Older informal caregiver experiences following the COVID-19 pandemic in Aotearoa New Zealand

Research project executive summary prepared by

Tyrone Barnard
Marcus Tamaira
Dr. Shinya Uekusa
Professor Christine Stephens

March 2024

Introduction

In 2022, we undertook a Health Research Council of New Zealand (HRC) funded project titled “The experiences of older informal caregivers following the COVID-19 pandemic in Aotearoa, New Zealand”. This was a collaboration between Massey University’s Health and Ageing Research Team (HART) and the University of Canterbury’s Sociology Department.

Recognising that informal caregivers are a vital part of Aotearoa New Zealand’s (New Zealand) health system, providing care and support for loved ones, whānau and friends, this study aimed to explore the experiences of older kaumātua, informal and family caregivers during the COVID-19 pandemic. A priority research question was: how do we care for informal caregivers during another pandemic, disaster, or national crisis? To our knowledge, this is the first exploration of such experiences in New Zealand. We wanted to understand the challenges and barriers informal caregivers faced during the pandemic and highlight the resilience and mana (power, strength) of older informal caregivers in overcoming them. The COVID-19 pandemic created considerable and unforeseeable challenges, or opportunities, for caregivers, care recipients, whānau, communities and the nation. This was layered over the existing diverse experiences of older informal caregivers, often associated with the differing levels of resources available to them, and the varying and complex needs of the care recipients they were looking after. The pandemic was an unprecedented event, and we hope the learnings from this study will enable a better, more effective response to assist informal caregivers during another pandemic, national shock, or disaster.

Research Method and Participant Demographics

The participants were recruited from among those in the Health, Work and Retirement study (HWR) who had previously agreed to receive invitations to take part in interview studies. Those who met the criterion were contacted via mail, and those who were interested contacted the HART researchers to discuss and schedule an interview. Between May 2023 and February 2024, we travelled across New Zealand to conduct 81 in-depth interviews, with 73 completed via face-to-face interviews, four via Zoom and four by phone. A total of 34 male and 47 female caregivers were interviewed, including 35 Māori and 46 non-Māori. The mean age of participants was 66 years old. 39 rural and 42 urban dwelling informal caregivers were interviewed, and the study covered both the North and South Islands. Participants’ social-economic situation varied as did their access to resources such as family and social support, health and digital literacy, information and knowledge, and health system access, among others. Using the Economic Living Standard Index (ELSI), 70% of participants living standard can be described as “good”, followed by 17% “comfortable” and 12% “hardships”. Please see

Table 1 for more details. A Kaupapa Māori researcher oversaw appropriate tikanga (processes), kōrero (discussion) and manaakitanga (care and support) for all the kaumātua interviewed.

Findings

The study revealed valuable insights into the diverse realities, challenges, opportunities and responses of older informal caregiver participants during the pandemic to deal with caregiving. Many participants had complex caregiving situations with high-needs care recipients and multiple people to look after.

Overall, informal caregiver participants demonstrated resilience and navigated the pandemic effectively. We identified several positive outcomes based on participants' lived experiences:

- Community spirit: Neighbourly aroha (love and empathy) and manaakitanga (kindness) were evident. Many participants reported that neighbours and communities banded together to help one another by, for example, dropping off groceries, checking on older residents that lived nearby, being social in supermarket queues, providing food and social support, and offering assistance to others.
- Proactive assistance by Kaupapa Māori organisations and community groups: Some participants reported that Kaupapa Māori organisations and community groups provided food packages and phone support.
- Enhanced relationships between participants and care recipients through the sharing of stories. Whānau, neighbourhood and community relations became further enhanced.
- Slower pace of life: Many participants, especially those in the urban areas, reported that, as work and social commitments and appointments were reduced or stopped completely, they had more free time and a relaxed life. Participants became aware of how structured and busy their lives were because of the pandemic.
- Pre-existing social ties: Overall experiences between rural and urban participants were predominantly similar, with some variations, including close-knit rural communities which were a positive factor.

Informal caregivers in this study demonstrated resilience, remarkable adaptability, and mana in the face of the pandemic because:

- Mana kaumātua: Participants were able to draw on experience, knowledge and wisdom.
- Creative problem solving: Participants created social interactions without breaking the COVID-19 rules and found creative ways of entertaining care recipients.
- Teamwork: Family, friends, and neighbours chipped into share the caregiving workload.
- Use of technology: Participants were able to use technology to find information, access health services remotely and stay in touch with loved ones.
- Hinengaro: Participants practiced mindfulness, including hobbies, reading, puzzles, passions, music, and pets.
- Tinana: Participants practiced physical activities including walking, yoga and gardening. For Māori, this extended into the important cultural implications of being connected to the land (whenua).
- A "Can do" attitude, positivity, humour, mental strength and faith.

However, the following areas reflect the challenges that participants faced:

- Communication: There were issues with the lack of information and unclear messaging from government, agencies, health sector organisations and media. Participants raised concerns about what support, if any, was available to them and where to go to access support.
- Bureaucracy and "red tape": Strict regulations presented challenges including the restrictions on movement which obstructed the delivery of care to loved ones, or the seeing of loved ones needing care. The process of obtaining an exemption to visit care recipients who did not live with participants and the processes to access respite (during and outside of the pandemic) was challenging and often required additional work from informal caregivers which outweighed the break they would receive once respite was accessed.
- Isolation and interference with relationships: Some participants became isolated, and relationships strained. Restrictions of movement and social distancing were felt hard by many. Rural dwellers in this study generally faced greater difficulties accessing health care than participants in urban areas, for Māori whānau caregiver participants, enforced restrictions on cultural expression including whanaungatanga (family gatherings and association) and tangihanga (ritual mourning) were highly stressful.
- Support availability: Some participants were uncertain of where to go for support related to their specific caregiving situations. Many were also unsure of what support was available specifically for informal caregivers, and they encountered problems with accessing the health system, which was believed to be due to high demands, understaffing and pressure on the health system caused by the COVID-19 pandemic. Informal caregivers in this study had to assess situations to determine the benefit vs the risk of accessing support, which often led to the reduction of physical support and the decline of professional caregivers coming into their homes to provide respite and extra support.
- Increased anxiety: Participants, who were looking after care recipients with compromised immune system and older age, reported increased anxiety. This led to difficult decisions: How long should they isolate? What support should they accept? Should they engage in social interactions?

Kaumātua Māori caregivers played a central role in caring for whānau members during the COVID-19 pandemic, often alongside their cultural responsibilities as leaders within their whānau, hapū and iwi. We heard stories emphasising the holistic and relational approach taken by Māori for hauora (health and wellbeing). "Māori taking care of Māori" was crucial and involved a whānau-based approach that placed whānau members at the center of a supportive network. Kaumātua Māori caregivers also drew on important Māori concepts during the pandemic to help with caregiving. Wairua (Māori spiritual dimensions) were leaned on, including karakia (chants and prayer). Whakapapa (genealogy) and tīpuna (ancestors) were an important source of strength as was a strong connection to Te Ao Māori, using te re and tikanga (cultural practices), ties to whenua and the natural and cosmological world. Key findings included:

- The cultural responsibility for Māori to look after their kaumātua and whānau was clear and emphases the unique needs of Māori whānau caregivers and cultural expectations put on them.
- A whānau-based approach to care is important. Kaumātua are a taonga (treasure) and the involvement of whānau in their care is vital to ensure the best care, that cultural needs are met and the health of the whānau is sustained.
- Lack of right to Tangihanga: Physical distancing and isolation from whānau-based supports led to implications on emotional wellbeing for Māori. The COVID-19 response in New Zealand diminished Māori cultural ways of being such as holistic approaches, importance of physical touch, whanau and family gatherings.
- There is a need to enhance cultural sensitivity within health systems and care agencies to avoid cultural misunderstandings and enhance service provision to whānau Māori.

- More Māori involved in the formal health care and aged-care sectors were considered important, as were Kaupapa Māori and iwi health providers.
- This study found Māori had unique cultural meanings of spirituality (extending beyond religion). Caregivers used karakia as part of their caregiving, going for walks, connecting with ancestors and spiritual beliefs to embrace spirituality. This form of spirituality extends into domains of emotional wellbeing and mindfulness.

Recommendations

It is clear from this research that no one-size-fits-all approach is appropriate for supporting informal caregivers as, although their experiences often reflect the same call for more support, the support they require is different depending on their diverse situations. This research suggests that supports need to consider and adapt to informal caregivers' individual needs, circumstances and for Māori kaumātua, their unique cultural needs.

Further exploration will likely be needed to provide support to informal caregivers based on their unique needs and individual circumstances. However, this study suggests the need for an organised system of support for informal caregivers, which includes; providing informal caregivers with clearer guidelines, creating more awareness about what support is available in a pandemic, addressing "red tape", and developing a mechanism to access required information and resources for informal caregivers.

Acknowledgements

The research team would like to thank all the participants of the Health, Work and Retirement (HWR) longitudinal study who participated in this particular research and who continue to provide valuable data on the experience of ageing in New Zealand.

The research team would like to thank the HART researchers, Hannah Phillips, and Vicki Beagley, for their assistance recruiting participants. This research is funded by the Health and Research Council of New Zealand (HRC) Emerging Researcher First Grants (22/558), and we would like to acknowledge the funder.

If you have any questions, concerns, or complaints about this research, please contact Dr. Shinya Uekusa (email: shinya.uekusa@canterbury.ac.nz or phone: 033691834). You can also contact the Health and Disability Ethics Committee (HDEC) that approved this study (email: hdecs@health.govt.nz or phone: 0800 4 ETHIC). HDEC reference Number: 2022 EXP 13416.

Table 1: Study participant demography (n=81)

				Note
Average age*		66.16		*oldest: 88, youngest 57
Gender	Men	34	42.0%	
	Women	47	58.0%	
Māori/non-Māori	Māori	35	43.2%	
	Non-Māori	46	48.4%	
Race/Ethnicity*	Pākehā/White	49	54.4%	*Some participants selected more than one race/ethnicity
	Māori	34	31.7%	
	Irish	2	1.8%	
	Dutch	1	0.7%	
	Fijian	1	0.5%	
	Japanese	1	0.5%	
	Samoan	1	0.4%	
	Zinbabwean	1	0.4%	
Rural	Rural	39	48.1%	
	Urban	42	42.4%	
Economic Living Standard Index (ELSI)	Good	57	70.4%	
	Comfortable	14	17.3%	
	Hardships	10	12.3%	
Location	Northland	4	4.9%	
	Auckland	13	16.9%	
	Waikato	13	16.9%	
	Bay of Plenty	11	14.3%	
	Taranaki	3	3.9%	
	Manawatū	6	7.8%	
	Gisborne	2	2.6%	
	Hawke's Bay	5	6.5%	
	Wellington	7	9.1%	
	Marlborough	2	2.6%	
	Tasman	4	5.2%	
	West Coast	1	1.3%	
	Canterbury	8	10.4%	
	Otago	1	1.3%	
	Southland	1	1.3%	
Care recipient	Parent	20	23.0%	
	Spouse/partner	29	33.3%	
	Sibling	2	2.3%	
	Child	7	8.0%	
	Grandchild	3	3.4%	
	Extended family	5	5.7%	
	Friend	6	6.9%	
	Neighbor	4	4.6%	
	Flatmate	1	1.1%	
	Other	10	11.5%	