Understanding factors associated with Australian mental health carers' employment

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Technical report
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Help, hope and purpose

Foreword

It is widely understood - indeed, perhaps self-evident - that people with intensive caring responsibilities are less likely to be employed than 'non-carers'. Carers not only provide an irreplaceable structural support to Australia's vast health and social care systems; they also routinely do so at the expense of their own careers, education, and long-term economic security. Unpaid carers in Australia are simultaneously underrepresented in the formal workforce, and an unrecognised part of the health care workforce.

In 2017, Sandra Diminic and her colleagues from the Queensland Centre for Mental Health Research at the University of Queensland published a landmark report that quantified the economic value of Australia's hidden workforce of unpaid mental health Carers[1]. In 2015, at least 240,000 mental health carers in Australia provided an estimated 208 million hours of informal care, at a replacement cost of $13.2 billion.

In their new report, they advance these findings through a detailed exploration of the disadvantage faced by mental health carers in accessing employment on an equal footing to other Australians, and an examination of the specific barriers many have to workforce participation.

The findings in this latest report are sobering. Mental health carers are significantly more likely not to be employed compared to working age non-carers. Young carers face specific and acute disadvantage, with almost 13% of children aged 5-14 with mental health caring responsibilities not attending school. It is vital that these young carers be identified, and that they receive appropriate support at home and in school, to mitigate against a lifetime of economic and social disadvantage.

The data also indicates cause for cautious optimism. Over 97% of employed primary mental health carers have special working arrangements available, indicating at least partial recognition of their intrinsic value in the workplace by their employers.

The data also points to a potential roadmap for meaningful policy intervention. Over 40% of carers who are not employed would like to work while caring. Better identification mechanisms, and targeted programs to support them in the full complexity of their lives are urgently needed.

This report, together with 2017's *The Economic Value of Informal Mental Health caring in Australia* reaffirms the need for an integrated and sophisticated policy response across all layers of Government[1]. Workforce participation is a critical part of social identity in Australia. Moreover, the right to work is also a human right, and a fundamental part of what it means to be a valued member of society. Every person should have the opportunity to gain his or her living by work which he or she freely chooses or accepts, and it is high time the Australian government at all levels took proactive steps to safeguard and ensure the realisation of this right for Australia's growing workforce of unpaid carers.

The solutions needed are multi-faceted and will require the involvement of employers and the private sector, as well as government. New policies and practices are needed that will improve mental health carers' participation in the workforce. We must do more to enhance and ensure carer inclusion in Australian workplaces. Crucially, as Australia's population ages, we must invest in the long-term economic security of mental health carers, and indeed all carers.

As I stated in the foreword to the *The Economic Value of Informal Mental Health caring in Australia*, a fundamental issue we must grapple with is how we as a society want to look after and support our most vulnerable – including those with mental health issues and the carers who support them. This research points to the need for a wider cultural change about the value we attach to those who provide unpaid care in Australia.

All Australians have a stake in this debate. This report provides an indication that pragmatic and rational health and social care policies can be remoulded, with a fairer and more equitable reconciliation of 'work' and 'care' at their core.

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Introduction

In late 2017 Mind Australia Limited (Mind) commissioned The University of Queensland (UQ) to conduct a research project, *Understanding the factors associated with Australian mental health carers' employment*. The main purpose of this project was a detailed exploration of the factors associated with employment for Australian mental health carers which might be targets to improve carers' labour force participation, using data from the 2015 Survey of Disability, Ageing and Carers (SDAC). This work builds on and extends previous research conducted by UQ for Mind to profile mental health carers and value their time spent caring in economic terms[1].

The following technical write-up accompanies the project summary report and provides a more detailed explanation of the methods and results, written as draft manuscripts for an academic audience. The work is presented in three parts:

1. Employment disadvantage and associated factors for mental health versus other disability carers;
2. Quantifying possible need for employment support among primary mental health carers; and
3. Vocational engagement of young mental health carers.

Part 1

Employment disadvantage and associated factors for mental health versus other disability carers

Introduction

Family, friends or neighbours of people with long-term health conditions and disabilities often take on the role of an informal carer, providing assistance with a range of practical and support tasks. For carers in paid employment, juggling the competing demands of both intensive caring and work can be stressful and exhausting[2,3]. Consequently, they may reduce their working hours, take more leave, exit the labour force altogether, or make other adjustments to accommodate caring, such as choosing a more flexible or conveniently located job associated with a less challenging role or poorer remuneration[4,5]. Internationally, a substantial number of cross-sectional and longitudinal studies have demonstrated that carers are less likely to be employed than non-carers[6], with the main effect seen at the level of employment or labour force participation rather than hours worked[7]. Carers' participation in employment has also been associated with a range of other characteristics of the carer, the person they care for and the nature of the caring role[5,6]. However, to date there has been comparatively little research exploring the relationship between caring for people with mental illness (e.g. psychotic, anxiety, depressive or personality disorders) and employment, despite evidence that the caring role in these circumstances is quite different[1].

Mental health caring differs in some key ways from supporting people with other types of conditions, particularly physical disabilities. Firstly, informal care of people with mental illness has a greater focus on emotional support, managing crises and supervision of behaviour, and often involves unexpected fluctuations in support needs associated with the episodic nature of mental illness, as well as significant amounts of time spent 'on call' in case a crisis should occur[1,8]. Mental health carers tend to report a higher caring burden and greater unmet support needs than carers of people with physical conditions[1,9]. It has been argued that this emotional and crisis-related caring places additional stress on carers and interferes more with paid employment than other types of care[10], although comparative evidence is lacking. One survey found that, beyond the practical challenges of needing to juggle caring and work tasks, mental health carers experienced significant anxiety and poor health associated with their caring, which in turn negatively impacted their work performance[10]. Alternatively, it is possible that the workplace may provide a form of respite for struggling mental health carers, similar to patterns described for emotionally strained dementia carers[11]. Further, mental illnesses have a younger age of onset than many other conditions such as cardiovascular, musculoskeletal and neurological disorders[12]. As a result, mental health caring is taken up by people at a broader range of ages and life stages and may be long-term[9,13]; this is important when considering its impacts on carers' employment[14].

A few previous studies suggest differences in employment across carers for different types of conditions, but findings have been mixed. One Australian study using the 2009 Survey of Disability, Ageing and Carers (SDAC) found significant differences in whether primary carers were in the labour force (employed or looking for work) across the different diagnoses cared for; however very small sample sizes in this study for some groups (such as carers of people with schizophrenia) made comparison of mental health caring versus other conditions difficult[15]. An analysis of the 2012 US National Health and Wellness Survey found no difference in employment between matched schizophrenia carers, other carers (including for bipolar disorder and dementia) and non-carers, although working schizophrenia carers reported higher absenteeism, presenteeism and overall burden[16]. Matching of these three groups on household income may have limited between-group differences in employment. Alternatively, in another large-scale sample from the 2009-10 Personal Social Services Survey of Adult Carers in England, whether any conditions of the person being cared were dementia, a mental health problem or learning disability was not associated with employment rates for men and women caring for 10 or more hours per week[17]. Drawing consistent conclusions from these diverse findings is challenging, and further complicated by differing labour market conditions, health care services and support arrangements for carers across countries[6,18].

In Australia, there has been limited quantitative research to guide efforts to support mental health carers in the workforce. Our recent analysis of the 2012 SDAC found only 53.5% of mental health carers were employed, while for primary mental health carers (i.e. the person providing the most support), the figure was even lower at 40.8%[1]. An earlier survey of mental health carers receiving a caring pension (Carer Payment) or supplementary financial assistance (Carer Allowance) from the Australian government showed that only 29% and 53% respectively were employed[10]. Many of these carers reported making other work accommodations due to their caring, such as not applying for jobs (45%), reducing working hours (44%), or changing to a role with less responsibility and pay (25%)[10]. Other studies including smaller samples of Australian mental health carers recruited through health services also report that less than half are employed[19,20]. By comparison, 62% of the Australian population were employed in late 2017[21]. These studies illustrate the apparent low employment rates of Australian mental health carers but did not provide direct comparisons with other carers or the general population.

There is a good economic and social rationale for supporting carers to maintain their employment. For the carer, time out of the workforce leads to lost income, disruption to their career trajectory, and the potential for other negative effects of unemployment such as reduced social networks and poorer health[22]. Conversely, employment has been linked to better mental health and quality of life for carers[23,24]. From a government perspective, the costs of inaction include lost tax revenue from employed carers' earnings, increased costs to provide income support to some carers (e.g. Carer Payment), and lost productivity and return on investment in education and training when skilled workers reduce their hours or leave the workforce[25-27]. Where unemployment contributes to poorer health for carers, there may also be increased health care and support service costs to government. Recognising these issues, one of the indicators of mental health reform outlined in Australia's Fifth National Mental Health and Suicide Prevention Plan[28] is the proportion of mental health carers in employment.

To guide supports for mental health carers' employment, specific information is needed about the factors most closely associated with employment, particularly those that may be amenable to policy intervention. Research conducted internationally on all disability carers has consistently identified that carers are less likely to be working if they are: female; nearing retirement age; less educated; in poorer health; or have a higher caring intensity, including but not limited to caring for more hours, being the primary informal caregiver, caring for a close relative, living with the person they support, and caring for more than one person or someone who is more disabled[5,6,29]. Additional factors found to be relevant in some studies include the carer's ethnicity or country of origin[30], marital status[29,31,32] and whether the person they care for is receiving formal disability support services[5,17]. In recent UK research, use of paid services by the person with disability – including home personal care, day care, short-term respite breaks, personal assistance and meals-on-wheels – was positively associated with employment for carers providing more than 10 hours of care per week[17]. The relative importance of these contributing variables has been found to vary between male and female carers[7,17,33]. However, it is not known which of these factors are most important for mental health carers, who may be at different life stages and have access to a different range of health and support services compared to other carers.

Aims

Using a nationally representative household survey, this study aimed to provide a quantitative profile of employment for

Australian mental health carers, and to identify: (1) whether mental health carers are more disadvantaged in employment than carers of people with other types of disabilities and non-carers; (2) which factors are most strongly associated with employment for mental health carers, to identify at risk sub-groups or areas amenable to intervention; and (3) whether there are unique factors associated with mental health carers' employment compared to carers for other conditions.

Method

Survey and sample

The 2015 SDAC[34] is a nationally representative household survey carried out by the Australian Bureau of Statistics (ABS) between July and December 2015. Households were selected from a stratified, multi-stage area sample developed by the ABS. Basic demographic data on all household members were collected from a responsible adult in each household by trained interviewers using a Computer-Assisted Personal Interview. The responsible adult also answered questions to identify the presence of a person with disability or a primary carer in the household, and where possible, additional personal interviews were completed for these persons. Proxy interviews were conducted for people unable to be interviewed due to language or impairment, children aged below 15 years, and people aged 15-17 years without parental consent to participate. The final household sample included 25,806 households comprising 63,515 persons (a response rate of 80.0%).

Key variables

Persons with a disability

Persons with a disability were identified by the responsible adult (e.g. “Does anyone in the household have a [nervous or emotional condition] that has lasted, or is likely to last for 6 months or more?”, “Are they restricted in everyday activities because of this condition?”, “Is anyone in the household receiving treatment or medication for any long-term conditions or ailments?”). Household members identified as having a disability were interviewed and provided additional information on: their main disabling condition; all conditions; level of activity limitations; and receipt of formal assistance (services) for their disability.

Informal carers

Carers were identified by the responsible adult (e.g. “Does anyone in the household help or supervise [another member of the household]/[someone living elsewhere] who has a long-term health condition or disability with everyday types of activities?”, “Do they provide this help on a regular, unpaid, informal basis?”). Carers could also be subsequently identified by a person with disability living in the household (e.g. “Have you received, or do you expect to receive, assistance to help with these tasks from a partner or spouse/parent, family, friends or neighbours for 6 months or more?”, “Which of your family, friends or neighbours provide this unpaid assistance?”). The 2015 SDAC classified household members as carers where they provided support to someone with a limitation to their mobility, communication or self-care and this support was ongoing, or likely to be ongoing, for at least six months. The informant provided information on the relationship of the carer to the person they cared for and the number of people supported. Information about the main disabling conditions of people being cared for was only available for carers who lived within the same household.

For this study, we limited the population of interest to carers aged 15-64 years to align with the youngest age at which Australians commence paid employment and with aged pension eligibility, after which significant proportions of the population begin to leave the workforce. Four carer groups were created based on the main disabling condition of the person being cared for: mental illness (e.g. psychosis, depression, anxiety, personality and behavioural disorders; n=520); other cognitive/behavioural conditions (e.g. dementia, autism, intellectual disability, acquired brain injury; n=312); and physical conditions (e.g. musculoskeletal, cardiovascular, neurological and sensory disabilities) with or without a secondary mental illness (n=577 and n=1,455 respectively). The full list of conditions is provided in Appendix Table A1. Carers for more than one person with different conditions were grouped hierarchically, in that order (i.e. mental illness first). Cognitive conditions and secondary mental illness were separately identified because the required behaviour management and fluctuating care needs were expected to have a more detrimental impact on carers’ ability to maintain employment[10]. We focused on carers of adults with disabilities;

carers providing support only to people aged below 15 years were excluded from the study because of the complexities in separating the effects of informal caring on employment from those of normal parenting in a cross-sectional analysis. A comparison group of non-carers included people aged 15-64 years who were not providing informal care to a person of any age with a disability or long term health condition.

The 2015 SDAC identified confirmed primary carers, a subset of all carers identified in the survey, as the person providing the most assistance to a person with disability. Confirmed primary carers aged 15 years or more were interviewed separately to collect additional information, including questions about the impact of their caring on employment and working hours (e.g. "Was providing care the main reason you left your job?").

Employment

The 2015 SDAC collected detailed data on employment for all household members aged 15 years or more. The main outcome of interest for this study was employment status – whether a person is employed or not (unemployed or not in the labour force). The 2015 SDAC defined employment as engaging in economic work of one hour or more in the survey reference week. Full-time employment is permanent, temporary or casual employment of 35 hours or more per week (across all jobs), or working 35 hours or more during the reference week even if the person usually works fewer hours[35]. Part-time employment is engagement in economic work for fewer than 35 hours per week[35]. Persons were classified as unemployed if they were: (1) aged 15 years or over and not working more at least one hour in the reference week; (2) actively looking for work in previous four weeks; and (3) available to start work in the reference week[36]. People who were not employed were asked to indicate their main activity since last looking for work. Apart from employment status, we also examined potential indicators of underemployment in the form of weekly hours worked and occupational category.

Data analysis

A Confidentialised Unit Record File (CURF) of the 2015 SDAC was obtained from the ABS (October 2016 version). Person-level, recipient-level and condition-level data files were merged to obtain estimates for all co-resident carers and their care recipients. Analyses were conducted in Stata 15[37], using survey weights provided by the ABS to account for possible selection and non-response biases, and differences between the sample and the Australian population. Survey-weighted proportions were produced to describe key demographic and employment characteristics of each carer group, and 95% confidence intervals (CIs) were calculated using jackknife repeated replication.

Aim 1: between group comparisons

To address aim 1, chi-square tests compared mental health carers to non-carers and carers for other disability types on key employment variables.

Aim 2: multivariate logistic regression Model 1 (mental health carers)

Factors potentially associated with employment for mental health carers were identified based on previous studies: carer age group, marital status, rurality, country of birth, highest level of education, whether the carer has a disability, whether any person cared for receives formal assistance from services for their disability, and indicators of the intensity of the caring role – including whether the carer is a confirmed primary carer, the number of people cared for, caring for a close family member (spouse/partner or adult child), and caring for someone who is profoundly or severely limited in core activities[5,6,17,29-31]. Education level was recorded as 'not determined' for 14 of 520 mental health carers and 45 of 2,344 other carers; this coding was not significantly related to employment status ($x^2(1, N=2,864)=0.10, p=0.75$), so these carers were excluded from all regression analyses.

Associations between the covariates and employment status were tested for mental health carers using multivariate logistic regression to calculate adjusted odds ratios (AORs) and 95% CIs. Separate models were conducted for male and female carers due to the potentially different relationships by gender[7,17,33]. Pairwise Cramer's V associations between independent variables revealed moderate relationships (V=0.37-0.64) between: age group, marital status and caring for a partner/child, as well as between primary carer status and disability level of the person cared for (Appendix Table A2). However, all variance inflation factors were below 3 and since these variables each represented distinct constructs of interest they were retained. All variables of interest were initially entered into each model and a final model was selected by removing non-significant variables via backwards elimination until only predictors with a p-value of <.10 remained.

Supplementary regression models explored whether the types, frequency and unmet need for assistance by the person being cared for were related to carers' employment. Since types and frequency of formal assistance were strongly related for both male and female mental health carers, these variables were analysed separately. For each gender, two further models were conducted, replacing receipt of formal services by the person being cared for (yes/no) with: (a) whether the supported person has an unmet need for assistance, receipt of formal assistance with cognitive or emotional tasks, and receipt of formal assistance with other tasks (including assistance with household chores, meal preparation, property maintenance, reading or writing, communication, transport, health care, mobility, and self-care); and (b) whether the person being cared for has an unmet need for assistance, and frequency of formal assistance received (none, less than weekly, weekly or more).

Aim 3: multivariate logistic regression Model 2 (carers of all disability types)

Further logistic regression models by gender were conducted to identify whether any factors associated with employment were unique to mental health carers, by testing the interactions between the disability group of the person supported, selected covariates, and employment status. To minimise loss of statistical power with the addition of interaction terms, education level and disability group were converted to dichotomous variables. Bivariate chi-square tests identified which covariates were significantly different between mental health versus other carers (see Appendix Table A3 for results). For each gender, all significant covariates as well as those identified as significantly related to employment in the mental health carer models were included in the initial regression analyses as interaction terms. Models were reduced via backwards elimination as above, and the final models are reported.

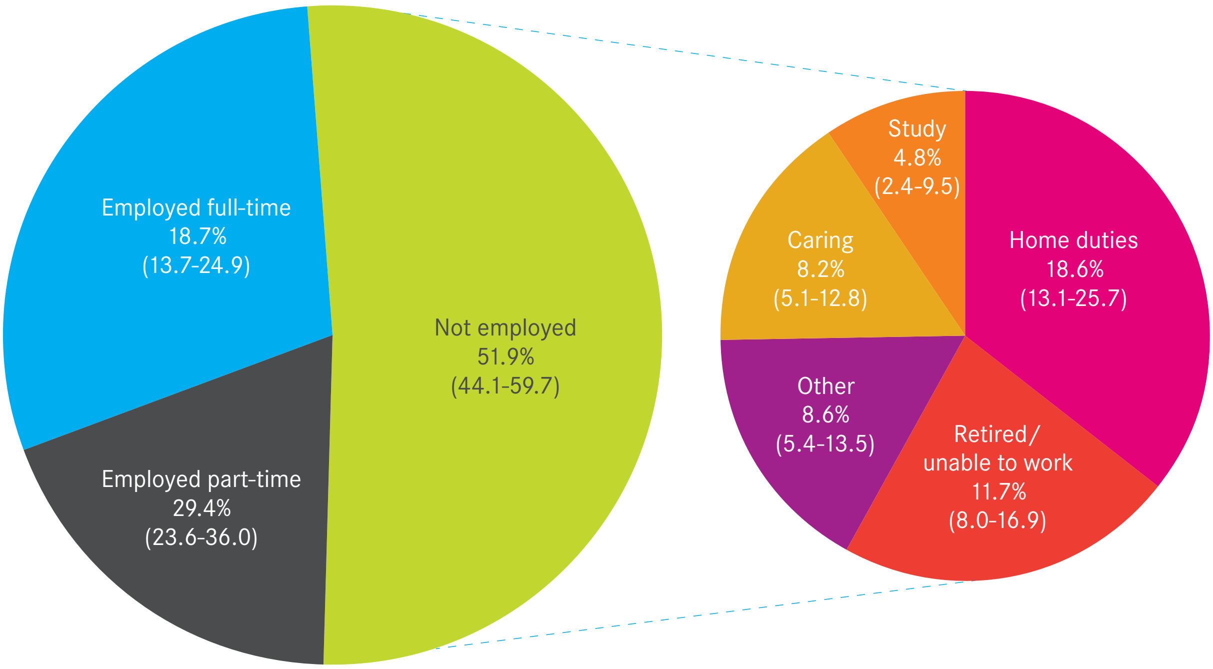
Results

Employment status

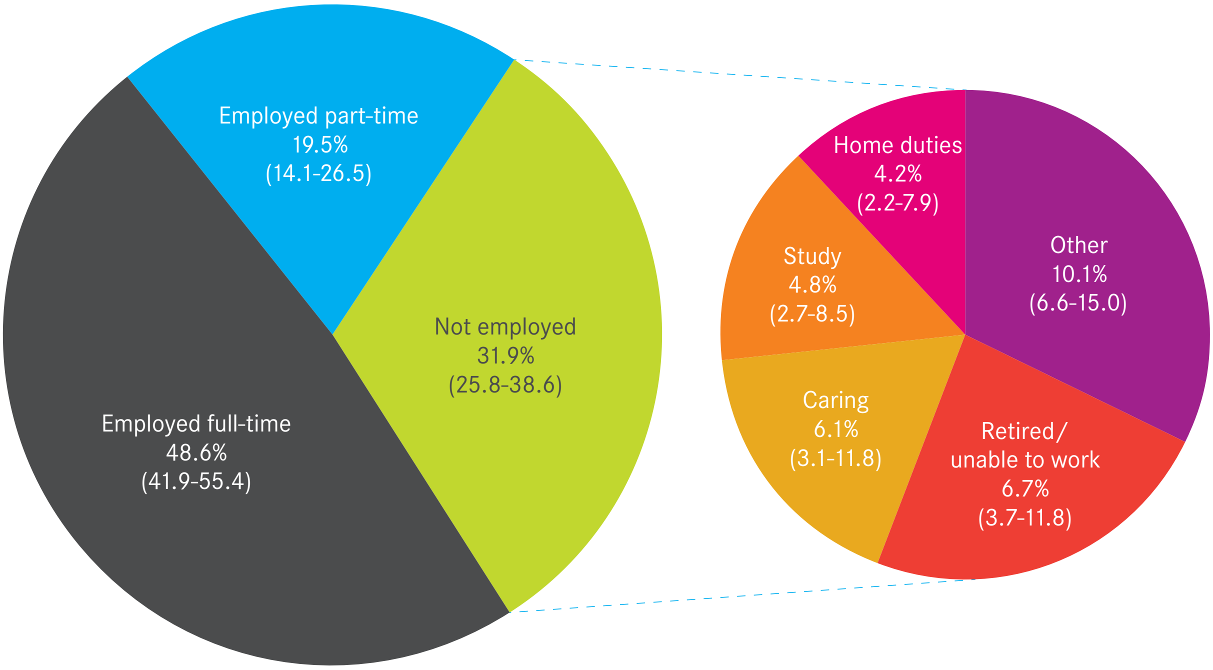
In 2015, 33.1% of working age mental health carers were employed full-time, 24.7% were working part-time, and 42.3% were either unemployed or not in the labour force (Figure 1.1a). Mental health carers who were not working reported a range of roles, including home duties and being retired or permanently unable to work. Seventeen percent of those who were not employed, or 7.2% of mental health carers overall, reported their main activity since last looking for work as caring. As seen in Figure 1.1b and c, more female than male mental health carers were working part-time or not employed and a larger proportion reported their main activity as home duties or retirement. When compared to working age non-carers, mental health carers were significantly less likely to be employed (Figure 1.2; $x^2(1, N=35,920)=189.55, p<0.001$). However, there was no significant difference in employment rates between mental health carers and carers for people with other disabilities (i.e. other behavioural/cognitive conditions and physical conditions with or without secondary mental illness; $x^2(3, N=2,864)=106.77, p=0.52$). Additional data on the main activities of non-working carers for other conditions are included in Appendix Table A4.

Figure 1.1 Employment status for co-resident carers aged 15-64 years of adults with mental illness, by sex (figures in brackets are 95% CIs)

Female carers (n=268) **Employment Status** **Main activity if not working**

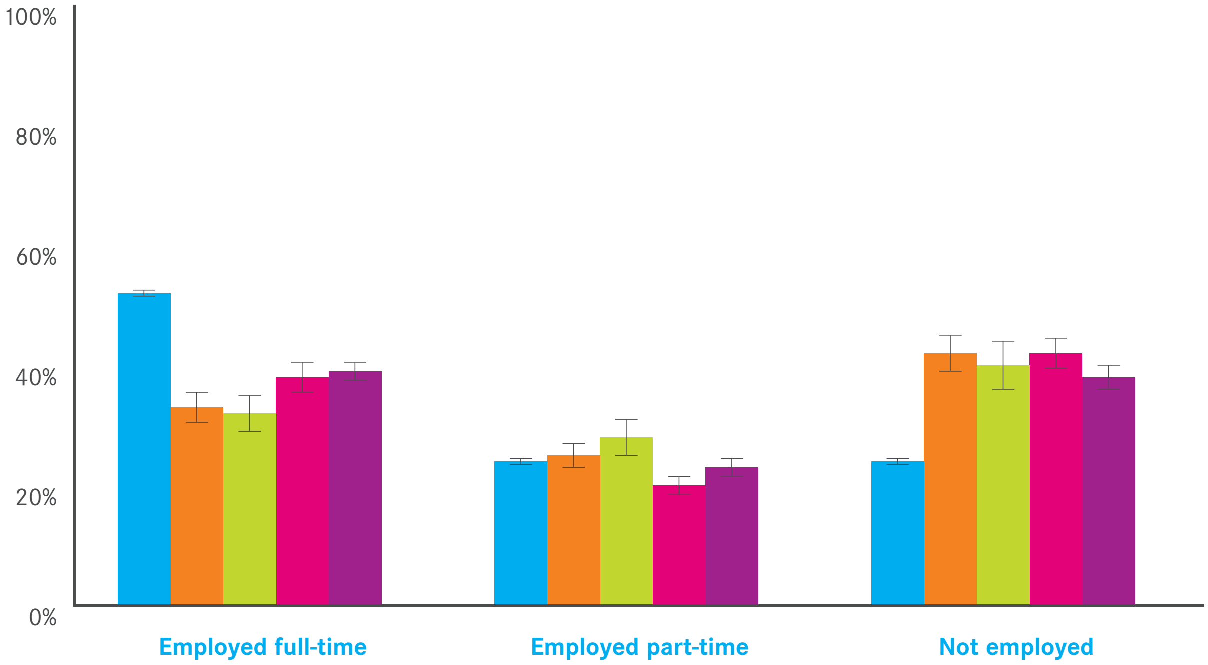


Male carers (n=238)



■ Caring for ill, disabled or elderly person
■ Retired, voluntarily inactive or permanently unable to work (e.g. due to own disability)
■ Home duties or caring for child(ren)
■ Attending an educational institution
■ Other: travel or leisure activity; unpaid voluntary work; own illness or disability; other unspecified activity

Figure 1.2 Employment status for co-resident carers and non-carers aged 15-64 years, by main condition of adult being cared for (error bars represent 95% confidence intervals)



		Employed full-time	Employed part-time	Not employed
🟦	Not a carer (n=35,400)	0.52	0.24	0.24
🟧	Mental illness (n=520)	0.33	0.25	0.42
🟩	Other cognitive / behavioural condition (n=312)	0.32	0.28	0.40
🟥	Physical condition with mental illness (n=577)	0.38	0.20	0.42
🟪	Physical condition only (n=1,455)	0.39	0.23	0.38

Hours and type of work

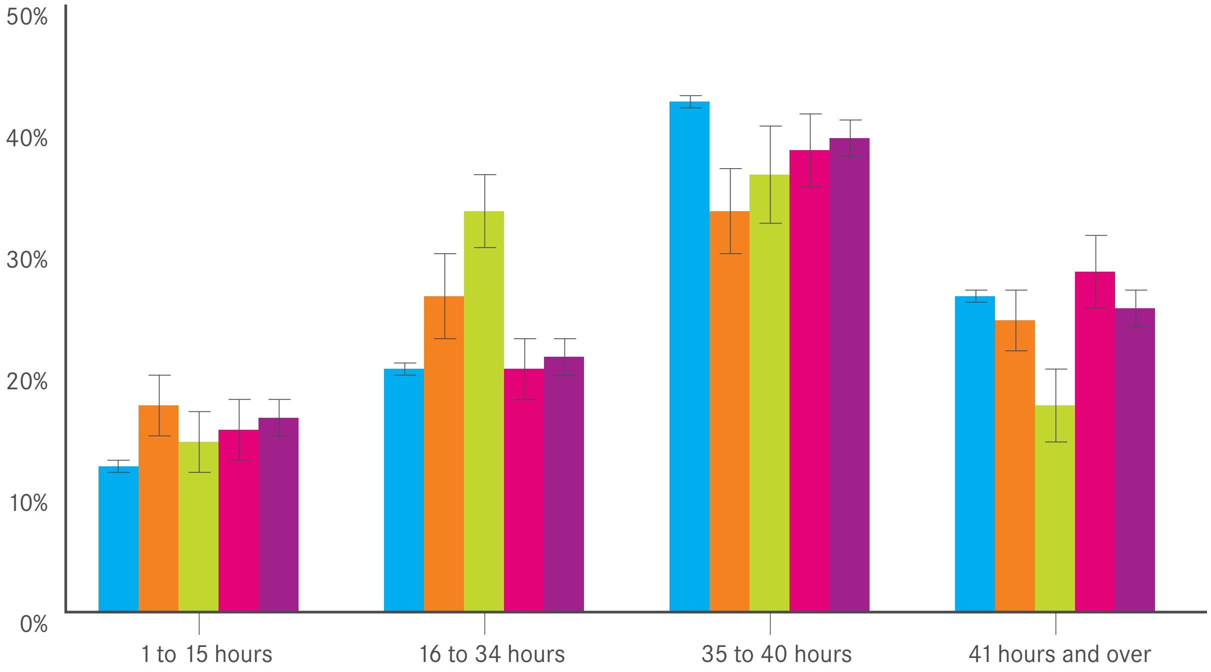
Employed mental health carers reported a range of working hours, with 17.2% working one to 15 hours per week on average, and 25.5% working 16 to 34 hours (Figure 1.3). Mental health carers were significantly less likely to be working 16 or more hours per week compared to non-carers (x^2(1, N=26,992)=23.89, *p*=0.01). There was no significant difference in working 16 or more hours per week between employed carers for different types of conditions (x^2(3, N=1,690)=61.51, *p*=0.72).

Applying high-level occupational groupings, 36.3% of employed mental health carers worked as a manager or professional; 41.1% in a technical, trade, service, sales or clerical role; and 22.6% as a machinery operator or driver, or labourer (Figure 1.4). Mental health carers were significantly more likely than non-carers to be employed as a machinery operator, driver or labourer rather than a higher-level technical or professional role (x^2(1, N=26,942)=29.30, *p*=0.005), but there was no significant difference between mental health carers and other condition carers (x^2(3, N=1,688)=360.84, *p*=0.07).

Impact of caring on employment

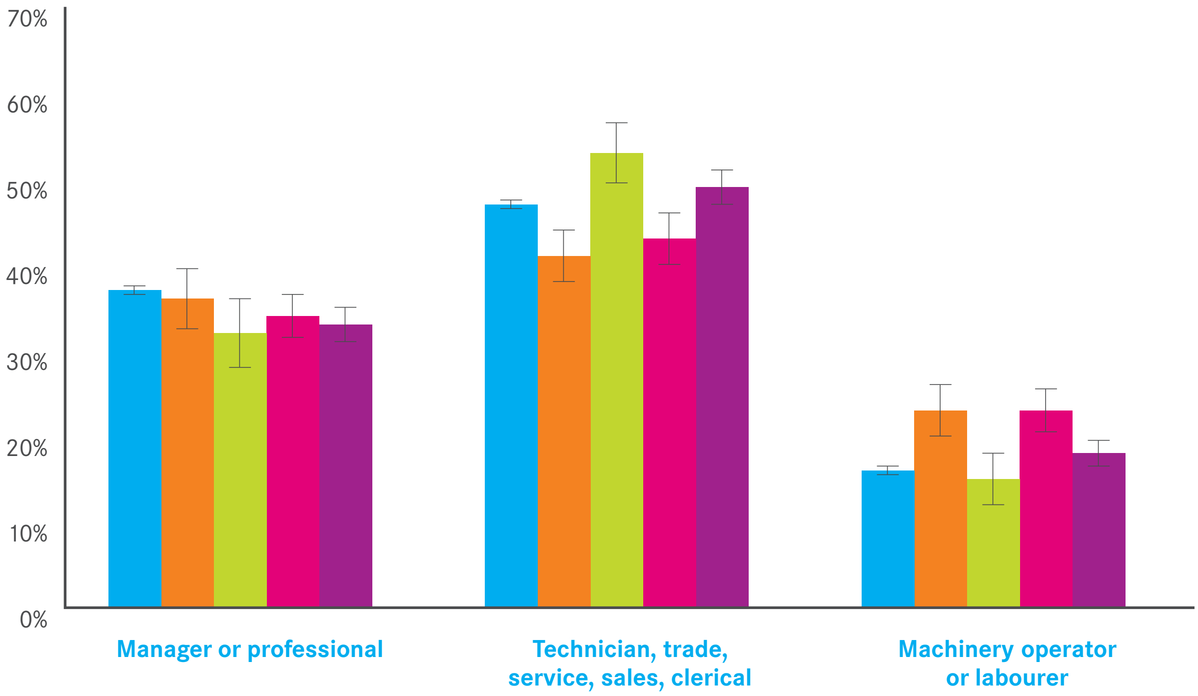
Within the subgroup of confirmed primary mental health carers (n=137), less than half were employed (43.8%, 95% CI: 33.4-54.8). For primary mental health carers who were not currently employed, 47.0% (95% CI: 32.7-61.8) reported working prior to commencing their caring role; these rates were similar across primary carers for all types of conditions (for additional data see Appendix Table A5). Excluding carers who were not currently employed and did not work prior to caring, more than half of primary mental health carers reported an impact of caring on their working hours: 26.4% (95% CI: 17.2-38.2) had stopped working altogether to care, and a further 25.8% (95% CI: 15.6-39.5) had reduced their working hours. This was comparable to carers for other disability groups, where between 45-56% of working primary carers had reduced their hours or left employment due to caring (Appendix Table A5; $x^2(3, N=702)=497.92$, $p=0.34$). Of employed primary mental health carers, 13.8% (95% CI: 7.0-25.5) had left work for at least three months to care for the main person they supported, and 28.9% (95% CI: 17.9-43.2) reported needing time off work to care.

Figure 1.3 Weekly hours worked by employed co-resident carers and non-carers aged 15-64 years, by main condition of adult being cared for (error bars represent 95% confidence intervals)



	1 to 15 hours	16 to 34 hours	35 to 40 hours	41 hours and over
🟦 Not a carer (n=35,400)	0.12	0.20	0.42	0.26
🟧 Mental illness (n=520)	0.17	0.26	0.33	0.24
🟩 Other cognitive/ behavioural condition (n=312)	0.14	0.33	0.36	0.17
🟥 Physical condition with mental illness (n=577)	0.15	0.20	0.38	0.28
🟪 Physical condition only (n=1,455)	0.16	0.21	0.39	0.25

Figure 1.4 Occupational group for employed co-resident carers and non-carers aged 15-64 years, by main condition of adult being cared for (error bars represent 95% confidence intervals)



🟦 Not a carer (n=35,400)	0.37	0.47	0.24
🟧 Mental illness (n=520)	0.36	0.41	0.42
🟩 Other cognitive / behavioural condition (n=312)	0.32	0.53	0.40
🟥 Physical condition with mental illness (n=577)	0.34	0.43	0.42
🟪 Physical condition only (n=1,455)	0.33	0.49	0.38

Factors related to employment for mental health carers

Table 1.1 shows the results of the multivariate logistic regression models on employment status for female and male mental health carers. Key demographic and caring role characteristics associated with employment status for female mental health carers were their age, education, own disability, and the disability level of the person cared for. Female mental health carers had more than three times lower odds of not being employed if they were aged 35–54 years (compared to 15–34 years) and two to three times higher odds of not being employed if they had: completed secondary education or less (compared to a post-secondary qualification), had a disability themselves, or cared for someone who had profound or severe limitations in core activities (communication, mobility and self-care). Whether the person they supported received formal services was not significantly associated with employment for female mental health carers. Supplementary regression models including the types, frequency, and unmet need for assistance by the person being cared for also found no significant association with female carers' employment (Appendix Tables A6 and A7).

For male mental health carers, fewer of the carers' demographic characteristics were associated with employment status. Rather, male mental health carers had three to four times greater odds of not being employed if they were caring for a person with profound/severe core activity limitations or had a disability themselves, and nearly three times lower odds of not being employed if the person they cared for received any formal services (Table 1.1). Supplementary regression models found that the type and frequency of formal assistance received by the person with mental illness were also relevant for male carers (Appendix Tables A6 and A7). Controlling for carer disability, relationship to the person supported, and disability level of that person, male mental health carers had lower odds of not being employed if the person cared for received formal assistance with cognitive or emotional tasks (vs. no assistance with cognitive or emotional tasks; AOR 0.35, 95% CI: 0.19–0.65, *p*=.001), as well as if the person with mental illness received any type of formal assistance at least weekly (vs. no formal assistance; AOR 0.23, 95% CI: 0.08–0.68, *p*=.009). Receipt of formal assistance with other practical or self-care tasks and unmet need for assistance by the person supported were not significantly related to employment status for male carers.

Table 1.1 Association between demographic and caring role characteristics and not being employed for co-resident carers aged 15-64 years of adults with mental illness

Carer characteristic	Female carers (n=268)			Male carers (n=238)		
	% not employed (95% CI)	AOR (95% CI)	*p*	% not employed (95% CI)	AOR (95% CI)	*p*
Age group					ns	
15-34 years	64.7 (46.5-79.4)	1.00		36.5 (23.0-52.4)		
35-54 years	40.7 (31.1-51.1)	0.31 (0.11-0.86)	**.03**	24.0 (16.1-34.2)		
55-64 years	65.9 (50.1-79.0)	0.74 (0.24-2.34)	.61	38.2 (26.0-52.0)		
Highest level of education					ns	
Post-secondary degree/certificate	36.6 (27.8-46.4)	1.00		23.4 (16.4-32.4)		
Year 11 or 12	67.9 (53.3-79.7)	3.09 (1.41-6.74)	**.005**	34.9 (21.6-51.0)		
Year 10 or less	74.1 (61.9-83.4)	3.86 (1.59-9.39)	**.004**	48.9 (33.8-64.2)		
Carer's own disability status						
No disability	40.3 (30.6-50.9)	1.00		24.7 (16.6-35.0)	1.00	
Has a disability	68.0 (58.5-76.1)	3.60 (1.68-7.69)	**.001**	48.6 (32.6-64.9)	3.64 (1.07-12.39)	**.04**
Cares for their spouse/partner or adult child		ns				
Cares for another relative/friend only	65.9 (48.9-79.7)			49.3 (34.7-64.0)	1.00	
Cares for their partner/child	49.7 (41.4-57.9)			24.7 (18.7-31.9)	0.38 (0.13-1.12)	.08
Care recipient disability level						
Moderate or less limitation in core activities	42.1 (33.4-51.4)	1.00		16.2 (8.5-28.6)	1.00	
Profound or severe limitation in core activities	64.1 (52.5-74.2)	2.13 (1.02-4.43)	**.04**	44.5 (34.0-55.5)	4.21 (1.45-12.25)	**.009**
Care recipient(s) receipt of any formal services		ns				
Does not receive services	55.3 (42.7-67.3)			44.3 (33.0-56.1)	1.00	
Receives services	51.7 (41.7-61.6)			22.8 (15.9-31.4)	0.34 (0.18-0.65)	**.001**

AOR – adjusted odds ratio; CI – confidence interval; ns – factor was not significantly related to employment at p>.10 and was not included in final model.

Notes: *p*-values in **bold** are significant at *p*<.05. The following variables were not significantly related to employment status and were removed from the final regression models: (1) for female mental health carers – marital status, rurality, country of birth, primary carer status, number of recipients of care, caring for their partner/child, and care recipient receipt of formal services; (2) for male mental health carers – age group, marital status, rurality, country of birth, education level, primary carer status, and number of recipients of care.

Unique factors related to employment for mental health carers versus other disability carers

Initial bivariate comparisons between mental health versus other carers showed that a greater proportion of the former were caring for their spouse/partner or adult child, or for a person receiving support from formal services (see Appendix Table A3 for full results). More female mental health carers than other female carers had a disability, but fewer were primary carers and a smaller proportion cared for a person with profound or severe activity limitations. A greater proportion of male mental health carers supported two or more people compared to carers for other conditions. These variables were entered into the multivariate logistic regression models for all disability carers, along with those factors identified as significantly related to mental health carers' employment for each gender.

Controlling for these between-group differences, disability group of the person supported (mental illness versus other) was not significantly associated with employment for male or female carers (Table 1.2). There were no significant differences between the factors associated with employment for female mental health carers versus those found for female carers of other conditions. For male carers, most characteristics associated with employment were the same for carers of people with mental illness and other conditions. For male carers only, there were insignificant trends towards group differences in the importance of the level of core activity limitation and receipt of formal services by the person being cared for, with a possible larger effect for mental health carers than for carers of other conditions; however the direction of effects were the same for all carers.

Table 1.2 Association between demographic and caring role characteristics and not being employed for co-resident carers aged 15-64 years of adults with a disability

Carer characteristic	Female carers (n=1,485)			Male carers (n=1,320)		
	% not employed (95% CI)	AOR (95% CI)	*p*	% not employed (95% CI)	AOR (95% CI)	*p*
Recipient disability group				ns		
Other condition	46.2 (42.7-49.8)	1.00		32.1 (28.8-35.6)	1.00	
Mental illness	53.3 (45.4-61.0)	1.32 (0.91-1.92)	.14	31.3 (25.2-38.2)	1.06 (0.64-1.77)	.81
Age group					n/a	
15-34 years	46.0 (39.7-52.4)	1.00		38.3 (32.7-44.1)		
35-54 years	40.0 (35.6-44.3)	0.65 (0.46-0.93)	**.02**	22.5 (18.7-26.9)		
55-64 years	60.6 (55.8-65.3)	1.27 (0.93-1.74)	.14	37.9 (33.1-42.9)		
Highest level of education					n/a	
Post-secondary degree/certificate	35.1 (31.2-39.2)	1.00		21.1 (18.5-24.0)		
Year 12 or less	61.2 (56.9-65.4)	2.73 (2.11-3.53)	**<.001**	45.9 (41.5-50.4)		
Carer's own disability status						
No disability	38.9 (35.1-42.8)	1.00		25.2 (22.4-28.2)	1.00	
Has a disability	65.8 (60.6-70.6)	2.93 (2.14-4.00)	**<.001**	50.7 (44.7-56.7)	4.01 (2.83-5.69)	**<.001**

Carer characteristic	Female carers (n=1,485)			Male carers (n=1,320)		
	% not employed (95% CI)	AOR (95% CI)	*p*	% not employed (95% CI)	AOR (95% CI)	*p*
Primary carer status					n/a	
Is not a primary carer	41.0 (37.2-44.9)	1.00		27.9 (24.9-31.1)		
Is a primary carer	56.6 (51.8-61.3)	1.62 (1.17-2.25)	**.005**	45.8 (40.4-51.4)		
Number of recipients of care		n/a				
One	45.9 (42.6-49.2)			30.4 (27.2-33.8)	1.00	
Two or more	52.7 (44.9-60.4)			38.7 (32.0-45.9)	1.50 (0.99-2.28)	.056
Cares for their spouse/partner or adult child		ns				
Cares for another relative/friend only	47.7 (42.8-52.5)			42.6 (37.9-47.4)	1.00	
Cares for their partner/child	47.3 (43.6-50.9)			23.4 (20.4-26.7)	0.34 (0.24-0.47)	**<.001**
Care recipient disability level						
Moderate or less limitation in core activities	38.0 (33.3-42.8)	1.00		23.1 (18.9-27.8)	1.00	
Profound or severe limitation in core activities	52.5 (48.7-56.4)	1.55 (1.14-2.10)	**.006**	38.0 (34.5-41.7)	2.47 (1.43-4.30)	**.002**
Care recipient disability level X recipient disability group interaction		ns				.09
Moderate or less (other condition)	36.7 (30.9-42.9)			24.8 (20.0-30.3)	1.00	
Profound/severe vs. moderate/less (other condition)	50.8 (46.5-55.1)			36.8 (32.7-41.0)	1.54 (1.06-2.24)	**.02**
Moderate or less (mental illness)	42.1 (33.4-51.4)			16.2 (8.5-28.6)	1.00	
Profound/severe vs. moderate/less (mental illness)	64.1 (52.5-74.2)			44.5 (34.0-55.5)	3.97 (1.40-11.29)	**.01**
Care recipient(s) receipt of any formal services						
Does not receive services	48.5 (44.5-52.5)	1.00		34.6 (30.5-38.9)	1.00	
Receives services	46.3 (41.9-50.8)	0.80 (0.62-1.04)	.096	29.5 (26.5-32.7)	0.53 (0.36-0.79)	**.002**

Carer characteristic	Female carers (n=1,485)			Male carers (n=1,320)		
	% not employed (95% CI)	AOR (95% CI)	*p*	% not employed (95% CI)	AOR (95% CI)	*p*
Care recipient(s) receipt of any formal services X recipient disability group interaction		ns				.08
Does not receive services (other condition)	47.3 (43.3-51.5)			33.0 (28.4-37.8)	1.00	
Receives services vs. not (other condition)	45.0 (39.7-50.4)			31.2 (27.6-35.2)	0.77 (0.58-1.03)	.07
Does not receive services (mental illness)	55.3 (42.7-67.3)			44.3 (33.0-56.1)	1.00	
Receives services vs. not (mental illness)	51.7 (41.7-61.6)			22.8 (15.9-31.4)	0.37 (0.17-0.79)	**.01**

AOR – adjusted odds ratio; CI – confidence interval; n/a – not included in the initial model because variable not significantly related to employment in the mental health carer regression model and not significantly different between mental health versus other carers; ns – factor was not significantly related to employment at p>.10 and was not included in final model.

Notes: p-values in bold are significant at *p*<.05. The following variables were initially included but were not significantly related to employment status and were therefore removed from the final regression models: (1) for female mental health carers – caring for their partner/child, and all interactions between recipient disability group and covariates; (2) for male mental health carers –interaction terms between recipient disability group and all covariates except care recipient disability level and receipt of formal services.

Discussion

This cross-sectional analysis of the 2015 SDAC showed that working age carers of adults with mental illness were significantly less likely to be employed and to be employed for fewer hours and in lower-level occupational categories than adults without caring responsibilities. This is consistent with the large body of previous research demonstrating reduced employment rates for informal carers[6], and research on Australian mental health carers suggesting low employment rates for this group[1,10]. However, contrary to our hypothesis that the focus of mental health caring on emotional and crisis support, the fluctuating needs of people with mental illness and the younger age of onset for mental health conditions would interfere more with carers' employment, there were no significant differences in employment rates between mental health carers and carers for people with other cognitive/behavioural conditions or physical conditions with or without secondary mental illness. It is possible that these caring role characteristics may affect other aspects of carers' employment not measured in this study, such as job performance, satisfaction, absenteeism, and stress levels. However, at the level of employment status, carers for all types of disabilities appeared similarly disadvantaged compared to non-carers. Future research could explore these other employment-related factors among carers for different types of conditions in Australia, since previous studies have shown that the stress associated with mental health caring contributes to poorer work performance[10], and that schizophrenia carers in the US reported higher absenteeism, presenteeism and burden compared to other carers[16].

The main characteristics associated with employment for female mental health carers were age, education level, having a disability, and disability level of the person cared for. For male carers, having a disability, disability level of the person cared for, and receipt of formal assistance by the person with mental illness were associated with employment. That these factors were related to employment is not surprising and is consistent with previous research on carers internationally[5,6,29], although other factors found to be relevant in previous studies, such as being a primary carer and the number of people supported, were not the most important for this 2015 SDAC carer group. For men, more of the significant factors were associated with the person they care for and caring role, whereas for female mental health carers their own socio-demographic characteristics were more prominent. A much greater proportion of female than male mental health carers in this study were not in the labour force due to home duties and child care, retirement or being permanently unable to work. The stronger association between the carer's own characteristics and employment for these women likely reflects this greater diversity of other roles and their influence on decisions about workforce participation.

Male mental health carers had greater odds of being employed if the person they supported was receiving formal assistance from organised services, and this was true specifically of assistance with cognitive or emotional tasks, and for services provided at least weekly. Further, both male and female mental health carers had greater odds of not being employed if the person they cared for had a higher level of disability. These findings suggest that improving the availability and impact of psychosocial support services for people with mental illness may assist their carers to maintain employment, but that this might have a greater impact for male compared to female carers. The results support and extend on previous work conducted in the UK for carers of all types of disabilities, which also found that a range of services provided to people with disability were associated with their carers' employment[5,17]. However, given our analysis was cross-sectional, the direction of effects cannot be assumed. While mental health services may support carers to remain in employment, it may also be true that carers who are employed and continue to work are more likely to be able to finance access to formal services, or to have people they support who consequently rely on these services. Longitudinal analysis of UK carers[5] has shown that services received by people with disability at baseline predicted their carers' employment two years later, supporting a direct impact of service availability on carers' work. Further confirmation of this relationship with longitudinal Australian data would be ideal.

Although the factors described above were related to employment status for mental health carers, these particular factors were not unique to just mental health carers. In fact, the employment picture was remarkably similar for carers of all types of disabilities, suggesting that the degree of impairment of the person being cared for, available supports and the carer's own personal circumstances are more important for whether they work than the nature of caring tasks required. Thus this study did not provide evidence to suggest that mental health carers need specially targeted programs to support them to work, separate from those for other carers. Nevertheless, as noted above we were only able to examine objective measures of workforce participation and did not have further information about carers' experience of employment, caring, or available supports, which may vary across different types of health conditions.

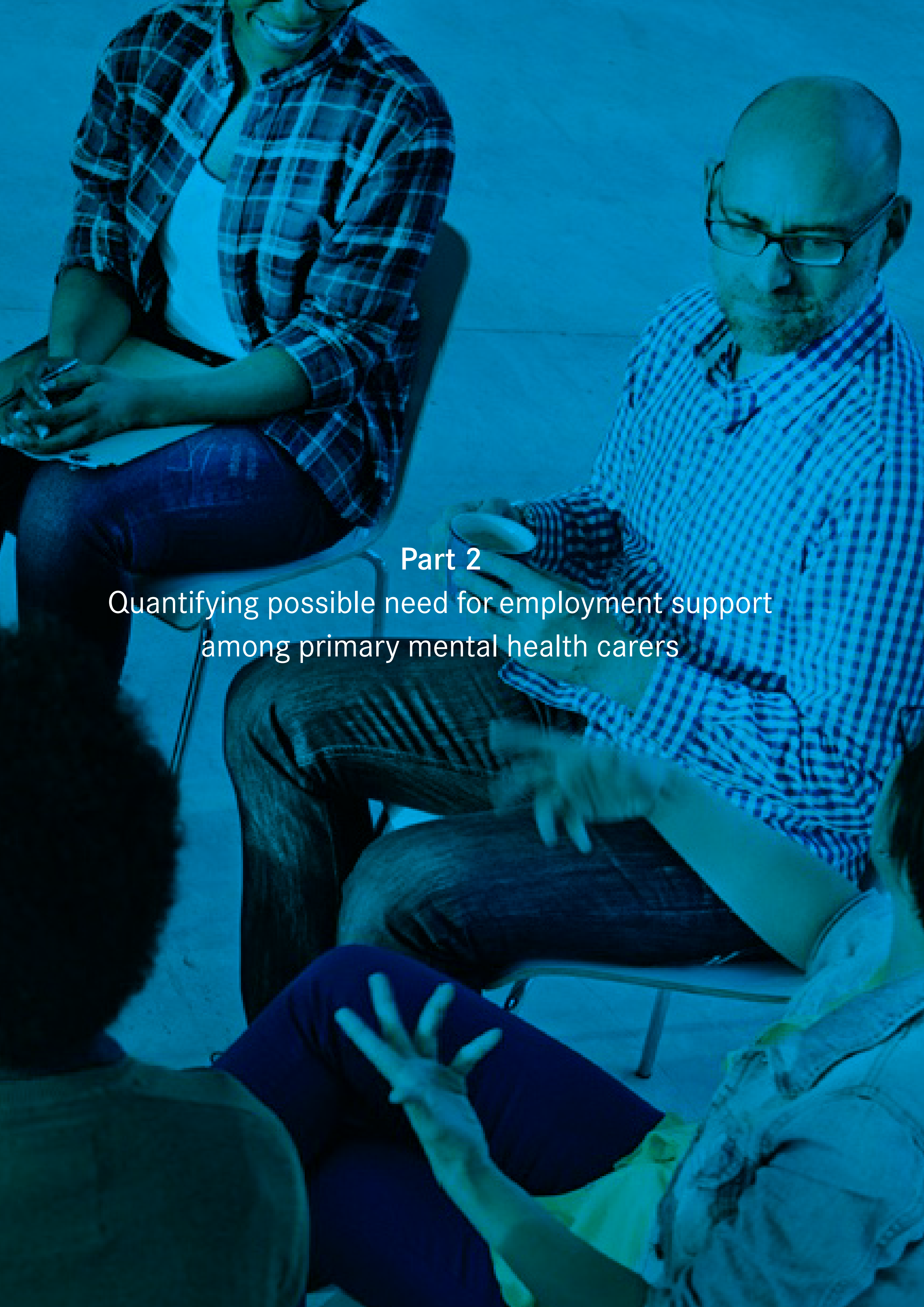
Limitations

This analysis drew on a large, nationally representative household survey to fill gaps in knowledge about employment for Australian mental health carers. Due to the cross-sectional nature of the 2015 SDAC data collection, all analyses were correlational and were not able to distinguish the direction of impact between carer and caring role characteristics and carers' employment. Carers may self-select to caring based in part on lower opportunity costs, for example being more likely to choose caring over employment if they are already nearing retirement age, in a less rewarding job or in poor health[6]. However a number of longitudinal studies of caring have shown that this gap widens over time as the caring role has a negative impact on later employment[5,29,38-40]. Unfortunately, available Australian longitudinal studies which include carers do not record the condition of the person cared for, meaning that the 2015 SDAC currently provides the most up-to-date, comprehensive and nationally representative data on Australian mental health carers. Hence this analysis should be considered an initial exploration of available data that should be confirmed in future when longitudinal studies of mental health carers are available. It is recommended that questions about the condition of the person being cared for be added to recurrent surveys such as the Household, Income and Labour Dynamics in Australia (HILDA) Survey or the Australian Longitudinal Study on Women's Health to allow such analyses.

The types of carers included in this analysis should be noted when interpreting the findings. Due to the limitations of the 2015 SDAC dataset, this study focused only on carers who live with the person they support, for whom data on the condition of that person were available. This focus is likely to have produced a stronger relationship between caring role characteristics and employment than might be seen in a broader sample of carers, since the impact of caring on employment has been found to be greater for co-resident carers than for carers living elsewhere[5,6,33]. It is important to emphasise that carers of people with mental illness who do not live with them may also face significant challenges and burdens; for some carers these may cause more interference with employment due to the additional time needed to travel to visit the person they support. Our sample was also restricted to carers of adults aged 15 or more. The relationship between caring and employment for parents with dependent children is likely to be complicated by the demands of normal parenting, and with the available cross-sectional data it was not possible to separate out the impact of these different needs. We also did not have data to analyse the relationship between stigma, employment history, or caring hours and mental health carers' employment. Hours of care were only recorded for co-resident primary carers in the 2015 SDAC, so we instead included a number of other indicators of caring intensity in the regression analyses for the broader group of primary and secondary carers (such as caring for a close relative, the number of people supported, and the level of impairment experienced by the supported person).

Conclusion

Mental health carers had significantly lower employment rates than non-carers in 2015, highlighting the continuing disadvantage associated with caring. Australian initiatives have attempted to support carers of children and people with disabilities in the workforce through encouraging employers to provide flexible work arrangements, and through funding limited support services for carers such as the Department of Social Services' Carers and Work program[41,42]. The results of this study highlight the need to consider the carer's employment journey in the context of their caring role, particularly the disability level of and supports received by the person cared for. Carers generally report needing better access to services for the person they support to help manage their own employment and overall caring burden[2,4,5], and mental health carers in particular have reported inadequate service assistance and higher unmet needs than their other carer counterparts[1,9]. The results seem particularly relevant given the current roll-out of the National Disability Insurance Scheme (NDIS) in Australia, which is moving disability support services from grant-funded programs accessed via non-government organisations to individual packages of care based on needs assessments. The NDIS is required to take into account both what support is reasonable to expect families and carers to provide, as well as risks to the wellbeing of the person with disability and their carer from continuing pre-existing intensive caring arrangements[43]. However, widespread concerns about the appropriateness of the Scheme for individuals with psychosocial disabilities and their carers has prompted a review of processes[44,45]. Given the clear benefits to mental health carers and society from their participation in employment[22,23,26], it is critical that the implementation of the NDIS maintains or improves the level of support available for carers and people with psychosocial disabilities, to prevent carers from feeling they have no choice but to leave employment in order to support their loved ones. Further, consideration is need of appropriate support arrangements for people with mental illness and their carers who are not eligible for the NDIS. Better access to community support services for people with mental illness will never completely substitute for informal caring, but would help to take the pressure off carers and allow them to better manage their multiple roles[5,6,46].



Part 2

Quantifying possible need for employment support among primary mental health carers

Introduction

Mental health carers are the family members, friends, and neighbours of people with mental illness who support them by providing unpaid assistance with a range of self-care, practical and emotional support tasks on an ongoing basis[1]. Where a person with mental illness receives this type of assistance from more than one person, their primary carer is the individual who provides the most unpaid support[47]. Taking on intensive caring responsibilities can have a significant impact on primary mental health carers' own paid employment. For example, national survey data show that only 40.8% of primary mental health carers in Australia were employed in 2012[1], and mental health carers report difficulty and associated anxiety with managing the competing demands of their caring and employment[10]. Preventing mental health carers from leaving the workforce where possible is important for their own finances, social networks, health and wellbeing, as well as the economic benefits to society[22,26,27].

Previous research on carers of people with all types of disabilities has shown that a range of characteristics of the carer and their caring role contribute to carers' subsequent workforce participation[6,38]. Pre-existing characteristics of the carer themselves, such as their age, gender, level of education, and prior employment history may differentiate groups of new carers whose employment is particularly at risk. However, aspects of the caring role are potentially more amenable to direct intervention to assist carers in maintaining their employment. Internationally, having a more intensive caring role has been linked to lower rates of employment for carers, in terms of the hours of support provided and related factors such as the level of disability experienced by the person cared for, or whether they also receive assistance from organised services[5,6,40]. Australian studies have replicated this finding[39,48,49]; for example O'Loughlin et al[50] found that 42% of older carers in the New South Wales 45 and Up Study caring for less than 10 hours per week were employed full-time, compared to around half that for carers providing 10 or more hours of support. Similarly, Leigh[39] identified a significant reduction in employment rates among carers providing more than 10, or more than 35 hours of care weekly. A number of studies suggest that there is a non-linear relationship between caring hours and employment, with a threshold of between 10-20 hours per week above which there is a significant drop-off in workforce participation[5,29,31-33,39,40,50]. However, this threshold varies and there is a lack of consensus on one specific level beyond which caring hours are detrimental to employment[49]. Further, this relationship has not been explored specifically for mental health carers, whose caring tasks tend to be unpredictable and more focused on emotional and crisis support, who report spending large amounts of additional time on standby should the person they support need them at short notice[1], and who experience significant anxiety about their caring role while at work[10]. The emotionally challenging nature of these tasks may more negatively impact mental health carers' employment at the same number of active support hours compared to other carers. Our recent analysis of the 2015 Australian Survey of Disability, Ageing and Carers (SDAC)[51] showed that impairment of the person cared for and their use of formal services were associated with employment for mental health carers, however our focus on the broader group of both primary and secondary mental health carers precluded an exploration of caring hours, which were only collected for primary carers. The current study was therefore designed to understand the association between caring hours and employment for primary mental health carers.

The Australian government has made progress in encouraging workplace flexibility to support carers and in funding programs to assist carers in accessing employment services[41,42]. These types of programs focus on the carer's job role and skillset rather than their caring, and may be time-limited. An alternative approach is consideration of the balance between caring and carers' other activities like employment. In the UK, government policy has moved towards a greater emphasis on ‘replacement care’, or providing more paid services for people with disabilities, in part as a strategy to support carers to maintain employment[17]. While carers play an important and necessary role in supporting people with mental illness, there is an equally important role for formal health and disability services to ensure that these people receive appropriate services so that carers are not overburdened beyond their capacity and to the detriment of their own health and wellbeing[43]. Improving the formal supports available for someone with mental illness would reduce to some degree the amount of time required from informal carers[6,46]. Mental health carers have consistently reported a high burden from their caring role and additional strain caused by a fragmented mental health system which often does not meet the needs of the person they care for or themselves[1,8,9]. Further, Canadian research has found that while carers providing less than five hours per week of support produced a cost saving to government, at the highest intensity of caring there was a net cost to government, where the lost tax revenue and carer transfer payments outweighed the economic value of the support provided[26]. The greatest contributor to these costs was carers leaving their employment, and caring for more than 15 hours per week significantly impacted carers’ labour force participation[26]. Hence there is a need to quantify when the intensity of caring becomes costly to the carer and society, and to balance the system to better support carers at risk of leaving the workforce.

King and colleagues[30] recently enumerated the number of working carers in England who were at risk of leaving the workforce based on the hours of care they provided, and estimated that 790,000 carers were at risk, more than previously identified. In Australia there has been little quantitative research to identify mental health carers who may need assistance either to maintain their employment or to re-enter the workforce. Mental health carers tend to report higher caring and unmet needs from their caring than physical health carers, and may have different support needs[1,9]. Despite this, not all carers will want to work so their caring situation and current needs should be taken into account when planning. To better support mental health carers in the workforce, we need to know how many of these carers are potentially at risk of losing their employment or are not working but would like to be, and what types of assistance would be most helpful for them.

Aims

The aims of this study were therefore to: (1) determine the threshold at which the hours of care provided by primary mental health carers are associated with significantly lower employment rates, controlling for other factors; (2) determine whether this caring hours threshold is lower for primary mental health carers than other disability carers; (3) enumerate Australian primary mental health carers with a possible need for more support to maintain, improve or re-enter employment based on their hours of care and other key factors; and (4) describe primary mental health carers’ self-reported unmet support needs and barriers to employment.

Method

Survey and sample

The 2015 SDAC[34] is a nationally representative household survey of people with disabilities and their informal carers. The Australian Bureau of Statistics (ABS) conducted Computer-Assisted Personal Interviews from July to December 2015 with households selected from a stratified, multi-stage area sample. The survey achieved an 80.0% response rate, covering 63,515 people in 25,806 households. A responsible adult from each household reported on the basic demographic characteristics of all household members and identified persons in the household with a disability or who were primary carers. Additional information was collected from these individuals via personal interview or via proxy interview for children and people unable to participate due to language or impairment.

Key variables

Persons with disability

The responsible adult identified individuals with a disability (e.g. "Does anyone in the household have a [nervous or emotional condition] that has lasted, or is likely to last for 6 months or more?", "Are they restricted in everyday activities because of this condition?", "Is anyone in the household receiving treatment or medication for any long-term conditions or ailments?"). Personal interviews with these individuals collected information about their main disabling condition, level of activity limitations, and receipt of formal disability services.

We classified main disabling conditions into mental illness (e.g. psychosis, depression, anxiety, personality and behavioural disorders) versus other conditions (including dementia, autism, intellectual disability, musculoskeletal, cardiovascular, neurological and sensory conditions). Assistance received by people with a disability was coded as: any formal assistance; type of formal assistance received; frequency of formal assistance received (none, less than weekly, weekly or more); and whether the person had an unmet need for assistance. The types of formal assistance were grouped into: assistance with cognitive or emotional tasks; assistance with practical tasks (including household chores, meal preparation, property maintenance, reading or writing, communication, transport, and health care); and assistance with activities of daily living (ADLs; including mobility and self-care), consistent with previous research on carers[1,8].

Informal carers

Carers were identified either by the responsible adult (e.g. "Does anyone in the household help or supervise [another member of the household]/ [someone living elsewhere] who has a long-term health condition or disability with everyday types of activities?", "Do they provide this help on a regular, unpaid, informal basis?") or by a person with disability in the household (e.g. "Have you received, or do you expect to receive, assistance to help with these tasks from a partner or spouse/parent, family, friends or neighbours for 6 months or more?", "Which of your family, friends or neighbours provide this unpaid assistance?"). Carers in the 2015 SDAC needed to provide support that was ongoing, or likely to be ongoing, for at least six months and to someone with a limitation in their mobility, communication or self-care.

For this analysis we focused on confirmed primary carers, identified in the 2015 SDAC as the individual providing the most unpaid assistance to a person with a disability. These confirmed primary carers completed personal interviews to provide additional details about their caring role, the impact of their caring on employment, their desire to work, and barriers to employment. The analysis included only primary carers aged 15-64 years to align with the working age population in Australia. Information about the conditions of people being supported was only available for primary carers who lived with the main person cared for. Primary carers were grouped by the main disabling condition of the main person they supported into primary mental health carers (n=137) versus other primary carers (n=821).

Carers whose main person supported was aged below 15 years were excluded from the analysis due to the challenge of distinguishing the impact of caring versus normal parenting in this age group.

Employment

The main outcome of interest was whether carers were employed or not employed (i.e. unemployed or not in the labour force). The 2015 SDAC defined employment as economic work for one or more hours in the survey reference week[35]. All employees identified in the 2015 SDAC were asked questions about whether they had available, used or wanted to use special working arrangements to care for someone. These included items such as paid and unpaid leave, flexible hours, and other arrangements. People who were self-employed or not employed did not answer questions on special working arrangements.

Data analysis

The ABS provided the October 2016 Confidentialised Unit Record File (CURF) for the 2015 SDAC. Person-level and recipient-level data files were merged to obtain more detailed estimates about primary carers and their recipients of care. Analyses were conducted in Stata 15[37], using survey weights provided by the ABS to account for the complex survey design and differences between the sample and overall Australian population, with 95% CIs produced using jackknife repeated replication.

Survey-weighted proportions and weighted population counts were calculated to describe key demographic, caring role, and employment characteristics of primary carers. Demographic and caring role characteristics of interest as potentially related to employment based on previous research[5,6,17,29-32] included: carer sex, age group, marital status, rurality, country of birth, highest level of education, whether the carer has a disability, the number of people cared for, whether the main person supported is their spouse/partner or adult child, whether the main person cared for is profoundly limited in core activities, duration of the caring role in years, average weekly hours of care provided to all persons supported, whether the main person supported receives formal assistance from organised services for their disability, receipt of formal emotional assistance by any person cared for, receipt of formal assistance with ADLs by any person cared for, receipt of formal assistance with practical tasks by any person cared for, frequency of assistance received by persons being cared for, and whether any person being supported has an unmet need for assistance. For carers supporting more than one person, we recorded the highest frequency of formal assistance received by any of these individuals.

A total of 13 of 137 primary mental health carers and 76 of 821 other primary carers were excluded from the regression analyses due to having ‘level not determined’ recorded for their education, or ‘does not know’ for their duration of caring or hours of care. Having one of these undetermined items was not significantly related to employment status for primary mental health carers (x^2(1, N=137)=1.34, p=0.25, V=.10) or all primary carers (x^2(1, N=958)=3.62, p=0.06, V=.06).

Aim 1: Multivariate logistic regression Model 1 (primary mental health carers)

A multivariate logistic regression analysis tested the association between different levels of hours of care and employment status for primary mental health carers, controlling for the effects of other covariates. Due to the relatively small sample of carers, categories were rolled up into higher groupings for duration of caring (<10, 10+ years), hour of care (1-9, 10-19, 20-39, 40+ hours) and type of formal assistance received by the person cared for (emotional vs. any other). Pairwise Cramer’s V associations between each pair of variables revealed moderate relationships between: marital status and caring for a partner/child (V=.34), level of limitation of the main person cared for and hours of care (V=.50), hours of care and receipt of other assistance by the person supported (V=.31), and receipt of emotional assistance and other assistance by the person cared for (V=.33; Appendix Table B1). More importantly, there were strong relationships between receipt of any formal services by the person cared for and other service variables (service frequency V=.97, emotional assistance V=.85, other assistance V=.57), and likewise for frequency of services received (emotional assistance V=.85, other assistance V=.61). These variables also produced high variance inflation factors (VIF=20.40 for formal services and 17.89 for frequency of assistance) and were therefore excluded from the regression analysis due to overlap with other service variable constructs. The initial regression model included all other variables of interest and the final model was selected through backwards elimination until only predictors with a p-value of less than .10 remained. Adjusted odds ratios (AORs) and 95% CIs were calculated for each variable included in the final model.

Aim 2: Multivariate logistic regression Model 2 (all primary carers)

A second multivariate logistic regression model tested the interaction between disability group of the person cared for, caring hours, and employment status for all primary carers, to identify whether the hours of care threshold related to not being employed was different for primary mental health carers compared to other disability carers. We identified between-group differences in demographic and caring role characteristics for primary mental health versus other primary carers by conducting bivariate chi-square tests for each covariate (see Appendix Table B2 for results). The initial regression model included covariates identified as significantly different or approaching significance between the two carer groups (carer disability, caring for their partner/child, level of activity limitation of the person supported [*p*=.09], receipt of formal emotional assistance by the person cared for, receipt of other formal assistance by the person cared for), as well as all significant variables from Model 1, and the interaction between disability group and hours of care. Pairwise Cramer's V associations between independent variables showed a moderate relationship (V=.46) between level of core activity limitation of the person cared for and hours of care, however all variance inflation factors were acceptable at less than 3, so both variables were retained. The model was reduced to a final version via backwards elimination until all p-values were less than .10.

Aims 3 and 4: Possible need for support

To identify possible needs for more support to maintain, improve or re-enter employment among primary mental health carers, these carers were first divided by employment status into those who were working or not working. For employed carers, possible unmet need for employment support was identified as including carers who: (1) provided 40 or more hours of care per week (based on the results of Model 1); (2) had reduced their working hours to commence their caring role; (3) worked part-time and wanted to work more hours; or (4) wanted more use of special working arrangements. For carers who were unemployed or not in the labour force, possible unmet support need was identified as including carers who: (1) had left employment to commence their caring role; or (2) reported wanting to work while caring. Weighted population estimates and 95% CIs were calculated for each of these groups to estimate the number of primary mental health carers with these needs at a national level. Survey-weighted proportions and weighted population counts were calculated to identify numbers of primary mental health carers reporting each of these indicators as well as additional detail on special working arrangements for employed carers and barriers to entering employment for carers who were not employed.

Results

Association between hours of care and employment for primary mental health carers

Table 2.1 shows the demographic and caring role characteristics of primary mental health carers in the 2015 SDAC. The majority of these carers provided less than 30 hours of care per week. There was an inverse relationship between hours of care and employment status for primary carers, with lower rates of employment among carers providing more hours of informal care (Figure 2.1). This pattern was present for both primary mental health carers and other primary carers. Unfortunately, small numbers within each hours of care category, especially for mental health carers, produced wide levels of uncertainty around the exact estimates, so subtle apparent group differences in Figure 2.1 should be interpreted with caution. There appeared to be lower levels of employment particularly for primary mental health carers providing care for 40 or more hours per week.

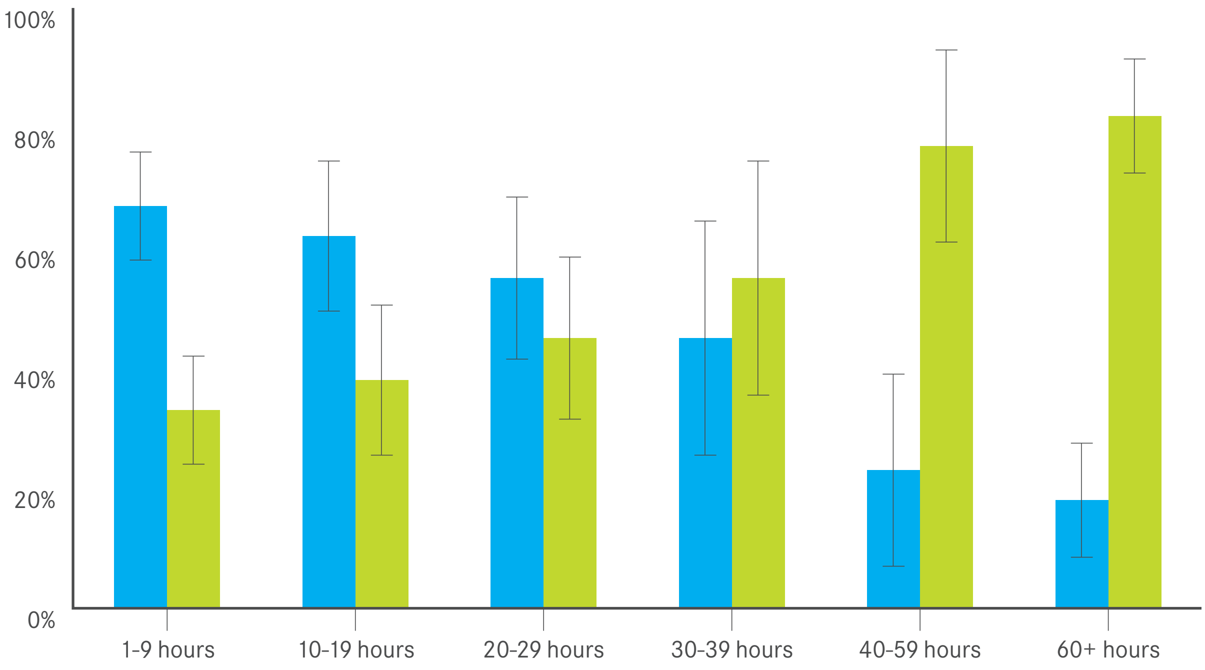
Table 2.2 provides the results of the multivariate logistic regression on employment status for primary mental health carers. After controlling for other relevant covariates, primary mental health carers providing 40 or more hours of care per week on average had greater odds of not being employed compared to those caring for less than 10 hours per week (AOR 13.38, 95% CI: 2.17–82.39). However, the magnitude of this effect should be interpreted with caution due to the wide confidence intervals around the estimated odds ratio. A series of equivalent regression models was subsequently run with binary hours of care variables representing the split at different levels (i.e. 10+ vs. <10 hours, 20+ vs <20 hours, 30+ vs. <30 hours, 40+ vs. <40 hours, 60+ vs. <60 hours). Primary mental health carers had significantly higher odds of not being employed at all hours of care cut-off levels compared to carers providing fewer hours of care, suggesting a fairly linear relationship between hours of care and employment (see Appendix Table B3).

Table 2.1 Demographic and caring role characteristics of primary carers aged 15-64 years caring for a person aged 15+ years whose main condition is mental illness (n=137)

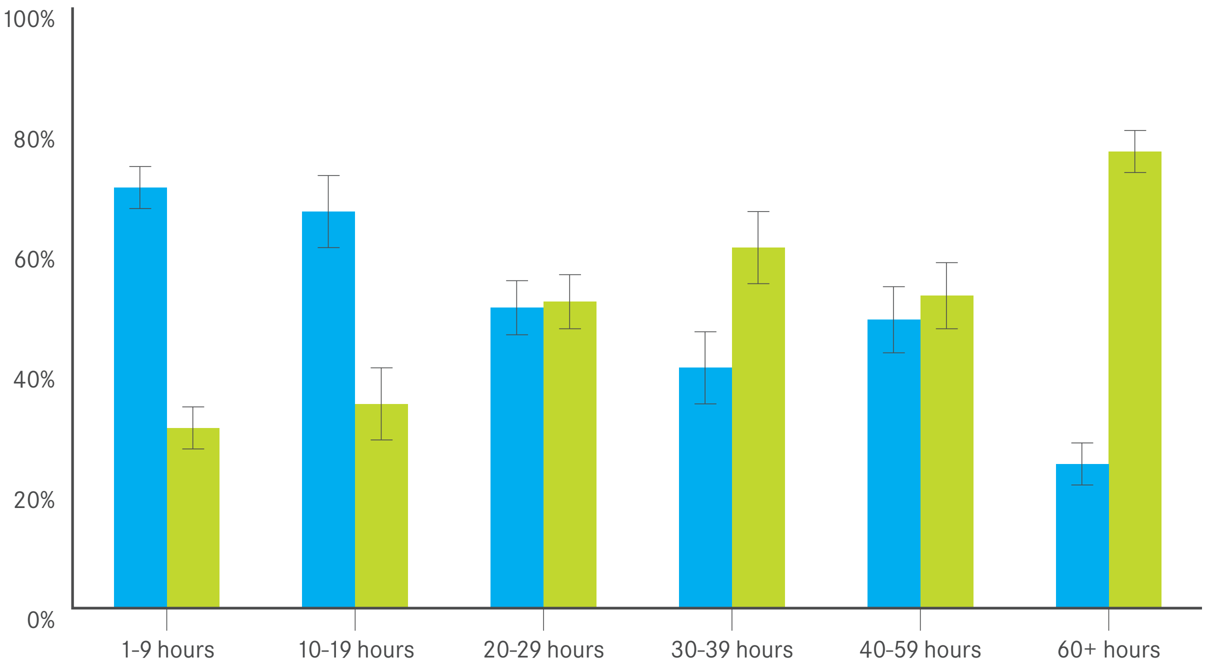
Characteristic	%	95% CI
Female	58.3	45.8-69.8
Age group		
15-44 years	33.4	25.6-42.3
45-54 years	29.3	21.8-38.1
55-64 years	37.3	28.9-46.4
Married	56.3	46.2-65.9
Lives in inner regional/other area (not major city)	34.3	23.7-46.6
Born outside Australia	27.8	19.7-37.8
Highest level of education: Year 12 or less[1]	54.5	43.9-64.8
Carer has a disability	46.3	35.9-57.0
More than one care recipient	26.8	19.3-36.1
Main recipient is their partner/adult child	79.7	69.8-86.9
Main recipient has profound limitation in core activities	35.6	27.4-44.8
Length of time caring[2]		
0-4 years	34.7	25.8-44.9
5-9 years	26.8	19.4-35.7
10+ years	38.5	28.8-49.2
Average weekly hours of care provided to all recipients[3]		
1-9 hours	27.9	20.2-37.1
10-19 hours	18.3	11.4-27.9
20-29 hours	11.4	5.7-21.3
30-39 hours	6.6	3.0-13.7
40-59 hours	6.7	3.1-13.8
60+ hours	29.2	20.4-40.0
Main recipient of care receives any formal services	53.3	44.1-62.3
Type of formal services received by care recipient(s)		
Assistance with cognitive or emotional tasks	45.9	37.0-55.0
Assistance with activities of daily living (ADLs)[4]	10.6	5.9-18.2
Assistance with practical tasks[5]	21.4	15.1-29.5
Frequency of formal assistance to care recipient(s)		
No formal assistance	45.8	36.5-55.3
Less than weekly	33.9	24.2-45.1
Weekly or more	20.4	13.6-29.3
Care recipient(s) has unmet need for assistance	43.9	35.3-52.9

1 Excludes two primary mental health carers whose education level was ‘not determined’.
2 Excludes two primary mental health carers who did not know how long they had been caring for.
3 Excludes nine primary mental health carers who did not know how many hours of care they provided.
4 Includes assistance with mobility and self-care.
5 Includes assistance with health care, household chores, meal preparation, property maintenance, reading or writing, communication, or transport.

Figure 2.1 Hours of care provided to all persons by primary mental health carers and other disability carers, by employment status (error bars represent 95% confidence intervals)



	1-9 hours	10-19 hours	20-29 hours	30-39 hours	40-59 hours	60+ hours
🟦 Employed	0.67	0.62	0.55	0.45	0.23	0.18
🟩 Not employed	0.33	0.38	0.45	0.55	0.77	0.82



	1-9 hours	10-19 hours	20-29 hours	30-39 hours	40-59 hours	60+ hours
🟦 Employed	0.70	0.66	0.50	0.40	0.48	0.24
🟩 Not employed	0.3 0	0.34	0.51	0.60	0.52	0.76

Table 2.2 Association between caring hours and not being employed for primary mental health carers aged 15-64 years (n=124)

Characteristic	% not employed (95% CI)	AOR (95% CI)	*p*
Average weekly hours of care			
1-9 hours	32.8 (17.1-53.6)	1.00	
10-19 hours	38.2 (16.5-65.9)	1.91 (0.40-9.06)	.411
20-39 hours	44.1 (22.7-67.9)	1.69 (0.53-5.45)	.371
40+ hours	81.8 (58.8-93.4)	13.38 (2.17-82.39)	**.006**
Sex			
Male	43.5 (27.8-60.7)	1.00	
Female	59.9 (44.3-73.7)	2.42 (0.85-6.92)	.097
Carer's own disability status			
No disability	42.3 (27.2-59.1)	1.00	
Has a disability	65.5 (51.0-77.6)	3.33 (1.13-9.84)	**.030**

AOR – adjusted odds ratio; CI – confidence interval.

Notes: *p*-values in **bold** are significant at $p<.05$. The following variables were initially included but were not significantly related to employment status and were therefore removed from the final regression model: carer age group, marital status, rurality, country of birth, highest level of education, number of care recipients, relationship to main recipient, main recipient of care limitation level, length of time caring, care recipient receipt of formal cognitive or emotional assistance, care recipient receipt of other formal assistance, and care recipient unmet need for assistance.

Association between hours of care and employment compared to other primary carers

Controlling for the impact of relevant covariates, there was no significant difference in the relationship between hours of care and employment status for primary mental health carers versus primary carers of other types of disabilities (Table 2.3). For both groups, primary carers who were providing more hours of support had significantly greater odds of not being employed. A series of equivalent regression models was subsequently run with binary hours of care variables representing the split at different levels (i.e. 10+ vs. <10 hours, 20+ vs <20 hours, 30+ vs. <30 hours, 40+ vs. <40 hours, 60+ vs. <60 hours), and the same results were observed regardless of the threshold (see Appendix Table B4).

Table 2.3 Association between caring hours, disability group of the person being cared for, and not being employed for primary carers aged 15-64 years (n=869)

Characteristic	% not employed (95% CI)	AOR (95% CI)	*p*
Recipient disability group			
Other condition	51.8 (47.5-56.1)	1.00	
Mental illness	52.8 (41.2-64.2)	1.06 (0.58-1.95)	.85
Average weekly hours of care			
1-9 hours	28.9 (22.6-36.1)	1.00	
10-19 hours	34.5 (24.8-45.6)	1.51 (0.68-3.38)	.30
20-39 hours	53.3 (47.2-59.2)	2.51 (1.34-4.71)	**.005**
40+ hours	72.1 (66.2-77.4)	8.31 (3.71-18.65)	**<.001**
Average weekly hours of care X recipient disability group interaction			.63
1-9 hours (other condition)	28.1 (21.5-35.8)	1.00	
10-19 vs. 1-9 hours (other condition)	33.8 (23.1-46.5)	1.37 (0.72-2.60)	.33
20-39 vs. 1-9 hours (other condition)	54.3 (47.8-60.6)	3.21 (2.18-4.73)	**<.001**
40+ vs. 1-9 hours (other condition)	70.9 (63.9-76.9)	6.96 (4.12-11.77)	**<.001**
1-9 hours (mental illness)	32.8 (17.1-53.6)	1.00	
10-19 vs. 1-9 hours (mental illness)	38.2 (16.5-65.9)	1.68 (0.40-7.03)	.47
20-39 vs. 1-9 hours (mental illness)	44.1 (22.7-67.9)	1.96 (0.59-6.47)	.26
40+ vs. 1-9 hours (mental illness)	81.8 (58.8-93.4)	9.93 (1.91-51.67)	**.007**
Sex			
Male	45.0 (39.2-50.8)	1.00	
Female	55.5 (50.2-60.7)	1.43 (1.02-2.00)	**.04**
Carer's own disability status			
No disability	44.9 (40.4-49.4)	1.00	
Has a disability	65.6 (59.0-71.6)	2.95 (2.05-4.24)	**<.001**
Main recipient is their partner or adult child			
Cares for another relative/friend only	58.6 (52.7-64.2)	1.00	
Cares for their partner/child	48.2 (43.3-53.1)	0.59 (0.43-0.82)	**.002**
Care recipient(s) receive other formal assistance			
Does not receive assistance	54.1 (49.7-58.5)	1.00	
Receives assistance	49.5 (43.6-55.4)	0.60 (0.46-0.79)	**<.001**

AOR – adjusted odds ratio; CI – confidence interval.

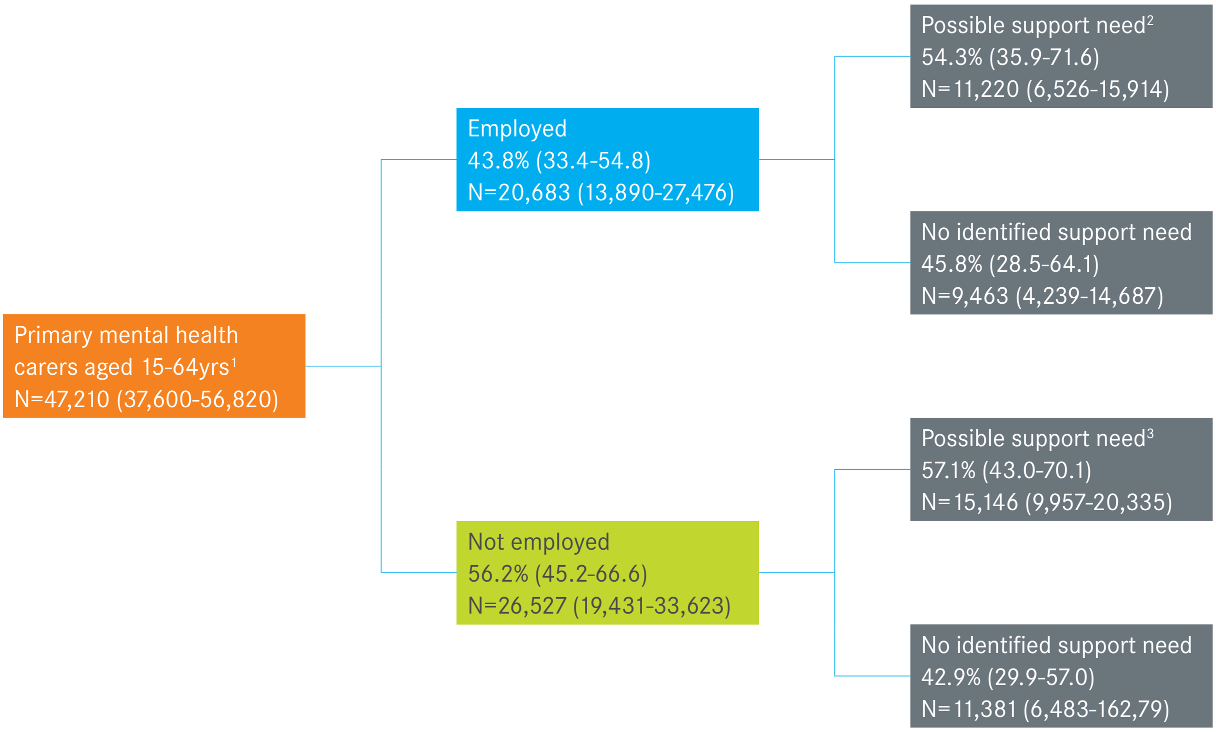
Notes: *p*-values in **bold** are significant at *p*<.05. The following variables were initially included but were not significantly related to employment status and were therefore removed from the final regression model: main recipient of care limitation level, and care recipient receipt of formal cognitive or emotional assistance.

Possible need for support

We estimated that just over half of primary mental health carers aged 15-64 years had a possible need for more support to maintain, improve or re-enter employment based on the available indicators (Figure 2.2). For employed carers, 54.3% or an estimated 11,220 people in 2015 had a possible support need based on caring for 40 or more hours per week, reducing their working hours to commence caring, wanting to work more hours, or wanting more use of special working arrangements. A further 3,116 (95% CI: 0-7,478) employed primary mental health carers had used special working arrangements to care for someone in the past 6 months but did not meet any of the above indicators and so were classified as having no identified unmet support need in their current employment situation. For carers who were not employed, 57.1% or an estimated 15,146 people had a possible support need based on having left employment to commence caring, or wanting to work while caring.

A more detailed breakdown of each of these factors is presented in Table 2.4. The vast majority (97.3%) of working primary mental health carers had some form of special working arrangement available to them, and 46.6% had made use of these in the past 6 months to care for someone. Only 12.1% reported wanting more use of these arrangements (either because they had not used them but wanted to, or they had used them but want to use more). Of carers who were not employed, 42.2% reported that they would like to work while caring. For those who wanted to work, the most frequently reported main barrier to re-entering the workforce while caring was that there were no alternative care arrangements available or it would cause disruption to the main person they supported (46.5% of carers who wanted to work). Workforce-related issues such as difficulty in arranging working hours, no work available, carer's age, lack of skills and experience, or a loss of skills from being out of the workforce were reported as the main barrier by a minority of carers who wanted to work (22.9%).

Figure 2.2 Weighted population estimates (N) of the number of working age primary mental health carers in Australia with possible needs for more support to maintain, improve or re-enter employment (n=137; brackets indicate 95% confidence intervals)



[1] Includes confirmed primary carers in the 2015 SDAC who are co-resident with their main recipient of care, where their main recipient of care is aged 15+ and has a mental illness as their main condition.

[2] Possible support need for working carers was identified as caring for 40+ hours per week, carers who reduced their working hours to commence caring, carers working part-time who report wanting more hours, or carers who wanted more use of special working arrangements.

[3] Possible support need for carers not currently employed was identified as carers who left employment to commence caring or those who reported wanting to work while caring.

Table 2.4 Employment status, barriers and unmet needs for primary mental health carers aged 15-64 years (n=137; weighted N 47,210)

Employment status and needs	Weighted N	95% CI	%	95% CI
Employed carers	20,683	13,890-27,476	43.8	33.4-54.8
Reduced working hours to care	8,554	4,612-12,495	41.4	25.5-59.2
Would like to work more hours (if part-time)	3,541	1,045-6,038	34.7	16.6-58.6
Special working arrangements (for employees)[1]				
Available to carer	15,978	9,518-22,437	97.3	89.8-99.3
Used in past 6 months for caring	7,660	2,175-13,145	46.6	26.0-68.5
Wanted more use of special working arrangements[2]	1,929	207-3,652	12.1	5.1-26.2
Unemployed or not in labour force carers	26,527	19,431-33,623	56.2	45.2-66.6
Worked just prior to commencing caring	12,476	7,553-17,400	47.0	32.7-61.8
Stopped working specifically to care (if worked prior to caring)	8,748	4,807-12,689	70.1	49.2-85.1
Main activity since last looking for work is caring	8,062	4,348-11,776	30.4	19.1-44.6
Would like to be employed while caring	11,181	7,056-15,306	42.2	30.3-55.0
Main perceived barrier to employment (if would like to work)				
No alternative care/disruption to care recipient	5,200	2,146-8,254	46.5	26.4-67.8
Workforce-related issues (age, skills, available jobs or hours)	2,561	162-4,960	22.9	8.7-48.0
Other (including own health) or none	3,420	964-5,876	30.6	14.4-53.6

[1] For carers who are employed but do not own their own business. Includes paid and unpaid leave (carer's or other), flexible working hours, rostered day off, working from home, shift work, casual work, part-time work , informal arrangement with employer, or other arrangements.

[2] The carer used special working arrangements but wanted more use, or did not use special working arrangements but wanted to. Excludes two primary carers who did not know whether special working arrangements were available and 1 who did not have access to these arrangements.

Discussion

As expected, for primary mental health carers in this study greater hours spent caring were significantly related to not being employed. In contrast with previous research[5,29-31,33,5]], we did not find a clear threshold at which this relationship became particularly significant, but rather a fairly linear inverse relationship where employment rates decreased steadily with increasing caring hours. Caring for as few as 10 hours per week was significantly related to not being employed compared to fewer hours, although we were not able to look at a threshold below 10 hours. When controlling for other factors related to employment, carers providing 40 or more hours of care per week showed significantly lower employment rates than those caring for less than 10 hours. This is understandable as 40 hours per week of caring is the equivalent time commitment to a full-time job, and would be difficult to manage alongside any significant paid employment role. There were no differences in the relationship between caring hours and employment for primary mental health carers versus primary carers for other conditions, consistent with our earlier finding from the broader 2015 SDAC mental health carer group that the types of caring tasks seem less relevant to employment status than the intensity of caring[51].

Roughly half of the primary mental health carers were identified as having a possible need for support to either maintain or increase their employment, or to re-enter the workforce for those not employed. This is higher than the proportion of carers identified in earlier UK work by King and colleagues[30], who classified 35% of all employed carers aged 16-64 years as at potential risk of leaving the workforce from caring for 10 or more hour per week, or 24% for 20 or more hours. However their study included all employed, working-age carers and focused only on caring hours, whereas our sample included just primary carers, who would be expected to provide more hours of care and to have higher support needs[33,49]. Since this study was limited to primary mental health carers, it is expected that the total number of mental health carers requiring support related to their employment would be higher, including those who are not primary carers but still provide significant assistance to a person with mental illness. The lack of information on caring impact and caring hours for this broader carer group in the 2015 SDAC prevented us from quantifying possible support needs in this larger cohort. In contrast to King et al[30], our judgement of support needs was also based on a composite variable of more than caring hours, taking into account adjustments carers had made to their employment to accommodate caring, high caring hours, wanting to work more, or reporting a need for more special working arrangements.

Of primary mental health carers who were not employed, 42.2% reported a desire to work. Since there are a range of benefits for carers to their finances, health and satisfaction from working[23,24], there is clearly scope to improve employment participation for these carers. Their reported perceived barriers to re-entering the workforce were more centred on the needs of the people they support than the suitability of the workforce or carers' own skills. Combined with the association between higher caring hours and lower employment rates, as well as our earlier findings that the level of impairment of the person supported and their use of formal services are related to mental health carers' employment[51], this suggests that a broader perspective on supporting carers in the workforce is warranted, taking into account their caring burden and the support needs of the person they care for.

Limitations

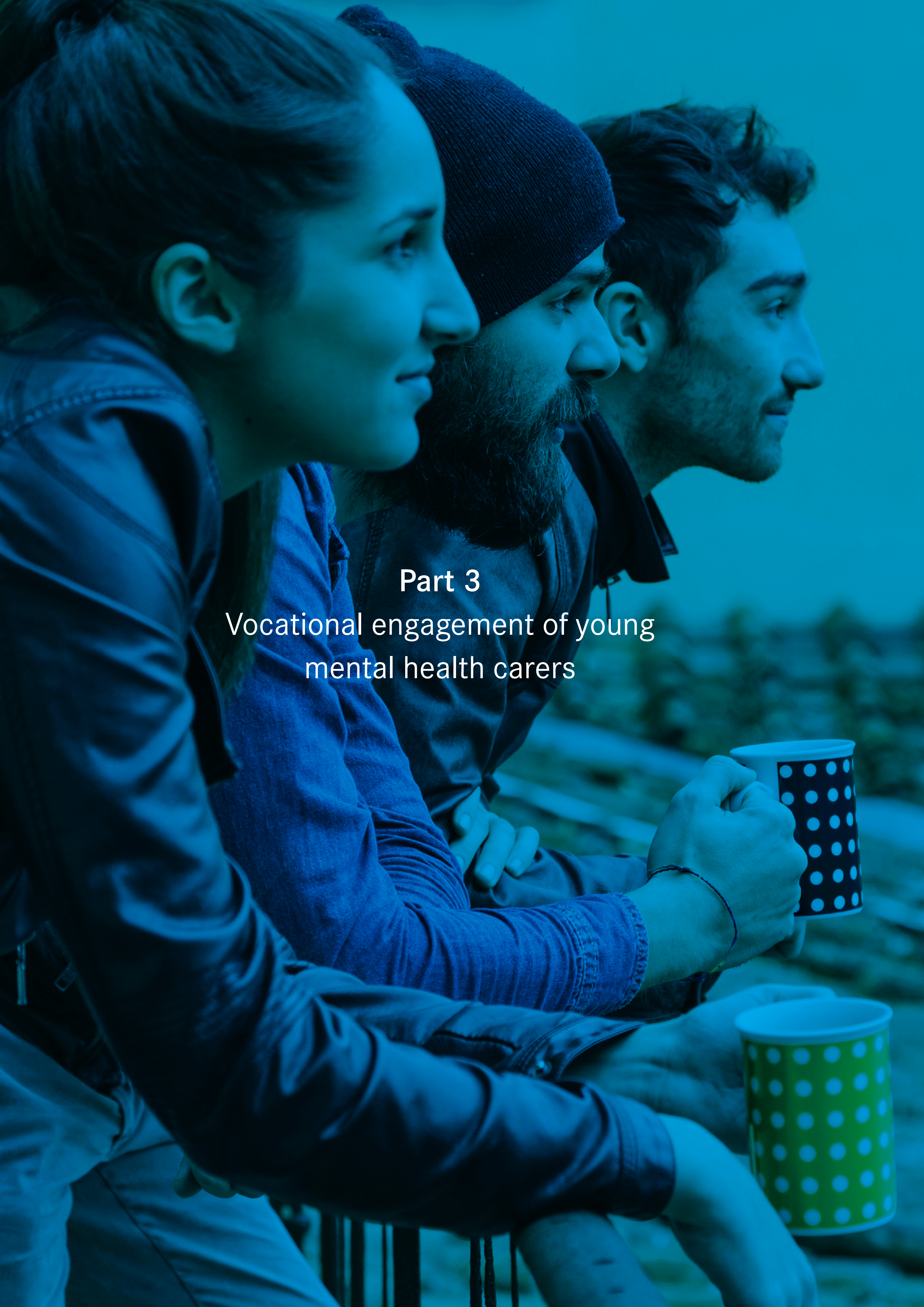
Use of the 2015 SDAC in this study, a comprehensive and nationally representative data source on Australian mental health carers', allowed for estimates at a national level. One key limitation of the analysis is that the data were cross-sectional. Hence it was not possible to identify the direction of the relationship between caring hours and employment; carers who provide a high number of support hours may need to exit the workforce, but also carers who are not employed may be able to provide more hours of support. Based on previous longitudinal studies, it is expected that intense caring hours for working carers do lead to a subsequent risk of leaving the workforce[5,31,39]. In future, available longitudinal carer studies could collect information about the conditions experienced by the people being cared for to allow the impact of caring hours on employment to be examined for mental health carers over time. Further, the hours of care data in the 2015 SDAC were collected in categorical format, limiting the analysis to set cut-off points.

This study was limited to co-resident primary mental health carers and may not generalise to a broader mental health carer population, including secondary carers and carers not living with the person they support. Generally, primary carers have the most intensive caring role, and have been found to have lower employment rates[33,49], so caring hours may be lower or less strongly associated with employment status for other carers. These other mental health carers still experience challenges in balancing their work and caring[51], and are also likely to need support even though we were not able to quantify that support in this study due to data limitations.

The 2015 SDAC did not include a specific module asking carers about their employment support needs. The categorisation of possible need for support in this study is therefore indicative based on the available data, but may have misclassified some carers. We did not include employed mental health carers who reported using special working arrangements in the past six months unless they also had other indicators of a possible support need. However, some of the carers who were caring for 40+ hours, or had reduced their working hours or left employment to care may have now managed in their current situation for a long period of time, or have already accessed additional support services which were not reported in the survey. Future research could build on these provisional results by collecting more information directly from mental health carers about their level of need for support to manage or engage with paid work.

Conclusion

While encouraging workplaces to provide more flexibility for carers and assisting those who are not in the workforce to access employment services are important, more could also be done to relieve some of the heavy reliance on carers to fill the gaps in mental health services[8]. Formal services never could or should completely replace the important and personalised support provided by mental health carers[1]. However, improving the effectiveness and accessibility of support services for both people with mental illness and their carers is likely to enable carers some respite and to help them sustain multiple roles of caring and paid work more easily[5,6,46]. Despite this, it should be noted that although many carers express a desire to work, some carers or the people they care for may be reluctant to accept help from organised support services. For example, analysis of the Survey of Carers in Households in England found that 15% of carers support people who would not want anyone else assisting them[52]. Further, the barriers to employment reported by primary mental health carers in our study may be related not just to the availability of other assistance for the individuals they support, but also the carer's assessment of the suitability, continuity and quality of these formal services. Therefore it is important that services are not only available but also meet the needs of service users. Assisting carers with an intensive support role to better balance their employment and caring responsibilities will have both economic benefits and significant benefits to carers' own financial stability and quality of life[26,53].



Part 3

Vocational engagement of young mental health carers

Introduction

Young carers aged under 25 years have been identified as a special interest group[54], where the caring tasks and responsibilities undertaken often go beyond what adults would normally expect of children and what most children would expect to do within the family[55-57]. In addition, these children and young people often carry out the same range of emotional and practical care activities as adult carers, and spend almost as much time thinking about and providing support to the people they care for[58]. Substantial time commitments to caring pose additional challenges in terms of participation in employment and education for young carers compared with their non-carer peers[59,60]. The impact of informal care on young people's futures may be most profound if they are unable to participate in either education or employment at the crucial stage of transition from high school to adulthood, with lasting negative effects on health, education, and skill development[59].

Young caring is surprisingly prevalent. The 2006 Australian Census of Population and Housing indicated that approximately 120,000 young people aged 15-24 years provide informal care on a regular or ongoing basis, whereas the 2003 Survey of Disability, Ageing and Carers (SDAC) found the number of young carers in this age group to be 240,000[54]. Of these young carers, an estimated one in three to four provides care to a person with mental illness[61-63]. Among mental health carers themselves, our recent report analysing the 2012 Survey of Disability, Ageing and Carers found that 14.7% of the 225,000 mental health carers were aged below 25 years[1].

National and international studies have consistently shown that young carers (regardless of the disability type of the person they support) tend to leave school earlier and are less likely to be in the labour force or employed compared to their non-carer peers[60]. Noble-Carr[64] reported that 60% of young primary carers aged 15-25 years were unemployed or out of the labour force, compared to 38% of the general Australian population aged 15-25. Only 4% of primary carers aged 15-25 years were still in education, in contrast with 23% of other young Australians of the same age[64]. In addition to leaving school earlier, young carers frequently report missing school, as well as having little or no time to complete homework due to their caring responsibilities[62].

Although there is growing evidence for employment and educational disadvantage among all young carers, little is known about young mental health carers in particular. Young mental health carers could be especially vulnerable, as the stigma attached to mental health problems means these young people may steer away from social activities and reduce opportunities for normal social and professional development[65,66]. In addition to mental health stigma, fear of unwanted intervention from social services has been identified in Australian and UK research as a key reason behind many young mental health carers' reluctance to seek support or assistance[66,67]. Also of particular relevance to this carer group are the unpredictable care requirements associated with episodic mental health problems[1], which could make regular school attendance and maintaining employment particularly difficult[65].

Small convenience sample studies of young carers have provided preliminary support for disadvantage among young mental health carers, where for example 68% of mental health carers aged 13-18 years (n=72) reported their caring role had affected their job prospects[68]. To our knowledge, no study to date has conducted a nationally representative analysis of employment and educational engagement of young Australian mental health carers, including comparisons with young non-carers and carers for other types of disabilities. The aim of this analysis was therefore to identify whether young mental health carers are less engaged in employment and education compared to young people who are not carers or who care for people with other conditions.

Method

Data source

We analysed data from the 2015 SDAC, a nationally representative household survey carried out by the Australian Bureau of Statistics (ABS) between July and December 2015. Details about this national survey and its sampling strategy have been described in earlier sections of this report.

Key variables

Informal carers

For this analysis, the population of interest was limited to carers aged 5-24 years, excluding those who are too young to participate in formal education. Consistent with the main employment analyses, four carer groups were created based on the main disabling condition of the person cared for: mental illness; other cognitive/behavioural conditions; and physical conditions with or without a secondary mental illness. Carers only providing support to people aged below 15 years were excluded. A comparison group of non-carers included young people aged 5-24 years who were not providing informal care to a person of any age with a disability or long-term health condition.

The 2015 SDAC identified confirmed young primary carers, a subset of all young carers aged 15-24 years, as the person providing the most assistance to a person with disability. Confirmed young primary carers (aged 15-24 years) were interviewed separately to collect additional information, including questions about the hours of care provided, duration of care, and other details about their caring role.

Education and employment

For those aged 5-14 years, we focused on whether participants were attending primary or secondary school (yes/no). For participants aged 15-24 years, a composite variable was developed for vocational engagement, incorporating both educational and employment roles, including: (1) full-time study (secondary school or post-secondary institution) or full-time employment; (2) part-time employment and/or study; and (3) not employed or studying (including other roles such as caring for someone with a disability or child care).

Data analysis

A Confidentialised Unit Record File (CURF; October 2016 version) of the 2015 SDAC was obtained from the ABS. Person-level, recipient-level and condition-level data files were merged to obtain estimates for all co-resident carers and their care recipients. Analyses were conducted in Stata 15, using survey weights provided by the ABS to account for possible selection and non-response biases, and differences between the sample and the Australian population. Survey-weighted proportions were produced to describe key demographic, educational and employment characteristics of each young carer group, and 95% confidence intervals (CIs) were calculated using Jackknife repeated replication. Chi-square tests compared young mental health carers to non-carers and carers of other disability types on: (1) school attendance for those aged 5-14 years; and (2) vocational engagement for those aged 15-24 years.

For the subgroup of young primary carers aged 15-24 years, a supplementary analysis was conducted to identify whether there was a relationship between caring load (i.e. duration of caring role and average weekly hours of care) and vocational engagement. Survey-weighted proportions and chi-square tests were produced for these carers across all disability types; young primary carer sample sizes were too small to focus specifically on mental health carers.

Results

Of the 537 young carers aged 5-24 years in the 2015 SDAC (weighted N=209,874), 14.6% (95% CI: 10.9-19.4) were caring for a person with mental illness. As seen in Table 3.1, just under half of young mental health carers and carers of other disability types were aged between 20-24 years. Most young mental health carers were male (68.3%), whereas for young carers of other disability types the gender ratio was fairly even. The majority of young mental health carers also lived in a major city, were born in Australia, and cared for their parent. This was similar to all other carers except for carers of other cognitive conditions, where less than 20% cared for a parent.

Vocational engagement

Nearly all young people aged 5-14 years were attending primary or secondary school, regardless of whether they were a carer or non-carer (Table 3.2). However, significantly fewer mental health carers were attending school compared to other carers (x^2(3, N=111)=11.26, *p*=0.03, Fisher's exact test, 2-tailed, unweighted), but not non-carers (x^2(1, N=7,975)=26.30, *p*=0.14).

Just over half (54.0%) of mental health carers aged 15-24 years were working or studying full-time, whereas 17.4% were engaged in work and/or study on a part-time basis (Table 3.2). Of young mental health carers aged 15-24, a sizeable proportion (28.6%) reported not studying or working at the time of the survey. There were significant differences between mental health carers and non-carers in terms of vocational engagement (x^2(2, N=7,014)=364.57, p<.001). Post-hoc pairwise comparisons (Bonferroni adjusted p-value) showed there were significantly more mental health carers who were not working or studying compared to non-carers (p<.001), as well as significantly less mental health carers employed or studying full-time compared to non-carers (p<.001). There was insufficient statistical power to compare vocational engagement across three levels by the four caring groups. When mental health carers were compared to all other carers aged 15-24 years, a significantly higher percentage were not employed or studying (x^2(1, N=426)=1128.22, *p*=0.03).

Table 3.1 Demographic characteristics for co-resident young carers aged 5-24 years caring for people aged 15+ years, by main condition of the person cared for

Carer characteristic	Co-resident young carer % (95% CI)				Not a carer (n=14,907) % (95% CI)
	Mental illness (n=82)	Other cognitive/ behavioural condition (n=47)	Physical health with secondary mental illness (n=133)	Physical health only (n=275)	
Female	31.7 (22.7-42.3)	55.4 (40.0-69.9)	51.7 (43.3-60.0)	46.0 (40.4-51.8)	48.8 (48.6-49.0)
Age group					
5-14 years	18.0 (9.7-30.8)	18.4 (9.4-32.9)	14.7 (9.6-21.8)	19.0 (13.4-26.1)	50.1 (49.9-50.4)
15-19 years	33.1 (21.9-46.6)	40.3 (22.8-60.6)	34.0 (25.8-43.3)	37.9 (31.2-45.2)	23.6 (23.4-23.8)
20-24 years	48.9 (34.4-63.7)	41.4 (26.4-58.1)	51.3 (41.1-61.4)	43.1 (36.1-50.5)	26.3 (26.0-26.6)
Lives in a major city	63.5 (45.4-78.4)	62.5 (42.5-79.0)	65.0 (52.4-75.8)	73.2 (63.6-80.9)	72.6 (70.9-74.3)
Born in Australia	85.1 (69.4-93.5)	91.4 (75.8-97.3)	87.5 (75.7-94.0)	84.8 (78.2-89.7)	85.8 (84.8-86.7)
Care recipient is their parent	72.4 (56.9-83.9)	16.9 (6.4-37.7)	79.1 (67.4-87.4)	73.6 (65.0-80.7)	N/A
Cares for >1 recipient	22.5 (12.2-37.7)	15.8 (7.5-30.0)	14.1 (7.6-24.7)	12.6 (7.8-19.7)	N/A

Table 3.2 Vocational engagement for co-resident young carers aged 5-24 years caring for people aged 15+ years, by main condition of the person cared for

Carer education (5-14 years)	Co-resident young carer % (95% CI)				Not a carer (n=7,958) % (95% CI)
	Mental illness (n=17)	Other cognitive/behavioural condition (n=12)	Physical health with secondary mental illness (n=24)	Physical health only (n=58)	
Attending primary/secondary school	87.2 (53.0-97.6)	100	100	100	95.7 (95.2-96.2)
Not attending school	12.8 (2.4-47.0)	0	0	0	4.3 (3.8-4.8)
Carer vocational engagement (15-24 years)	**Co-resident young carer % (95% CI)**				**Not a carer (n=6,949) % (95% CI)**
	Mental illness (n=65)	**Other cognitive/behavioural condition (n=35)**	**Physical health with secondary mental illness (n=109)**	**Physical health only (n=217)**	
Full-time employment or study	54.0 (39.8-67.7)	81.9 (64.4-91.9)	65.4 (53.8-75.3)	75.8 (68.1-82.2)	79.0 (77.9-80.1)
Part-time employment and/or study	17.4 (7.3-36.2)	9.6 (3.5-23.8)	12.2 (6.7-21.2)	11.4 (7.6-16.9)	12.3 (11.3-13.3)
Not employed or studying[1]	28.6 (17.2-43.5)	8.5 (2.3-26.7)	22.5 (14.6-33.0)	12.7 (8.1-19.6)	8.7 (7.8-9.6)

[1] This includes people who responded that their main activity since they last looked for work was: retired or voluntarily inactive; home duties or caring for children; attending an educational institution (in the past but not currently); own long-term health condition or disability; own short-term illness or injury; caring for ill/disabled/elderly person; travel, holiday, or leisure activity; working in unpaid voluntary job; other; or permanently unable to work.

Association with caring intensity

Within the subgroup of young primary carers aged 15-24 years (n=49), the relationship between caring load (duration and hours of care) and employment/education was investigated (Table 3.3). Among these primary carers, there were no statistically significant associations between vocational engagement and either duration of caring role in years, or average weekly hours of care.

Table 3.3 Association between caring role and vocational engagement for co-resident primary carers aged 15-24 years caring for people aged 15+ years, all conditions (n=49)

Caring intensity	Any employment or study % (95% CI) (n=29)	Not employed or studying % (95% CI) (n=20)	x^2 (df), p
Duration of caring[1]			
0-4 years	57.5 (36.9-75.8)	42.6 (24.3-63.2)	356.7 (1), .71
5+ years	65.0 (27.6-90.1)	35.0 (9.9-72.4)	
Weekly hours of care[2]			
1-19 hours	65.3 (41.3-83.4)	34.7 (16.6-58.7)	195.8 (1), .80
20+ hours	60.3 (28.9-85.0)	39.7 (15.0-71.1)	

1 Excludes two young primary carers who did not know how long they had been caring for.

2 Excludes five young primary carers who did not know how many hours of care they provided per week.

Discussion

Our analysis showed that in Australia, young mental health carers may be disadvantaged in terms of participation in education and employment compared to other young people of the same age. The majority of mental health carers aged 5-14 years were attending primary or secondary school (87.2%); however, this was significantly less than other carers, where 100% were in attendance at the time of the survey. For mental health carers aged 15-24 years, a greater proportion were not working or studying compared to non-carers and all other carers aged 15-24 years. The supplementary analysis of primary carers showed no significant association between caring intensity and vocational engagement for young primary carers. However, the latter analysis was conducted in a very small sample and results should be interpreted with caution.

Limitations

This analysis was based on data from a nationally representative household survey, which is considered to provide a more accurate estimate of the prevalence of young carers compared to the Australian Census[54], and captures young carers in the community, not just those who contact support services. However, there are limitations to the identification of carers, especially young carers in such surveys, and this data should be considered representative of households which include child caregiving and comprise people who are willing to discuss their situation. It is widely accepted that national surveys do not capture the full extent of caregiving provided by young people[56,69]. Reasons for undercounting of young carers include the fact that some people may not wish to reveal care needs and caregiving within their family, preferring to keep the matter private, while others may not recognise that the support they provide qualifies as 'caregiving'[54]. Further, only primary carers aged 15 and over in the 2015 SDAC were interviewed to report additional information about the intensity of their caring role, meaning very limited information was available for carers aged 5-14 years. Unfortunately this limitation is applicable to other available datasets on young carers, as there are lower age restrictions on most Australian nationally representative surveys. One Australian study[54] reported that roughly one third of primary carers aged 15-24 years for all types of conditions had left school at or before the age of 16 years. However due to the different age groups and measurement it is difficult to compare those findings with our results. There is still a gap in knowledge about caring in this difficult to reach younger age group which would benefit from targeted future research.

Some of the analyses suffered from small cell sizes (see Table 3.3), corresponding to the relatively small numbers of young carers included in the 2015 SDAC. This was particularly true for the 5-14 years group, where there were only 17 mental health carers, two of whom reported not attending school. Due to these small cell sizes, some estimates were produced with wide confidence intervals and therefore the size of the estimates should be interpreted with caution, as the inclusion of one or two atypical young people could have a significant impact on the overall results. Further, the 'not working or studying' category of our vocational engagement variable incorporated participants with fairly diverse responses ranging from volunteering to caring for children as their main activity. Interpretation of the results should take this into consideration – although a young person may not be currently studying or working, they may still be engaged in a socially valued role. Small numbers within this category prevented a further analysis of these diverse roles.

Finally, due to the cross-sectional nature of the 2015 SDAC survey, we are not able to draw conclusions from the analysis about the direction of relationship between caring and vocational engagement. While the mental health caring role may directly impact on young people's participation in work and study, it may also be true that young people caring for a relative with mental illness possess correlated factors like family disadvantage or their own health problems which contribute to their lower participation rates. It is well established that children living with a parent with mental illness, especially a severe illness, are at an elevated risk of a range of poorer outcomes compared to other young people, including future mental health problems and socio-economic disadvantage[70-72].

Implications

This analysis found that young mental health carers had lower rates of participation in education and employment than other carers and young people without caring responsibilities. Although we were not able to attribute these differences directly to the caring role, it is a likely contributing factor to these differences, along with other areas of disadvantage that may arise from living in a household where a family member has a mental illness. Young mental health carers may require additional support within the school context and potentially from the wider family environment. Specifically, processes may be required in the school system to better identify those students that provide intensive care to a relative with mental illness, to allow for ongoing monitoring, additional assistance from teaching staff, and provision of support from school counselling services where need be to prevent disengagement or poor outcomes. For older youth aged 15–24 years, similar policies may be required within the post-secondary education sector. This may require collective action from vocational, academic and administrative staff, as well as across university and vocational education counselling services to help identify and support tertiary students caring for a person with mental illness in order to prevent low attendance and dropout. Further changes in Australian workplaces may be required, particularly improvement of the awareness and understanding of the burden of mental health caring among industries who largely employ a young, casual workforce. Mental health literacy and stigma reduction programs have been improving community awareness about mental illness over time[73], however one of the challenges for better supporting young mental health carers may be in overcoming the remaining stigma to ensure that young people are willing to come forward and to access available supports.

Given the significant limitations of the small sample sizes and limited data on people aged below 15 years in the 2015 SDAC, the current findings need to be replicated in larger samples of young mental health carers of both age groups. These gaps provide suggestions for improving the collection of data about young Australian mental health carers. As outlined above, there is a need for more detailed information on carers below 15 years within the existing collections. Australian datasets, especially longitudinal studies, should routinely collect information about the condition of people being cared for to allow more detailed analyses and comparisons between carers of different conditions. Longitudinal analyses would allow researchers to track the educational and employment trajectories of young mental health carers over time, particularly during the critical transition from high school to adulthood, and to better determine whether the caring role precedes lower participation in work and study. It would also be useful for datasets to incorporate more information on education and employment histories, attendance and performance. This would allow for more nuanced investigations of carer vocational engagement; for example exploring the ‘not working or studying’ category further depending on whether a person only recently became unemployed or was experiencing an atypical week at the time of the survey, or exploring levels of absenteeism from school or work for young people engaged in these roles. While some data on young mental health carers are available through studies of service users or payment recipients, work to build more robust community datasets on these carers would enrich our understanding of the impact of caring for these young people.

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Appendix A

Table A1. Classification of main disabling condition of recipient of care from the 2015 Survey of Disability, Ageing and Carers

1. Mental illness	
0500	Mental and behavioural disorders n.f.d.
0512	Schizophrenia
0513	Depression/mood affective disorders (excluding postnatal depression)
0519	Other psychoses
0521	Phobic and anxiety disorders
0522	Nervous tension/stress
0529	Other neurotic, stress related and somatoform disorders
0591	Mental disorders due to alcohol and other psychoactive substance use
0594	Adult personality and behavioural disorders
0595	Attention deficit disorder/hyperactivity
0599	Other mental and behavioural disorders
2. Other cognitive/behavioural condition	
0511	Dementia
0530	Intellectual and developmental disorders n.e.c.
0531	Mental retardation/intellectual disability
0532	Autism and related disorders (including Rett's syndrome and Asperger's syndrome)
0539	Other developmental/learning disorders
0596	Speech impediment
0605	Alzheimer's disease
1605	Congenital brain damage/malformation
1709	Memory loss n.f.d.
1711	Insomnia n.f.d.
1798	Agitation or confusion n.f.d.
1801	Head injury/acquired brain damage
1908	Memory problems or periods of confusion
3. Physical condition	
0199	Certain infectious and parasitic diseases
0203	Skin cancer
0204	Breast cancer
0205	Prostate cancer
0211	Bowel/colorectal cancer
0299	Other neoplasms (including benign tumours)
0301	Anaemia
0399	Other diseases of the blood and blood forming organs and certain disorders involving the immune system
0401	Disorders of the thyroid gland
0402	Diabetes
0403	Obesity
0404	High cholesterol
0499	Other endocrine, nutritional and metabolic disorders
0602	Systemic atrophies primarily affecting the central nervous system
0604	Parkinson's disease
0606	Brain disease/disorders–acquired
0607	Multiple sclerosis
0608	Epilepsy
0609	Migraine
0611	Cerebral palsy

0612	Paralysis
0699	Other diseases of the nervous system (including T.I.A.'s)
0702	Cataracts
0703	Retinal disorders/defects
0704	Glaucoma
0707	Sight loss
0708	Macular degeneration
0799	Other diseases of the eye and adnexa
0802	Diseases of the middle ear and mastoid
0803	Diseases of the inner ear (except noise induced deafness)
0804	Tinnitus
0810	Deafness/hearing loss
0811	Deafness/hearing loss–noise induced
0812	Deafness/hearing loss–congenital
0813	Deafness/hearing loss–due to accident
0819	Other deafness/hearing loss
0899	Other diseases of the ear and mastoid process
0910	Heart disease
0913	Angina
0914	Myocardial infarction (heart attack)
0919	Other heart diseases
0920	Diseases of the circulatory system n.e.c.
0922	Hypertension (high blood pressure)
0923	Stroke
0925	Hypotension (low blood pressure)
0929	Other diseases of the circulatory system
1004	Emphysema
1005	Asthma
1007	Chronic Airflow Limitation (CAL)
1099	Other diseases of the respiratory system
1101	Stomach/duodenal ulcer
1102	Abdominal hernia (except congenital)
1103	Enteritis and colitis
1104	Other diseases of the intestine
1106	Diseases of the liver
1199	Diseases of the digestive system
1201	Skin and subcutaneous tissue infections
1202	Skin allergies (Dermatitis and Eczema)
1299	Other diseases of the skin and subcutaneous tissue
1301	Arthritis and related disorders
1303	Back problems (dorsopathies)
1304	Repetitive strain injury/occupational overuse syndrome
1306	Other soft tissue/muscle disorders (including Rheumatism)
1307	Osteoporosis
1399	Other disorders of the musculoskeletal system and connective tissue
1401	Kidney and urinary system (bladder) disorders (except incontinence)
1402	Stress/urinary incontinence
1403	Prostate disorders
1405	Menopause disorders

1499	Other diseases of the genitourinary system
1599	Certain conditions originating in the perinatal period
1699	Other congenital malformations and deformations
1701	Breathing difficulties/shortness of breath
1704	Pain n.f.d.
1705	Unspecified speech difficulties
1708	Blackouts, fainting, convulsions n.e.c.
1710	Incontinence n.f.d.
1713	Dysphagia (difficulty in swallowing)
1799	Other symptoms and signs n.e.c.
1802	Arm/hand/shoulder damage from injury/accident
1804	Leg/knee/foot/hip damage from injury/accident
1805	Amputation of toe/foot/leg
1808	Complications/consequences of surgery and medical care n.e.c.
1899	Other injury, poisoning and consequences of external causes
1901	Limited use of arms or fingers
1902	Difficulty gripping or holding things
1903	Limited use of feet or legs
1904	Restriction in physical activity or physical work
1905	Has disfigurement or deformity
1906	Receiving treatment/medication for other long term condition
1907	Has other long term condition

Table A2. Relationships between pairs of independent and dependent variables for multivariate logistic regression analyses, by carer sex (moderate associations >.30 in bold)

Variable 1	Variable 2	Cramer's V	*df*	*p*
Female mental health carers (n=268)				
Employment status	Age group	.30	2	<.001
	Marital status	-.04	1	.50
	Rurality	-.06	1	.36
	Country of birth	.13	1	.03
	Education level	.34	2	<.001
	Carer disability	.30	1	<.001
	Primary carer	.08	1	.18
	Number of recipients	.01	1	.83
	Cares for partner/child	-.10	1	.11
	Recipient disability level	.15	1	.01
	Recipient formal services	-.03	1	.60
Age group	**Marital status**	**.37**	**2**	**<.001**
	Rurality	.06	2	.66
	Country of birth	.18	2	.01
	Education level1	.17	4	.003
	Carer disability	.09	2	.38
	Primary carer	.11	2	.19
	Number of recipients	.06	2	.57
	Cares for partner/child	**.52**	**2**	**<.001**
	Recipient disability level	.03	2	.86
	Recipient formal services	.04	2	.76
Marital status	Rurality	-.02	1	.79
	Country of birth	.13	1	.03
	Education level	.13	2	.11
	Carer disability	-.10	1	.11
	Primary carer	-.03	1	.59
	Number of recipients	.11	1	.07
	Cares for partner/child	**.39**	**1**	**<.001**
	Recipient disability level	-.08	1	.18
	Recipient formal services	-.06	1	.36
Rurality	Country of birth	-.20	1	.001
	Education level	.05	2	.67
	Carer disability	-.10	1	.11
	Primary carer	.08	1	.17
	Number of recipients	-.01	1	.88
	Cares for partner/child	-.01	1	.89
	Recipient disability level	-.02	1	.71
	Recipient formal services	-.09	1	.14
Country of birth	Education level	.03	2	.87
	Carer disability	.05	1	.46
	Primary carer	.04	1	.47
	Number of recipients	.01	1	.85
	Cares for partner/child	.03	1	.57
	Recipient disability level	-.02	1	.67
	Recipient formal services	-.06	1	.32

Variable 1	Variable 2	Cramer's V	*df*	*p*
Education level	Carer disability	.13	2	.11
	Primary carer	.15	2	.05
	Number of recipients	.06	2	.57
	Cares for partner/child	.12	2	.14
	Recipient disability level	.20	2	.01
	Recipient formal services	.08	2	.43
Carer disability	Primary carer	.02	1	.71
	Number of recipients	.09	1	.13
	Cares for partner/child	.06	1	.32
	Recipient disability level	.05	1	.39
	Recipient formal services	-.01	1	.81
Primary carer	Number of recipients	.08	1	.19
	Cares for partner/child	-.06	1	.29
	Recipient disability level	**.57**	**1**	**<.001**
	Recipient formal services	.03	1	.64
Number of recipients	Cares for partner/child	.05	1	.37
	Recipient disability level	.13	1	.03
	Recipient formal services	.04	1	.54
Cares for partner/child	Recipient disability level	-.16	1	.01
	Recipient formal services	-.05	1	.40
Recipient disability level	Recipient formal services	.05	1	.39
Male mental health carers (n=238)				
Employment status	Age group	.14	2	.10
	Marital status	-.20	1	.003
	Rurality	.01	1	.92
	Country of birth	.07	1	.31
	Education level	.22	2	.003
	Carer disability	.25	1	<.001
	Primary carer	.14	1	.03
	Number of recipients	.06	1	.33
	Cares for partner/child	-.27	1	<.001
	Recipient disability level	.25	1	<.001
	Recipient formal services	-.19	1	.003
Age group	**Marital status**	**.58**	**2**	**<.001**
	Rurality	.12	2	.16
	Country of birth	.07	2	.57
	Education level1	.27	4	<.001
	Carer disability	.13	2	.14
	Primary carer	.20	2	.01
	Number of recipients	.05	2	.74
	Cares for partner/child	**.64**	**2**	**<.001**
	Recipient disability level	.11	2	.23
	Recipient formal services	.03	2	.90

Variable 1	Variable 2	Cramer's V	*df*	*p*
Marital status	Rurality	.07	1	.29
	Country of birth	.09	1	.19
	Education level	.22	2	.003
	Carer disability	-.09	1	.15
	Primary carer	.08	1	.19
	Number of recipients	.11	1	.08
	Cares for partner/child	**.58**	**1**	**<.001**
	Recipient disability level	.01	1	.83
	Recipient formal services	-.02	1	.80
Rurality	Country of birth	-.22	1	.001
	Education level	.17	2	.03
	Carer disability	.06	1	.35
	Primary carer	-.04	1	.49
	Number of recipients	-.12	1	.06
	Cares for partner/child	.05	1	.47
	Recipient disability level	.02	1	.74
	Recipient formal services	-.20	1	.003
Country of birth	Education level	.08	2	.50
	Carer disability	-.09	1	.15
	Primary carer	.06	1	.35
	Number of recipients	-.004	1	.96
	Cares for partner/child	.03	1	.70
	Recipient disability level	.08	1	.24
	Recipient formal services	-.06	1	.37
Education level	Carer disability	.08	2	.45
	Primary carer	.06	2	.65
	Number of recipients	.13	2	.12
	Cares for partner/child	.30	2	<.001
	Recipient disability level	.08	2	.43
	Recipient formal services	.16	2	.04
Carer disability	Primary carer	.13	1	.05
	Number of recipients	.11	1	.08
	Cares for partner/child	.02	1	.79
	Recipient disability level	.03	1	.61
	Recipient formal services	.05	1	.43
Primary carer	Number of recipients	.09	1	.15
	Cares for partner/child	.11	1	.08
	Recipient disability level	**.45**	**1**	**<.001**
	Recipient formal services	-.06	1	.37
Number of recipients	Cares for partner/child	.06	1	.38
	Recipient disability level	.22	1	.001
	Recipient formal services	.08	1	.20
Cares for partner/child	Recipient disability level	-.14	1	.03
	Recipient formal services	.07	1	.25
Recipient disability level	Recipient formal services	-.09	1	.16

Variable 1	Variable 2	Cramer's V	*df*	*p*
Female carers (all disability groups; n=1,485)				
Employment status	Recipient disability group	.04	1	.10
	Age group	.20	2	<.001
	Marital status	-.03	1	.26
	Rurality	.04	1	.13
	Country of birth	.07	1	.004
	Education level	.27	1	<.001
	Carer disability	.26	1	<.001
	Primary carer	.15	1	<.001
	Number of recipients	.04	1	.16
	Cares for partner/child	-.01	1	.64
	Recipient disability level	.14	1	<.001
	Recipient formal services	.001	1	.98
Recipient disability group	Age group	.06	2	.08
	Marital status	-.03	1	.33
	Rurality	.03	1	.27
	Country of birth	-.02	1	.52
	Education level	-.01	1	.75
	Carer disability	.13	1	<.001
	Primary carer	-.07	1	.008
	Number of recipients	.06	1	.02
	Cares for partner/child	.15	1	<.001
	Recipient disability level	-.13	1	<.001
	Recipient formal services	.09	1	<.001
Age group	**Marital status**	**.42**	**2**	**<.001**
	Rurality	.07	2	.04
	Country of birth	.10	2	.001
	Education level	.16	2	<.001
	Carer disability	.14	2	<.001
	Primary carer	.23	2	<.001
	Number of recipients	.06	2	.05
	Cares for partner/child	**.52**	**2**	**<.001**
	Recipient disability level	.06	2	.05
	Recipient formal services	.03	2	.44
Marital status	Rurality	.02	1	.36
	Country of birth	.16	1	<.001
	Education level	-.05	1	.05
	Carer disability	-.05	1	.04
	Primary carer	.11	1	<.001
	Number of recipients	.03	1	.30
	Cares for partner/child	**.52**	**1**	**<.001**
	Recipient disability level	.03	1	.21
	Recipient formal services	-.03	1	.21

Variable 1	Variable 2	Cramer's V	*df*	*p*
Rurality	Country of birth	-.21	1	<.001
	Education level	.04	1	.09
	Carer disability	.07	1	.01
	Primary carer	.04	1	.09
	Number of recipients	.01	1	.82
	Cares for partner/child	.13	1	<.001
	Recipient disability level	-.04	1	.18
	Recipient formal services	-.10	1	<.001
Country of birth	Education level	-.05	1	.046
	Carer disability	-.08	1	.003
	Primary carer	.02	1	.45
	Number of recipients	-.06	1	.02
	Cares for partner/child	-.01	1	.75
	Recipient disability level	-.004	1	.88
	Recipient formal services	-.06	1	.03
Education level	Carer disability	.09	1	.001
	Primary carer	.03	1	.31
	Number of recipients	-.05	1	.07
	Cares for partner/child	-.03	1	.23
	Recipient disability level	.05	1	.04
	Recipient formal services	-.05	1	.04
Carer disability	Primary carer	.05	1	.04
	Number of recipients	.08	1	.001
	Cares for partner/child	.13	1	<.001
	Recipient disability level	.02	1	.54
	Recipient formal services	.04	1	.15
Primary carer	Number of recipients	-.01	1	.57
	Cares for partner/child	.08	1	.001
	Recipient disability level	**.53**	**1**	**<.001**
	Recipient formal services	.11	1	<.001
Number of recipients	Cares for partner/child	.11	1	<.001
	Recipient disability level	.09	1	.001
	Recipient formal services	.15	1	<.001
Cares for partner/child	Recipient disability level	-.08	1	.003
	Recipient formal services	-.04	1	.11
Recipient disability level	Recipient formal services	.15	1	<.001

Variable 1	Variable 2	Cramer's V	*df*	*p*
Male carers (all disability groups; n=1,320)				
Employment status	Recipient disability group	.01	1	.64
	Age group	.17	2	<.001
	Marital status	-.19	1	<.001
	Rurality	.04	1	.13
	Country of birth	.04	1	.18
	Education level	.26	1	<.001
	Carer disability	.27	1	<.001
	Primary carer	.16	1	<.001
	Number of recipients	.04	1	.12
	Cares for partner/child	-.21	1	<.001
	Recipient disability level	.15	1	<.001
	Recipient formal services	-.04	1	.19
Recipient disability group	Age group	.05	2	.16
	Marital status	.05	1	.09
	Rurality	.04	1	.12
	Country of birth	.01	1	.80
	Education level	-.01	1	.73
	Carer disability	.04	1	.20
	Primary carer	-.01	1	.71
	Number of recipients	.13	1	<.001
	Cares for partner/child	.16	1	<.001
	Recipient disability level	-.03	1	.20
	Recipient formal services	.11	1	<.001
Age group	**Marital status**	**.50**	**2**	**<.001**
	Rurality	.07	2	.03
	Country of birth	.10	2	.001
	Education level	.18	2	<.001
	Carer disability	.21	2	<.001
	Primary carer	.17	2	<.001
	Number of recipients	.04	2	.39
	Cares for partner/child	**.51**	**2**	**<.001**
	Recipient disability level	.02	2	.69
	Recipient formal services	.05	2	.20
Marital status	Rurality	.01	1	.76
	Country of birth	.15	1	<.001
	Education level	-.26	1	<.001
	Carer disability	.06	1	.03
	Primary carer	.01	1	.60
	Number of recipients	.06	1	.03
	Cares for partner/child	**.63**	**1**	**<.001**
	Recipient disability level	-.03	1	.23
	Recipient formal services	.03	1	.25

Variable 1	Variable 2	Cramer's V	*df*	*p*
Rurality	Country of birth	-.26	1	<.001
	Education level	.04	1	.19
	Carer disability	.11	1	<.001
	Primary carer	-.02	1	.57
	Number of recipients	-.02	1	.48
	Cares for partner/child	.10	1	<.001
	Recipient disability level	-.01	1	.65
	Recipient formal services	-.07	1	.01
Country of birth	Education level	-.05	1	.06
	Carer disability	-.06	1	.02
	Primary carer	.03	1	.36
	Number of recipients	-.05	1	.07
	Cares for partner/child	.03	1	.27
	Recipient disability level	.04	1	.16
	Recipient formal services	-.02	1	.47
Education level	Carer disability	.07	1	.008
	Primary carer	-.02	1	.46
	Number of recipients	-.02	1	.46
	Cares for partner/child	-.25	1	<.001
	Recipient disability level	.03	1	.32
	Recipient formal services	-.02	1	.54
Carer disability	Primary carer	.08	1	.002
	Number of recipients	.04	1	.16
	Cares for partner/child	.12	1	<.001
	Recipient disability level	.03	1	.34
	Recipient formal services	.02	1	.43
Primary carer	Number of recipients	.03	1	.36
	Cares for partner/child	.05	1	.10
	Recipient disability level	**.42**	**1**	**<.001**
	Recipient formal services	.08	1	.004
Number of recipients	Cares for partner/child	.07	1	.01
	Recipient disability level	.14	1	<.001
	Recipient formal services	.15	1	<.001
Cares for partner/child	Recipient disability level	-.17	1	<.001
	Recipient formal services	.003	1	.92
Recipient disability level	Recipient formal services	.14	1	<.001

[1] Although age group and education level are both ordinal, there was a non-monotonic relationship between the two variables and so a test of ranked association was deemed inappropriate.

Table A3. Characteristics of co-resident carers aged 15-64 years, by main condition of the adult being cared for[1]

Carer characteristic	Female co-resident carer % (95% CI)			Male co-resident carer % (95% CI)		
	Mental illness (n=268)	Other condition (n=1,217)	x^2 (df), p	Mental illness (n=238)	Other condition (n=1,082)	x^2 (df), p
Age group			204.50 (2), .19			202.19 (2), .36
15-34 years	20.7 (15.7-26.8)	26.8 (24.1-29.6)		31.4 (24.8-38.8)	33.5 (30.0-37.2)	
35-54 years	49.2 (42.3-56.1)	44.8 (41.7-48.0)		44.6 (37.5-52.0)	38.1 (34.7-41.7)	
55-64 years	30.1 (23.8-37.3)	28.4 (25.9-31.0)		24.0 (17.1-32.6)	28.3 (25.3-31.6)	
Married	52.5 (45.6-59.3)	55.4 (52.1-58.7)	36.60 (1), .47	56.5 (49.2-63.5)	49.7 (46.2-53.2)	199.10 (1), .11
Lives in inner regional/other area (not major city)	36.7 (29.8-44.2)	31.5 (28.4-34.8)	128.58 (1), .22	31.0 (23.4-39.7)	30.1 (27.0-33.3)	4.32 (1), .84
Born outside Australia	22.7 (17.3-29.2)	25.9 (23.3-28.8)	57.85 (1), .33	28.0 (21.2-36.1)	25.8 (23.2-28.7)	26.47 (1), .57
Highest level of education: Year 12 or less	47.4 (40.3-54.5)	47.1 (43.8-50.4)	0.34 (1), .94	43.6 (34.8-52.7)	43.8 (41.0-46.7)	0.27 (1), .96
Carer has a disability	46.8 (40.2-53.5)	28.6 (25.8-31.6)	1611.33 (1), **<.001**	27.8 (21.9-34.7)	26.4 (23.5-29.6)	11.40 (1), .70
Is a confirmed primary carer	32.2 (25.6-39.8)	42.7 (39.4-46.1)	473.92 (1), .01	23.4 (18.1-29.7)	22.7 (20.2-25.5)	2.68 (1), .85
More than one care recipient	26.4 (20.9-32.8)	21.2 (18.7-23.8)	170.55 (1), .09	29.6 (22.6-37.8)	16.7 (14.3-19.4)	1175.53 (1), **<.001**
Cares for their partner/adult child	77.9 (71.6-83.1)	60.5 (57.5-63.4)	1369.81 (1), <.001	73.1 (66.1-79.1)	51.7 (48.4-55.0)	1990.68 (1), **<.001**
Recipient has profound or severe limitation in core activities	50.8 (42.8-58.7)	67.8 (64.7-70.7)	1340.59 (1), **<.001**	53.5 (44.5-62.2)	61.0 (57.5-64.4)	251.39 (1), .11
Care recipient(s) receives any formal services	56.8 (48.8-64.5)	47.2 (43.2-51.3)	387.71 (1), **.03**	60.1 (51.6-68.0)	49.7 (45.2-54.1)	465.91 (1), **.02**

[1] Excludes 59 carers whose education level was 'not determined'.

Table A4. Employment characteristics of carers and non-carers aged 15-64 years, by main condition of the adult being cared for

	Any co-resident carer % (95% CI)				Not a carer (n=35,400) % (95% CI)
	Mental illness (n=520)	Other cognitive/ behavioural condition (n=312)	Physical health with secondary mental illness (n=577)	Physical health only (n=1,455)	
Employment status					
Employed full-time	33.1 (28.1-38.4)	32.2 (26.3-38.6)	38.0 (33.6-42.6)	39.1 (36.3-41.9)	51.8 (51.1-52.4)
Employed part-time	24.7 (20.7-29.1)	27.9 (22.5-33.9)	19.7 (16.5-23.3)	22.6 (20.0-25.5)	24.2 (23.7-24.7)
Unemployed or not in labour force	42.3 (36.6-48.1)	40.0 (32.6-47.9)	42.3 (37.6-47.2)	38.3 (34.8-42.0)	24.0 (23.5-24.6)
Hours worked per week (if employed)					
1 to 15 hours	17.2 (12.8-22.8)	13.8 (9.7-19.3)	14.6 (10.6-19.8)	16.0 (13.6-18.8)	11.7 (11.3-12.1)
16 to 34 hours	25.5 (19.3-33.0)	32.6 (27.1-38.6)	19.5 (15.1-24.9)	20.6 (18.1-23.4)	20.2 (19.6-20.8)
35 to 40 hours	32.9 (26.4-40.2)	36.4 (28.7-44.9)	38.3 (32.1-44.8)	38.7 (35.5-42.1)	42.2 (41.4-42.9)
41 hours and over	24.3 (19.7-29.6)	17.1 (12.2-23.5)	27.6 (22.2-33.8)	24.6 (21.6-27.9)	26.0 (25.3-26.7)
Occupational group (if employed)1					
Manager or professional	36.3 (29.5-43.6)	32.3 (25.2-40.4)	33.6 (28.4-39.3)	32.9 (29.1-36.9)	37.1 (36.3-37.9)
Technician, trade, service, sales, clerical	41.1 (35.0-47.6)	52.9 (45.8-59.9)	43.1 (37.2-49.2)	48.7 (44.8-52.7)	47.3 (46.6-48.0)
Machinery operator, driver or labourer	22.6 (17.5-28.7)	14.8 (10.1-21.2)	23.3 (18.9-28.3)	18.4 (15.2-22.0)	15.7 (15.1-16.2)
Main activity (if not employed)					
Retired or permanently unable to work	22.1 (16.5-28.8)	23.0 (14.1-35.3)	21.2 (15.6-28.0)	22.0 (18.5-26.0)	18.7 (17.7-19.6)
Home duties/childcare	27.6 (20.8-35.6)	25.6 (18.4-34.4)	15.0 (10.8-20.1)	25.5 (21.9-29.5)	28.5 (27.5-30.0)
Study	11.4 (7.2-17.4)	10.8 (6.2-18.3)	13.8 (9.3-20.0)	14.2 (11.1-18.0)	30.7 (29.5-32.0)
Informal caring	17.0 (12.4-22.9)	31.8 (22.4-43.0)	30.8 (24.9-37.5)	22.1 (18.6-26.1)	0.7 (0.5-0.9)
Other (e.g. own health, travel, volunteering)	22.0 (17.0-27.9)	8.8 (4.8-15.3)	19.2 (14.4-25.2)	16.1 (12.9-20.0)	21.4 (20.4-22.4)

1 Excludes 2 carers of physical health only conditions and 50 non-carers who inadequately described their occupation.

Table A5. Impact of caring on employment for co-resident primary carers aged 15-64 years, by main condition of the adult being cared for

	Primary carer % (95% CI)			
	Mental illness (n=137)	Other cognitive/ behavioural condition (n=119)	Physical health with secondary mental illness (n=232)	Physical health only (n=470)
Employed	43.8 (33.4-54.8)	45.5 (33.9-57.6)	44.5 (37.6-51.7)	49.4 (44.4-54.4)
Worked prior to caring (if not employed)	47.0 (32.7-61.8)	53.6 (39.4-67.3)	53.8 (45.7-61.8)	46.9 (40.6-53.3)
Impact of caring on working hours (if employed or worked prior to caring)				
No reduction in hours[1]	47.8 (34.1-61.9)	44.1 (33.6-55.2)	51.1 (43.6-58.6)	55.4 (48.9-61.8)
Reduced working hours	25.8 (15.6-39.5)	31.5 (21.5-43.7)	21.0 (15.3-28.2)	23.6 (18.5-29.7)
Stopped working to care	26.4 (17.2-38.2)	24.3 (15.0-37.0)	27.8 (21.0-35.8)	21.0 (17.0-25.5)
Has had to leave work for 3+ months to care (if employed)	13.8 (7.0-25.5)	21.3 (10.0-39.6)	13.3 (7.4-22.8)	10.9 (6.9-16.9)
Needs time off work to care (if employed)	28.9 (17.9-43.2)	33.6 (20.5-49.9)	35.8 (27.3-45.3)	38.5 (31.8-45.7)

[1] Includes primary carers who have maintained or in some cases increased their working hours, and those who have since left work for a reason other than caring (e.g. own disability, retirement). Excludes primary carers who are not employed and did not work before commencing caring.

Table A6. Supplementary logistic regression analyses of association between recipient types of formal assistance, unmet need for assistance, other carer characteristics and not being employed for co-resident carers aged 15-64 years of adults with mental illness

Carer characteristic	Female carers (n=268)			Male carers (n=238)		
	% not employed (95% CI)	AOR (95% CI)	*p*	% not employed (95% CI)	AOR (95% CI)	*p*
Age group					ns	
15-34 years	64.7 (46.5-79.4)	1.00		36.5 (23.0-52.4)		
35-54 years	40.7 (31.1-51.1)	0.31 (0.11-0.86)	**.03**	24.0 (16.1-34.2)		
55-64 years	65.9 (50.1-79.0)	0.74 (0.24-2.34)	.61	38.2 (26.0-52.0)		
Highest level of education					ns	
Post-secondary degree/ certificate	36.6 (27.8-46.4)	1.00		23.4 (16.4-32.4)		
Year 11 or 12	67.9 (53.3-79.7)	3.09 (1.41-6.74)	**.005**	34.9 (21.6-51.0)		
Year 10 or less	74.1 (61.9-83.4)	3.86 (1.59-9.39)	**.004**	48.9 (33.8-64.2)		
Carer's own disability status						
No disability	40.3 (30.6-50.9)	1.00		24.7 (16.6-35.0)	1.00	
Has a disability	68.0 (58.5-76.1)	3.60 (1.68-7.69)	**.001**	48.6 (32.6-64.9)	3.76 (0.90-15.67)	.07
Cares for their spouse/partner or adult child		ns				
Cares for another relative/ friend only	65.9 (48.9-79.7)			49.3 (34.7-64.0)	1.00	
Cares for their partner/child	49.7 (41.4-57.9)			24.7 (18.7-31.9)	0.38 (0.14-1.05)	.06
Care recipient disability level						
Moderate or less limitation in core activities	42.1 (33.4-51.4)	1.00		16.2 (8.5-28.6)	1.00	
Profound or severe limitation in core activities	64.1 (52.5-74.2)	2.13 (1.02-4.43)	**.04**	44.5 (34.0-55.5)	3.87 (1.35-11.15)	.01
Care recipient(s) receipt of formal assistance with cognitive or emotional tasks		ns				
Does not receive emotional assistance	57.5 (46.3-68.1)			44.1 (34.1-54.5)	1.00	
Receives emotional assistance	48.8 (38.1-59.7)			19.8 (13.5-27.9)	0.35 (0.19-0.65)	.001

AOR – adjusted odds ratio; CI – confidence interval; ns – factor was not significantly related to employment at p>.10 and was not included in final model.

Notes: *p*-values in **bold** are significant at *p*<.05. The following variables were not significantly related to employment status and were removed from the final regression models: (1) for female mental health carers – marital status, rurality, country of birth, primary carer status, number of recipients of care, caring for their partner/child, care recipient unmet need for assistance, care recipient receipt of formal assistance with cognitive or emotional tasks, and care recipient receipt of formal assistance with other tasks; (2) for male mental health carers – age group, marital status, rurality, country of birth, education level, primary carer status, number of recipients of care, care recipient unmet need for assistance, and care recipient receipt of formal assistance with other tasks.

Table A7. Supplementary logistic regression analyses of association between recipient frequency of formal assistance, unmet need for assistance, other carer characteristics and not being employed for co-resident carers aged 15-64 years of adults with mental illness

Carer characteristic	Female carers (n=268)			Male carers (n=238)		
	% not employed (95% CI)	AOR (95% CI)	*p*	% not employed (95% CI)	AOR (95% CI)	*p*
Age group				ns		
15-34 years	64.7 (46.5-79.4)	1.00		36.5 (23.0-52.4)		
35-54 years	40.7 (31.1-51.1)	0.31 (0.11-0.86)	**.03**	24.0 (16.1-34.2)		
55-64 years	65.9 (50.1-79.0)	0.74 (0.24-2.34)	.61	38.2 (26.0-52.0)		
Highest level of education					ns	
Post-secondary degree/ certificate	36.6 (27.8-46.4)	1.00		23.4 (16.4-32.4)		
Year 11 or 12	67.9 (53.3-79.7)	3.09 (1.41-6.74)	**.005**	34.9 (21.6-51.0)		
Year 10 or less	74.1 (61.9-83.4)	3.86 (1.59-9.39)	**.004**	48.9 (33.8-64.2)		
Carer's own disability status						
No disability	40.3 (30.6-50.9)	1.00		24.7 (16.6-35.0)	1.00	
Has a disability	68.0 (58.5-76.1)	3.60 (1.68-7.69)	**.001**	48.6 (32.6-64.9)	3.99 (1.02-15.54)	**.046**
Cares for their spouse/partner or adult child		ns				
Cares for another relative/ friend only	65.9 (48.9-79.7)			49.3 (34.7-64.0)	1.00	
Cares for their partner/child	49.7 (41.4-57.9)			24.7 (18.7-31.9)	0.36 (0.12-1.12)	.08
Care recipient disability level						
Moderate or less limitation in core activities	42.1 (33.4-51.4)	1.00		16.2 (8.5-28.6)	1.00	
Profound or severe limitation in core activities	64.1 (52.5-74.2)	2.13 (1.02-4.43)	**.04**	44.5 (34.0-55.5)	4.39 (1.43-13.48)	**.01**
Care recipient(s) frequency of formal services		ns				
Does not receive services	55.3 (42.7-67.3)			44.3 (33.0-56.1)	1.00	
Receives services less than weekly	48.8 (36.6-61.2)			25.2 (17.1-35.5)	0.50 (0.23-1.09)	.08
Receives services weekly or more	57.5 (41.7-71.9)			18.2 (8.9-33.4)	0.23 (0.08-0.68)	**.009**

AOR – adjusted odds ratio; CI – confidence interval; ns – factor was not significantly related to employment at p>.10 and was not included in final model.

Notes: *p*-values in **bold** are significant at *p*<.05. The following variables were not significantly related to employment status and were removed from the final regression models: (1) for female mental health carers – marital status, rurality, country of birth, primary carer status, number of recipients of care, caring for their partner/child, care recipient unmet need for assistance, and care recipient frequency of formal assistance; (2) for male mental health carers – age group, marital status, rurality, country of birth, education level, primary carer status, number of recipients of care, and care recipient unmet need for assistance.

Appendix B

Table B1. Relationships between pairs of independent and dependent variables for multivariate logistic regression analyses (moderate associations >.30 in bold)

Variable 1	Variable 2	Cramer's V	*df*	*p*
Primary mental health carers (n=124)				
Employment status	Sex	.12	1	.18
	Age group	.16	2	.19
	Marital status	-.01	1	.94
	Rurality	-.04	1	.64
	Country of birth	.21	1	.02
	Education level	.19	1	.03
	Carer disability	.30	1	.001
	Number of recipients	.08	1	.38
	Cares for partner/child	-.16	1	.08
	Recipient disability level	.17	1	.06
	Length of time caring	-.07	1	.42
	Weekly hours of care	**.43**	**3**	**<.001**
	Recipient receives services	-.02	1	.80
	Recipient service frequency	.07	2	.73
	Recipient unmet need	.02	1	.80
	Recipient emotional services	-.08	1	.37
	Recipient other services	-.12	1	.18
Sex	Age group	.01	2	.99
	Marital status	-.10	1	.27
	Rurality	.08	1	.39
	Country of birth	-.03	1	.75
	Education level	.10	1	.29
	Carer disability	-.02	1	.86
	Number of recipients	-.02	1	.82
	Cares for partner/child	-.04	1	.69
	Recipient disability level	-.02	1	.81
	Length of time caring	-.01	1	.93
	Weekly hours of care	.10	3	.76
	Recipient receives services	.02	1	.81
	Recipient service frequency	.07	2	.77
	Recipient unmet need	-.16	1	.08
	Recipient emotional services	-.02	1	.85
	Recipient other services	.06	1	.52

Variable 1	Variable 2	Cramer's V	*df*	*p*
Age group	Marital status	.19	2	.10
	Rurality	.06	2	.79
	Country of birth	.13	2	.34
	Education level	.18	2	.14
	Carer disability	.14	2	.30
	Number of recipients	.09	2	.62
	Cares for partner/child	.16	2	.19
	Recipient disability level	.13	2	.35
	Length of time caring	.23	2	.03
	Weekly hours of care	.06	6	.99
	Recipient receives services	.07	2	.71
	Recipient service frequency	.06	4	.94
	Recipient unmet need	.03	2	.95
	Recipient emotional services	.02	2	.98
	Recipient other services	.21	2	.06
Marital status	Rurality	-.06	1	.48
	Country of birth	.12	1	.17
	Education level	-.10	1	.27
	Carer disability	.01	1	.90
	Number of recipients	.09	1	.30
	Cares for partner/child	**.34**	**1**	**<.001**
	Recipient disability level	-.18	1	.05
	Length of time caring	.25	1	.006
	Weekly hours of care	.18	3	.26
	Recipient receives services	-.07	1	.45
	Recipient service frequency	.07	2	.76
	Recipient unmet need	.003	1	.98
	Recipient emotional services	-.08	1	.36
	Recipient other services	-.01	1	.94
Rurality	Country of birth	-.17	1	.06
	Education level	.05	1	.57
	Carer disability	-.03	1	.77
	Number of recipients	-.10	1	.26
	Cares for partner/child	-.05	1	.62
	Recipient disability level	-.18	1	.05
	Length of time caring	.11	1	.23
	Weekly hours of care	.08	3	.83
	Recipient receives services	-.08	1	.36
	Recipient service frequency	.18	2	.12
	Recipient unmet need	.02	1	.86
	Recipient emotional services	-.07	1	.47
	Recipient other services	-.08	1	.40

Variable 1	Variable 2	Cramer's V	*df*	*p*
Country of birth	Education level	.20	1	.03
	Carer disability	-.05	1	.60
	Number of recipients	-.15	1	.10
	Cares for partner/child	.01	1	.90
	Recipient disability level	.19	1	.03
	Length of time caring	.02	1	.83
	Weekly hours of care	.28	3	.02
	Recipient receives services	-.09	1	.30
	Recipient service frequency	.16	2	.20
	Recipient unmet need	.02	1	.83
	Recipient emotional services	-.13	1	.15
	Recipient other services	-.05	1	.57
Education level	Carer disability	.10	1	.27
	Number of recipients	-.23	1	.01
	Cares for partner/child	-.13	1	.14
	Recipient disability level	.06	1	.54
	Length of time caring	-.01	1	.88
	Weekly hours of care	.20	3	.16
	Recipient receives services	-.02	1	.84
	Recipient service frequency	.06	2	.83
	Recipient unmet need	-.01	1	.88
	Recipient emotional services	-.08	1	.37
	Recipient other services	-.06	1	.48
Carer disability	Number of recipients	.12	1	.17
	Cares for partner/child	-.02	1	.82
	Recipient disability level	-.11	1	.22
	Length of time caring	.07	1	.46
	Weekly hours of care	.15	3	.43
	Recipient receives services	.03	1	.77
	Recipient service frequency	.13	2	.37
	Recipient unmet need	.07	1	.43
	Recipient emotional services	-.02	1	.86
	Recipient other services	.07	1	.43
Number of recipients	Cares for partner/child	.04	1	.67
	Recipient disability level	-.08	1	.39
	Length of time caring	.05	1	.60
	Weekly hours of care	.10	3	.74
	Recipient receives services	.03	1	.74
	Recipient service frequency	.22	2	.05
	Recipient unmet need	.15	1	.09
	Recipient emotional services	.11	1	.23
	Recipient other services	.11	1	.21

Variable 1	Variable 2	Cramer's V	*df*	*p*
Cares for partner/child	Recipient disability level	-.26	1	.004
	Length of time caring	.29	1	.001
	Weekly hours of care	.24	3	.08
	Recipient receives services	.05	1	.62
	Recipient service frequency	.07	2	.71
	Recipient unmet need	.04	1	.69
	Recipient emotional services	.14	1	.12
	Recipient other services	.02	1	.82
Recipient disability level	Length of time caring	-.06	1	.51
	Weekly hours of care	**.50**	**3**	**<.001**
	Recipient receives services	-.06	1	.49
	Recipient service frequency	.06	2	.80
	Recipient unmet need	-.01	1	.95
	Recipient emotional services	-.10	1	.26
	Recipient other services	-.08	1	.38
Length of time caring	Weekly hours of care	.08	3	.83
	Recipient receives services	-.01	1	.93
	Recipient service frequency	.04	2	.91
	Recipient unmet need	.01	1	.93
	Recipient emotional services	<.001	1	1.00
	Recipient other services	-.03	1	.71
Weekly hours of care	Recipient receives services	.12	3	.64
	Recipient service frequency	.12	6	.72
	Recipient unmet need	.13	3	.55
	Recipient emotional services	.05	3	.96
	Recipient other services	**.31**	**3**	**.007**
Recipient receives services	**Recipient service frequency**	**.97**	**2**	**<.001**
	Recipient unmet need	.18	1	.04
	Recipient emotional services	**.85**	**1**	**<.001**
	Recipient other services	**.57**	**1**	**<.001**
Recipient service frequency	Recipient unmet need	.19	2	.11
	Recipient emotional services	**.85**	**2**	**<.001**
	Recipient other services	**.61**	**2**	**<.001**

Variable 1	Variable 2	Cramer’s V	*df*	*p*
Recipient unmet need	Recipient emotional services	.26	1	.004
	Recipient other services	-.004	1	.96
Recipient emotional services	**Recipient other services**	**.33**	**1**	**<.001**
All primary carers (n=869)				
Employment status	Recipient disability group	<.001	1	.99
	Sex	.11	1	.001
	Carer disability	.23	1	<.001
	Cares for partner/child	-.10	1	.005
	Recipient disability level	.15	1	<.001
	Weekly hours of care	**.35**	**3**	**<.001**
	Recipient emotional services	-.05	1	.16
	Recipient other services	-.01	1	.74
Recipient disability group	Sex	-.04	1	.22
	Carer disability	.09	1	.01
	Cares for partner/child	.11	1	.001
	Recipient disability level	-.09	1	.01
	Weekly hours of care	.08	3	.18
	Recipient emotional services	.27	1	<.001
	Recipient other services	-.13	1	<.001
Sex	Carer disability	-.001	1	.97
	Cares for partner/child	.07	1	.04
	Recipient disability level	.01	1	.79
	Weekly hours of care	.14	3	.001
	Recipient emotional services	.01	1	.67
	Recipient other services	.001	1	.97
Carer disability	Cares for partner/child	.11	1	.001
	Recipient disability level	-.07	1	.06
	Weekly hours of care	.03	3	.89
	Recipient emotional services	.03	1	.37
	Recipient other services	.02	1	.66
Cares for partner/child	Recipient disability level	-.21	1	<.001
	Weekly hours of care	.15	3	<.001
	Recipient emotional services	.13	1	<.001
	Recipient other services	-.10	1	.002
Recipient disability level	**Weekly hours of care**	**.46**	**3**	**<.001**
	Recipient emotional services	-.03	1	.36
	Recipient other services	.14	1	<.001
Weekly hours of care	Recipient emotional services	.04	3	.76
	Recipient other services	.18	3	<.001
Recipient emotional services	Recipient other services	.15	1	<.001

Table B2. Characteristics of primary carers aged 15-64 years, by main condition of the adult being cared for[1]

Carer characteristic	Primary mental health carer % (95% CI) (n=124)	Other primary carer % (95% CI) (n=745)	x^2 (df), *p*
Female	56.8 (43.0-69.7)	67.4 (63.8-70.7)	416.72 (1), .12
Age group			37.39 (2), .80
15-44 years	34.6 (25.8-44.6)	31.5 (28.1-35.1)	
45-54 years	28.9 (21.0-38.3)	30.1 (26.8-33.7)	
55-64 years	36.5 (27.4-46.7)	38.4 (35.0-42.0)	
Married	57.0 (46.1-67.2)	59.8 (54.8-64.5)	27.60 (1), .62
Lives in inner regional/other area	36.9 (25.7-49.8)	32.8 (29.1-36.7)	64.01 (1), .50
Born outside Australia	26.9 (18.3-37.6)	27.5 (23.8-31.6)	1.64 (1), .90
Highest level of education: Year 12 or less	53.0 (42.9-62.8)	45.2 (41.3-49.1)	205.29 (1), .20
Carer has a disability	45.4 (34.3-57.0)	32.5 (28.9-36.4)	620.84 (1), .04
More than one care recipient	26.3 (18.4-36.2)	22.3 (19.2-25.7)	77.63 (1), .39
Main recipient is their partner/adult child	77.0 (66.4-85.0)	61.8 (58.1-65.4)	837.72 (1), .008
Main recipient has profound limitation	40.0 (30.7-50.1)	49.9 (46.0-53.7)	327.30 (1), .09
Caring for 10+ years	36.6 (26.5-48.1)	39.0 (35.0-43.2)	20.63 (1), .69
Average weekly hours of care			403.90 (3), .28
1-9 hours	29.0 (21.1-38.2)	21.9 (18.6-25.7)	
10-19 hours	19.0 (11.8-29.1)	15.8 (13.5-18.5)	
20-39 hours	17.2 (10.2-27.4)	23.0 (19.7-26.7)	
40+ hours	34.9 (25.5-45.6)	39.2 (35.1-43.5)	
Main recipient receives any formal services	53.7 (44.1-63.0)	53.7 (49.3-57.9)	0.01 (1), .99
Frequency of formal assistance to care recipient(s)			124.11 (2), .56
No formal assistance	45.2 (35.5-55.3)	43.7 (39.4-48.1)	
Less than weekly	32.2 (22.9-43.2)	28.6 (25.5-31.9)	
Weekly or more	22.6 (15.2-32.2)	27.7 (23.9-31.9)	
Recipient(s) receive formal emotional assistance	46.6 (37.4-55.9)	17.8 (14.9-21.2)	4108.42 (1), <.001
Recipient(s) receive other formal assistance	29.3 (20.3-40.2)	50.2 (45.6-54.8)	1476.26 (1), <.001
Care recipient(s) has unmet need for assistance	40.7 (32.6-49.3)	46.3 (42.9-49.8)	107.97 (1), .23

[1] Excludes 89 carers with undetermined education level, unknown caring duration or unknown hours of care.

Table B3. Logistic regression model adjusted odds ratios for binary hours of care categories for primary mental health carers (n=124), controlling for sex and carer's own disability (see Table 2.2 for further model description)

Average weekly hours of care	AOR	95% CI	*p*
10+ vs. 1-9 hours	4.29	1.36-13.58	**.014**
20+ vs. 1-19 hours	4.57	1.64-12.75	**.004**
30+ vs. 1-29 hours	7.56	2.16-26.47	**.002**
40+ vs. 1-39 hours	9.49	1.91-47.02	**.007**
60+ vs. 1-59 hours	7.90	1.33-46.93	**.024**

AOR – adjusted odds ratio; CI – confidence interval.

Notes: *p*-values in **bold** are significant at *p*<.05.

Table B4. Logistic regression model adjusted odds ratios for binary hours of care categories for primary carers by disability group of the person cared for (n=869), controlling for sex, carer's own disability, caring relationship, and receipt of other formal assistance by the person supported (see Table 2.3 for further model description)

Average weekly hours of care	Recipient disability group	AOR	95% CI	*p*
10+ vs. 1-9 hours	Other condition	3.84	2.54-5.80	**<.001**
	Mental illness	3.69	1.18-11.54	**.03**
20+ vs. 1-19 hours	Other condition	4.50	3.10-6.53	**<.001**
	Mental illness	4.27	1.59-11.47	**.005**
30+ vs. 1-29 hours	Other condition	4.03	2.71-5.98	**<.001**
	Mental illness	5.93	1.91-18.44	**.003**
40+ vs. 1-39 hours	Other condition	3.92	2.64-5.81	**<.001**
	Mental illness	7.19	1.62-32.00	**.01**
60+ vs. 1-59 hours	Other condition	5.14	3.23-8.17	**<.001**
	Mental illness	6.02	1.12-32.22	**.04**

AOR – adjusted odds ratio; CI – confidence interval.

Notes: *p*-values in **bold** are significant at *p*<.05.

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