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Objectives: As our knowledge about the experiences of grandparents when their grandchild has a disability is extremely limited, the purpose of this research was to explore the emotional journey of Australian grandparents.

Method: This qualitative research utilised purposive sampling and semi-structured in-depth interviews to explore the experiences of 22 Australian grandparents, whose grandchild had been diagnosed with a disability.

Results: Three key themes characterised grandparent's emotional journey: Adjusting (the transition from anger to acceptance), The 'Double Grief' (sadness about what might have been for both their child and grandchild) and Pride in Family (pride in family's ability to adjust to the challenges of the situation).

Conclusion: As the first Australian study to explore the experiences of grandparents when their grandchild has a disability, the research provides important new knowledge about the emotional journey for grandparents. Unlike overseas research, Australian grandparents view themselves as being there to support their own children, rather than 'holding the family together'. The findings will inform current policy debates about the role of grandparents and highlight the importance of support services that help facilitate grandparent's role within their family

Key words: grandparents, children with disability, emotional experiences

Key Points

- This is the first Australian study to explore the emotional experiences of grandparents when their grandchild has a disability.
- The findings illustrate how grandparents adjust emotionally to the diagnosis, describing their journey from anger to acceptance. Critically, grandparents also report feelings of pride about how their family is coping with this unanticipated situation.
- This exploratory research suggests that there may be cultural differences in how grandparents support families when a grandchild has a disability, with further qualitative and quantitative research needed.

The birth of a child is a time of celebration for families, providing opportunities for relationships to develop between the generations of grandchild, parent, grandparents and great-grandparents. Typically, grandparents approach the birth of a grandchild with a variety of emotions, including joy and optimism about the future, excitement about transmitting parenting skills and knowledge to their child and, sometimes, feelings of anxiety and apprehension about the grandparent role [1][2]. When a grandchild is born with a disability, however, their emotional responses may be quite different from those they typically experience on the birth of a non-disabled child. This paper explores the emotional responses of grandparents coming to terms with the diagnosis that their grandchild has a disability and how these emotions influence the roles and relationships they have with the grandchild and their family.

The birth of a grandchild with a disability, such as Down's syndrome, cerebral palsy, or cystic fibrosis, requires the grandparent to draw on previous life experiences to make some sense of the event. Critically, the experiences of grandparents are influenced by societal attitudes to disability that have evolved over time and have changed significantly during the lifetime of today's grandparents. When these grandparents were growing up, it would have been unusual for children with disabilities to be visible; historically, children with disabilities were withdrawn from their families, spending their childhood years in institutions and rarely seen in public [3].

Thus, it is not surprising that many of today's grandparents might find the diagnosis of their grandchild having a disability a significant emotional experience. Moreover, with advances in pre-natal testing and medical technology ensuring the survival of many more children, an increasing number of grandparents will have a grandchild with a disability [4]. Yet, whilst there is a significant body of literature about the experiences of parents of children with a disability [5] and parent's perceptions of grandparents [6], less is known about grandparent's perspectives and experiences. This is despite increasing awareness of the important symbolic and instrumental role grandparents play in the lives of grandchildren [7][8], and significant literature investigating various issues such as their experiences with individual grandchildren [9], the impact of parental separation [10], relationship with donor-conceived grand-children [11] and the experience of grandparents who are primary care-takers of their grandchildren [12].

Only a handful of studies have explored the role and experiences of grandparents when their grandchild has a disability, with a recent review describing the limited research to date as predominantly small-scale, North American and focused on parents' perceptions [13]. In the United States, Scherman, Gadner, Brown and Schutter [14] conducted telephone interviews with 32 grandparents of children with special needs, primarily spina bifida. These grandparents described going through an adjustment process, reporting initial feelings of grief and then focusing on providing emotional and financial support to their child and grandchild. They expressed concern about the stress their child was experiencing and wondered whether their grandchild would ever form a close bond with a non-family member or function independently. Baranowski and Schilmoeller [15] explored mothers' perceptions about the grand-parents adjustment to the birth of their grandchild with a disability. Focussing on issues of support, Mirfin-Veitch et al. [16] found that grandparental failure to provide support was not determined by the grandchild's disability but rather due to pre-existing family relationship dynamics and history. In the United Kingdom, Margetts, Couteur and Croom [17] qualitatively explored the experiences of six grandparents of children with autism spectrum disorder and identified three key themes: 'the parental bond' (striving to protect

child and grandchild), 'striving for answers' (searching for meaning) and 'keeping intact' (holding the family together).

Within the Australasian region, despite recent research exploring the experience of grandparents raising grandchildren [12], our knowledge about the role of grandparents in families of children with disabilities is non-existent. Thus, this research explores the emotions and interpretations Australian grandparents give to their experience of being a grandparent of a child with a disability. The results will enable comparisons to be made between these overseas studies and the experiences of Australian grandparents.

Method

This qualitative research utilises a phenomenological approach, which is appropriate when the purpose of the exercise is to "understand" the real life experience of the participants and enables the researcher to better appreciate the phenomena of being a grandparent of a child with a disability [18][19] A purposive sampling technique was utilised, with participants recruited for in-depth interviews via advertisements in the newsletters of older people's organisations. This approach, whilst often criticised for its limited reliability, facilitates an indepth understanding of the phenomena that would not be achieved using a random survey or experiment. [19]

A total of 22 grandparents (5 men, 12 women) of children with a disability were interviewed; 18 were the grandparents of one child with a disability, whilst 4 grandparents had 2 grandchildren with a disability. The grandparents ranged in age from 55 to 75, with approximately half (n=12) aged between 55 and 65. Their grandchildren were under 17 years of age at the time of interview, with a wide variety of disability diagnoses. These are summarised in Table 1, with nearly half of grandchildren diagnosed with Autism, Aspergers Syndrome, Cerebral Palsy or Down Syndrome.

Table 1: Grandchildren's disability diagnoses and characteristics

Disability	Cognitive	Sensory	Physical
DeGeorges Syndrome	x	x	X
Autism (x 2)	x		
Cerebral Palsy (x 2)	x		X
Down Syndrome (x 3)	x	x	X
Lissencephaly	x	x	X
Aspergers Syndrome (x 2)		x	X
Trychorhina Thalanygl		x	X
Agenesis of the corpus callosum	x	x	X
Ulcerative colitius/mental illness	x		X
Trigeminal Neuralgia/Discoform keratitis		x	X
Rhetts Syndrome	x	x	X
ADHD			
Spina Bifida	x	x	X
Selective Mutism		x	
Placenta Abruption	x	x	X

Procedure

The study received ethical approval from the Queensland University of Technology Human Ethics Committee. Semi-structured discussion format interviews lasting between 60 and 90 minutes were conducted in participant's homes. On three occasions, both the grandfather and the grandmother were interviewed. The following key areas were covered: their recall of their experiences at the time of diagnosis; their relationship and activities with their grandchild (and whether this differed from other grandchildren), and what factors influenced their own grand-parenting role. Interviews were recorded and later transcribed, with Nvivo 7 utilised to identify categories, themes and patterns [19]. Follow up interviews were also held to seek further clarification and validation of key themes.

Results

One of the most significant and consistent themes identified by the grandparents was the range of emotions that they had confronted since the birth or diagnosis of their grandchild with a disability. These emotions could be categorised into three clear sub-themes: Adjusting (the transition from anger to acceptance), The 'Double Grief' (sadness about 'what have been' for child and grandchild), and Pride in Family (pride in family's ability to adjust to the challenges of the situation).

Sub-Theme 1: Adjusting

All grandparents described the emotional experience of adjusting to the diagnosis, recalling a very painful emotional journey from anger to acceptance and action. Grandparents spoke of initial feelings of 'hitting rock bottom' after the diagnosis, describing how "*well it was sort of like there was a death in the family, really, because you sort of expect to have naturally good children* {#2} and "*I guess you have the expectations of something with the birth of the baby and then suddenly it is something different*" (#14). Whilst there were often initial feelings of shock and anger that this had 'happened to them', these feelings of bitterness passed and were replaced by a "lets get on with it" attitude. Grandparents clearly saw their role as supporting their own child and the family: "*We just want to support them. We don't want to interfere or you know we have confidence in their judgement and their desire to keep things going in a positive way*" (#19). Notably, the experience had challenged grandparent's value systems, who wondered why this had happened to "their family".

I have to say that I was very bitter um I felt you know. All I had ever prayed for all my life – I had never ever prayed for anything materialistic, all I had really prayed for was for God to watch over my family. Let them be healthy in mind and body and to be always gainfully employed and this was what he came up with and for quite some time I couldn't pray and I wouldn't pray. .. This isn't fair and I went through this for quite some time and then I picked myself up and said come on [name] just get on with it... And I do think that after the initial experience of hitting rock bottom the old saying is there is only one way of going and that is true (#13)

Well at first it was hard to accept, well you know reasonably hard to believe, not accept to believe that it had happened to us, these sorts of things always happen to other people, don't they, but once you accept it you're there for your daughter, you're there for your grandson and I feel great about having him (#3).

Sub-theme 2: The Double Grief

The grandparents consistently reported that they often felt sad at the situation, particularly as they adjusted their expectations and grieved for 'what might have been' for both their grandchild and child. Essentially, as one grandmother commented, "*I have got that sorrow inside of [me] for them*" (#12). These feelings of sadness arose at different times for the grandparents. For some it was

there early on, for others it was an underlying sadness for both their grandchild and for their own child. Two grandmothers summed it up in the following way:

There is just a sadness you carry with you all the time. There is a double grief because you grieve for the child but you also grieve for your child (#19)

I was devastated for the parents, as you are because it was unexpected and they were in shock and I mean he was always loved – he was just their boy, but it was just terrible. I went through a period of grieving. (#6)

Whilst the grandparents described these feelings of sadness in a variety of ways, the overall impression appeared to be a feeling of sadness not so much for the child themselves, but more for what the child would not be able to achieve: *“Its rather lovely, but it is sad because it is not like the others”* (#13) and *“I guess its sad, that’s the only thing. I guess it’s sad that he’s not going to be able to live a so-called normal life”* (#15). Grandparents grieved for the lost potential, especially when there were other grandchildren with which to compare expected milestones of careers, marriage and children; *“I think deep down emotionally you feel so much for them and the fact that they’re never going to get any better. You do worry about them, what’s going to happen to them in the end”* (#4). Grandparents also described how their relationship with this grandchild was not as they had anticipated, with one commenting that the relationship was not as open as *“you can be as loving and caring, but you can’t share a joke as readily as you can with a hearing child”* (#6). Another grandmother described how the role was different then she had dreamed; she had always expected to be a grandmother like her own, who she had adored and had taught her to sew, embroider, knit and crochet. Unfortunately, *“now it’s a bit different, because I know I’m not going to be able to teach him to do those sorts of things”* (#2).

Sub-theme 3: Pride in Family

As well as dealing with these feelings of sadness, however, grandparents reported immense feelings of pride in their family; they were proud of how their child was coping, they were proud when their grandchild achieved the unexpected, and some reported feeling pride in how their spouse overcame traditional societal conditioning about ‘the place and abilities’ of people with disabilities to love and interact with the grandchild.

Grandparents were often brought to tears when describing situations when the grandchild had achieved the unexpected; *“there is a sense of identity in seeing him, well... seeing him trump and seeing him cope and not feel poor me in the situation. I can cope with this. You know, there is a feeling of pride and elation at his achievement”* (#19). Grandparents also frequently spoke of the special place this particular grandchild held in their lives and hearts, noting how *“you know, in terms of love and affection, it is a very rewarding experience. It’s often these children who are very special (#11)* and *“he just loves to go where I go.... where as the other grandchildren are not in the least concerned”* (#18).

Grandparents also reported feeling pride in their children. One grandparent said that she had never been so proud of the way her daughter and family were coping, whilst others noted conflicting feelings of sadness and pride: *“I can remember feeling this tremendous pride in a daughter who could cope as well as she was coping. But I mean, I am sure there are things we are not seeing”* (#19) and *“you know it is just so desperately sad for them. You are watching but you feel so helpless. I mean she is a very capable person. If anyone could handle the situation...no one could do it better than her”* (#8). Several grandparents also commented on how, in their lifetime, there had

been a significant societal change in how people with disabilities are viewed. Whilst they were extremely grateful for this change, they still felt that, “*you know, I don’t think that society does deal with them very well* (#14). Notably, one grandmother described her pride in how her spouse had put aside these negative expectations, commenting:

Not that he was ever nasty about them or anything but he grew up in a society where children like that tended to be put in cupboards in Europe they were a shameful secret and so he had that background and so one of the consequences has been it’s been beautiful to see how much he loves them (#1).

Discussion

This exploratory Australian research has highlighted the intense emotional journey that grandparents experience when their grandchild is diagnosed with a disability. This roller coaster of emotions can be categorised into three clear sub-themes: Adjustment, Double Grief and Pride in Family. Consistent with the small body of existing research [17] [14], Australian grandparents report experiencing a range of emotions including anger, sadness and optimism as they make sense of and accept the diagnosis, frequently describing a ‘double grief’ as they mourn for both their child and grandchild. However, contrary to existing research, Australian grandparents frequently spoke of their pride in their child and grandchild. In particular, grandparents took pride in how well their children faced the challenges associated with this unanticipated situation, which they felt reflected positively on both their own parenting and their family’s unique values [20].

Interestingly, Australian grandparents do not appear to see themselves as holding the family together; rather, they view their child as the family ‘lynchpin’. They are keen to let their child be the parent, to not overstep boundaries and to play a supporting role in the family relationship. This is contrary to recent research in the United Kingdom, where grandparents reported feeling responsible for ‘keeping intact’ and holding the family together [17]. Whilst our research suggests that Australian grandparents view their role very differently, the relatively small sample sizes in both studies means that further research is needed to explore whether there might be cultural differences in how grandparents support families when a grandchild has a disability.

Given the paucity of research to date, our findings provide an important preliminary understanding of grandparent’s emotional experiences and insight into how to better support their needs. Clearly, as well as supporting parents, consideration needs to be given to assisting grandparents to process these emotions and to develop on-going strategies for coping with their situation. It is important that support services, information providers and resources acknowledge and help facilitate the important role grandparent’s frequently play within their family. Grandparents of children with disabilities experience unique pathways in developing relationships and support roles within the lives of their family. This research highlights the challenges experienced by these grandparents on a daily basis in supporting the on-going needs of their child and grandchild.

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