Parents' experiences of caring for a young person with neurofibromatosis type 1 (NF1): a qualitative study

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Abstract Neurofibromatosis type 1 (NF1) is a variable and unpredictable genetic condition that can lead to changes to an individual's appearance. Research has started to explore children's and young people's experiences of living with the condition; however, there is a lack of research with parents. This exploratory qualitative study set out to examine parents' experiences of caring for a young person with NF1. Seven parents took part in semi structured interviews which were subjected to a thematic analysis. Three key themes were identified which related to managing the uncertainty of the condition, the impact of an altered appearance, and others' awareness and understanding of NF1. Parents felt that understanding NF1 themselves in order to support their child was beneficial whilst a perceived lack of understanding by others was cited as a significant challenge. Parents require trustworthy information and also more widely call for greater understanding and awareness of the condition.

Keywords Neurofibromatosis type 1 · Body image · Qualitative · Parents

Introduction

Neurofibromatosis type 1 (NF1) is a progressive, genetic condition which is highly variable and unpredictable. It is one of

the most common genetic disorders, affecting 1 in 2500 to 1 in 3000 individuals (Ferner et al. 2007). Approximately 50 % of cases are inherited from a parent, and 50 % are de novo. NF1 is caused by a genetic mutation which can cause tumours to grow on nerve endings; these cutaneous neurofibromas are benign tumours which grow on the skin, often first appearing during the hormonal changes that occur in teenage years. They vary in size and can appear anywhere on the body. The number of neurofibromas present differs greatly between individuals and over a lifetime (Duong et al. 2011).

Café au lait spots (coffee coloured birthmarks) are often the first and most common sign of NF1, and these are often found at birth and are usually evident by 2 years of age. Ten percent of the population have these marks on their skin (Ferner et al. 2007); however, nearly every person with NF1 has six or more of them. The number of Café au lait spots may increase in childhood and occasionally later in life. Other features of NF1 can include Lisch nodules of the iris (small pigmentation in the iris which causes no disturbance to vision), skin-fold freckling (freckling/pigmentation in the groyne and armpits), plexiform neurofibromas (or sub cutaneous neurofibromas) which are diffuse tumours that grow along a nerve and are found in at least 25 % of people with NF1 (Huson 1989), optic gliomas (tumour of the optic nerve), and skeletal complications including pseudoarthrosis and scoliosis. Macrocephaly (large head size) is also common, and short stature is found in around a third of people with NF1 (Hersh 2008). Rare complications include a risk of malignancy, organs being compromised by neurofibromas, seizures, and hypertension (Ferner and Gutmann 2012).

In addition, up to 65 % of people with NF1 may have learning difficulties (Cutting et al. 2004), and attention deficit hyperactivity disorder (ADHD) and autistic spectrum disorders (ASD) are common in this population (Lehtonen et al. 2013). Furthermore, and separate to the presence of ASD or

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ADHD, young people with NF1 have been identified as having lowered social skills and difficulties processing social information (Barton and North 2004, 2007; Huijbregts et al. 2010).

Appearance concerns have been identified as an important aspect of some patients' experiences of NF1 (eg Ablon 1999; Granström et al. 2012; Hummelvoll and Antonsen 2013), and both the unpredictability of the progression of the condition and appearance changes associated with it have consistently been shown to have a detrimental impact on quality of life and psychological adjustment (Samuelsson and Riccardi 1989; Mouridsen and Sørensen 1995; Ablon 1996; Zoller and Rembeck 1999; Gaff et al. 2007; Ferner et al. 2007; Noll et al. 2007; Krab et al. 2009). However, until recently, research in this area has tended to focus on adults with NF1, and there has been a dearth of research into young people's experiences of the condition. In response to this, Barke et al. (2013) conducted a qualitative study with nine young people with NF1 and found that the condition appeared to become a more prominent part of many peoples' lives during adolescence. Young people described feeling that there was a general lack of awareness about NF1 and particular challenges related to managing other people's reactions to their appearance and living with the uncertainty of the condition.

Previous research has pointed to differences in young people's and their parents' perceptions of living with NF1; parents have been found to be more pessimistic on measures such as social inclusion (Sebold et al. 2004; Wolkenstein et al. 2008), and whilst parents play a crucial role in supporting young people to develop the skills needed to positively manage chronic health conditions as they transition from childhood to adulthood (Michaud et al. 2004; WHO 2013), and play a central role in young people's adjustment to visible difference (Prior and O'Dell 2009; Williamson et al. 2010), there has been a lack of research specifically into their experiences of caring for a child or young person with NF1 and their own support needs. We therefore set out to address this gap in the literature, in order to inform the provision of support and care for young people and their parents.

Methods

We took an exploratory in-depth qualitative approach due to the paucity of research in this area. Seven parents (two fathers and five mothers) were interviewed after they responded to adverts for the study; four were recruited from an advert in a Neuro Foundation newsletter (a UK-based support group for people with Neurofibromatosis and their families; <http://www.nfauk.org>) and the remainder through online forums and social media. Four parents reported that their child was the first member of their family to be diagnosed as having NF1, and three reported that their child had inherited the condition.

Two participants (Rachel and Simon) were married to one another and were joint parents of a child with NF1. All parents had a child who had been diagnosed with NF1 and was aged between 14 (the age at which neurofibromas commonly appear) and 24 years of age (in line with the World Health Organisation's upper definition of youth) (WHO 2013). See Table 1 for participant details; pseudonyms are used throughout.

Potential participants contacted the first author and were sent a study information pack. Parents did not have to have a diagnosis of NF1 themselves, although having a diagnosis did not exclude them from participation. Participants were recruited until data saturation was deemed to have been reached.

Interviews were conducted by the first author (JB), digitally audio recorded, and transcribed verbatim. Ellen was interviewed by phone, and the remainder of interviews was conducted face-to-face in the participants' homes. Interviews lasted between 30 min and 1 h. Participants were from across the UK (Northern Ireland, Wales, Northern England, the South West, the South East and Southern England).

The study was approved by the Research Ethics Committee of the first author's host institution. Written informed consent was obtained from all participants, who were also verbally reminded that interviews could be paused or stopped at any point and that they did not have to answer any questions if they were uncomfortable doing so, or were uncertain of their answer. Confidentiality was assured.

NF1 is a highly variable condition, and participants themselves, as well as their children, could be expected to have many diverse experiences of it. As such, thematic analysis was employed in order to maintain the richness of data whilst allowing areas of commonality to be analysed. Each transcript was coded line-by-line, and codes were developed into subthemes and themes, following the recommendations of Braun and Clarke (2006). Individual transcription codes, sub themes, and themes were verified throughout the research process; all themes and interpretations made by the first author were reviewed

Table 1 Interviews with parents: participant demographic details

Participant pseudonym	Gender of child with NF1	Age of child with NF1	Do others in immediate family have NF1? (aside from child)
Gwen	Female	17	No
Michael	Male	20	No
Ellen	Female	24	Yes (child's father)
Angela	Female	14	Yes (Self, child's mother)
Linda	Female	16	Yes (child's father)
Rachel	Male	21	No
Simon	Male	21	No

by the second and third authors and discussed until there was consensus (Morse et al. 2002).

Results

Parents described their children as having a variety of NF1-related symptoms and having been treated by a variety of health professionals in both NF1 specialist and non-specialist clinics. Some families had several members with the condition, and in others, just one child was affected. Yet whilst individual experiences were diverse, there were similarities in the types of experiences parents described. The analysis of interview data identified three key themes: ‘Uncertainty and Diversity’, ‘Appearance and Noticeability’ and ‘Information and Understanding’ which are outlined below. Pseudonyms are used throughout.

Uncertainty and diversity

All the parents discussed the uncertainty of NF1 and the variety of ways in which it could impact on them and their child in terms of medical symptoms, appearance, healthcare, education and the psychological impact.

Parents, including those whose child inherited the condition, explained that they generally knew nothing or very little about NF1 when their child was first diagnosed and described the diagnosis as a shock which caused great uncertainty and concern about the future, “I think your big concern is just what does the future hold. So, how bad can it be? How mild can it be? Where is {my child} going to fit amidst those two extremes?” (Simon). “It was completely new, yeah obviously it’s one of those....it’s not a sexy disease is it?There is no typical scenario with NF so we just didn’t know where it was going to go” (Michael).

In the early stages, just after their child was diagnosed, parents described monitoring their child for symptoms and worrying about the worst case scenario.

Every time you see {child} you just sort of, well especially if he’s been away, it’s like well how are your lumps and your bumps and what, is there anything that’s hurting and then maybe you have a look at it and you think oh yeah ok (Simon)

However, they explained how this changed as time went by and although managing the uncertainty became easier over time, concerns never disappeared completely, “You realise that you have to learn with it, face it as it comes....it {the worst case scenario} may not happen” (Gwen).

Hearing about other people’s difficulties or reading articles about NF1 still reminded parents such as Ellen about previous events and emotions they had experienced;

It {newspaper article about NF} brings back all the struggles that you had because now that I mean {my child} is 24 those problems have faded a bit. You forget about them, you cope with them at the time and you forget about them but that brings it back to you....you forget how you coped with it that it was even there even. You block it out; yeah yeah definitely.....I don’t know how I did it but you just do it don’t you? (Ellen)

There seemed to be a general agreement that it was important to carry on with making life as normal as possible. Several parents felt uncomfortable using the word ‘coping’ in this context because this implied there was a problem, and they felt they had no choice but to manage the situation they were in as best as they could. As Michael explains, ‘not coping’ is not an alternative, so coping is just getting on with the situation and living with the uncertainty and challenges they and their child faced, “you know when you are out people say how can you cope? How do you think you do? You can’t just say I can’t cope and walk away” (Michael).

Appearance and noticeability

All the parents talked about the impact NF1 had, or might have, on their child’s appearance, both in response to the interviewee’s direct questions about appearance and in response to more general questions about the challenges they faced. They discussed how they thought their child felt about their appearance as well as how they, and their child, managed the reactions of others.

Some parents felt appearance concerns were central to their child’s experience of NF1 whilst others felt it had not been an issue for them. Parents’ appearance-related concerns centred around café au lait marks, plexiforms and neurofibromas. Gwen described how a plexiform on her daughter’s cheek meant her daughter avoided looking in mirrors and often expressed concerns about her appearance.

She doesn’t like mirrors and if she gets new clothes, she loves new clothes, but won’t go and look at them on hershe says ‘I wish I didn’t have this lump’ and she would ask me ‘why have I got this lump?’ and things like that (Gwen)

Parents often described their child’s appearance in terms of what was, or was not, noticeable;

She has got a few fibromas.....so she wouldn’t have worn a bikini or something like that because then people would have seen. She has got a plexiform but it is on her back so nobody would see that....the only thing with {daughter} is she has got a large plexiforms on her forearm and she sometimes gets upset about that and people do ask. (Ellen)

Parents also discussed how difficult it could be for them to see their child looking different to others. For many, the appearance changes resulting from NF1 were distressing and caused them great concern “I think even 4 or 5 years ago I couldn’t talk about it without crying, my beautiful little girl...” (Linda).

The very visible nature of some aspects of NF1 meant that it was always apparent to others, and the fact that symptoms cannot always be hidden was upsetting for some parents who felt that the condition would be easier to manage if it could be camouflaged or, as below, if it was not highly visible:

It’s sad I wish she didn’t have it and emotionally yes I do wish I could take it away from her, it’s not like any other condition where you have a lump on your arm you can remove it, you can hide..... but because it’s her face it’s more difficult and it causes problems when she goes outside and I just wish it wasn’t on her face (Gwen)

For many, the visibility of NF1 meant managing other people’s questions and reactions to their child’s appearance and supporting their child to do the same. Participants talked about how difficult it could be when other people asked questions, often at inappropriate times or in insulting ways. However, they differed in how they would like others to respond to their child. Some wished they would just ask about their child’s appearance so that they could use this as an opportunity to pass information on to other parents:

...then I would say if you want, I had some little leaflets, if they wanted leaflets and I would, I’d just say to people that it’s one of those conditions that a nodule could grow on any nerve ending, they’re inside, they’re outside the body we don’t quite know what’s going to happen. (Rachel)

In contrast, other parents thought people should never comment on their child’s appearance. For example, Gwen felt quite defensive about the way others sometimes reacted to her daughter:

I would be very defensive; what are you doing don’t stare at my child she doesn’t deserve that.....in Majorca, she {stranger} actually came to me and said um ‘you don’t mind me asking what’s wrong with her eye’ and I said ‘I do mind you asking’ because I thought you are not concerned you’re nosey. (Gwen)

Information and understanding

Learning about NF and understanding it themselves, as well as ensuring that their child and others (including the wider family, friends, teachers and health professionals) understood it

and how it impacted on their child, were all important issues for the parents in this study.

Participants talked of diagnosis being a time of information seeking in order to understand how the condition might impact on their child’s life in the future. Many looked to The Neuro Foundation in the first instance and also sought information from medical professionals and/or the internet. Their experiences of seeking information in these ways were both positive and negative, and some found that too much information at once was overwhelming.

I didn’t really worry at that stage {diagnosis} because I could not see any lumps or tumors it was just these birthmarks and I thought which was fine but then I went on the internet and read up.....which is the wrong thing to dothen I got quite upset is this what her life’s going to be? (Gwen)

Participants described very mixed experiences with health professionals. Some described challenging situations where professionals had not heard of NF1, or misunderstood it. For example, Gwen described taking her daughter to a dentist who questioned, in front of a group of people, what she had been feeding her daughter because she needed to have seven teeth removed. She explained a subsequent visit to a NF specialist showed a tumour growing on her daughter’s gum which had caused the damage.

There was a tumour in her gum that was attacking it and that’s why she had to get them seven teeth and I knew myself that I was right and I could argue back with her that I was not feeding her junk food and sweets and coke because her diet was restricted it was not everything within her mouth and that made me angry... and it made me think I wasn’t a good mother... I mean she humiliated me in front of those people. (Gwen)

Experiences like this left parents feeling frustrated and angry, and, for some, this led them to believe that health professionals would not understand the condition or situation they were in. However, those who had contact with NF1 specialists had very positive experiences, describing their consultants and nurses in glowing terms, of being able to trust and rely on the information they gave them, and feeling reassured that they were receiving good quality care and advice.

You look at the information and sometimes it focuses on the extreme so you get a little scared by it and just think actually until I know, I won’t take any information off the internet. I’ll wait to hear what the specialists that see {my child} have to say about it.the doctor that we saw seemed to have a good understanding of the

condition rather than fumbling through books and not really knowing. (Simon)

There was a strong feeling that schools did not understand NF1 and the learning difficulties that could be associated with it. Parents reflected that the variability of the condition made it difficult to explain and that very few teachers knew about it. Angela explained that her daughter had an ASD diagnosis, and she felt that this, because it was better known and understood by schools, was the reason she received the support she needed, not the NF1:

There is probably more support for the autism than there is for you know if I just said oh they just have neurofibromatosis and they have you know perhaps some difficulties with social skills and things.....But in a way I feel a bit cheated sometimes but yeah having just a genetic condition almost doesn't seem to be enough sometimes. (Angela)

Discussion

This research aimed to understand parents' experiences of having a child with NF1. The findings demonstrate that managing the uncertainty of NF1 and the diverse ways in which it can impact on young people were key issues for parents. They described appearance changes and managing others' comments and reactions being a concern for their child and felt that managing NF1 was particularly challenging because of the lack of awareness and understanding about it.

Early encounters with professionals and information about NF1, including how it might affect a child's appearance, seemed to have great meaning and a lasting impact for the parents in this study and support previous studies that have included parents (including Benjamin et al. 1993; Cnossen et al. 1998). Parents talked of their child seeing a variety of health professionals; some of whom were NF1 specialists, and some are not. The current study further highlights the value many parents place on specialist involvement in their child's healthcare, particularly against a backdrop in which they worry that many healthcare professionals do not know about or understand NF1. Furthermore, this study also highlights parents' ongoing and changing information needs, both for their child and themselves. Previous studies investigating the information needs of parents with a chronically ill child have also highlighted the individual, shifting and changing information needs of parents (e.g. Hummelinck and Pollock 2006). Changing information needs may also reflect a child's age and a parent's desire to be an intermediary, providing their child with information throughout childhood (Starke and Möller 2002).

Parents discussed their use of a range of coping strategies. Many described initially worrying about the worst case scenario, followed by a period of searching for information and understanding, and then a realisation that they could not function with that level of worry. They described how, over time, NF1 became a part of their lives, but it was always on their mind and events could act as triggers that easily took them back to a very emotional state of being. Similar patterns of adjustment and coping are reported in Grootenhuys and Last's (1997) review of coping and adjustment of parents of children with cancer. Fisher (2001) writes that a change of lifestyle clearly takes place for parents when their child has a chronic condition. What is less clear is how parents manage the changes that chronic illness brings. Adaptation may be related to informational needs being met (Cavallo et al. 2009), individual personality traits (Vermaes et al. 2008), social support and optimism (Grootenhuys and Last 1997). Yet parents in the current study highlighted the challenges of accessing social support due to a perceived lack of understanding of NF1, and finding trustworthy information about the condition was a concern for some parents.

Their child's appearance and, in particular, the noticeability of their child's NF1 was highlighted as being a particularly salient issue. This contrasts with findings from interviews with young people with NF1 (Barke et al. 2013) in which the young people themselves specifically highlighted that it was the uncertain nature of the condition and potential appearance changes rather than the current noticeability of NF1 that caused them the greatest concern. Parents felt that NF1 that was more visible to others impacted to a greater degree on their and their child's lives. They monitored their child's appearance and checked for any changes associated with NF1 and often discussed the condition in terms of quantifying how visible it was. They were concerned that some people did not know how to interact with their child; there were several stories about strangers staring and asking invasive and personal questions. Parental support of young people with an altered appearance has previously been discussed by researchers including Williamson et al. (2010) who found that parents of adolescents who seemed to be coping well with an altered appearance were those who felt confident and able to support their child's integration. Williamson et al. also noted that parents often wanted advice on helping their child to feel positive about their appearance and manage their concerns or negative reactions from others.

There are some limitations to this study. NF1 is highly variable, and interviewing seven parents is unlikely to capture the breadth of experiences of parents with a child with the condition. It is therefore not possible to generalise findings from this study. Yet, although this sample is small, it is appropriate for an exploratory account of parents' experiences. A particular strength of this study is that participants reported their children were treated for NF1 in different types of

settings, including specialist NF1 centres, genetics departments and primary care and were geographically diverse, so they are not reflecting on experiences of a single clinic or NF1 service.

Until now, research has tended to focus on biomedical and treatment aspects of NF1 and has not specifically considered the lived experiences of young people with NF1 and their families. Both the current study and concurrent research exploring the experiences of young people themselves (Barke et al. 2013) have explored this overlooked area. Findings highlight the value parents place on information about NF1, access to health professionals with experience and knowledge of the condition and greater awareness and understanding of it amongst the general public, and teachers. These findings suggest the need for psychoeducational interventions addressing parents' information needs regarding the condition itself and how to support their children at key points of their child's development. As parents highly valued interactions with specialists, this could be delivered by health professionals specialising in NF1. However, more research is needed to identify how young people and their parents can best be supported through targeting interventions during childhood and adolescence in order to promote resilience as they become young adults with NF1.

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Compliance with ethical standards

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Conflict of interest The authors declare they have no competing interests.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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