

# Mental Health Carers' Support Experiences in Australia: A Mixed Methods Study

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## ABSTRACT

Informal mental health carers play a crucial role in supporting individuals with depression and anxiety. However, there is a lack of knowledge on how to effectively support these carers and promote their well-being. This mixed-method study aimed to explore the support needs of carers of a person with depressive or anxiety symptoms, living in Australia. Sixty-seven carers (female 76 %, median age 48) completed an online survey, and 22 completed semi-structured interviews about their support experiences. Over half of the survey respondents reported high levels of psychological distress on the Kessler Psychological Distress Scale (K10), and 63% reported understanding and adjusting to the caregiving role as the most needed areas of support, as identified on the Caregiver Perspective Questionnaire (CPQ). Through thematic analysis of the interviews, four key themes emerged describing carers' support experiences and needs: connecting with formal services, responding to the care-recipient, connecting socially, and caring for the self. The analysis also found that time constraints and stigma can be significant support barriers for these carers. This is the first time that a study has investigated the support experiences and needs of carers of a person with depressive or anxiety symptoms, living in Australia. The findings contribute to current literature on mental health carers and offer novel and tangible insights into future research and support opportunities.

## 1. Introduction

An informal carer is a person, such as a relative, friend or spouse, who provides ongoing, unpaid support or assistance to someone who is elderly, living with health concerns or has a disability (Australian Bureau of Statistics, 2018). Informal care provision encompasses a wide range of psychosocial, financial, and emotional assistance. The type and level of this support are influenced by many factors, such as the evolving care relationship, characteristics of the carer and care recipient, and their surrounding environment (Gérain & Zech, 2019; Liu et al., 2020).

Although attributes of this support role vary greatly, informal care is correlated with many benefits to care recipients and can offer distinct advantages compared to professional support.

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One such advantage is the established social relationship within the carer dyad, which enables the carer to possess a unique understanding and insight into the care recipient's specific needs. This emotional bond can afford the carer the capacity to comprehend the care-recipient's strengths and interests and support their recovery (Birchwood & Smith, 1990; Sin et al., 2005, 2012). In roles where emotional support is a key responsibility, such as supporting someone with a mental health condition, this bond is particularly important.

Mental health carers are informal carers who provide support to someone living with a mental health concern (either diagnosed or symptomatic) (Diminic, Hielscher, Harris, et al., 2019). These individuals support approximately 970 million people worldwide living with a mental health condition (Estrada-Fernández et al., 2022) and many others living with undiagnosed or subthreshold mental health concerns.

This support role is complex and unique. Research has shown that mental health carers provide more emotional support to care recipients than carers of a person with a physical health condition (68.1% v. 19.7%) (Diminic, Hielscher, Harris, et al., 2019). As a result, although mental health carers report many positive aspects of their roles, such as personal growth, feelings of appreciation from the care recipient, and a strengthened relationship with this person (Cheng et al., 2012; Li & Loke, 2013; MacKenzie & Greenwood, 2012), they also commonly report similar experiences to care-recipients, such as high levels of psychological distress (Baruch et al., 2018; Shah et al., 2010) and mental health-related stigma (Serchuk et al., 2021). These experiences can present additional challenges for the dyad, such as affecting social relationships and access to supports, depending on the context (e.g., Ae-Ngibise et al., 2015; Monnapula-Mazabane & Petersen, 2021).

The extant literature has found that due to the unique characteristics and challenges of mental health care, targeted support is most effective for these carers (Diminic, Hielscher, Harris, et al., 2019; Harris et al., 2015; Visa & Harvey, 2019). However, support is limited for certain groups.

In Australia, 85% of mental health carers support someone with depression or anxiety (Diminic et al., 2016), but there is a lack of available supports addressing their specific needs. A recent systematic review identified limited supports for these carers, particularly for carers of a person with anxiety symptomology (Fitzgeraldson et al., 2022).

This finding highlights the need to examine the support experiences of these carers. While previous research has investigated perspectives of individuals supporting someone with depression in Australia (Highet et al., 2004; McNair et al., 2002), less is known about carers of a person with anxiety. The objective of the present study is to address this gap in evidence by exploring the support experiences and needs of carers of a person with depressive or anxiety symptoms living in Australia.

The study sought to answer the following research questions:

1. What are the support needs of carers of a person with depressive or anxiety symptoms living in Australia?
2. What are the gaps in support for these carers?

## **2. Method**

### **2.1. Design**

The study used a mixed method approach across two stages. The first stage involved community-dwelling participants Australia-wide completing an online survey. The second

stage comprised telephone interviews with interested participants from the survey sample. Data collection took place from May 2019 to October 2019. This research has ethics approval from Hunter New England Human Research Ethics Committee of Hunter New England Reference 2018/ETH00444.

### **2.1.1. Participants and Recruitment**

Study participants were 16 years of age or older, living in Australia, comfortable responding to a survey or telephone interview in English and providing informal care for an adult (16 years of age or older) with symptoms of depression or anxiety. Participants were recruited through social media posts and recruitment advertisements, and other mental health and carer organisations. Media posts and recruitment advertisements included a link to the study survey and respondents gave online consent to participate.

### **2.1.2. Data Collection**

#### **2.1.2.1. Survey**

The online survey was designed to collect information about the support needs of carers of persons with depression or anxiety symptoms. The survey included demographic questions and standard measures to assess psychological distress and carers' goals.

Demographic questions centred on the carer (e.g., carer's sex, age, relationship status), the care-recipient (e.g., care-recipient's sex, age, time living with symptoms of depression, anxiety or both) and the type of the care-relationship (e.g., spouse, parent or friend).

The Kessler Psychological Distress Scale (K10; Kessler et al., 2002) was used to measure carers' symptoms of psychological distress. The K10s consists of 10 items that assess the frequency of symptoms experienced in the past four weeks (e.g., "About how often did you feel tired out for no good reason?"). Each item is rated on a 5-point Likert scale ranging from "none of the time" (1) to "all the time" (5). Respondents can receive a minimum sum score of ten and a maximum score of 50.

To measure carers' support goals, the survey included an adapted version of Foster and colleagues' Caregiver Perspective Questionnaire (CPQ; Foster et al., 2009). The CPQ asks respondents about 11 goal areas of interventions commonly used in carer-focussed support (e.g., the goal to "feel more competent in my ability to care for"). Participants were asked to select the goals that were relevant to their carer situation.

#### **2.1.2.2. Interviews**

At the conclusion of the online survey, participants were asked whether they would like to participate in a telephone interview. The purpose of the interviews was to understand personal views on, and experiences with being a carer or support person for an adult with depression or anxiety. Survey participants who were interested in taking part in the interviews were then contacted to arrange an interview date. An interview schedule was used to explore participants' views and experiences as carers of an adult with depression or anxiety. The interviews (n = 22) were conducted over the phone, lasted on average 44 minutes (range = 20 to 82 minutes), were audio-recorded and then transcribed verbatim with participants' consent. Personal identifiers were removed from the transcripts.

### 2.1.3. Data Analysis

#### 2.1.3.1. Survey

The survey data were analysed using SAS version 9.4. Continuous variables were summarised as median (range) and categorical variables were presented as counts and percentages. The percentages, medians and ranges reported in the results section were calculated based upon the number of answers to each survey question without imputing missing values.

#### 2.1.3.2. Interviews

Transcripts were analysed using Braun and Clarke's (2006) six-step framework for thematic analysis. The process was undertaken deductively, having as a guide the research aim of exploring carers' needs. To become familiar with the data (step one), the primary author (EF) read the transcripts multiple times. EF then extracted relevant sections of text, or 'codes' using Nvivo (step 2). Patterns across these codes were searched to develop themes (step 3) and reviewed following discussions with a qualitative researcher (JC) (step 4). As part of this process, participant codes and quotes were grouped into categories to help organise data into thematic areas, decide whether any codes should be moved, and to further define themes (step 5) prior to writing up the results (step 6).

## 3. Results

### 3.1. Survey Results

A total of 67 carers completed the survey. Most participants were female (75.8%), the median age in years was 48 (range 19-77) and the most frequently reported relationship to the care recipient was spouse or partner, parent and son or daughter (Table 1). Most survey participants reported that the care recipient had received a formal diagnosis, with depression and anxiety being the most frequently reported, followed by depression only and depression, anxiety and other diagnosis.

Overall, 52% of participants experienced high or very high levels of psychological distress according to the K10. The most frequently reported goal for carers was being able to understand and adjust to what it means to support someone experiencing depression or anxiety (63%; Table 1).

Table 1.  
*Characteristics of Survey Participants (N = 67)*

Characteristic		
Age, Median (range)	48.0	(19-77)
Gender, n (%)		
Male	15	(22.7)
Female	50	(75.8)
Other	1	(1.5)
Relationship to care recipient, n (%)		
Spouse or partner	23	(40)
Parent	13	(23)
Son or daughter	7	(12)
Friend	5	(9)
Sibling	4	(7)
Former spouse or ex-partner	2	(4)
Grandson or granddaughter	1	(2)
Other	2	(4)

<b>Characteristic</b>		
Care recipient's age, Median (range)	49	(14-82)
Care recipient's gender, n (%)		
Male	34	(59.6)
Female	23	(40.4)
Care recipient has received formal diagnosis yes/no, n (%)		
Yes	46	(83.6)
No	9	(16.4)
Diagnosis of care recipient a		
Anxiety and depression	11	(24)
Depression only	10	(22)
Anxiety, depression and other diagnosis	7	(15)
Depression and other diagnosis	3	(7)
Anxiety only	2	(4)
Anxiety and other diagnosis	1	(2)
Other	3	(7)
K10, M (SD)	23.6	(8.4)
K10 categories, n (%)		
Low	12	(17.9)
Moderate	20	(29.8)
High	20	(29.8)
Very high	15	(22.4)
Carer Perspective Questionnaire, n (%)		
better able to understand and adjust to what it means to support someone experiencing depression or anxiety	42	(63)
identify and manage burnout	32	(48)
cope with family conflict or disharmony	30	(45)
an increased ability to care for myself	29	(43)
feel more competent in my ability to care for	29	(43)
develop a social support network with other carers	24	(36)
a better understanding of the symptoms of depression and/or anxiety	22	(33)
feel less anxious (nervous, restless, fearful)	22	(33)
feel less sad or depressed	17	(25)
develop a better sense of self	17	(25)
better understand feelings of distress or sorrow	16	(24)

Note. Among participants reporting that the care recipient has received a formal diagnosis.

Table 2.

*Characteristics of Interview Participants (n = 22)*

<b>Characteristic</b>		
Age, Median (range)	50	(27-70)
Gender, n (%)		
Male	5	(22.7)
Female	17	(77.3)
Relationship to care recipient		
Care recipient's age, Median (range)	56.5	(14-82)
Care recipient's gender, n (%)		
Male	13	(59.1)
Female	9	(40.9)

### 3.2. Interviews Results

Interviews were an average of 44 minutes in length (range = 20 to 82 minutes). Demographic details of interview participants are available in Table 2. Responses to questions about support experiences and needs were categorised under four themes: (1) connecting with

formal services, (2) responding to the care-recipient, (3) connecting socially, (4) caring for the self. A summary of each theme and supporting data is presented below:

### **3.2.1. Connecting with Formal Support**

Interview participants discussed their experiences with formal supports to manage the carer role. Two common reasons for seeking out professional support included information needs and support for their own health and wellbeing.

#### **3.2.1.1. Information Needs**

Participants indicated that having more information would support them in the caring role. Carers said that information about depression and anxiety, carer specific information and knowing what to do in between appointments would be helpful. Participants also reported that they wanted information that was accurate and specific to the age of the care-recipient (e.g., caring for an elderly person) and relevant to the stage of depression. Additionally, they indicated that having comprehensive information, or a 'one stop shop' would be useful, yet this should not be 'too wordy' or 'technical' (Interview 10, woman supporting mother with depression and anxiety). Information that is accessible online was also preferred.

One challenge around information needs was not knowing where to seek support. For example, one carer described this challenge following the care-recipient's diagnosis as feeling like 'you're out on a little boat in the middle of sea, trying to navigate through without any support' (Interview 1, mother supporting daughter with depression and anxiety).

#### **3.2.1.2. Support for Own Health and Well-Being**

Some carers said they had spoken to professionals about their support role. Moreover, some participants had spoken to health professionals (e.g., psychologist, counsellor) about their own mental health needs, but the financial costs associated with this type of support was a challenge for some carers.

Doctors and other professionals were perceived as using medical jargon and focussing on the care-recipients' needs, despite the carer describing personal challenges. When asked what would address these challenges one participant said:

'...knowing what website to look at or knowing a number. I think it's about knowing what's involved, so just having that information generally available. I don't know if that's through advertising or on the TV, like how do you know about it?' (Interview 12, woman supporting male partner with depression).

### **3.2.2. Strengthening the Care-Relationship**

Participants suggested that knowing how to respond to the care-recipient was an important skill in the care role. Participants concerns in this area focussed on interacting with the care-recipient and maintaining individual boundaries.

#### **3.2.2.1. Interacting with the Care-Recipient**

While participants did not always know how to respond to the care-recipient, they indicated their effort and goals in this area. Communicating with the care recipient was a common concern and focus for participants. Carers said they experienced challenges sharing their 'point of view' (Interview 15, woman supporting male partner with depression and anxiety), and responding when '(the care-recipient) is resisting' (Interview 3. Woman supporting male partner). One participant expressed the importance of knowing how to respond to the care-recipient in everyday life, beyond information about their psychopathology, stating:

‘I know... the neurology, the psychology of what’s going on, it’s more like strategies to know how far I try to push him out of his comfort zone’ (Interview 11, woman supporting husband with depression).

### **3.2.2.2. Maintaining Individual Boundaries**

Participants also spoke about the importance of having individual boundaries within the care relationship. They identified physical strategies that can help to establish or maintain these boundaries. For example, participants said that sharing household chores, having a routine and physically separating from the care-recipient are helpful strategies. Some carers however also indicated challenges when trying to implement boundaries in this way. For example, carers said that planning and physically separating from the care-recipient is not always possible. Or as one participant put it,

“We are very close; we are really great friends. We get on really, really well. But because it is just, he and I, it is very intense sometimes, because he is very, very dependent on me. Neither of us has got much freedom, which is very important at his age, being 16” (Interview 19, mother caring for son with depression and anxiety).

### **3.2.3. Connecting Socially**

Participants said that social support help them better manage the carer role. Friends and family, and other carers were described as offering different types of support.

#### **3.2.3.1. Connecting with Friends and Family**

Many carers said that speaking with friends and family was an important part of coping with care-related challenges. Support from friends and family was described as ‘valuable’ (Interview 1, mother supporting daughter with depression and anxiety) and as providing ‘lots of listening ears’ (Interview 10, Woman supporting mother with depression and anxiety). However, carers also spoke about sharing with friends being difficult due to concerns about judgement and a lack of understanding.

#### **3.2.3.2. Connecting with Other Carers**

Finding support from other carers, particularly online, was a common experience and preference for participants. Some said that engaging with a carer Facebook group has been particularly helpful, and they particularly enjoyed the flexibility and anonymity of this modality

### **3.2.4. Caring for the Self**

Participants expressed that using strategies to care for their own health and wellbeing are helpful for managing their caring role. Carers indicated physical activities that they undertake to care for themselves, such as, exercising, spending time with pet animals, reading, gardening, or watching movies.

Some carers also said that they use strategies focussed on awareness of their thoughts and emotions, such as journaling, mindfulness, meditation and acknowledging emotions. One participant stated:

“I practice mindfulness and meditation. So, I really focus on those little moments throughout the day that I can look after myself, and make sure that I have something to look forward to each day”. (Interview 19, mother caring for son with depression and anxiety).

Support barriers to self-care included time, needing more information about self-care and feeling selfish caring for oneself when the care-recipient is unwell.

“It feels really selfish when you know your partner has suicidal ideation and then has this such severe anxiety and depression to then go, you know what and they’re struggling to get to their support services to then say ‘oh you know what I think I need to go’, it feels really silly to even suggest that” (Interview 17).

#### **4. Discussion**

This study explored support needs of carers of a person with depressive or anxiety symptoms by conducting an online survey and in-depth qualitative interviews with this carer group. High or very high levels of psychological distress were experienced by more than half of the participants, and a common goal for this carer group was to better understand and adjust to their carer role. Participants described an interest in strengthening their relationship with their care recipient, while being able to care for oneself and engaging with both formal and informal sources of support. Connecting with family, friends and other carers was a common thread across needs for this carer group.

The risks associated with supporting someone with mental ill health to a person’s own psychological well-being and general health are well-established in the literature (e.g., Broady & Stone, 2015; Pinquart & Sörensen, 2011). The present study extends previous findings to the context of supporting someone with depressive or anxiety symptoms. Over half of the participants experienced high or very high levels of psychological distress, and almost one-third reported moderate levels of distress. Identifying carers’ psychological needs is important as even moderate levels can place an individual at risk of later significant psychological distress (Sartorius, 2001), social and familial relationship difficulties, financial strain (Jungbauer et al., 2004), poorer physical health and more need for formal services (Perlick et al., 2007). Additionally, cumulative psychological distress can adversely affect the carer’s ability to respond appropriately to the care recipient (Sullivan & Miller, 2015), or undertake self-care or health maintenance practices (Feinstein, 2007) which may impact their ability to continue providing care.

The findings of this study also suggest that role adjustment and relationship support are key priorities for this carer group. Consistent with previous research, the findings indicate that carers can benefit from a range of formal and informal supports, such as counselling, information about the care-recipient's illness, social and community engagement, and self-care activities (Berk et al., 2013; Efthymiou et al., 2017; Racey et al., 2018; Reynolds et al., 2022; van Exel et al., 2008; Visa & Harvey, 2019). These results extend previous research by providing multi-methodology evidence about the support preferences of carers of a person with depressive or anxiety symptoms. Specifically, survey findings showed that adjustment to the care role was the most important concern for most participants, which is consistent with previous studies on other carer groups (e.g., Ireland & Pakenham, 2010; Mackay & Pakenham, 2012). Similarly, interview findings showed that carers value their relationships, a finding that aligns with previous studies (Bieber et al., 2018; Spruytte et al., 2002), but further suggests that this is important for mental health carers specifically.

Consistent with other literature, this study also found that time constraints, geography, and a lack of information about available supports can present support barriers to mental health carers (Diminic, Hielscher, Harris, et al., 2019). Moreover, the results show that how a person views their role as a carer is sometimes associated with additional barriers, such as feeling selfish about seeking support. This evidence is important for highlighting the role of physical and internalised barriers to support for this carer group.



#### **4.1. Study Strengths**

The key strength of this research was an understanding of the support needs and priorities of carers of a person with depressive or anxiety symptoms, which is currently missing from the literature.

National data indicates that more 60% of mental health carers are supporting someone with a moderate or mild mental illness (Diminic, Hielscher, Harris, et al., 2019). Yet, carer-focused interventions typically target carers of a person with significant psychopathology (e.g., bipolar and psychosis; Gottlieb et al., 2013; Hubbard et al., 2016; Reinares et al., 2016; Sin et al., 2019a, 2019b; Varambally et al., 2013). Understanding the distinct support requirements of carers of individuals living with depressive or anxiety symptoms within this study will serve as a foundation for creating suitable supports, tailored to their needs.

Self-care strategies and one's social network were found to be important sources of support for this carer group, suggesting that carers of a person with mental health concerns can benefit from strategies other than professional intervention. These insights reveal opportunities for developing interventions aimed at strengthening relationships within and beyond the care relationship, including strategies for both the carer and care-recipient, such as social and peer-support. Additionally, the findings emphasise the importance of identifying and addressing support barriers to empower carers in their roles.

#### **4.2. Limitations**

While this study holds valuable insights, it is important to acknowledge and consider its limitations when interpreting the findings.

The included participants were mostly caring for someone with a formal diagnosis of depression or anxiety which suggests that they have been engaged in the service system. In addition, research focussed on identifying support gaps is likely to attract people who have adverse experiences and unmet needs to report, which can lead to an overrepresentation of carers experiencing adverse psychological outcomes (Highet et al., 2004). Consequently, the findings of the present study may not be generalisable to the broader carer community.

A second limitation in this research is the focus on the challenging aspects of the informal care experience. Although the use of a multi-methodology approach in the current study aimed to acknowledge the nuance and complexity of care experiences beyond care-related challenges, the use of predefined survey measures and semi structured interviews may have led some respondents to only discuss the challenging aspects of the role. It is acknowledged that care experiences are complex, nuanced and temporal (Gérain & Zech, 2019; Liu et al., 2020) and that carers can also experience many benefits in their roles (Cohen et al., 2002; Li & Loke, 2013).

#### **4.3. Future Directions**

This study has indicated several promising avenues for research and practice in supporting mental health carers.

Firstly, expanding the scope to encompass a more diverse range of carers, including those with different engagement levels with formal services may yield more comprehensive insights into the support needs of mental health carers living in Australia. Future work is also needed to examine the complete caregiving experience, including the positive aspects of this role to gain insights into how to promote carers' well-being and satisfaction. Carers' lived experience stories can also give insight into the intersection of caregiving with demographic

and identity factors, such as gender, socioeconomic status, and cultural backgrounds, to inform more inclusive and equitable support approaches.

Ongoing collaboration between researchers, carers and service providers is crucial for ensuring supports are meaningful and adequately targeted. Additionally, future research should evaluate the impacts of current policies and initiatives in Australia to inform resource allocation and policy development. The present study provides a foundational understanding of caregiving for individuals with depressive or anxiety symptoms, and future research should continue to expand and refine this knowledge, to contribute to improvements to the well-being of both carers and care recipients.

This is the first study to explore the support needs and barriers of carers of a person with depressive or anxiety symptoms living in Australia. The findings indicate a need for interventions that support these carers to manage psychological distress, adjust to the caring role, and navigate relationships with the care recipient and others. Interventions should also consider time constraints and stigma as potential barriers to support for these carers. The findings from this study demonstrate how investigating the support needs and experiences of specific carer groups can provide tangible insights for future developments in this area.

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