Distress in informal carers of the elderly in New Zealand
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ABSTRACT
AIMS: Informal care, which is unpaid and often provided by family and friends, is the primary source of aged care in New Zealand. In addition to financial costs there are known psychological costs of being a carer, including poor mental health.

METHODS: This research aimed to interview a group of New Zealand carers and describe their rates of depression and anxiety, their motivations for providing care, costs of care and their experience of aggression. Interviews used standardised questions and were conducted over the phone.

RESULTS: Results are reported from interviews of 48 carers and suggest this group have elevated symptoms of depression and anxiety. Most of the carers are partners or children of the carees and likely do the caring out of love. Unpaid family carers experience low levels of aggression. Carers reported personal and social restriction, and physical and emotional health the most burdensome aspect of being a carer.

CONCLUSIONS: Carers of the elderly in New Zealand show elevated levels of distress. Higher levels of emotional support are needed for New Zealand carers. If the health system continues to rely on unpaid carers more should be done to support them.

In New Zealand, it is estimated that 480,000 people provide regular care for someone who is ill or disabled. While this statistic recognises support for people across the whole lifespan, an increasing number of older people require care. Most older people with disabilities and high dependency on others in New Zealand are known to live in private households within the community rather than in specialised facilities. Thus, care for the aging population becomes an increasingly important topic.

This paper focuses on informal unpaid carers; they will be referred to as carers throughout. Informal care provides many benefits, including improved patient outcomes and reduced unnecessary re-hospitalisations and residential care placements. There are also considerable financial benefits to society. Unpaid caring is an essential part of the health system and saves a large amount of money that would otherwise need to be provided by other parts of the health system and would be increasing each year. A large proportion of people providing informal care in New Zealand are also in paid employment (65%).

In addition to financial issues, there is also a psychological cost to informal care. Previous studies report poorer mental health of informal carers. While depression and anxiety are known to be prevalent in community samples (14% depression and 6% anxiety lifetime diagnosis in New Zealand), carers are thought to be at increased risk. Family carers of COPD patients reported 34% had depression and 64% had anxiety. Similarly, 30% of carers of cancer patients were reported to have depression. Of pancreatic cancer carers, 15% had depression and 39% had anxiety. In a review of dementia assessment and management it was reported that dementia carers had 23–85% incidence of depression and 16–45% have anxiety. This wide range of findings represents a lack of consistency of measurement, each study using different criteria and scales, and carer burden being highly variable. A sense of carer burden was considered as a possible influence on the...
dementia patient. They also noted carers are likely to have low self-efficacy and poor physical health and wellbeing. In a recent review of carer burden in aged care it was concluded that the interventions had little effect as it is difficult to change carer burden in real life, as caring will always involve burden, stress and negative consequences.14

A carer’s ability to cope does not directly relate to their demographics characteristics or the patients physical or psychological health status.15 Therefore, without prior knowledge of the people involved, it is difficult for clinicians to make assumptions about the ability of a caregiver to cope with their patient or indeed know what the personal costs might be. Even with information available there may be few options available for clinicians to consider. Typically the available options would be to move the caree to residential care or provide paid caregivers rather than specific support for the carer. This may be difficult, as carers may be motivated to provide care themselves for a wide range of reasons, including religion, traditions, duty, guilt, social pressure16 or finances.15 Further data are needed on whether aged care family carers in New Zealand are experiencing wellbeing issues as a result of caring, and if so the extent of these issues.

Although there is some research on health outcomes of caring, little is known about the experience of aggression among carers. A recent study of paid caregivers in New Zealand used the POPAS-NZ scale to investigate aggression towards care workers. These authors reported high rates of aggression towards paid carers in New Zealand.17 Aggression in this research includes measures of verbal aggression, physical aggression, sexual aggression and threats. This is of potential interest as a further possible risk to the wellbeing of carers.

The objectives of this research were to quantify the burden of care for a sample of people providing informal aged care in New Zealand. Specifically, this research had four aims: firstly it aimed to document motivations to care. Secondly to examine the rates of anxiety and depression in this group. Third, report on the psychosocial cost to care, and fourth, describe the experience of aggression towards carers. The aim of this research was to examine New Zealand-specific data and broaden the measures from typical mental health focus to include aggression and burden.

**Method**

**Design**

This study was observational using a single interview method and standardised questionnaires.

**Participants and recruitment**

The inclusion criteria were: a person who considered themselves to be providing care for another person over 60; 16 years or older; and able to understand and converse in English. Opportunity to participate was advertised on Carers New Zealand Facebook site and a Carers Otago Newsletter. People interested in participating contacted the research assistant for more information. Carers Otago also contacted people directly to ask for their details to be passed on to the researcher. In addition, the research assistant contacted a local organisation (Carers Otago) who had agreed to contact carers from their client list. They passed on contact details of those who have agreed to participate.

**Measures**

Data were collected via phone interviews and began with a list of demographics questions including age and disability of carees. A short checklist of depression and anxiety symptoms was used, known as the Hospital Anxiety and Depression Scale (HADS).18 It consists of 14 questions, with responses rated from 0–3, giving a possible score of 0–42, with higher scores representing greater impairments.

All of the carers reported on motives for helping using a standardised questionnaire called the Caregiver Appraisal Measure.19 This is a four-item questionnaire which examines the values base of the carer on a four-point scale. It examines whether the caring experience is shaped by family or religious tradition, self-esteem or modelling for others. Its reliability and validity are unknown. This was followed by a qualitative question: “why do you care for this person?”.

The Cost of Care Index was used to examine caregiver burden.20 This is a 20-item
scale developed for identifying potential and existing adverse consequences for caregivers of elderly people. The measure contains five sub-scales: personal and social restrictions, physical and emotional health, economic costs, value investment in caregiving and the perception of the care recipient as inflaming the situation. Items are scored on a four-point scale (strongly agree, agree, disagree, strongly disagree), giving a possible range of 20 to 80. A mean of 56 would be considered high cost. The authors of the index suggest that the sub-scores will identify specific problem areas.

The POPAS-NZ is used to measure aggression and violence experienced in the previous 12 months from the person that they care for. The POPAS-NZ questionnaire is a brief outcome scale consisting of 12 questions related to the experience of aggression. For each type of aggression people score: 0, never; 1, rarely; 2, sometimes; 3, often; or, 4, very often. To score all of these numbers are added. The lowest category is verbal anger rising up to physical assault and making formal complaints. Previously a test of the psychometric properties of this measurement instrument was conducted. The POPAS-NZ scale has high internal validity, with Cronbach's alpha of 0.89.17

Procedure
Participants contacted the researcher or had agreed to her contacting them. Information and consent forms were posted before interviews. Consent was either posted back in or recorded verbally. Phone surveys were conducted with participants at a time that suited them. The interviewer for most participants was a registered clinical psychologist (n=36), for the remainder was a trained research assistant (n=12). Interviews took around an hour. Ethical approval was gained from the University of Otago Ethics Committee (Health) - D15/405.

Data analysis
Data were recorded and then entered onto a spreadsheet for analysis. Planned analyses were descriptive statistics of demographic data, HADS depression and anxiety sub-scores, Cost of Care Index mean scores and sub-scores and Caregiver Appraisal Questionnaire. There was a qualitative question asked “why do you care for this person”, this would be analysed by creating an online wordcloud app (http://word-itout.com/word-cloud/create) which would produce a visual representation of the range and frequency of responses.

Results
This study reports data from 48 people who were interviewed over the phone or in person. All volunteers met inclusion criteria. Participants median age was 67 years (range 41 to 92). There were 13 men and 35 women carers. The average hours care per day was 17, with a mode of 24 hours. The caree ages ranged from 60 to 96, with a median of 81 years. The caree was most often a spouse (54%) or parent (42%). Of the remaining three carers, two cared for their brother and one cared for a non-relative. Thirty-eight percent of the carees had dementia, as reported by their carers. Two people reported being Māori, 37 New Zealand European and 12 other ethnicities. Ethnicity was not diverse enough to allow sub-group analyses.

Motivation to care
Carers largely disagree with the statements that they provide care “to be a good model for others to follow”, and as “a way to

Table 1: Responses to Caregiver Appraisal Questionnaire in percentages (numbers) n=47.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>To provide a good model for others to follow</td>
<td>28(13)</td>
<td>42(20)</td>
<td>15(7)</td>
<td>19(9)</td>
</tr>
<tr>
<td>A way for me to live up to religious principles</td>
<td>43(20)</td>
<td>28(13)</td>
<td>21(10)</td>
<td>13(6)</td>
</tr>
<tr>
<td>Gives my self-esteem a boost</td>
<td>19(9)</td>
<td>34(16)</td>
<td>43(20)</td>
<td>9(4)</td>
</tr>
<tr>
<td>True to family traditions</td>
<td>9(4)</td>
<td>21(10)</td>
<td>43(20)</td>
<td>28(13)</td>
</tr>
</tbody>
</table>

The modal response is in bold.
live up to religious principles” (see Table 1). There was somewhat more agreement with the statement, “I do it to give my self-esteem a boost”. Clearly the highest agreement was for the statement “I care because caring is true to family traditions”. The caregiver Appraisal Questionnaire included a fifth open question “what other reason do you have for caring for this person”. Responses are collated and presented in Figure 1. This shows a wide range of responses with “Love” being the most often reported.

**Depression and anxiety**

Using a standard cut-off of 8+ for caseness on the HADS, 34% (16 people) of this sample have depression and 36% (17 people) of this sample have anxiety. For anxiety, scores range from 0 to 17 with a median of 7. For depression, scores range from 0 to 13 with a median of 6.

**Cost of care index**

The mean score reported was 56 with a range of 39–77. Sub-scores for this sample are: personal and social restrictions 6.3, physical and emotional health 6.4, value 1.9, care recipient as provocateur 4.5 and economic costs 4.6. This indicates that the carers found personal and social restriction, and physical and emotional health most burdensome.

**Experienced aggression**

Reported aggression was low. When summed the mode of the POPAS-NZ was 0, with 17 people reporting no aggressive behaviour. The remaining 32 carers scores ranged from 1 to 17. The median score across the sample was 2.5. This would indicate responding “sometimes” to just one question, like verbal aggression, or “rarely” to two types of aggression.

**Discussion**

This study reports findings of a descriptive study examining motivations to care, cost of care, depression and anxiety in carers and carers experience of aggression.

Of the statements offered in the Caregiver Appraisal Questionnaire, the highest endorsement was for the statement, “A strong reason for taking care of this individual is to be true to family traditions”. The Cost of Care index was used to examine the aspects of caring that the respondents found to be most burdensome. Results showed that personal and social restrictions, and physical and emotional health were comparatively more of a burden that the financial costs, the value of the activity of caring and the demands of the caree.
Respondents indicated elevated levels of depression and anxiety. Thirty-four percent of this sample reported symptoms of depression that reached a standard clinical cut-off. Using the same measure (HADS), previous research has cited a population norm of 23% in Germany or 4% in the UK. Similarly, the participants in this study reported anxiety symptoms which led 36% to be above the cut-off for likely clinical diagnosis. The population norm reported was 21% in Germany and 13% in the UK. A British study reviewed norms by age and gender using HADS and for the average participant in this study we might expect depression rates of 15% and anxiety rate of 33%. Using these data our sample seem to have increased rates of depression but close to normal rates of anxiety. There are no norms in New Zealand for the HADS scale, however the rates found in the present study are higher than those reported for people who have had a stroke and pacemakers. While population norms remain problematic for the HADS, we conclude that this sample of carers have elevated rates of depression and anxiety.

This study shows less aggression than a previous New Zealand study on paid care workers. The previous study reported a median score of 5, and mode of 0 and a range of 0–26. This compares to a median of 2.5, a mode of 0 and range of 0–17 in the present study. This shows that family carers experience less aggression from their carees than paid caregivers. This is an interesting finding and may reflect severity of illness, as people often move into care when their family are no longer able to take care of them at home. It might also suggest that carees are more compliant at home and for family carers.

A limitation of this study is that ethnicities in this study do not match the population. Māori were under-represented and New Zealand Europeans over-represented. This is of concern and future studies might consider other ways of recruiting Māori participants. Specific recruitment strategies might be needed. A recent study of older Māori people reported that social support was important for quality of life. Another limitation is the small sample size, these self-selected carers may not be representative of the population of carers in New Zealand.

It is clear that more support needs to be offered to support people to ameliorate these elevated levels of depression and anxiety. Our data also suggests that financial help is not what is most required but support around physical and emotional health, and personal and social restrictions. This was supported by a previous New Zealand study that reported 96% of carers were not satisfied with the support they received. Jorgenson et al (2010) conclude that: “There does seem to be a contradiction between the value we place on caregivers and what we provide to support them, both materially and psychosocially.” The intervening years between these two studies do not seem to see any progress made in supporting these people essential to our health system.

However, another possibility is that improved care for carees would also improve things for carers. This has been suggested by other researchers for example, Janda et al (2017) suggest reducing patients’ distress would be helpful. Thus, the care job would become easier if there was more support for the carees in their home.

Mittelman et al (2006) reported that psychosocial interventions, including support groups, can improve outcomes for carers. A meta-analysis of interventions found that those most likely to succeed in improving carer wellbeing included both the carer and the caree in structured programmes. In a recent Australian study, a single session of behavioural activation, which involved a 90-minute appointment with a clinician, improved measures of stress and valued living two weeks after the intervention in a small community sample of carers.

In conclusion, this research suggests that in New Zealand Carers experience elevated levels of anxiety and depression and at significant personal cost are motivated to care for their family member out of love. They are an essential part of our healthcare system and further support is needed. Future research trialling methods of support in New Zealand would be helpful.
Competing interests:
Nil.

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