

Parenting a child with medically diagnosed severe food allergies in New Zealand: The experience of being unsupported in keeping their children healthy and safe

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ABSTRACT

Aims: To explore parental experiences of caring for a child with medically diagnosed severe food allergies (MDSFA) in New Zealand. **Method:** This study employed a qualitative methodology, interpretive descriptive analysis, and involved interviews with four parents of children with MDSFA from two different regions in New Zealand. **Results:** The analysis of the interviews revealed that the experience of parenting a child with MDSFA is an experience of feeling unsupported in the effort to keep the child healthy and safe. Three major themes emerge from this study: the experience of isolation, the burden of accessing resources, and the cost of living with MDSFA. **Conclusion:** The general lack of support experienced by these families from health care professionals is a significant concern both for primary and tertiary health care providers. Multi-disciplinary support is required for these families, and currently there is a lack of health care professionals with the knowledge to support these families. This research highlights that there is a significant need for both workforce development and further research in the area of MDSFA in New Zealand.

KEYWORDS: food allergy; anaphylaxis; parenting; family; chronic illness; qualitative

INTRODUCTION

There has been a significant rise in the number of people diagnosed with medically diagnosed severe food allergies (MDSFA) in western countries, and these allergies are more

common among children with 6–8% being affected, whereas adults where only 2–2.5% are affected (Bannon, Astwood, Goodman, Hefle, & Taylor, 2004; Boros, Kay, & Gold, 2000; Dahl, Andersen, Chivato, Valovirta, & De Monchy,

2004; Grundy, Matthews, Bateman, Dean, & Arshad, 2002; Nowak-Węgrzyn & Sampson, 2006; Roehr et al., 2004). One of the significant risks associated with severe food allergies is life-threatening anaphylaxis, and research shows that 1 in 12 people have an anaphylactic reaction have a re-occurrence within 12 months (Clark, Long, Gaeta, & Camargo, 2005).

There is significant morbidity experienced by children with severe food allergies. There is consensus amongst researchers that MDSFA effects at least two body systems, and can include; allergic respiratory conditions, atopic eczema, gastrointestinal symptoms, associated restlessness, and irritability (Arvola, Tahvanainen, & Isolauri, 2000; Heine, 2006; Lawson, Lewis-Jones, Finlay, Reid, & Owens, 1998). If not managed appropriately the symptoms experienced by these children, particularly those with atopic eczema, can lead to impaired growth and development (Avery, King, Knight, & Hourihane, 2003; Gill, 2006; Hawkins, 2005). Eighty percent of food allergies during childhood are related to peanuts, milk or eggs (Charles, Sabouraud, Lavaud, Lebagry, & Motte, 2004). While many are outgrown, allergies to nuts and fish are usually carried for life (Bannon et al., 2004; Charles et al., 2004). Therefore, severe food allergies offer significant hurdles for parents to overcome and usually require life-time prevention and management rather than cure (Bannon et al., 2004).

Only a few studies that have explored living with severe food allergies (Avery et al., 2003; Confino-Cohen, Melamed, & Goldberg, 1999; LeBovidge et al., 2006; Mandell, Curtis, Gold, & Hardie, 2005; Marklund, Wilde-Larsson, Ahlstedt, & Nordstrom, 2007; Sicherer & Bock, 2006; Sicherer, Noone, & Munoz-Furlong, 2001) these studies show remarkable correlation to studies completed that have explored living with a child with a chronic condition (Ogden Burke, Kauffmann, Harrison, & Wiskin, 1999; Leonard, Brust, & Nelson, 1993). These results offer significant challenges for health care professionals when attempting to provide the support required for

the parents of children with MDSFA. The daily management of severe food allergies may create chaotic circumstances that are difficult for parents to control through their inability to manipulate all external environmental factors. Accordingly, one of the key aspects that needs to be explored further is constantly living in the face of potential anaphylactic reactions.

There are no published research studies exploring the experience of parenting a child with severe food allergies in New Zealand (NZ). This research addresses this gap through an exploration of the experience of parenting a child with MDSFA in NZ.

METHOD

This research explored the question: 'What is the experience of parents of children living with MDSFA in NZ'. This research question demands a methodology that allows for the exploration of an experience therefore, a qualitative methodology was chosen for this study, an interpretive descriptive approach was utilised (Edwards & Titchen, 2003). Whilst individual experiences were analysed common themes emerged between study participants that offer insights in to the phenomena. This type of approach provides a meaningful basis upon which the inductive reasoning used by the researcher can be assessed (Thorne, Reimer-Kirkham, & MacDonald-Emes, 1997).

The participants of this study were four parents of children with MDSFA who have resided in NZ, since their child(ren) were diagnosed with SFA. The participants for this study were volunteers, and were recruited using the snowball method (Robson, 2004). Although not specifically targeted all the parents were women. All of the participants described their ethnicity of European decent, and they each lived with a male partner. The participants had between one and three children, and in two cases the participants had two children with MDSFA. All four women had professional occupations, including registered nurses, and a police officer. Each participant received both an information sheet and a consent

form. Both of these documents were provided to the participants for a period of at least 2 weeks prior to the interview. The information sheet provided participants with information regarding the aim and method of the study. They were also informed about their right to have access to copies of their own transcripts and copies of the completed research reports if requested.

This study received ethical approval from the Northern X Regional Ethics Committee of NZ, prior to any study procedures being commenced.

The data collection method was in-depth unstructured interviews. All the interviews were conducted at a time and place nominated by the participant, and they were approximately 60 minutes in length. Participants were asked the simple lead-in question 'what is your experience of parenting a child with MDSFA?' All interviews were tape recorded, and later transcribed by a professional transcriber who signed a confidentiality agreement. Participant confidentiality was maintained at all times. All participants had the opportunity to review and amend any of the information collected. This review allowed an opportunity for participants to validate the information to ensure a true reflection of each participant's experience. Pseudonym names have been utilised in the excerpts provided, which is a standard technique in qualitative research (Robson, 2004).

An analysis framework was used as discussed by Pope, Ziebland, and Mays (2000). This five step process included the following steps: familiarisation, identification of a thematic framework, indexing, charting, mapping and interpreting. This analysis is followed until the phenomenon is more fully understood and the meaning of the human experience under study emerges (Denzin & Lincoln, 2000). The use of this thematic framework allowed for an audit path, an important step to ensure validity and reliability were maintained (Smith & Deemer, 2000, p. 881; Pope et al., 2000).

Familiarisation involved a process of dwelling with the text, this involved reading and re-reading the interview transcripts (Edwards & Titchen, 2003). It also entails immersing oneself in the participants' narratives, becoming intimately familiar with the nuisances and context of the participants' lives.

Following the familiarisation process, the researchers identified a thematic framework that took into account pertinent issues within the participants' narratives. This was achieved by meeting as a research team and developed consistent themes, which we then applied individually to each transcript. The research team then regrouped and reanalysed the interviews as a team. The researchers constantly used other literary sources to promote dialogue with the data, in turn this information supported the themes that emerge from the data (Ryan & Bernard, 2000, p. 773). The developed framework assisted the researchers to systematically comb the transcripts in a comprehensive manner. Following this the indexing phase began where all the participants' narratives were analysed in accordance with the thematic framework. Once this phase was complete, the findings were organised and structured into themes. These themes encapsulate a description of the phenomenon under study and became the foundation for the interpretive description.

Charting is a process of re-analysing and organising the themes into coherent patterns, which provide a full picture of the phenomenon under study. Following this, the researchers engaged in the final stage of interpreting. This involved a process of calling forth meaning, with the purpose of extending understanding (Koch, 1996). This process involved numerous hours spent writing and re-writing interpretations until the phenomenon is more fully understood and the meaning of the human experience under study emerges (Ryan & Bernard, 2000, p. 770). It is important to note that this interpretation is never complete, but an ever evolving process of greater understanding (Koch, 1996).

RESULTS

Three major themes emerged from this study they are: the experience of isolation, the burden of accessing resources, and the cost of living with MDSFA.

The experience of isolation

Participants described multiple ways in which isolation was experienced due to their child's MDSFA, this included their child, themselves as parents, and also their entire family unit. Many activities within a community for children and families involve food, so attempting to keep a child with severe food allergies safe was very difficult, and carried significant risks for these children (Bannon et al., 2004; Clark et al., 2005). In an attempt to keep them safe, the parents in this study chose on many occasions to not attend events, resulting in isolation for the child, parent and family. Melissa, one of the participants, explained;

Trying to mix and do things is such a nightmare, sometimes its just easier not to mix... You're just constantly reminded that you're different, that you have to look at every situation and assess the risk, and then decide if it's an okay thing to go to, constantly. Or if you go to something you have to say to people who have got food, which would be normal in every other walk to life, 'could you please either wipe that child's hands after the food, or could you put the food away', which doesn't go well. So you withdraw, you are reminded that Sam's different. We can't participate in everyday normal childhood activities, without a lot of thought and planning or withdrawing basically, so [we experience] isolation, your isolated.

The parents of children with severe food allergies needed determination to overcome the difficulties of integrating their children into 'normal' everyday life. The participants in this research highlighted that they worked hard to minimise the isolation their children experience however, they reported feeling unsupported in

their endeavours to reduce this. Ruth elaborated on this idea:

To actually get through to people how serious his allergy is some times it's really hard. Even friends that I've had for years, who I consider really good friends, just don't get it. And I would never leave him with them because they just don't understand. And even my own mother doesn't really get it, so I wouldn't leave him with her either. Its just awareness of allergies in general and that they can be really serious.

Parents in this study all acknowledged the judgements they had encountered from the public when attending events and attempting to keep their child safe. This is consistent with the study by 'Mandell et al. (2005)' which found a lack of public understanding and willingness to accommodate these families can be an obstacle in coping with MDSFA. Similarly establishing social supports has been identified as an important adaptive feature of learning to live with a child with chronic illness (Ogden Burke et al., 1999). This research show that parents of children with MDSFA feel isolated when caring for their children therefore, this could impact significantly on their coping mechanisms.

The burden of accessing resources

All the participants described the burden of accessing health care. They experienced frustration trying to access the support needed to manage the symptoms of MDSFA prior to diagnosis. The severity of their children's symptoms required many visits to multiple different health care professionals, which frequently resulted in inappropriate or unhelpful, or contradictory, advice. Frustration was exacerbated by lengthy waiting times for public health care services. Melissa described her experience of delays in accessing care for her son:

It was very frustrating, and even now, I find I struggle. There is not enough information

out there, and like we went up to our recent appointment up in Auckland, and I really like the immunologist, but 15 minutes a year is just not enough of an appointment.

Delays in accessing appropriate care can potentially have a significant impact on these children's health. For example, if a child's eczema is managed through the elimination of an allergen, he/she will get more sleep, be less irritable, and have increased levels of growth hormone (Gill, 2006; Hawkins, 2005). Timely interventions result in children being better able to concentrate for learning, and less likely to be absent from school due to illness. The management of the diet for these children can also increase their absorption of essential nutrients in food thus, decreasing the rates of failure to thrive and aiding normal growth and development (Gill, 2006; Hawkins, 2005). This limited access answers reportedly added significantly to the stress these parents experienced. Melissa further expounds these issues:

You discuss the issues [during the appointment] and then new questions come up... I feel like I need more time, but they just don't have the people there to help you. Or the educated nurses, [or] like an educated dietician, the dietician is not an allergy focused dietician department in [the city where we live]. I'm very biased, I'm very angry about this. The team [in the city where we live] has a different philosophy to food allergies than the [Immunologists] team. Like I was told not to carry adrenalin, but he's got a really high rash, because we were 15 minutes to medical care, just different [information, which is], frustrating.

Another participant discussed the transition after diagnosis of MDSFA, when attempting to access information on how to manage the diet. Angela described her experience:

Where do I buy this? Where do I buy that? How do I manage this? How do I manage that? I had no idea what to do. I mean absolutely no idea what to do.

The participants all reported that health care professionals did not provide them with the information they needed, instead it came from other unexpected sources such as other parents, the internet, books and Allergy NZ. The information the parents received only covered the most basic of elements, including how to read ingredients lists, what to avoid, how to access community-based services, and parent-to-parent support mechanisms. A lack of information about MDSFA potentially undermines the health of these children, because it increases the risk of allergen exposure and associated complications (Arvola et al., 2000; Boros et al., 2000; Kapoor et al., 2004; Notaras et al., 2002). In turn, this added to the parents' feelings of anxiety about their children's diagnosis, and contributed to their experience of stress. All of the participants described their surprise at their primary source of support being other parents with children with severe food allergies. Ruth explained:

A lot of it [information on allergies] seems to come from overseas, like the more helpful websites and they seem to be American or Canadian. There isn't any specific New Zealand information... Some of the overseas websites and books aren't that relevant to New Zealand, and what [products are] actually available here. I think what we have here is actually quite limited [in relation] to what other countries have.

And you can see what I've got [a recipe sheet] from her has been photocopied from someone else, and some one else has written stuff on it, and that's been photocopied from somebody else. So, I think its almost like your in that [allergy] network, and it doesn't seem to matter where you are in the country, but once your in [that network] and then the information starts flowing. But it's flowing from other mum's and dad's - its not coming from the medical [community].

Several studies have described how each developmental milestone that children with MDSFA

reach is associated with an increase in parental anxiety and stress (Hu, Grbich & Kemp, 2007; Mandell et al., 2005). Every time a child develops a new skill and gains access to new experiences, they also potentially increase their risk of exposure to allergens. This was especially evident when the participants discussed accessing safe and appropriate pre-school, and later school-based, education for their children. The stress associated with keeping their children safe in a pre-school, or school environment emerged as a significant concern for the participants in this study. Melissa shared her experience:

I [asked]... kindy 'would you consider having a sit down morning teas?' They [the kindergarten teachers] said 'maybe you want to go look elsewhere, we don't have to deal with this'. They have a right after reading the special education service [guidelines], they can actually say because of Sam's health issues we can't manage him safely here so you can't come to kindy... I'm feeling very frustrated at the moment... it just worries me that I'm being a negligent parent by wanting him to have a normal education. Like going to kindy and taking him along to an environment that may increase his rasts [levels], but then if I don't he'll never mix socially with other children appropriately, and he won't know how to handle it when he goes to school. And that's another thing, schools scary, I'm not thinking about that I've got to get past kindy first. We're really disadvantaged and people just don't get it and we're stone walled. What do you do?

Currently in NZ there is little support, or resources, to assist these parents to educate school teachers and school principals about their children's illness, a point noted by all the participants. In particular, the participants indicated they struggled to keep their children safe in the school environment, as there is no legislative protection, or national policy support for them when attempting to engage education facilities. This lack of support further adds to the burden

and isolation that these parents experience. The participants all indicated a desire for support at a national level to assist them to keep their children safe. Currently, due to the lack of recognition of the health or educational impact of MDSFA on children there are no formal protocols or guidance provided to schools in NZ.

The cost

Increased financial costs were noted as a significant aspect of the experiences of parenting a child with MDSFA, and participants in this study talked at length about the financial impact of keeping their children healthy. All of the participants in the study accessed private health care to ensure they received timely care as this was unavailable in the public system. In addition two of the four participants had to travel significant distances to access appropriate health care, which was at extra cost to them.

Once the children had been diagnosed with MDSFA, the participants encountered the cost of prescriptions, which included epi-pens at a cost of (ca. \$150) that are not subsidised by the NZ public health care system. One participant noted that she now receives the Work and Income New Zealand Disability Allowance, but was unaware of her eligibility and subsequently missed 2 years of this financial assistance. In addition to the cost of medications, low allergen foods are often difficult to access and frequently cost significantly more than the usual equivalent available to those without allergies. Many of the participants noted the need to visit multiple stores to access the required foods. Melissa explained:

The cost of his medications, [the] epi-pens are \$280 just for the two epi-pens for the next year... plus we're going to kindy [kindergarten] so I want to leave a [epi-pen] kit at kindy... His skin creams and his pepti-junior [low allergen formula] it is subsidised but we still have to pay extra. So our pharmacy bill is like four times a year approximately between \$280 to \$300 over and above the subsidies, plus the epi-pens [is] on top [of that]. So we're looking at

\$1200 to \$1500 extra that we have to pay. It is everything – his clothes, I have to buy cotton, I can't buy anything polycotton cause he'll get hot and he'll itch.... It's huge, and because I've chosen not to work, I don't know how I could go back to work with all the allergies, and put him into child care – I just couldn't. Financially as a couple, there's my wage [that is gone], I had planned to go back when he was two or something like that, to go back a couple of days a week, or part time. We've decided [that I will] not to go back to work, because I don't want to expose him to any more than I need to so my wage [is] basically not coming in.

The cost of the diet when he was on rice milk and still having four bottles a day, it was costing us \$45 to \$50 a week just for his milk. Your very limited when you go shopping you can often buy the cheaper brands but that's not an option, your very much down to specific types of brands, or having to source different foods from other places, that you wouldn't be able to get from your general supermarket.

The emergence of the theme 'the cost' further highlighted the impact of MDSFA on the participants. The commitment required by the participants to keep their children healthy and safe was unmistakably evident during the interviews. There were significant hurdles in accessing information about MDSFA. Despite this, the participants needed to educate family, friends and education providers about the condition and the importance of keeping their children safe. This process can result in feelings of frustration, isolation, and anxiety for these children's parents as well as the family unit.

In addition to this, based on the participants' narratives, the health care professionals and education providers they encountered failed to recognise the impact that severe food allergies have on their children and families. The narratives provided by the participants in this study clearly describe the impact of the lack of recognition in

health care service provision and the difficulty in accessing safe education environments, all of which added to the financial burden these families experience. The following section discusses the findings of this study.

DISCUSSION

This discussion locates the findings in relation to other research into severe food allergies, focusing on the contribution that this research makes to the body of knowledge in this field. The implications for health care professionals working alongside these parents and families are discussed. The participants in this research highlighted that a diagnosis of severe food allergies leaves them feeling isolated on multiple levels and has far-reaching implication for their children and families. This finding adds further weight to the results of Bollinger et al.'s (2006) research into the impact of food allergies on children and their families.

The frustration when trying to access answers to the symptoms of MDSFA prior to diagnosis was also evident when interviewing the study participants. They discussed how they made multiple visits to a variety of different health care professionals; however, these visits would often fail to provide the desired answers about their children's health. This theme does not appear elsewhere in the literature on severe food allergies however, a major issue for NZ children is the lack of access to appropriate health care (Kiro, 2006).

The primary results of this research indicate that there is a need for parents to have access to timely and appropriate health care, which has also been highlighted in other studies (Marklund, Wilde-Larsson et al., 2007; Nowak-Węgrzyn & Sampson, 2006; Thong & Hourihand, 2004). The parents in this study described the challenges they experienced in accessing a health care professional capable of diagnosing their children's severe food allergy. Mandell et al. (2005) also describe this finding in their study, the present research illustrates that the burden of accessing information is considerable for these parents, particularly in the NZ context. The parents also noted that this

undermined their ability to manage the on-going symptoms of MDSFA, which was perceived as a significant burden for them. Multi-disciplinary support is required for these families, and currently there is a lack of health care professionals with the knowledge to support these families (Pope et al., 2000; Thong & Hourihand, 2004). This represents a significant issue for workforce development in NZ. There is a need for on-going education and support for those interested in pursuing this area of speciality in both the primary and tertiary health care areas.

The issue of the financial impact and cost to parents in caring for a child with MDSFA does not appear in the international literature. However, it is mentioned in one NZ-based paper (Fitzharris et al., 2006), which highlights that MDSFA is treated differently in other countries, and that the cost is a significant issue for sufferers. For example, adrenalin auto-injectors are funded for those at risk for anaphylaxis in both Australia and the United Kingdom.

To circumvent delays in accessing appropriate health care, the participants in this study often opted to access private care, which also incurred cost for the families. This suggests there are significant concerns for those children affected by food allergies who are unable to access and or pay for private health care. This study, although small, adds to the evidence that there are disparities in child health in New Zealand. Difficulty accessing timely health care has also been identified in the literature exploring similar topics around life-threatening allergies in other countries (Mandell et al., 2005; Marklund, Ahlstedt, & Nordstrom, 2007; Marklund, Wilde-Larsson et al., 2007).

This research also highlights a need to review the provision of education for children with MDSFA. All of the participants in this study cited this as a source of grave concern for them when considering their children's risk of exposure to an allergen. Such concerns stemmed in part from the inconsistent approach of schools to care for their children, and the general lack of knowledge

about MDSFA. This disadvantages children with MDSFA and inhibits their ability to participate within the NZ education system. Therefore, the findings of this research concur with previous findings which highlighted the stress associated with accessing education for parents of children affected by MDSFA (Hu et al., 2007; Mandell et al., 2005). The lack of a consistent approach by schools reflects a lack of recognition that MDSFA is a chronic illness. Establishing a consistent approach across all schools would then allow the same level of support services offered to children with other chronic illnesses within the education environment be provided to children with MDSFA. There also needs to be recognition at a national policy level to support a consistent approach to help non-health care professionals understand the needs of children with MDSFA (Gold, 2006; Kilanowski, Stalter, & Gottesman, 2006).

Indications for further research

Very little research has been conducted on children's or families' experiences of living with life-threatening food allergies (Mandell et al., 2005; Marklund, Wilde-Larsson et al., 2007). Indeed, this is the first study of its kind within the NZ context. Therefore, there is a need for additional research into the experience of living with MDSFA in NZ. The themes that emerged from this research demonstrate that the parental experience of caring for a child with MDSFA is an experience of being unsupported, this presents a significant challenge to health care professionals. There are strong links between the literature exploring the experience of families with children with chronic illness and the experience of parenting a child with MDSFA (Marklund, Ahlstedt et al., 2007). A comparative analysis exploring these correlations is needed to help further understand and support these families.

This study identified an inconsistent approach by health care professionals within different regions of NZ. All participants also reported that

they experienced a lack of timely and appropriate health care for their children with MDSFA. This spanned the process of receiving a diagnosis, through to the provision of the support they required to manage the illness. There is a need to undertake research that is generalisable to the wider NZ population, such as a national survey exploring the impact of MDSFA on families. In addition, clinical guidelines to direct health practitioners and education providers are also an important part of responding to the health needs of this population group.

It is unknown how many children are affected by MDSFA in NZ. This is essential information to enable planning for future services for these children and their families. International literature indicates that the incidence of MDSFA is rising, making this pertinent information for NZ health care service provision (Marklund, Wilde-Larsson et al., 2007; Niggemann & Heine, 2006; Sicherer & Bock, 2006). The participants in this research spoke of the difficulties in obtaining accurate diagnoses, which speaks to the lack of specialist health care professionals in NZ. Epidemiological studies into the number of affected children may highlight the need for additional workforce development so that these children can receive the help they need to maintain their health.

CONCLUSION

This research study has highlighted the experiences of parenting a child with MDSFA as one of being unsupported. This concept is further explicated through the themes 'the experience of isolation', 'the burden of accessing resources', and 'the cost of living with MDSFA'. The findings suggest that health care professionals and educators are underprepared to address the needs of children with MDSFA. Additional research is urgently needed to better understand the population of children impacted by this condition in NZ. Further work is also needed on national clinical practice guidelines so care provision can be consistent and effective.

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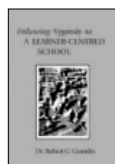
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