

**Experiences of compassion among family carers of older adults:
Qualitative content analysis of survey free-text comments**

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Abstract

Objectives: To provide qualitative insight into the experiences of compassion (to self, to others, and from others) among family carers of older adults by exploring the written responses provided within a cross-sectional survey that asked about carers' levels of compassion, mindfulness, emotion regulation, coping strategies, and psychological health.

Methods: Family carers of adults aged ≥ 65 years from around the world completed the survey between July – December 2019. To provide carers with an opportunity to describe experiences in their own words and expand on issues beyond the limits of closed-response items, the survey included eight free-text boxes. These appeared after each self-report measure, and at the end of the survey. From a total of 127 carers providing 504 written responses, inductive qualitative content analysis identified and evaluated 245 comments from 105 family carers' that were about their experiences of compassion (to self, to others, and from others).

Results: Some family carers perceived a lack of compassion, both for themselves and from others, and several barriers to carers' openness to receiving compassion were identified. Factors influencing carers' compassion to others in general included how carers were feeling themselves, the person it was directed towards, and the situation. Within the caregiving relationship specifically, this included care recipients' level of need and behaviour.

Conclusions: Findings provide qualitative understanding about family carers' realities of compassion (to self, to others, and from others) within their role, and highlight the applicability and warranted focus of compassion-based approaches within family caregiving research and practice.

Keywords: caregivers, compassion, dementia, qualitative, self-report

Introduction

The effects of providing care to an older family member has been the focus of much gerontological research over recent decades and, from this, we know that family carers can experience a range of both positive and negative aspects (1). Studies show that, although family caregiving can be a rewarding and satisfying experience (2, 3), it can also be stressful and pose many challenges (1). A host of adverse effects have been identified and this has included impacts on carers' psychological health. Extensive data shows that rates of depression, anxiety, and stress are higher in family carer than non-carer populations (4, 5) and that subjective wellbeing declines when assuming a caregiving role (6). Alongside this, access to professional help to manage stress and emotional health has been specifically identified as a key need by families providing informal care to older adults and people living with dementia (7, 8). For this reason, research has increasingly focused on exploring how psychological approaches can help to buffer against the emotional demands of family caregiving. These efforts have been largely directed at testing the efficacy of talk therapies, and this has included cognitive behavioural therapy (CBT), which has demonstrated moderate-to-large effects on reducing family carers' depression, anxiety, and perceived burden (9). More recently, however, there is also emerging evidence for the potential utility of newer therapies, including approaches that aim to cultivate compassion (9).

Despite having a long history in Eastern culture and spiritual teachings, compassion is a relatively new concept within secular science and research, and it is currently defined and measured in a number of ways (10). In some definitions, compassion is understood as an emotion (11), whereas others regard it as a multifaceted construct (12), or have focused on a particular aspect, such as self-compassion (13). Within evolutionary-focused models specifically, compassion is defined as 'a sensitivity to suffering in self and others, with a commitment to try to prevent or alleviate it' (14 p19). In this approach, compassion is

understood as a prosocial motivation that involves three interactive flows – compassion for self, compassion to others, and compassion from others – that each have two processes: compassionate engagement (i.e., sensitivity to suffering) and compassionate action (i.e., alleviation or prevention of suffering).

Drawing on these various definitions, there are currently six empirically-supported compassion-based approaches reported within the literature that, broadly, all seek to cultivate feelings of compassion through a combination of psychoeducation and guided exercises (i.e., mindfulness, imagery, breathing practices). Collectively, these approaches have demonstrated positive impacts on psychological distress, depression, anxiety, and wellbeing in a range of clinical and non-clinical populations (10). Emotion regulation has been implicated as the potential mechanism of change in the compassion-psychological distress relationship, and this is mainly in terms of emotional awareness, appraisal, and acceptance (15), and tolerance of negative emotions (16). These findings highlight the potential applicability of compassion-based interventions to promote healthy emotion regulation within populations experiencing considerable stress (16) and, as such, it may be a helpful focus in psychological programs for family carers of older adults (17).

The current evidence-base exploring compassion as an intervention target within family caregiving is in its early stages, being limited in number, scope, and quality (18, 19). However, preliminary studies involving family carers of older adult populations – including carers of people living with dementia – have demonstrated promising findings. In cross-sectional work, greater self-compassion has been associated with lower levels of psychological distress and burden (20, 21), and higher levels of reported compassion satisfaction has been associated with lower levels of caregiver burden (22). Further, a six-week Compassion-Focused Therapy group has shown post-intervention improvements in carers' anxiety, depression, and physiological wellbeing (23).

Building on this initial work, and to advance understanding in the area further, we undertook a cross-sectional study to explore the role of compassion (to self, to others, and from others) in the psychological health of family carers of older adults (24). In the absence of both quantitative and qualitative studies in the area, and to maximise the data collection opportunity, we supplemented the validated self-report measures included within the survey with eight free-text comment boxes. By doing so, we sought to provide carers with a purposeful opportunity to expand on their experiences beyond the known limits of closed-response items (25) and, importantly, aimed to address the potential power imbalance between researcher-imposed questions and carers' realities (25). Within this article, we present the findings from the qualitative analysis of the written responses provided by family carers within the free-text comment boxes that were about their experiences of compassion (to self, to others, from others). Our aim was two-fold: (a) to explore carer experiences of compassion in their own words, and (b) to identify considerations for future research and practice.

Methods

Design

A qualitative content analysis approach was used to condense extensive and varied raw text data, to explore and interpret the data, and to establish links between the research objectives and the data interpretation (26, 27). This method was chosen because of its known suitability in analysing large amounts of text and because of its appropriateness of use within topic areas of a sensitive nature (27). An inductive approach was employed, whereby carers' experiences of compassion were explored in their own words (i.e., from a new perspective

not previously studied (27)). The study was ontologically positioned in relativism and epistemologically positioned in subjectivism (28).

Participants and Procedure

The survey was open to any individual from around the world who was aged 18 years or older, could read and write in English, and who provided regular unpaid care to a family member, friend, or neighbour aged 65 years or older. Recruitment involved targeted promotional activities, via carer organisations; print, online, radio, and social media; and word-of-mouth. The survey could be completed either online (LimeSurvey GmbH, Hamburg, Germany), via hardcopy, or in verbal conversation with the lead author. Ethical approval was obtained from Griffith University Human Research Ethics Committee (GU ref. no. 2019/481). Participants were informed that all data were anonymous, and that completion constituted informed consent. Participants could stop the survey at any time and were encouraged to take breaks during completion. The contact details of various mental health support organisations around the world were provided, as well as those for the research team and institutional ethical committee. The survey was piloted in June 2019 with seven family carers. Round one piloting ($n = 3$) resulted in minor changes to the introductory text and demographic questions. Round two piloting ($n = 4$) saw no further changes and these data are included in the sample. The final survey was available to complete between July and December 2019.

The Survey

A series of questions about the demographic and caregiving profile of participants were included at the start of the survey. Seven self-report measures then followed, and these

appeared in the subsequent order: Compassionate Engagement and Action Scales (CEAS) (29); Depression, Anxiety, and Stress Scales – 21 (DASS-21) (30); Mindful Attention Awareness Scale (MAAS) (31); Brief Coping Orientations to Problems Experienced Scale (COPE) (32); and Difficulties in Emotion Regulation Scale (DERS) (33). After each measure, a free-text comment box was provided, and participants were asked to use the space to write about anything that they considered relevant to the questions asked in that particular section (Table 1). A free-text box also appeared at the end of the survey to capture any general comments participants had about their health and wellbeing while providing informal care. There were no character limits for any of the free-text boxes and it was not mandatory to provide a comment.

[Insert Table 1]

Data Analyses

A sample of 259 participants completed the survey. Data from the online version ($n = 239$) were exported into IBM SPSS Version 26 (IBM Corp, Armonk, NY), and data from hardcopies ($n = 20$) were manually entered. Frequency statistics were checked for missing values, spread of responses, and against the eligibility criteria; 17 cases were removed. Chi-square/fisher's exact tests or independent t-tests were used to test differences between family carers who provided a response about their experiences of compassion in the free-text comment boxes and those who did not ($p < .05$).

Data in all of the eight free-text comment boxes were analysed in NVivo (QSR International Pty Ltd) using qualitative content analysis (26, 27). Commensurate with the aims of the study, the analysis focused exclusively on comments related to family carers' experiences of compassion (to self, to others, and from others). All analysis was undertaken by the lead author who started the preparation phase by familiarising themselves with the data

through repeated rereading, and by running word frequency searches. The lead author also kept an ongoing memo during this process to record their developing insights. To begin organising the data, line-by-line inductive open coding was undertaken on all free-text boxes, seeing data-driven labels applied to groups of words, phrases, or sentences to summarise their meaning. Once all data were coded, the lead author inspected the codes for similarity/difference and subsequently grouped codes with similar meaning into categories. Each category was defined using content-characteristic words, and the process of abstraction occurred until all identified categories were deemed to sufficiently describe the data. To uphold trustworthiness of the analysis, an iterative approach was taken, whereby the data were repeatedly reread to confirm the overall representativeness of the categories, and to check for overlap and uniqueness. The second author also independently coded a random sample of 10% of the data using the codebook inductively developed from the analysis. The level of agreement between the first and second authors' coding was 100%.

The final coding frame produced from the described process of analysis is shown in Table 2, with six categories identified in family carers' comments about compassion to self, four categories identified about compassion to others, and four categories about compassion from others. Selected quotations are used to illustrate and support the analysis, and these are reproduced verbatim with no changes made to correct spelling or grammar. Family carer identification codes for quotations are provided as Supplementary Material (Table 4).

Findings

A total of 127 family carers (52.5% of all survey respondents) provided 504 comments in at least one of the eight free-text boxes. Of these, 105 family carers wrote 245 comments that were specifically about their experiences of compassion (to self, to others, or

from others). Although there was broad similarity in the profile of family carers who provided a comment about their experiences of compassion in the survey compared to those who did not, there were some significant differences (Table 3). Carers differed in their country of residence (fisher's exact test ($N = 241$, 2-sided) = 16.84, $p = .007$), with carers from Australia more likely to provide a comment about compassion, and carers from the USA more likely not to. Individuals who provided care to an older adult with either dementia ($\chi^2(1, N = 242) = 17.57, p < .001$) and/or a musculoskeletal disorder ($\chi^2(1, N = 242) = 7.96, p = .005$) were also significantly more likely to leave a comment about compassion than their survey counterparts.

[Insert Tables 2 & 3]

Compassion to Self

Issues around self-compassion featured in the comments of 69 family carers (54.3%). Typically, statements focused on the perceived difficulty of carers to be compassionate with themselves, with many acknowledging that they were either not self-compassionate or 'find it hard' (#121). Alongside this, many carers expressly stated that they found it much easier to give compassion to others rather than direct it towards themselves: 'it feels easier and more natural to help others when they are in distress. it feels awkward to help yourself' (#165). In qualifying these statements, carer comments suggested a fear of, or reluctance to, receiving compassion from themselves. For some, giving themselves compassion was 'a very hard topic to even think about' (#130), and individuals indicated that they did not think themselves deserving of self-compassion and 'do not have the right to be' (#153). There was also a sense that being self-compassionate would stop the carer from being able to fulfil their role: 'I don't have the energy and think if I lose focus on caring...I will collapse myself' (#270); and 'i'm not always compassionate with myself, as i feel if i allow these feelings to come to the front

of my mind i would not be able to care for my mother' (#210). Many carers also identified the inherent outward focus of the caregiving role as another barrier to self-compassion, stating that 'when caring, life becomes compartmentalised. Active caring becomes the focus' (#243). As a result, carers felt that they lacked the time to practice self-compassion because 'you have no time to think of yourself' (#328) and it is 'an internal process that you don't have time to dwell on, really. There is a job to do' (#136). Further, external stressors outside of the caregiving role were also perceived to prohibit self-compassion, with carers describing the difficulties of 'other things going on in my world' (#172) and how 'there really isn't much I can do to help myself right now. i have many stresses not just looking after mum' (#69).

Overall, these comments suggested that family carers were generally limited in their self-compassion, and that their capacity and openness to self-compassion was inhibited by the demands and outward focus of the caregiving role, fears/reluctance to being compassionate with themselves, and a perception of compassion as something for others and not for the self.

Compassion from Others

Around half of all family carers (53.5%, $n = 68$) wrote about receiving compassion from others. In the main, statements focused on the perceived lack of compassion from others, with many participants feeling that 'no one really cares' (#31). Some indicated that people avoided them because of their caregiving role, and others wrote of losing friends and seeing family members distance themselves: 'I have lost several long term friends that wouldn't put up with the time I spend caring' (#274). Carers highlighted family difficulties as a particular barrier to receiving compassion, with some writing that relatives did not want to be involved: '[compassion is] seemingly becoming more difficult with slightly increasing

frequency as peoples differing interests in managing family estate become foregrounded’ (#145); and ‘My immediate family think his dementia is my fault & I deserve whatever aggression he dishes out & should just get over it’ (#67). Carers also expressed that formal support services often did not meet their needs and were ‘inadequate and lacking in compassion for the care recipient...support services do not consider the carers at all – especially hospitals’ (#30). However, some comments also suggested a reluctance to accept compassion from others: ‘It often takes a long time to actually allow people to help you. For many years I was too proud to let on that I was struggling!’ (#244); and ‘I can’t accept help/support easily and try to figure out solutions myself and just get on with things’ (#345).

Although comments tended to focus on the difficulties of receiving compassion from others, there were some carers who wrote about the compassion that they did receive. As the following quotation illustrates, these statements typically focused on compassionate action from family and friends: ‘A neighbour takes out my bins, my care worker is always caring for me in so many practical ways, my friends help out’ (#83).

In the main, these comments suggested that family carers perceived a lack of compassion from others, particularly from family and formal support services, and that this was also influenced by their own reluctance to receiving compassion from others.

Compassion to Others

The comments of 34 family carers (26.8%) were focused on the issue of giving compassion to others. Notably, some carers wrote that they either worked or had worked in a caring profession and that this helped them to ‘offer others compassion when they are distressed or upset’ (#274). However, carers also indicated that giving compassion to others was dependent on a complex interplay of factors. This included how carers were feeling

themselves ('Because I use a lot of energies taking care of my dad, I sometimes don't have a lot left for the other people in my life' (#279)), as well as the person and the situation, with compassion generally restricted to immediate family and closest friends. In terms of how carers were actively compassionate towards others, comments suggested the importance of offering emotional support rather than seeking to solve problems, reasoning that 'some ppl do not want advice, they just want to be heard' (#28). Finally, a minority talked about compassion in relation to the care recipient, highlighting the difficulties in remaining compassionate when dealing with high levels needs and behaviour as a result of their family members' chronic condition:

Have to provide compassion but until you get past the point of knowing its the illness etc that causes that distress and not the person themselves it makes things difficult to move past all the emotions that can cloud judgements. (#150)

I am ashamed to say that I am becoming less compassionate towards my own mother when she is distressed or upset. She can no longer remember her family and the relationships they have with her, or where she has lived in the past. Often, when she asks me about these things, she does not believe my answers and becomes angry with me and, on occasions, a little abusive. (#317)

Collectively, these comments suggested that family carers' compassion to others was dependent on various influencing factors and that, within the caregiving relationship specifically, this included the level of needs and behaviour of the family member they provided care for.

Discussion and Implications

This study sought to provide qualitative insight into experiences of compassion among family carers of older adults by exploring the written responses provided within an international cross-sectional survey. By using free-text comment boxes throughout the survey, we sought to provide carers with a purposeful opportunity to describe their experiences in their own words and expand on issues raised in the survey that were important to them. In doing so, we aimed to give original insight into carers' realities of compassion within their role, and identify key considerations for future research and practice. Overall, our novel qualitative findings show that carers perceived a lack of self-compassion and compassion from others, but also had several barriers to receiving compassion. Giving compassion to others was influenced by several factors and, within the caregiving relationship, this included care recipients' level of need and behaviour. Taken together, these findings highlight the potential applicability of compassion-based approaches to support to family carers of older adults, and underline it as a warranted focus within future family caregiving research and practice.

A key finding arising from our study was that although family carers perceived a lack of compassion, both for themselves and from others, they also had several barriers in their openness to receiving compassion. Given growing evidence that shows an inverse relationship between self-compassion and psychological distress in family caregiving populations (20, 21, 24), as well as a positive association between fears of receiving compassion (both from self and others) and poorer mental health (34), these findings support compassion as an important focus within this population (17). Currently, there are six empirically-supported compassion-based approaches (10) and this includes, most notably, Compassion-Focused Therapy (35), and Mindful Self-Compassion (36, 37). These approaches directly address the known fears, blocks, and resistances to compassion that many populations experience (38), and which were similarly shown in the comments of the carers

in our study. However, in light of the limited evaluation of these approaches within family caregiving to date (18, 19), we support the need for further research in the area to explore their potential utility and efficacy. Additionally, in order for these interventions to be tailored to the needs of this population specifically, we also encourage further qualitative work be undertaken to explore, in-depth, the barriers to receiving compassion (both from self and from others), among family carers of older adults. Our findings can be used to help determine the key issues and questions to guide this work and develop a more nuanced understanding of compassion as it relates to family carers of older adults.

In terms of the perceived lack of compassion from others specifically, our findings also raise the potential of training compassion more overtly within formal support services, and also in undertaking education and awareness-raising within the community generally. Although the evidence-base for compassion training within a professional healthcare context is sparse, early work proposes the value of training compassion within care organisations, including those involved in direct delivery of care, as well as policy and administration (39, 40). Further, given that we know that stigma related to conditions associated with ageing is linked to limited knowledge of the condition (41), there is also scope to develop compassion-based education programs in areas such as dementia for extended family members and the wider community. These efforts would help individuals to develop skills to support greater engagement with the challenges family carers face, as well as ways of taking action to directly reduce and alleviate these demands (14). This could increase carers' perceived compassion from others and could improve their wellbeing.

Although compassion to others was not a central feature of carers' comments within this study, our findings give some insight into compassion within the caregiving relationship. Carers highlighted the complex interplay of factors and influences on giving compassion to others, with it specifically noted that their extent to be compassionate was at risk when faced

with the more challenging behaviours of their family member. In-keeping with transactional models of caregiver stress (42), as well as previous research exploring compassion satisfaction and fatigue in family caregivers (22), these findings show that care recipient needs are an independent stressor within the caregiving process, and is one that can impact carer outcomes. As such, although we encourage the application of compassion-based psychological support to carers, we likewise highlight the importance of also reducing objective stressors for the carer, including providing carers with appropriate opportunities to take a break through use of various respite care services (1).

Strengths and Limitations

This is the first known study to qualitatively explore the three orientations of compassion among family carers of older adults. Aside from this originality, the study also has strength in the size of its sample, which addressed the question at hand while also attaining saturation without having repetitive data. Nonetheless, the study is limited in a number of ways. First and foremost, the findings may not reflect the experiences of all family carers of older adults and wider generalisability is limited. The survey asked about compassion, mindfulness, ways of coping, and emotional health and wellbeing, and this included direct questions about psychological distress and difficulties in emotion regulation. Such questions may have influenced the comments provided and could have resulted in carers focusing to a greater extent on the negative, rather than the positive, aspects of caregiving. Similarly, given that previous research has shown that free-text comments are more often made by people with negative experiences (43), it is also possible that carers who experienced greater negative experiences were more likely to undertake the survey because it provided an emotional outlet for them and an opportunity to comment on their difficulties.

Alongside this, carers who provided a response were typically female and, when compared to those who did not provide a comment, were also more likely to live in Australia and care for an older adult with either dementia and/or musculoskeletal disorders. This profile of respondents may have been a result of the study's targeted recruitment strategy (i.e., the organisations engaged to assist with promotional activities), and therefore reflects a potential sampling limitation. Second, although the rigour, reliability, and validity of the qualitative analysis was upheld in multiple ways (i.e., an inductive iterative approach, memo-keeping, and independent coding checks) the qualitative nature of the study means findings are inherently subjective and open to interpretation. Further, due to data collection being via written responses in a survey, we were unable to clarify comments or probe further, and we do not have the richness or level of data that would have been garnered from in-depth qualitative work involving interviews or focus groups.

Conclusions

This study provides original qualitative insight into carers' realities of compassion (to self, to others, and from others) within their role and identifies several considerations to advance the field further. In doing so, our novel findings highlight the potential applicability of compassion-based approaches as a warranted focus within future family caregiving research and practice.

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Disclosure Statement

The authors report no conflict of interest.

Author Contributions

JM conceived and designed the study, undertook data collection and analysis, and wrote, revised, and finalised the paper. WM checked the coding of the analysis, and WM and AOD supervised the study, advised on aspects of study design and data collection, and conceptually commented on and revised the paper. All authors read and approved the final manuscript.

Data Availability Statement

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, therefore supporting data is not available.

Ethical Standards

This research was approved by Griffith University Human Research Ethics Committee (GU ref. no. 2019/481) and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments. Informed consent was obtained from all participants prior to their inclusion in this study.

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Table 1. Free-text comment boxes

Box	Statement preceding free-text comments box	Preceding heading	Preceding measure
	<i>Please use this space to add any comments about:</i>		
1	how compassionate you are with yourself when you are distressed or upset	Feelings of Compassion: Compassion for Self	CEAS: Compassion for Self
2	your compassion to others when they are distressed or upset	Feelings of Compassion: Compassion for Others	CEAS: Compassion for Others
3	receiving compassion from others when you are distressed or upset	Feelings of Compassion: Compassion from Others	CEAS: Compassion from Others
4	your recent emotional health	Emotional Health	DASS-21
5	your day-to-day experience	Day-to-Day Experience	MAAS
6	the things you do to cope with stress in your life	Ways of Coping	Brief COPE
7	how you manage your feelings and emotions	Managing Feelings and Emotions	DERS
8	your own health and wellbeing while providing care for a family member, friend, or neighbour	Any Other Comments?	

Note. CEAS = Compassionate Engagement and Actions Scale; DASS-21 = Depression Anxiety Stress Scales – 21; MAAS = Mindful Attention Awareness Scale; Brief COPE = Brief Coping Orientations to Problems Experienced Scale; DERS = Difficulties in Emotion Regulation Scale.

Table 2. Coding frame

Experiences of compassion (<i>n</i> = 105)		
Compassion to self (<i>n</i> = 69)	Compassion from others (<i>n</i> = 68)	Compassion to others (<i>n</i> = 34)
Limited in self-compassion (<i>n</i> = 20)	Little compassion from others (<i>n</i> = 24)	Dependent on many factors (<i>n</i> = 12)
Focus on care recipient/others (<i>n</i> = 24)	Receive compassion from others (<i>n</i> = 22)	Worked in job supporting others (<i>n</i> = 10)
External stressors (<i>n</i> = 16)	Family politics & difficulties (<i>n</i> = 22)	Importance of emotional support (<i>n</i> = 8)
Compassion to others easier (<i>n</i> = 13)	Support services (<i>n</i> = 20)	Chronic condition of care recipient (<i>n</i> = 9)
No time in caregiving role (<i>n</i> = 12)		
Fears of self-compassion (<i>n</i> = 11)		

Note. *n* = number of participants.

Table 3. Characteristics of family carers who did, and did not, provide a comment about their experiences of compassion (to self, to others, from other)

Characteristic	Comment about compassion (<i>n</i> = 105)	No comment about compassion (<i>n</i> = 137)
Age (yrs) ^a	60.5 (10.5)	58.5 (11.7)
Identifying gender ^b		
Female: Male	94 (89.5): 11 (10.5)	120 (87.6): 16 (11.7)
Highest level of education ^b		
University degree or higher	42 (40.0)	59 (43.0)
Post-secondary certificate or diploma	48 (45.7)	54 (39.4)
Secondary school	13 (12.4)	19 (13.9)
Primary school	1 (1.0)	2 (1.5)
Employment status ^b		
Employed	38 (36.2)	50 (36.5)
Unemployed, not seeking work	19 (18.1)	25 (18.2)
Unemployed, seeking work	6 (5.7)	7 (5.1)
Retired	42 (40.0)	52 (38.0)
Student	2 (1.9)	3 (2.2)
Country of residence ^{b*}		
Australia	86 (81.9)	82 (67.2)
United Kingdom	10 (9.5)	10 (7.3)
United States of America	6 (5.7)	28 (20.4)
Canada	2 (1.9)	1 (0.7)
Kenya	-	1 (0.7)
Caribbean	-	1 (0.7)
China	-	1 (0.7)
Republic of Ireland	-	1 (0.7)
South Africa	-	1 (0.7)
Sweden	-	1 (0.7)
Relationship to older adult ^b		
Offspring	59 (56.2)	73 (53.3)
Partner	34 (32.4)	43 (31.4)
Relative	7 (6.7)	15 (10.9)

Sibling	3 (2.9)	3 (2.2)
Friend or neighbour	1 (1.0)	3 (2.2)
Type of carer ^b		
Primary: Secondary	91 (86.7): 12 (11.4)	116 (84.7): 19 (13.9)
Living full-time with older adult ^b		
Yes: No	68 (64.8): 36 (34.3)	94 (68.6): 43 (31.4)
Time caring for older adult (yrs) ^a	6.0 (5.3)	5.7 (5.2)
Age of older adult (yrs) ^a	80.9 (8.7)	80.8 (8.8)
Identifying gender of older adult ^b		
Female: Male	59 (56.2): 45 (42.9)	81 (59.1): 50 (36.5)
Main chronic conditions of older adult ^b		
Dementia*	57 (54.3)	38 (27.7)
Musculoskeletal disorders*	31 (29.5)	20 (14.6)
Cardiovascular disease	25 (23.8)	24 (17.5)
Cancer	9 (8.6)	5 (3.6)
Parkinson's disease	6 (5.7)	5 (3.6)
Family carer psychological distress (DASS-21)		
Depression ^{a,c}	17.1 (12.4)	19.3 (14.0)
Anxiety ^{a,d}	10.9 (9.4)	9.7 (10.2)
Stress ^{a,e}	20.5 (9.9)	19.7 (11.1)

Note. yrs = years. May not add up to the total or 100% due to missing data, rounding, or multiple response options. ^acontinuous variables reported as *M* (*SD*) and analysed using independent t-tests; ^bcategorical variables reported as *n* (%) and analysed using chi-square or fisher's exact tests. Manualised cut-off scores, as defined by Lovibond and Lovibond (30). ^cDepression: normal = 0-9; mild = 10-23; moderate = 14-20; severe = 21-27; extremely severe = 28+. ^dAnxiety: normal = 0-7; mild = 8-9; moderate = 10-14; severe = 15-19; extremely severe = 20+. ^eStress: normal = 0-14; mild = 15-18; moderate = 19-25; severe = 26-33; extremely severe = 34+ *N* = 242. **p* < .01

Supplementary Material (Online only)

Table 4. Identification codes of family carers for selected quotations

ID #	Identifying gender	Country of residence	Relationship to older adult	Chronic conditions of older adult
28	Female	United Kingdom	Offspring	Dementia; musculoskeletal disorder; cardiovascular disease; mental health condition; inflammatory bowel disease; diabetes
30	Female	Australia	Offspring	Musculoskeletal disorder; cardiovascular disease; eye/vision condition
31	Female	United States	Offspring	Musculoskeletal disorder; cardiovascular disease
67	Female	United States	Partner	Dementia; musculoskeletal disorder; diabetes
69	Female	Australia	Offspring	Dementia; musculoskeletal disorder; cardiovascular disease
83	Female	Australia	Partner	Dementia; musculoskeletal disorder
121	Female	United Kingdom	Offspring	Dementia
130	Female	Australia	Offspring	Not specified
136	Female	Australia	Offspring	Dementia; cancer; cardiovascular disease
145	Female	Australia	Partner	Musculoskeletal disorder; cardiovascular disease
150	Female	Australia	Relative	Dementia; diabetes; cardiovascular disease
153	Female	Australia	Offspring	Musculoskeletal disorder
165	Female	Australia	Offspring	Musculoskeletal disorder
172	Female	Australia	Relative	Cardiovascular disease
210	Female	Australia	Offspring	Dementia
243	Male	Australia	Partner	Musculoskeletal disorder; ear/hearing conditions; mental health condition
244	Female	Australia	Partner	Cancer; mental health condition
270	Female	United Kingdom	Offspring	Dementia; diabetes
274	Female	Australia	Offspring	Dementia
279	Female	United States	Offspring	Inflammatory bowel disease; diabetes
317	Female	United Kingdom	Offspring	Dementia
328	Female	Australia	Partner	Acquired brain injury
345	Female	Australia	Partner	Dementia