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Courtesy stigma and help-seeking delay among grandparents raising autistic grandchildren

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Abstract

Grandparent-headed households represent a growing yet understudied caregiving configuration within families affected by autism spectrum disorder (ASD). When grandparents assume primary responsibility for raising autistic grandchildren, they encounter a distinctive intersection of courtesy stigma and age-related service navigation challenges that may substantially delay help-seeking behaviours. This mixed-methods research investigated the relationship between courtesy stigma experiences and help-seeking delay among eighty-six grandparent primary caregivers of autistic children across Aotearoa New Zealand. Participants completed the Affiliate Stigma Scale, a purpose-designed Help-Seeking Timeline Questionnaire, and the Kessler Psychological Distress Scale. Semi-structured interviews were conducted with a purposive subsample of twenty-four grandparents to explore the mechanisms through which stigma influences service engagement decisions. Quantitative findings revealed that grandparent caregivers reported moderate to high levels of courtesy stigma, with affective and behavioural stigma dimensions demonstrating the strongest associations with help-seeking delay across diagnostic assessment ($r = 0.56$, $p < 0.001$), therapeutic intervention ($r = 0.48$, $p < 0.001$), and respite care domains ($r = 0.45$, $p < 0.01$). Multiple regression analysis indicated that courtesy stigma severity predicted help-seeking delay duration beyond the variance accounted for by psychological distress, socioeconomic status, and caregiver age (delta R-squared = 0.14, $p < 0.001$). Extended family members (31.4%) and community acquaintances (24.7%) constituted the most frequently identified sources of stigmatising encounters. Qualitative thematic analysis yielded four interconnected themes: anticipatory shame and social withdrawal, intergenerational blame attribution, navigating dual invisibility as both elderly and disability-associated caregivers, and protective concealment as a maladaptive coping strategy. These findings highlight the need for stigma-informed service design that explicitly addresses the unique positioning of grandparent caregivers within autism service systems, including targeted outreach strategies, peer support networks, and practitioner training to recognise and mitigate courtesy stigma effects on service access.

Keywords: Courtesy stigma, Grandparent caregivers, Autism spectrum disorder, Help-seeking delay, Affiliate stigma, Kinship care

Introduction

The increasing recognition of diverse family configurations within autism spectrum disorder (ASD) caregiving has drawn scholarly attention to grandparent-headed households, a caregiving arrangement that has expanded considerably over recent decades (Hillman *et al.*, 2019; Hillman, 2007) [1, 2]. Demographic shifts, including rising rates of parental incapacity related to substance use, mental health difficulties, incarceration, and mortality, have positioned grandparents as primary caregivers for a substantial proportion of children with developmental disabilities (Woodbridge *et al.*, 2011; Hastings *et al.*, 2002) [3, 4]. Within the ASD context specifically, grandparents may assume custodial responsibility due to the intensive caregiving demands that exceed parents' resources, or may gradually transition into primary caregiver roles as family structures evolve (Hillman *et al.*, 2019; Margetts *et al.*, 2006) [1, 5].

Despite the demographic significance of grandparent-led ASD caregiving, research examining this population remains notably sparse compared with the extensive literature addressing parental experiences (Hillman, 2007; Sullivan *et al.*, 2012) [2, 6]. The extant evidence suggests that custodial grandparents of autistic children face a confluence of challenges that differ qualitatively from those encountered by parents, including age-related health limitations, generational knowledge gaps regarding neurodevelopmental conditions, financial constraints associated with fixed retirement incomes, and social isolation from peer groups whose grandparenting experiences diverge substantially from their own (Hillman *et al.*, 2019; Woodbridge *et al.*, 2011; Margetts *et al.*, 2006) [1, 3, 5]. These factors collectively create a caregiving context in which the need for external support services is particularly acute, yet paradoxically, access to such services may be disproportionately impeded.

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Central to understanding the service access difficulties experienced by grandparent caregivers is the concept of courtesy stigma, originally articulated by Goffman (1963) [7] as the stigmatisation experienced by individuals closely associated with a stigmatised person. Contemporary formulations, particularly the affiliate stigma framework developed by Mak and Cheung (2008) [8], conceptualise this phenomenon as encompassing cognitive, affective, and behavioural dimensions through which caregivers internalise the societal devaluation directed toward their care recipients. The cognitive dimension involves endorsement of negative stereotypes about the condition; the affective dimension encompasses emotional responses including shame, embarrassment, and diminished self-worth; and the behavioural dimension manifests as social withdrawal and concealment behaviours (Mak *et al.*, 2008; Ali *et al.*, 2012) [8, 9].

Empirical evidence has established that stigma experiences among caregivers of individuals with developmental disabilities are associated with diminished psychological well-being, reduced quality of life, and compromised caregiving capacity (Werner *et al.*, 2013; Papadopoulos *et al.*, 2019; Broady *et al.*, 2017) [10, 11, 12]. However, the specific pathway through which courtesy stigma operates to delay help-seeking behaviour in grandparent caregivers has received minimal empirical attention. Theoretical models of stigma and service utilisation, derived primarily from mental health contexts, posit that anticipated stigma functions as a deterrent to help-seeking by increasing the perceived social costs of engaging with service systems (Corrigan *et al.*, 2002; Corrigan *et al.*, 2014) [13, 14]. For grandparent caregivers, these generic stigma processes may be compounded by additional dynamics, including intergenerational blame narratives that attribute the grandchild's condition to parenting failures, and a dual invisibility wherein both advanced age and disability-associated caregiving are marginalised within service structures designed for younger parents (Hillman *et al.*, 2019; Hillman, 2007) [1, 2].

The New Zealand context presents distinctive considerations for examining grandparent caregiver stigma and help-seeking. The whānau-centred orientation of Māori culture positions grandparental caregiving within a broader framework of intergenerational responsibility, yet encounters between indigenous caregiving models and Western disability service systems may generate additional friction points that influence stigma experiences and service engagement (Margetts *et al.*, 2006) [5]. Furthermore, New Zealand's geographic dispersal of specialist autism services creates practical barriers that interact with stigma-related avoidance to amplify help-seeking delays, particularly for grandparent caregivers in rural and semi-rural communities.

The present research addresses a significant gap in the literature by examining the relationship between courtesy stigma and help-seeking delay among grandparent primary caregivers of autistic children in Aotearoa New Zealand. Three research questions guided this investigation: first, what are the prevalence and dimensional characteristics of courtesy stigma experienced by grandparent caregivers; second, to what extent does courtesy stigma predict help-seeking delay across different service domains; and third, what mechanisms underlie the relationship between stigma experiences and service engagement decisions from the perspective of grandparent caregivers themselves.

Material and methods

This research employed a convergent parallel mixed-methods design, integrating quantitative survey data with qualitative interview findings to provide a comprehensive account of courtesy stigma and help-seeking delay among grandparent caregivers. The research protocol received ethical approval from the University of Canterbury Human Ethics Committee (Reference: HEC-2023/67) and complied with the Treaty of Waitangi principles of partnership, participation, and protection in the conduct of research with Māori participants.

Participants were grandparent primary caregivers recruited through autism service organisations, kinship care networks, grandparent support groups, and social media platforms across Aotearoa New Zealand. Eligibility criteria required that participants were grandparents serving as the primary caregiver for at least one grandchild with a confirmed ASD diagnosis, had held this caregiving role for a minimum of twelve months, and were aged fifty years or older. Primary caregiver status was defined as having the grandchild residing in the grandparent's household for a minimum of five days per week and assuming principal responsibility for the child's daily care, educational engagement, and therapeutic coordination. The final sample comprised eighty-six grandparent caregivers, with recruitment ceasing upon achievement of data saturation for the qualitative component and adequate statistical power for the planned quantitative analyses.

Quantitative data were collected through a structured survey battery administered either online or via postal questionnaire according to participant preference. The Affiliate Stigma Scale (ASS; Mak *et al.*, 2008) [8] was employed to measure courtesy stigma across its three subscales: cognitive (seven items), affective (seven items), and behavioural (eight items). Each item is rated on a four-point Likert scale ranging from one (strongly disagree) to four (strongly agree), with higher scores indicating greater affiliate stigma. The scale has demonstrated adequate psychometric properties in caregiver populations across cultural contexts (Mak *et al.*, 2008; Ali *et al.*, 2012) [8, 9]. The Help-Seeking Timeline Questionnaire (HSTQ), developed for this investigation, measured the duration in months between caregivers' initial recognition of concern regarding the grandchild's development and their first formal contact with services across five domains: diagnostic assessment, behavioural therapy, speech-language therapy, occupational therapy, and respite care. Content validity of the HSTQ was established through expert review by three developmental paediatricians and two experienced autism service coordinators, with pilot testing conducted among twelve grandparent caregivers not included in the main sample. Psychological distress was measured using the Kessler Psychological Distress Scale (K10), a well-validated ten-item measure of non-specific psychological distress.

Demographic data collected included grandparent age, gender, ethnicity, educational attainment, household income, geographic location, duration of caregiving role, and grandchild characteristics including age at diagnosis, current age, ASD severity level, and presence of co-occurring conditions. Reasons for assuming the custodial role were recorded through a categorical response item with an open-ended option for unlisted circumstances.

Semi-structured interviews were conducted with a purposive subsample of twenty-four grandparents, selected to represent variation in stigma severity levels, ethnic backgrounds, geographic locations, and grandchild characteristics. Interviews were conducted in participants' homes or via video conferencing according to preference, lasted between fifty and ninety minutes, and were audio-recorded with participant consent. The interview schedule explored experiences of stigmatisation in caregiving contexts, the influence of stigma on decisions regarding service engagement, coping strategies employed in response to stigmatising encounters, and perspectives on how services could better accommodate grandparent caregivers.

Quantitative analyses included descriptive statistics, bivariate correlations between stigma dimensions and help-seeking delay variables, and hierarchical multiple regression examining courtesy stigma as a predictor of help-seeking delay whilst controlling for psychological distress, caregiver age, socioeconomic status, geographic location, and grandchild ASD severity. Effect sizes were interpreted according to Cohen's conventions. Qualitative data were analysed using reflexive thematic analysis, with initial codes generated through line-by-line reading of transcripts, followed by iterative theme development through collaborative discussion between two researchers. Trustworthiness was enhanced through member checking with eight interview participants, peer debriefing, and maintenance of an audit trail.

Results

The sample comprised eighty-six grandparent primary caregivers with a mean age of 64.3 years (SD = 7.8, range 51-82). The majority were female (74.4%), identifying as New Zealand European (61.6%), Māori (23.3%), or Pacific Peoples (9.3%). Grandchildren's mean age

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at the time of data collection was 8.1 years (SD = 3.2), with 72.1% being male. The most common reason for assuming custodial responsibility was parental substance use difficulties (34.9%), followed by parental mental health conditions (24.4%), child protection intervention (18.6%), and parental death (8.1%). Mean duration of the custodial caregiving role was 5.4 years (SD = 2.9).

Descriptive analysis of the Affiliate Stigma Scale indicated moderate to high levels of courtesy stigma across the sample (total mean = 2.61, SD = 0.58, on a four-point scale). The affective subscale yielded the highest mean score (M = 2.84, SD = 0.63), followed by the behavioural subscale (M = 2.59, SD = 0.61) and the cognitive subscale (M = 2.41, SD = 0.54). The distribution of stigma sources identified by grandparent caregivers is presented in Figure 1. Extended family members were the most frequently reported source of stigmatising encounters (31.4%), followed by community acquaintances (24.7%), healthcare professionals (18.2%), and educational personnel (13.6%).

Table 1 presents demographic and clinical characteristics stratified by courtesy stigma severity. Grandparents with high stigma scores were significantly more likely to reside in rural locations, report lower household incomes, and care for grandchildren with higher ASD severity levels compared with those reporting low stigma. No significant differences were observed for caregiver age or gender across stigma severity groups.

Bivariate correlations between stigma dimensions and help-seeking delay variables are displayed in Figure 2. The affective stigma dimension demonstrated the strongest correlations with delay across all service domains, with the largest associations observed for support group avoidance (r = 0.62, p < 0.001), diagnostic delay (r = 0.56, p < 0.001), and therapy delay (r = 0.48, p < 0.001). Internalised shame showed a similar pattern, with correlations ranging from r = 0.45 to r = 0.67 across delay domains. The cognitive stigma dimension showed the weakest, though still statistically significant, associations with help-seeking delay.

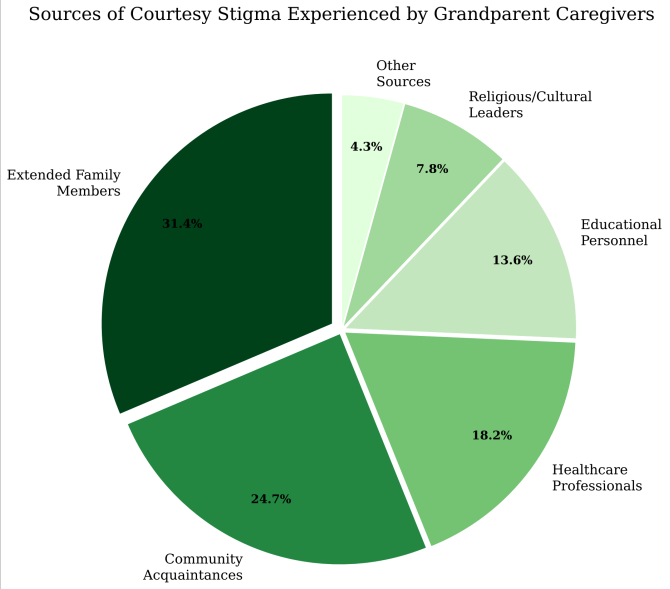


Figure 1. Distribution of Courtesy Stigma Sources Identified by Grandparent Caregivers

Figure 3 illustrates the relationship between stigma severity and help-seeking delay duration across service types. Grandparents in the high stigma group experienced markedly longer delays across all service domains compared with those in the low stigma group. The most pronounced differential was observed for respite care, where high-stigma grandparents delayed an average of 19.4 months compared with 6.3 months for low-stigma grandparents.

Table 1. Demographic and Clinical Characteristics by Courtesy Stigma Severity (* p < 0.05)

Characteristic	Low Stigma (n = 27)	Moderate Stigma (n = 38)	High Stigma (n = 21)
Age, mean (SD)	63.1 (7.2)	64.8 (8.1)	65.4 (7.9)
Female, n (%)	20 (74.1%)	28 (73.7%)	16 (76.2%)
Rural location, n (%)	6 (22.2%)	14 (36.8%)	12 (57.1%)*
Household income <$40K, n (%)	8 (29.6%)	16 (42.1%)	14 (66.7%)*
ASD Level 2-3, n (%)	11 (40.7%)	22 (57.9%)	16 (76.2%)*
K10 Distress, mean (SD)	18.4 (5.1)	24.7 (6.3)	31.2 (7.4)*

Hierarchical multiple regression examined courtesy stigma as a predictor of composite help-seeking delay (Table 2). In the first step, demographic variables (caregiver age, socioeconomic status, geographic location) and grandchild ASD severity accounted for 18.3% of the variance in help-seeking delay (R-squared = 0.183, F(4, 81) = 4.54, p = 0.002). The addition of psychological distress in the second step contributed an additional 8.7% of variance (delta R-squared = 0.087, p = 0.003). The entry of total courtesy stigma score in the third step explained a further 14.1% of variance beyond the demographic and distress variables (delta R-squared = 0.141, F-change(1, 79) = 18.62, p < 0.001), yielding a final model accounting for 41.1% of total variance. Courtesy stigma emerged as the strongest individual predictor in the final model (beta = 0.43, p < 0.001).

Table 2. Hierarchical Multiple Regression Predicting Composite Help-Seeking Delay (** p < 0.01, *** p < 0.001)

Model/Predictor	Beta	SE	p-value	R-squared	Delta R-sq
Step 1: Demographics				0.183	0.183**
Caregiver age	0.08	0.11	0.472		
SES	-0.22	0.09	0.018		
Rural location	0.19	0.10	0.061		
ASD severity	0.26	0.08	0.002		
Step 2: + Distress				0.270	0.087**
K10 Distress	0.31	0.08	0.003		
Step 3: + Stigma				0.411	0.141***
Courtesy stigma (ASS)	0.43	0.07	< 0.001		

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Qualitative analysis of grandparent interview transcripts yielded four interconnected themes. The first theme, "Anticipatory shame and social withdrawal," captured how grandparents progressively restricted their social participation in response to experienced or anticipated stigmatising encounters. Participants described avoiding public spaces, community events, and even family gatherings where their grandchild's behaviour might attract negative attention. One grandmother explained: "I stopped going to church because people would stare and whisper. I know they were thinking I had done something wrong to make him that way, or that his mother must have been on drugs, which she was, but that is not why he has autism."

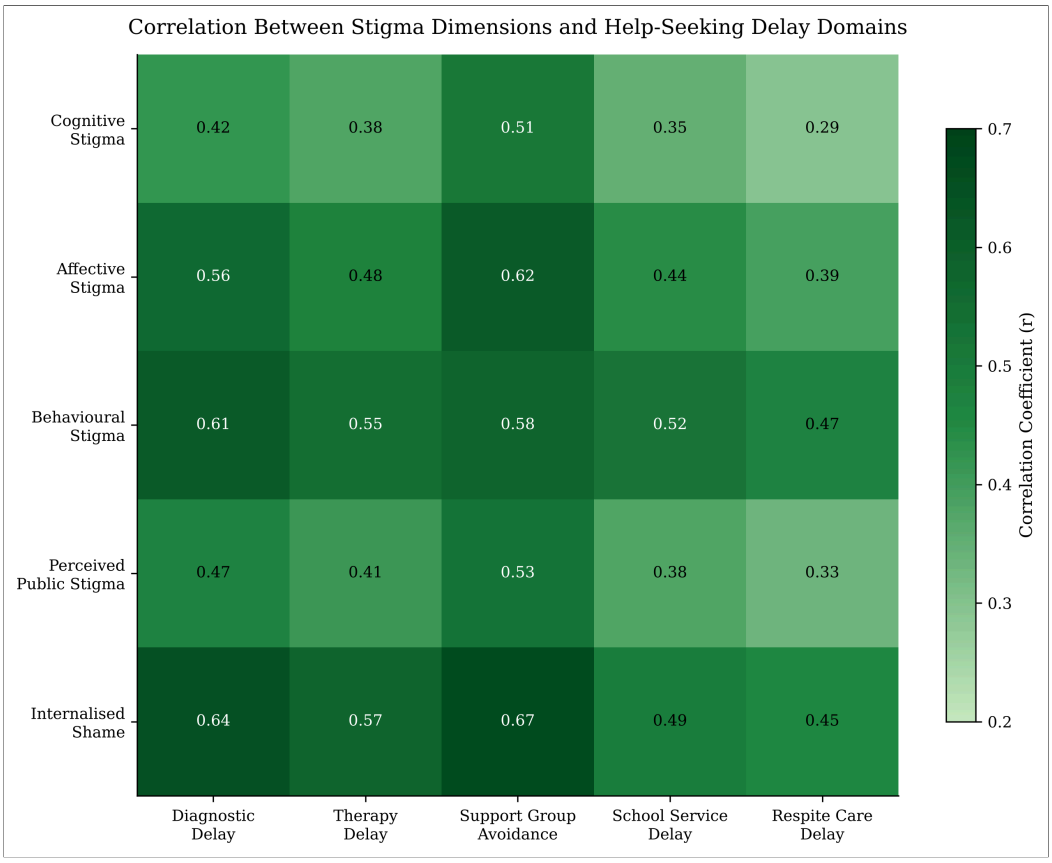


Figure 2. Heatmap of Correlations Between Stigma Dimensions and Help-Seeking Delay Domains

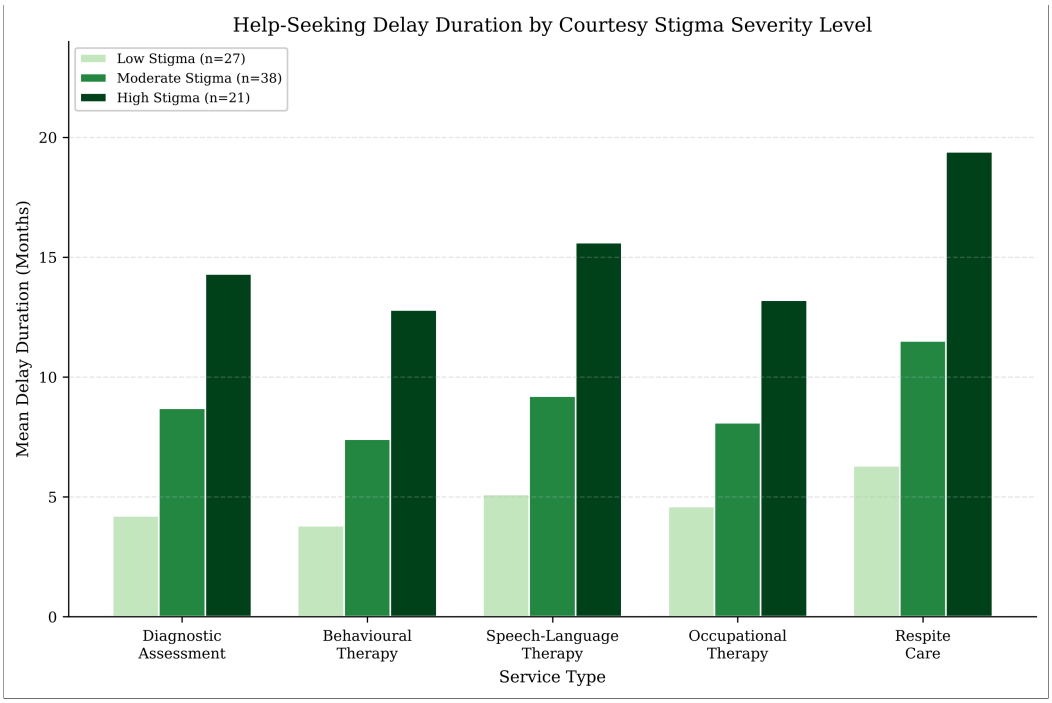


Figure 3. Help-Seeking Delay Duration (Months) by Service Type and Courtesy Stigma Severity Level

The second theme, "Intergenerational blame attribution," described grandparents' experience of being held personally responsible for their grandchild's condition through narratives linking autism causation to perceived failures in parenting the grandchild's parent. Grandparents reported encounters in which family members and community acquaintances suggested that their earlier parenting had contributed to their adult child's difficulties, which in turn led to the grandchild's developmental differences.

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The third theme, "Navigating dual invisibility," captured the intersection of age-related marginalisation with disability-associated stigma. Grandparent caregivers described feeling invisible within service systems designed for younger parents, whilst simultaneously experiencing heightened visibility as elderly individuals managing challenging behaviour in public contexts. A grandfather stated: "At the therapy centre, nobody expects you to be the main caregiver at seventy-two. They keep asking when mum is coming, and you have to explain again and again."

The fourth theme, "Protective concealment as a maladaptive coping strategy," described how grandparents strategically withheld information about their grandchild's diagnosis and their caregiving circumstances to avoid stigmatisation. Whilst providing short-term emotional protection, this concealment strategy directly impeded help-seeking by preventing disclosure of the grandchild's needs to professionals who could facilitate service access.

Discussion

The present findings demonstrate that courtesy stigma constitutes a substantive and independently significant barrier to help-seeking among grandparent primary caregivers of autistic children. The moderate to high levels of affiliate stigma reported across the sample, with affective dimensions predominating, accord with broader patterns observed in caregiver stigma research (Mak *et al.*, 2008; Werner *et al.*, 2013; Papadopoulos *et al.*, 2019) [8, 10, 11] whilst extending these findings to a previously unexamined caregiving population. The identification of courtesy stigma as a predictor of help-seeking delay, explaining fourteen percent of unique variance beyond demographic factors and psychological distress, provides quantitative evidence for a pathway that has been theoretically proposed but empirically underexplored (Corrigan *et al.*, 2002; Corrigan *et al.*, 2014) [13, 14].

The prominence of extended family members and community acquaintances as stigma sources carries particular implications for intervention design. Unlike institutional stigma, which can be addressed through professional training and policy reform, familial and community stigma operates within the grandparent caregiver's most proximate social environment, creating conditions that are both pervasive and difficult to remediate through conventional service-level interventions (Goffman, 1963; Broady *et al.*, 2017) [7, 12]. The qualitative finding that intergenerational blame attribution constitutes a distinctive stigma mechanism for grandparent caregivers extends existing conceptualisations of courtesy stigma (Goffman, 1963; Mak *et al.*, 2008) [7, 8] by identifying a form of stigmatisation that is structurally unique to skip-generation caregiving arrangements (Hillman *et al.*, 2019; Margetts *et al.*, 2006) [1, 5].

The dual invisibility experienced by grandparent caregivers represents a theoretically significant finding that has not been articulated in previous stigma or caregiving research. The simultaneous experience of being overlooked within youth-oriented disability service systems and hyper-visible as elderly individuals managing challenging behaviour in public spaces creates a paradoxical positioning that compounds help-seeking reluctance (Hillman, 2007; Woodbridge *et al.*, 2011) [2, 3]. This finding suggests that service systems may inadvertently perpetuate courtesy stigma through structural assumptions about caregiver demographics that exclude grandparent-headed households from routine outreach and engagement strategies (Hillman *et al.*, 2019; Wallace-Watkin *et al.*, 2023) [1, 15].

The identification of protective concealment as a dominant coping strategy among high-stigma grandparents has direct implications for clinical practice and service design. Whilst concealment provides temporary relief from stigmatising encounters, its operation as a help-seeking barrier creates a self-reinforcing cycle in which avoidance of disclosure delays access to services that could ameliorate both the grandchild's developmental difficulties and the grandparent's caregiving burden (Corrigan *et al.*, 2002; Corrigan *et al.*, 2014; Pescosolido *et al.*, 2010) [13, 14, 16]. Breaking this cycle requires service approaches that reduce the disclosure burden for grandparent caregivers, potentially through proactive outreach, referral pathways that do not require repeated narrative explanation, and peer support models that normalise help-seeking within the grandparent caregiver community (Papadopoulos *et al.*, 2019; Gardiner *et al.*, 2012; Angermeyer *et al.*, 2004) [11, 17, 18].

These findings should be contextualised within the specific cultural and geographic characteristics of the New Zealand service environment. The whānau-centred orientation of Māori culture, which positions grandparental caregiving as a culturally normative arrangement, may have moderated stigma experiences for the Māori participants in this sample (Margetts *et al.*, 2006) [5]. However, the intersection of cultural caregiving norms with Western disability service frameworks creates unique navigation challenges that warrant specific cultural consideration in service design. The rural-urban differential in stigma severity aligns with previous research indicating that geographic isolation compounds stigma-related barriers to service access in developmental disability contexts (Phelps *et al.*, 2009; Hastings *et al.*, 2002) [19, 4].

Ethical considerations

This research received ethical approval from the University of Canterbury Human Ethics Committee (Reference: HEC-2023/67). All participants provided written informed consent prior to data collection, with Māori cultural consultation conducted through the University's Ngāi Tahu Research Centre to ensure alignment with Treaty of Waitangi principles. Participants were informed of their right to withdraw from the research at any stage without consequence. Interview transcripts were anonymised, and all data were stored in accordance with the New Zealand Privacy Act 2020. Participants reporting elevated psychological distress scores were offered referral to appropriate support services.

Limitations

Several methodological limitations warrant consideration. The cross-sectional design precludes causal inferences regarding the directionality of the stigma-delay relationship, as grandparents who delay help-seeking may subsequently develop higher stigma through prolonged isolation from normalising service environments. The sample was recruited through organisations and networks connected to autism and kinship care services, potentially excluding the most severely stigmatised grandparents who are disconnected from such networks entirely. The Help-Seeking Timeline Questionnaire relies on retrospective self-report, introducing potential recall bias, particularly for grandparents with longer caregiving histories. The Affiliate Stigma Scale, whilst psychometrically validated, was developed for parents of individuals with intellectual disability and may not capture all stigma dimensions unique to grandparent caregivers. Finally, the sample size of eighty-six, whilst adequate for the planned analyses, limits statistical power for detecting smaller effects and precludes examination of potential interaction effects between cultural background and stigma processes.

Conclusion

This research provides the first systematic empirical examination of the relationship between courtesy stigma and help-seeking delay among grandparent primary caregivers of autistic children. The convergence of quantitative evidence demonstrating dose-response relationships between stigma severity and service access delay with qualitative insights into the experiential mechanisms of stigma-mediated avoidance offers a robust foundation for developing targeted interventions within this underserved caregiver population.

The findings carry several actionable implications for autism service provision. First, service systems should implement proactive identification and outreach strategies for grandparent-headed households, rather than relying on caregiver-initiated help-seeking that is demonstrably compromised by courtesy stigma processes (Hillman *et al.*, 2019; Hillman, 2007; Corrigan *et al.*, 2014) [1, 2, 14]. Paediatric and educational professionals should receive training to recognise the distinctive indicators of stigma-related service avoidance in grandparent

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caregivers, including delayed presentation, inconsistent engagement, and reluctance to disclose the caregiving arrangement (Papadopoulos *et al.*, 2019; Wallace-Watkin *et al.*, 2023) [11, 15]. Second, the development of grandparent-specific peer support programmes could provide normalising social environments that counter the isolating effects of courtesy stigma whilst simultaneously facilitating information sharing regarding available services (Sullivan *et al.*, 2012; Gardiner *et al.*, 2012) [6, 17].

Third, *anti*-stigma interventions targeting the broader community, and particularly extended family networks, represent a necessary complement to service-level modifications. The finding that family members constitute the primary source of stigmatising encounters suggests that psychoeducational approaches addressing intergenerational blame narratives and the neurobiological basis of ASD could meaningfully reduce the courtesy stigma experienced by grandparent caregivers (Corrigan *et al.*, 2002; Pescosolido *et al.*, 2010; Angermeyer *et al.*, 2004) [13, 16, 18]. Such interventions might be integrated into existing family therapy or mediation services accessed by grandparent-headed households navigating custody arrangements.

Fourth, service intake processes should be redesigned to minimise the repeated narrative disclosure that grandparent caregivers identified as a significant deterrent to service engagement. Consolidated referral pathways, shared assessment documentation across service providers, and designated grandparent liaison roles within autism service organisations could collectively reduce the disclosure burden that amplifies stigma-related avoidance (Phelps *et al.*, 2009; Corrigan *et al.*, 2014; Wallace-Watkin *et al.*, 2023) [19, 14, 15]. The cultural competency of these modifications should extend beyond generic cultural sensitivity to incorporate specific understanding of how intergenerational caregiving norms, including whānau-centred Māori frameworks, intersect with Western disability service paradigms.

Future research should examine the longitudinal trajectory of courtesy stigma in grandparent caregivers, including whether stigma intensity diminishes as familiarity with diagnostic terminology and service systems increases. Intervention research evaluating the effectiveness of grandparent-specific peer support programmes and *anti*-stigma educational initiatives would provide the evidence base required to justify targeted resource allocation. Cross-cultural comparative investigations would establish the extent to which the present findings generalise beyond the Aotearoa New Zealand context, particularly regarding the cultural mediation of stigma processes in skip-generation caregiving arrangements (Ali *et al.*, 2012; Werner *et al.*, 2013; Broady *et al.*, 2017) [9, 10, 12].

The growing demographic reality of grandparent-headed households within the autism community demands a corresponding evolution in service design that acknowledges and addresses the courtesy stigma these caregivers experience. The evidence presented here demonstrates that failure to accommodate the distinctive needs and barriers facing grandparent caregivers carries measurable costs in delayed service access, with downstream consequences for both grandchild developmental outcomes and grandparent well-being (Mak *et al.*, 2008; Hillman *et al.*, 2019; Gardiner *et al.*, 2012) [8, 1, 17]. Recognising grandparent caregivers as a population requiring targeted, stigma-informed support represents an essential advancement in the pursuit of equitable autism service provision.

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