

'It's not fair': Custodial grandparents' access to services and supports in Australia

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Abstract

Grandparents become custodial carers of their grandchildren for a variety of reasons, including love, fear of losing the children to the system, efforts to protect children while managing relationships with the adult child (parent), policy impetus, and even for the convenience of child protection systems. As obvious candidates for care provision, grandparents report feeling pressured to take on care, and yet many grandcarers are poorly supported and feel taken for granted. Drawing on a mixed method study of grandparent carers and service providers located in Western Australia, we argue that there are important issues of inequity and injustice associated with being a grandcarer, in particular due to systemic and discursive failures to recognize the complexity and challenges of care provision. Misrecognition and epistemic injustice result in further marginalization and disempowerment, compounding barriers to accessing services and supports, which in turn impact upon child and family wellbeing. The aim of this article is to analyse the complex circumstances described by grandcarers and service providers in interview and survey data, highlighting issues of inequity and injustice and therefore areas for improving policy and services to support grandfamilies.

KEYWORDS

carer support services, grandcarers, grandfamilies, inequity, kinship care, social justice

1 | INTRODUCTION

Grandparents with full-time care of their grandchildren (grandcarers) are a growing group of kinship carers in Australia and worldwide; a hidden and marginalized group whose needs are often overlooked in policy and practice (Backhouse & Graham, 2012; Gair et al., 2018; Simpson & Lawrence-Webb, 2009; Tarrant et al., 2017). In Australia, grandparent-headed families (grandfamilies) form the majority of formal and informal kinship care arrangements, with over half (52%) of Australian children in out-of-home care formally placed with their grandparents (Australian Institute of Health and Welfare, 2018). Similarly, in the United Kingdom, 83% of 1114 kinship carers surveyed were grandparents who took on the role, primarily at the request of social workers due to parental substance use (Grandparents Plus,

2019). Many more children are in informal kinship care; that is, kinship care that is not formalized through a statutory agency or court order (Kiraly, 2019). Kinship and grandparent care are increasingly the preferred placement outcome for statutory authorities for a range of reasons, primarily due to perceived positive impacts on grandchildren and for care continuity, including contact with siblings and extended family (Kiraly, 2015).

The impact on grandparents of providing care is detailed extensively in the literature, especially in relation to their physical and mental health and wellbeing (Kiraly, 2015; Taylor et al., 2016; Taylor, Marquis, Coall, Batten, et al., 2017). However, discussion of inequity and/or injustice is glaringly absent, despite evidence of intersectional experiences of poverty, isolation, disadvantage and marginalization associated with socio-economic and legal (formal or informal carer)

status, gender, culture and racial identity (Duckett, 2011; Hingley-Jones et al., 2019; Simpson & Lawrence-Webb, 2009). In particular, experiences of significant financial disadvantage (Tarrant et al., 2017) are seen to exacerbate negative impacts on child and carer wellbeing, resulting in further social isolation and compounding the challenges of accessing support (Taylor et al., 2020). Grandcarers who do not have legal status as formal carers have been identified as facing significant hardship, including financial disadvantage and difficulty accessing services (Duckett, 2011; Grandparents Plus, 2019; Hingley-Jones et al., 2019; Kiraly, 2019; Simpson & Lawrence-Webb, 2009). More recently, there is also growing recognition of grandcarers' resilience (Hayslip & Smith, 2012) and the rewards and enjoyment they experience through their caring role (Kiraly, 2015).

Grandcarers' experiences of social isolation arising from care responsibilities and concomitant disconnection from friend and social networks is reported as a key area of impact (Baldock, 2007). Isolation can arise as a result of role conflict (Taylor et al., 2016), and from caring for children with disabilities (Hillman & Anderson, 2019). There are also increased impacts on some cohorts, such as younger grandcarers whose paid work responsibilities prevent them from accessing social support groups (Brennan et al., 2013). Stigma and feelings of shame associated with the absent birth parents or the birth parents' substance use (Baldock, 2007; Taylor, et al., 2016) or incarceration (Greeling, 2017) can lead to and/or further exacerbate isolation. The positive effect of social support (from friends and family) on health is evidenced in the literature as improving health and lessening stress, which in turn may prevent depression (Hayslip et al., 2015). However, not all grandcarers have the social capital to access formal social support, and support from relatives may pose additional challenges, including stress related to contact with birth parents (Taylor et al., 2020).

Another key theme in the literature is the financial impact of caring; here the focus is on the existence of financial difficulties or stress incurred as a result of caring responsibilities, without locating these as sources or examples of inequity. For example, Bailey et al. (2013, p.671) refer to the 'economic bind' experienced by rural North American grandcarers, highlighting the help they need to 'navigate these new financial waters'. Simpson and Lawrence-Webb (2009) report the financial difficulties experienced by African-American grandmothers who are informal kinship carers, and flag the disparity of resource distribution between formal and informal carers, but like much of the literature, focus on identifying service and support needs. Langosch (2012) observes that, despite significant cost savings for the US government, grandparents receive very little financial assistance; Langosch, too, focuses on clinicians understanding grandcarers' situations and the general need for more coordinated and specialized care.

The influences and experiences of poverty are also well-documented in the literature: Dolan et al. (2009) note that grandmothers were more likely to be living below the poverty line in the US than foster carers. Bachman and Chase-Lansdale (2005) compared mothers and grandmothers and found that the financial impact was the highest for younger low-income grandmothers and those who accessed

social support. Park (2009) found that poverty had a negative impact on grandcarer's psychological health, and Kelley et al. (2000) suggest that an improvement in the financial situation for grandmothers could lessen psychological distress. When considering the impacts of poverty, race is an important intersecting factor. Kelch-Oliver (2011) and Nwokeji (2009) both report that poverty was often a factor in African-American grandmothers needing to take on care of grandchildren, and remained a significant source of distress for African-American grandfamilies. Mendoza et al. (2018) reviewed the published research on Latino grandparents' challenges and strengths and remarked that, although the influence of poverty is discussed, there is insufficient evidence regarding existing and potential outcomes of financial assistance. Although concerned with grandfamilies' experiences of disadvantage and the importance of addressing these issues, injustice and inequity are not discussed explicitly in any of these articles, rendering these concepts invisible in this key area of literature.

Increased 'burden of care' impacts upon diverse sub groups are identified in the literature; for example, those with low incomes may face significant financial burdens when caring in the context of parental substance use (Taylor, Marquis, Coall, & Wilkinson, 2017). Children's disability as a factor is also reported, for example, the stressors of caring for children with autism spectrum disorders are identified as a predictor of caregiver distress (Hillman & Anderson, 2019). The need for interventions which recognize and address grandcarers' unique and contextualized needs is clearly acknowledged. For instance, Kaplan and Perez-Porter (2014) note the importance of a 'mosaic of intervention strategies' to address financial (and other) challenges.

Despite the extensive international literature detailing the challenges they face, grandfamilies, as a family unit, remain largely unrecognized within policy frameworks (Gair et al., 2018; Kiraly, 2019; Simpson & Lawrence-Webb, 2009) and service design and delivery fails to adequately address their diverse needs. This is particularly pronounced for families with complexity in their circumstances, including informal grandcarers (Kiraly, 2019). Although improving support for kinship carers has been identified as a priority for policy reform (Kiraly, 2019), grandfamilies' lived experiences of injustice, inequity and misrecognition are often not explicitly captured in literature, policy, or practice. In this article we aim to outline the needs and experiences of grandcarers in Western Australia, drawing on research conducted with grandcarers and service providers. Additionally, we identify the barriers to accessing support reported by both grandcarers and service providers. Our analysis foregrounds issues of inequity injustice (Bauer, 2014), and misrecognition (Fraser & Honneth, 2003). We draw on Miranda Fricker's (2007, p.1) notion of epistemic injustice, that is, 'a wrong done to someone specifically in their capacity as a knower'. We ground our analysis in the impact upon grandfamilies, in terms of barriers and enablers to service access. We then consider implications for practice and suggest areas for future focus in policy and practice development. Our hope is that through purposeful examination of the inequity and injustice inherent in grandfamilies' experiences, equity and justice in policy and service provision can be promoted (Bauer, 2014).

2 | METHOD

The overarching research project, conducted in partnership with Edith Cowan University (ECU) and industry partner Wanslea, focused on an examination of the experiences and needs of grandcarers and their grandchildren. Our nested study sought specifically to explore Western Australian (WA) grandcarers and service providers' perceptions of the barriers and enablers in service provision. Data included in this article are drawn from interviews and focus groups with service providers, and interim findings from a grandcarer survey conducted by ECU. The grandcarer survey sample includes both formal grandcarers and those without a formal care arrangement.

Ethical approval was received from Curtin University Human Research Ethics Committee (approval number HRE2018). A Grandcare Research Working Group, which included representatives from the research partners and key service stakeholders, an Aboriginal elder and two grandcarers, guided the project, and 236 grandparent carers participated in the survey conducted by ECU (Coall et al., 2018, unpublished data). For this article, selected data on grandcarers' experiences, needs and health from the survey were analysed by the ECU team. Data from service providers were collected via audio recorded and transcribed interviews (60–75 minutes) and focus groups (120–150 minutes). Sixty-nine participants representing 37 organizations participated in a total of 29 interviews (some group interviews) and nine focus groups across metropolitan and regional locations.

Transcripts were thematically analysed using Nvivo (v.12), following the method outlined by Braun and Clarke (2006) and are discussed drawing on a framework of critical social theory. A methodological audit trail was used to record key decisions and progress of the analysis (Bowen, 2009). Reflexivity through intentional group reflection was undertaken to more deeply understand and therefore mitigate any impacts of prior experiences and assumptions influencing interpretations within this project (Kitto et al., 2008). Trustworthiness of the analysis findings was established through triangulation between research team members, as coding categories were first discussed and then agreed upon. Quantitative data from the Grandparent Health and Wellbeing Survey were analysed using SPSS. Descriptive statistics were calculated to summarize the data.

3 | FINDINGS

This study identified a number of intersecting barriers to service access and highlighted grandcarers' experiences of misrecognition, injustice, and inequity; particularly for those who lack formal carer status. Shame, stigma, distrust of systems, and culturally inappropriate responses compound the marginalization of grandfamilies. In this section, barriers are first discussed, followed by enablers.

3.1 | 'I never knew you existed'

Grandfamilies' poor access to services was characterized by the following: a scarcity of grandfamily-specific services; a lack of

knowledge by grandfamilies and service providers about service options; and finally, inaccessible service access-routes. This service knowledge gap was not confined to grandcarers; service providers similarly noted their own lack of knowledge of grandcarer-specific services.

Service providers spoke of seeing grandcarers being overwhelmed with a new and demanding set of responsibilities in a completely different environment to that in which they raised their own children, and the negative impact of this on service access. Although cognisant of their needs, grandcarers may not have accessed some potentially helpful services because they had little or no knowledge about available services or their eligibility to access these services:

I think because of their age, they don't know where to go, because they never had to contact a service provider for any assistance while they were bringing up their own children. Suddenly having to look after their grandchild, it's: "Where do I go, who do I contact, where do I start looking for assistance, some support?" (Service Provider)

Information was not easily available, which intersected with both a lack of time and resources to 'run around and look':

One of the ladies who came yesterday said, "I've been raising my grandchild for four years, I never knew you existed until I heard you on the radio." It's just not out there in the community. (Service Provider)

Additionally, most information is increasingly online and grandcarers' digital literacy, time and capacity challenges - at a time when they are often already overwhelmed with their care responsibilities - exacerbate poor access to services and support. Indeed, digitally literate grandcarers may not have the financial capacity to purchase computers and other related items to access online services.

Service providers and grandcarers noted a lack of grandfamily-specific services, as well as complications created by the separation of formal and informal carers. This resulted in a feeling of not 'fitting' anywhere:

I was informed that grandparents who are through [the child protection authority] were not very welcome at the [grandparent peer support] group. I really wanted to form friendships with grandparents in a similar situation as I feel isolated from people our age who don't face our challenges of raising a child. I would have been grateful for the support of friendship as there is no grandparent support group run by [the statutory child protection authority]. (Grandcarer)

Service providers were frustrated by the scarcity of funding to provide targeted, grandcarer-specific services. They observed that

grandcarers' ability to make-do with little was an unrecognized strength; however, they were aware of their own limitations to support grandfamilies financially due to the paucity of funds available:

They know how to manage their money ... So we just need the money to help them. The funds to help them.
(Service Provider)

3.2 | It's just not fair

Similar to other jurisdictions such as the United Kingdom, the current Australian system remunerates foster carers and grandparents with formal custody; however informal grandcarers, who provide the same care activities, are not financially compensated for their care activities. This was clearly identified as unjust and requiring review as grandcarers were perceived as being taken for granted and denied financial recognition and remuneration. Grandcarers in the ECU survey identified 'the same financial compensation as foster carers', 'Centrelink assistance' and 'recognition as a carer' as essential to support their care provision. One grandcarer interviewed contrasted this care and the fiscal savings for the state:

Our grandchild has the highest level of needs and if in care the amount of funding required to care for him would exceed \$150.00 per hour 24/7.... Stop the inequity for self-funded retirees as grandparent carers. Enable the grandchild/ren to receive the funding in their name rather than means testing the grandparents as it now is. The current system is inequitable.
(Grandcarer)

The manner in which grandchildren entered grandparents' care was also identified as a source of inequity. Grandcarers assume caring responsibility for a number of reasons, but some reported feeling unable to say no due to the pressure placed upon them by statutory agents, family, and societal care expectations. Feeling 'emotionally blackmailed into the situation' was reflected in this comment by a service provider about the ways in which the statutory child protection agency was seen to have relinquished responsibility for care of the grandchildren once safety was established:

I can think of 30 or 40, they have been coerced into taking their kids by Child Protection and then Child Protection will not give them a cent. They'll say, "The kids are safe with you" Now these grandparents are being rung up at 10 o'clock at night, "Can you go and pick up the kids? The grandkids are in immediate danger" "So we go and we pick them up", and then [the Grandparents will contact] Child Protection and say, "Well, can you help me out?" "Oh sorry, they are safe now. We closed the case." (Service Provider)

Some service providers spoke about the cultural obligations and responsibilities of Aboriginal grandcarers who also felt compelled to take responsibility:

... the other thing is that they wouldn't have it any other way, but culturally they actually don't have a choice. They have a responsibility to those children, so even if they're worn out and tired and really overwhelmed, they still have an obligation to take those children, so they wouldn't complain about it and they don't. (Service Provider)

Grandcarers are often denied real choices, and the aforementioned quote highlights how familial and cultural obligations can be exploited by the system. Although these emotional, relational and cultural complexities might be implicitly understood by service providers, they are nonetheless often constrained by the structures of an inequitable system, which disempowers grandcarers and those who seek to support them.

3.3 | Invisibility and misrecognition

Grandfamilies are largely hidden from view of services: even the most dedicated service providers had difficulty identifying numbers of grandfamilies accessing their services, and were uncertain whether some grandcarers were formal or informal carers. Grandcarers felt unsupported: of the 236 ECU survey respondents, 51% ($n = 113$) of those who answered the question identified that they had received no practical, hands-on help from services and 15% ($n = 32$) reported unhelpful assistance. Social networks were no help in terms of practical assistance for 54% ($n = 121$) of grandcarers. A lack of specific services results in grandcarers trying to navigate generic services which often did not meet their contextualized needs or provide pathways for them to access resources and support. In these ways, invisibility and misrecognition within service systems results in marginalization and disempowerment for grandfamilies.

In addition, conventional methods of parental engagement and support such as playgroups and parenting classes may not suit grandcarers:

... some of the grandparents that I've spoken with find it really difficult, energy-wise, to engage. They are parenting again, it depends on how many grandchildren they are looking after as to how engaged they can be with the different things on offer. I'm not sure whether visits at home would be more useful rather than grandparents trying to cart three under three [years old] to a playgroup (Service Provider)

Even respite, which is a conventional support provision for other types of carers, was not readily available. This disparity was noted by service providers: '... respite in aged care is a lot more open' as was the importance identified by grandcarers of alleviating stressors on the grandfamily as a whole: '... so the child can have a break from us

and us from the child'. Available services were sometimes difficult for grandcarers to access due to the realities of their lives as carers; a service provider provided an example of a grandparent-specific play-group that non-custodial grandparents could access but grandcarers with full-time caring responsibilities could not, due to their caring commitments. This highlights the inequity of a system that excludes those who most need support.

3.4 | Complex family situations

Invisibility and misrecognition for grandcarers is also evident in a lack of acknowledgement of the complex reasons grandcarers may not seek formalization of their carer status. The complexity of family relationships is not well recognized by current systems and may create further danger for grandfamilies. Ostensibly straight forward responses, such as formalizing care responsibility via the legal or child protection system (registering as a kin foster carer), are not clear-cut options due to the potentially destructive interaction and communication with the grandchildren's parents. Fear of potential repercussions on the children were highlighted:

Many grandparents are being threatened by their children that if they seek to take the Commonwealth childcare allowance, to support the kids, they'll [the parents] try and get the kids back or they will create an issue. (Service Provider)

Legal processes could also be lengthy, intrusive and risky in relation to continuity and stability for the grandchildren. For example, a service provider spoke of grandchildren being placed into out-of-home care during complex foster care assessment processes. Confidentiality concerns were a barrier to service access; grandcarers were concerned that help-seeking could result in agencies inadvertently providing information that could compromise the grandchildren's safety. In cases involving violence, aggression and intimidation, there could be anxiety about the adult child or their partner being able to find out about agency involvement, which could then put the grandcarer or the child/ren at risk of harm. Fear of potential repercussions or retribution from their children if they try to access financial support linked to formalized custodial care can be paramount for grandcarers. As the potential return of children to the parents could put the grandchild's safety at risk, grandcarers sometimes then avoided attempts to access remuneration via formalized grandcaring status.

3.5 | Shame, stigma and distrust

Service providers were aware of the impact of shame, and reflected on how it might influence grandcarers engagement with services:

You know, it's not easy to have to ring somebody to say, "Look I'm caring for my grandchild because my

adult child isn't doing it or can't do it". Or was doing it poorly. (Service Provider)

Stigma was associated with using some services, with 39% ($n = 198$) grandparents identifying it as a key impact, including judgements around their parenting skills:

Fancy giving the grand kids to grandparents. They did a lousy job of their own kids now they get a second chance to wreck the grand kids. (Grandcarer).

Grandcarers' shame at feeling judged was a factor in reluctance to self-identify or access services. Service providers also spoke about a lack of cultural understanding in some services, and how difficult it can be for Aboriginal grandcarers to access services:

Like the shame factor, embarrassment, all of that kind of stuff. Then they've got the whole history of Aboriginal people and probably a lack of understanding within the white community, lack of cultural awareness, and all the rest that goes with it. It's quite complex. (Service Provider)

The influence of shame affects grandcarers' sense of safety and trust, and was particularly debilitating in culturally and linguistically diverse (CaLD) communities. Even with trust in a service, barriers to communication arose because of lack of trust in interpreters' confidentiality and the fear of stigmatization within communities should privacy be breached:

And I have one family that I look after, there's 14 people in the family, and every time I say, "Oh can we get a-", "Oh no, don't get an interpreter", "because somebody would - they might know us. We cannot lose face, we can't do this." (Service Provider)

Grandcarers living with their children and grandchildren were unable to talk openly about the extent of their hidden care-giving role, for a range of reasons, including shame and stigma. 'Tradition' contributes to systemic inequity because grandcarers do not feel comfortable to speak out about their situation:

... too many Asian grandparents living with violence and "shame" because traditionally you cannot "dob in" a son or daughter. (Grandcarer)

3.6 | Culturally insecure services, racism and intergenerational trauma

Aboriginal grandcarers were identified by service providers as one of the largest groups of grandcarers, especially in rural and remote areas. However, these grandcarers often do not access mainstream services

and supports, as they do not feel comfortable using them and/or language and cultural needs were not recognized sufficiently within available services. This was described as being related to several different factors, including intergenerational trauma from Stolen Generations practices and consequent distrust of specific services, as well as language and cultural barriers. The 'Stolen Generations' refers to the removal of Aboriginal and Torres Strait Islander children from their families by government agencies and church missions between the late 1800s and the 1970s under assimilation policies, and is source of significant ongoing trauma for Australia's Indigenous peoples (Department of Health, 2016). Many service providers were aware of these issues and spoke about the effect of intergenerational trauma and the grandmothers who are 'looking after little ones and doing their very, very best'. Experiences of historical and current racism were acknowledged as affecting access to services, especially statutory child protection authorities and government departments:

Aboriginal people won't necessarily want to contact the Department for Child Protection. We have a history. We were Native Welfare. Our history has stolen generations. So, they will try to cope in tremendously difficult circumstances. Things have to be really dire before they contact us. Or they're really, really worried about their grandchildren. (Service Provider)

One regional participant relayed that fears of child removal and the perception that child protection services still frequently took Aboriginal children away from their families:

... that does happen, especially up here. DCP [the state child protection agency] will then swoop in. They'll go, "Well, the mother's not here." Even though the child's in the grandparents' care, they'll still come and take their child to put it into the care. (Service Provider)

3.7 | Enablers to accessing services

A number of key enablers were identified to address the barriers identified above, including the development of a central access point with enhanced service integration and collaboration. Consideration of equity in a number of areas is essential, including provision of culturally relevant and appropriate material, resources and services, especially practical support, regardless of carers' formal or informal status. Improving dissemination of information in accessible forms is also necessary to address epistemic injustice; in this instance, hermeneutical epistemic injustice (Fricker, 2007), as grandcarers are disadvantaged through the inaccessibility of crucial knowledge.

The support service deemed most useful by grandcarers was an organization funded specifically to support grandcarers, with a specific focus on informal grandcarers. In the ECU survey, personal social and family networks (39.4%; $n = 87$) and the grandchildren's school (9.5%) were also deemed important. Although a wide range of services were

identified as being helpful, 3.2% of grandcarers surveyed indicated that they had no experience of useful services or supports. This speaks to the diverse needs of grandfamilies, and the need for versatile and diverse services in order to meet their needs.

Grandcarers and service providers were united in their call for a simplified service system with more accessible information about available supports. Service providers recommended that service delivery could be significantly aided by simplifying access to relevant information and having transparency and clarity in service availability and eligibility criteria. A central access point was proposed:

Having a "one-stop shop" that can be contacted for all the information would be wonderful. This would mean that carers can access whatever is available and not miss any resources on offer. (Grandcarer)

Although grandcarers' limited ability to access online information was noted as a barrier, the economic and functional imperatives around digital access were acknowledged: this could be the 'one door' for grandparents who do have the ability and skills to access online material. However, online information can only be one part of integrated service delivery, not a mode in itself:

Online information is great. But it can only part of a toolkit. It can't be the toolkit. Because often all it does is raise further questions and then "Where do you go?" (Service Provider)

Sharing of information between service providers was noted as a facilitator of service engagement and cooperation. Additionally, flexibility within the funding system to allow for more complex situations was noted as enabling agencies to help grandcarers. This highlights how grandcarers' knowledge of and access to services, as well as service provider's ability to refer appropriately, hinged on effective collaboration between services. Metropolitan service providers spoke about the 'siloed' nature of service provision and suggested that more collaboration was required between services and education and that a more holistic approach was needed to address the overlapping needs of grandparents and grandchildren. Working collaboratively was described as benefitting organizations and grandcarers on many levels:

I wouldn't be able to survive without other organisations. I tap into whoever I need to get what my granny needs. (Service Provider)

Collaboration was a broad term for a range of processes and alliances between government, non-government, consumer-led organizations and community, and included: organizations working together to provide services, service coordination, smoother referral processes, consumer and non-government organizations collectively advocating around issues affecting grandcarers or providing respite, and the creation of programs that reflected joined up service delivery. The

importance of relationship and consistency were noted by service providers: 'Taking time to have a cup of tea and get to know each other' and 'We talk about partnership and we write in your documents that talk about partnership but it's actually getting out there and doing that partnership work'.

Collaboration could also involve a smooth 'back and forward' process of referrals where each person knew and trusted the other. Although there was some collaboration occurring, this sat alongside a lack of communication between services and within departments:

... people think the government talk to each other.
We can barely speak to the other side of the floor.
(Service Provider)

Although fewer services were available overall in regional areas, they were often found to work well together, with formal collaborative groups a '... movement in the right direction', because bringing people together can surface opportunities for further development and collaboration. This kind of collaboration and reflexivity exemplifies service providers' efforts to find creative solutions and meet grandcarers' needs despite the challenges of working in a system which does not currently recognize or respond well to the challenges faced by grandfamilies.

4 | DISCUSSION

The experience of caring for one's grandchildren on a full-time basis is a demanding, difficult and often unsupported experience, but one that also brings joy and love. We frame grandcarers' experiences as an issue of inequity and argue that informal carer status intersects with other aspects of identity and positionality, including race, culture, and experiences of colonial trauma. Grandcarers' socio-economic status, ability to access social capital, and their own and grandchildren's health needs also contribute to experiences of disempowerment and marginalization, leaving many families isolated and unsupported. Discussion of inequity and injustice is often partial and neglected in the literature; we propose that the inequity discussed in this article highlights a need for urgent policy reform.

The lack of accessible information for grandcarers results in systematic hermeneutical epistemic injustice (Fricker, 2007), whereby grandcarers are excluded from accessing the knowledge that they need to navigate complex systems and have their needs met. Grandcarers, the majority of whom are older women, are also assigned a 'deflated level of credibility' (Carel & Kidd, 2014, p.531) resulting in testimonial injustice (Fricker, 2007) and a lack of a collective understanding of the inequitable circumstances in which they provide care. Grandcarers are often excluded from representation in knowledge held by service providers, as exemplified in the lack of systematic data collection regarding this group. Grandcarer's invisibility is a form of misrecognition (Fraser & Honneth, 2003), which compounds inequity by creating further barriers to service access, as services and pathways to access support are not attuned to the needs and capabilities

of grandcarers. It also results in exclusion from many of the benefits associated with being a valued citizen in the community, including access to power, material resources and legal security (Fraser & Honneth, 2003). To remedy this injustice, grandcarers – and particularly informal grandcarers – must be recognized in structural as well as representative ways, including through the redistribution of resources such as financial support and legal status (Fraser & Honneth, 2003), and improved access to epistemic resources.

The widespread effect of intergenerational trauma from the impact of colonization, institutional racism and the Stolen Generations on Aboriginal grandcarers is identified as a key factor influencing grandcarer's service access, in our and other research (Gair et al., 2018). Indigenous and CaLD participants in this study described ambivalence about engaging with child protection and welfare authorities, due to shame, stigma, and understandable mistrust of authorities. Research shows that similar issues exist for grandparent carers in other countries; particularly those with intersectional disadvantage related to poverty, ability, race, and informal caregiver status (Bertera & Crewe, 2013; Grandparents Plus, 2019), and yet understanding of the cultural aspects of grandcarers' experiences is largely absent from policy and service design (Valentine et al., 2013).

This study also highlights the importance of understanding the emotional and relational contexts of grandparent care, as fear and shame were reported as having significant influence on grandcarers' engagement with services. Grandcarers are a unique and heterogeneous group with diverse experiences: they are not homogenous in identity, position, or experience, and they are not simply 'parenting again'. We argue that developing deeper understanding of grandcarer's emotional and relational concerns and a nuanced understanding of grandfamilies contextualized experiences - including exploring the position of children's birth parents in the family dynamic - is essential to attuned practice in this area.

5 | CONCLUSION AND IMPLICATIONS FOR PRACTICE

Grandcarers' invisibility and poor access to services are clear challenges for practice: the lack of legal and financial recognition for informal grandcarers is a potent challenge for a number of reasons, not least in terms of the striking financial inequity with foster carers and formal kinship carers, the fiscal savings from which are significant. This financial inequity could be addressed through policy reform to create more flexibility in funding models, and increased recognition and support for informal grandcarers.

The lack of specialized services and support for grandfamilies could be remedied through recognition of their experiences and needs, and provision of attuned, accessible support. Having grandcarer-specific, easily accessed information and services via a simple, central access point or 'one door', 'one-stop shop' is a potent enabler to service access. For this to happen, service providers need enhanced coordination and service coordination by a lead agency, or a case management coordinator model would potentially bridge the

communication gap. A suite of options may also be necessary: for example, home-based visitation services show benefits for grandmothers' health (Kelley et al., 2010). Peer support groups are effective in combating isolation and providing access to information (Strozier, 2012) within the context of specialist whole-of-family support (Yardley et al., 2009). Improving whole-of-family psycho-social support is also necessary to address the relational challenges identified in this study, which influence grandcarers' capacity to pursue formal carer status. Acknowledgement of grandcarers' resilience and capacity as agentic beings is fundamental to any intervention strategies which should focus on resilience in both grandmothers and grandchildren (Dolbin-Macnab et al., 2016) and empowerment processes that emphasize building existing capacities (Tang et al., 2015).

Communication with grandcarers and improving access to information must be addressed at the level of policy and individual practice; particularly if the inaccessibility of information is considered an issue of discriminatory practice and epistemic injustice. A 24-hour grandcarer helpline could bypass the problems identified with online access, as well as reducing the shame associated with grandcarers having to tell their story again and again. However, careful consideration of how such a helpline is advertised and promoted in the community remains important. As Bell (2014) argues, countering epistemic injustice is within the remit of social work practice, and should be a priority for social workers engaging with grandfamilies.

Other practice suggestions include services and practitioners being more proactive and on the lookout for grandparent-headed families; they should work with them as families and not individuals, with an eye to understanding their unique social, cultural, relational, and emotional experiences and needs. Social workers' efforts to improve intra- and inter-agency collaboration and communication, engage in advocacy work, and build individual practice skills with regard to relationships, cultural competency, and reflexive, justice-oriented practice may improve the quality of support for grandfamilies, even without significant changes in resourcing. In summary, this article has highlighted not only grandcarer vulnerability, but the often-ignored issues of inequity and injustice. We call for increased visibility and recognition of grandcarers and the vital role they play in society.

6 | LIMITATIONS

The authors are concerned that the gendered nature of care provision is not adequately investigated or reported in this study, possibly due in part to researcher and service provider acceptance of gender-role expectations. Additionally, the findings from the grandcarers survey included in this article are not the complete dataset as these were not available at the time of analysis.

ETHICS STATEMENT

Ethical approval for the research was received from Curtin University Human Research Ethics Committee (Approval number HRE2018-0035).

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CONFLICT OF INTEREST

The authors have no competing interests in the conduct of this research or the preparation of this manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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