

Impact of disability on families: grandparents' perspectives

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Abstract

Background Caring for a child with a disability can be a unique and challenging experience, with families often relying on informal networks for support. Often, grandparents are key support resources, yet little is known about their roles and experiences. Reporting on data collected in a larger Australian study, this article explores grandparents' experiences of caring for a child with a disability and the impact on their family relationships and quality of life.

Method A qualitative purposive sampling design was utilised; semi-structured interviews were conducted with 22 grandparents (17 women, 5 men) of children with a disability. Grandparents ranged in age from 55 to 75 years old and lived within a 90-min drive of Brisbane, Australia. Interviews were transcribed and responses analysed using a thematic approach, identifying categories, themes and patterns.

Findings Four key themes characterised grandparents' views about their role in the family: *holding own emotions* (decision to be positive), *self-sacrifice* (decision to put family needs first), *maintaining family relationships* (being the 'go-between') and *quality of life for family in the future* (concerns about the future).

Conclusions Grandparents are central to family functioning and quality of life, but this contribution comes with a significant cost to their own personal well-being. Implications for policy, practice and

research are discussed, particularly grandparents' fear that their family could not cope without their support.

Keywords communication, family relationships, grandparents, intellectual disability

Introduction

Families are the primary carers for children with intellectual and developmental disabilities; in Australia, one in eight families have at least one child with a disability living at home, with intellectual (59%) and sensory/speech (53%) disabilities the most common (Australian Bureau of Statistics 2008). While parents frequently focus on and make positive meaning from the experience (Bayat 2007; Reichman *et al.* 2008), the reality is that caring for a child with a disability can be an emotionally, financially and personally challenging experience. A significant factor influencing overall family functioning and how well parents cope is the encouragement, friendship and advice they receive from their informal support networks, specifically close friends and extended family, such as grandparents (Mayes *et al.* 2008). Yet, to date, very little has been known about how these invaluable support people view their role, specifically their expectations, experiences, ability and willingness to be a resource to parents and families.

Research has predominantly focused on the experience of mothers (who are typically the primary caregivers), with much less known about the role of other key members in the family, such as fathers (e.g. Ricci & Hodapp 2003), siblings (e.g. Cuskelly & Gunn 2006) and extended family members such as aunts, uncles, in-laws and grandparents (e.g.

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Margetts *et al.* 2006; Woodbridge *et al.* 2009). In particular, grandparents typically play a central role in family life – supporting their adult children, caring for their grandchildren and maintaining extended family relationships. When a child has a disability, grandparents can be an important resource and support to the family. For example, in Australia, 10% of primary carers report that the child's grandparents provide significant assistance and share in the caring responsibilities (Australian Bureau of Statistics 2008). However, to date, very little has been known about grandparents' experiences and how playing this critical support role impacts on both their personal lives and family interrelationships.

The role of grandparents

Very few research studies focus specifically on grandparents' role in the family when a grandchild has a disability, with a recent review describing the limited research to date as primarily small-scale, North American and focused on parents' perceptions (Dunne & Kettler 2007). For example, Baranowski & Schilmoeller (1999) explored mothers' perceptions about the grandparents' adjustment to the birth of their grandchild with a disability, while Heller *et al.* (2000) surveyed mothers of a child with intellectual disability about sources of social support and linked maternal depression to reduced emotional support from grandparents. When grandparents do not provide support, however, research suggests that it is not about the disability but about pre-existing family relationships (Mirfin-Veitch *et al.* 1997). In a longitudinal study of Canadian families whose children have developmental disabilities, Trute (2003) developed a grandparent support index and found that emotional (but not practical) help from grandparents predicted mothers and fathers psychological well-being.

Only a handful of studies have directly explored grandparents' viewpoints. In telephone interviews with 32 American grandparents of children with special needs (primarily spina bifida), Scherman *et al.* (1995) documented an initial emotional grieving and adjustment process as grandparents focused on providing emotional and financial support to their child and grandchild. In the UK, Margetts *et al.* (2006) interviewed six grandparents

of children with autism and identified three key themes that typified the experience, including the parental bond (caring for adult child and grandchild), striving for answers (struggling with diagnosis) and keeping intact (worrying and feeling responsible for wider family). Of particular interest is that grandparents were concerned about successfully managing wider family relationships, raising issues of sibling rivalry, keeping the family united and remaining aware of the needs of their other children and grandchildren. In Australia, we have also explored the relationships between grandparents and their grandchild who has a disability, using a phenomenological approach to understand the everyday lived experiences of 22 grandparents (Woodbridge *et al.* 2009). In that research, we found that grandparents conceptualised the experience as 'an emotional roller coaster' but felt pride in their family's ability to adjust to the challenges of the situation. Specifically, we identified three key themes characterising grandparents' emotional journey: adjusting (transition from anger to acceptance), double grief (sadness about what might have been) and pride in family (regarding their ability to cope with this unexpected situation).

While this small body of research demonstrates that grandparents are a key resource providing emotional and instrumental support to families, research to date has not fully explored how adopting the role as a critical support person might impact grandparents' lives and wider family relationships, particularly relationships between family members. The reality is that contemporary grandparents are diverse individuals, balancing multiple roles and responsibilities that may potentially conflict with their role as key informal support person – they are also parents, spouses, workers and community residents, with their own dreams and aspirations as they age and approach retirement (Tepper & Cassidy 2004). Thus, this article focuses on another key theme identified in our qualitative study of 22 Australian grandparents, issues associated with family quality of life. This article explores the impact being a critical support person had on the quality of the grandparents' own lives, their families and grandparents' ability and willingness to provide support now and in the future.

Method

To better understand the everyday lived experiences of the grandparents, qualitative phenomenological method was chosen (Brantlinger *et al.* 2005). Phenomenology emphasises adopting an open approach to understanding the unique 'lived experience' (activities, meanings, beliefs) of a particular phenomenon from the perspective of those who experience it, where the 'participant is the knower and it is the researcher's ability to engage with the participant's reality that enables an honest and trustworthy account of the lived experience' (Paton *et al.* 2004, p. 178). Through first-person description, phenomenology provides rich and unique insight into an individual's experience and is very appropriate when exploring grandparents' experience of disability.

Participants

A total of 22 grandparents (17 women, 5 men) of children with a disability were interviewed; 18 were grandparents of one child with a disability and four had two grandchildren with a disability (one grandmother was not the biological grandmother of the child in question). Grandparents ranged in age from 55 to 75 years old (over half, $n = 12$, were under 65) and lived within a 90-min drive of Brisbane, the capital city of Queensland in Australia (three in rural areas, six in coastal communities and 13 in urban areas). All self-identified as being of Anglo-Saxon origin, having a secondary or tertiary education and being married (two were widowed). The majority were retired (10 were self-funded retirees and nine receiving government-funded pensions), with many (16) reporting significant prior experience of working with children with disability in their pre-retirement occupations as teachers/teachers aides (10), registered nurses (4) and aged/disability support workers (2). At the time of interview in 2007, the 20 grandchildren were all under 17 years of age (ranging from 2 to 14 years, with nine under eight years) and had a wide variety of disability diagnoses – based on the grandparent report, these included cerebral palsy ($n = 2$), Down syndrome ($n = 3$), autism/Asperger's syndrome ($n = 4$) and a range of other low-incidence disabilities (see Woodbridge *et al.* 2009 for specific details).

For the majority, the child with a disability was male and all were already grandparents of at least two other grandchild without a disability (total number of grandchildren ranged from 3 to 18, with most having at least five grandchildren).

Procedure

The study received ethical approval from the Queensland University of Technology Human Ethics Committee and standard good practice ethical protocols were followed, with written consent obtained from each participant. A non-probability purposive sampling technique was utilised to recruit grandparents of a grandchild with a disability. Baker (1999) describes purposive sampling as useful when a number of key characteristics are used to identify participants who may be otherwise difficult to locate. In this case, participants who were recruited to the study met the following characteristics: (1) grandparents of a grandchild with a disability who was still living; (2) the grandchild was under the age of 17 years of age at time of recruitment; and (3) the grandchild's disability was diagnosed at birth, within the first 12 months of age or as a result of illness or trauma after 12 months of age. Advertisements placed in the newsletters of older people's organisations in Queensland (including Council on the Ageing and National Seniors) to ensure that older people were able to respond in their own right, rather than relying on other family members to pass on details of the study. Unfortunately, a number of grandparents that responded to the advertisements were excluded from participating ($n = 6$), as their grandchild was over the age of 17 or had passed away. The semi-structured discussion format interviews were conducted in participant's homes and lasted approximately 90 min. On three occasions, both the grandfather and the grandmother were interviewed.

After beginning with background information about socio-demographic characteristics and their grandchild's disability diagnosis, the interview followed a semi-structured interview schedule and explored the following key areas: their recall of their experiences at the time of diagnosis, positive and negative impact of their grandchild's disability on their lives and personal choices, impact on family relationships and interactions, their relationship and

activities with their grandchild with a disability (and whether this differed from other grandchildren), perceptions of their role and expectations for the future. Critically, while semi-structured interviews provide a guide of key issues to be covered, they give the interviewer the freedom to explore any emergent issues and probe with follow-up questions. All interviews were conducted by the third author, herself a grandparent.

Analysis

All interviews were digitally recorded and later transcribed verbatim into text for analysis, thus capturing participants' views, experiences and feelings in their own words. To ensure confidentiality, participants names were replaced with numbers and identifying information changed. Data were managed using NVivo7 computer software, but were coded and analysed manually using a thematic approach to identify categories, themes and patterns (Brantlinger *et al.* 2005; Liamputtong & Ezzy 2005). The identification of themes occurred through 'careful reading and re-reading of the data' (Rice & Ezzy 1999, p. 258), with four key iterative steps in thematic data analysis: mechanics (data preparation and transcription), data immersion (i.e. reading and re-reading the transcripts and listening to audio recordings), generating initial codes and emergent patterns (i.e. initial pattern recognition within the data) and searching for key themes and subthemes (i.e. identification and categorisation of meaningful categories and themes). Emerging themes become the categories for analysis and were reviewed, refined and named into main themes and subthemes (Liamputtong & Ezzy 2005).

First and second level member checking occurred, with follow-up interviews conducted for further clarification and validation of key themes. Investigator triangulation ensured interpretive rigor and credibility. All three authors read and applied an initial thematic analysis to the transcripts, discussed the data and agreed on the final themes, which purposely included multiple excerpts from the raw data using the exact words of participants to allow readers to evaluate our thematic structures (Brantlinger *et al.* 2005). Previous analysis of this data focused on the emotional experience of being a grandparent of a grandchild with a disability

(Woodbridge *et al.* 2009); this article focused on the issues associated with family quality of life and responses to questions exploring their role in the family, relationships with and impact on family members and expectations for the future.

Results

These grandparents viewed their role as 'being there' to support their children, consistently describing their pride in how well their children managed this unexpected and often challenging situation. However, grandparents were honest about the pressure having a child with a disability placed on their entire family. They described the significant impact on their family quality of life and how family members often delayed life goals: they personally postponed travel and retirement plans, their children had deferred career opportunities and other family members, while generally supportive, struggled with the change to family relationships and were sometimes jealous about the attention the family whose child had a disability received from grandparents. Focusing on the family experience, as described by the grandparents, four key themes arose from the data: *holding own emotions* (decision to be positive), *self-sacrifice* (decision to put family needs first), *maintaining family relationships* (being the 'go-between') and *quality of life for family in the future* (concerns about the future).

'Holding their emotions'

The grandparents struggled with feelings of anger, disbelief and fear at the time of diagnosis and then with ongoing questions about making the best decisions for the future. Yet, while the diagnosis and experience was extremely stressful and emotional for all, grandparents knew that they had to be strong for their children and 'hold their own emotions'. They felt that the best way they could help their family was to be positive for their children. Thus, rather than dwell on their own emotions and the question of 'why us', grandparents purposely chose to deal with the immediacy of what was in front of them, developing an emotional toughness and resilience to work positively to influence family dynamics.

You basically think to yourself, well what can I do to contribute to him? Well you know they can't fully recover, but you have to think about how you can approach the situation so that you benefit both the child and the mother by being as positive as you can, particularly for the mother. (#5)

I don't know about [husband] but I just have to get on, with what has to be done and you just get on with it. I mean my mind does wonder to the future sometimes, but I have to tell myself that it will be OK. I've not to get all emotional about all that. I think it is about holding your emotions where you want them to be a bit. (#19)

'Self-sacrifice – putting family needs first'

Grandparents sacrificed much for their families, describing how they put plans and dreams on hold, moved houses to be closer and more able to help, and reduced their work hours so they could better support their child and grandchild with a disability. Several grandparents had intended to travel in their retirement, but were reluctant because of the long distance and duration of trips. For example, one grandfather took early retirement to be able to be there for his family when his grandson was diagnosed with Down syndrome, and many grandparents had regular child-mind days so the mothers could maintain their careers.

I feel that once you accept that you've got a child or a grandchild with a disability, then your whole concept of what lies ahead of you completely changes, because you know then that your life isn't going to pan out the way you thought it would, because there is this so much extra responsibility involved with a child with a disability . . . because they need you. This is why I feel I can't just walk away. I can't afford to say, well I'm sorry you've got all these problems, I'm going to walk away and retire. (#5)

Well, I'm trying to do more, that's one of the reasons I gave up my job. [its created] a bit of constraint about the way we lead our own lives. . . . our life would go in a different direction now if they didn't exist. I don't think we would stay here but the fact that we're 10 kilometres

away and 10 minutes in the car. I think we would head for a little fishing village or something, but it's not an option. There's been once or twice I was offered a job teaching in Japan but I couldn't even contemplate it . . . I'm not saying I'm martyr of the year, at all, but it has been a fact, you know, you sort of think that . . . well it's not an option. (#1)

Dealing with the situation also created tensions in their own marriages as some participants were unable to fully discuss the situation with their spouse or disagreed about the extent to which they should put their own dreams and aspirations 'on hold' to support their family.

I find it hard with my husband, because he doesn't speak to me, we never talk about it. I don't know what's going through his mind. (#2)

Actually my husband's been talking about moving away and particularly since we've found out about [grandchild with disability]. I've just felt that now is not the time, so I'm not thinking about us as far as moving away. My husband wants to retire. . . . he wants to go away from the coast, I just said to him [daughter's] situation is so difficult, she needs the back-up and I'm not prepared to go just yet. I do see myself as a hands-on grandparent to help her wherever I can. (#5)

Grandparents expressed concern about sacrificing their own lives and yet being taken for granted, as one grandmother who was about to retire explained: '*I'm excited to be embarking on a new part of my life . . . but we do need to think a little bit about that, we don't want to be used as a doormat*' (#14). Grandparents were often hesitant to raise these issues directly with their children as they were concerned about the repercussions. One set of grandparents moved in with the family, until another daughter intervened and encouraged them to move out because their relationship and quality of life was suffering.

We had no other interest, no other people and we are both quite outgoing and always had a huge circle of acquaintances and people and what have you, and we had no one there and we started to get cross with each other. (#10)

Maintaining family relationships – being the 'go-between'

Grandparents described how raising a child with a disability creates unique challenges for families and emphasised the importance of '*an extended family and to think outside beyond the nucleus of Mum, Dad and the kids*' (#19). They explained how children with a disability are born into a family, impacting not only on the parents but on the extended family members as well – aunts, uncles, cousins and paternal grandparents. Maternal grandparents described how they served as an interface between the child with a disability and other family members, with most believing that the experience of disability was positive and had brought their extended family together.

Well, I think it's probably made the family stronger because you have to blend together to give each other support. It's really united the family. (#2)

We have a very close family, we all work in well together, they're all very supportive of one another whatever the situation but particularly since finding out that young [child with disability] has got autism, so everyone draws together nicely. I think more than anything it's drawn us closer to him for myself and the rest of the family, his other grandma, we all pull closer together and we do spend as much time with him as we possibly can. If we have family get-togethers, he's just as much cared for everybody looks out for him that he doesn't hurt himself or anything like that. The other kids all accept that he just the way he is and they understand, even though they're young themselves, all the other grandchildren, they still look out for him. (#5)

A trigger for family conflict

A third of grandparents, however, acknowledged that having a child with a disability in their family created additional challenges, tension and conflict. For some families, this conflict was pre-existing, whereas for others it was due primarily to the circumstances. There were two main areas of conflict. First, family members often expected that equal

amounts of attention would be given to all children and grandchildren, regardless of need and expressed anger, jealousy and possessiveness about how grandparents spent their time. One grandmother explained that she needed to justify her actions, as her daughters were keeping a track of the hours she spent with each: '*well, it is very hard to spread my time equally. They're almost adding up the hours, my two daughters*' (#8).

The second main area of conflict was parent's expectations about how the family should interact with their child with a disability. Many family members, particularly aunts and uncles of the grandchild with a disability, complained to grandparents that they wanted to be helpful but felt that they could not do anything right. Miscommunication and little actions (or inactions) triggered significant family conflict, with one grandparent describing the impact of events at a recent family birthday party. The grandparents felt caught in the middle between their daughters because of their differing expectations regarding interactions and responses with the child with a disability, specifically when the younger cousins forgot the appropriate response protocol. These grandparents believed the experience of disability had really '*fractured everything*' (#10) in their family.

He forgot to reply to what [child with a disability] was saying. He realised that he went out and kicked the ball out there whilst she was evidently still talking to him. And that sparked off another argument that we had. We never ever have arguments. . . . the problem is they're [cousins] not getting their response, so you can't expect this boy to sit and talk to her. Of course, she [mother girl with disability] does expect it. We can't take a stand against one or the other. You know . . . we just have to work with them. Otherwise we lose them altogether and we don't want to do that. (#10)

Grandparents were saddened by this conflict, feeling as if they were being made to choose between the families. They felt the stress of the situation also exacerbated minor family disagreements and negative personality traits, with one grandmother describing how she was treated by her son-in-law after an argument and her resolution not to come around anymore unless expressly invited.

I understand that she has to support her husband, but at the same time you don't treat me like that. As everyone says, they need me. . . . obviously with all the stress in this home, the worst parts of our personality comes to the fore and so his [son-in-law] impatience and his rudeness has come up. (#8)

The 'other' grandchildren

Grandparents passionately described the importance and challenge of ensuring that the rest of grandchildren were not overlooked. In particular, one grandparent described the desire to spend more time with *all* their grandchildren. Yet, the mother of the child with a disability will not let her children do anything without their sister with a disability, because she does not want her to 'miss out'. The grandparent struggled to understand this reasoning, explaining that she and her husband did not have the ability to care for their grandchild with a disability overnight.

We would love them to spend time with us, we would love them . . . I've got little games, I'd love to be able to teach them things and [daughter] will not let them come, even for an overnight stay, unless they all come. And I said [daughter] you know that is impossible. We cannot have [child with a disability] here, as we just can't manage her. Well if [child with a disability] can't come, then they can't come, because we are a family. Other families, a little one goes to stay overnight, it doesn't have to be the whole family. (#10)

Quality of life for family in the future

Grandparents were extremely concerned about the functioning of the family in the future, particularly given their declining health and physical abilities as they age. They understand the significant role they play in maintaining family functioning and cannot envision their children successfully managing the family workload without their on-going assistance. Circumstances mean these grandparents are involved in many everyday 'hands-on' support activities, yet there are no resources, information or support to assist them and 'no back-up for grandpar-

ents in situations like this' (#5). Some grandparents describe how their children did not understand or did not want to accept their restrictions because of declining health.

I don't feel safe going downstairs with him. Upstairs is not so bad, you feel that if you trip . . . My balance isn't as good as it was and I've told [daughter] that and she doesn't really want to accept that. He's very difficult, it's very awkward. I suppose she thinks I am big and able but you know as you get older, my back isn't that wonderful. (#8)

There must be other people in these situations. How do they deal with it? The trouble is you don't get a second chance with these sought of things. You deal with it the best you can . . . the best you can do and if you make a mistake, it is done. (#10)

Grandparents describe how they struggle to do their best for the entire family and worried about whether they were making the best decisions. They also expressed fear about dying, not for themselves but because of the negative impact this would have on their family.

If I have any health scares I just get petrified . . . I just think I can't go. I will, but the thought of [daughter] coping without me is not good either, it's terrible. [Husband] and I have talked quite a bit about that contingency and I've helped her to find other avenues but basically we can't do much about it. (#1)

Discussion

With little known about the role and experience of grandparents in families when a child has a disability, this study has highlighted the challenges and the significant role they play in sustaining quality of life for families. Grandparents' views about how the experience of disability has impacted both them and their families were categorised into four key themes: *holding own emotions, self-sacrifice, maintaining family relationships* and *quality of life for family in the future*. Consistent with the small body of existing research (e.g. Scherman *et al.* 1995; Margetts *et al.* 2006; Woodbridge *et al.* 2009), grandparents were

extremely involved in the lives of the family whose child has a disability, providing emotional and instrumental support to their child and grandchild. Critically, this research demonstrates that maintaining family functioning and quality of life comes with significant cost to grandparents, as they work to maintain family ties (e.g. Margetts *et al.* 2006).

Grandparents play a key role in families when a child has a disability; they have a strong sense of fulfilling their 'duty', which they see as doing anything to keep their family both together and happy. Yet, maintaining their family's quality of life presents many challenges, with two key issues impacting on grandparents' ability to support their family – ageing and conflict. First, the reality of the ageing process meant that grandparents were anxious about what might happen when, because of either increasing frailty or death, they could no longer provide emotional and instrumental support. Second, grandparents described experiencing significant conflict, both personally and within the family. Grandparents experienced personal conflict as they balanced energy-intensive support roles with other responsibilities and personal interests. Many made conscious choices to sacrifice or delay work opportunities and retirement dreams in order to be closer and more able to support their family. While they did not regret these choices, they sometimes felt their children did not fully appreciate this. Within the family, there was also sometimes conflict about their contribution and appropriate family interactions. This saddened grandparents who felt as if they were being made to choose between their children. Of course, regardless of the presence of disability, many of these family functioning issues exist for all families. However, these issues are often exacerbated by the presence of disability and requirements for caring, which may act as a catalyst for increasing family conflict.

Limitations

Despite providing important new insight into grandparents' experiences, the study limitations need to be acknowledged. First, like much qualitative research, a purposive sampling methodology was utilised. Because only 'interested grandparents' self-nominated, it is possible that our sample over-represents either well-functioning and engaged

grandparents and/or those who are experiencing family conflict. Second, we only have the grandparents', primarily grandmothers', perspective at one point in time and do not know the extent to which other family members would concur with their interpretation. Third, these children ranged in age and had a wide range of severe disabilities, with their intellectual disability often combined with significant sensory and physical disabilities. Future research should address these limitations and utilise random recruitment, longitudinal and triangulation approaches to explore the experiences and views of multiple family members particularly siblings and aunts/uncles, over time.

Implications and recommendations

Grandparents clearly make an important contribution to overall family well-being, with this research raising many practical and policy implications. For grandparents, there needs to be better information and support mechanisms – many spoke about the pressure having a child with a disability placed on their entire family, how it had influenced their own life choices and their desire to know how other grandparents and families in the same situation coped. Grandparents reported living very much day-to-day without a longer-term plan for how their family would cope in the future, when they no longer provide care. Therefore, there is a need for resources that enable communication within families about planning for the future. These may include the identification and development of alternative support strategies, such as virtual or physical psycho-educational peer support groups designed specifically for grandparents.

For families, this research highlights the importance of remaining aware about the expectations, experiences and capabilities of grandparents. Often, grandparents are working hard to conceal their own concerns and maintain quality of life for *all* family members, necessitating a delicate balancing act to meet family needs and minimise conflict. Families need to remember that, like them, grandparents are doing the best they can in a difficult situation and would really value positive feedback and affirmation from time to time. Finally, from a public policy perspective, the important contribution of grandparents must be acknowledged (Trute 2003; Weston &

Qu 2009). With an ageing population and changing modern family structures, grandparents are potentially more likely than ever before to play a significant role in families. Thus, the nuclear definition of family should be expanded to include grandparents, understand their critical role in the family and identify ways to better support them. This, in turn, would enable grandparents to better support the family.

As there has been relatively little specific research or policy attention paid to the role and experience of grandparents. Our hope is that this research helps highlight the significant contribution grandparents are making to their families, their wider communities and, ultimately, to society. They are balancing multiple social roles, putting aside personal life goals and managing disagreement and conflict within their own marriages and families to facilitate quality of life for the family whose child has a disability. Yet, although grandparents are *currently* willing and able to provide quality emotional and instrumental support, the reality of the ageing process means families must prepare for a future without this contribution.

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