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ORIGINAL PAPER

Hours of Care and Caring Tasks Performed by Australian Carers of Adults with Mental Illness: Results from an Online Survey

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Abstract

The aim of this study was to provide a detailed profile of the hours of care Australian mental health carers provide for different types of caring tasks. The UQ Carer Survey 2016 was administered online to 105 adults caring for someone aged 16 years or older whose main condition is mental illness. Mental health carers reported providing on average 37.2 h of care per week to their main care recipient. Carers spent most of their active caring time providing emotional support, and the least of their time assisting with activities of daily living. Carers highlighted that this care time fluctuates with the undulating nature of mental illness, and many noted additional hours devoted to being 'on call' in case of emergency. Carers provide large amounts of support on a long-term and often unpredictable basis. Government services need to match the undulating nature of the illness by providing more flexible support options for mental health carers.

Keywords Carers · Caregivers · Mental health · Mental illness · Australia

Introduction

Having a mental illness, particularly a more severe illness, can have significant negative impacts on social relationships, vocational outcomes, and motivation and ability to complete regular household activities and self-care (Australian Bureau of Statistics [ABS] 2007). These functional difficulties can persist even when clinical symptoms of the illness respond to treatment, leading to an ongoing need for formal or informal support (Harris et al. 2015). Informal caring i.e. unpaid caring usually provided by a family member or friend (Australian Institute of Health and Welfare [AIHW] 2004) plays a significant role in providing support and assistance to people with mental illness. Informal carers are essential for providing intensive, ongoing support, and in turn reducing the demands on formal mental health support services (van Excel et al. 2007). In 2009, 1% of Australians aged 15 years or over (177,900 persons) reported providing informal care to a co-resident with a psychological disability (Harris et al. 2015). In an Australian national survey of adults living with psychosis (n = 1825), 25% reported receiving support from an informal carer in the previous 12 months (Morgan et al. 2012).

In spite of the important role of carers in the lives of those with mental illness, surprisingly little is known about the hours of care and caring tasks performed by informal carers. Previous Australian studies (ABS 2008, 2012; Coomber and King 2013; Jardim and Pakenham 2010; Loi et al. 2015) have relied on a mixture of national epidemiological surveys and small carer samples recruited through carer organisations, with widely varying results. Available studies have tended to focus on either the number of hours of care provided by mental health carers each week to their care recipients, or the proportions of these carers who perform different types of caring tasks as part of their role. More detailed information about the types and amount of support provided by Australian mental health carers is needed to better understand the needs of carers and their care recipients, and to better design our

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mental health system to support them in their caring role. In particular, a breakdown of hours of care by caring tasks, including time spent actively caring versus standby time, is required.

Estimates of the average hours spent caring vary by study and country. In small-scale Australian studies, adult mental health carers report providing on average 53–104 h of care per week to their care recipient or recipients with mental illness (Coomber and King 2013; Jardim and Pakenham 2010, 2009; Loi et al. 2015; Mackay and Pakenham 2012; Mental Health Council of Australia [MHCA] 2000). Australian national surveys, including the 2003 and 2009 Survey of Disability, Ageing and Carers (SDAC) (ABS 2008, 2012), have taken an alternative approach and recorded average hours of weekly care in categories. The two surveys were fairly consistent, with 59% (2009 SDAC) to 66% (2003 SDAC) of co-resident primary carers i.e. the person who provides the most informal assistance (AIHW 2004) providing 40 h or more of care per week to persons with a psychological disability. However, these estimates are crude, with the majority of survey participants grouped into the third category of 40 h or more per week. International studies have mainly focused on hours of care provided by all types of carers (13.9 h of care per week in WHO Mental Health Survey of 43,732 adults in 19 countries (Viana et al. 2013)), or specifically carers of people with schizophrenia and other psychotic disorders (3–6.1 h of care per day (Grover et al. 2014; Kate et al. 2013; Mangalore and Knapp 2007); 22.5–68.19 h per week (Aranda-Reneo et al. 2013; Flyckt et al. 2013; Patel et al. 2014; Roick et al. 2007)). International hours of care estimates tend to be lower than Australian studies, which could be due to differences in mental health systems across countries, as well as different sampling methodologies.

In terms of the types of tasks performed by mental health carers, the 2009 SDAC (ABS 2012) found that 91.7% of co-resident primary carers of someone with a psychological disability (n = 75,500) provided cognitive and emotional assistance; 71.4% provided assistance with transport or other practical support; and 54.8% provided assistance with self-care. Estimates from the 2007 National Survey of Mental Health and Wellbeing (NSMHWB) (Pirkis et al. 2010) were smaller, which could be due to its more inclusive definition of 'carer'; of those adult carers of relatives with a mental illness, 60.4% provided emotional support; 37.8% provided practical support; and 11.7% helped with washing, dressing, or eating. Neither of these national survey estimates captured any information about the frequency at which these tasks were performed or the time spent on each task. A survey in one Australian state (Carers Victoria 2013) presented richer data on the care activities performed daily by a proportion of survey participants. Of the total convenience sample of 165 mental health carers, 87% provided daily emotional support; 58% supervised household tasks on a daily basis; and 43–44% provided daily support for eating/drinking and self-care.

A pattern emerges in the literature, with provision of emotional support reported by the majority of mental health carers, followed by practical support (e.g. transportation, managing finances), and lastly support for activities of daily living (ADL) e.g. feeding and dressing. However, few studies even in the general carer literature provide data on the breakdown of hours of care by type of care activity (Gaugler et al. 2003; Haro et al. 2014; Hassink and Van den Berg 2011; Pressler et al. 2013; van den Berg and Spauwen 2006; Wimo et al. 2010). To our knowledge, only one study (Flyckt et al. 2013) presents data on hours dedicated to different types of mental health caring tasks. Flyckt et al. (2013) collected daily diary data from Swedish carers of people with a psychotic disorder, where they reported on hours of care for household work (5.1 h per week), support in practical and economics work (0.6 h per week), contacts with health care (0.9 h per week), travel to the care recipient (1.3 h per week) and standby time (11.2 h per week). These findings are important for carers of persons with psychosis; however, they cannot be generalised to carers of people with other mental illnesses (e.g. anxiety, depression, personality disorders), or to mental health carers in other countries where the formal support systems may be quite different and would likely impact on how much responsibility falls to the informal carer. Also, the caring tasks captured were limited, notably it did not measure the provision of emotional support and, like many existing studies (ABS 2012; Pirkis et al. 2010; Carers Victoria 2013), it did not follow a standardised list such as the Caring Tasks in Caring for an Adult with Mental Illness Scale (CTiCAMIS) (Pakenham 2012).

The interpretation of available data is further complicated by differences in definitions and sampling. Most carer studies did not distinguished between primary and secondary carers, where the secondary carer is the person who shares or assists with the informal care duties (AIHW 2004). Secondary carers have typically been overlooked and therefore estimates of hours of care are likely positively skewed. Many studies were ambiguous or inconsistent in terms of which disorders were in scope for 'mental illness' (Jardim and Pakenham 2010; Mackay and Pakenham 2012; MHCA 2000), particularly in terms of neurological disorders (e.g. dementia), intellectual disability, and primary substance use disorders, which have been recognised by the American Psychiatric Association and other authorities as overlapping but distinct conditions from mental illness (Andrews et al. 2009; Chaplin 2004; Einfeld et al. 2011). Some studies only included co-resident carers (ABS 2008, 2012; Loi et al. 2015), whilst others included carers of persons under the age of 16 years (ABS 2008, 2012; Coomber and King 2013; Loi et al. 2015). Caring for a child with mental illness is entangled with the regular responsibilities of parenting

and tends to involve caring for a substantially different profile of mental and behavioural disorders (Merikangas et al. 2009). Finally, many studies have not distinguished active caring time (i.e. the time spent caring as a result of the care recipient's mental illness) from standby time, or time 'on call' or in close connection to the care recipient in case of emergency (Flyckt et al. 2013); thus may overestimate the time carers spent actively caring for their care recipient.

The aim of this study was to provide a detailed profile of the hours of care Australian mental health carers provide for different types of caring tasks (i.e. psychosocial or emotional care, practical tasks, ADLs), with a breakdown of primary versus secondary carer and active caring versus standby time. This analysis was undertaken to inform an economic modelling study estimating a replacement cost for informal mental health care in Australia. The results of the economic modelling will be reported elsewhere (citation will be supplied in a future erratum).

Methods

Design and Context

The UQ Carer Survey 2016 was an online survey of Australian adults caring for someone aged 16 years or older whose main condition is mental illness. The survey was created using SurveyMonkey (SurveyMonkey 2016) and its results contributed to a broader project commissioned by Mind Australia, to estimate the replacement cost of mental health carers in Australia.

Ethical approval for survey data collection was obtained from The University of Queensland Behavioural & Social Sciences Ethical Review Committee (Approval Number 2015001907). Informed consent was obtained from all individual participants included in the study.

Participants and Recruitment Procedure

Participants were a convenience sample of 105 informal carers of people with a mental illness. For this survey, a person was deemed a mental health carer if they were: aged 18 years or older; cared for someone aged 16 years or over whose main condition was mental illness; and were not employed to provide their caring role. This did not exclude people receiving a government benefit such as Carer Payment or Allowance. Mental illness included schizophrenia, schizoaffective disorder and other psychoses; bipolar disorder; major depression; anxiety disorders; personality disorders; eating disorders; and behavioural disorders. It did not include a primary diagnosis of autism spectrum disorder, intellectual disability, substance use disorder or neurological disorder e.g. stroke, epilepsy and dementia.

Participants were recruited from Australian state and territory carer networks and organisations, including members of Mental Health Carers Arafmi Australia (MHCAA) and the Mental Illness Fellowship in each state and territory. An email invitation containing the SurveyMonkey link was sent to each of these carer organisations to circulate within their networks. The survey was open for 7 weeks (28 March 2016–16 May 2016).

Measures

Demographics

The survey included a section comprising questions about the carer's demographics characteristics (age, sex, country of origin, state of residence, language spoken at home, Indigenous status); their caring role (number of care recipients, number of years caring, relationship to care recipient, receipt of government income support payment); and each care recipient's demographic and disability characteristics. The majority of these questions were modified from the 2012 SDAC interview schedule (ABS 2013) and the 2011 Carers Victoria Survey (Carers Victoria 2013).

Caring Relationship

The Caring Relationship section included questions about the average weekly hours of care and types of caring tasks provided by the carer, which were based on previous caring task studies (Jardim and Pakenham 2010; Mackay and Pakenham 2012; Pakenham 2012; Pakenham et al. 2005).

Caring Tasks Most caring tasks included in the survey were derived from the CTiCAMIS (Pakenham 2012; Pakenham et al. 2005). This scale has three underlying caregiving factors: activities of daily living (ADL), instrumental ADL (IADL; or practical tasks), and psychosocial care. Caring tasks included in the current survey were divided into these three factors. In addition to the CTiCAMIS, caring tasks were derived from the 2012 SDAC (ABS 2013) and the 2011 Carers Victoria Survey (Carers Victoria 2013).

For each caring task, participants were asked "do you provide regular assistance with any of the following tasks?" Following this, carers were asked to estimate the average weekly hours spent on a higher-level categorisation of these tasks: emotional support and encouragement; supervising and monitoring; responding to behaviour; household tasks; health care coordination; literacy and communication; transport; other practical tasks; and ADLs. To be consistent with previous studies and to reduce the burden on survey participants, these questions were asked with respect to the main mental health care recipient only.

Hours of Care Participants were asked about the total time spent actively caring for their main care recipient as a result of their mental illness versus time spent in standby or 'on call'. Participants were firstly asked, "On average, how many hours do you spend each week providing care to your main recipient of care?" Participants were prompted to consider, "all the hours you listed in the previous question, adjusted for any overlap across tasks, as well as any additional time spent on caring tasks that have been overlooked". In this question (and in the other hours by care task questions), we clarified that this was the care that goes beyond what would normally be expected of the relationship e.g. more than support you provide to other relatives who do not have a mental illness. Following this question, participants were asked, "Do you spend time in your own home or in your care recipient's home or in close connection to their location so you can be available to them quickly if necessary? If yes, in an average week how many hours do you spend in standby for your main recipient of care?"

Participants were also asked about time in transit (hours: minutes) and mode of transportation, if they did not live with their main recipient of care. If a carer provided support to more than one mental health care recipient, they were also asked to estimate the average time spent caring for these additional care recipients each week. Of this total caring time, they were asked how many hours on average each week they devoted to (1) emotional support, (2) practical tasks, and (3) ADLs.

Data Analysis

Quantitative Analysis

Completed survey data were exported from the SurveyMonkey website into SPSS version 22.0 (IBM Corp 2013). Analyses were descriptive, involving the calculation of proportions and means. Bootstrapping was used to calculate 95% confidence intervals for proportions. Outliers were identified in the hours of care data. In response to average weekly hours of care, some carers reported providing 168 h of active care to their main care recipient (n = 7), and to their other care recipients (n = 2), not including standby time. These outliers were removed prior to data analysis because it would be almost impossible to provide this level of care over the course of a week without ever sleeping.

Thematic Analysis

At the end of the UQ Carer Survey 2016, carers were asked, "If you have any other comments to add about your caring role, please outline below". This was an optional, open-ended response type, which allowed carers to provide comprehensive qualitative responses about any topic they wished to discuss. A thematic analysis (Braun and Clarke 2006) was conducted to summarise the open-ended responses. An initial reading was conducted by one researcher (EH), using an inductive or bottom-up approach to allow themes to emerge from the data, rather than searching for pre-defined themes. A second researcher (SD) then read the original qualitative responses as well as the key themes proposed by EH, and the themes were discussed and refined with agreement between the two researchers. A final review was conducted by EH by taking each theme separately and re-examining the original qualitative data.

Results

Carer and Care Recipient Demographics

Table 1 describes the demographic characteristics of the carer and care recipients. The majority of mental health carers were female, married, of working age (25–64 years), and lived in the capital cities of Victoria and Queensland. Most had been caring for either their child or partner for more than 10 years. Over 80% identified as a primary carer, i.e. the person who provides the most informal assistance (AIHW 2004). Just over half (55.8%) received any form of government income support. The Australian Government provides two main types of income support payments to mental health carers (as seen in Table 1). The Carer Payment is a means-tested pension payment available to eligible applicants who provide 'constant care' to a person with either a permanent disability or a disability with an expected duration greater than 6 months. On the other hand, the Carer Allowance is a smaller payment in recognition of the caring role which is not means tested, paid at a flat rate per fortnight. In terms of care recipients, most were working-aged (25–64 years) males living with schizophrenia (or psychosis), depression or anxiety. The majority were also living with a comorbidity, particularly a physical restriction or substance abuse disorder.

Caring Tasks

Nearly all carers provided assistance with emotional support (100%) and practical tasks (98.1%) to their main mental health care recipient (see Table 2). The most commonly reported tasks included: 'encouraging and/or prompting to do things'; 'encouraging and motivating'; and 'liaising with health professionals'. Assistance with ADLs was provided by a smaller but still sizeable percentage of carers. The most commonly reported ADL task was personal hygiene and grooming (37.1%).

Table 1 Socio-demographics of mental health carers, their care recipients and the caring role in the UQ Carer Survey 2016

Variable	n	% (95% CI)
Carer (n = 105)		
Age in years		
M (SD)	–	56.6 (14.0)
Range	–	20–87
18–24 years	2	1.9 (0.0–4.8)
25–64 years	72	68.6 (60.0–78.1)
65 + years	31	29.5 (21.0–38.1)
Gender		
Male	12	11.4 (5.7–18.1)
Female	93	88.6 (81.9–94.3)
Marital status		
Married	67	63.8 (54.3–73.3)
Widowed	4	3.8 (1.0–7.6)
Separated/divorced	26	24.8 (17.1–33.3)
Never married	8	7.6 (2.9–13.3)
Country of birth		
Australia	84	80.8 (73.1–88.5)
Other	20	19.2 (11.5–26.9)
Aboriginal or Torres Strait Islander	2	1.9 (0.0–5.7)
Language spoken at home		
English	103	99.0 (97.1–100)
Other	1	1.0 (0.0–2.9)
Urbanicity		
Capital city	70	68.0 (59.2–76.7)
Balance of state	33	32.0 (23.3–40.8)
State of residence		
New South Wales	17	16.5 (9.7–23.3)
Victoria	27	26.2 (18.4–35.0)
Queensland	32	31.1 (22.3–39.8)
South Australia	12	11.7 (5.8–18.4)
Western Australia	12	11.7 (5.8–18.4)
Tasmania	1	1.0 (0.0–2.9)
Northern Territory	1	1.0 (0.0–2.9)
Australian Capital Territory	1	1.0 (0.0–2.9)
Caring role (n = 128 carer-care recipient dyads)		
Number of mental health care recipients[a]		
One	84	80.0 (71.5–87.6)
Two or more	21	20.0 (13.3–28.6)
Carer status		
Primary[b]	109	85.8 (79.5–91.3)
Secondary[b]	12	9.4 (4.7–15.0)
Unsure	6	4.7 (1.6–8.7)
Relationship: care recipient is a…		
Parent	7	5.5 (1.6–9.4)
Spouse/partner	33	25.8 (18.8–33.6)
Child	70	54.7 (46.1–63.3)
Other relative, friend, neighbour	18	14.1 (7.8–20.3)
Lives with care recipient	74	57.8 (49.2–65.6)
Length of time caring		
0–4 years	26	20.3 (14.1–27.3)
5–9 years	25	19.5 (13.3–27.3)

Table 1 (continued)

Variable	n	% (95% CI)
10–14 years	20	15.6 (9.4–21.9)
15–19 years	18	14.1 (7.8–20.3)
20 + years	39	30.5 (22.7–39.8)
Recipient of government income support payment[a]		
Carer payment (with/without carer allowance)	15	14.4 (7.7–21.2)
Carer allowance (with/without carer payment)	33	31.7 (22.1–41.3)
Carer payment and allowance	13	12.4 (6.7–19.0)
Age pension	17	16.3 (9.6–23.1)
Disability support pension	7	6.7 (1.9–12.5)
Parenting payment	2	1.9 (0.0–4.8)
Newstart allowance	6	5.8 (1.9–10.6)
Other[c]	7	6.7 (1.9–12.5)
Care recipient (n = 128)		
Age in years		
M (SD)	–	42.0 (17.0)
Range	–	16–84
16–24 years	17	13.3 (7.8–18.8)
25–64 years	94	73.4 (65.6–80.5)
65 + years	17	13.3 (7.8–19.5)
Gender		
Male	84	65.6 (57.0–74.2)
Female	44	34.4 (25.8–43.02)
Mental illness diagnosis[d]		
Schizophrenia/psychosis	42	33.1 (25.2–40.9)
Depression	30	23.6 (17.3–31.5)
Anxiety	26	20.5 (13.4–26.8)
Borderline personality disorder	12	9.4 (4.7–15.0)
Bipolar disorder	10	7.9 (3.1–12.6)
Other mental illness[e]	7	5.5 (1.6–10.2)
Comorbidities[d]		
Physical restriction	31	26.1 (18.5–33.6)
Substance misuse or dependence	26	21.8 (15.2–29.4)
Acquired brain injury, epilepsy, dementia	9	7.6 (3.4–12.6)
Autism spectrum disorder	7	5.9 (1.7–10.1)
Intellectual disability	6	5.0 (1.7–9.2)
Sensory and speech	3	2.5 (0.0–5.9)

[a]In reference to the 105 carers, not the 128 carer-care recipient dyads

[b]Primary carer is the person responsible for the majority of informal caring, whereas a secondary carer shares or assists with informal care duties

[c]Other centrelink payment types: family tax benefit, assistance for isolated children scheme, senior supplement

[d]Care-recipient diagnoses were reported by the carer. This was not verified with a formal diagnosis

[e]Other mental illnesses: anorexia or bulimia nervosa, attention deficit hyperactivity disorder (ADHD)/attention deficit disorder (ADD), suicide risk

Hours of Care

Carers estimated that they provide on average 37.2 h of care per week (*SD* = 31.7, Range = 1–127) to their main mental health care recipient. Most carers were primary mental health carers; when secondary carers were excluded, the mean was slightly higher at 39.6 h of care per week (*SD* = 32.1, Range = 2–127)[1]. When hours of care were

[1] Missing data for hours of care dedicated to main care recipient. All carers: missing data for 5 participants, 5 outliers excluded who reported 168 h of care weekly. Primary carers: missing data for 6 participants, 10 not applicable (either secondary carer or not sure), 5

Table 2 Caring tasks and proportion of carers performing tasks in the UQ Carer Survey 2016 (n = 105)

Type of caring task	% (95% CI)	Source of item
Emotional support and psychosocial care	100	
Emotional support and encouragement		
Encouraging and/or prompting to do things	94.3 (89.5–98.1)	CTiCAMIS
Encouraging and motivating	93.3 (88.6–97.1)	Carers Victoria Survey
Providing intensive emotional support and companionship	82.9 (75.2–89.5)	CTiCAMIS
Supervising and monitoring		
Keeping recipient occupied	58.1 (47.6–67.6)	CTiCAMIS
Supervising to prevent wandering, pacing, damage to self, others or property	29.5 (21.9–38.1)	CTiCAMIS
Responding to behaviour		
Managing crises	88.6 (81.9–94.3)	Carers Victoria Survey
Managing inappropriate behaviours	56.2 (45.7–66.7)	CTiCAMIS
Other emotional support tasks	49.5 (41.0–59.0)	–
Practical tasks	98.1 (95.2–100)	
Household tasks		
Preparing meals	61.9 (52.4–71.4)	CTiCAMIS
Housework	60.0 (50.5–69.5)	CTiCAMIS
Grocery shopping	59.0 (49.5–68.6)	CTiCAMIS
Property maintenance	53.3 (42.9–61.9)	2012 SDAC
Health care coordination		
Assisting/informing/liaising with health professionals	81.9 (74.3–89.5)	Carers Victoria Survey
Supervision/prompting of medication	52.4 (42.9–61.9)	Carers Victoria Survey
Assisting with carrying out treatment plan (other than medication)	50.5 (41.0–60.0)	Carers Victoria Survey
Arranging supervision/services	45.7 (35.2–55.2)	CTiCAMIS
Literacy and communication		
Managing finances/paying bills	68.6 (59.0–77.1)	CTiCAMIS
Other paper work on behalf of care recipient	61.0 (50.5–70.5)	Carers Victoria Survey
Communication	44.8 (36.2–54.3)	2012 SDAC
Reading and writing	18.1 (11.4–24.8)	2012 SDAC
Transport	53.3 (42.9–62.8)	CTiCAMIS
Other practical tasks	40.0 (30.5–49.5)	–
Activities of daily living	61.0 (52.4–69.5)	
Personal hygiene/grooming	37.1 (28.6–47.6)	–
Bathing/showering	25.7 (18.1–34.3)	CTiCAMIS
Eating	24.8 (16.2–33.3)	CTiCAMIS
Dressing	11.4 (5.7–18.1)	CTiCAMIS
Mobility e.g. getting in/out of bed	7.6 (2.9–13.3)	CTiCAMIS
Other ADL tasks	14.3 (7.6–21.0)	–

CTiCAMIS caring tasks in caring for an adult with mental illness scale, *2012 SDAC* survey of disability, ageing and carers, *ADL* activities of daily living

grouped into categories equivalent to those in an Australian national survey (i.e. the SDAC), 40.0% of all carers reported providing 40 h or more of care per week, which is greater than a standard full-time working week in Australia (see Fig. 1). The majority of secondary carers reported providing less than 20 h of care per week (see Fig. 1).

On average, carers spent most of their caring time providing emotional support and psychosocial care (67.9% of support time), and spent the smallest proportion of their caring time providing assistance with ADL tasks (3.0% of support time) (see Fig. 2). Summing the hours of care reported separately against each of these categories produced a total hours

Footnote 1 (continued)

outliers excluded who reported 168 h of care weekly. Secondary carers: missing data for 2 participants, 88 not applicable (either primary carer or not sure).

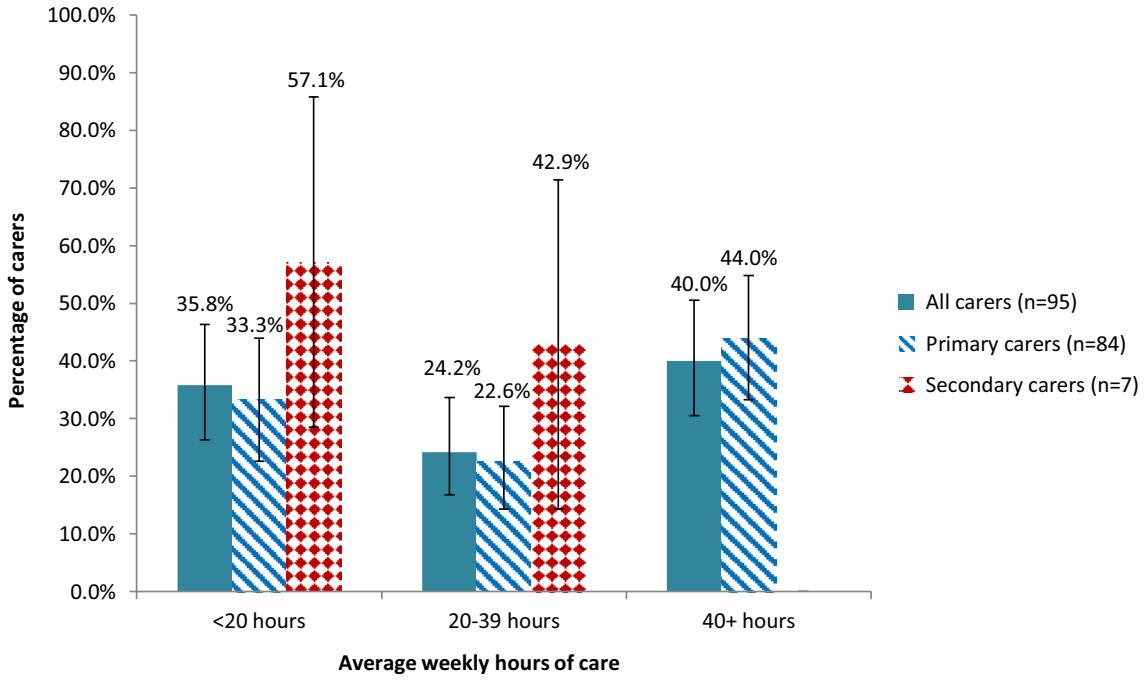

Fig. 1 Average hours of care per week (95% CI) reported by all carers, primary carers and secondary carers, UQ Carer Survey 2016

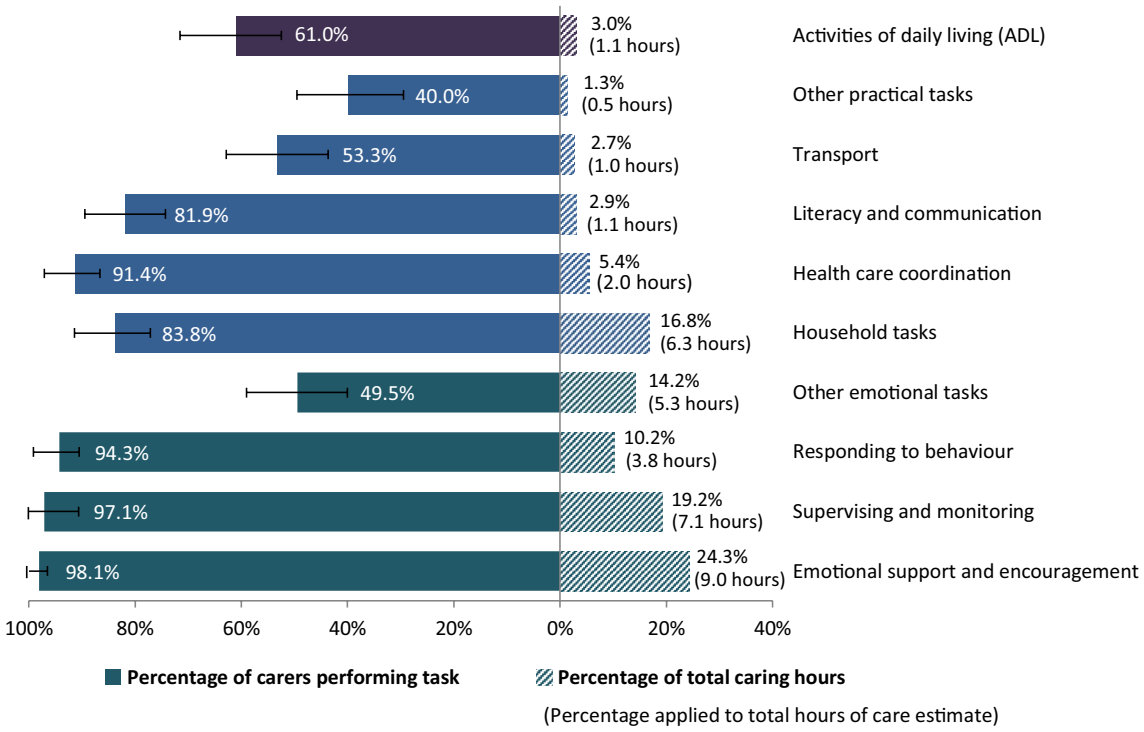

Fig. 2 Percentage of carers (95% CI) and care time for subtypes of caring tasks, UQ Carer Survey 2016

of care (52.1 per week) higher than the total hours of care reported overall; this may be due to some tasks overlapping, or recall bias. To adjust for this, we applied the proportion of time devoted to each caring task to the total hours of care estimate (37.2 h per week). The adjusted hours of care estimates for each task can be seen in brackets in Fig. 2.

Standby Time

In addition to active caring time, participants were asked how much time in an average week they spend 'on call' or in close proximity so they can be available to their care recipient quickly if needed e.g. in a crisis. The majority of carers (81.4%, 95% CI 73.5–89.2) reported providing this standby time for an average of 58.8 ($SD = 61.4$, Range = 1–168) hours per week. The substantial burden of standby time is further elaborated on in the qualitative responses below.

Time in Transit

Less than half (40.0%, 95% CI 31.4–50.5) of carers did not live with their main recipient of care. Of these non co-resident carers, 87.8% (95% CI 78.0–97.6) drove a car to visit their care recipient, spending on average of 2.4 h ($SD = 2.2$, Range = 0.3–10.5) per week in transit.

Caring Time for Other Care Recipients

One-fifth of carers (20.0%, 95% CI 13.3–28.6) had more than one care recipient with a primary diagnosis of mental illness. These carers reported that on average, they spent 17.6 h ($SD = 17.6$, Range = 1–70) caring for their other care recipient(s) with mental illness, with the majority of this time focused on providing emotional support (79.0% of support time); relative to practical support (14.8%) and ADLs (4.8%).

Open-Ended Responses of Carers

Responses to the open-ended question were provided by 77 (or 73.3%, 95% CI 64.8–81.0) carers. Although a broad set of themes was identified (see Table 3), we focus here on themes related to hours of care, including the fluctuating nature of the mental health role, standby/on call time, and lack of services for consumers forcing additional burden and time commitments on carers.

Fluctuating Nature of the Mental Health Carer Role

Many carers noted that they had trouble estimating average hours of weekly care. The main reason for this was the fluctuating nature of mental illness, as highlighted by the following two carers:

> This survey was challenging to answer because the 'hours a day' caring for a mentally unwell person is so intrinsically variable that it is challenging to quantify. [Respondent 21]

> Some questions are difficult to answer specifically eg number of hours for emotional care. This varies very much and relates more to the episodic nature of mental ill health. [Respondent 105]

Carers explained that on a good day their care recipient requires minimal or even no care at all. On bad days, this can increase to almost 24/7 care, particularly if they are on suicide watch or if their care recipient needs to be hospitalised:

> …for him it's hard to put into [hours] weekly because some weeks it's a maintenance call and other weeks more. Especially if he is going into hospital he needs support because of his bi-polar. [Respondent 31]

> If my spouse is not doing well, it is a challenging and resource draining day. On his good days/weeks we are without any need for care, aside from the unavoidable assessment and concern on my end, of each moment and action to ensure we are still having a good day. [Respondent 21]

The time elapsed between the 'good' and 'bad' days also appears to be quite variable. One respondent outlined that "during a relapse my role (which occurs about every 3 years) increases significantly and consumes most of my time each day for a period of 3 months" [Respondent 40]. Evidently, the care provided by mental health carers is episodic, and the frequency and duration of these care episodes is variable depending upon the nature of the care relationship, as well as the care recipient's condition and recovery journey. This is important for further understanding and profiling mental health carers.

Standby/on Call Time

Another common theme reported by carers was the issue of standby time, or being 'on call' for their care recipient. Many carers reported that this takes up most of their time:

> I am forever on standby and do not see this changing. [Respondent 28]

> For the past 24 years I have been on 24 h call. I cannot make plans for my own life as the situation is very unpredictable and unsettling. [Respondent 20]

Many carers reported that this has a substantial impact on their life, to the point where carers feel that their life is controlled by their caring role. Because they feel the need to be close by, in case of an emergency, many carers reported being unable to go away on holiday or even socialise with friends:

> I have not been able to take a holiday longer than a week away as this creates a lot of anxiety. [Respondent 4]

Table 3 Other themes in carer qualitative responses, UQ Carer Survey 2016 (n = 77)

Theme	Example carer responses in UQ Carer Survey 2016
Lack of services and support for carers	'We are expected to provide care and support at the drop of the hat and visit as often as we can, as well as do their personal shopping, all without any support for us. We are virtually ignored by the medical teams (doctors and nurses) and even though we would like to know what is going on with our loved one and we also know the person better than the so called medical team. Yet we have to plead to get any information.' 'There is nowhere near enough support for mental health carers.' 'As they are my spouse and children (and now my grandchildren are impacted by my daughters' health, and it has fallen to me to provide them with the stability she is unable to) there has been NO supports available.'
Need for more respite services or improved accessibility	'I gave up asking for respite and services… can't wait for NDIS and self management.' 'I rarely get a break and whenever I do manage to get respite I only get half because of the numerous phone calls from my loved one; I have to answer at least two calls out of many.' 'I am not entitled to respite due to my husband's chronic suicidality.'
Lack of understanding or recognition of mental health carers	'I am disappointed that the Carer is not regarded as an integral and informed person as to their care recipient by many of the mental health doctors. There does not seem to be a constant and consistent plan on discharge in their ongoing treatment for any great length of time. Client and carer are not really inclusive in the treatment plan, and their point of view and choices are not always respected.' 'The govt does not understand the pressure on a single parent, nor do they want to know. Caring for mental health problems is often seen as less important and yet, sometimes the outcomes are the worst.' 'The government has no idea how much we do.'
Financial costs to carers and issues with government payments	'There is no way known someone could be employed to fulfil all the jobs that I do for my son that would not cost a lot of money. I only get $120 fortnight for all the work I do and am basically available 24/7 for him.' 'Financial compensation doesn't come anywhere near covering the time spent over many years to create a supportive care program that allows the carer to take a step back into a more supervisory & monitoring role.' 'We've use our pension income to pay for allied health and support workers.' 'The Dr. that was providing support would not sign a form for Centrelink so that I could receive carers assistance because he said that 'they were well', without consideration that they were well because they were being cared for.' 'Centrelink requirements for payments are exhausting and the staff seem to treat people with a mental illness as if they are "faking" the illness… feel there is very little compassion from Centrelink. The financial burden of living with someone with a mental illness, and who is unemployed, is a financial and emotional drain on our family.'

Table 3 (continued)

Theme	Example carer responses in UQ Carer Survey 2016
Lack of career opportunities for carers	'I have been limited in career opportunities - I need to be close to home just in case I need to respond to an issue.' 'The care of my family members impacts directly my ability to hold a job (and has now done so for 34 years, as I have had and lost many jobs due to the need to 'drop everything' to care for them and deal with arising crisis situations).' 'I work part-time across several jobs so as to have the flexibility to manage my son's condition with him. When he is unwell he tends to be very unwell and has to be admitted to a mental health facility. This means I take time from work to work with the staff to get him well again.' 'There is a real challenge for carers of someone with an ongoing mental illness when as the carer you are also trying to maintain your employment - as a family/couple you require an income but you also need to be there for your loved one.'
Carers changing their housing situation to accommodate the care recipient	'We had to move to [capital city] from [regional area] for specialist help for our son.' 'My daughter has been ill with clinical depression for about 20 years… [Currently] she lives with me in a one bedroom villa in a retirement village.' 'My child does not live at home, but I fetch him every weekend to stay at home with me on a Friday night, and take him back on Sunday afternoon, and have been doing so for the last 12 years.' 'My son has a bed sit near my wife's home in [capital city], but is always very nervous when in the city. I have a farm in the country, 5 h from my wife's home. I bought this so that he has a place to be where he is comfortable and feels well. He loves being in the quiet of the country and so I take him away 2 weeks out of 3. He says he feels so much better in the country in all respects, but he could not live here alone and does not want to. He relies very, very much on me. When in [capital city] he receives treatment etc. My wife and I had to separate so that I could take him to the country area, in a home he was comfortable in. My wife has to stay in [capital city] as she assists her elderly parents, and minds two of her grandchildren while their parents work.'
Poor mental and physical wellbeing of carers	'The caring role takes an enormous toll on the carer's emotional and physical health especially with no Government support for the caree.' 'This role has been extremely stressful on my own mental health, so much so that I have myself deteriorated. I now see a psychologist myself!' 'It is difficult to allow myself the proper time to relax and rest so that I can care for myself.' 'It's a truly lonely thing to be a carer. People who you once believed to be your friends drop by the wayside. Social occasions are few and far between and when they do happen, can be fraught.' 'Care for my daughter full time- increasingly difficult to have any private life or relationship with my husband.'
Feelings of hopelessness and exhaustion among carers	'I'm constantly exhausted' '.. this is never ending. And there is no end in sight…' '[S]upporting a person with mental illness can be intense and exhausting. It is essential to learn to appreciate the highs & normal because the lows can be debilitating.' 'Its stressful caring for someone with an unpredictable condition… It's also hard when the person you care for refuses treatment or their condition makes them think nothing is wrong with them. To them, nothing you are doing is of any use to them, and they even grow to resent you.' '…it is the hardest time of my life... [I'm] at my wits end and finding life very depressing and hard.'

Table 3 (continued)

Theme	Example carer responses in UQ Carer Survey 2016
Issues and recommendations for consumer services	'I am concerned about the level of support from government funded psychiatrists. They seem to have a time limit of support and then the local GP has to deal with the problem.' 'Psychologists and psychiatrists need to be able to offer unlimited and free treatment for Bpd as 10 sessions just doesn't cut it for long term, serious mental illness. Dual diagnosis is also a problem, we need integrated, wrap around services for the most vulnerable.' 'What we need to lighten our load, are services providing emotional help and support for the carees. Government funding to provide regular sessions which teach skills in the management of mental illness, using methods from CBT, ACT and other strategies would be a boon in the community.' 'What we need is long-term, permanent accommodation services, that are free (provided by the government), with a mental health nurse present for 24 h, for those with a severe mental illness.' 'Conventional systems have been hopeless at providing a service that integrates person back into workforce.'
Lack of services to support care recipients in rural areas	'My wife and I would be a functioning couple - no burden on society - if resources weren't so scarce. Our ability to find psychiatric care while living in rural Australia has been difficult.' 'We live in regional Vic, and this means there are no appropriate psychiatrists or psychologists anywhere near here. They are only in capital cities and their books are usually closed.'
Older parent carers and their concern about the lack of support after they pass away	'We are concerned about what will happen when we are dead and our child will have to live independently.' 'My husband and I are in [our later years]…We are deeply concerned about his care and emotional support when we both die; we are working on an Advanced Planning document.' '[Currently] she lives with me in a one bedroom villa in a retirement village. I am concerned that I will become incapacitated or die before appropriate arrangements can be made for my lovely daughter. At the moment I am fit and well though grieve for my children. We have no other family in Australia.' 'Often older parents are caring for their older children even into their 80's, what then. I think it's very disturbing that if you have a child with a mental illness that there is nowhere for them to go, no decent accommodation for them to go to.'
Easier to access consumer services in the private sector	'Since my husband has been able to be in a private hospital, he has had greater care and after care…Before private cover, his condition was always chronic and had frequent trips and long stays in public psychiatric hospitals which was horrific at times.' 'It should also be noted that since I've been able to engage in private health insurance; rather than rely on the public mental health system, access to hospitalization prior to crisis is easier.'

> We can't go on holidays longer than 10 days or so. Have to be contactable by telephone 24 h/7 days. [Respondent 62]

> We no longer socialise, when we do occasionally visit friends, most times our son will come with us, if we go alone he will ring up to see how long we will be, so most times we choose not to go out as a couple because going out solo is easier and less stressful. [Respondent 101]

Mental health carers frequently noted that they experience little to no relief from their caring role. Even when carers do receive respite, they are still in contact with their care recipient, as explained by one respondent:

> I rarely get a break and whenever I do manage to get respite I only get half because of the numerous phone calls from my loved one; I have to answer at least two calls out of many. [Respondent 33]

Lack of Services for Consumers Forcing Additional Burden and Time Commitments on Carers

Poor quality or poorly accessible consumer services were discussed as an additional burden on carers. Most respondents conveyed a sense that if they were not around, their care recipient's situation would not be as hopeful. Their loved one may be at stable point now, but that would not have been possible without the carer dedicating considerable time to brainstorming new and effective ways to obtain support; ensuring that the care recipient accessed the right services; and continually advocating for them in the face of adversity. As one respondent reported:

> Having been very heavily involved in helping her manage her illness which developed when she was [in her late teens], and which was poorly controlled for [several years], her situation is now fairly stable. However, she would not manage without considerable input from her family... [Respondent 87]

Carers felt they were filling in the gaps of consumer services in Australia. However, as outlined by one respondent "I am tired of filling in the gap of the shortfall in services" [Respondent 33]. Another noted that carers "often don't have the skills to cope with someone who is unwell with mental illness" [Respondent 103].

Discussion

This study contributes new knowledge by quantifying the breadth and depth of the caring role of mental health carers. A substantial proportion of carers reported actively caring for their care recipient for more than a standard working week, a distinction (active vs. standby time) which has not been made in previous Australian studies. To our knowledge, this is the first study to demonstrate that the vast majority of this active caring time is devoted to emotional or psychosocial support (67.9% of support time), followed by practical support (29.1%). Notably, only 3% of carers' time was devoted to assistance with ADLs, which are often the most prominent caring tasks for people with physical and sensory disabilities (Forbes et al. 2007; Haro et al. 2014; Savundranayagam et al. 2011). The caring tasks performed by carers were diverse, ranging from encouraging and motivation to assisting with personal hygiene. On top of this active caring time, carers highlighted that they were on standby for an additional 59 h a week. Coupled with the qualitative data, it is apparent that carers of people with a mental illness are providing a large amount of support on an often unpredictable basis, but are experiencing little to no relief from their caring role. This is particularly troubling considering that around 44% reported receiving no financial support from the government to assist them in maintaining their caring role. These findings have important implications for service planning and provision, particularly to do with carer support services and government income support payments, which are further discussed below.

The average weekly hours of care reported (37.2 h) was smaller than what has been previously identified by Australian mental health carers (53–104 h) (Coomber and King 2013; Jardim and Pakenham 2010, 2009; Loi et al. 2015; Mackay and Pakenham 2012; MHCA 2000). This is likely due to the fact that all previous studies did not separate active caring time from standby time, potentially resulting in an overestimation of carers' weekly hours of care. Also, previous studies incorporated varying definitions of 'mental health carer', for example, some studies only focused on co-resident carers (53.1 h of care, Loi et al. 2015; or 59–66% providing 40 + h, ABS 2008, 2012), some did not exclude care recipients younger than 16 years of age (71.13 h of care, Coomber and King 2013; or 59–66% providing 40 + h, ABS 2008, 2012), and others did not specify that participants were only meant to account for the time spent caring as a result of the care recipient's mental illness (53.1–104 h; Loi et al. 2015; MHCA 2000). All of these parameters would likely increase the hours of care estimate. In addition, some studies were unclear about whether they included or excluded carers of people with dementia, autism and intellectual disability (83.07–104 h of care; MHCA 2000; Jardim and Pakenham 2010, 2009; Pakenham 2012), who tend to report higher hours of care relative to carers of people with common mental illnesses (78.4 vs. 53.1 mean hours of care; Loi et al. 2015). The current findings were more consistent with some of the international literature. Taiwanese carers of people with severe and persistent mental illness ($N = 92$) reported providing on average 42 h of care per week (Hsiao 2010) and among a cross-cultural sample of carers of people with schizophrenia, 43% of carers in Britain (N = 170) and 45% of carers in Germany (N = 333) reported providing equal to or greater than 32 h of care per week (Roick et al. 2007).

Emotional or psychosocial support was identified as the key dimension of mental health caring, which is consistent with the nature of the mental health caring role presented in previous studies (ABS 2012; Carers Victoria 2013; Hadrys et al. 2011; Pirkis et al. 2010). The hours per care activity estimates were slightly larger compared to those reported by Flyckt et al. (2013), including household work (6.3 vs. 5.1 h per week), contact with healthcare (2.0 vs. 0.9 h per week), and time in transit (2.4 vs. 1.3 h per week). Flyckt et al. (2013) incorporated the time diary method which is the gold standard for measuring informal care time (van den Berg et al. 2006). In comparison, the current study asked participants to separately recall their time spent on each task, and then

total care time, and therefore it is plausible that a person would overestimate their care time in the current format. Flyckt et al.'s (2013) study did not support this; participants actually underestimated their care time in recall as compared to the diary method, which they explained was the result of an adjustment to these long-term conditions as normal routine. It is important to note that their study did not capture the emotional support provided by carers, potentially as a result of participants finding it difficult to record this type of support in a diary, or the authors not prompting participants to do so. This likely contributed to an overall care time (22.5 h per week) that was considerably lower than the current study and previous international studies (Aranda-Reneo et al. 2013; Grover et al. 2014; Patel et al. 2014). In addition, the current study included carers of people with all types of mental illnesses, as opposed to only carers of people with psychosis, which could explain the differences in hours of care by care activity estimates. Martín et al. (2015) investigated the burden of caring for different mental illnesses and found that carers of people with an eating disorder spent significantly more time with their care recipient than carers of people with depression or schizophrenia.

The key issue identified in the qualitative data was the fluctuating nature of the mental health carer role, which as a result led to carers finding it difficult to respond to the average hours of care questions. This was reflected in the survey responses of the 2011 Carers Victoria Survey (Carers Victoria 2013), where mental health carers found it difficult to reliably estimate how many hours of care they provide for the same reason. The episodic nature of mental health caring is particularly pertinent to carer support needs, which should be flexible and available for short- or longer-term periods as required; however, tends to be collated with support for all types of informal carers. The qualitative data extends upon existing literature (Ae-Ngibise et al. 2015; Carers Victoria 2013; Jungbauer et al. 2003; McCann et al. 2011; Ohaeri 2003; Patel et al. 2014) by further highlighting the constant burden experienced by mental health carers of being 'on-call', a burden on carers' time which is rarely discussed in carer valuation studies. Flyckt et al. (2013) found that carers of people with psychosis spent on average 11.2 h per week in standby. The current study reported a considerable larger estimate (59 h per week) as many carers outlined they were on-call almost 24/7 via a standalone recall question, as opposed to the diary method. In spite of the potential inaccuracies of this time estimate, the qualitative data was particularly useful as it highlighted that standby time is a pervasive and ongoing burden, where some carers felt they could not take time off to go on a holiday or even socialise with friends.

Strengths and Limitations

One of the key strengths of this study was incorporating a more refined definition of mental health caring, which was achieved by excluding overlapping but distinct patients groups from the sample including a primary diagnosis of substance abuse, dementia and autism spectrum disorder. Another strength was that we separated primary and secondary caring, as well as standby and transit time from active caring time, which is rarely reported in the carer literature (Flyckt et al. 2013). We also presented hours of care estimates specific to the time spent caring as a result of the care recipient's mental illness, as well as hours of care devoted to different types of mental health caring tasks. We adjusted for time spent caring by task by applying it to total estimates of hours to reduce bias. Collectively, our estimates provide a more complete and detailed profile of Australian mental health carers and their caring role.

The current study was reliant on a small convenience sample of mental health carers and as a result, there are limitations to the generalisability of the findings. Convenience samples typically include small numbers of underrepresented subgroups (Bornstein et al. 2013), including carers who are not in contact with carer support organisations, secondary carers of people with mental illness (9.4% of the current sample) and young carers (< 18 years), with the latter excluded from this study to manage ethical implications.The current results may therefore overestimate hours of care, as secondary carers and those not in contact with services likely provide less care on average. For carers who had access to the survey, there may also have been differences between those who did versus did not participate. Although we did not have enough information to determine how many people did not participate, it is possible that these people were too stressed or pressed for time due to the demands of their caring role or alternatively, that they were less engaged or identified less with their caring role. The impact of any differences on our hours of care data could be to either over- or underestimate the caring hours provided by Australian mental health carers. When compared to a more representative sample of Australian mental health carers, such as the SDAC 2012 primary carer group, our sample was comparative in terms of marital status, country of birth, language spoken at home, and urbanicity. The differences included more carers living in Queensland and Victoria, more females, and an older age range. As a result, this survey may not have adequately captured potential state-based differences in carer burden due to the variability in available carer support services across Australia (Department of Social Services [DSS], 2016). Carers from Indigenous and culturally diverse backgrounds may also be underrepresented in this sample. Overall, our results for hours of care may be most relevant to the Australian service landscape and differences in health

systems across countries mean that the caring role may vary elsewhere.

Another limitation was that the hours of care estimates were collected using the recall method. Recall data are subject to bias, including carers encountering difficulties in retrospective recall of activities, and in reliably estimating average weekly hours of care when the care recipient's needs may fluctuate over time (Carers Victoria 2013; van den Berg et al. 2006). We were also unable to adjust for joint production or overlap between mental health caring tasks and other activities a carer would complete regardless of their caring role (Goodrich et al. 2012; van den Berg and Spauwen 2006). For example, a carer may allocate time spent going for a walk in the park with their care recipient as both personal exercise and a part of their caring duties. Joint production can be measured and adjusted for when using the time diary method but not the recall method. However, we chose to apply the recall method for this study to reduce the burden on survey participants and to facilitate timely data collection to inform the subsequent economic valuation. Finally, the qualitative data, although rich and insightful, did not take a systematic approach such as asking participants key questions to capture specific aspects of the mental health caring role. Future research should further explore carers' experience of the burden related to hours of care in a semi-structured interview, and potentially incorporate more formal methods of qualitative analysis. Some questions of interest include capturing the undulating nature of mental health caring, and when do carers feel they need the most assistance.

Implications and Future Research

These results have key implications for service planning and provision of support to mental health carers. It is apparent that mental health carers provide a large amount of support, with little reprieve from their caring duties. The provision of carer services such as income support, respite, and counselling is important to ensure that carers are supported to maintain their significant caring role, as well as their own health and wellbeing. Despite the current funding of these services in Australia (DSS 2016), carers' qualitative responses outlined the many difficulties with accessing support services at all or that meet their needs, particularly in terms of the flexibility of existing services. Carers highlighted the episodic and unpredictable nature of mental illness, which means government support needs to match the undulating nature of the illness, with short- or longer-term periods of assistance as required. These flexible support demands were echoed in the responses from mental health carers in previous Australian surveys (Harris et al. 2015; MHCA 2010, 2012). Another key finding was that most of mental health carers' support time is devoted to emotional support, a form of care which tends to be overlooked in the process of gaining access to carer income support (i.e. carer payment or allowance) (Carers Victoria 2013). Eligibility for carer payments is based on an assessment of the care needs of the person requiring care. This is achieved by carers completing a questionnaire about their care recipient's level of functioning, known as the Adult Disability Assessment Tool (ADAT) (Department of Human Services 2016). Questions in the ADAT are more relevant to those who cannot feed, dress or bathe themselves (Carers Victoria 2013), and as seen in our results, only 3% of carers' support time is devoted to these activities of daily living. The lack of questions in the ADAT about emotional care or supervision of practical tasks has raised concerns among the Royal Australian and New Zealand College of Psychiatrists (RANZCP), that the current assessment process is too heavily geared toward carers of people with a physical disability, and in turn disadvantages those caring for someone with mental illness (RANZCP 2015). Carers Victoria recommends alternative tools to be incorporated into the ADAT, including psychosocial disability assessment tools which cover need for emotional care (Carers Victoria 2013).

The current study presents a richer picture of the mental health caring role than previous literature, but future research to replicate and further investigate the hours and types of care in a large and representative carer sample would be beneficial, collecting data from both primary and secondary carers and allowing adjustments for joint production. In particular, data is required to replicate the current finding that emotional support occupies most of mental health carers' support time. This would be best accomplished through a diary methods study which captures both the objective and subjective burden of the informal mental health caring role. Such a study would further highlight the size and nature of mental health carer input into the Australian healthcare system. It would also help guide governments to potentially redesign support programs or income support payments to better address the unique and fluctuating caring profile of mental health carers.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of The University of Queensland Behavioural & Social Sciences Ethical Review Committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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