Short Title: Mental Health and Experiences of Abuse in Australian Carers

Title: Experiences of Abuse in Australian Family Carers and Predictors of Mental Health and

Wellbeing

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Abstract

Caregivers for family or friends who are elderly or have a disability provide critical supports, with a range of positive and negative consequences associated with their role. This research explores the positive and negative aspects of caregiving, including the experience of abuse within the caring relationship through an anonymous online survey of the mental health, wellbeing and caring experience of Australian family carers (N = 305). The voluntary participants were recruited through local and national carer associations. Over 40% of respondents reported having experienced abuse by the person they cared for, with the most common form of abuse being verbal abuse (35% of the respondents reporting abuse) and physical abuse (14%). The experience of abuse was related to poorer mental health as measured by the DASS-21 and a lower reported quality of life. Financial stress, lack of support, and the negative impacts of caregiving were also significantly associated with mental health and wellbeing outcomes. The current research is among the first to directly assess the experience of abuse within a broad sample of caregivers, identifying this as a significant issue for caregivers. The findings have clear implications for programs and policies that protect the rights, safety and wellbeing of caregivers.

Keywords: Caregiving; abuse; mental health and wellbeing; Australian family carers

What is known about this topic?

- Approximately 2.65 million Australian carers provide unpaid care for family or friends

- Family carers often experience negative consequences from their role that contribute to poorer mental health

- A stress coping framework suggests that positive appraisal may have a protective effect on carer mental health

What this paper adds.

- A significant proportion (41.6%) of participating carers reported experiences of abuse in their caring relationship and abuse significantly predicted lower levels of wellbeing

- The positive value that carers placed on their role was a significant protective factor of mental health and wellbeing

Mental Health and Experiences of Abuse in Australian Carers

Experiences of Abuse in Australian Family Carers and Predictors of Mental Health and

Wellbeing

The relationship shared between a carer and the individual they are caring for is an important bond of support and trust. The provision of care can have positive and negative consequences for carers (Al Krenawi, Graham & Al Gharaibeh, 2011; De Oliveira & Hlebec, 2016; Loughland, Lawrence, Allen, Hunter, Lewin, Oud & Carr, 2009; Tan, Williams & Morris, 2012). Positive consequences commonly reported by carers include increased satisfaction with oneself and added meaning in their life (Cohen, Colantonio, & Vernich, 2002; Kuuppelomäki, Sasaki, Yamada, Asakawa & Shimanouchi, 2004; Loughland et al., 2009). However, the negative consequences may contribute to the higher levels of stress, anxiety, depression, and suicidality reported by carers than seen in the general public (Shah, Wadoo, & Latoo, 2010). Carers can also experience abuse within the carer relationship (Loughland et al., 2009); however, most policy and literature focus on the abuse experienced by the individuals being cared for and little research has examined the experience of abuse on carer mental health and wellbeing.

In Australia, approximately 4.3 million people live with a disability and 2.65 million carers provide unpaid care for family or friends who are elderly (over the age of 65) or have a disability (Australian Bureau of Statistics [ABS], 2018). Caring can include assisting with mobility (e.g., moving around the home, moving from bed to chair), self-care (e.g., bathing, dressing, toileting), communications (e.g., reading and writing), cognitive and emotional support, household chores, and transport (ABS, 2015). Carers therefore provide critical supports and represent a large and important segment of the Australian population.

Mental Health and Wellbeing

A large body of research has demonstrated that caring for a family member can have both positive and negative consequences that influence the mental health and wellbeing of the carer (Al Krenawi et al., 2011; De Oliveira & Hlebec, 2016; Loughland et al., 2009; Tan et al., 2012). The current research positions mental health and wellbeing not as two dichotomies on a single continuum, but rather two related dimensions that often intersect in psychological research. This research follows the Keyes (2002) conceptualisation of wellbeing with emotional, social, and psychological wellbeing contributing to one's ability to not only function but also flourish throughout their life. Previous research examining carer wellbeing in Australia demonstrates that carers often experience significantly lower levels of wellbeing compared to the general population (e.g., Cummins, Hughes, Tomyn, Gibson, Woerner, and Lai, 2007).

Mental health relates to a person's emotional and psychological health including psychological issues such as depression and anxiety. Recent data published in the National Health Survey (ABS, 2018) reported that 10.4% of Australians over 18 reported symptoms of depression, including persistent low mood, feelings of worthlessness, inability to feel pleasure, changes in weight, and decreased concentration and energy levels. However, rates of depression among carers reported in research are much higher, ranging between 15-40% across different samples (Berg, Palomäki, Lönnqvist, Lehtihalmes, & Kaste, 2005; Covinsky et al., 2003; Livingston, Manela, & Katona, 1996; Loi et al., 2016; Orive et al., 2013; Synapse, 2019).

Anxiety and anxiety-related disorders were the most prevalent mental health conditions (13.1%) reported in the National Health Survey and a similar proportion of Australians over 18 (13.6%) reported high levels of distress (ABS, 2018). Anxiety in carers ranges between 23 and 56% (Mahoney, Regan, Katona, & Livingston, 2005; Orive et al., 2013; Price et al., 2010), more than double the national prevalence. Furthermore, a staggering

62% of carers report moderate to severe levels of distress (Halkett, 2017). Such statistics raise concerns for the quality of life of carers.

Stressors that Impact Mental Health and Wellbeing of Carers

Several researchers have applied adaptations of the Lazarus and Folkman (1984) Stress Coping model to the carer population (e.g., Mackay & Palenham, 2012; Shah et al. 2010). The Stress Coping model posits the interactive nature of stress and the ways in which people appraise and respond to stress as including factors about the person and their environment (Lazarus & Folkman, 1984). Research with caregivers using this model has demonstrated a number of stressors that arise from the direct and indirect strains of caregiving which may lead to poorer mental and physical health (Shah et al., 2010). Several resources and coping factors have also been identified among carer populations that mitigate risk (De Oliveira & Hlebec, 2016). Thus, attention to both the risk and protective factors influencing caregiver mental health and wellbeing is necessary.

Risk factors. A number of risk factors have been found to contribute to carer stress and poorer mental health. These factors include the amount of time spent caring, financial problems, type and quality of relationship between the carer and the person being cared for or supported, behavioural problems displayed by the person being cared for, and lack of social support (Hirst, 2005; Huang et al., 2009; Loi et al., 2016; Mahoney et al., 2005; Shah et al., 2010). Behavioural problems displayed by the person being cared for have been shown as an additional risk factor for carer depression (Huang et al., 2009; Shah et al., 2010). It can be presumed, therefore, that experiencing abusive behaviour from the individual being cared for may be a contributor to stress and poorer mental health, but to date little research has examined the impact of abuse on carer wellbeing or mental health.

Loughland and colleagues (2009) found that 77% of family carers ($N = 106$) experienced moderate to severe levels of verbal abuse from family members with psychosis.

Vaddadi, Gilleard, and Fryer (2002) found that carers who do experience abuse are likely to experience more than one type of abuse in their caring relationship. Factors such as a poor relationship between the carer and the person being cared for, the more time spent caring, or if the person being cared for had either a criminal history, a history of drug use, or a range of psychotic or anti-social symptoms were all associated with carer reports of abuse. Carers who have experienced abuse report higher levels of emotional distress, depression, and higher levels of perceived burden (Loughland et al., 2009; Vaddadi et al., 2002). There is limited data on the prevalence of abuse for carers in Australia and outside the context of caring for someone with a psychotic disorder or severe mental illness.

Protective factors. Research has found evidence for a number of protective factors that contribute to carers coping with the stressors associated with their caring role. Demographic protective factors include the carer being younger in age, having a lower level of care burden, having a partner, being in paid employment, and having sufficient financial resources (De Oliveira & Hlebec, 2016). Engaging in physical and social activities, having strong social networks, and access to formal and informal support have also been shown to be protective factors for carer wellbeing (De Oliveiria & Hlebec, 2016; Lethin et al., 2019).

From a Stress Coping framework, a number of these clearly fall into positive coping strategies, but another key factor to emerge in the research is the importance of positive appraisal, such as acceptance, feeling needed and appreciated, and finding personal satisfaction and meaning in the carer role (Kuuppelomäki et. al., 2004; Mackay & Pakenham, 2012). Therefore, research examining the caregiver experience should include appraisal processes as important in influencing mental health and wellbeing.

This Study

The literature demonstrates that the mental health and wellbeing of family carers is impacted by a number of stressors inherent in the caring role. Experiencing abuse within the

caring relationship may have particular impact on carer mental health and wellbeing. Very limited research has examined carers experience of abuse, and this research tends to have focused on specific populations such as carers caring for someone with a mental illness. The current research examined the experience of abuse in a broad sample of Australian family carers. Utilising a stress and coping framework, the current study sought to examine the impact of abuse on carer mental health and wellbeing and to explore potential protective factors. The research provides a descriptive exploration of the carers' experiences of abuse and the types of abuse experienced. It then tests a model of carer wellbeing and mental health, which includes key influential demographic factors from the literature (age, gender, hours a week spent caring, and financial stress), carer experience of abuse, the negative impacts of caring, and the protective factors of positive value of caring and the quality of support for carers.

Methodology

Sampling and Participants

Selection criteria were that participants resided in Australia and were unpaid family carers who were supporting a family member with disability, mental health problems, chronic medical condition, life-limiting illness or frailty. The invitation to participate in the research was disseminated widely to family carers through State Carer Associations as the peak bodies with which family carers are registered. While the total number of carers who viewed the invitation is unknown, 397 family carers entered the survey. Of these, 92 did not complete any items or only completed the demographic section, leaving a final sample of 305 carers and a completion rate of 75%. Table 1 displays the demographic details of the final 305 participants in comparison to data from the general Australian population of family carers and primary carers where available. As can be seen in Table 1, the current sample has a

higher proportion of females with high levels of education and a lower proportion of carers who also work full time than the general Australian population of family carers.

Study Design and Analysis

The current research engaged in a cross-sectional survey design. Analyses were correlational and descriptive in nature and conducted using the Statistical Package for the Social Sciences (Version 25). Frequencies were used to describe participants characteristics and carer experiences. T-tests and ANOVAs were run to examine the impact of categorical demographics and experiences on mental health and wellbeing measures. Regression analyses were used to develop models of risk and protective factors for mental health and wellbeing outcome measures. Although a large number of analyses were run, they were considered separate families of tests and alpha levels were set at $p <. 05$.

Data from the 305 participants were examined for any patterns in the missing data, and missing data was found to be random (Little's MCAR (9072) = 9034.90, $p = .607$) and estimated means imputation was used to replace missing items when constructing scale totals. If participants were found to have more than 75% missing data on any scale, then a scale total was not calculated. Listwise deletion was used in analysis to maximise the use of participants with usable data in each set of analyses.

Examination of descriptive statistics and visual inspection of plots demonstrated minor breaches of normality with DASS subscales scores positively skewed. However, examination of residual scatterplots for regression analyses indicated that homoscedasticity was not breached. As both ANOVA and regressions are robust to normality breaches, original data was used for all analyses.

Procedure

Following approval from the Institutional Human Research Ethics Committee (Approval 1700000931); participants were recruited through the dissemination of the

research information and survey link through social media platforms and newsletters for

Carers Queensland and the other state and territory carer associations across Australia. The

anonymous survey was generated through institutional online survey software and consisted

of 140 items, taking approximately 15-20 minutes to complete. Upon clicking the link, a

participant information sheet was presented, and participants provided active consent by

agreeing to participate before accessing the survey. The survey was open from February

2018 to June 2018 and reminders were sent out regularly to ensure maximum opportunity for

participation.

Measures

Demographics. A series of questions assessed demographic and individual factors

such as age, gender, geographic location, education and qualifications, employment status,

household income, relationship status, and religion and spirituality. Additional questions

related to the participants experience as a carer; such as their relationship with the person

they were caring for, the number of years spent caring, and how many hours per week were

spent caring; and about the individual they were caring for, such as age, gender, and type of

disability.

Depression, Anxiety, and Stress Scale (DASS-21). The DASS-21 consists of 21

items that measure mental health through 3 subscales (depression, anxiety, and stress) and

demonstrates strong reliability ($\alpha = .88$ in Lovibond and Lovibond, 1995; $\alpha = .94$ in the

current study). All items (e.g., I find it hard to wind down) were measured on a 4-point Likert

scale, ranging from 0 representing "Did not apply to me at all" to 3 representing "Applied to

me very much, or most of the time". The scores for specific items were summed to create

scores for each 7-item subscale, with scores ranging from 0 to 21. The scores were

categorised into normal, mild, moderate, severe, and extremely severe ranges according to

the scale developers' instructions (Lovibond & Lovibond, 1995). Total scores were summed (range 0-63), with higher total scores indicating lower levels of mental health.

Quality of Life Scale (QLS). The 15-item QLS was used to measure the carers' perceptions of quality of life and demonstrated high internal consistency with a Cronbach's alpha of .94 in Cummins, McCabe, Romeo, Reid & Waters (1997) and the current study. The scale uses an 11-point Likert scale measuring satisfaction, where 0 "Means you feel completely dissatisfied" and 10 "Means you feel completely satisfied". Responses to items (e.g., "How would you rate your current quality of life?") were averaged to create a mean score (range 0-10), with higher values indicating a higher quality of life.

Abuse. Three items extracted from the Carers Queensland (2018) Quality of Life Audit, were used to capture carers' experiences of abuse in their caring relationships. The first item, "Do you think you have experience abuse from the person you care for?" used a yes/no response scale. Participants were reminded that they did not have to respond to the question if they did not feel comfortable. The second item asked participants to specify the types of abuse they had experienced, where participants could select all that applied from verbal abuse, threatened harm, physical abuse, financial abuse, actual physical injury, and/or violence/abuse towards property. The abuse variable used in the analyses was constructed based on the number of types of abuse experiences and ranged from 0 to 6.

Carer Stress Factors. To examine what factors carers thought contributed to stress in their caring relationships, respondent were asked to select any stressors that applied to them from a list including: lack of regular sleep; financial hardship; unemployment or underemployment; family conflict; pressure from family; lack of formal support from service providers; level of family support; fear and/or grief and loss; health or medical problems; housing stress; alcohol and/or other drug use; mental health problems; cognitive impairment or decline; sexual abuse; physical abuse; and emotional abuse.

Negative Impact, Positive Appraisal and Quality of Support. To assess the broad negative impact of these stressors on carers lives, the positive value of caring and the perceived quality of support for their caring role, the Carers of Older People in Europe Index (COPE Index) was utilised. The 15-item brief COPE Index was developed as a tool for service providers to assess carers subjective experience of both the negative impacts and positive outcomes of caring for a family member with responses on a 4-point Likert scale from "Never" to "Always" (McKee et al., 2003). The scale consists of three subscales: negative impact of caring (7 items, e.g., "Does caregiving cause difficulties in your relationship with your friends?"), positive value of caring (4 items, e.g., "Do you find caregiving worthwhile"), and also assesses the quality of support received from family, friends and services (4 items, e.g., "Do you feel well supported by your friends and neighbours?"). Each subscale demonstrated strong internal consistency in the current study: negative impact ($\alpha = .81$), positive impact ($\alpha = .73$), and quality of life ($\alpha = .74$). The items in each subscale were averaged (range 1- 4) with higher scores indicating higher degrees of positive or negative impact from caring or a greater sense of support.

Results

Participant Descriptive Statistics

The majority (67.2%) of carers in this study cared for two individuals, 19.0% cared for three individuals, 12.5% cared for four or more individuals, and only 1.3% of participants cared for only one individual. Most participants stated they were either the parent (40.7%) or the partner (30.2%) of the person being cared for or supported, 21.3% of participants were caring for one of their parents, 4.9% were a non-direct family member of the person being cared for, and 3.0% were caring for friends. The majority of carers (60.0%) reported caring for someone with a with physical disability, 38.0% cared for someone with a developmental

disability, 25.9% someone with a mental health disability, 17.0% with dementia or

Alzheimer's, 2.6% with a drug or alcohol disorder, and 20.3% someone with a disability that

did not fit one of these categories.

Table 1 Here

Mental Health and Wellbeing

Carer's mental health was measured through analysis of DASS subscale mean scores

and revealed that the majority of carers reported moderate levels of depression ($M = 8.51$, SD

$= 5.46$), mild levels of anxiety ($M = 4.82$, $SD = 4.54$), and mild levels of stress ($M = 9.99$, SD

$= 4.73$). Table 2 displays the descriptive statistics of each DASS subscale and the

frequencies in each level of clinical significance. Quality of Life Scores were normally

distributed and ranged from 0.20 to 9.87 ($M = 5.55$, $SD = 2.06$).

Table 2 Here

Carer Reported Stressors

Carers reported a range of stressors that contributed to the negative impacts on their

lives of their caring role. Table 3 displays the frequencies of each stressor and its correlation

with carer mental health and wellbeing. Predictably, stressors were positively correlated with

DASS scores and negatively correlated with QLS scores. Correlations between QLS and

financial stress, lack of access to formal support services, and impact on health of caring were

above 0.3.

Table 3 Here

Experiences of Abuse

Of the 305 carers who participated in this survey, 285 responded to the items

surrounding abuse experienced in their caring relationship. Of those, 41% ($n = 117$) reported

experiencing abuse from the person they were caring for. T-test comparisons

revealed that carers who experienced abuse had significantly higher scores on the DASS (M =27.08, SD = 13.43) than carers who had not (M = 20.40, SD = 11.69; t (283) = 5.01, $p <$ .001). Carers who experienced abuse had significantly lower quality of life (M = 27.45, SD = 13.38) than carers who had not (M = 20.45, SD = 11.92; t (283) = -4.02, $p < $ .001).

When analysed by type of abuse, 35.4% of participants who reported having experienced abuse reported experiencing verbal abuse, 14.1% physical abuse, 14.1% property abuse, 12.1% threatened harm, 8.2%financial abuse, and 6.6% reported physical injury as a result of abuse. In this sample, abuse was more frequently reported in older carers (see Table 4); however, this finding is descriptive and needs to be confirmed in a more stratified sample.

Table 4 Here

To examine the influence of demographic variables of the carer and the person being cared for on having experienced abuse, a standard regression analysis was run. The outcome variable was calculated from the number of types of abuse carers reported having experienced from 0 (no abuse) to 6 (experienced all forms of abuse). Demographic variables accounted for a small proportion of the variance in experiencing multiple forms of abuse (R^2 = .12, F (16, 269) = 3.52, $p < $ .001). As seen in Table 5, carers without partners, those caring for more people, and caring for someone with a mental health or drug and alcohol related disability were related to reporting more types of abuse.

Table 5 Here

Factors Predicting Carer Mental Health and Wellbeing

Bivariate correlations between demographic characteristics and variables of interest are provided in Table 6. A three-step hierarchical regression was run on the DASS and QLS total scores. Demographic variables including gender, age, hours spent caring per week, number of years spent caring, and income sufficiency were entered in Step 1. Experiences of

abuse was entered at Step 2. Negative impacts of caring (COPE Neg), positive value of caring (COPE Pos), and the quality of support (COPE QoS) were entered into the model at Step 3. The statistical results of this regression analysis are presented in Table 7.

Table 6 Here

Table 7 Here

The demographic variables entered at Step 1 contributed significantly to the regression model for DASS total scores, accounting for 10.2% of the variation in carer mental health (F (5, 277) = 4.32, p < .001). As seen in Table 7 greater income sufficiency was significantly associated with lower DASS scores, while spending more years caring was significantly associated with higher DASS scores. The addition of experiencing abuse entered at Step 2 explained an additional 2.7% of variance in DASS scores (F_{change} (1, 276) = 8.73, p = .003) and was significantly related to higher DASS scores. While income sufficiency remained significant in Step 2, the number of years caring became non-significant. The addition of the three COPE subscales in the final Step explained an additional 19.3% (F_{change} (3, 274) = 26.58, p <.001) of the variance in mental health. Positive impacts of caring and quality of support were negatively associated with DASS scores; however, only positive impacts of caring was significant. Negative impacts of caring was significantly and positively associated with DASS scores. These impacts of caring subsumed the impact of all other variables except income in predicting carer mental health. Together, the predictors in the final model accounted for 31.7% of the variance in carer mental health (F (9, 273) = 15.52, p <.001).

The demographic variables entered at Step 1 accounted for 30.0% of the variation in carers' quality of life as measured by QLS scores, F (5, 277) = 25.13, p <.001; however, only

income sufficiency emerged as a significant predictor and was positively associated with QLS scores. The addition of having experienced abuse at Step 2 explained an additional 1.0% of variance in QLS scores (F_{change} (1, 276) = 4.13, p = .043) and was significantly and negatively associated with quality of life. The addition of the positive and negative impacts of caring as well as quality of support in the final step explained an additional 28.0% (F_{change} (3, 273) = 64.12, p <.001) of the variance in carer quality of life. Positive values of caring, quality of support, and income sufficiency were all significantly and positively associated with QLS scores, while negative impacts were significantly and negatively associated. Experience of abuse was eclipsed by the inclusion of the COPE subscales, no longer significantly predicting carer quality of life. Together, the predictors in the final model accounted for 60.2% of the variance in carers' quality of life (F (9, 273) = 45.95, p <.001).

Discussion

Australian carers experience a wide range of stressors in their caregiving role, which are linked to poorer mental health and reduced wellbeing. The stressors associated with the caring role, including experiencing abuse from the person they are caring for, have implications on the wellbeing of caregivers as well as on their ability to continue in their role. With 2.65 million people in Australia providing unpaid care for family or friends who are over the age of 65 or have a disability, these findings have significant public health implications.

The current research identified a high level of risk for abuse among caregivers, with over 40% of participating carers reporting experiences of abuse in their caring relationship. The most common type of abuse reported was verbal abuse, followed by physical abuse, property abuse, threatened harm and financial abuse. Those who experienced abuse had significantly poorer mental health and significantly lower quality of life, even after accounting for key demographic risk characteristics. Carers without a partner, caring for

more people, and caring for someone with mental health or an alcohol or drug disorder were more likely to experience abuse. These findings have implications for identifying caregivers at higher risk of abuse by the person they are caring for and highlight the need for systematic screening and support for caregivers.

The majority of carers who participated in this study reported elevated mental health symptoms. Nearly 65% reported moderate to extremely severe levels of depression, with 1 in 5 carers in the extremely severe range. Nearly half of carers in the sample reported moderate to extremely severe levels of stress, and approximately a third reported moderate to extremely severe levels of anxiety. These numbers are striking and are consistent with national data that identifies that Australian caregivers have significantly poorer levels of mental health as compared to the general population (Cummins et al., 2007). This elevated risk for mental health concerns highlights the need for additional supports for carers in their role.

Experiencing abuse within the carer relationship emerged as a major stressor for family carers with direct impacts on both their mental health and wellbeing. The effect of abuse on mental health was subsumed within the general negative impacts of caring but remained a direct contributor to carer wellbeing. The negative impacts of caring subscale was a strong predictor of both the mental health and wellbeing of the caregivers in this sample. These impacts included a broad range of outcomes such as impact on other relationships, impact on health and activity, as well as financial stress. Finding ways to reduce these negative impacts provides a meaningful target for working with caregivers and to improve their mental health. For example, interventions should support carers' positive coping mechanisms, including maintaining their own health and positive social networks outside the carer relationship (Mackay & Pakenham, 2012). Extended social support networks may be of particular importance in carer relationships that may involve abuse.

Income sufficiency was a consistent strong predictor of caregiver wellbeing. Carers reporting insufficient income has significantly poorer mental health and lower quality of life. Of note is that over half of the sample reported financial challenges associated with caregiving. The over-representation of low-income individuals within the care sector has been reported elsewhere, with the Australian Bureau of Statistics (2018) identifying that 50% of carers were in the two lowest income quartiles. These numbers are significant and should inform policy and program efforts to better support these unpaid carers in their critically important role.

The current research also aimed at exploring buffers against these stressors experienced by family carers. The positive value scale emerged as a strong predictor of both mental health and wellbeing. Consistent with previous research (Kuuppelomäki et. al., 2004; Mackay & Pakenham, 2012), finding positive value in their role as a carer mitigated against negative impacts of the associated stressors. Such findings suggest that interventions that build carers positive appraisal of their role and help them to find value and meaning in providing care can have a positive impact on the mental health and wellbeing.

Quality of support was significantly associated with wellbeing in caregivers, but not with mental health. This finding suggests that quality support and strong networks are a key aspect of carer wellbeing, but the negative impacts and appraisal mechanisms are more directly associated with mental health. It is of note however, that the most common caregiving-related stressors included family conflict and a lack of family support for caregiving reported by 45.9% and 56.1% of the sample, respectively. Therefore, assumptions cannot be made that caregivers are embedded within their own familial and social support networks to help them in addressing the caregiving challenges they face. Additional supports from carer associations, family support workers, and others working with carers across the country are critical and should be expanded to ensure additional training and supports can be

put in place for caregivers. These networks may also prove important for facilitating pathways for addressing abuse that may arise in the caregiving relationship.

Strengths and Limitations

The current research aimed to directly assess carers experience of abuse by the individuals they are caring for in a sample of unpaid Australian family carers. The findings have important implications for practice within the carer sector. The use of an anonymous online survey provided a confidential and accessible forum for carers to report their experiences. While the sample was broadly representative of the Australian carer population (see Table 1), there was an overrepresentation of older, female, and educated participants. Further, the self-selected sample, lack of reportable response rates, and a large number of non-completers, may have resulted in a number of biases within the sample, such as an over representation of those who had experienced abuse. The abuse questions were responded to in a dichotomous format (yes/no) and did not measure the carers perceptions of the severity of the abuse.

Conclusion

The current study has provided important insights into the experience of abuse and the impact on the wellbeing of family carers. Further research using mixed methods and longitudinal approaches is urgently needed to provide greater insights into the complexities of the caregiving experience and, in particular, the experience of abuse and the severity of that abuse within the caring relationship. More systematic screening within carer services might help to facilitate outreach to those caregivers experiencing high levels of distress and at greatest risk for abuse by the person they are caring for.

These findings have clear implications for programs and policies that protect the rights, safety and wellbeing of caregivers. Expansion of supports offered by carer organisations through increased federal and state funding could help to support the carers who engage in this

challenging and uncompensated role. Programs targeting mental health and wellbeing, increasing social supports, and addressing the financial strains and abuse experienced by caregivers are warranted, especially for those caring for multiple people or for individuals with mental health and drug and alcohol-related disability. Similarly, programs that seek to give carers a greater voice, both systemically and individually, would support the establishment of new assessment tools and services to support carers who are at risk or experience abuse within the caring relationship. Such strategies are critical for the approximately 2.65 million Australian carers who provide unpaid care for family or friends.

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Table 1.

<mark>Demographics Characteristics of Current Study Sample of Family Carers compared to Australian Family Carers Population Data</mark>

Demographics	n	%	% of Carer Population (ABS, 2018)
Age in years			
18-24	2	0.7	7.1 (15-24)
25-34	10	3.4	10.1
35-44	41	13.5	14.0
45-54	73	23.9	21.1
54 and over	178	58.5	46.6
Gender			
Males	26	8.5	42.5 (28% Primary Carers)
Females	277	91.5	57.5 (72% Primary Carers)
Geographical location			
Urban	154	50.7	68.9
Regional	117	38.4	21.9
Rural/ remote	33	10.9	9.2
Education			
High school	54	17.9	41.2
Certificate/ diploma	130	43.0	33.1
Bachelor degree	68	22.5	16.45
Postgraduate degree	50	16.6	8.2
Employment			
Full-time	25	8.2	32.1
Part-time/Casual	82	27.0	21.7
Not employed and looking for work	17	5.6	3.4
Not employed and not looking for work	97	31.9	42.8 (Not in Labour Force)
Retired	83	27.3	
Relationship with individuals who are cared for			% of Primary Carers
Parent	124	40.6	36.6
Spouse/partner	92	30.2	26.2
Child	65	21.3	27.1
Other relative	15	4.9	10.1 (other all)
Non-relative	9	3.0	
Number of hours a week spent caring			% of Primary Carers
2-5.99	12	3.9	
6-8.99	13	4.3	1-19 hrs = 42.4
9-11.99	11	3.6	
12-14.99	15	4.9	20+ hrs = 57.6
15 above	253	83.2	
Number of years spent caring			
1 year	13	4.3	
2-3 years	28	9.2	
4-6 years	57	18.7	
6-8 years	50	16.4	
10 and above years	157	51.5	
Religion			
Not at all	127	41.9	
A little	64	21.1	
Somewhat	72	23.8	
Very	40	13.2	

Table 2.

Descriptive Statistics and Grouped Frequencies of DASS Subscale Items

N = 305	*M*	*SD*	% in each DASS category				
			Normal	Mild	Moderate	Severe	Extremely severe
Depression	8.51	5.46	24.92%	16.07%	28.52%	16.07%	20.33%
Anxiety	4.82	4.54	48.85%	17.38%	9.84%	9.18%	14.75%
Stress	9.99	4.73	34.10%	16.39%	19.02%	20.00%	10.49%

Notes. Depression cut-off scores: 0-4 = normal, 5-6 = mild, 7-10 = moderate, 11-13 = severe, and 14+ = extremely severe; Anxiety cut-off scores: 0-3 = normal, 4-5 = mild, 6-7 = moderate, 8-9 = severe, and 10+ = extremely severe; Stress cut-off scores: a score of 0-7 = normal, 8-9 = Mild, 10-12 = moderate, 13-16 = severe, and 17+ = extremely severe.

Table 3.

Frequency of Reported Caring Related Stressors and their Correlations with Carer Mental Health and Wellbeing

Stressor	% Reported (N=305)	DASS correlation (N=305)	QLS correlation (N=296)
Lack of Sleep	70.2%	.175**	-1.74**
Financial Stress	54.4%	.169**	-.412**
Employment Stress	34.4%	.147**	-.290**
Family Conflict	45.9%	.259**	-.297**
Other Family Pressure	17.0%	.154**	-.162**
Lack of Family Support	56.1%	.088	-.213**
Lack of Access to Support Services	32.8%	.205**	-.342**
Fear/Grief	47.2%	.198**	-.124*
Impact on Health of Caring	60.0%	.235**	-.312**
Housing Instability	18.7%	.023	-.270**
Alcohol/Drug Use	6.6%	.160**	-.029
Mental Health Issues	35.4%	.184**	-.248**
Cognitive Decline	21.0%	.057	-.037
Physical Abuse	7.9%	.094	-.130*
Emotional Abuse	27.5%	.248**	-.263**

Notes: * p <.05. ** p <.01; missing cases deleted listwise; responses were dichotomous yes or no to having experienced listed stressor

Table 4.

Types of Abuse Experienced by Carers in Each Age Category (N =285)

Type of Abuse	55+	45-54	35-44	25-34
	n = 169	*n* = 70	*n* = 38	*n* = 8
Verbal	71 (42.0%)	26 (37.1%)	9 (23.6%)	2 (25.0%)
Physical	14 (8.2%)	18 (25.7%)	9 (23.6%)	2 (25.0%)
Property	17 (10.1%)	17 (24.2%)	7 (18.4%)	2 (25.0%)
Threatened Harm	16 (9.4%)	13 (18.6%)	5 (13.2%)	3 (37.5%)
Financial	18 (10.6%)	8 (11.4%)	1 (2.6%)	-
Physical Injury	7 (4.1%)	10 (14.3%)	1 (2.6%)	2 (25.0%)

Note: Respondents were able to choose more than one category of abuse; Responses were dichotomous yes or no

Table 5.

Beta and B weights from Standard Regression of Demographic Predictors on Cumulative Experiences of Abuse (N=285)

	Cumulative Abuse	
Variables	β	B 95% CI
Gender	-.03	-.13 [-.71, .46]
Age	-.02	-.03 [-.26, .21]
Income sufficiency	-.03	-04 [-.21, .12]
Relationship Status	.15*	.45 [.10, .80]
Religious	.10	.13 [-.02, .28]
Number of people being cared for	.14*	.23 [.04, .41]
Years caring	.08	.09 [-.06, .25]
Hours caring per week	.04	.06 [-.10, .22]
Age of the person being cared for	-.04	-.02 [-.12, .07]
Gender of the person being cared for	-.11	-.29 [-.62, .04]
Caring for a person with a physical disability	.03	.10 [-.25, .44]
Caring for a person with a developmental disability	.09	.26 [-.21, .72]
Caring for a person with a mental health disability	.13*	.42 [.03, .81]
Caring for a person with Dementia or Alzheimer's	.04	.16 [-.32, .65]
Caring for a person with a drug or alcohol related disability	.12*	1.08 [.02, 2.14]
Caring for a person with another disability	.09	.33 [-.09, .75]

Note: * *p* < 05; Categorical variables were coded, 1= male, 2= female; 1= partnered, 2= not partnered; for all disability types of the person being cared for 1= does not have disability, 2= has this disability.

Table 6.

Carer Mental Health, Wellbeing, and Demographic Variables: Correlations and Descriptive Statistics.

	1	2	3	4	5	6	7	8	9	10	11
1. DASS total	(N=305)										
2. QLS total	-.60**	(N=296)									
3. Gender	-.00	-.08	(N=303)								
4. Age	-.07	.15**	-.20***	(N=304)							
5. Hours spent caring/wk	.08	-.10*	-.06	-.01	(N=304)						
6. Years spent caring	.17**	-.15**	.09	.10*	.14**	(N=305)					
7. Income sufficiency	-.32***	.55***	-.12*	.19**	-.11*	-.19**	(N=304)				
8. Abuse	.22***	-.19**	.07	-.03	.09	.21***	-.15**	(N=285)			
9. COPE Neg	.49***	-.52***	.08	-.10*	.15**	.19**	-.26***	.33***	(N=289)		
10. COPE Pos	-.40***	.45***	-.12*	-.06	.10*	-.09	.10	-.35***	-.48***	(N=288)	
11. COPE QoS	-.35***	.58***	-.12*	.08	.02	-.10*	.24***	-.16**	-.35***	.50***	(N=288)
M	23.73	5.51	1.91	4.39	5.59	4.05	2.96	.94	2.56	2.75	2.02
SD	13.10	2.08	.29	.85	1.02	1.22	1.04	1.45	.65	.64	.65

Note. * *p* <.05. ** *p* <.01. *** *p* <.01; Depression Stress and Anxiety Scale (DASS) range 0-63; Quality of Life Scale (QLS) range 0-10 ; Carers of Older People in Europe Index Quality of Support subscale (COPE QoS), range 1-4; Carers of Older People in Europe Index Negative Impacts of Caring subscale (COPE Neg), range 1-4;; Carers of Older People in Europe Index Positive Impacts of Caring subscale (COPE Pos), range 1-4; missing data deleted listwise in all correlational analyses.

Table 7.
Hierarchical Regression Analysis of Predictors of Carer Wellbeing and Mental Health (N =)

Variables	Mental Health (DASS)			Wellbeing (QLS)		
	β	B (Standard Error)	ΔR²	β	B (Standard Error)	ΔR²
Step 1			.10			.30
Gender	-.06	-2.52 (2.64)		.00	.01 (.37)	
Age	-.05	-.69 (.91)		.06	.14 (.13)	
Hours spent caring	.03	.36 (.74)		-.04	-.08 (.10)	
Years spent caring	.12*	1.34 (.64)		-.05	-.08 (.09)	
Income sufficiency	-.29***	-3.63 (.75)		.53***	1.06 (.10)	
Step 2			.13			.31
Gender	-.06	-2.84 (2.61)		.01	.04 (.37)	
Age	-.04	-.64 (.90)		.06	.13 (.13)	
Hours spent caring	.02	.24 (.73)		-.03	-.07 (.10)	
Years spent caring	.09	1.01 (.64)		-.03	-.05 (.09)	
Income sufficiency	-.27***	-3.41 (.74)		.52***	1.04 (.10)	
Abuse	.17**	1.53 (.52)		-.10*	-.15 (.07)	
Step 3			.32			.59
Gender	-.10	-4.32 (2.32)		.05	.36 (.29)	
Age	-.04	-.58 (.81)		.05	.12 (.10)	
Hours spent caring	.02	.25 (.66)		-.05	-.10 (.08)	
Years spent caring	.07*	.68 (.57)		.01	.01 (.07)	
Income sufficiency	-.18**	-2.32 (.67)		.40***	.80 (.08)	
Abuse	.01	.08 (.50)		.05	.08 (.06)	
COPE Neg	.30***	6.03 (1.22)		-.23***	-.74 (.15)	
COPE Pos	-.19**	-3.87 (1.35)		.16**	.52 (.17)	
COPE QoS	-.11	-2.20 (1.20)		.33***	1.06 (.15)	

Note. * p <.05. ** *p* <.01, *** p<.000; *B* (unstandardized coefficients); *β* (standardised coefficients); Depression Stress and Anxiety Scale (DASS); Quality of Life Scale (QLS); Carers of Older People in Europe Index (COPE); Listwise deletion used for cases with missing data on a variable.