

Financial Health and Wellbeing of Unpaid Caregivers

Study Summary

Study Aim

To expand on what is already known about the experience of caregiving to illuminate the financial and lifestyle impacts of caregiving for unpaid caregivers of older people and explore potential improvements to emotional, social and financial supports, access to services, and interactions with health and support agencies.

How can lifestyles and financial wellbeing of unpaid caregivers of older people be improved in an ageing society?

Enrolment and Participation

Caregivers were eligible if they were aged 65 years or over, and the care they gave was unpaid and given to someone middle aged or older.

Twelve unpaid caregivers were enrolled and participated in either a small in-person focus group or an interview online.

National
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Challenges



Research Team

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Study Funding

Ageing Well National Science Challenge

Read the Full Report

<https://hdl.handle.net/2292/69362>

Summary of Findings

The data highlight the 'relentless', 24/7, nature of unpaid caregiving and its impacts on lifestyle, social, family and professional interactions, and income. Unpaid caregivers reported feeling under-valued and under-resourced. Findings from this work highlight unpaid caregivers' need for:

- access to clear and timely information that is accurate and up to date,
- empathetic and respectful communication with professional services, including retirement villages and aged residential care,
- support systems that recognise and value their role as an unpaid caregiver,
- system flexibility that consults with them and considers their needs,
- organisational support that aims to maximise wellbeing for older people,
- acknowledgement of the financial costs of unpaid caregiving.

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Study Details

In the 2018 New Zealand census, 432,000 individuals were caring for someone close to them without financial compensation. Many of these families, whānau and friends provide unpaid care to an older person. As the population ages and chronic conditions increase in middle- and older-age groups, informal care of this type is likely to increase.

We know that caregiving can be very rewarding but balancing increasing levels of care provision with employment and social, family, and financial commitments can also be challenging, particularly for older unpaid caregivers who are ageing themselves. Constraints to lifestyle and financial wellbeing may also not be adequately addressed by service and resource provision. The 2022 State of Caring in Aotearoa report highlights inadequate levels of wellbeing, formal support, and access to time-out options such as respite care for unpaid caregivers.

Previous Research from the Research Team

The current study is informed by the research team's previous work. Unpaid caregivers to people aged 85 years and older were interviewed annually from 2010 to 2016, and in 2020, in two sub-studies affiliated with LiLACS NZ (Life and Living in Advanced Age – a Cohort Study in New Zealand; *Te Puāwaitanga o Ngā Tapuwai Kia Ora Tonu*), a longitudinal study of successful ageing.

In those studies, many unpaid caregivers saw themselves as a 'kaiāwhina' or 'supporter' rather than as a carer. While they commonly perceived care to be obligatory, they also reported a range of positive feelings about their caregiving and their relationships with others, including the older LiLACS NZ participant. Caregiving did also interfere with lifestyle and income with respect to time constraints and the necessity to change work patterns, and, over time, caregivers looked more to support-seeking - from formal resource offerings and from other family members. While the intensity of care increased for some unpaid caregivers, changes in care roles and need for support varied by changes in the care recipient's and their own health. The *Financial Health and Wellbeing of Unpaid Caregivers* project sought to expand on those findings to include those caring for someone middle-aged or older.

The Current Study

In June 2024, twelve unpaid caregivers were enrolled through Carers NZ, Parkinson's NZ, Stroke Foundation, and through research networks and word-of-mouth. They were asked the question: **“How can lifestyles and financial wellbeing of unpaid caregivers of older people be improved in an ageing society?”**

Two focus groups of five people each were held in Tauranga and two individual online interviews were conducted with unpaid caregivers who couldn't attend a focus group. The meetings were audiotaped, and the audiotapes were transcribed into written text using a computer programme. The research team discussed the transcripts, and coded and grouped the text into common themes.

Participant characteristics

Relationship to CR	Started caring	Age range	Ethnicity	Gender	Living situation of CR
spouse/partner (8) daughter (1) son (1) daughter-in-law (1) friend (1)	> 2yrs ago (8) 1-2 years ago (4)	65-83	non-Māori (10) part-Māori (2)	female (11) male (1)	living with caregiver (7) same property (1) same city (3) aged residential care (1)

Study Findings and Recommendations

Interview transcripts highlighted the complexities and challenges of an older unpaid caregiver's life, including how they navigated the 'system', how they balanced their caregiving role and lifestyle, and the concerns they had about being valued as a pivotal contact point for care recipients. Unpaid caregiver's perspectives were grouped under four key themes, although it was clear that some perspectives and comments could have fitted into more than one theme.

- ❖ System-centric privilege
- ❖ Feeling valued
- ❖ Caregiving challenges and transitions
- ❖ Impacts and consequences of the caregiving role

The table on the next page describes the context and content of participants' perspectives under each theme. Selected quotes from the participants are included as illustration of the theme content.

In a report to the Ageing Well National Science Challenge, evidence informed solutions, guided by the key themes, were proposed that could be applied to health and social service development. Solutions included:

- ❖ the development and evaluation of a regionally relevant navigator role
- ❖ written information about certain health conditions (e.g. Parkinson's Disease) and providing local contact details to be made available in community spaces, retirement villages and online
- ❖ clear and accurate information publicised about assessment processes, health results, and up-to-date service eligibility and availability
- ❖ improved flexibility for long and short stay respite care, daycare and home-based care delivery
- ❖ improved referral and query response times
- ❖ improved retirement village induction processes
- ❖ greater general publicity and health practitioner training about the unpaid caregiving role
- ❖ inclusion of unpaid caregivers in information sharing and NASC assessments, whilst also maintaining care recipients' rights to privacy
- ❖ better coordination and continuity of paid caregivers' client lists to improve efficiency
- ❖ effective delivery of condition-specific support groups, including funded roles for nursing support
- ❖ greater recognition of the financial implications of caregiving
- ❖ increased funding or subsidies for GP visits

The full list of proposed solutions can be found in the study report, <https://hdl.handle.net/2292/69362>

Findings: Key study themes and content

THEME AND THEME CONTEXT	CONTENT DESCRIPTION
<p><u>System-centric privilege</u> <i>Navigating access to services</i></p> <p><i>“... I think there's a lack of listening and hearing...there's a loud discontentment that organisations are not listening to what is required.”</i></p>	<p>Participant comments emphasised a lack of empathy and timeliness (especially in regard to communication) in their interactions with services as well as frequent mismatches between service need and service provision</p> <p>A ‘cloak of invisibility’ – consultations with healthcare professionals and other service providers were almost exclusively focused on the care recipient with little or no acknowledgement as to how the unpaid caregiver was coping</p> <p>Current systems did not provide realistic choices about when and where care could happen</p>
<p><u>Feeling valued</u> <i>The challenge of invisibility</i></p> <p><i>“...as much as people want to help, from the hospital and everywhere else, they're interfering in my life and my routine.”</i></p> <p><i>“...they've got their lives and their work and things, so I don't try to ask too much there.”</i></p>	<p>Participants felt the nuances of their daily lives that were important to them were considered problems to be ‘fixed’ by health professionals or care agencies</p> <p>Family and friends sometimes perceived the situation differently to the way the unpaid caregiver did, but unpaid caregivers were often reluctant to ask for help.</p>
<p><u>Caregiving challenges and transitions</u> <i>Support through changes in care needs</i></p> <p><i>“I actually do the roles of 12 different jobs around the place to keep us going and keep him at home ...grocery shopping ... cooking ... organising ... making medical [and] physio appointments... cleaning up things.”</i></p>	<p>Many participants described how they now do ‘everything’</p> <p>Unpaid caregivers also spoke about feeling responsible for their loved one’s emotional wellbeing</p> <p>Being able to cope with the flow-on effects caused by care and housing transitions can be challenging</p> <p>Unpaid caregivers’ own physical and emotional needs were met in a variety of ways, e.g., through support groups and informal connections</p> <p>Unpaid caregivers were willing to activate their own support</p>
<p><u>Impacts and consequences of the caregiving role</u> <i>Lifestyle and personal impacts of caregiving</i></p> <p><i>“it's a heavy weight to bear because everything relies on me and then I have to be careful that I don't fall and break my ankle or whatever.”</i></p> <p><i>“We don't have a normal life by any stretch of the imagination...”</i></p>	<p>Older unpaid caregivers are coping with their own health needs as well as the care recipient’s</p> <p>The never-ending workload exerted an emotional toll on unpaid caregivers</p> <p>Unpaid caregivers expressed limitations in their ability to work, go away for a break, or to delegate their caring responsibilities</p>

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