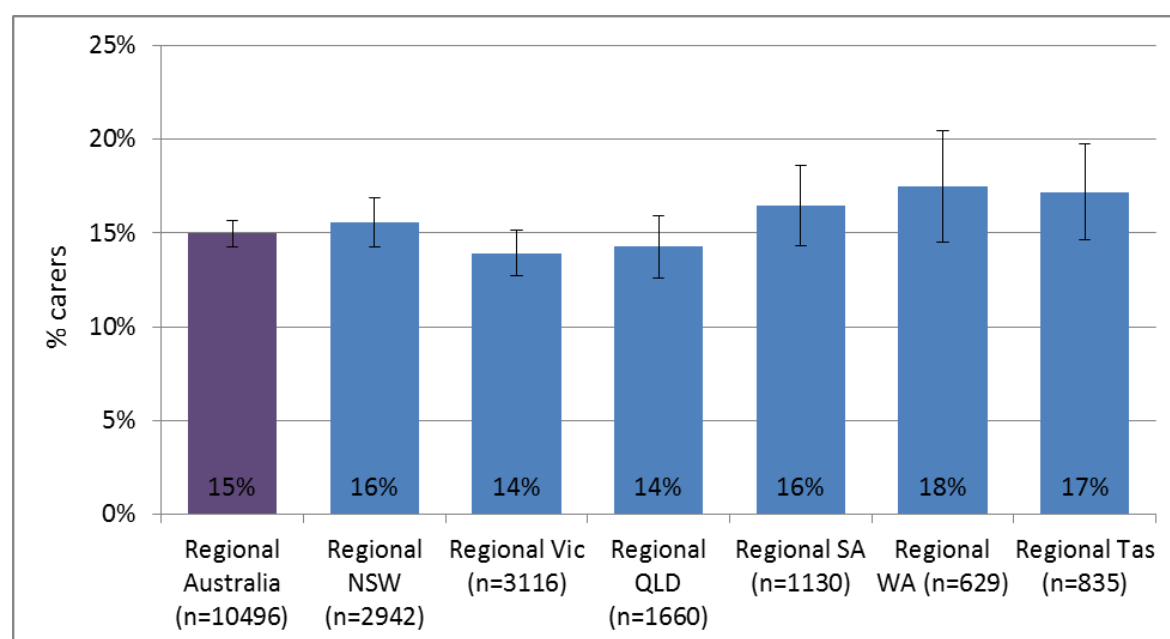


Figure 2 Percentage of adult population of who reported being carers – regional Australia and States

More women (17%) than men (12%) are carers, something identified in multiple previous studies. Those aged under 30 were much less likely to report being a carer, and those aged 50 to 64 much more likely to be carers, compared to those in other age groups (Figure 3). These figures are relatively similar to ABS estimates for all of Australia in 2015, which estimated that 5% of those aged under 34 were carers, 14% of those aged 35 to 44, 19% of those aged 45 to 64, and 18% of those aged 65 and over. The only significant difference in regional carers compared to Australia as a whole was a slightly lower proportion of carers aged 65 and over.

¹ As only a small sample was obtained in the Northern Territory (140 people) and Australian Capital Territory (34), these regions are excluded from this report.

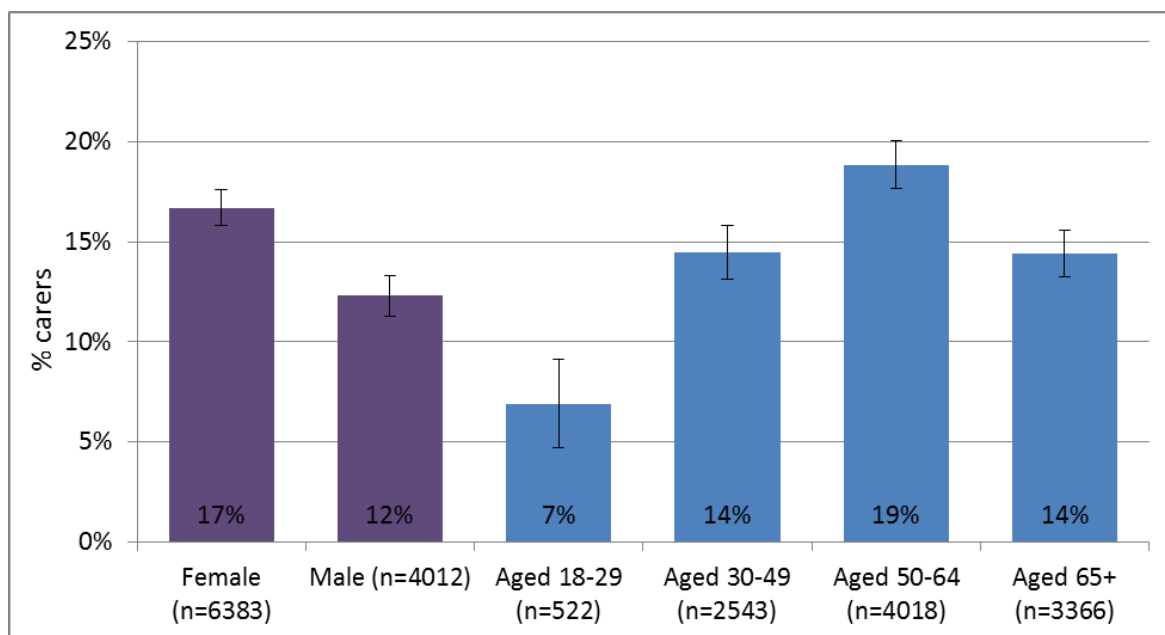


Figure 3 Percentage of adult population of who reported being carers – by gender and age

Regional Australia varies substantially, ranging from large cities on the coast and in inland areas (for example, Albury, Wagga Wagga, areas of the Sunshine Coast in Queensland, Newcastle) to very remote areas with sparse population. The experiences of people living in these different types of regions are likely to be very different. To help understand this better, the Australian Bureau of Statistics (ABS) 'remoteness' geographic classification was used to classify survey respondents based on the 'remoteness' of the area they lived in, with five categories used, shown in Figure 4:

- **Major cities of Australia** – Large cities with high density population. This includes not only the major capital cities (e.g. Melbourne, Sydney), but also highly urban areas of large regional cities. The Regional Wellbeing Survey includes a sample of people living in the major capital cities as well as a sample of those in large regional cities, particularly large coastal regional city areas such as Port Macquarie and Noosa. When reporting for 'major cities', the data include approximately 350 people living in Sydney, Melbourne, Brisbane, Adelaide, Perth and Canberra who participated in the survey, as well as those living in large regional cities such as Port Macquarie, Newcastle and similar.
- **Inner regional Australia** – Areas where geographic distances imposes a small restriction on the accessibility of some goods, services and social interactions; this includes some cities such as Tamworth, Wagga Wagga, Bunbury and Launceston
- **Outer regional Australia** – Towns and regional cities where there is a moderate restriction on accessibility of services and social interaction, including places such as Swan Hill, Albany, Burnie, Gunnedah, Griffith
- **Remote Australia** – regions with high restrictions on accessibility of goods, services and social interaction, e.g. Cobar, northern Wimmera, Cooktown, Port Lincoln
- **Very remote Australia** – regions with very high restriction on accessibility of goods, services and social interaction opportunities, e.g. western parts of Queensland and northern NSW, northern parts of South Australia, much of Western Australia and the Northern Territory.

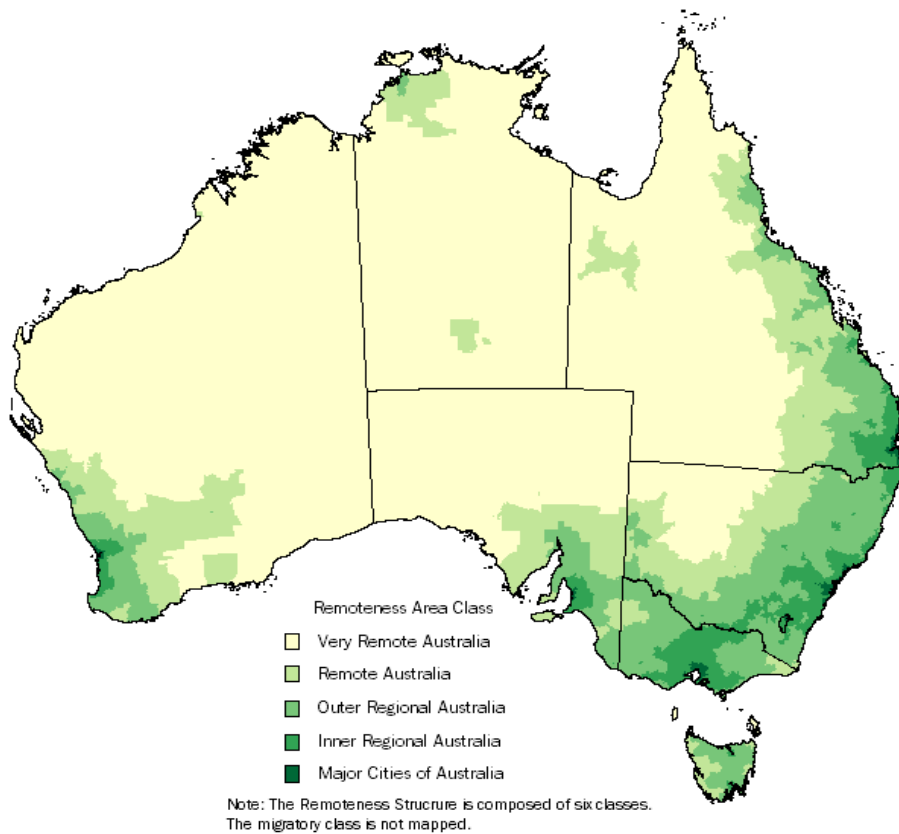


Figure 4 Remoteness regions of Australia (data source: ABS 2013)

When the proportion of carers is examined by remoteness region, there are some differences. Fewer people reported being carers in major cities, remote, and very remote regions; and more reported being carers in inner and outer regional Australia (Figure 5). This may be a result of many factors, including:

- Some people may be forced to leave remote and very remote areas when caring for others, in order to access services
- Those living in major cities are often somewhat younger and less likely to be carers
- The survey sample may be biased in major cities and remote and very remote areas, with fewer carers participating in the survey. Further work is needed to identify if this result is repeated over time and shows the same relationship, in order to identify if survey response bias played a part in the results.

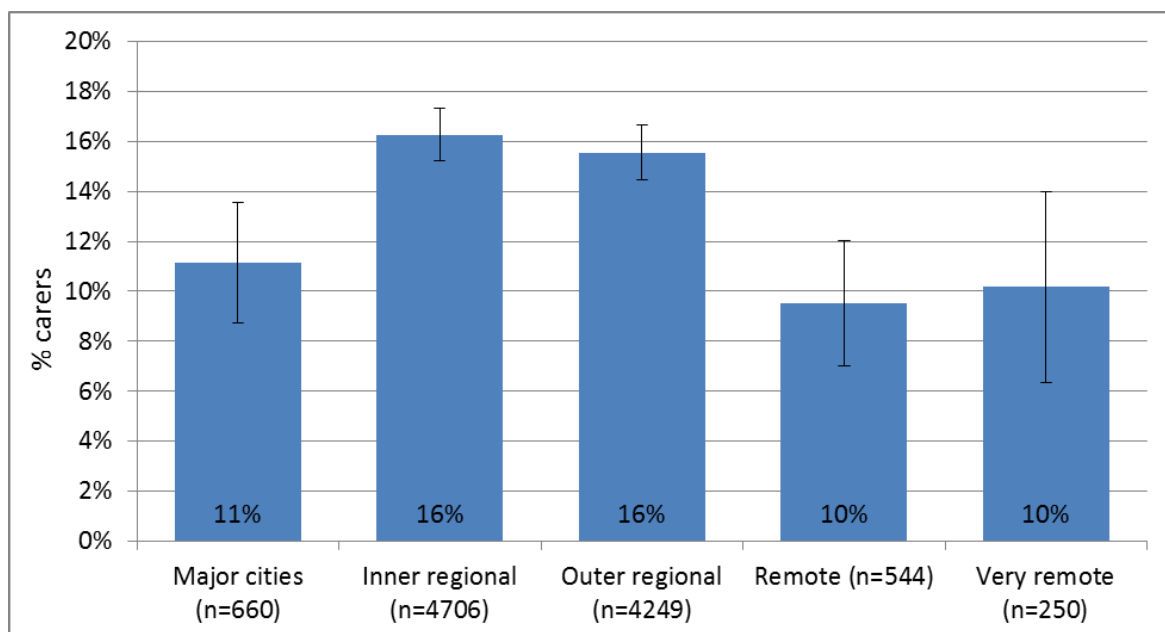


Figure 5 Percentage of adult population of who reported being carers – by remoteness region

Caring responsibilities

Carers were asked how many people they cared for, whether they cared for different types of relatives or friends, and the types of caring needs the people they cared for had.

Number of people cared for

Most carers in regional Australia (68%) care for one person, while 20% care for two people, and 12% care for more than two people (Figure 6). Carers aged 30 to 49 were most likely to care for more than one person, with 44% caring for two or more. Carers aged 65 and over were least likely to care for more than one person, with only 13% reporting caring for more than one person. This indicates a higher average caring burden for many carers aged 30-49 in particular, and to a lesser extent all carers aged under 65 compared to those 65 and older.

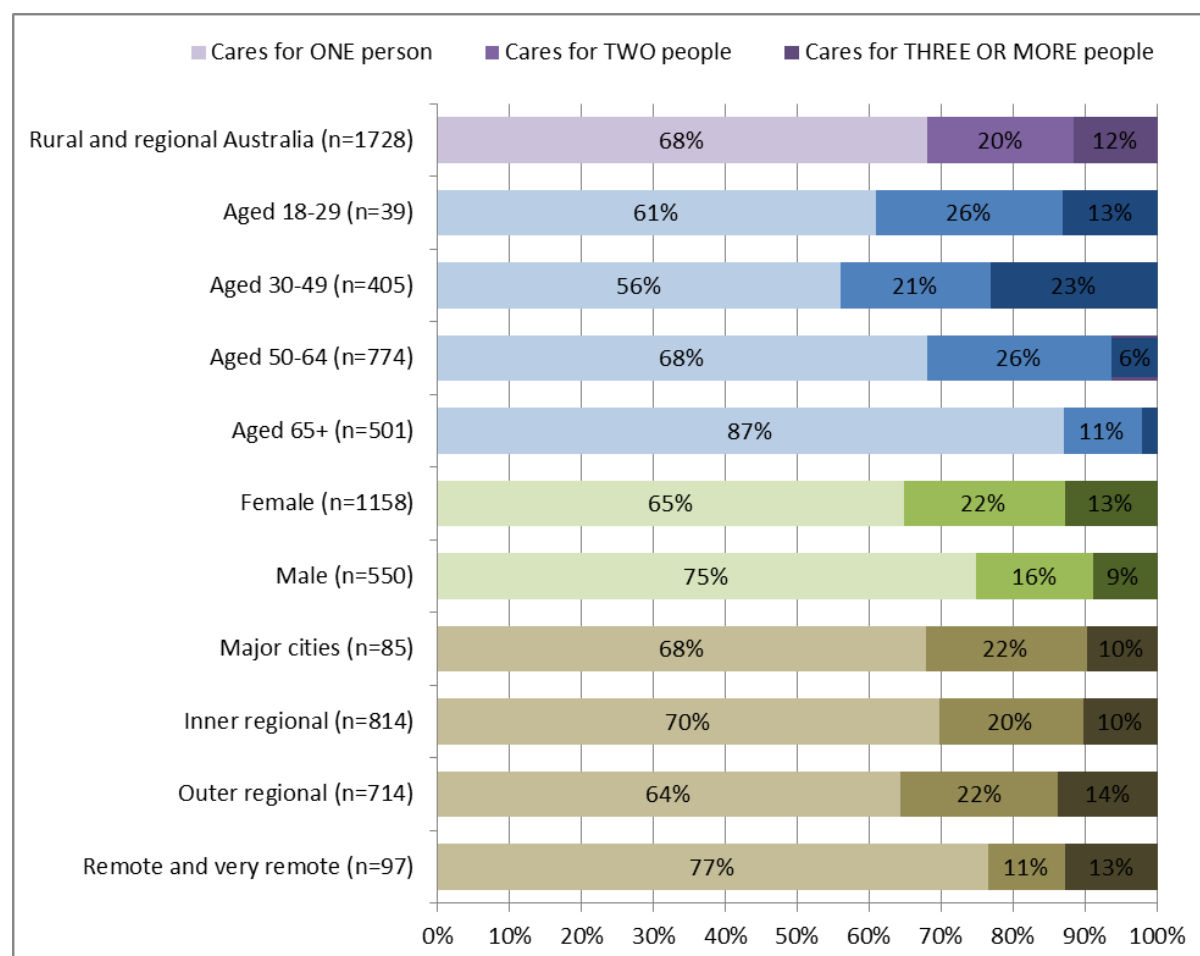


Figure 6 Number of people cared for

Type of people cared for

Carers were asked if the person or people they cared for were their children, spouse/partner, parents or parents-in-law, sibling or sibling-in-law, or others such as friends or ex-spouses. Across regional Australia (defined as all areas outside the six largest capital cities), almost equal proportions of carers reported caring for children (35%), a spouse/partner (35%), or parents or parents-in-law (33%), while fewer cared for a sibling or another type of person such as a friend (Figure 7).

Caring obligations are highly age and gender specific, and change substantially through the life course, with younger people caring for a wide range of people including siblings, those aged 30 to 49 more likely to be carers for children with disability or illness, those aged 50 to 64 more likely to be caring for ageing parents, and those aged 65 and over most likely to be caring for a spouse or partner:

- Women were more likely than men to be caring for children and parents
- Men were more likely than women to be caring for a spouse/partner
- Those aged 65 and older were predominantly caring for a spouse/partner (56%), while fewer (19%) were caring for a child, and 13% for parents
- The youngest group of carers, aged 18-29, cared for a very diverse range of people, and were more likely than any other group to be caring for a sibling (18%)
- Those aged 30-49 were most likely to be caring for children (53%)
- Those aged 50-64 were most likely to be caring for a parent (49%).

The higher proportion of men than women caring for a spouse or partner suggests that men often take on caring obligations when their female partner becomes ill or frail, whereas for women caring obligations are more broadly spread amongst a range of groups including children, partners, and parents.

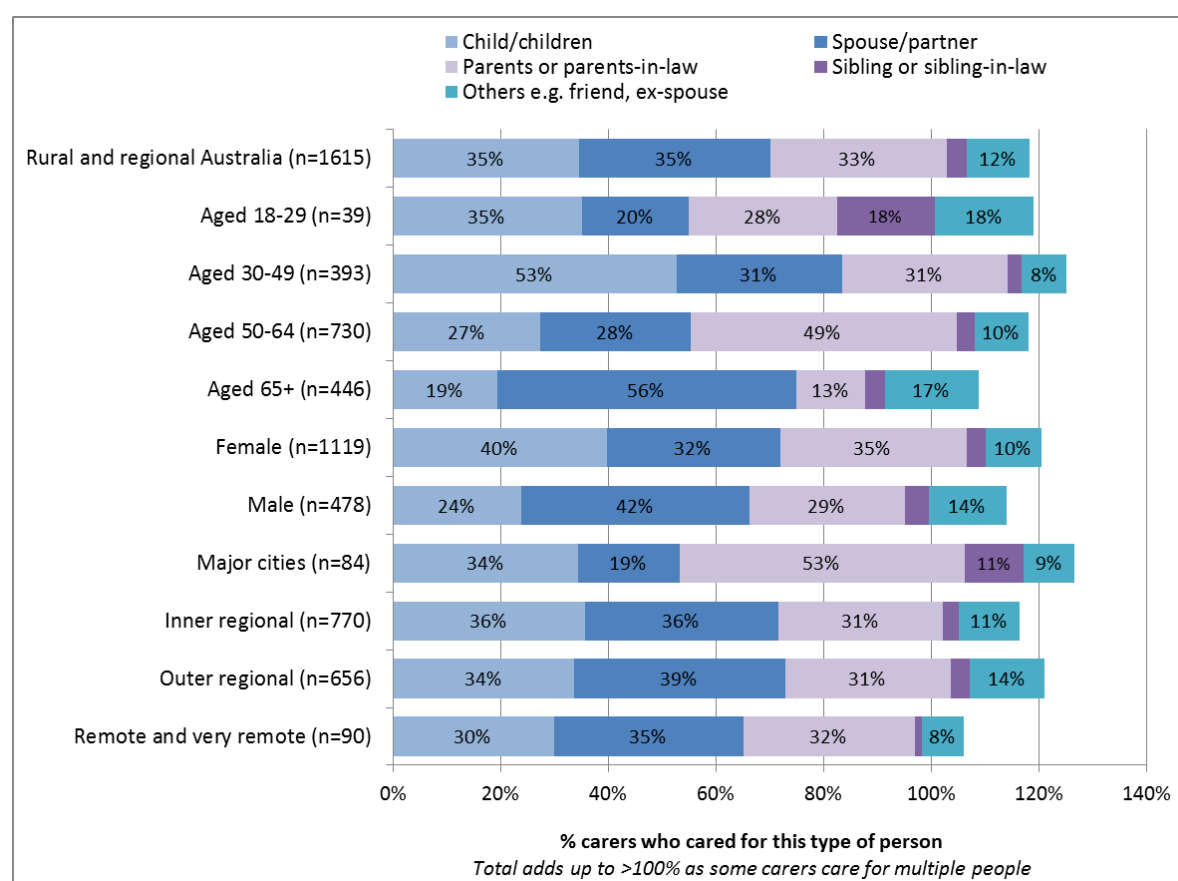


Figure 7 Types of people cared for

Caring needs

Carers were asked what types of needs the person or people they cared for had. Across regional Australia (Figure 8):

- 36% of carers were caring for someone with a medical condition such as a long term illness or recovery from an accident
- 34% were caring for someone with old-age related health problems or frailty
- 33% were caring for a person with a permanent disability other than mental illness or dementia (this group included those caring for people diagnosed with autism, developmental delays or intellectual disability)
- 27% were caring for someone with a mental illness
- 12% were caring for a person with dementia, and
- 7% cared for a person with drug or alcohol addiction or dependency.

When compared by groups:

- Younger people were more likely to be caring for a person with a mental illness (38% of 18-29 year old carers compared to 19% of carers aged 65 and over), and for people with medical conditions other than a permanent disability or mental illness
- Those aged 50 to 64 were most likely to be caring for someone with old-age related frailty or illness (47%)
- The proportion of people caring for someone with a medical condition such as long term illness increased with remoteness, with those living in remote and very remote regions most likely to be doing this (43%).

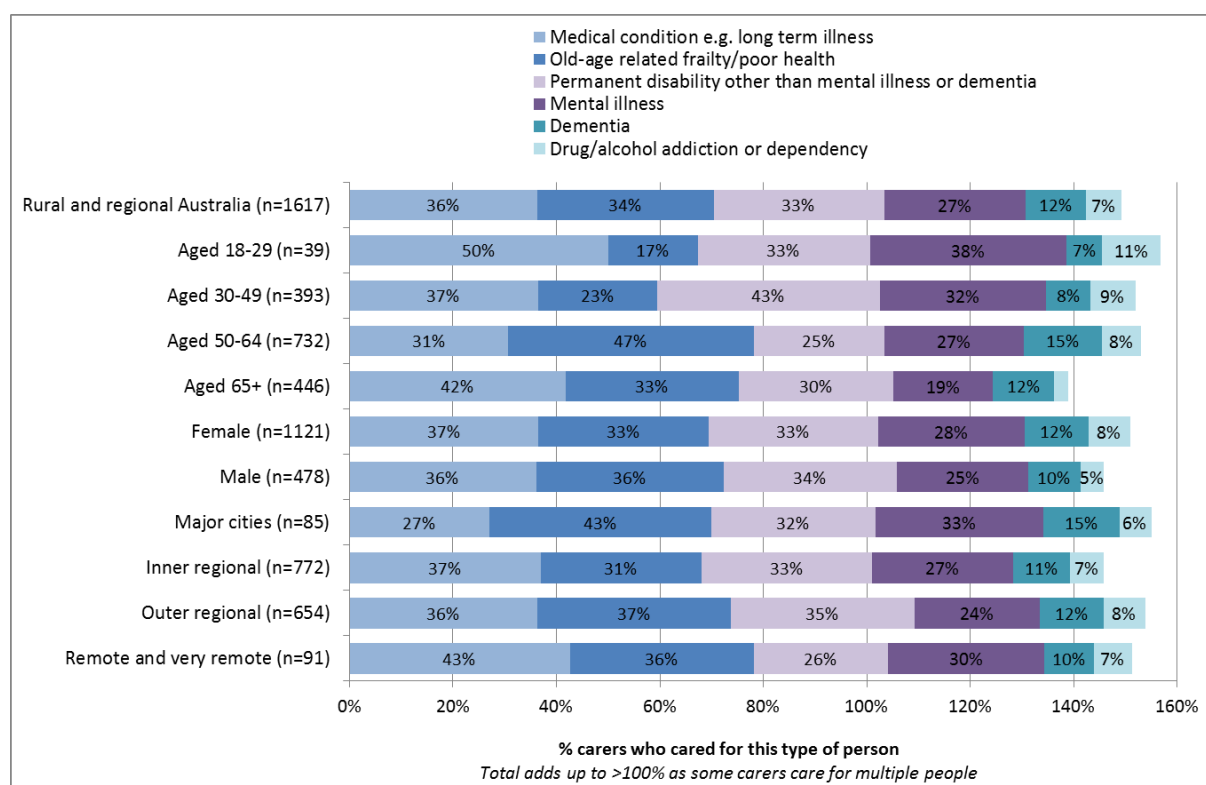


Figure 8 Needs of people being cared for

Hours spent caring

The hours carers spend each week on their caring responsibilities varies substantially. Almost one in three (30%) reported that it was either hard to calculate the hours spent caring, or that their caring hours varied substantially each week (Figure 9). Of the remainder, 32% spent less than 15 hours a week on caring, 13% spent 15 to 29 hours, and 24% spent 30 hours or more per week. Those aged 30 to 49 were most likely to report spending 30 hours or more a week on their caring responsibilities (33%), and those aged 50 to 64 least likely to report spending more than 30 hours a week (15%). Those aged 50 to 64 were more likely than those in other age groups to have caring responsibilities of less than 15 hours per week (43%).

When compared by region, people living in remote and very remote areas reported spending more hours on caring responsibilities compared to those in cities and inner and outer regional areas: 32% of carers living in remote and very remote areas spent 30 hours or more a week on their caring responsibilities, and only 17% spent less than 15 hours a week engaged in caring activities.

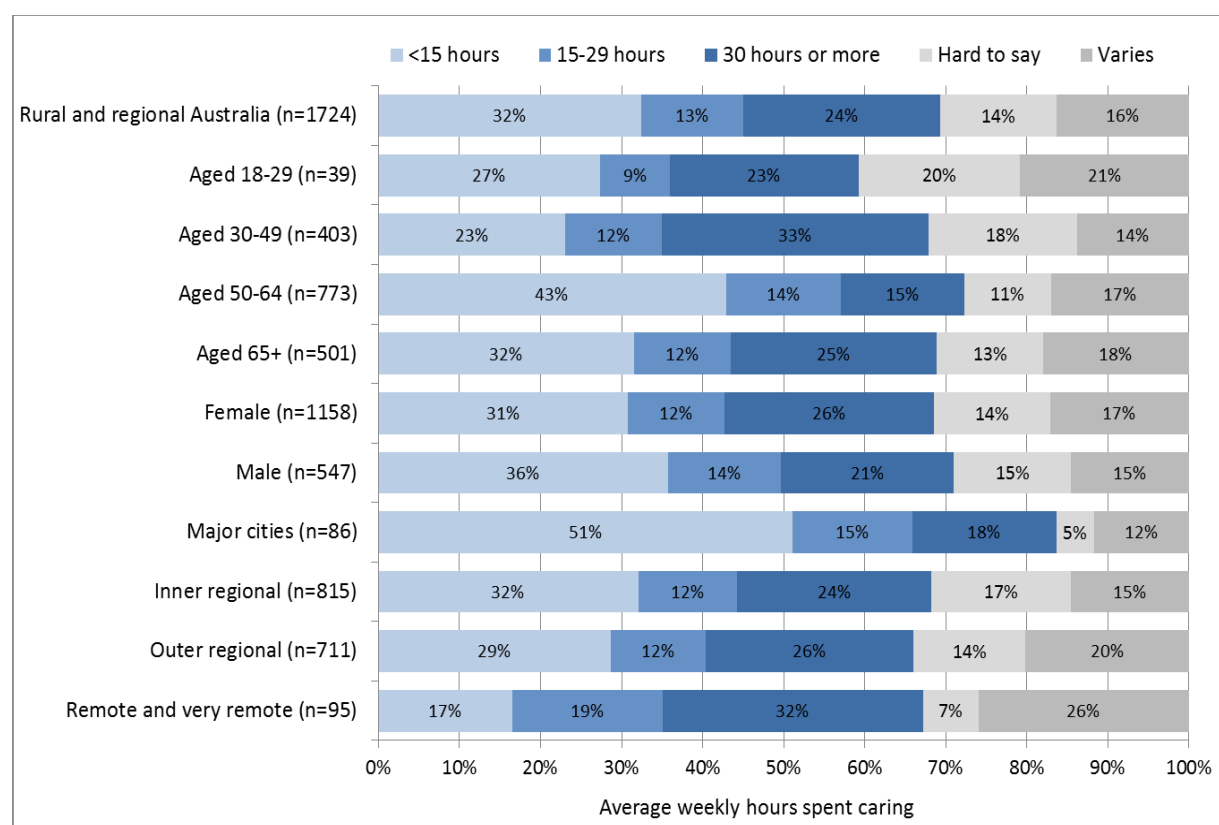


Figure 9 Average hours spent on caring responsibilities each week by carers

Motivations for being a carer

Carers were asked if any of the following were reasons why they were a carer, instead of other people taking on caring responsibilities:

- Caring is the responsibility of family members
- I can provide better care than others could
- I feel an obligation to care for this person/people
- I had no other options for care for this person/people.

Respondents could select all the options that applied to them. Across rural and regional Australia, 61% of carers felt that caring was the responsibility of family members, and 52% that they had an obligation to care for the person or people they cared for. One quarter (25%) reported they had no other options but to care for the person/people they had responsibility for, and another 25% felt they could provide better care than others could (Figure 10).

Having no other option for care was reported more commonly by younger and female carers and less commonly by older and male carers. Younger carers were more likely to report that caring was the responsibility of family members than older people, as were those living in remote and very remote regions, while those aged 30 to 64 were more likely than others to feel they could provide better care than others would.

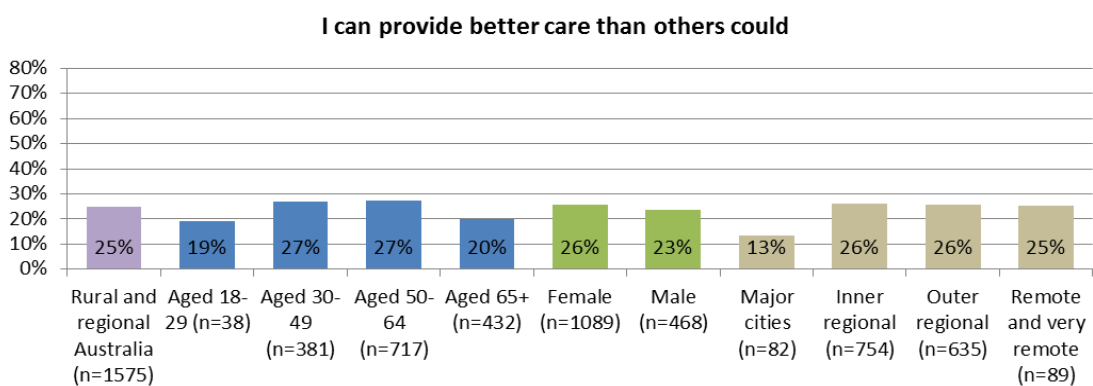
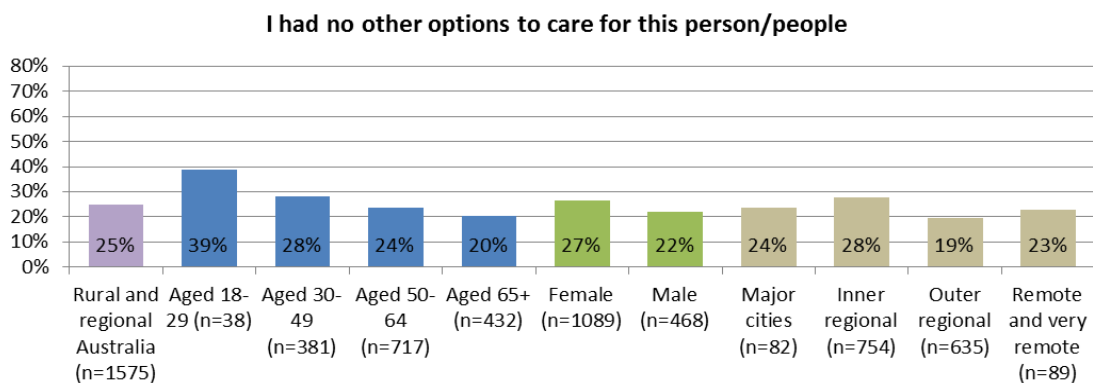
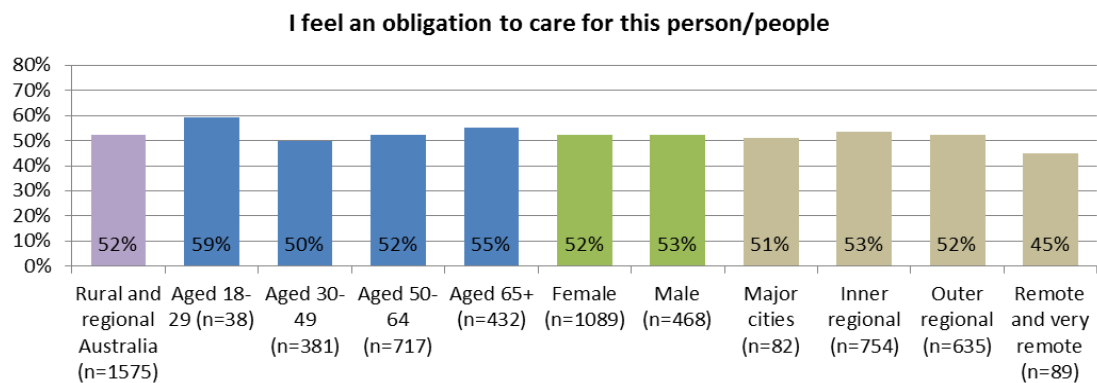
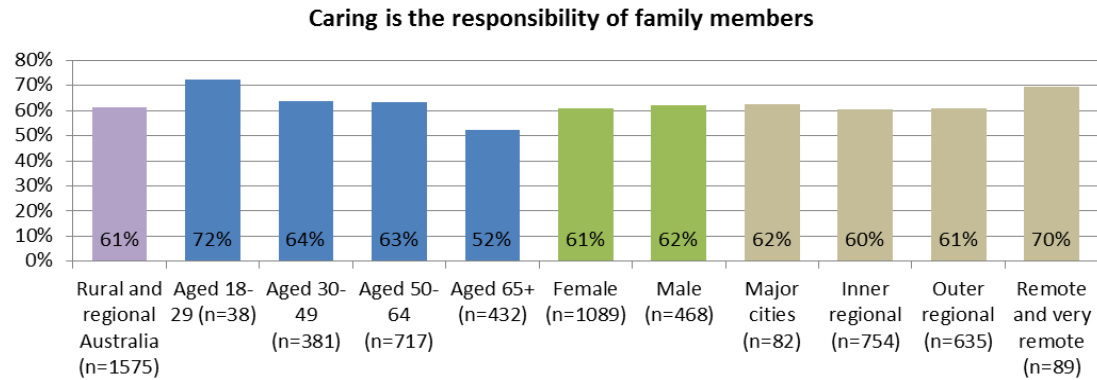


Figure 10 Reasons for being a carer instead of seeking others to take on caring responsibilities

Experience of caring

The experience of caring for another person can be very different for different people. Past studies have suggested that many carers report that financial issues, lack of recognition and increased isolation are challenges experienced due to their role as a carer. To better understand the extent to which these issues were experienced by carers in regional Australia, carers were asked the extent to which they agreed or disagreed that:

- The contributions carers make is recognised by the broader community
- I feel isolated because of my caring responsibilities
- I have experienced financial stress due to my role as a carer
- I have stopped work or reduced work hours due to my role as a carer
- I can't socialise as much as I want to because of my role as a carer.

This section examines which carers were more and less likely to experience these issues, providing some understanding of which carers are most likely to have a positive caring experience, and which are more likely to experience reduced financial and social wellbeing due to their role as a carer.

Recognition of contributions

When asked if they felt the contributions carers make are recognised by the broader community, 44% of carers felt they were not, 31% felt they were, while 25% either said they neither agreed or disagreed, or were unsure. Carers aged under 50 were most likely to feel the role of carers was not recognised by the broader community (with 53% feeling it was not), while those aged 65 and older were most likely to feel it was recognised (41%). Women, men, and people in different regions reported very similar views (Figure 11).

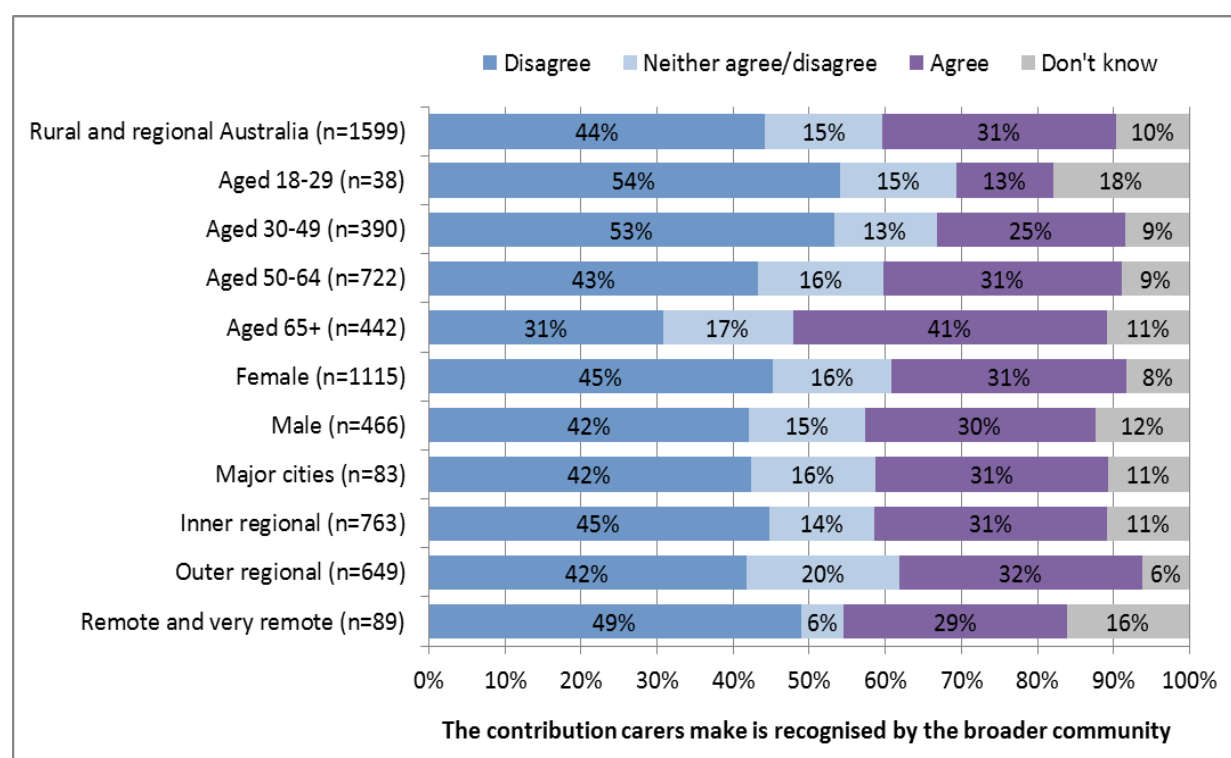


Figure 11 Experiences of caring: recognition by the broader community

Experience of isolation

When asked if they felt isolated due to their caring responsibilities, 55% of carers did not feel isolated, 29% did feel isolated, and 17% were neutral or unsure. Carers aged 30 to 49 were more likely than those in other age groups to report feeling isolated (40%), while those aged 65 and older were least likely to (19%). Women were more likely than men to feel isolated (32% compared to 24%). Carers living in remote and very remote areas were the most likely of any group of carers to report feeling isolated (44% compared to 29% on average in other regions) (Figure 12).

This highlights that, while a significant proportion of carers experience isolation, many do not. Understanding the factors that assist some carers to avoid social isolation can help identify strategies for reducing the isolation experienced by others. Isolation is clearly related at least in part to geographic location, with those in remote areas more likely to feel isolated. However, it is also strongly age related: the high proportion of carers aged 30-49 experiencing isolation irrespective of where they lived suggests that factors such as the number of people cared for and hours spent caring (both of which are higher amongst this age group of carers) are factors that may contribute to a higher likelihood of experiencing social isolation as a carer. The low proportion of older carers experiencing isolation suggests that factors related to life stage, the types of caring responsibilities they have, and their personal situation reduces experience of isolation. This may for example include the social norms of different caring amongst different age groups: caring for an ageing partner, the most common form of caring for those aged 65 and older, may be considered a common and normal part of life for this age group, and there may be better provision of social opportunity for carers as a result.

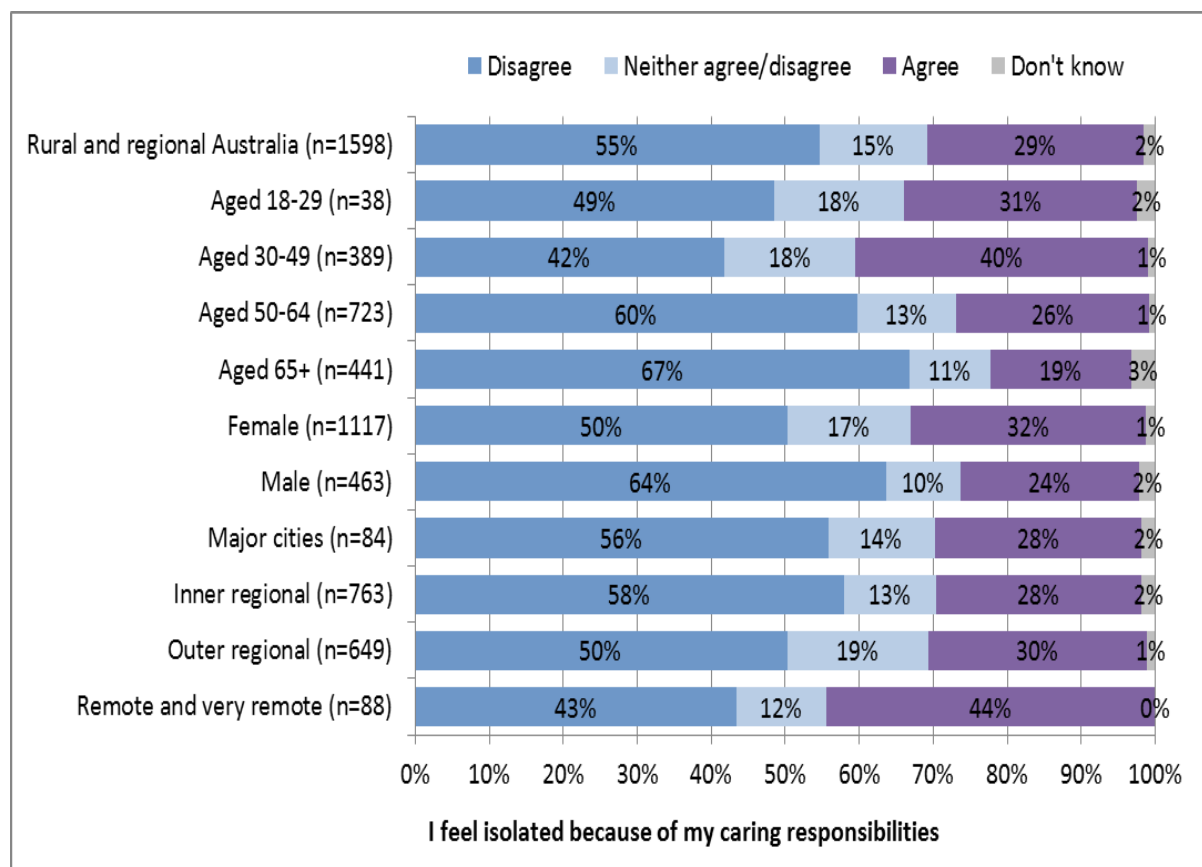


Figure 12 Experiences of caring: feeling isolated

Experience of financial stress

When asked if they had experienced financial stress due to their role as a carer, 48% of carers had not experienced financial stress, 42% had, and 9% were neutral or unsure. Carers aged 30 to 49 were most likely of any age group to report experiencing financial stress (56%), while those aged 65 and older were least likely to have (25%). Women were more likely than men to have experienced financial stress (44% compared to 37%), and those in remote and very remote areas were much more likely than those in other regions to have experienced financial stress due to their role as a carer (54% compared to 42% on average in other regions) (Figure 13).

These findings highlight the importance of understanding the relative financial impact of being a carer at different life stages, and in different locations. Despite older carers having lower household income (discussed later in this report), they are least likely to experience financial stress due to their role as a carer, while it is the carers in earlier life stages where they are more likely to have financial obligations such as mortgages, childcare and schooling costs, who are most likely to experience financial stress due to their role as a carer.

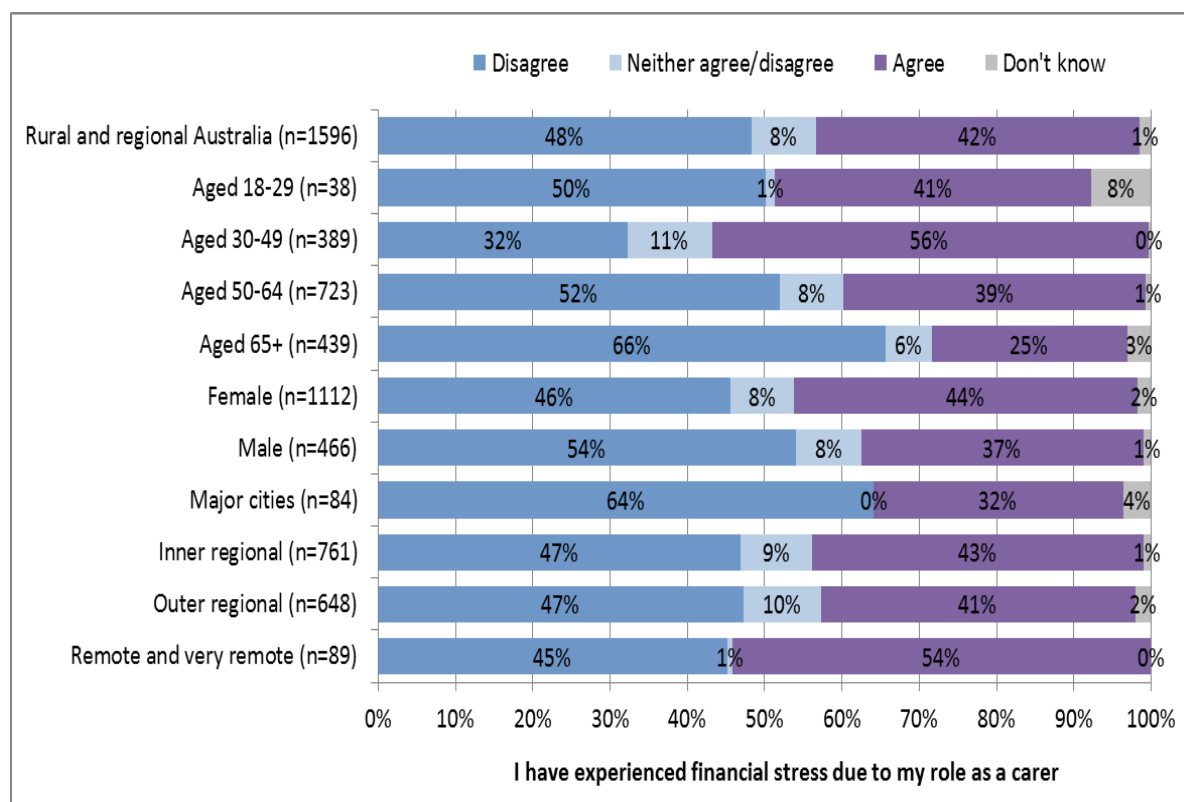


Figure 13 Experiences of caring: financial stress

Stopping or reducing work

When asked if they had reduced working hours or stopped work due to their role as a carer, 54% of carers did not do this, 35% had, and 11% were neutral or unsure. Carers aged 30 to 49 were most likely of any age group to have reduced or stopped work (48%), and those aged 65 and older were least likely to have (16%). Women were more likely than men to have stopped or reduced work (37% compared to 30%) (Figure 14). This again highlights the importance of life stage in influencing the experience of being a carer: people who become carers during retirement appear less likely to experience significant negative financial impact due to their role as a carer, in large part due to not having to make the choice between maintaining paid employment and their role as a carer.

However, even amongst carers aged 65 and older, 16% had reduced or stopped work in order to engage in their caring responsibilities, highlighting that this can occur at any age, despite being most common amongst carers in younger age groups.

The difference between men and women suggests that within a household, it is more commonly women than men who reduce or stop work in order to take on caring responsibilities.

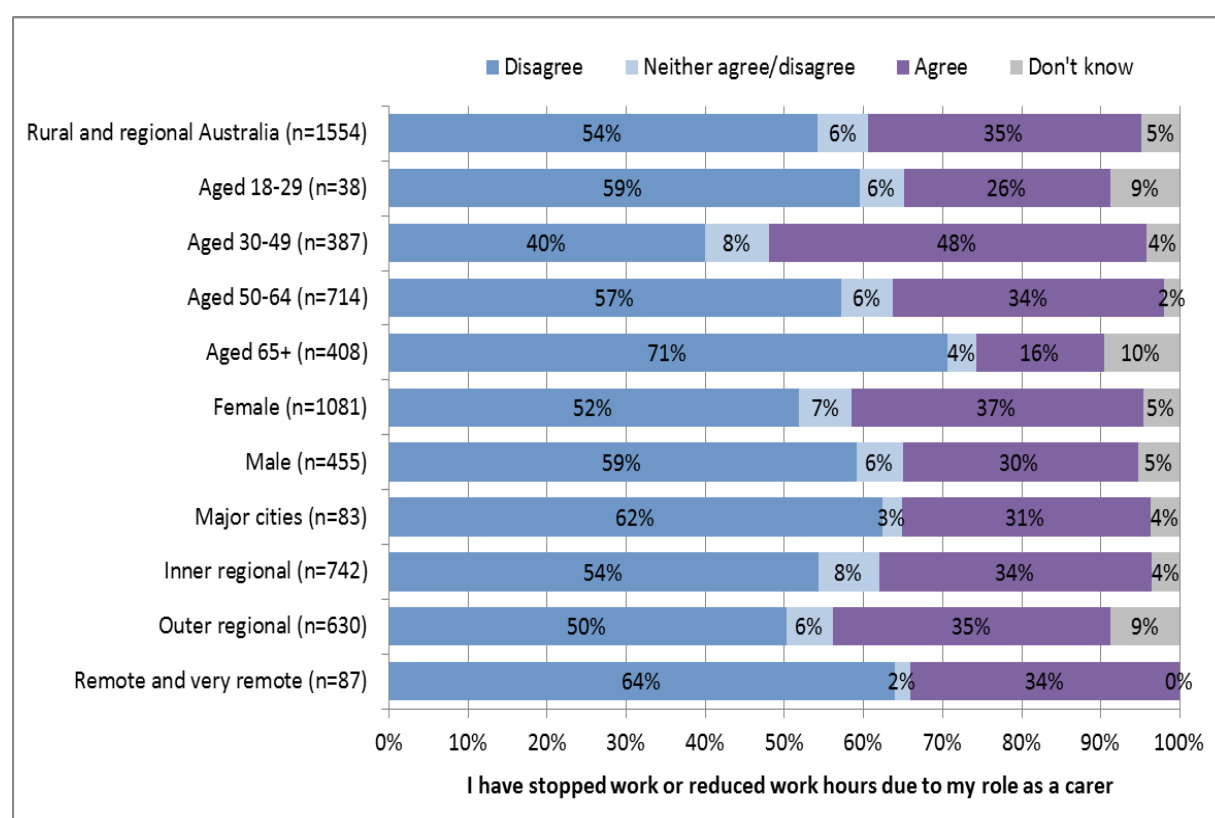


Figure 14 Experiences of caring: stopping or reducing work

Ability to socialise

When asked if being a carer meant they could not socialise as much as they wished to, 46% of carers did not experience this as an issue, 42% were unable to socialise as much as they wished to, and 12% were either neutral or unsure.

Carers aged 30 to 49 were the most likely of any age group to report being unable to socialise (54%), and those aged 65 and older were least likely to report this as an issue, although almost one in three in this older age group still experienced this (31%). Women were more likely than men to reported being unable to socialise as much as they would like to due to their caring obligations (45% compared to 36%). Carers living in inner and outer regional areas were more likely to report this as an issue (42% and 45% respectively) and those living in major cities (34%) and remote and very remote regions (37%) slightly less likely to (Figure 15).

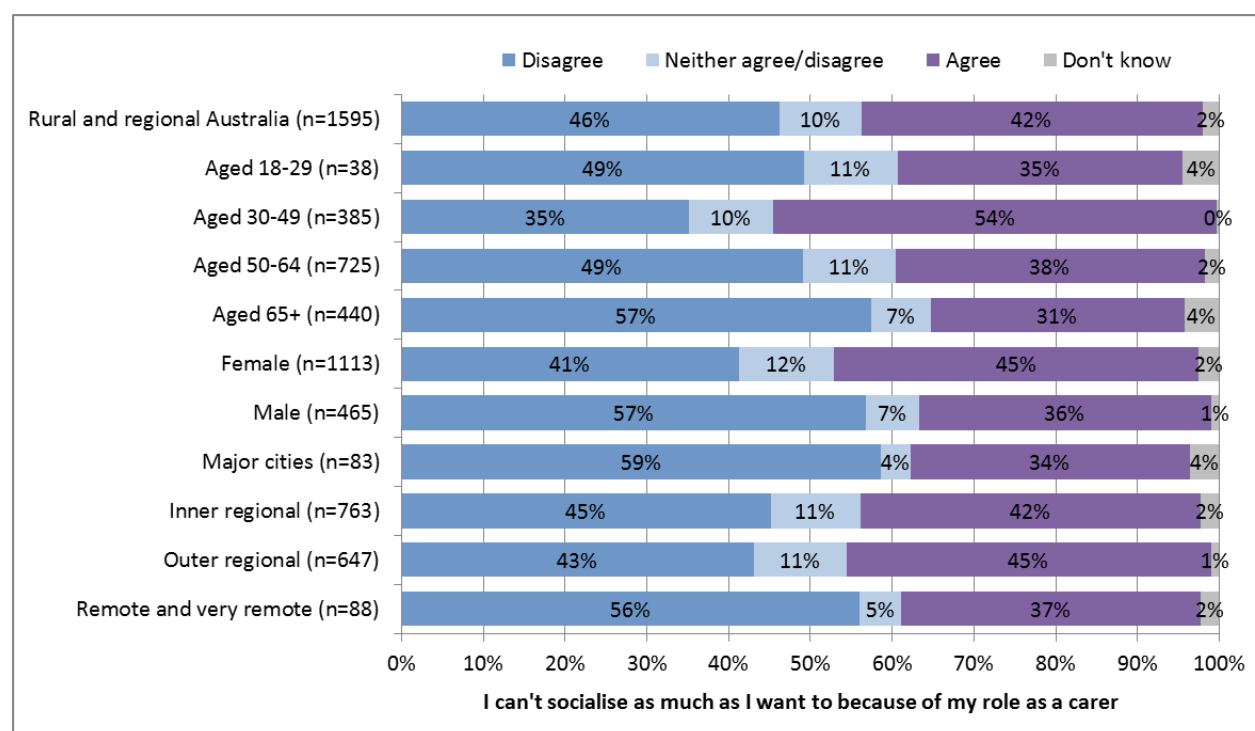


Figure 15 Experiences of caring: effects on ability to socialise

Access to support

Carers were asked whether they had access to any form of assistance if they were ill or needed a break. They were then asked if they had access to any of a number of types of support to assist them in their role as a carer.

Overall access to support

Carers were asked 'can anyone else help you in your caring responsibilities if you are ill or need a break?' They could select one of the following options:

- No, I don't have access to help
- I could find someone to help but it would be difficult
- Yes, I could find someone to help easily.

Just over two in five carers (41%) could easily find someone to help if they needed to. The majority (58%) either could not access any help (22%) or could find help only with difficulty (36%). Carers aged 65 and over were most likely to find it easy to access assistance (49%), as were those younger than 30 although in this age group the small sample means the difference may not be meaningful. Those who found it hardest to access help were people living in remote and very remote regions, where 40% had no access to help and only 33% could access help easily. Those aged 30-49 found it more difficult to access help than other age groups, with 27% having no access to help and only 36% having easy access to help (Figure 16).

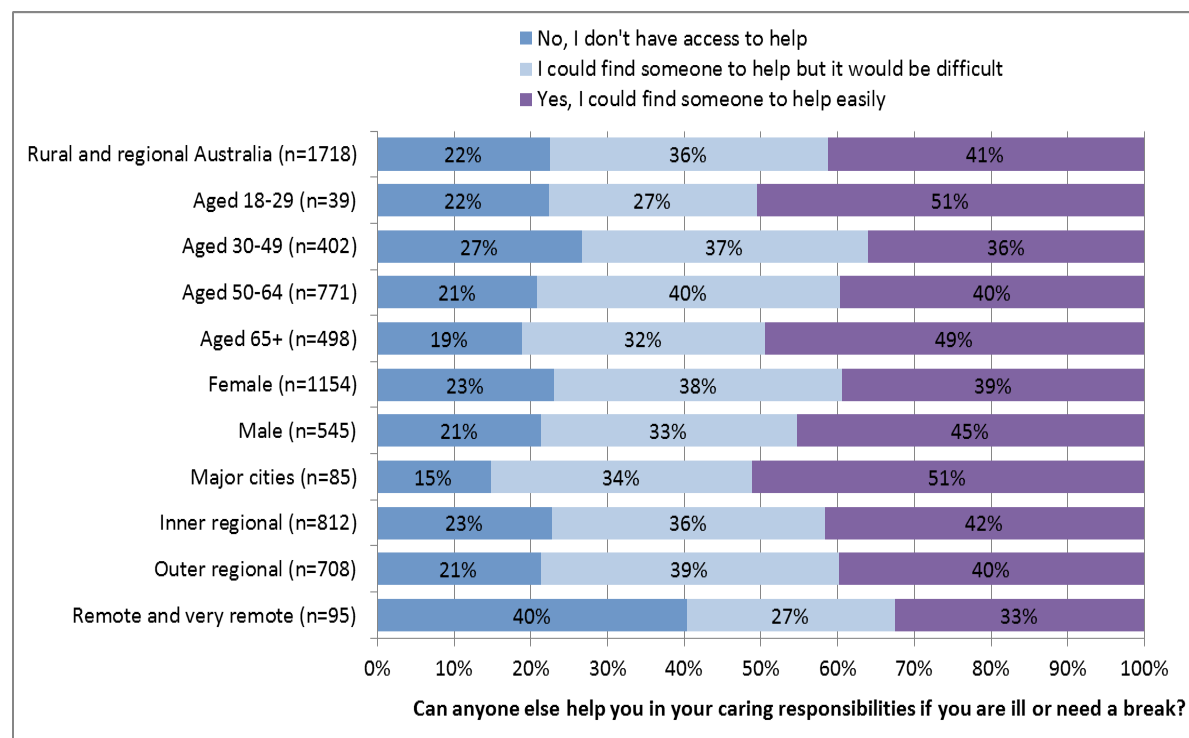


Figure 16 Overall access of carers to help

Access to different forms of support

Carers were asked whether they had access to any of the following types of support to assist them in their caring role:

- Regular breaks from caring
- Respite care services
- Supportive and understanding GP who recognises your role as a carer
- Access to counselling for you as a carer
- Access to practical home support, e.g. care workers, domestic help
- Access to advice and information for you as a carer
- Financial support for you as a carer
- Support from family and friends for you as a carer

They could identify that they had no access, some access but not as much as they would like, good access, or that they were unsure if they had access. When the survey was pilot tested, results show the 'don't know' response was usually selected when a person had not attempted to access a particular type of support, and hence was unsure if they would have poor or good access to it if they did try to access it. Across Australia, 53% of carers reported having good access to supportive and understanding GPs, while 44% reported good access to support from family and friends and 42% were able to have regular breaks from caring (Figure 17). Fewer reported having access to advice and information for carers (37%), counselling for carers (30%), practical home support (29%), respite care services (23%), or financial support for carers (16%). In some cases, this was because the carer had not sought to access assistance, with many being unsure if they had access to counselling or respite care options in particular.

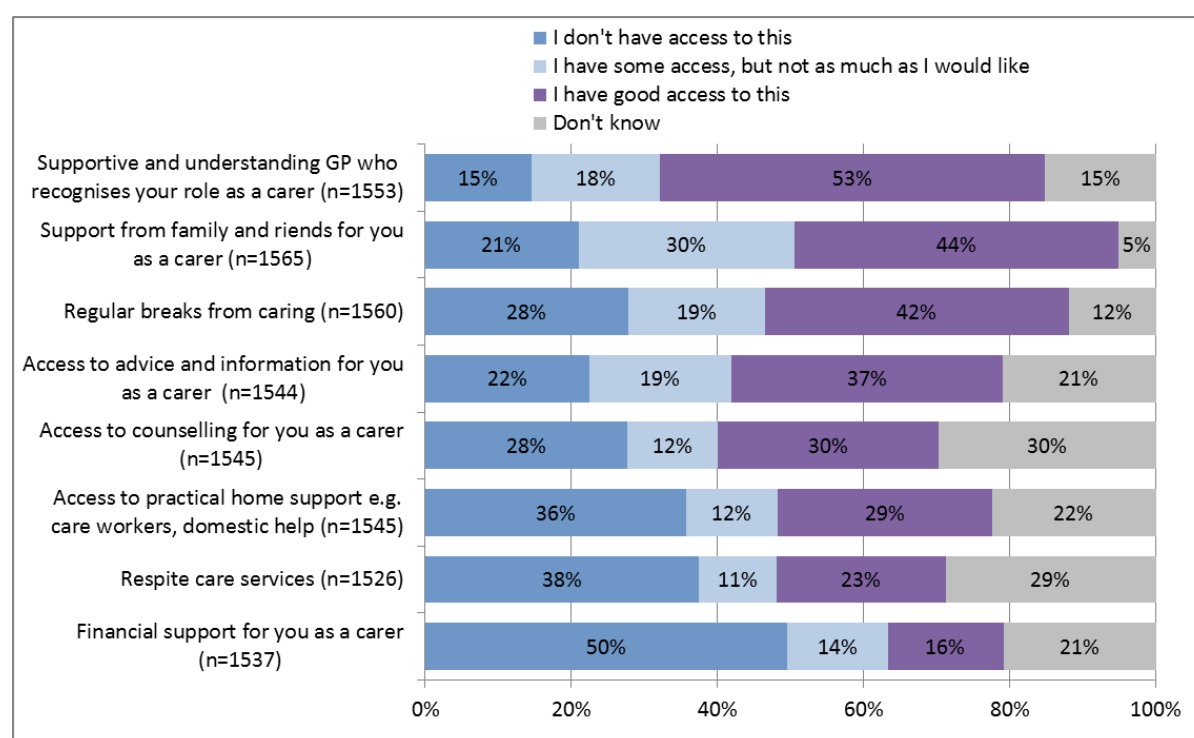


Figure 17 Access to different types of support reported by carers living in regional, rural and remote Australia

Access to breaks from caring

Older carers were more likely to report having access to regular breaks from caring, with 47% of 50-64 year old carers and 46% of carers aged 65 and older reporting this (although almost as many – 41% and 40% - had no or limited access to breaks in these age groups).

Carers aged under 50 were significantly less likely to have regular breaks from caring compared to older carers, with only 35% of those aged 30 to 49 having this. Those living in remote and very remote regions were even less likely to report having regular breaks, with only 25% having breaks from caring, and 51% reporting they had no access to regular breaks from caring. Those living in major cities were most likely to report having access to regular breaks from caring (Figure 18).

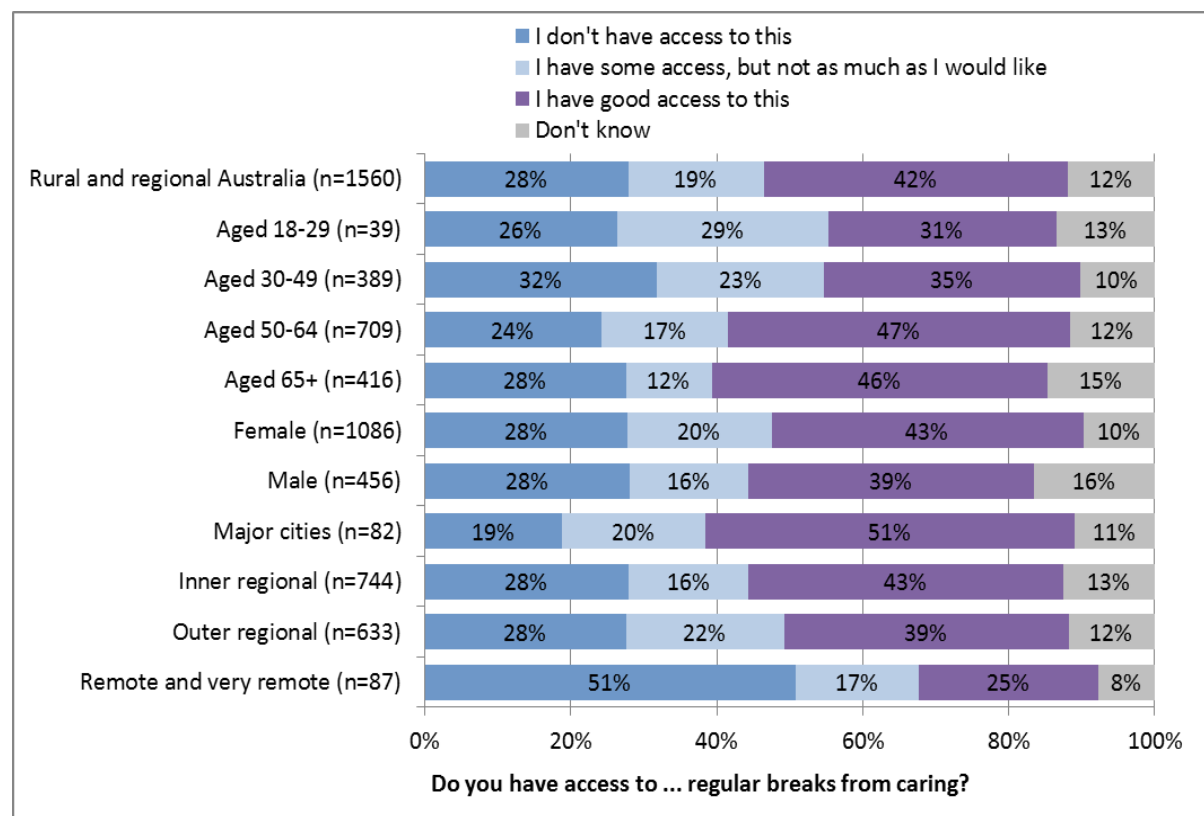


Figure 18 Access to support: regular breaks from caring

Access to respite care services

When asked if they had access to respite care services, 38% of carers reported having no access, 29% were unsure (likely because they had not sought to access this type of service), 23% reported having good access, and 11% limited access (Figure 19). Access to respite care was poorer for younger carers, and higher for those aged 65 and older: 42% of carers aged 30-49 had no access to respite care compared to only 31% of carers aged 65 and older. Only 16% of those aged 30-49 reported having good access compared to 33% of those aged 65 and older. The poorest access to respite care was reported by carers living in remote and very remote regions: 68% of these carers had no access to respite care services. More broadly, access to respite care was poorer the more remote the region a carer lived in: 32% of those living in major cities had good access to respite care, compared to 23% of those in inner regional areas, 22% in outer regional areas, and 14% of those living in remote and very remote regions.

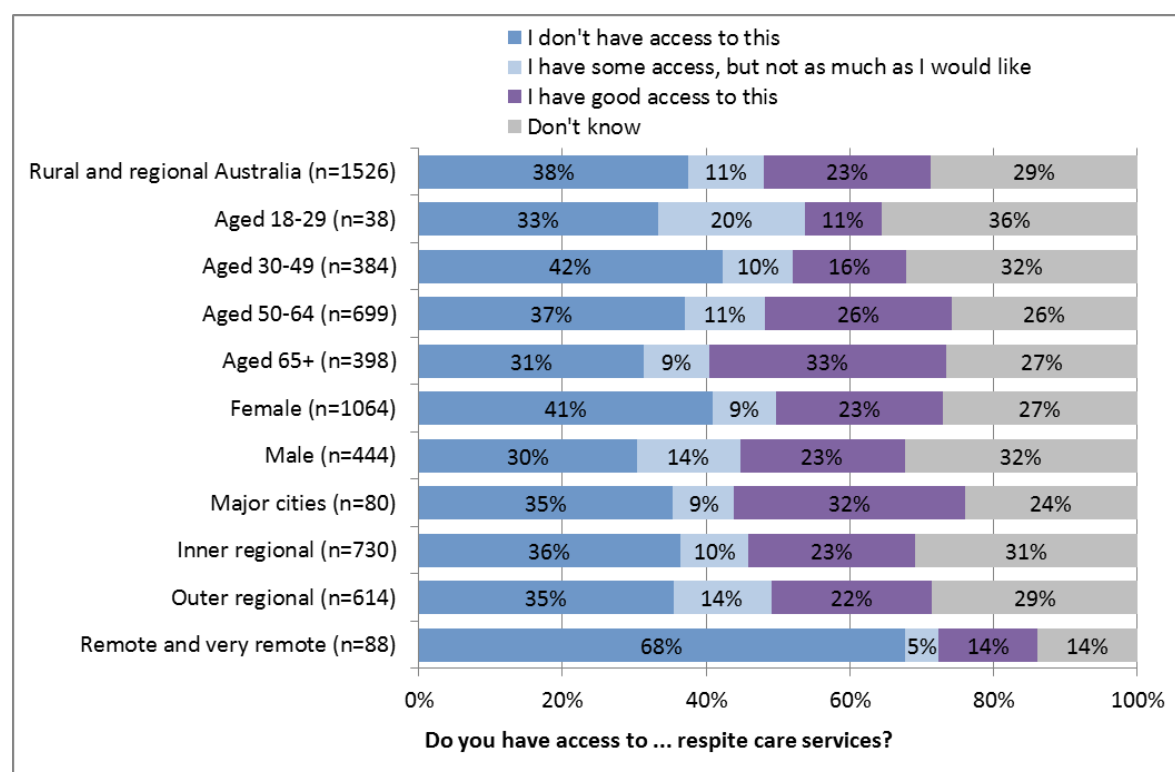


Figure 19 Access to support: respite care services

Access to a supportive GP

Having a GP who understands their role is an important form of support for carers. Across Australia, 53% of carers reported they had access to a supportive and understanding GP, and only 15% did not, while 18% had limited access and 15% were unsure (Figure 20). There was a strong age-related difference: younger carers were less likely to report having access to a supportive GP, and older carers much more likely to. While 66% of carers aged 65 and older had access to a supportive GP, this dropped to 54% for those aged 50-64, 45% for those aged 30-49, and 36% for the youngest group of carers. Those living in remote and very remote regions were less likely than carers in other regions to have access to a supportive GP, with 28% reporting no access, although almost half of carers living in remote/very remote regions (47%) did have this type of support.

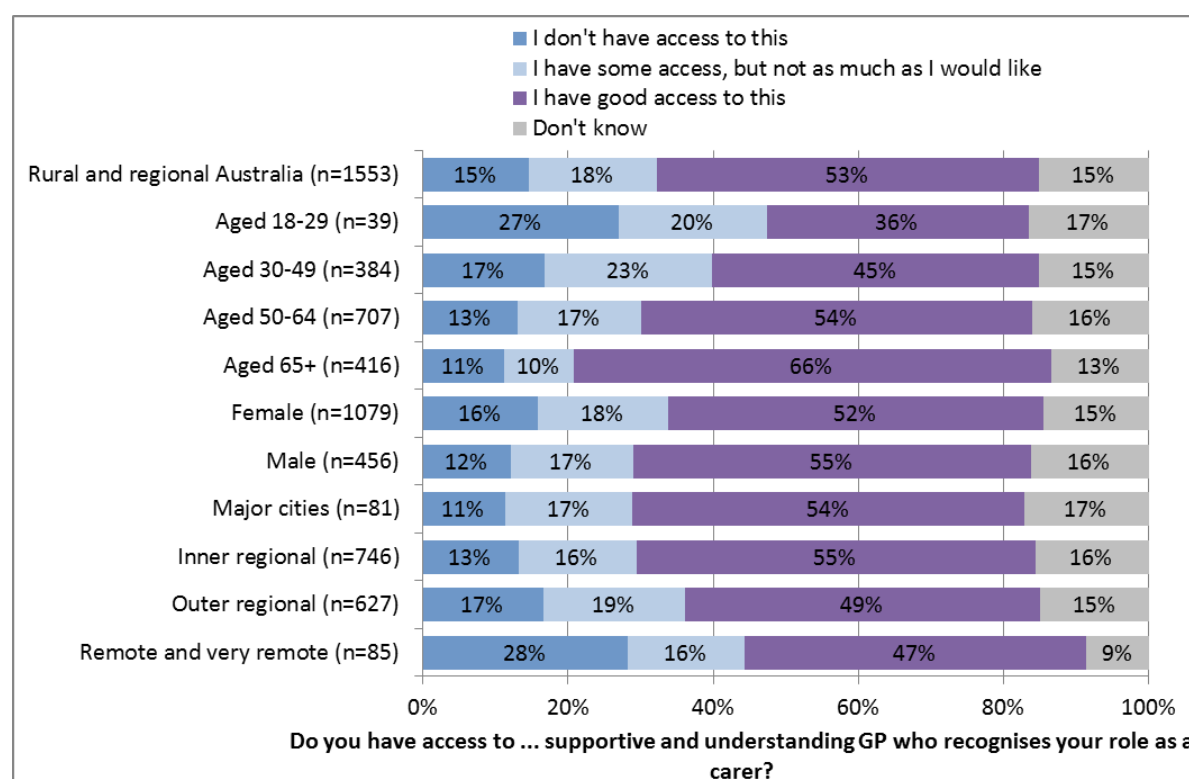


Figure 20 Access to support: Supportive and understanding GP

Access to counselling for carers

Caring for others is often simultaneously rewarding and challenging. Having access to counselling can assist carers in coping successfully with their role. When asked if they had access to counselling for themselves as a carer, 30% of regional carers reported having good access, 30% were unsure, 28% had no access and 12% had limited access (Figure 21). The poorest access was reported by those living in remote and very remote regions, with 52% reporting no access and only 21% having good access.

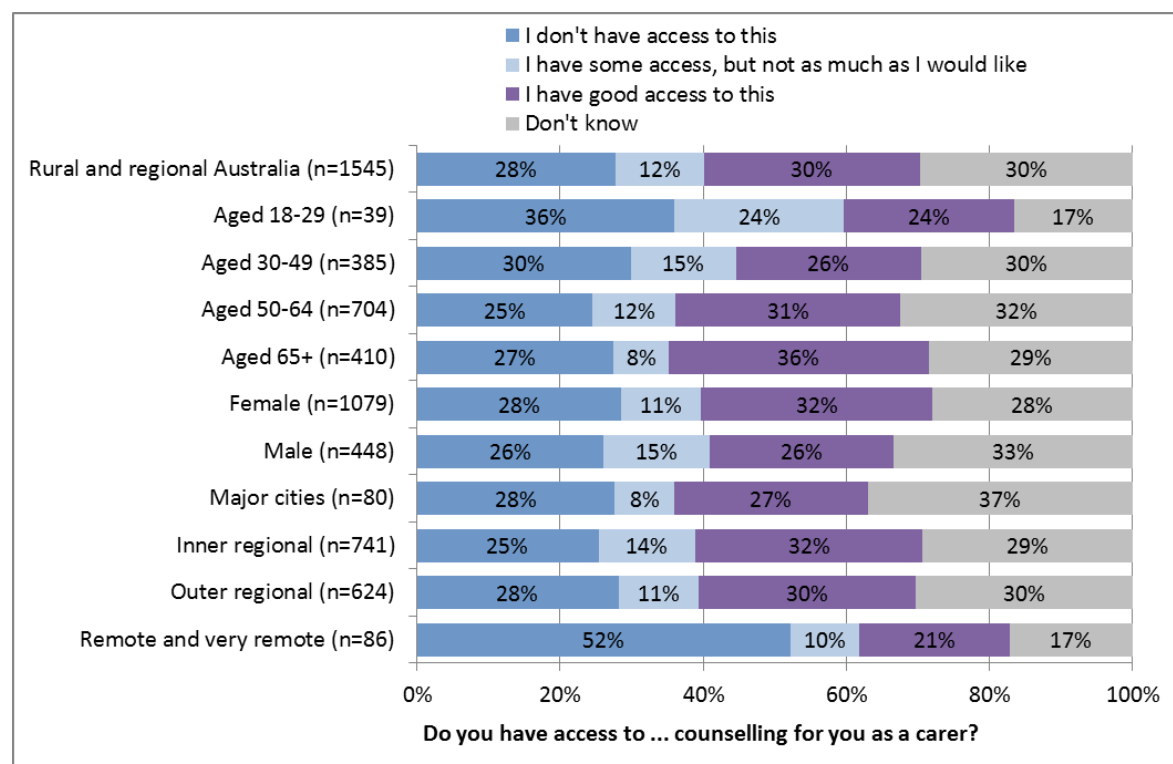


Figure 21 Access to support: counselling for carers

Access to practical home support

Regional carers have widely varying levels of access to practical support around the home in the form of things such as care workers or assistance to help complete domestic work. In total, 36% of regional carers had no access to practical home support, 29% had good access, 22% were unsure if they could get access and 12% had limited access (Figure 22). Younger carers were least likely to report having this type of assistance: 45% of carers aged 30-49 had no access to practical home support compared to 26% of carers aged 65 and over. More than two in five carers aged 65 and over (43%) had good access to practical home support, compared to only 19% of carers aged 30-49. Female carers were more likely than male carers to report having no access to this type of support (39% compared to 29%). In remote and very remote regions, the majority of carers – 59% - had no access to practical home support, and only 18% had good access.

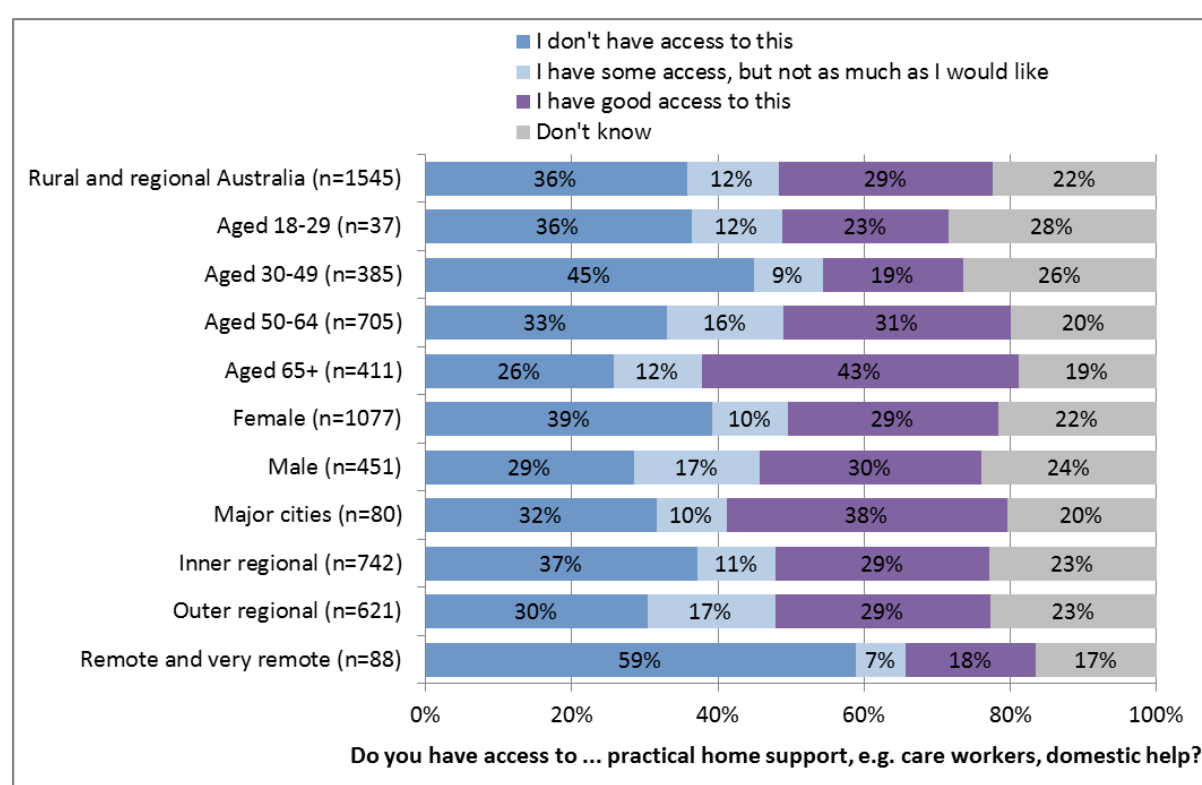


Figure 22 Access to support: home support

Access to carer advice and information

Having access to advice and information on things such as how to access support services and assistance for carers is important. In total, 37% of carers felt they had good access to this type of advice, while 22% felt they had no access, 21% were unsure (likely due to not having recently sought advice or information), and 19% had limited access (Figure 23). Carers aged under 50 were less likely to feel they had access to information, with only 26% of those aged 30-49 reporting having good access compared to 44% of those aged 50-64 and 47% of those aged 65 and older. Those living in remote and very remote regions also reported poor access, with 45% reporting having no access to information and advice, and only 28% having good access.

The differences in access to information and advice may in part reflect differing availability of information for people with different caring needs: older carers who are most commonly taking care of ageing partners were more likely to have good access to information and advice. This age group may also be better targeted by information providers compared to younger carers.

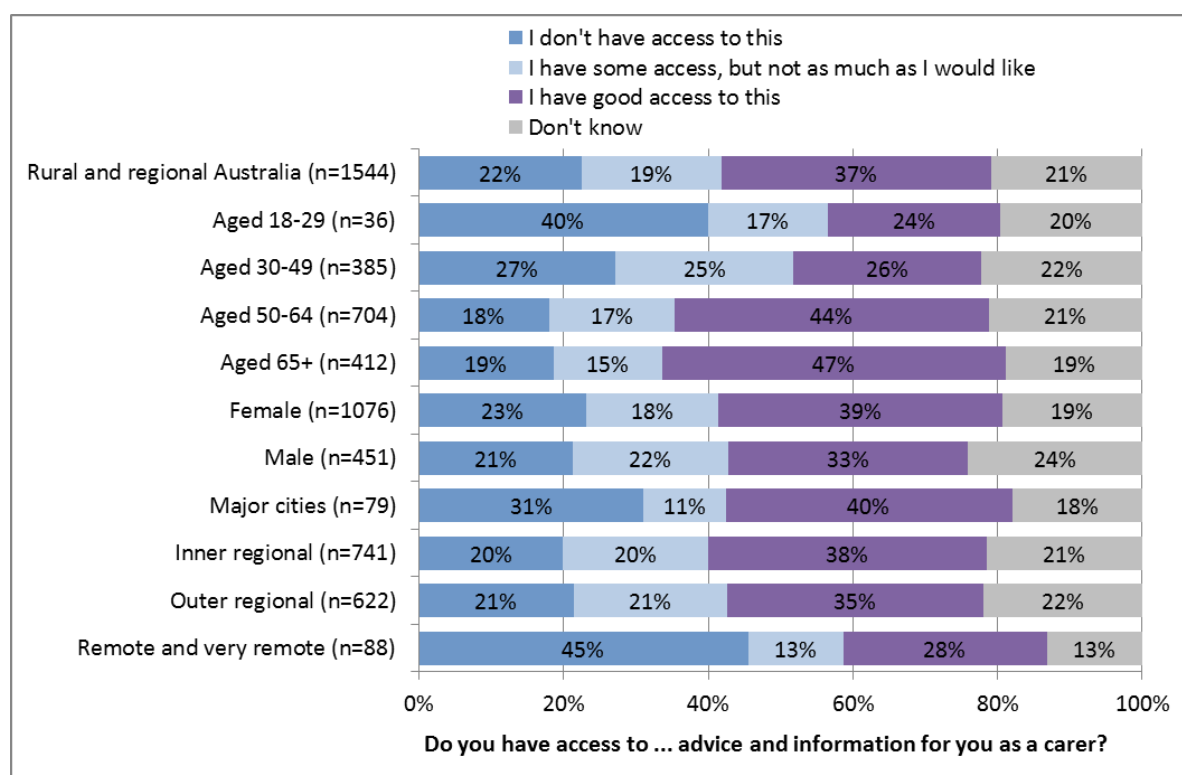


Figure 23 Access to support: Advice and information for carers

Access to financial support

Carers were asked if they had access to financial support for their carer role, for example in the form of a carer's pension, or assistance provided for care as part of a National Disability Insurance Scheme plan for the person they cared for. Half of carers (50%) had no access to financial support for their caring role; 16% had good access, 14% limited access, and 21% were unsure, likely due to not having sought financial assistance (Figure 24). Similar rates of access were reported by most groups, with the exception of carers in remote and very remote regions, who reported significantly poorer access, with 62% having no access. The youngest group of carers, 18-29 year olds, also reported very poor access, but included only a very small sample of carers so may not be representative.

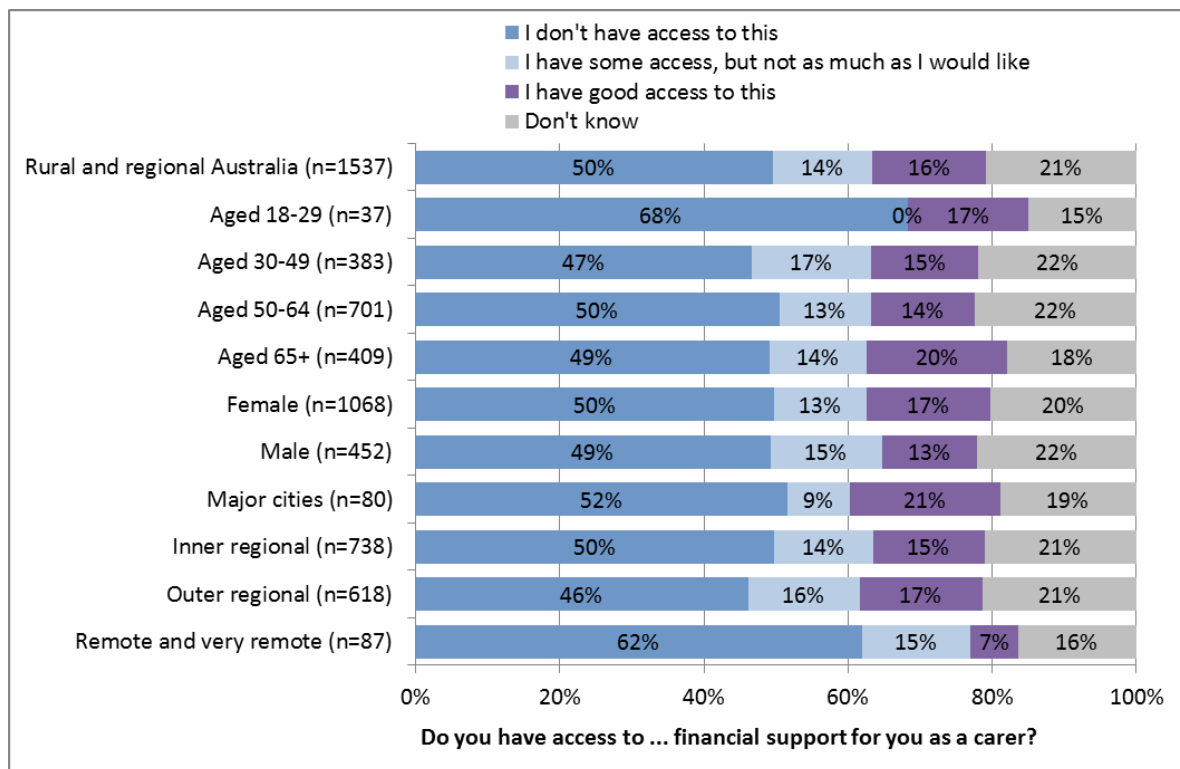


Figure 24 Access to support: financial support for carers

Access to support from family and friends

Support from family and friends can make an important difference to the experience of being a carer. While 44% of carers had good support from family or friends, 30% had limited support, and 21% had no support (Figure 25). Carers living in remote and very remote regions reported the lowest levels of support, with 36% having no access to support from family or friends, and only 32% good access. When age groups were compared, those aged 30-49 reported having less support from family or friends than other groups of carers, with only 38% having good access to this type of support, and one in four (25%) having no access to support from family or friends. Carers aged 65 and over reported the highest levels of support from family or friends: 52% had good support and only 19% had no support.

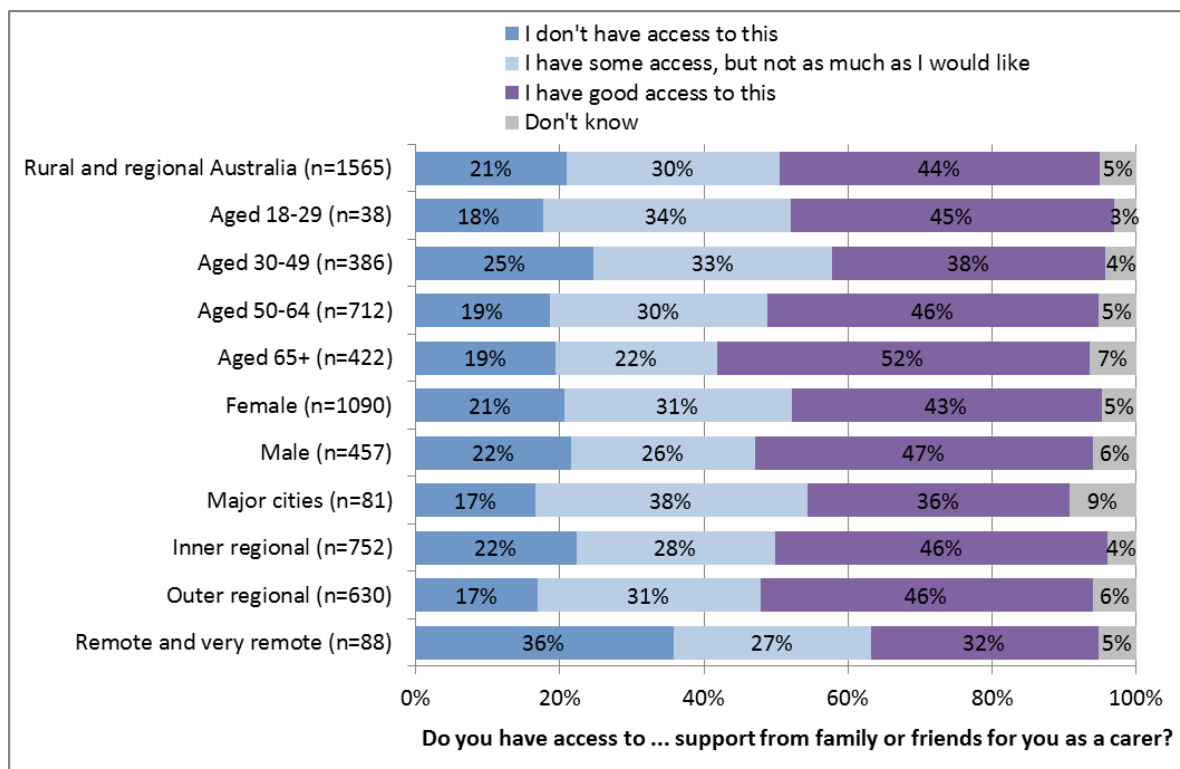


Figure 25 Access to support: supportive family or friends

Income and household finances

Previous sections of this report identified that 42% of carers had experienced financial stress due to their role as a carer, and 35% had reduced or stopped work. This highlights the importance of understanding the financial wellbeing of carers. This was examined by asking carers:

- Their household income in the 2015-16 financial year
- To rate their overall household financial wellbeing, from poor to prosperous
- Whether they had experienced any of a number of types of financial stress in the last year, such as being unable to pay bills on time, or going without meals.

Household income

Survey participants were asked to identify which category their household income fell into in the 2015-16 financial year. Household income was defined as including salaries, wages, investment income and income from pensions and allowances, for all people living in the survey respondent's household. On average, carers reported lower household income than non-carers: 28% of carers had a household income of less than \$31,200 in 2015-16, compared to only 22% of non-carers. Only 41% of carers had household income above \$62,400 compared to 55% of non-carers (Figure 26). Older carers were most likely to report an income below \$62,400.

Household income is often not a very informative measure of financial wellbeing: the same amount of income can mean very different things to people at different stages of life. For example, a household with a large mortgage and several dependent children is likely to need a higher household income to cover basic living expenses compared to a household with no dependent children and in which the home is owned outright.

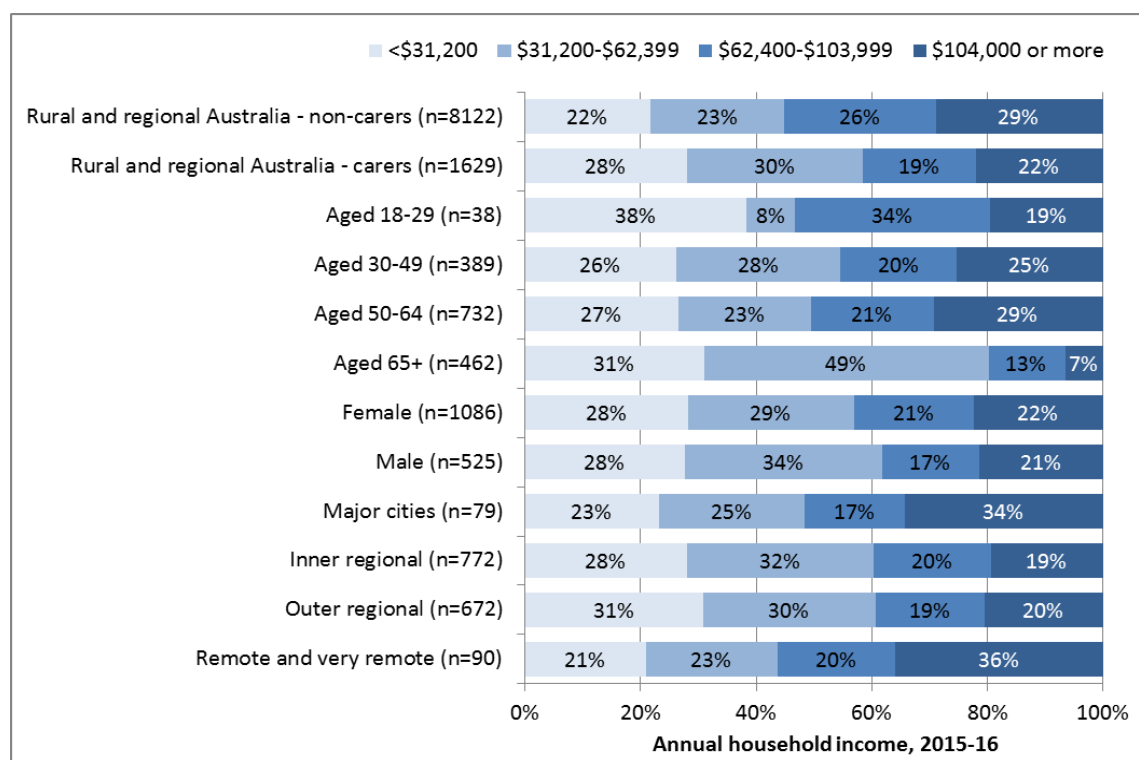


Figure 26 Annual household income in 2015-16, reported by carers and non-carers

Household financial wellbeing

To gain a better understanding of household finances that took into account both income and financial obligations, survey participants were asked 'given your current needs and financial responsibilities, would you say that you and your family are (i) very poor, (ii) poor, (iii) just getting along, (iv) reasonably comfortable, (v) very comfortable or (vi) prosperous.

Carers were much more likely than non-carers to report they were very poor, poor or just getting along, with 49% of carers reporting this compared to only 35% of non-carers (Figure 27). Despite having lower household income, carers aged 65 and older were more likely than other carers to report being reasonably comfortable, very comfortable or prosperous (55% compared to only 29% of those aged 30-49). Only 33% of those aged 65 and older reported being very poor, poor or just getting along, compared to 64% of those aged 30-49. There were fewer differences between regions and carers of different genders, although those in major cities were less likely to report being poor/just getting along than those in regional and remote areas.

These findings highlight that despite earning higher household income on average, the often higher financial commitments of carers aged under 50, such as mortgages and childcare and schooling costs, mean they are more likely to be experiencing financial stress than older carers.

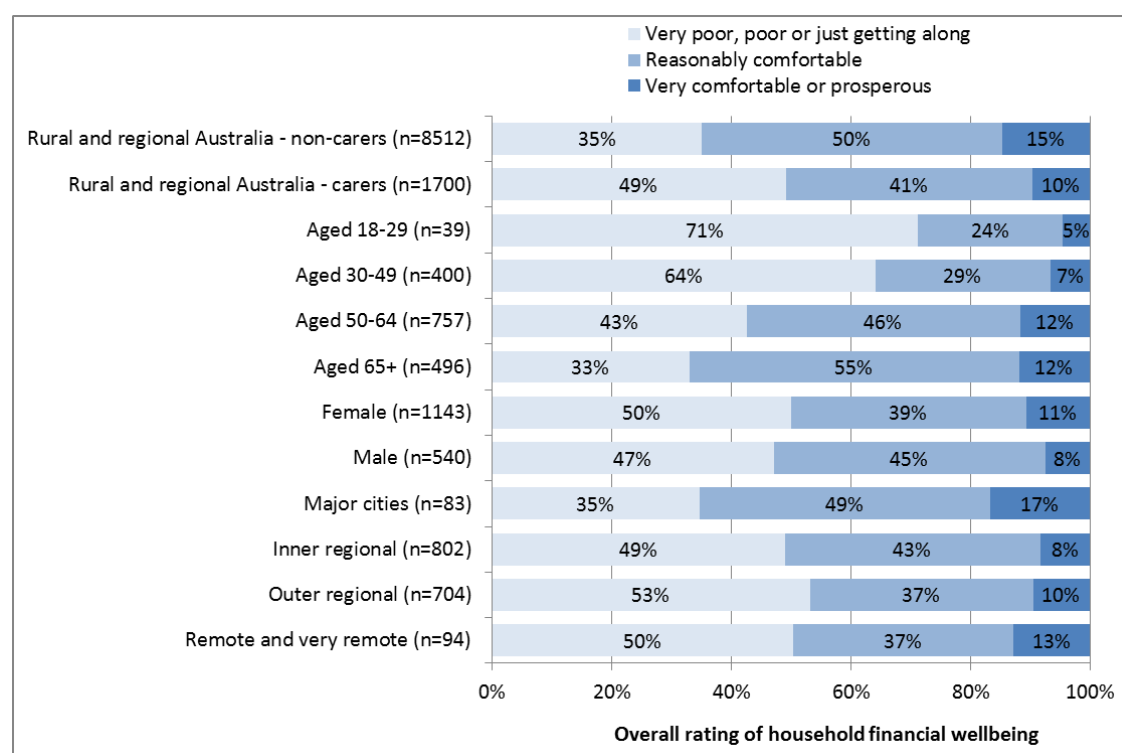


Figure 27 Self-rated household financial wellbeing

Financial stress events

Survey participants were asked if any of the following happened to them in the last year because they didn't have enough money:

- Had to delay or cancel non-essential purchases e.g. holidays, going to a restaurant or movie, buying clothes
- Could not pay bills on time e.g. electricity, rent, gas
- Went without meals, or was unable to heat or cool home
- Asked for financial help from friends or family
- None of these.

If a person had experienced more than one of the four types of financial stress asked about, they could select all those they had experienced.

Carers were much more likely than non-carers to have experienced each of the financial stress events asked about (Figure 28):

- 48% of carers had delayed or cancelled non-essential purchases in the last year, compared to 36% of non-carers
- 29% of carers had not been able to pay one or more bills on time, compared to 18% of non-carers
- 18% of carers had asked for financial help from friends or family, compared to 13% of non-carers
- 13% of carers had gone without meals or been unable to heat or cool their home, compared to 7% of non-carers.

When different groups of carers were compared, those aged under 50 were more likely to report experiencing all four types of financial stress event, and those aged 65 and over least likely to. Carers aged under 50 were more than twice as likely as older carers to have been unable to pay bills on time (51% of those aged 30-49 compared to 8% of those aged 65 and older), gone without meals or been unable to heat or cool their home (20% compared to 6%), or asked for financial help from friends and family (28% compared to 6%). This suggests a strong age-related experience of financial stress amongst carers.

Female carers reported higher incidence of all four types of financial stress than male carers: 33% of female carers had been unable to pay some bills on time in the last year, compared to 20% of male carers.

Carers living in outer regional, remote and very remote areas were more likely than other carers to report delaying or cancelling non-essential expenses, being unable to pay bills on time, and asking for financial help from friends or family. The incidence of financial stress increased with remoteness.

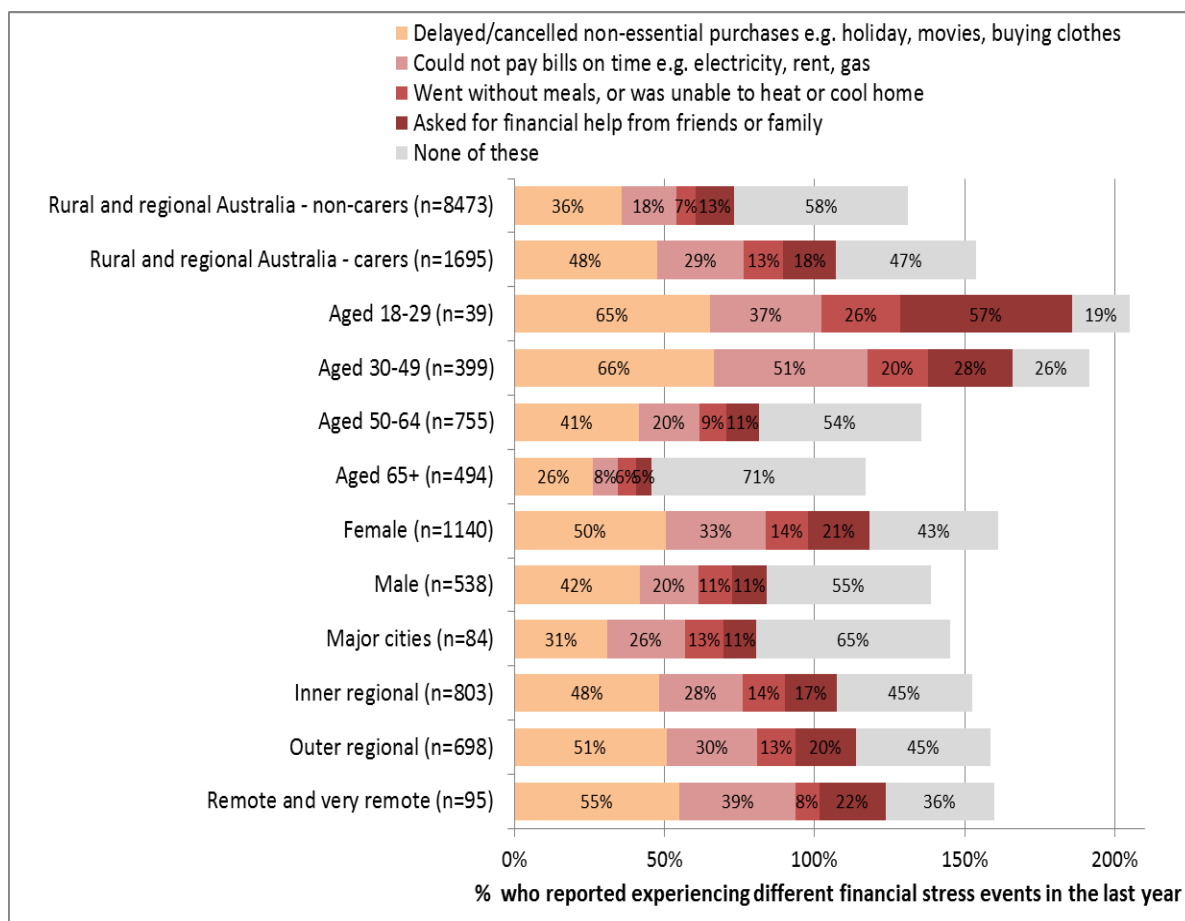


Figure 28 Financial stress events experienced in the last year

Wellbeing of regional carers

Multiple previous studies have found that carers on average report poorer wellbeing and health compared to non-carers. 'Wellbeing' here is a term used to refer to the overall quality of life reported by a person, sometimes defined as:

a state ... in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community. (World Health Organization, 2013)

Many factors contribute to a person's overall wellbeing, including their safety and security, their physical and mental health, their relationships and social networks, their access to goods and services, and the fairness of the society they live in, amongst others (Wilkinson and Marmot 2003). When considering wellbeing, it is important to identify both those people experiencing 'positive' wellbeing – in other words, those people with high levels of wellbeing – and those who are experiencing poor wellbeing, sometimes called 'illbeing'.

Many measures are used to examine wellbeing. The wellbeing of carers and non-carers was compared using the following measures of wellbeing:

- 'Hedonic' measures: These measures examine how pleasant or satisfying life is for a person
- 'Eudaimonic' measures: These examine how meaningful and worthwhile a person finds their life
- 'Distress' measures: These examine the level of distress a person is experiencing, and are a measure of 'illbeing'.

Each of these measures of wellbeing matters: for example, a person can feel their life is pleasant but that some aspects of it lack meaning or are distressing. Each therefore provides different insight into which carers are experiencing good versus poor wellbeing.

Wellbeing – Global Life Satisfaction

The first wellbeing measure, 'global life satisfaction', measures satisfaction with life, or hedonic wellbeing. This simple measure of overall quality of life has been shown in multiple studies to be correlated with both physical and mental health outcomes, despite measuring quality of life rather than health (Smith et al. 1999).

What was measured?

Global life satisfaction is measured using a single item that asks respondents to indicate how satisfied they are with their 'life as a whole', a measure used widely in wellbeing surveys in Australia and internationally. Responses are recorded on a scale ranging from 0 (not at all satisfied) to 10 (very satisfied). In this hedonic measure of wellbeing, the person answering the question is not asked to identify which aspects of their life they are more or less satisfied with, but instead to give an overall rating of satisfaction. The 11 point scale is generally accepted as user-friendly while having higher sensitivity to a person's differing levels of wellbeing than five or seven point scales (Cummins, 2003). When reporting this measure, scores have been multiplied by 10 to adjust the scale to a measure from 0 to 100.

Findings

Carers had consistently and significantly poorer wellbeing than non-carers (Figure 29). This was the case for all groups of carers who were compared, although in some cases the difference was not statistically significant. The wellbeing 'gap' between carers and non-carers was most significant for carers aged under 50, particularly the 30-49 age group. This group of carers both reported the lowest overall wellbeing of any of the groups compared, and had the largest wellbeing 'gap' between carers and non-carers. Female carers and male carers reported similar levels of wellbeing, while women who weren't carers reported significantly higher wellbeing than either male non-carers or carers. The older a person was, the less difference there was in the wellbeing of carers versus non-carers.

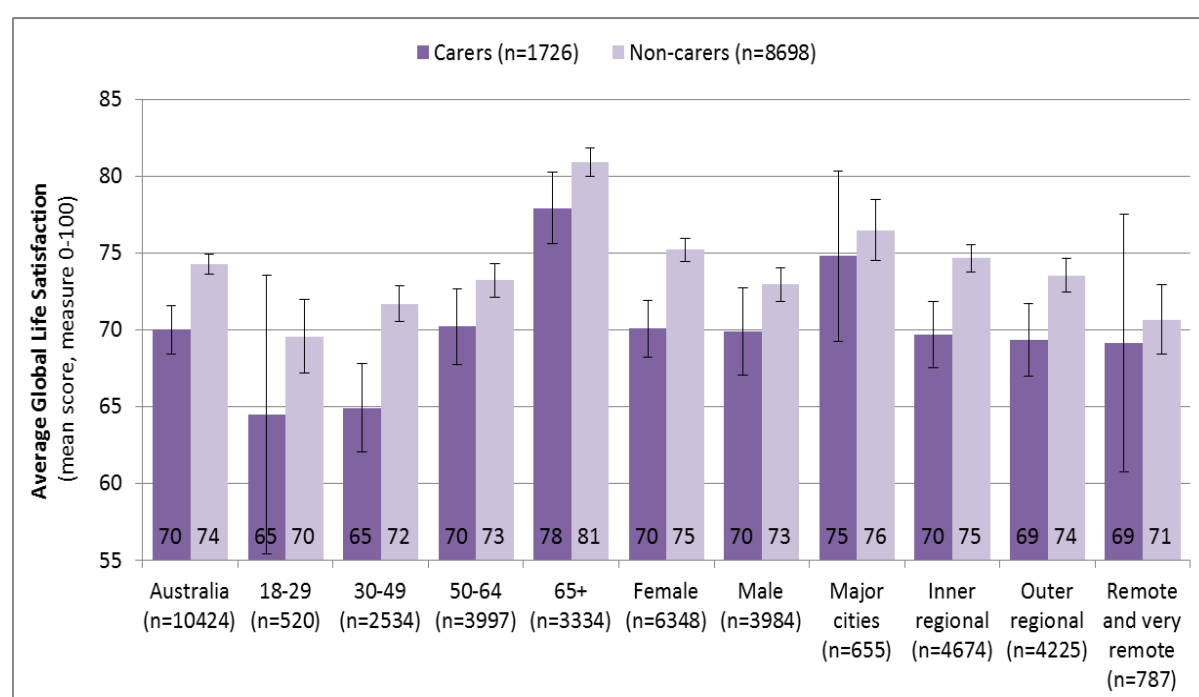


Figure 29 Wellbeing: Comparison of Global life satisfaction scores of carers and non-carers

Wellbeing – Feeling life is worthwhile

The second measure of wellbeing examined how meaningful people find their lives, which can differ from their overall satisfaction.

What was measured?

The 'worthwhileness' wellbeing measure is a eudaimonic measure of wellbeing that examines how meaningful a person is finding their life. This measure is different to satisfaction, as it is possible for a person to feel dissatisfied with their life but also that they are achieving meaningful things. The measure is based on a person's response on a scale of 0 (not at all) to 10 (completely worthwhile) to the question 'Overall, to what extent do you feel the things you do in your life are worthwhile?' This measure has been less widely used than the other wellbeing measures examined in this report, but has been found to differ to other wellbeing measures (OECD, 2013).

Findings

Overall, carers were slightly less likely to find their lives meaningful than non-carers, although the difference was only just statistically significant, and only for female carers and for those aged 30 to

49. Carers aged 50 and over reported very similar levels of eudaimonic wellbeing to non-carers, and it was carers in the 30-49 year age group who reported the poorest levels of eudaimonic wellbeing (Figure 30). This finding suggests that while their overall satisfaction with life is lower, most carers experience only slightly lower meaningfulness of their lives compared to non-carers.

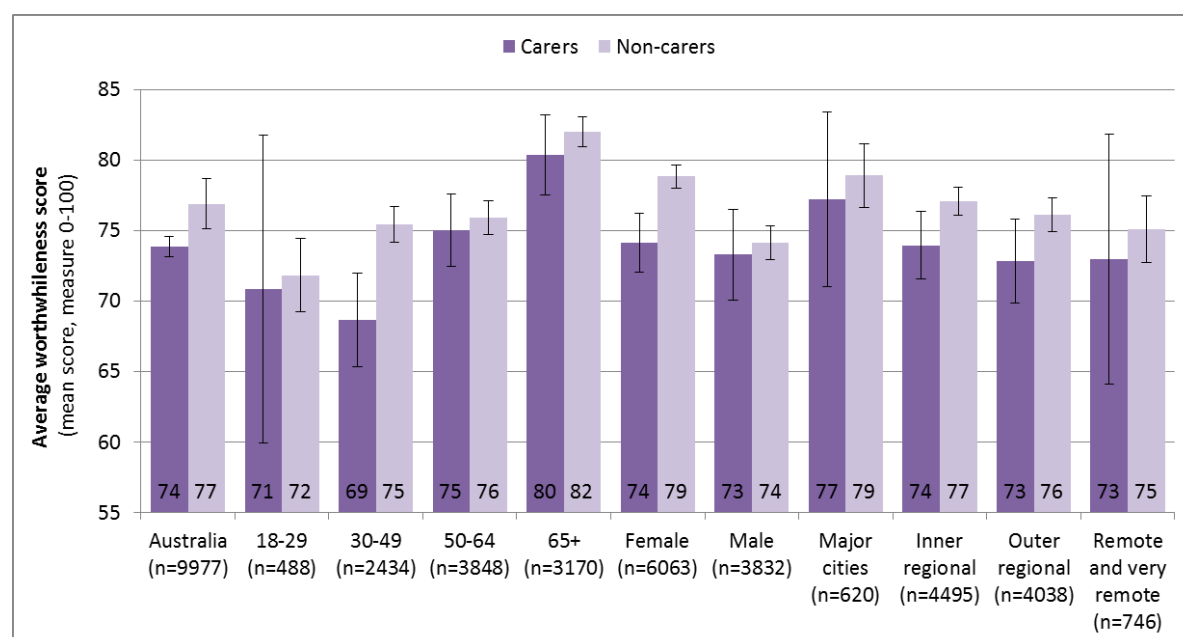


Figure 30 Wellbeing: Comparison of 'Feeling life is worthwhile' scores of carers and non-carers

Illbeing – Psychological distress

Psychological distress is an important measure of 'illbeing'. High distress is an indicator of potentially poor mental health outcomes.

What was measured?

Psychological distress was measured using the Kessler 6 item psychological distress measure (K6). The K6 is designed to measure non-specific symptoms of psychological distress. Scores are derived from six questions about anxiety and depression in which the respondent is asked '*in the last four weeks, how often have you felt... (i) nervous, (ii) hopeless, (iii) restless or fidgety, (iv) depressed, (v) that everything was an effort, and (vi) worthless*'. Respondents are able to identify whether they felt each of these ways none of the time (1), a little of the time (2), some of the time (3), most of the time (4), or all of the time (5). Scores for the six measures are added to give a total score ranging from 6 to 30, with higher scores indicating higher distress. A score of 19 or above has been identified in previous studies as indicating a high likelihood that a person has a serious mental illness (Kessler et al. 2010).

Findings

A significantly higher proportion of carers reported high psychological distress levels compared to non-carers: 14% of carers reported distress levels above the threshold considered to indicate probable serious mental illness, compared to 9% of non-carers (Figure 31). Rates of distress varied substantially between age groups and genders, but were similar across regions. Carers aged under 50 reported much higher levels of distress compared to those aged over 50: 23% of carers aged 30 to 49 had high distress levels, compared to 12% of non-carers in this age group. This compared to

10% of 50-64 year old carers (not significantly different to the 8% of non-carers in this age group with high distress), and 4% of carers aged 65 and over (not significantly different to the 3% of non-carers in this age group). Male carers and non-carers did not report significantly different levels of distress. A significantly higher proportion of female carers reported high distress (15%) when compared to women who were not carers (8%).

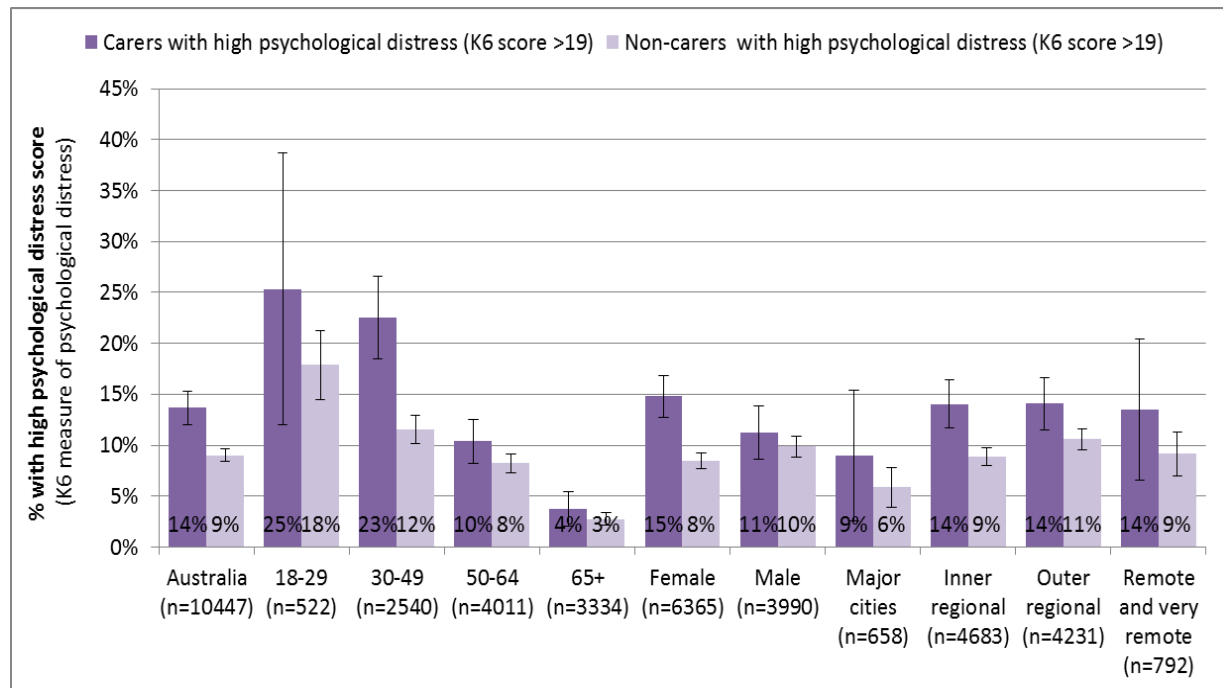


Figure 31 Illbeing: Comparison of psychological distress scores of carers and non-carers

Wellbeing – Personal Wellbeing Index

The Personal Wellbeing Index (PWI) is a measure of satisfaction with life. While it is a hedonic measure, similar to global life satisfaction, it is measured differently to global life satisfaction. Instead of asking a person to rate their overall satisfaction with their life, the PWI asks them to evaluate how satisfied they are with several different aspects of their life, and then averages these to provide an overall rating of subjective wellbeing.

What was measured?

The PWI was developed in Australia by researchers based at the Australian Centre on Quality of Life. Detailed information about its measurement and use can be found at

<http://www.acqol.com.au/iwbg/wellbeing-index/>. Survey participants are asked how satisfied they are with the following aspects of their life: (i) your standard of living, (ii) your health, (iii) what you are currently achieving in life, (iv) your personal relationships, (v) how safe you feel, (vi) feeling part of your community, and (vii) your future security. A mean score is then calculated. This produces a measure which ranges from 1 to 99 after removing extreme measures (International Wellbeing Group, 2013). In addition to the overall measure, it is possible to analyse each individual item, to better understand which aspects of their life a person is more and less satisfied with.

Findings

When the overall PWI score was examined, findings were very similar to the global life satisfaction measure, but more pronounced: there was a bigger ‘wellbeing gap’ between carers and non-carers when wellbeing was measured using the PWI than when it was measured using the single ‘global life satisfaction’ measure, with carers reporting poorer wellbeing compared to non-carers. As with other measures, while carers consistently reported lower levels of wellbeing than non-carers, and these differences were statistically significant across the whole population of carers, when individual groups of carers were examined the differences were largest and statistically significantly for specific groups of carers: those aged under 50, women, and those living in inner regional and outer regional areas (Figure 32). It is likely that the differences between wellbeing for other groups would be statistically significant if a larger sample of carers was examined.

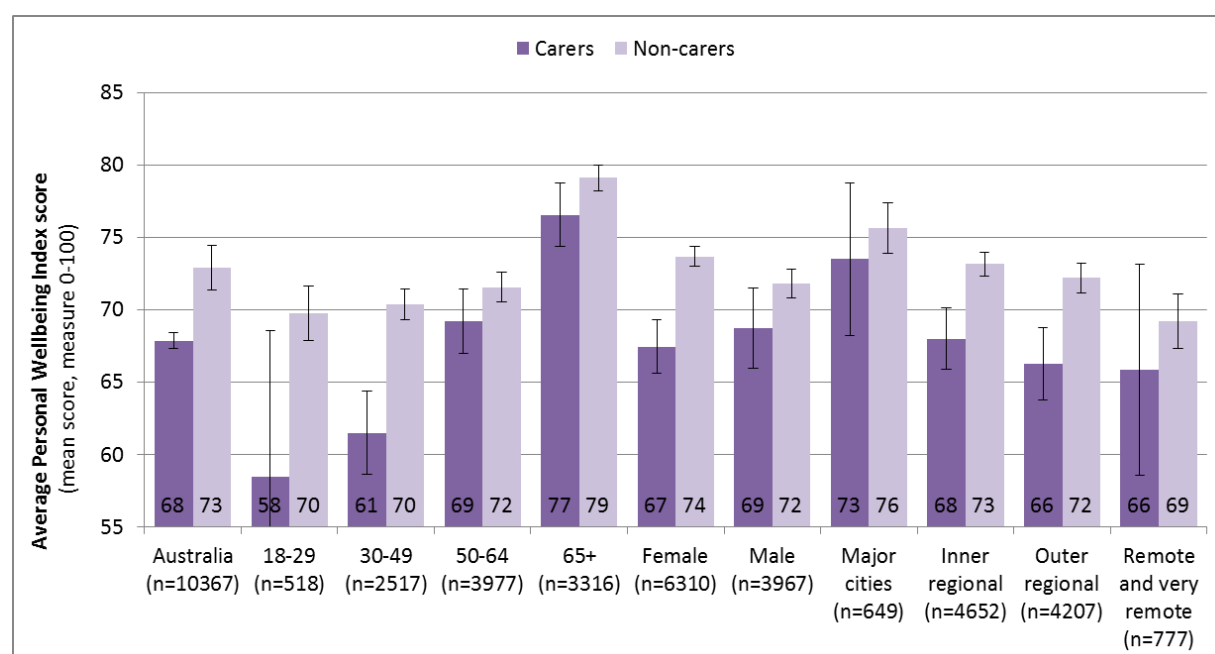


Figure 32 Wellbeing: Comparison of Personal Wellbeing Index scores of carers and non-carers

By comparing individual components of the Personal Wellbeing Index, it was possible to identify the aspects of life for which there were the greatest differences between carers and non-carers. Overall, both carers and non-carers had similar patterns in their responses to the seven individual items that make up the PWI (Figure 33): they were most likely to feel satisfied with how safe they felt, their personal relationships, and their standard of living; and less likely to be satisfied with feeling part of the community, what they are currently achieving in life, their health and future security. The differences between carers and non-carers were greatest for (i) health (carers had a score on average 6.6 points lower than non-carers), (ii) future security (difference of 5.9 points), (iii) standard of living (5.7 points), and (iv) what the person was achieving in life (5.7 points).

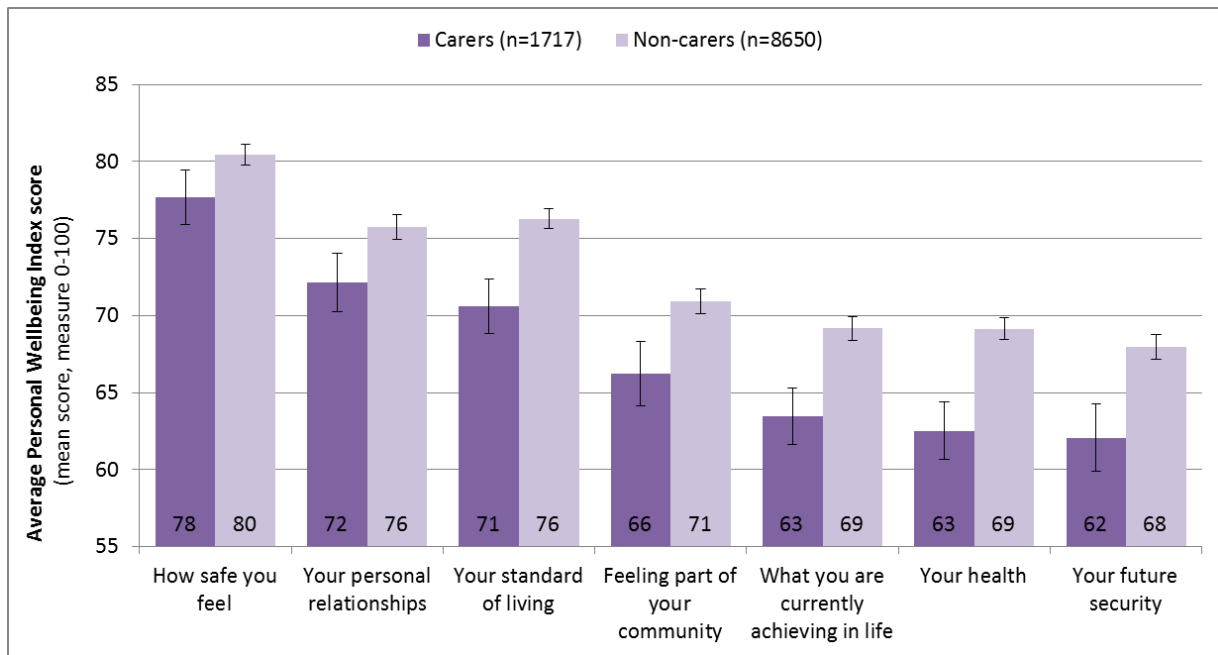


Figure 33 Comparison of scores for individual components of the Personal Wellbeing Index – all regional Australian carers and non-carers

Some of these factors varied depending on the type of carer involved. Figures 34 and 35 compare individual components of the PWI by group. Key differences included that:

- Carers aged under 50 had the largest ‘wellbeing gap’ between carers and non-carers, as well as the lowest scores overall, for most individual wellbeing items. The ‘wellbeing gap’ between carers and non-carers was largest for satisfaction with standard of living, feeling part of the community, sense of achieving things in life, health, and future security
- Carers aged 50 and older reported lower wellbeing than non-carers in the same age groups on most measures, but the difference was smaller than for carers aged under 50
- Female carers reported significantly poorer satisfaction with their future security, safety, and relationships compared to non-carers and male carers. They also had a larger gap between carers and non-carers for life achievement and health, however this was largely due to the overall higher satisfaction of female non-carers compared to male non-carers
- Carers living in remote and very remote regions had lower satisfaction with their standard of living than those in other regions, and satisfaction with future security decreased with remoteness, being poorer the more remote a region a carer lived in.

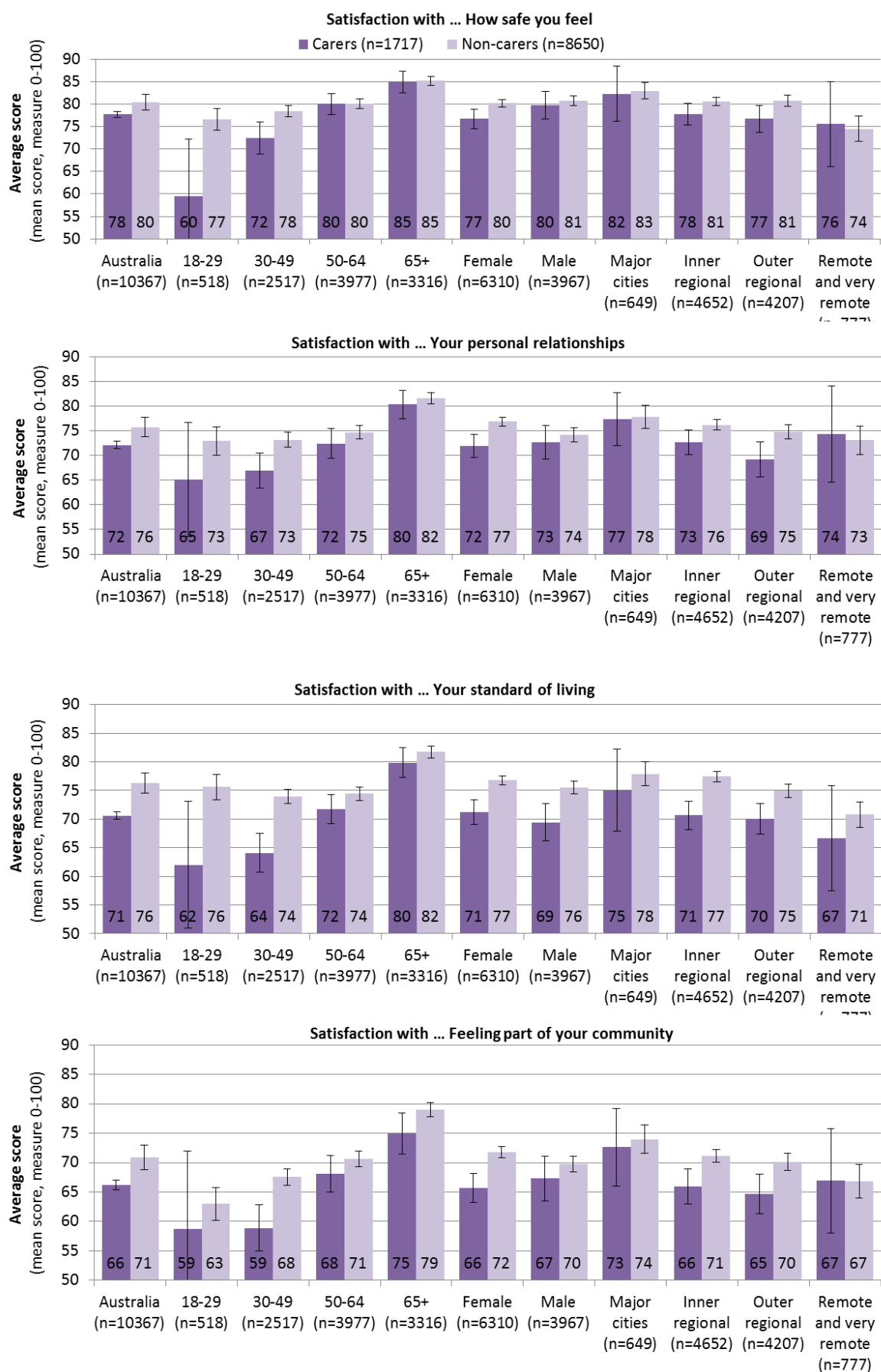


Figure 34 Comparison of scores for individual components of the PWI – by group (i)

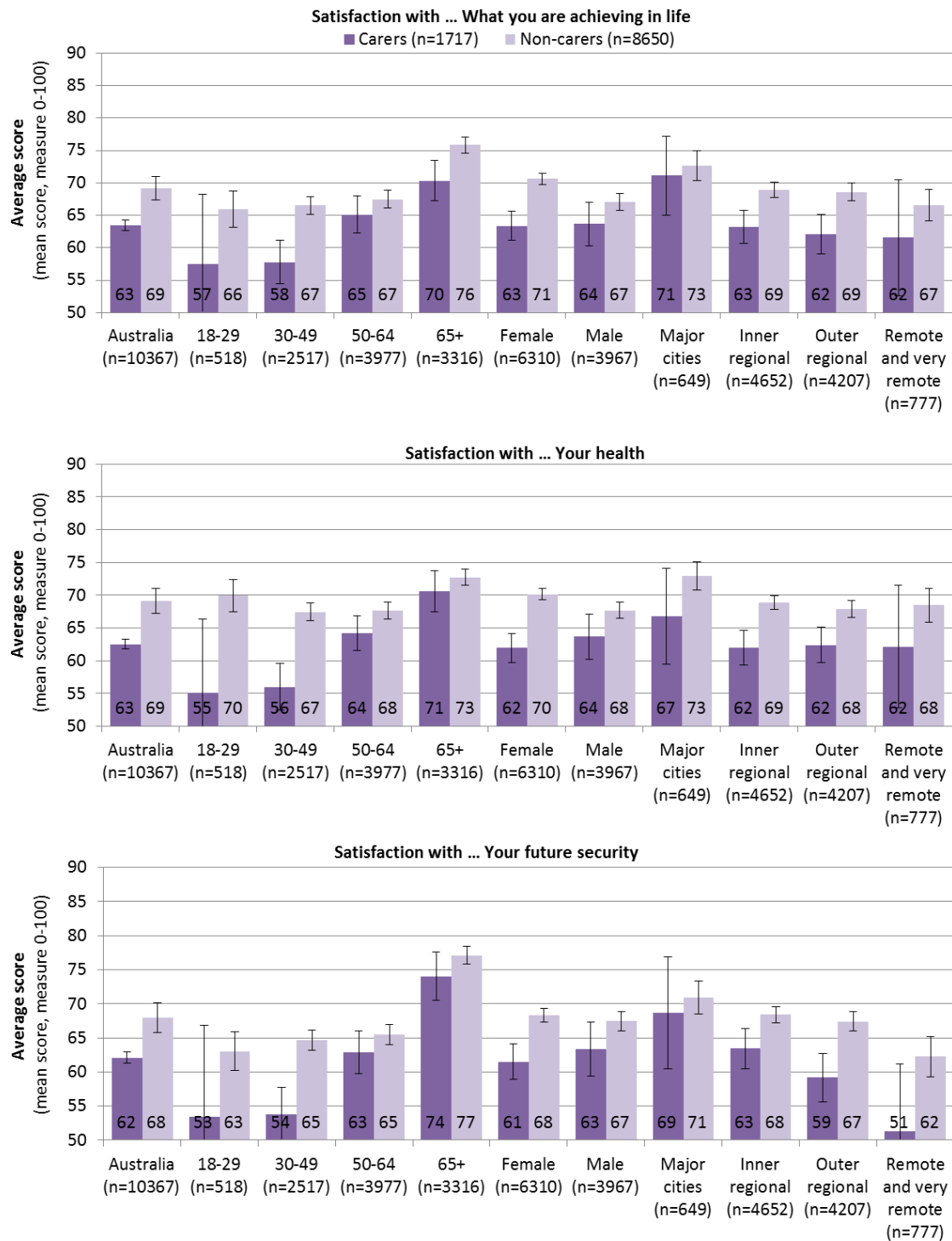


Figure 35 Comparison of scores for individual components of the PWI – by group (ii)

Caring obligations and wellbeing

In many cases, the differences between carers of different ages and gender, and those living in different location, may be due to factors such as differences in the time they spend on their caring responsibilities, and their access to support. To better understand this, the wellbeing of carers was compared based on the types of caring they engaged in and types of support they had access to as carers.

Carers who had good access to help reported significantly higher levels of wellbeing compared to those who had no access to help, or who could find help only with difficulty (Figure 36). The difference was large and statistically significant, highlighting the importance of having access to assistance for caring duties.

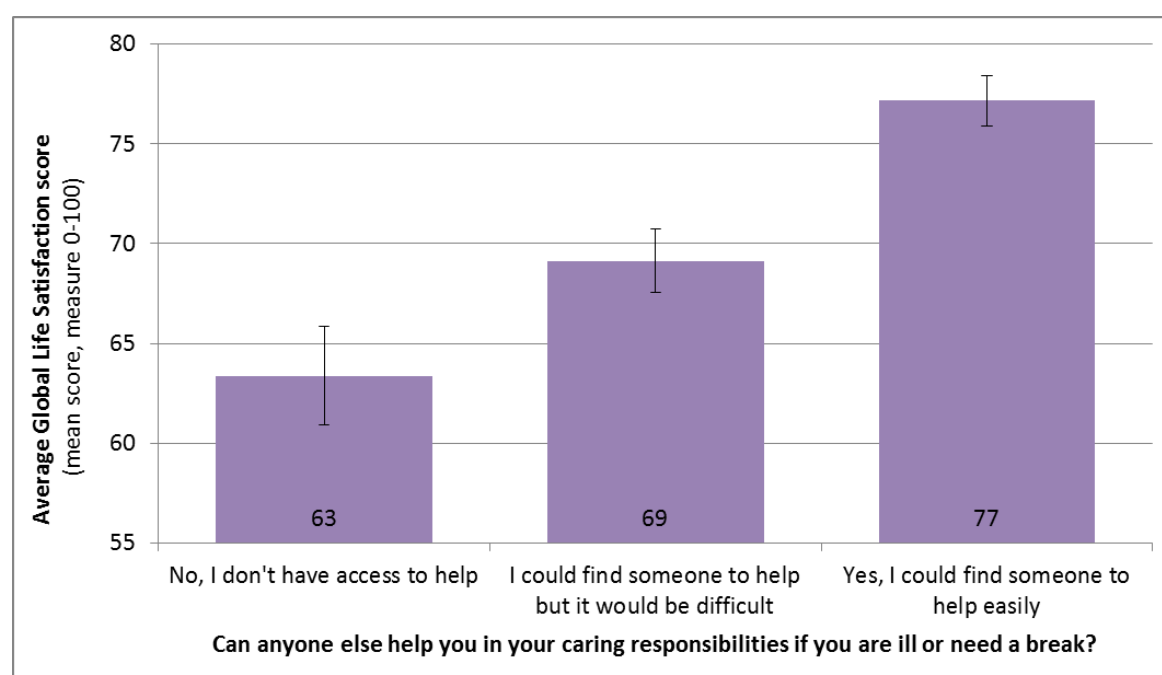


Figure 36 Wellbeing of carers who had no, little and good access to help in their caring role (Global Life Satisfaction)

The wellbeing of carers was also poorer if they spent more hours each week engaged in caring, further reinforcing the importance of carers having access to support. Those who spent less than 15 hours a week caring reported levels of wellbeing similar to the average for all Australians (an average score of 76 compared to 74 for all Australians), whereas wellbeing was significantly poorer than the average Australian for those carers who were engaged in caring activities for 30 or more hours a week (an average score of 69 for those spending 30-44 hours per week engaged in caring, and 66 for those engaged in 45 hours or more per week) (Figure 37).

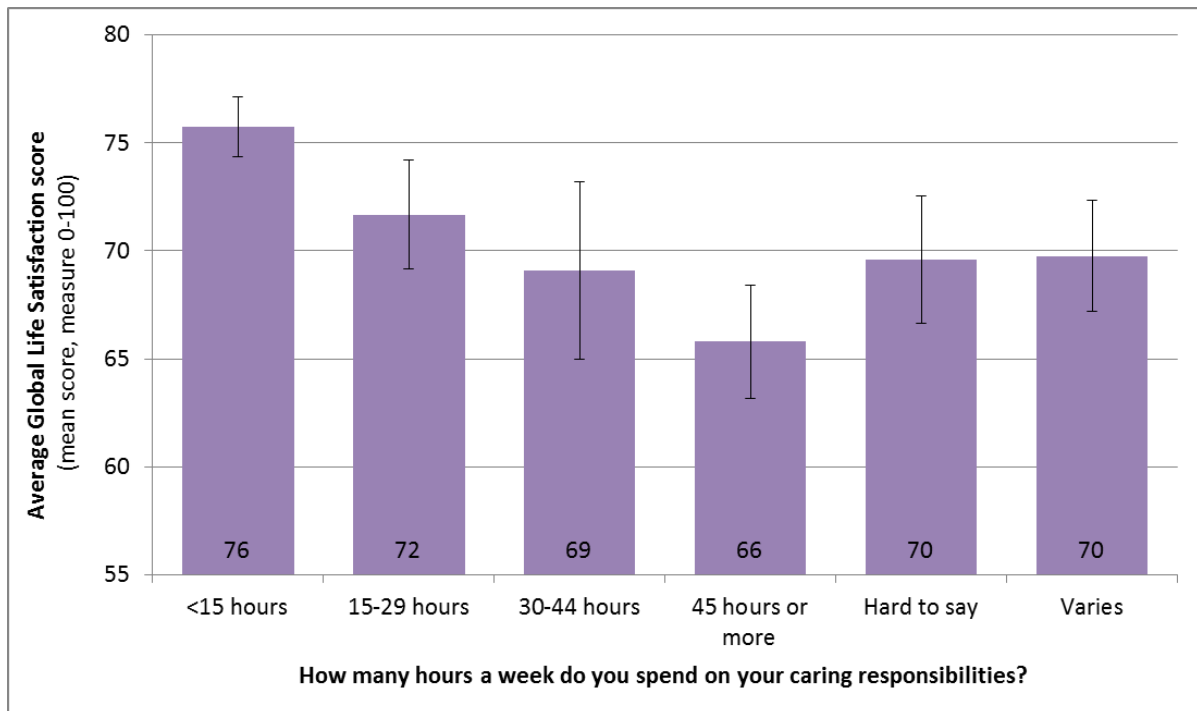


Figure 37 Wellbeing of carers by weekly hours spent caring (Global Life Satisfaction)

The type of caring responsibilities held also matter. Overall, carers who care for those with old age related conditions reported better wellbeing compared to other carers (Figure 38). The poorest wellbeing was reported by those who were caring for people with drug or alcohol addiction or dependency, followed by those caring for people with mental illness. It is important to note that while those caring for people with old age-related needs reported better wellbeing than those caring for people with other needs, their wellbeing was often still below the Australian average.

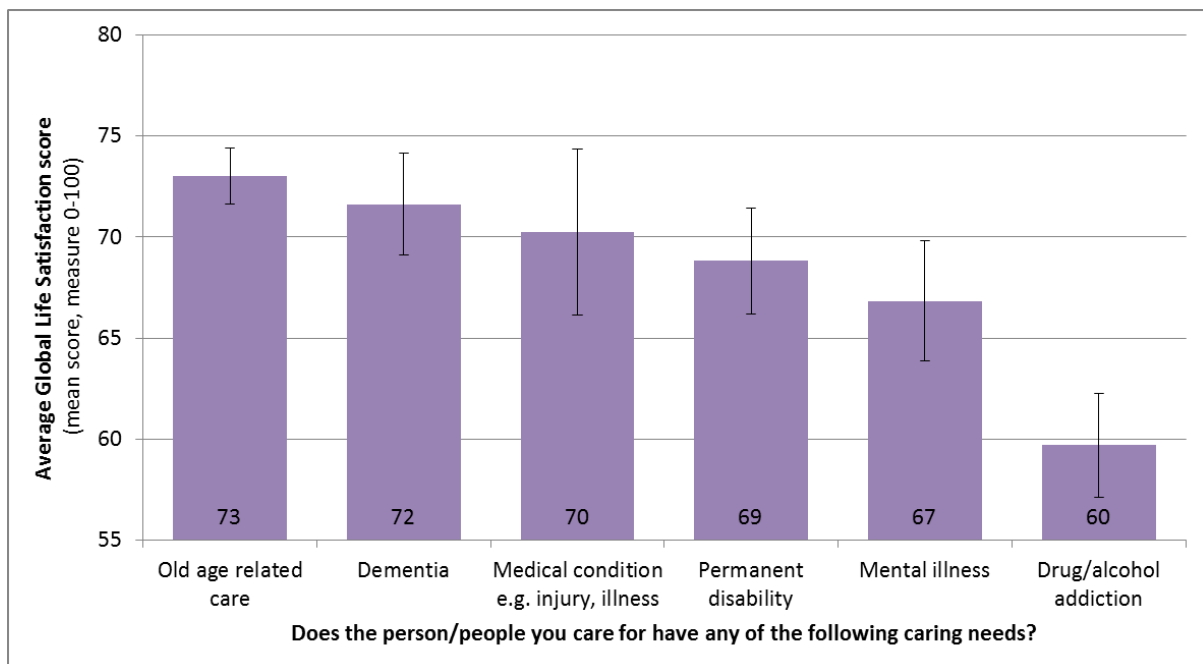


Figure 38 Wellbeing of carers by type of caring responsibility (Global Life Satisfaction)

Having access to specific types of support is also associated with better wellbeing. Carers who had good access to breaks from caring, respite care, a supportive GP, counselling, home support, advice and information, financial support and support from family and friends, all reported significantly better wellbeing compared to those with no or limited access to these supports (Figure 39). The poorest wellbeing was reported by those who had no access to support from family and friends (average wellbeing score of 62 compared to 77 for those with good access), no access to advice or information (score of 65 compared to 76), and no access to regular breaks from caring (65 compared to 76).

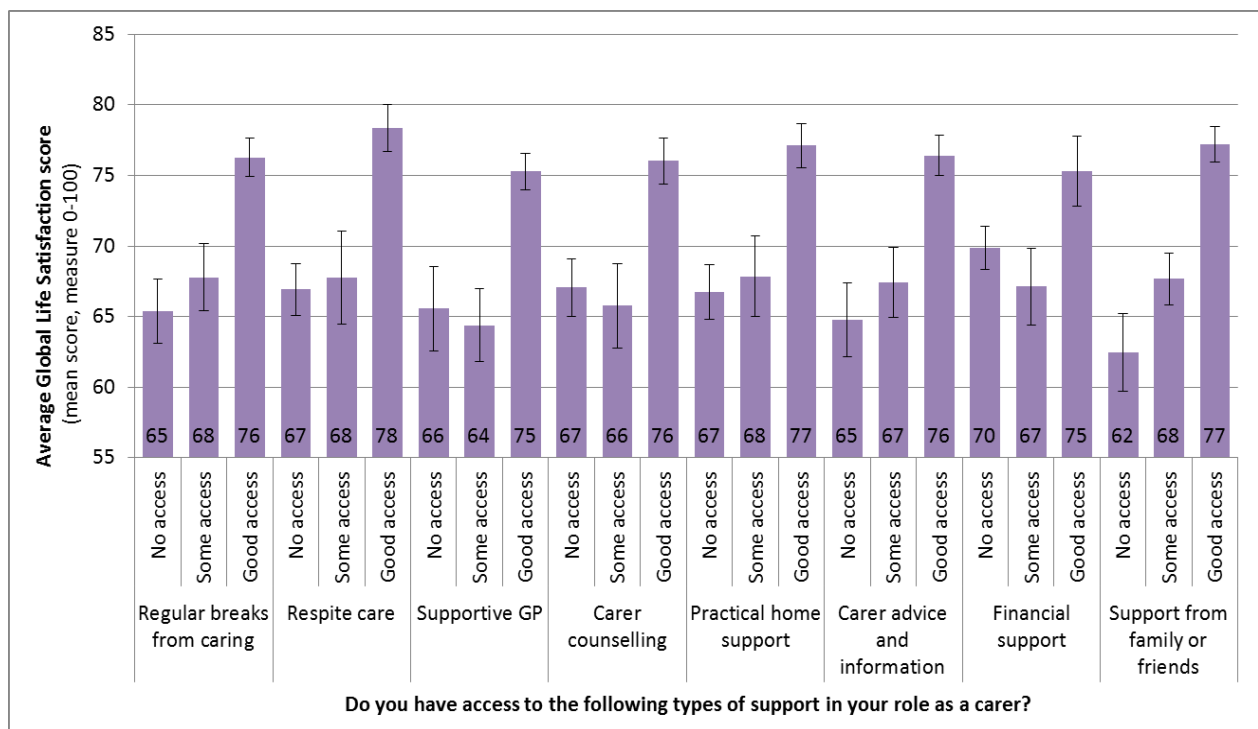


Figure 39 Wellbeing of carers by access to different types of support (Global Life Satisfaction)

The extent to which carers felt their contributions were recognised by others, felt isolated, experienced financial stress, had to reduce or stop work, and were able to socialise, was also strongly associated with their overall wellbeing (Figure 40). Feeling isolated and experiencing financial stress were particularly strongly associated with poorer wellbeing.

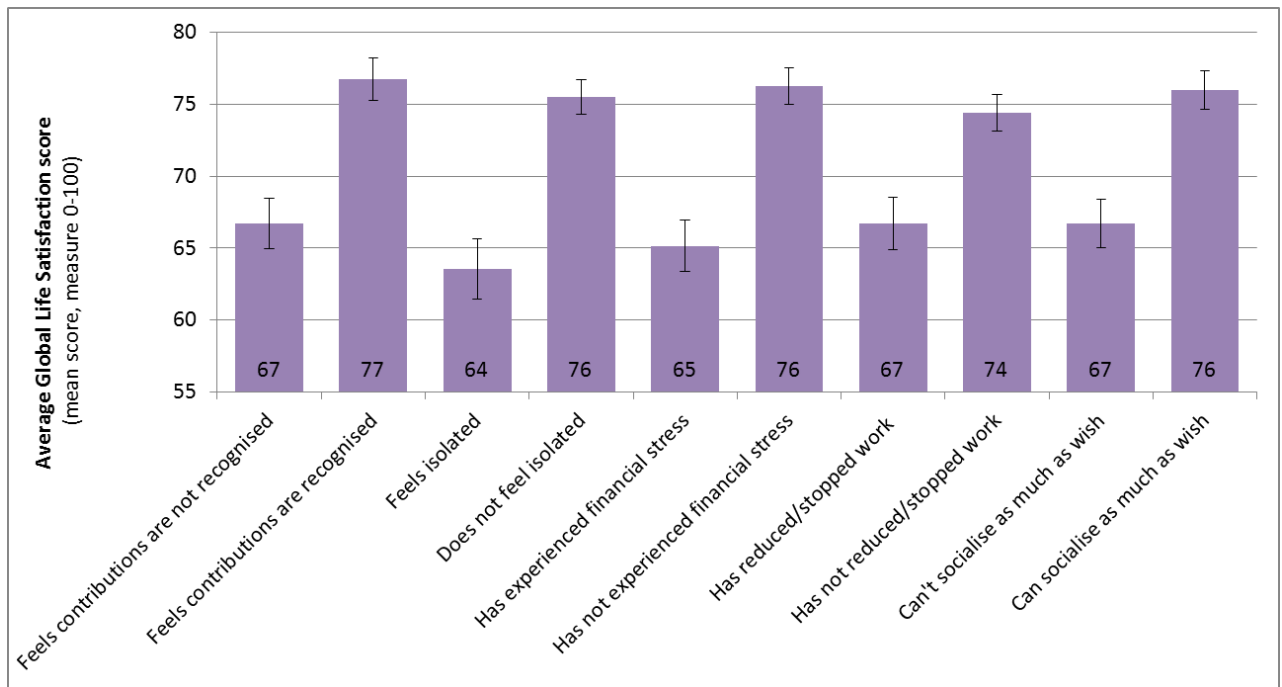


Figure 40 Wellbeing of carers by experience of caring (Global Life Satisfaction)

Discussion and conclusions

This study, consistent with multiple previous studies, found that carers on average have poorer health and wellbeing than non-carers, lower access to financial resources, and that many have little or no access to support in their role as a carer (see for example Gill et al. 2007; Carers NSW 2016). These issues are just as relevant for carers in rural and remote regions as they are for those in urban settings and even more relevant for those living in remote and very remote regions away from town centres, who often have extremely limited access to support services. The findings of this study point to important differences in the experiences of carers of different ages and living in different locations, as well as some gender based differences. These differences are discussed below.

Carers at different life stages

The findings of this study consistently point to a need to better support ‘younger’ carers, defined as those aged under 50. This group of carers has significantly higher incidence of psychological distress, financial stress, social isolation, poor wellbeing, and lack of access to support, compared to carers in older age groups. While multiple previous studies have identified that older carers may experience social isolation (e.g. Winterton and Warburton 2011), this study suggests that while carers as an entire group are more likely to report a range of negative outcomes related to their quality of life, the extent of this is very different across the life span. Older carers, while still reporting often low levels of access to support and poorer wellbeing, as a whole reported a more positive carer experience compared to carers aged under 50.

Multiple factors are likely to be contributing to the more negative experiences of younger carers, and the more positive experiences of older carers. The first is the financial impact of caring at a younger age, when people are typically in a life stage involving high mortgage costs, as well as costs of raising children. Being a carer during this life stage, particularly if it involves reduction in paid work in the household, is associated with much higher incidence of financial stress. The carers most likely to experience financial distress are working age carers aged under 50: this is also the group most likely to report having reduced or stopped work due to their caring responsibilities. This suggests a strong need to identify how to better support carers to maintain employment, as well as ensuring those who are experiencing financial stress due to reducing employment can access support. Previous studies have identified that decisions around engaging in work versus accessing government support are often difficult for carers, due to the often complex rules that govern when and what level of government support a carer is eligible for (Arksey and Glendinning 2010). Carers have to make challenging decisions about whether they can cope better with competing demands of the hours required of them in their caring and work responsibilities, versus the household income they can achieve with differing levels of each.

Younger carers also typically have a different type of caring responsibility. Those aged under 50 are more likely than older carers to be caring for people with mental illness or with a permanent disability other than mental illness or dementia. They are also more likely to be caring for more than one person, and on average report spending more hours each week engaged in caring-related activities, compared to older carers. This appears to be associated with higher caring burden and poorer wellbeing. Older carers, meanwhile, are more likely to be caring for someone with age-related illness or frailty (a parent or a partner); while still challenging and associated with poorer wellbeing, it is possible that this type of carer role is less isolating, more socially accepted, and better supported compared to the types of carer roles undertaken by many younger carers in particular.

Younger carers reported having less access to many forms of support compared to older carers, including respite care, breaks from caring, a supportive GP, practical home support, and advice and information, as well as support from family or friends. While access to many of these types of support is low for all groups of carers, it was particularly low for carers aged under 50. This finding needs further exploration to understand the factors contributing to these lower levels of access. Factors that may contribute include a lack of targeting of support services to younger carers, a lack of availability of support for the types of caring typically undertaken by younger carers (more often involving children and younger people, and less likely to involve elderly people, than is the case for older carers), and lack of targeting of information and advice about accessing support to younger carers.

Carers in different regions

The differences identified between carers living in regional, rural and remote regions were often significant. They appear strongly related to the level of access carers living in more versus less remote regions have to support services such as respite care, with carers in remote and very remote regions having very limited access to most forms of support for their caring responsibilities. Experience of financial stress related to caring also increased with the remoteness of the place a person lived. Past studies have also suggested that differences are also caused by differing characteristics of the carer and types of caring responsibilities (McKenzie et al. 2010): in this study, those living in remote and very remote regions had a higher caring responsibility in terms of hours spent on caring responsibilities compared to those living in less remote regions.

Male and female carers

Female and male carers often reported differing experiences of caring: female carers on average spent more hours per week engaged in caring, and were more likely to be caring for two or more people, than male carers. Female carers were more likely to be experiencing financial stress, social isolation, and high psychological distress, compared to male carers.

Supporting the wellbeing of carers

Having access to all the forms of support asked about in the survey was associated with higher wellbeing, but particularly having access to breaks from caring, respite care (one form of a break from caring), a supportive GP, counselling for carers, advice and information, and practical home support, as well as support from family and friends. Having access to financial support was also associated with higher wellbeing, although not to the same extent as support in the form of breaks, home support, information and supportive people in the carer's life.

Conclusions

This study highlights that carers in rural and remote regions experience most of the same challenges and those living in urban areas: carers on average report poorer wellbeing, relatively low levels of access to support, higher rates of financial distress, and many feel undervalued and unrecognised in their role as a carer. This is particularly acute for many carers aged under 50, and less so for carers aged 65 and over. Lack of access to support – formal and informal – and experience of financial distress are also typically higher in more remote regions, and better in more urbanised regions. The findings also highlight that there is considerable diversity in the experience of different carers. Some carers are able to maintain their financial wellbeing and overall quality of life while engaging in their carer role, and have access a range of types of support, while others are not able to achieve these

things. These differences are important to understand: being a carer does not and should not mean a person has to experience poorer wellbeing and financial stress. Understanding the factors that help maintain carer wellbeing provides avenues for addressing the issues that currently contribute to poorer wellbeing for many – but not all – carers. In particular, providing support that enables carers to have a break from caring, to connect socially to others, and to feel recognised and supported by others in the family and their community, is likely to support the wellbeing of carers.

References

- ABS (Australian Bureau of Statistics). 2013. Australian Statistical Geography Standard (ASGS) Volume 5 – Remoteness structure, July 2011. Cat. No. 1270.0.55.005. Australian Bureau of Statistics, Canberra ACT.
- ABS (Australian Bureau of Statistics). 2016. Disability, ageing and carers, Australia: summary of findings, 2015. Cat. No. 4430.0. Australian Bureau of Statistics, Canberra ACT.
- Arksey, H., & Glendinning, C. (2008). Combining work and care: carers' decision-making in the context of competing policy pressures. *Social Policy & Administration*, 42(1), 1-18.
- Carers NSW. 2016. Carers NSW 2016 Carer Survey Main Report. Carers Australia, Sydney.
- Cummins, R.A. 2003. Normative Life Satisfaction: Measurement Issues and a Homeostatic Model,. *Social Indicator Research*, 64, 225-256.
- Cummins, R., Hughes, J., Tomy, A., Gibson, A., Woerner, J., & Lai, L. (2007). Wellbeing of Australians: carer health and wellbeing. Australian Centre on Quality of Life, Deakin University, Melbourne.
- Deloitte Access Economics 2015. The economic value of informal care in Australia in 2015. Report prepared for Carers Australia, June 2015. Canberra ACT.
- Dow, B., Moore, K., Scott, P., Ratnayake, A., Wise, K., Sims, J., & Hill, K. (2008). Rural carers online: a feasibility study. *Australian Journal of Rural Health*, 16(4), 221-225.
- Gill, T., Jury, H., Avery, J., Warmington, R., Stacey, A., & Taylor, A. (2007). The health and wellbeing of adult family carers in South Australia: an epidemiological analysis 1994-2004.
- Holland, K. E. (2008). Carers' perspectives on caring: A qualitative analysis of open-ended responses to the Carer Health and Wellbeing Index survey. Report prepared for Carers Australia. University of Canberra, Canberra.
- International Wellbeing Group 2013. Personal Wellbeing Index: 5th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University.
- Kessler, R. C., Green, J. G., Gruber, M. J., Sampson, N. A., Bromet, E., Cuitan, M., ... & Lara, C. (2010). Screening for serious mental illness in the general population with the K6 screening scale: results from the WHO World Mental Health (WMH) survey initiative. *International journal of methods in psychiatric research*, 19(S1), 4-22.
- McKenzie, S. J., McLaughlin, D., Dobson, A. J., & Byles, J. E. (2010). Urban–rural comparisons of outcomes for informal carers of elderly people in the community: A systematic review. *Maturitas*, 67(2), 139-143.
- Nepal, B., Brown, L., Ranmuthugala, G., & Percival, R. (2008). Lifetime health and economic consequences of caring: Modelling health and economic prospects of female carers in Australia. National Centre for Social and Economic Modelling, University of Canberra, Canberra.

OECD. (2013). *OECD guidelines on measuring subjective well-being*. Organisation for Economic Co-operation and Development, Paris.

Schirmer, J., Yabsley, B., Mylek, M. and Peel, D. 2016. Wellbeing, resilience and liveability in regional Australia: the 2015 Regional Wellbeing Survey. University of Canberra, Canberra.

Smith, K. W., Avis, N. E., & Assmann, S. F. (1999). Distinguishing between quality of life and health status in quality of life research: a meta-analysis. *Quality of life research*, 8(5), 447-459.

Wilkinson, R. G., & Marmot, M. G. (eds.). 2003. *Social determinants of health: the solid facts*. World Health Organization.

Winterton, R., & Warburton, J. (2011). Models of care for socially isolated older rural carers: barriers and implications. *Rural and Remote Health*, 11(3), 1678.

World Health Organization. 2013. Mental health: a state of well-being. URL http://www.who.int/features/factfiles/mental_health/en/ (Accessed 12 May 2014)