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The New Zealand informal caregivers and their unmet needs

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Abstract

Aim To identify the characteristics and demographics of the New Zealand caregiver and their unmet support needs.

Method During December 2007–August 2008, 300 caregivers were recruited to participate throughout New Zealand. Mixed methods data were collected by telephone, using two well validated scales: Centre for Epidemiology Studies Depression and Caregivers Reaction Assessment. Caregivers were also asked open-ended questions regarding their support and additional help needed. Analysis was by descriptive statistics and General Inductive approach

Results Caregivers aged 30–39 had the highest depression, while a larger group shared the highest stress (ages 30–59). Caregivers commonly discussed adverse effects of caregiving on lifestyle, health and financial situations. Lack of information and assistance were concerns, and respite was inadequate. Overall, less than 1% of caregivers of people under the age of 65 and 4% of caregivers of older people were happy with the support received. Caregivers wanted more financial assistance, information, reliable support workers, flexible respite, and recognition for their caregiving role.

Conclusion If the government wishes to have more people with disabilities or chronic illness living at home, greater resources are needed to adequately support caregivers. At present this important sector of the population is undervalued and under provided for.

It is well recognised that New Zealand, like other countries, has concerns about its long-term care of people who are chronically sick or who have disabilities, and the likely supply of informal caregivers. Many factors are encouraging and promoting people to stay in their own homes, such as deinstitutionalisation of younger people and ageing-in-place for older people. This undoubtedly increases the demand for more informal caregivers.

Informal caregivers are unpaid and are usually family or friends who support and care for people with disabilities or illness for anything up to 24 hours, 7 days a week. We have already seen a dramatic increase of about 50,000 informal caregivers since 2001, with the total number now estimated to be 10% of the population at 420,000.^{1,2} This need will continue to increase in the coming decades with the ageing population.

Caregiving is known to be extremely stressful, have adverse impacts on health, loss of free time and long-term financial disadvantages, such as loss of income and/or savings.³⁻⁶ The Government has responded recently by introducing the *Carers' Strategy and Five-year Action Plan*² which has five objectives; to provide information, protect the health and wellbeing of caregivers, enable caregivers to take a break, provide financial support for caregivers and provide training and pathways to

employment for caregivers. The Flexible Working Arrangements Amendment⁷ has also relatively recently been introduced and allows caregivers in paid employment to seek time off for emergencies or appointments.

New Zealand in comparison to other countries has a very small evidence base on caregivers' support needs. One small New Zealand study found caregivers experienced negative impacts on family relationships, as well as 32% of caregivers of people with Alzheimer's disease giving up paid employment.⁸

When examining studies from other countries it was found that caregivers in England and Europe were more likely than non-caregivers to report health problems, social isolation and family relationship difficulties,^{9,10} and over half of a large sample in Australia reported depression.¹¹

The main aim of this study was to identify the characteristics and demographics of the New Zealand caregiver and their unmet support needs. This study could also be used as the basis for an evaluation of the caregiving policy implementation.

Methods

Both qualitative and quantitative data were collected to fully explore, strengthen and describe the complex and divergent aspects of caregiving situations and relationships. Caregivers were invited to participate through an advertisement in support organisations' newsletters, such as Carers New Zealand. The potential participants were provided with a toll-free telephone number or an email address by which to respond. After contact they were sent an information sheet and consent form to return in a prepaid envelope. This method of recruiting was used to gain widespread geographical coverage of New Zealand, however it is recognised there may be a bias in the final study sample due to the self selection of participants.

People who identified themselves as unpaid caregivers were invited to participate, with no criteria given for the amount of time spent caregiving. Exclusion criteria were paid caregivers (support workers). A total of 300 caregivers participated in the study between December 2007 and August 2008.

The participants were interviewed by telephone (lasting from 1–1.5 hours) using two well validated scales and open-ended questions about their caregiving roles and support. The scales were: Center for Epidemiologic Studies Short Depression Scale [CES-D 10]¹² was 10 questions ranked from 0 (rarely or none of the time) to 3 (all the time) with a maximum score of 30. People with scores of 10 or more were judged to be showing signs of depression.¹² The Caregivers Reaction Assessment (CRA)¹³ was 24 items with a total score of 120. Scoring from 1 (strongly disagree) to 5 (strongly agree), with higher scores relating to higher degrees of stress or burden.¹³

Quantitative data were entered into the statistical programme SPSS for Windows 14 and divided into variables according to demographics and scales from which descriptive statistics, such as means and frequencies were calculated. Qualitative data were entered verbatim into NVivo analytical programme and analysed using a General Inductive approach.¹⁴ The raw data were read many times to form codes line by line and then condensed into themes. Themes formed were based on frequently reported patterns found during the analytic process. These themes formed the basis for the qualitative results. Five transcripts were given to two senior researchers to recode and compare for consistency of interpretation and reliability.¹⁵

The study was given ethical approval by the Multi-regions Ethics Committee.

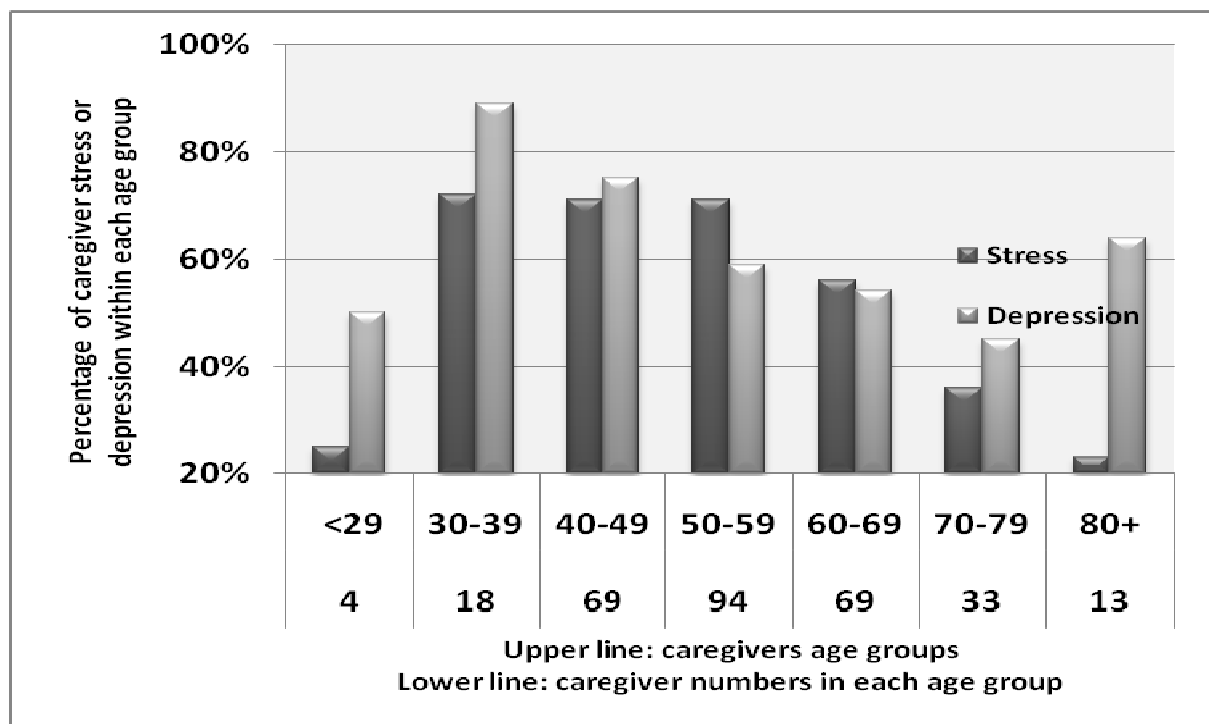
Results

Out of the 300 participants, 242 were female (81%) and 180 were aged 30 to 59 (60%). In relation to the care recipients caregivers were; mothers 111 (37%), daughters 63 (21%) female partners 60 (20%), male partners 42 (14%), son 9 (3%) father 3(1%) and others 12(4%). The greatest number of care recipients were in the 70–89 age group 87(29%) and the 0-19 age group 75(25%). For care recipients over

the age of 20, dementia 57(19%) and other neurological conditions 57(19%) were most prominent, and next stroke 39(13%). For younger care recipients behavioural disorders 27(9%) were most common, followed by other neurological disorders 15(5%) and developmental disorders 12(4%).

By taking the score of 60/120 as signs of stress, 70/120 as moderate stress and 90/120 as severe stress the results showed 255(85%) had signs of stress, 183(61%) had moderate stress and 30(10%) were severely stressed. The mean total CRA score was 73.04/120, (SD 13.6) and mean depression was 12.13/30, (SD 6.05) Figure 1 shows the percentage of caregivers with stress and depression within each age group.

Figure 1. Caregivers' stress and depression within each age group



The highest levels of stress were in caregivers aged 30 to 59. Out of a total CRA score caregivers 50 to 59 had a mean stress level of 78.16/120 (SD 15.2), while caregivers in the 40 to 49 and 30 to 39 age groups had mean stress levels of 75.53 (SD 11.56) and 73.40 (SD 11.8) respectively. Depression was highest (out of a total score for the CES-D 10 of 30) in caregivers aged 30 to 39 with 89% (mean 14.2 [SD 5.57]). The next two highest groups were caregivers aged 40 to 49 where 75% of caregivers showed signs of depression (mean 13.3 [SD 4.9]) and caregivers aged 80 to 89 where 62% showed signs of depression (mean 11.40 [SD 6.4]).

Out of all the caregivers the father and son groups had the highest mean stress score 87/120(SD 0) and 79.6/120 (SD 15.9) respectively, but showed no signs of depression. The groups showing the highest signs of depression were mothers and daughters (means 13.3 [SD 5.8] and 12.6 [SD 7.1] respectively).

The mothers and daughters also had high stress mean scores at 75.1 [SD 10.3] and 74.1 [SD 14.1] respectively. The care recipients' conditions where the caregivers showed the most signs of stress and depression were: attention deficit hyperactive disorder, autism, brain injury, developmental problems, dementia, schizophrenia and cardiac conditions in that order.

When caregivers were asked how they were supported and what they thought would improve their lives and those of the care recipients their responses could be grouped into two main themes; comments about the support they were or were not receiving; and the impact of caregiving on their lives.

The support caregivers were receiving depended largely upon the information they were given. Accessible, up-to-date timely information is essential if caregivers are to access services and support to assist them in their caregiving role. However, striking similarities between caregivers taking part in the study were lack of information they received when first becoming a caregiver, and inappropriate financial support (two-thirds stated they experienced moderate to severe financial difficulties). A total of 81% of caregivers felt they could not find information to help them obtain support or funding. A mother of two children with disabilities said:

People should know about the carer's benefit which I didn't know about for the first 16 years of caring for my children. When I found out and applied for some back pay they only let me have 6 months.

People found information was fragmented. One agency, such as WINZ would assist with benefits, while the health professionals dealt with their segment of expertise and other people, such as voluntary agencies would fill in pieces of knowledge as it came to hand.

Caregivers supporting children and young people found if they did not have a definite diagnosis they were not eligible to access funding or information, particularly from the Education services. Language difficulties were mentioned in relation to health professionals, particularly when the care recipient was first diagnosed. One Pacific caregiver of an older person said:

We find it difficult to ask for help because of the language and not understanding properly, so we would usually just persevere rather than rely on a stranger.

It was reported there were extra costs associated with caregiving, such as special foods, medications, incontinence products (not always funded), extra heating, petrol and hot water. However, the difficulty with bureaucracy and paperwork to get financial help was illustrated by this comment from one caregiving daughter:

Dealing with WINZ you have to go to them, no one will come to us. It is very difficult dragging mum in there for their very frequent assessments. We moved a while ago and they didn't have the correct address in their computer so we had to revisit them several times before they got it all sorted out. They try hard, but need to be more adaptive.

Many caregivers claimed that due to poor services and inflexible working arrangements, they were unable to continue to work at the same level, or even work at all in paid employment. No caregivers thought they had been assessed for the support they felt they needed, arguing that the focus of assessments for service provision was on the needs of the care-recipient.

Some families chose to home-school their children with disabilities because of the lack of appropriate supervision and support within the schools. Respite care is

designed to give caregivers time away from their caring duties, however there were problems particularly with respite for younger people. There were difficulties in finding appropriate age-related facilities, as well as the small amount of money paid to respite support workers to look after their children, either in the child's home or elsewhere. Several parents were doubling the amount paid to respite support workers by using half the allowable days.

Overall, 0.7% of caregivers of people under the age of 65 and four percent of caregivers of older people were happy with the support they received.

Generally, caregivers felt there was no other choice but to take on a caregiving role and "*accept the cards dealt.*" Caregivers discussed their responsibilities as large, with little free time for their own life, such as going out, isolation from work, lost social contacts, and loss of a partner to talk with (in the case of care recipients with dementia). There was an acute lack of awareness from others of the roles of caregivers, particularly by friends and those not intimately involved with the family. For example, at the diagnosis stage, caregivers tended to report a good deal of support from family and friends, but over time this dissipated. Many people did not, or could not, have family support.

Other siblings were seen as suffering due to the increased requirements of care-recipients. In these situations, there were lots of responsibilities placed on other siblings, or children of parents with support needs. Having disabled children was reported as being isolating for the caregiver, because they could not go out together as a family, not even to church or community groups. Some male caregivers believed it was particularly hard for them looking after a female; they felt people judged them incapable of those duties.

To summarise, the predominant wishes of caregivers were; more financial assistance; flexible and reliable respite provision; the opportunity and ability to be in paid employment; one national place for information; and recognition for their caregiving roles.

Discussion

This study examined the profile of caregivers and what they regarded as their unmet support needs in an effort to bring to light issues which must be addressed to reduce what the findings illustrate to be a significant problem, their stress and depression. These findings are consistent with literature from Europe, Australia and North America.^{3, 9, 10} Caregivers, similar to support workers¹⁵ look after vulnerable people, have financial difficulties and feel unsupported, however differences are that many caregivers provide 24 hours, 7 days a week care and are unpaid.

The study data were collected prior to the launch of the Carers' Strategy and Five-year Action Plan,² hence the five objectives have been used as a basis for the discussion. The Strategy suggested a generic caregivers' information pack, which has since been launched (September 2009) however, the information is still difficult for new caregivers to know about or access.

While the Domestic Purposes Benefit office provided some information caregivers, as other studies have reported, found it was not consistent, nor easy to access.^{8, 16} Many caregivers here suggested one point of contact for information, similar to Carpinter et

al's (2000) study that found caregivers wished for a liaison person who was personally knowledgeable. A toll-free telephone number for caregivers to access manned during working hours and in all telephone directories would seem a practical, cost effective future solution.

To protect the health and wellbeing of caregivers is the second and most important over-riding objective. It has been well documented in literature and demonstrated in this study that caregivers have high rates of depression and stress.^{3,17} These symptoms have multiple causes, including inadequate respite, lack of time for themselves and financial pressures. The Strategy's solution is to provide learning and training however, time for themselves was consistently reported both in this and other studies.⁵

To enable the caregivers to take a break, another of the Strategy's objectives suggested assessing the financial support for respite and seeking additional beds in some areas (particularly for younger people). This may improve some financial problems associated with attracting suitable caregivers for younger people, however the inappropriate timing and inadequate facilities found by this study and others^{4,18} for both the older and younger care-recipients warrants attention also.

Enabling caregivers' choice is specifically stated in the Strategy, however in reality this could be a tension because, as reported in this study it is the care recipients who are assessed for the services and support, not the caregivers.

Financial difficulties found by this study is a well documented phenomenon^{19, 20} and addressed in the Strategy by examining access options for income support. It also discussed assessing the eligibility of caregivers and the affect means testing had on work incentives. The same situation of lack of money for basic essentials like food, extra heating and medication causing stress was noted in a New Zealand article.²¹ This article written from 'experts' perspectives showed more than half considered home-based support services and financial assistance to be insufficient.

Caregivers in this study said the financial assistance received if taken over a 24-hour period amounted to approximately \$1.87 per hour, whereas support workers (at the time) were receiving approximately \$12 per hour, a situation similar to the USA.²² Caregivers wanted a "normal" life-style, but similar to Ireland the implementation gap between Government rhetoric and interaction on the ground is large.²³ One author suggested itemising caregiving duties (such as showering, dressing etc) to gain more attention and value from funders and policymakers.²⁴

The Flexible Working Arrangements amendment, while this is a good start, caregivers did not feel it really addressed the issues of pathways to employment. It may assist caregivers who are fortunate enough to be able to leave the care recipient for longer periods, but not those with substantial responsibilities.

The fish-hooks are caregivers need to have been working for 6 months and employers can take 3 months to consider the request. No caregiver mentioned they had the luxury of deciding to be a caregiver beforehand, so therefore would not be able to wait up to three months for their employer's response.

While having to be working with that employer for six months may be reasonable, the allowable response time is not. The caregiver could, in the worst situation be waiting for nine months to use the advantages noted in this amendment. The Strategy does say

it will look at recognising caregivers' skills and explore removing financial barriers for employers.

There are limitations to the conclusions that can be drawn from our study firstly, the small number of male caregivers and secondly, caregivers were self-selected, which may have provided a bias to those with 'tales to tell.' Even though caregiving is the mainstay of our long-term care, New Zealand, similar to other countries has not adequately addressed the glaring needs of this important sector.

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. Caregivers need to be assessed, supported and respected within our communities.

Competing interests: None known.

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