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Love, support and structural holes: Māori whānau carer experiences in collective family care systems

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Abstract
As the population of Aotearoa New Zealand ages, informal family carers will play an increasingly important role in caring for older adults at home. Multi-generational living arrangements are a growing trend, particularly among Māori communities, where caring for older relatives within the family home is widespread. This article uses in-depth, semi-structured interviews with Māori *whānau* (extended family members) caring for *kaumātua* (older family members) at home to explore how carers experienced care coordination in the broader care collective. The findings centred on three interconnected factors that described the collective organisation of care: (1) *whānau* care as normal; (2) *whānau* care as collective coordination; and (3) *whānau* carer knowledge and needs as unseen. The findings show that although *whānau* care of *kaumātua* is highly valued, 'structural holes' within care systems contribute to challenges in care coordination. Despite extensive *whānau* support for *kaumātua*, primary carers often felt that their knowledge, preferences and self-care needs remained unseen and not translatable to those outside the everyday care situation. Rather than assuming an artificial binary difference between 'collective' and 'individually oriented' care contexts and cultures, analysing the cultural norms surrounding *whānau* care-giving confirms that collective care system members face similar and different challenges to carers with smaller caring capacities.

Introduction

Aotearoa New Zealand's population is ageing: approximately one in four individuals will be 65 years old or older by 2048 (Stats 2022). Therefore, it is predicted that unpaid family and kin carers (*e.g.* spouses, daughters, sons, children-in-law, siblings

and friends) will play an increasingly important role in caring for older adults at home (McAllum et al. 2021; Ministry of Social Development 2019). Moreover, extended family – or *whānau* – care is a norm for Māori families (*e.g.* Durie 1999; Nikora et al. 2004; Williams et al. 2018) and Māori women are more likely to be carers than others (Ministry of Social Development 2019, 10). Although the term 'carer' is internationally recognised, in Aotearoa New Zealand alternative words such as 'supporter' and '*manaakitanga*' (caring) may better express how *whānau* carers see their role (Ministry of Social Development 2019, 9). Also, Māori values, such as *aroha* (love), *whānaungatanga* (relationships/connections), *whakapapa* (genealogy) and living within *Te Ao Māori* (the Māori world), situate care as involving reciprocal and collective efforts. These are based on bonds of association and obligation derived from kinship ties (Mead 2003; Tate 2012). Kin includes close family (*whānau te rito*) and broader groups of relations (*whānui*) such as great-grandparents, grandparents, parents, aunts, uncles, siblings, nieces, nephews and cousins (Tukukino 1985 cited in Collins and Willson 2008).

Normalised expectations of giving and receiving support within the *whānau* may lead to *whānau* carers under-reporting the care given to other *whānau* when surveyed. In addition, such normalisation may create situations where *whānau* do not seek or access external support when needed (Ministry of Social Development 2019). Consequently, Māori are likely under-represented in the estimated 10 per cent of the population caring for a relative or friend with an illness or disability (Kia Piki Ake Group 2019). Other international studies report similar findings for different cultural groups (*e.g.* Greenwood et al. 2015).

Empirical studies in cultural contexts where multiple individuals habitually make up support and care networks (*e.g.* Canadian First Nations, Hawai'i, Mexico) show that family interdependence, intergenerational and intragenerational solidarity, and norms that emphasise reciprocity all shape how care is organised. Yet, studies also suggest that the ideal of shared family responsibility is not always realised in practice (Akinrolie et al. 2020; Browne et al. 2014; Habjan et al. 2012; Mendez-Luck et al. 2016). This disconnect is problematic because unmet expectations of collective care, where multiple care-givers take on care-giving responsibilities, may lead to heavier burdens for primary carers, splintered care coordination and heightened tensions within family systems. Furthermore, although the roles and tasks of Māori *whānau* carers have been explored (*e.g.* Collins and Willson 2008; Nikora et al. 2004; Simpson et al. 2022; Wiles et al. 2018; Williams et al. 2018), limited reporting exists about their support needs within *whānau* care networks (Kuluski et al. 2018; Lay-Yee et al. 2017). Therefore, this exploratory study investigated the experiences of *whānau* carers looking after *kaumātua* (older relatives) in *whānau* care collectives considering the international literature about collective care.

The literature review defines collective care systems, explores care system models and how care responsibilities are shared within families, and situates Māori *whānau* care within these frameworks. The research question, methods, findings and discussion follow.

Literature review

Care systems, networks and models of family care

A *care system* incorporates the division of care responsibilities and the contributions to care recipients and other carers (Keith 1995). Most care systems studies use network theory, with networks defined as social structures constituted in communication (Stohl 2004). This approach assumes that 'specific commitments exist in systems of relationships and that formation and negation of commitments occur in the context of one's connections to a network of others' (Piercy 2007, S382). Through this lens, care systems are networks comprising actors with varying levels of commitment, including those who, due to their relationship with the care recipient, are 'involved in care, support family members involved in care, and/or could be involved in care' (Marcum et al. 2020, 128). Such relationships include immediate and extended family (*i.e.* kin), non-kin and formal carers.

Within a care system, however, social, support and care networks can be assessed separately to estimate a care system's 'caring capacity' by identifying current and potential informal carers (Keating et al. 2003). *Social networks* encompass all social ties and linkages, whereas *support networks* comprise a smaller subset of individuals willing to provide emotional and tangible aid to care recipients. Smaller than support networks, *care networks* require a greater range of more frequent care-related tasks. They may comprise as few as two members (or 1.5 on average when emotional support is excluded; Fast et al. 2004).

A care system includes these three types of network as it encompasses multiple forms of care-giving and care-receiving by network members who care for care recipients and carers (see Marcum et al. 2020). Thus, positioning care, support and social networks as components of a broader care system avoids reducing care to hands-on tasks without accounting for emotional ties among network members. In addition, this more comprehensive conceptualisation enables us to explore how differences in caring capacity (*e.g.* among primary carers, occasional carers and potential carers) contribute to divisions in seen and unseen aspects of care within the care system.

Analyses of care systems also use the *convoy of care* (Antonucci et al. 2011) and *social care* (Cantor 1991) models. These models document differences in carers' commitment levels and changes in care responsibilities. The convoy model depicts transformations within the care system over time as individuals engage and disengage with the carer role – like passing a baton between members in a convoy. Cantor's social care model also acknowledges multiple carers represented in a series of widening concentric circles around the care recipient. However, Cantor's model ignores the possibility that carers support other carers as well as the care recipient and reinforces the notion of a primary carer. Such limited role distribution and care organisation may not represent the case of those in collective care systems.

Collective care systems

We define collective care systems as those where multiple individuals make up support and care networks instead of having one primary carer. Two empirical studies illustrate why the assumption of a single primary carer is problematic: one US study of 30 care

networks found only 6 networks that nominated one individual as the primary carer; the other 24 had multiple primary carers (Marcum et al. 2020). Another US researcher (Keith 1995), who examined how siblings organised care for an older parent, identified several multi-carer models of collective care, including partnership and team systems. In partnership systems, same-sex siblings consulted each other, made decisions jointly and took responsibility for care, often criticising absent, non-participative siblings. In team systems, care responsibilities were dispersed among siblings and, although responsibilities were not equally shared, siblings did their part to avoid overburdening any one sibling care-giver.

Collective care can involve individuals caring for multiple family members simultaneously or successively and multiple carers looking after one care recipient (*e.g.* Evans et al. 2017). Exploring collective family care systems with multiple carers and recipients requires researchers to investigate pluralistic family formations (Roberto and Blieszner 2015, 306). Such formations include extended kin, stepfamilies, neighbours and friends (Barker 2002; Crosato et al. 2007) and cultural contexts where kinship ties are central in the care of any family members (Dumit et al. 2015). Within such collective care systems, members must determine either implicitly or explicitly how to share care responsibilities (Finch and Mason 1993) – a consideration for the next section.

Organising care responsibilities within collective care systems

A key to the functioning of collective care systems is how care responsibilities are allocated across the social, support and care networks. Not all care systems use explicit discussion or negotiation as a means of decision-making about how care will be organised and coordinated (McAllum et al. 2021). Transitions to care roles can be 'characterised by non-decisions [where] situations simply emerge regarding the distribution of responsibility' (Aasbø et al. 2017, 613). Yet, conflict may erupt when care-giving is not explicitly labelled as such from the outset. For example, one sibling may become a parent's carer by default and stay in the role for their adult life. Other siblings may see the carer as avoiding participation in the paid workforce and 'using' care to live rent-free in the family home (Lashewicz 2011). Here, care and its value become taken for granted and unsupported within the family system.

Explicit negotiations, which require 'open discussions in which people develop a common understanding of balancing the responsibility between giving and receiving help, and who should bear that responsibility' (Aasbø et al. 2017, 613), seem to offer more opportunities for collaboration within family systems. However, a lack of consensus within networks can generate considerable conflict (Marcum et al. 2020). For example, some family members may be propelled into a care role when others are unwilling to give up employment or move closer to the care recipient (Connidis and Kemp 2008; Leopold et al. 2014). Others may reject care responsibilities imposed by other family members' unexpected role transitions (Burton 1996).

Indeed, the allocation of roles in collective care systems takes different forms. Davis (1997) provides a helpful typology of collective care in a study of how US families managed conflicts about coordinating care for an older family member. She found that conflicts arose within three intra- and intergenerational care models: substitutive, complementary and conjoint care. *Substitutive care* involves a family member temporarily

taking on the primary carer's role to provide respite. *Complementary care* refers to other family members independently providing different services (*e.g.* the primary carer takes on activities of daily living (ADLs), which are basic personal care functions such as feeding, bathing and dressing, while other family members take responsibility for instrumental activities of daily living (I/ADLs), which enable one to care for oneself and one's home (*e.g.* cooking, cleaning, shopping and taking medication)). Finally*, conjoint care* requires collaboration, as family members offer the same care services in conjunction with one another.

Similar patterns are evident in Katz and Lowenstein's (2002) study of Arab Israeli families' decision-making patterns regarding care responsibilities. The four rigid-to-flexible styles include (1) one-off, 'unilateral' decision-making by the care recipient about who will care (no substitutive care occurs); (2) a 'working machine' style where specific tasks are allocated to certain family members (a form of complementary care); (3) a 'roundtable' pattern where family members collectively (re)define tasks and renegotiate responsibilities as needs evolve (a successful form of conjoint care); and (4) '*Rashomon*' style (referring to a classic Japanese film depicting an event from different viewpoints) characterised by ambiguity and chaos with no clear decision-making patterns. Families who organised care according to unilateral and Rashomon patterns experienced the most carer burden, 'working machine' families some burden and the roundtable families the least burden. Care tasks were made visible in roundtable families and shared more effectively among more family members.

A study of home-based collective care networks in Argentina and Chile (Gutierrez and Ochoa 2021) offers additional insight into how various forms of care organising influence task allocation, care-givers' awareness of others' work and the quality of care. The way that tasks were delineated gave rise to four distinct roles: assistants, monitors, helpers and outsiders. *Assistants*, primary carers who lived with care recipients, were key in coordinating others' interventions. Among assistants, female family members typically attended to older adults' social and affective needs, and male family members to instrumental, safety and security needs that improved the comfort of the living environment (see also Montgomery and Kosloski 2009). *Monitors*, family members who lived elsewhere, actively engaged with care recipients' needs. Finally, *helpers* assisted with instrumental tasks and *outsiders* assumed no direct care responsibilities. Unfortunately, monitors could be unaware of each other's and helpers' care work, leading to blind spots in the collective care system. This resulted in older care recipients' needs being either over-supplied or unaddressed. Network theory's 'bridging ties' support this finding: when members of the care system are connected to the older adult but not to each other, care coordination becomes fragmented and pressure on primary carers increases (Goldman 2016).

These studies of intra- and intergenerational family care and decision-making patterns illustrate different ways of organising care-giving responsibilities within collective care systems in Argentina, Chile, Israel and the United States. Importantly, they problematise two assumptions: (1) that collective care occurs only or primarily in cultural contexts where extended or pluralistic family ties are common; and (2) that structural elements of social relations that shape expectations of care, such as gender, birth order or marriage status, matter only in such cultural contexts. Such structural elements, however, matter in all contexts, and, because they are complex, dynamic features of

care organising must be situated within the carer's specific cultural context rather than assuming that similarities exist across collective cultural contexts. To this end, the following section outlines cultural aspects of Māori *whānau* care.

Māori whānau care

Māori *whānau* care is inherently collective, with multiple individuals, joined by bonds of association and kin-connectedness, supporting a *whānau* member. Such connectedness includes close family (*whānau te rito*) such as great-grandparents, grandparents, parents, aunts, uncles, siblings, nieces, nephews and cousins, and broader groups of relations (*whānau whanui*) (Collins and Willson 2008). *Whānau* carers may take on multiple roles, including being medication and care-diary managers, and *whānau* support at medical appointments (Nikora et al. 2004). *Whānau* carers also mediate between the *whānau* member receiving care, healthcare professionals, other *whānau* carers, service providers and the support network of family and friends (Simpson et al. 2022; Wiles et al. 2018). Such roles and tasks are reflected in Collins and Willson's model of *whānau* care, which identifies three layers of support: *primary informal support* from close family, *formal tertiary support* from health professionals and in-between layers of *secondary support* from extended *whānau* members. Coordinating care roles and tasks with these layers of the *whānau* care collective is complex.

Building upon the literature about the challenges of providing collective care, this study explores how Māori *whānau* carers looking after *kaumātua* (older relatives) talk about organising care within a cultural context where collective *whānau* care is valued, expected and normal. Hence, we ask the following research question: How do Māori *whānau* members experience care coordination within a *whānau* collective?

Methods

The original study design included 20 past and current family carers of an older *whānau* member or *kaumātua*. However, Covid-19 regulations halted interviews in 2020, with only 16 carer participants having taken part, of whom 14 were Māori. Therefore, in 2021, we determined to work with the Māori carers' contributions, taking a culture-centred approach (Simpson et al. 2016) to the data analysis.

Participant recruitment

Two non-Māori researchers and two Māori research assistants (with experience in caring for older relatives) used snowball (Patton 2002) and networking methods to identify potential participants. Beginning with interviewing *whānau* carers they knew, interviewers asked interviewees (snowball method) and others (*e.g.* family members, friends) for referrals to people they knew were or had been *whānau* carers of *kaumātua* (network method). During the first interaction, interviewers introduced themselves and the study, outlining the interview process, goals and expected outcomes. Before starting, they offered to review the information sheet with the participant, which covered the likely time commitment and participants' rights to question, clarify or decline answers and to halt the interview. They explained data storage, publication presentation

and identity protection by using pseudonyms and removing potentially identifying personal information or family situations.

Data collection

Māori communication protocols (McClintock et al. 2012; Mead 2003; Tate 2012) guided the interviews with *whānau* carers. Qualitative semi-structured interviews (each lasting 40–90 minutes) were jointly or individually conducted with one or two *whānau* carers. One researcher guided and supported the Māori research assistants' first three interviews involving one or more *whānau* carers. The interviews were audio-recorded and transcribed into 134 pages of single-spaced transcripts, with each participant being assigned a pseudonym. The University of Waikato (reference WMS 18/38) granted ethical approval. As part of the approval, Māori interviewers were involved, and *whānau* carer participants were invited to have support persons present. We were sensitive to the possibility of health and loss issues emerging during the interviews, and, therefore, follow-up resources for care-givers were available if needed. If a participant became distressed during the conversation, the research team was prepared to seek professional, family and/or other assistance, with the participant's permission.

Culture-centred participation was facilitated with Māori communication protocols and invitational, conversation-generating enquiry. Such protocols in the semi-structured interviews included meeting face-to-face (*kanohi ki te kanohi*), beginning with a greeting (*mihi*) and establishing relational connections centred on kin and/or experience with *whānau* care (*whakawhānaungatanga*); acknowledging the strength of *whānau* experience for the study; *whaikōrero*, which allowed for 'respectful listening, in-depth focused discussion, and the collection of information' (McClintock et al. 2012, 97); using Māori language (*te reo*) where possible; providing a *koha* (gift) as compensation for participation (grocery voucher for $50 and morning or afternoon tea); and ending with a prayer (*karakia*). Although such processes may be similar to general qualitative interview approaches (*e.g.* Patton 2002), the cultural meaning of these communication protocols lies within *Te Ao Māori* (see Mead 2003).

Conversation starter questions included 'What brought you to care for your [*whānau* member]?', 'Who else is involved in caring for [—]?', 'What kind of relationship(s) do you have with [—], other members of your siblings or cousins, and your children or partner?', 'How do these relationships help or hinder your or others' care role(s)?' and 'How do others (*whānau*, friends, co-workers) respond to or talk about your care role?'

Data analysis

Thematic analysis identified patterns across the data (Braun and Clarke 2006; McAllum et al. 2019). Within this approach, carers' talk about caring for a *whānau* member was interpreted through a cultural-discursive analytical framework (Simpson et al. 2016). Within this framework, talk is a resource whereby people reveal their ideas, concerns and goals in words and meanings shaped by shared beliefs (Tracy 2020). This lens examined expressions of Māori values within kin relationships (*whānaungatanga*),

such as nurturing others (*manaakitanga*) and love (*aroha*), that help to shape *whānau* care.

The data analysis began with initial coding focused on how carers talked about care situations and what they and other *whānau* members did in caring for their *kaumātua*. Such talk included shifts in context ('in my head/in reality'); pronouns and labels that indicated groups (us/them, visitors); changes in verb tense from past to present; and expressions that suggested layers of meaning ('she'd look all right'). Next, these codes were organised into second-level axial codes using the constant comparative process (Charmaz 2014). Then, the axial codes were transformed into themes that 'describe the scope and content of each theme in a couple of sentences' (Braun and Clarke 2006, 92). Table 1 illustrates the process with examples of initial codes, second-level codes and initial themes.

Two researchers independently coded the transcripts in consultation with the Māori research assistants and some participants. The initial codes were reconciled, and new codes were re-examined and cross-checked between coders. To enhance analytical rigour and cultural resonance, participants were invited to comment on the preliminary thematic analysis. Three participants met in person; three read the summary document; three could not take part; and five did not respond. Ongoing conversations between participants and researchers resulted in the initial themes being further delineated, collapsed, renamed or eliminated. During these processes, participants offered English approximations of Māori concepts. The outcome was three themes, each with sub-themes.

Findings

Of the 14 Māori *whānau* carers (aged 23 to 72 years; 12 female and 2 male), seven current carers had 6 months to 7 years of experience, and seven past carers had 7 to 20 years of experience (see Table 2). Three were past carers of the same *whānau* member, and two were current or past carers within the same extended *whānau* and cared for different members.

The findings illustrate how *whānau* carers talk about their experiences with care coordination within a *whānau* collective. Three themes were related to the collective organisation of care: (1) *whānau* caring for *kaumatua* as normal; (2) *whānau* care as collective coordination: and (3) *whānau* carer support needs and knowledge as unseen.

Whānau caring for kaumātua as normal: 'It's what we do'

This theme encapsulated two norms that underpinned participants' transition from belonging to a *kaumātua*'s broader social network to taking on a role within their support or care network (Keating et al. 2003): (1) expectations of intergenerational reciprocity and (2) Māori cultural values of *whānau* care. In privileging these norms, participants indicated the value and positive contribution of care practices that differ from those of the dominant culture, where institutional care for older adults is more common (Holdaway et al. 2021). However, even though caring for older relatives was valued, its normalcy meant that the range and impact of caring were not always seen or understood by *whānau* carers before taking on the role.

Table 1. Examples from the coding process

Raw data	First-level codes	Second-level codes	Initial themes
Having Nan there to actually give us attention and love and care and make sure the house is clean make sure there's dinner on the table stuff like that made life a little bit easier for my parents as well as us (1Ma/13)	'made life a little bit easier for my parents'	Gratitude for the care recipient's past contribution Desire to give back	Carers are motivated to contribute to care for their *whānau*. Norms of intergenerational reciprocity underpin carers' motivation.
You get to a stage where you wonder if you're doing enough sometimes. Like just doing the daily things like cooking meals and taking care of the house, taking care of the financial side of things and visitors and people … but then sometimes there's a person – an elderly person needs more than just those things … having that closer relationship with your carer is really important (4Me/18)	'you wonder if you're doing enough' 'doing the daily things' 'taking care of [finances]' 'looking after visitors' 'having that closer relationship'	Multiple facets of care: Help with ADLs Emotional/relational support Material assistance Caring for the carer	One person cannot carry out the many and varied tasks involved in caring for an older adult. *Whānau* care involves distributing and coordinating efforts across the *whānau*.
I just tried to take things day by day. I just didn't expect things to be as hard as they were. I knew they'd be hard but you don't know until you actually live it (12Tu/60a) I just had this idea that I could help her walk from A to B, help her get out of bed, make her bed, simple household chores. But it was more than that (9Pe/57).	'I just didn't expect things to be as hard as they were' 'you don't know until you actually live it' 'I just had this idea'	Learning by doing Under-estimating and lacking language to describe the role	The challenges and intensity of the care role are invisible to primary carers before they take it on. Primary carers develop a growing insider awareness of the care role's scope through first-hand lived experience

Table 2. Whānau carer participant demographics

Code	Code name	Age	Sex	Family member (*whanaunga*)
1Ka	Kara	23	F	Aunty
2Ma	Maria	30	F	Grandmother
3Ha	Hana	38	F	Grandfather
4Me	Mere	50s	F	Father
5Ra	Rangi	60s	F	Mother
6An	Ani	50s	F	Parents
7Mo	Mokena	25	F	Grandparents
8Ni	Nia	19	F	Grandmother
9Pe	Peti	19	F	Grandmother
10Ti	Tiana	50s	F	Father
11Ra	Rawiri	24	M	Uncle
12Ma	Maia	30	F	Grandmother
13We	Wiremu	40s	M	Father
14Tu	Tui	22	F	Grandmother

Expectations of intergenerational reciprocity: Often, expectations of giving and receiving intergenerational care meant that talk about who would care did not occur because care was the 'natural' and 'normal' thing to do. For example, Kara mentioned: 'I ended up with [Auntie] in my care. Well, I wasn't going to argue because it's family, you know? … Yeah, you don't argue. You just do it' (1Ka/17). Participants also noted that *kaumātua* might expect such support. Mere's comment illustrates this: 'You do make sacrifices. Where you might have had personal freedom before becoming that care person …. But the person you're looking after … expects you to give up these things' (4Me/58). Likewise, Maia emphasised how a 'mindset' based on reciprocal *whānau* relationships normalised care: 'I suppose everyone in my family, like my extended family, like Nan's siblings and their children and grandchildren, it was just normal, what's supposed to happen. You're supposed to look after your Nan because she looked after you, which was my mindset as well; that's why I did want to do it' (12Ma/84).

Although the expressions 'You just do it,' 'it was just normal' and 'what's supposed to happen' may imply a lack of choice, participants often expressed 'wanting to' and 'feeling like' giving back. For instance, Mokena commented: 'Especially with my grandmother when we were young; she would always look after us as kids. She did it for us, and I feel like I would do it for them too' (7Mo/42). Peti explained: 'I just feel like looking after [Nan] shouldn't be something that people should … put as much focus on. It was just something I did because I wanted to, so I don't think it matters how you describe it to them. It wasn't a task; it wasn't a duty; it was just me looking after Nan' (9Pe/88).

Ani described her purposeful decision to care for her parents: 'I had made a decision that … I was going to make sure that [my parents] lived the kind of life they wanted to until they dropped dead … As the youngest, I wanted to give back' (6An/3–15).

By connecting the present to the past, Tiana downplayed care's impact on her current life situation when considering her father's lifetime of sacrifice: 'I think to myself, am I doing the right thing? … Because this is just a moment in time, really, compared to a lifetime that's he's worked hard for me and my siblings' (10Ti/50a).

Māori cultural values of whānau care: Participants normalised care by invoking relationships characterised by love (*aroha*) and nurturing care (*manaaki*). As Rangi explained, '[Our mother] loved us, and so we expressed that same love … When we're in that energy of good vibrations with people and that *aroha* is strong, you stay there' (5Ra/24). Here, the positive aspects of care (giving and receiving love) for the person cared for and carers are foregrounded and made possible because multiple *whānau* members (as indicated by 'we' and 'our') are involved. This collective effort is also evident in Rangi's account of how other *whānau* members talked about her mother's care. 'A couple of my aunties [said] that my Mum was a very spoilt and well-loved woman because they could see the care that the children and grandchildren were giving [her] just at the *marae* [Māori community meeting place]' (5Ra/22a).

Importantly, these excerpts suggest that nurturing care (*manaaki*) involves emotional and spiritual care within the relationship and extends beyond assistance with ADLs. Likewise, love (*aroha*) is expressed by being with (rather than only doing for) the *kaumatua*, supporting them to live their lives as they want and continuing in the spirit of positive *whānau* relationships. For example, Nia stressed, 'Just being closer with Nan, so she has someone to talk to. She gets really lonely' (8Ni/68). Tui also acknowledged the relationship with her nan (grandmother): 'It was my kuia, my nan, my mum's mum. She pretty much brought me up when I was younger … We had a very beautiful relationship my whole life' (14Tu/7–15). Ani differentiated between nurturing her parents' desired way of living and giving care within the relationship: 'I supported my parents in how they wanted to view life, how they wanted to live their life, and I tried to make that happen, which is different from waiting on them hand and foot. That would be care' (6An/33–39).

This comment underscores the parents' and carers' agency; care was not servitude. Thus, expectations and enactment of intergenerational reciprocity and collective *whānau* values of love (*aroha*) and care (*manaaki*) normalise *whānau* care. Intergenerational reciprocity may mean that decisions to care are unseen by some *whānau*. Even so, the positive emotional and spiritual dimensions of care are evident in the collective commitment to love and nurturing care.

Whānau care as collective coordination: 'We're all in this together'

This theme described how *whānau* organised care by coordinating various responsibilities across multiple individuals within a *kaumatua*'s support network at specific times to meet *kaumātua* needs. Although all support network members were expected to contribute, the first subtheme, care coordination's complexity, shows that *whānau* carers had diverse understandings of what care tasks were needed. The second subtheme shows that care coordination extended beyond kin relationships. When care roles were not linked to kinship-relational roles, it was less obvious who was doing what. The third subtheme, care coordination holes, illustrates the impact of disconnections in the collective care network.

Care coordination's complexity: All participants identified as 'carers' within the support network, but interpretations varied regarding what activities were needed. Mere understood care activities as including I/ADLs such as 'daily things like cooking meals and taking care of the house, taking care of the financial side of things and visitors'. She also included relational activities like 'sitting down and talking, having that closer relationship' with the *kaumātua*. Yet, trying to 'be everything to somebody' was 'hard at times' (4Me/19–20). Here, Mere identified the challenge of juggling responsibilities, highlighting the importance of multiple *whānau* members taking on diverse care roles.

Care roles also included offering material support (*e.g.* financial and in-kind contributions). For instance, Rangi appreciated having 'five awesome brothers … [who] would come in on a Friday night … chop a whole bunch of kindling, and wood … [for our mother and] stack the wood up to a certain height [to] last for the week' (5Ra/44b). She also talked of her organising role in the *whānau* care system:

> We had a book – a diary, and I used to ask my family to diarise Mum's journey, but I was really checking what they were up to. Did you feed my mother? Did she eat? … Is she in a good mood? … We first put it into place to make sure that she was getting her right medication. (5Ra/64–82)

Sometimes, the primary carer coordinated other *whānau* members (*e.g.* Mere). In other cases, a designated 'organiser' took on this role (*e.g.* Rangi). Primary carers who also managed coordination found it challenging to juggle everything (*e.g.* Rawiri, Tui and Kara).

Care coordination extends beyond kin relationships: Role distribution did not depend on *whānau* members' position within the broader social network or their familial relationship with the *kaumātua* receiving care (*e.g.* daughter, grandchild, cousin, niece). Participants with the same kin-relationship role often took on different carer roles. For instance, Maia, Peti and Hana were all *mokopuna* (grandchildren). Maia took on a primary carer role: 'My grandmother was particular as with whoever touched her [for personal care] … So, it was always just certain people, and I was fortunate enough to be one of those certain people' (1Ma/46b). Peti and Hana, in contrast, offered relational roles. Peti managed difficult conversations with her grandmother: 'I was a big help because she was a very fussy person, so the chances of her listening to anyone bar me were quite slim' (9Pe/18). Hana's role in caring for her grandfather was more sporadic, as she would 'just go in to give my mother a break for a day or two. … I'd just go and spend time with Koro. My relationship with him was really good' (3Ha/18a). Yet, Tiana's niece could not sit with her grandfather (Tiana's father) for a few hours, despite their positive relationship and her training as a nurse. Tiana explained: 'It was still hard for her. She only came for three hours so I could go out. … But when I got back, she was stressed because it's her *Papa* [grandfather]. … I can't expect them to come and care for him, but they can still visit him' (10Ti/41–44a).

Mere described another possibility, that of a grandchild who supports the carer: 'Although my youngest daughter lives here, she doesn't have a role in [my father's] care. She's more a sort of support person for both of us. His everyday carer is me' (4Me/4). The various care and support roles of *whānau* members increase the difficulty in identifying the multiple types of care surrounding the *kaumātua* receiving care.

Care coordination holes: Although most *whānau* networks coordinated care reasonably well, disconnections appeared at the centre and peripheries. For example, sometimes a primary carer at the care network's centre excluded other support network members who would care for a *kaumātua*, even when they were over-stretched. Fortunately, primary carers could repair or plug care coordination holes. For instance, Peti, who initially referred to herself as 'superwoman', shared that she had to 'shift from thinking "I can do everything for Mum"': 'I had to give that up, and … it was difficult, more so because I felt confident that I could care for her, and so I knew what to do, and I didn't want to leave her to someone else who might not know quite as much as what I did' (9Pe/68).

Whereas Peti had to decrease her vigilance, Ani commented on the relief she felt when she moved from saying 'No thank you' to acknowledging 'I did need help and people would help':

> There was no judgement [from them of me], and it was just pleasure on the part of those whom I let help me … I thought, 'Why didn't you do this before, much earlier? Could have been a relief.' … I found out what it was like not to be alone … and the huge amounts of love and respect they had for [my mother]. (6An/158–162)

Other participants mentioned that *whānau* members other than the primary caregiver contributed to creating care coordination holes. In some cases, *whānau* members seemed to contest their role in the care or support network. For example, when Kara, the primary care-giver, told her cousin 'Your Mum's health is not really great', she was 'fobbed off' (her cousin sidestepped the issue) and realised that 'they don't want to know' (1Ka173). Rawiri, another primary carer, also mentioned his cousins' lack of support: 'Our cousins would be a lot of help for me [if they came, because] a few times when I've been away, and I've come back home to find my uncle could have done with some help that day' (11Ra/77). In another example, competing personal interests or lack of awareness of the *kaumātua*'s needs meant that other potential carers did not step in. Tui, another primary carer, mentioned her cousin's refusal to help: 'Me and my cousin began to fight a lot because I would need him to come and watch [Nan] so I could just do things like the shopping or go to appointments, … he'd rather go out on Friday after work' (14Tu/17a). Refusing to help with caring for the *kaumātua* led to uncompleted care tasks and a breakdown in the support network's functionality.

Whānau carer knowledge and needs as unseen: 'You look okay'

Whānau inside the social network but outside the support or care network did not see primary carers' need for self-care and thus did not always provide material and relational support. This 'not seeing' occurred because *whānau* within the social network knew who occupied the carer role but not necessarily what the role entailed. The first subtheme of '*Whānau not realising the scope of care*' shows that care work specifics were often not (able to be) spoken about before becoming a primary *whānau* carer. The second subtheme, '*Whānau not noticing primary carers' knowledge and preferences*', concerns how *whānau* carers' 'knowing' was not easily translated to other *whānau* members in the support network. The third subtheme, '*Whānau carers' needs*

as unseen', refers to a lack of appreciation of carers' need for self-care by *whānau* members in the support network.

Whānau not realising the scope of care: Several primary carers commented on their lack of awareness of what care work involved before becoming a carer. For instance, Maia said, 'In my head, it was like just make sure Nan's had a feed, and the telly's on, the house is clean to her standard, and it's all good. But, just the reality of that is so much more' (1Ma/22). Likewise, Peti said, 'I just had this idea that I could help her walk from A to B, help her get out of bed, make her bed, simple household chores. But it was more than that' (9Pe/57). Phrases such as 'I just had this idea' and 'the reality is so much more than that' revealed the learning involved in taking on a carer role and the aspects of care unknown to those outside the role. Kara highlighted the dimensions of care that 'nobody' thinks of when she commented: 'Layers come in, like the personal care, emotional care, nobody actually thinks about that … It's not until you've actually been through it or you're actually enduring it; it's like "Wow this is it!"' (1Ka198–201). Additional dimensions of care work were gradually accommodated so that they became normal and unlikely to be talked of. Hence, the primary carer's specific tasks tended to be opaque to those not directly involved.

Whānau not noticing primary carers' knowledge and preferences: This subtheme concerns how *whānau* members did not always appreciate the extent of *whānau* carers' knowledge, experience and preferences. Some *whānau* members in the support and social network acknowledged that the primary carer had more knowledge of the care situation than themselves. Maia explained, 'If there's one person that sticks out in terms of how to care for someone, then most of the responsibility naturally goes on them because no one else really knows what to do' (1Ma/62). In other situations, however, conflict emerged when the primary carer's perspective was not given due weight or importance. Ani, for example, spoke of having 'a falling out' with a relative during a family meeting about the ongoing care of her parents. She said that although 'the level of care was getting quite intense', she had 'categorically stated, "I don't want [our parents] to go to [residential care]."' Then, '[relative-in-law] walked out of the family meeting – total aggro [aggressive attitude]. I told [other *whānau*], "I don't care; [relative-in-law] can stay out if [he/she] wants. I will deal with this with my [sibling]"' (6An/116). In this situation, the ideas of a *whānau* member outside of the primary care situation did not align with the primary *whānau* carer's desire to continue caring for her parents; she sought support, not substitution.

Whānau carers' needs as unseen: Primary *whānau* carers talked about other *whānau* who dropped in to provide relational care or material support for the *kaumātua*, not appreciating the impact of the care demands on the primary carer. Tiana mentioned that her family, who did not see the behind-the-scenes work, thought her job was lightweight: 'Of course, they thought "it's easy, there's not a lot to it," but I'm on the phone all the time trying to sort things and arrange things and get in to see so and so' (10Ti/93). Mere commented, 'When you're the carer, you can see so many things. When you're on the other side of the fence, it just looks like "Oh well, they're all right, she's handling it"' (4Me/121). Similarly, when Tiana's brother arrived, he asked, 'How are you? You look okay' (10Ti/158). Such statements shut down opportunities to learn about the day-to-day support needs of the carer. *Whānau* carers found the 'hidden-in-plain-sight' nature of everyday care work problematic because their needs were not

noticed. Rangi compared *whānau* care to what is 'unseen after dark' where visiting *whānau* members did not perceive 'a normal night's work' (5Ra/118). Ani also commented: '[Others] don't understand when you want a break, or you want to get out; it's supposed to be sunshine and roses, and it's not' (6An/69). Another primary carer, Kara, referred to the differences in appearances and lived reality: 'They would see Auntie [care recipient], and she'd be happy and stuff and she'd look all right, but they'd never ask [me], "Oh, how's your health?"' (1Ka/159–161). Comments like 'they're all right', 'she'd look all right' and 'You look okay' indicate that *whānau* members outside the care network often failed to see beyond immediate appearances of coping; they did not probe further to promote meaningful exchange.

In these situations, *whānau* within the support network did not help the *whānau* carer to engage in self-care. Mere suggested that *whānau* ask questions like 'How are things going? Do you need some help with something? Can we do this for you guys?' (4Me/123). Instead, it often took a crisis for primary carers' responsibilities to be apparent. For example, after 'a really tough nine days', Tiana received a text message from a younger sister: 'I was thinking about you today, and I just wanted to see if you were okay.' Tiana said she 'cried and sent a sad face with a tear coming down, and then communication started' (10Ti/108). Not knowing the extent of primary care tasks or noticing *whānau* carer needs meant that support for primary carers was reactive more often than proactive.

Discussion

This study, which focused on how Māori *whānau* members experience care coordination within a *whānau* collective, makes two key contributions to ongoing debates within the field of culture-centred social gerontology. Firstly, the locally grounded analysis of cultural norms surrounding *whānau* care-giving in Aotearoa New Zealand supports the idea that members of collective care systems within Indigenous and pluralistic family contexts comprising many carers face similar and different challenges to carers within systems with a smaller caring capacity. Similarities include the difficulty of coordinating multiple actors within the care network, network members' divergent interpretations of what care-giving involves and the extent of unseen work carried out by primary carers (*e.g.* Akinrolie et al. 2020; Browne et al. 2014; Tang et al. 2018). Differences relate to cultural values that influence willingness to move from the broader *whānau* network to take on a more defined carer role (Nikora et al. 2004; Simpson et al. 2022; Wiles et al. 2018; compare with Connidis and Kemp 2008; Leopold et al. 2014).

Secondly, the study suggests that carers in all contexts, including collective care systems, need multiple forms of support. Support can operate at multiple levels, including support for learning how to care (socialising potential carers as they take on the caring role), for coordinating care activities (ensuring care quality for the older adult) and for primary carers within a collective system, where their work and their self-care needs may be unseen (harnessing collective strength to bolster carer resilience). We explain how these dynamics played out in the findings by mobilising Keating's (2003) distinction among social, support and care networks. Social networks encompass all social ties and linkages, whereas support networks comprise a smaller subset of individuals willing to provide emotional and tangible aid to care recipients. Members of care networks,

which are smaller than support networks, engage in the most frequent, intensive and extensive range of care tasks.

More specifically, the findings show that *whānau* care is highly valued and accepted as normal (Collins and Willson 2008; Nikora et al. 2004). Māori norms of intergenerational solidarity and reciprocity, the special status of *kaumātua* and expectations about the collective *whānau* care of them (Durie 1999; Mead 2003; Tate 2012) make *kaumātua* and their care needs highly visible to potential and actual carers within the *whānau* social network. Indeed, *whanaungatanga* (relationships), where 'individuals expect to be supported by their relatives [and] the collective group also expects that support and help of its individuals' (Mead 2003, 28), embrace social and support networks. Being part of the broader *whānau* social network creates an expectation that *whānau* will form part of the support network. Faced with *kaumātua* needs, participants tended to accept care responsibilities 'naturally' without a second thought (compare with Aasbø et al. 2017). Within the dataset, there was often little talk within the *whānau* about which members would take on a care role. Consequently, *whānau* were unaware of the total weight of *mahi* (work) needed to care for *kaumātua* before starting out.

Yet, because *whānau* care is understood through the values of *manaakitanga* (nurturing care) and *aroha* (love), potential carers invoked emotional and spiritual dimensions of care when expressing their desire to accept the role. The positive sense of collective responsibility, care and love means that the collective care system is extensive (Goldman 2016) with *whānau* assisting with I/ADLs and providing relational and material support for their *kaumātua* (Nikora et al. 2004). *Whānau* carer activities reflected the 'catch-all roles' (Nikora et al. 2004, 51) that supported the *whānau* and the *kaumātua* in their care.

The second finding showed that, although caring for and by *whānau* was a norm, role allocation within the *whānau* varied. For instance, primary carers (Keating et al.'s (2003) included adult children and grandchildren of *kaumātua* – some of whom worked together. Because care roles did not map neatly onto family role relationships, *whānau* members did not always understand how the support network was organised, leading to structural holes in care provision. Structural holes occur when individuals focus on activities *within* their groups at the exclusion of sharing information *between* groups, thereby creating gaps in information flow between the various groups (Burt 2004). This finding resonates with Tang et al.'s (2018) study of coordination failures and fault lines in nuclear families. Yet, we contend that the likelihood of structural holes within collective care systems such as the *whānau* support network increases due to its size and heterogeneous composition. Although *whānau* relational bonds are often close, *whānau* carers may be only loosely connected through their care and support of their older *whānau* member. Often, only primary carers and care organisers (care network members) could identify individual *whānau* members' contributions (Goldman 2016; Gutierrez and Ochoa 2021). Such gaps meant that over- or under-contribution became invisible to others within the support network.

Structural holes that prevent communication between *whānau* carers with complementary knowledge and experience of the care situation explain how *whānau* carers (*e.g.* assistants, helpers and monitors; Gutierrez and Ochoa 2021) act in information isolation without appreciating other *whānau* members' care work. As a result, *whānau*

carers experience stress and care activities may not be fully informed, although they aim to meet *kaumātua* needs. Another challenge related to the second finding was that role investment within the *whānau* varied considerably. Some *whānau* members chose a high level of involvement in the care network (*e.g.* primary carers), while others, who remained members of the *kaumātua*'s social network, did less than was needed. When these potential carers didn't step into the support or care networks, the *kaumātua* needs (*e.g.* Rawiri) or the primary carer's self-care (*e.g.* Tui) was negatively impacted. We suggest that potential care-givers who could have engaged in substitutive care but did not were unable to see care tasks performed out of sight, with negative consequences for primary carers.

The third finding demonstrated that *whānau* members outside the care network did not notice the specific content of primary carers' knowledge, preferences or self-care needs. We draw upon the invisible work literature to explore how the 'unseen' shaped primary carers' experience of care coordination within the *whānau* collective. Invisible work includes activities that are 'unrecognised [as work], unaccounted-for or taken-for-granted' (Vlasses 1997, 1). Even though some care tasks (*e.g.* Tiana's organising appointments and coordinating other *whānau* members) were invisible to the broader social and support network, primary carers were highly visible to those within the entire *whānau* network. Carers were not 'invisible workers' or non-persons (Poster et al. 2016). Monitors and helpers could identify the primary carer(s) in the care system, but they were often unaware of the time and effort carers invested in assisting with I/ADLs, emotional care and coordinating others' contributions unless primary carers confided in them.

Socio-spatial and temporal separation of care performed 'after hours' in out-of-sight, private and intimate spaces contributes significantly to care work's invisibility (Hatton 2017). Indeed, even primary carers reported that, because initial care responsibilities tended to be less demanding, they underestimated the range of care tasks at the outset (Suchman 1995). This was particularly the case for tasks such as 'organising work' (Allen 2014), coordinating (Tang et al. 2018) or 'articulation work … that gets things back "on track" in the face of the unexpected and modifies action to accommodate unanticipated contingencies' (Star and Strauss 1999, 10). In contrast, because all accepted the positive, relational aspects of care, helpers and potential carers often perceived primary care-giving as 'easy'. Primary carers thus engaged in invisible work insofar as others defined their care work as simple, routine and easy, although it required considerable knowledge and skill (Nardi and Engeström 1999).

Notably, a more expansive notion of care that foregrounds the cultural, emotional and spiritual dimensions of *whānau* care (see first finding) could reduce the recognition of the very real and tangible demands of physical care for the *kaumātua* (Macdonald and Merrill 2002). Invisibility based on lack of recognition had significant consequences for role allocation and care provision within the care system (Vlasses 1997). Because *whānau* helpers within the support network often believed that primary carers managed the care network very well without them, care responsibilities were not always collectively discussed and allocated (compare with Katz and Lowenstein's [2002] 'roundtable' pattern). Instead, some potential carers who stayed on the fringes in the social network refused to contribute (*e.g.* members of Tui's *whānau*; compare with Gutierrez and Ochoa's [2021] notion of 'outsiders'). In addition, several

primary *whānau* carers expressed difficulty organising substitutive care, where someone replaces the primary carer (Davis 1997). Faced with the *kaumātua*'s evolving care needs, talk about care responsibilities was often conflictual (*e.g.* Ani; Aasbø et al. 2017).

The third finding also indicated that some primary carers' self-care needs remained unseen within a collective care system underpinned by norms of love, care and respect (*aroha, manaakitanga, whakaute*). This lack of attention to primary carers' needs indicates that extensive 'social resources that stem from family ties' (Goldman 2016, 137) must be actively translated into supportive action for the *kaumātua* and those doing the heavy lifting. If latent ties within the social and support network are left to self-activate, the risk is that the norms of *whānau* care may inadvertently downplay the challenges when more support is needed.

Study strengths, limitations and directions for future research

This study's strengths are twofold. First, its culture-centred methodology, evidenced by engaging Māori interviewers and designing data collection for culture-centred participation, helped participants feel comfortable sharing the well-functioning and challenging aspects of care coordination. Second, the study problematises and overturns the binary distinction between 'collective' and 'individually oriented' care contexts that appear in much work about care-giver socialisation and care organisation. Context, cultural or otherwise, will always influence the complexities and dynamics of family care-giving. The findings show that some members within the collective care system simultaneously recognised *kaumātua* needs (a more 'collective' orientation) and their own needs (a more 'individual' orientation). In addition to contributing to our understanding of in/visibility of care-giving and structural holes within extended and pluralistic family care systems, these findings have practical implications. Regular *hui* (meetings), where current and potential carers within large collective care systems can clarify roles, identify and allocate tasks, and offer and receive support, are essential.

One limitation was that, because most participants came from different *whānau* care collectives, it was not possible to access multiple perspectives or explore similarities and differences in the experiences of *whanau* carers within the same *whānau* care collective. Thus, future research may focus on the similarities and differences within Māori *whānau*. A second limitation was that we did not include the perspectives and experiences of living *whānau* care recipients (those well enough to participate) within a *whānau* care collective. Third, because our sample contained only two men, we obtained more insight into how women *whānau* members experience care coordination within a *whānau* collective. Future research could focus more directly on the impact of gender on the experience of *whānau* care. Fourth, we did not specifically ask about *kaumātua* health conditions. As some health conditions (*e.g.* dementia) discourage family members from providing care, future research may also incorporate care recipients' health conditions in understanding how collectives negotiate family care. Such research is critical in the context of ageing populations where increased pressure is likely for families, community services and formal health support. Finally, in addition to studying strategies for bridging problematic structural holes in family collectives, it is vital to examine the transformative potential of caring for older family members in *whānau* and other family care collectives.

Conclusion

This study supports a Māori worldview of *whānau* care centred on *kaumātua* and carried out within care collectives built around *aroha, manaakitanga* and *whakaute*. The study highlights the existence of structural holes within collective care systems that prevent *whānau* carers from sharing their complementary knowledge and experience of the care situation. Such structural holes create obstacles to care coordination and the potential for primary carer invisibility. Addressing these questions will enhance *whānau* members' ability to care for *kaumātua*, primary carers and each other.

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