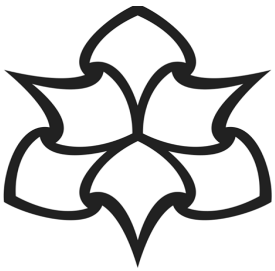

Manchester Metropolitan University

The Lived Experiences of Parents Accessing Special Educational Needs (SEN) Support for their Children with Neurofibromatosis Type 1 (NF1)

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ABSTRACT

Background **-** The lived experiences of parents accessing SEN support for their child with NF1 are overlooked throughout research despite it being common throughout the United Kingdom (UK) with 1 in 20,000 children presenting with NF1 and associated comorbidities. The aim of this study is to understand how parents make sense of their experiences of accessing SEN support for their child with NF1.

Method **-** This study utilised semi structured interviews with eight participants who had children with NF1 and were accessing SEN support. Verbatim transcripts were analysed using an Interpretative Phenomenological Analysis (IPA).

Results **-** Three themes emerged from the data: (1) Educating systems and communities (2) Finding strength amidst adversity (3) A fight to be heard. The first theme illuminated how parents are educating both schools and medical professionals on the requirements of their child with NF1. Parents are often disregarded when many speak of managing their child's needs as a second job. The second theme highlighted the importance of focussing on the child's strengths in the classroom and within their NF1 to encourage them to harness their differences. The final theme gave light to the battle, isolation, and sacrifice of parents to ensure their child is supported.

Clinical Implications **-** This study provides a much-needed insight into parents' lived experiences of accessing SEN support, showcasing the importance of the parent's voice. Schools and medical professionals need to work together to ensure child-centric holistic education is provided which plays to the child's strengths. Two recommendations emerged from the research; a 'get to know my child' poster to enable teachers to know more about the child and any adjustments, and secondly, behaviour change techniques will be utilised to improve the conversations between teachers and parents to enhance shared learning in the education setting.

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INTRODUCTION

Understanding NF1

The National Health Service (NHS) summarises NF1 as a genetic condition whereby non-cancerous tumours grow along the nerves (NHS, 2021). Over half of all new cases of NF1 occur as sporadic mutations, where no parent has NF1 (Miller et al., 2019). The condition can vary between individuals and is characterised by several symptoms such as café au lait spots (brown birthmarks), clusters of freckles, and problems in the bones, eyes and nervous system. Typically, the condition is usually recognised in early childhood when pigmentary manifestations emerge and there is clinical variability within development (Miller et al., 2019). Within the UK there are approximately 25,000 people with a diagnosis of NF1, however, diagnosis can be difficult as some symptoms take years to develop and require thorough testing (NHS, 2021).

In addition to these somatic features, learning difficulties are often prevalent with the most common being autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). Approximately 80% of children with NF1 have a cognitive dysfunction (Garg et al., 2013; Ottenhoff et al., 2020), with the reported number of those with ADHD or ASD being 25%-26% (Garg et al., 2013; Plasschaert et al., 2016). It remains unclear why children with NF1 develop learning and behavioural problems (Biotteau et al., 2020; NHS, 2021).

Plasschaert et al. (2016) found executive function (EF) deficits in children with NF1 despite having significantly less ASD symptoms, providing evidence that ASD is not the main basis for executive dysfunction in individuals with NF1. Further research is required to investigate the intricacies of EF and NF1 as academic difficulties and school attainment are the most common reported effects of NF1 in childhood, which can have implications in later life (Garg et al., 2013).

Often, the extensive literature for developmental dyslexia can be applied to children with NF1 as it is the most common cause of reading disorders in children (Chaix et al., 2018). Research by Chaix et al. (2018) gave support to phonological abnormalities being inherent to NF1, consequently recognising how the neurological underpinnings of NF1 are still being understood. Despite the numerous clinical manifestations associated with NF1, it is still rarely studied. Given these findings, the need for children with NF1 to have bespoke SEN support is apparent.

Rare Conditions and SEN

When considering the impacts of NF1 and SEN support, it is imperative to look at other rare conditions to see how the literature has developed and what can be learnt when producing educational interventions to support children. It is important to note that conditions such as Cerebral Palsy (CP) and Cystic Fibrosis (CF), both with a prevalence of less than 20,000 within the UK (NHS, 2020) have a greater body of research compared to NF1 (Fluss and Lidzba, 2020; O'Connor and McNabb, 2021).

Throughout research it is accepted that CP is associated with cognitive, linguistic, and communicative disturbances (Fluss and Lidzba, 2020), despite this it is often not acknowledged in the school setting, indicating potentially inappropriate SEN support. Similarly, children with CF often do not have ADHD but have reduced specific EF which can impair their educational attainment (Borschuk et al., 2019). Furthermore, one report showed 10% of children under 18 with CF met the diagnostic criteria for ADHD (Tluczek et al., 2014). However, the mechanisms for the development of psychosocial problems within CF remains unclear, like that of NF1 (Chaix et al., 2018).

One curriculum lesson that children with CF and CP find difficult to interact with is Physical Education (PE). Past research has indicated that young people with SEN, CF or CP in mainstream schools' experience fewer options to partake in sports than their peers (Craig et al., 2019; O'Connor and McNabb, 2021). This is also determined by teachers' confidence in their ability to accommodate children who require SEN. However, PE can lead to more cognitive control for individuals with ADHD, providing evidence for intervention development to encourage teachers to have more confidence in educating a child with SEN (O'Connor and McNabb, 2021).

Parents face multiple problems obtaining support in the schooling process (Craig et al., 2019; Verger et al., 2020), one of these being the delay in a clear diagnosis for their child, impacting the ability to get adaptations to their curriculum to suit their needs. Verger et al. (2020) summarised that effective inclusion of those with rare conditions depends on the knowledge of them among teaching staff. For a condition such as NF1 many teachers have little to no knowledge on what support should be given to these individuals (Foster et al., 2022). As the development of ADHD is often related to more specific EF, teachers and

parents are often oblivious to the support needed, making it difficult for SEN support to be provided (Borschuk et al., 2019).

Barriers to SEN for children with rare conditions

Children with rare conditions need to be viewed through a holistic ecological standpoint (Foster et al., 2022). Often in schools, these children are likely to not have the correct support systems or educational plans in place. Foster et al. (2022) concluded that this is largely due to schools not being equipped to support children with disability due to a lack of understanding of the rare condition in question. This has been summarised in previous literature as being the largest barrier for children with rare conditions not getting the right education plans to help them achieve to their fullest potential (Cleary et al., 2019; Verger et al., 2020; Foster et al., 2022).

Similarly, for individuals with CP the beneficial impact of PE is often neglected for the student's learning and development (Cleary et al., 2019). With the subtleties of the symptoms of ADHD in children with CF, CP and NF1 and the longevity of diagnosis, it is no surprise these students are neglected in education.

Furthermore, due to the late diagnosis prevalent in children with NF1 this can subsequently be a barrier to their education. Learning disabilities are more prevalent in the NF1 population than in the general population with 70% showing ADHD or other neuropsychological deficits (Cutting and Levine, 2011). Children with NF1 also have a higher rate of dyslexia and dyscalculia, which can often lead to further barriers and delays when accessing SEN support due to more tests required (Johansson et al., 2021).

Parental experiences

There is currently a plethora of research considering parental experiences when they have a child with NF1, however, all of this has considered the parents' face-value comments in the form of a Thematic Analysis (TA) or a questionnaire (Pelentsov et al., 2016; Rietman et al., 2018). Leading to a reductionist view to be gathered for parents and has not considered their lived experience or their interpretations of these. One paper by Rietman et al. (2018) used focus groups to consider multiple angles of young adults and children with NF1 and their respective parents. Throughout the analysis parents mentioned 'a need for support

and recognition', this was interpreted by Rietman et al. (2018) as parents having limitations in their environment.

Parents' perspectives were not considered due to the research following a TA, indicating parents may have a view on the support or multidisciplinary working that could support them. One UK study by Barke et al. (2015) highlighted a lack of research into parents' experiences of caring for a child with NF1 and their own support needs. Despite this acknowledgement of research sparsity, this research missed the key aspect of parents' diverse interpretations of their experiences in the environment (Barke et al., 2015). Similarly, Pierre-Louis et al. (2018) discussed the multiple stressors that were presented within their study such as family conflict, medical and emotional needs. However, there was a lack of focus on educational stressors which, as alluded to, can be a significant burden for parents.

Pierre-Louis et al. (2018) concluded that parents are interested in a programme to support the management of stress, but their views were not gathered on who would be responsible for this. Considering this would have provided essential clinical recommendations to support parents and their child's educational setting. Despite the links between NF1 and ADHD/ASD (Garg et al., 2013; Stavinoha et al., 2021) there is yet to be a clear research project allowing parents to discuss these links in an informal manner. Consequently, despite an acknowledgment in considering parental experiences, an IPA has yet to be the preferred method of analysis.

This lack of insight has informed the development of the following research question:

> *'How do parents make sense of their lived experiences of accessing SEN support for their child with NF1?'*

METHOD

Design

A qualitative design was appropriate for this project to understand the nuances of parents' lived experiences of accessing SEN support. The ontological position of interpretivism was encapsulated to understand parental insights into the construction of their realities (Pietkiewicz and Smith, 2014; Larkin et al., 2019), hermeneutic

phenomenological epistemology was also followed to further make sense of parental and researcher interpretations (Pietkiewicz and Smith, 2014).

Due to the rarity of NF1, this study was able to maintain the ontological position and further understand parental lived experiences (Nizza et al., 2021). Often, qualitative research is less common in health research due to the approaches having less value placed on them (Lippe et al., 2017). Exploring SEN support in NF1 in this manner it allowed for more in- depth recommendations and understandings to be drawn from the participants. When children are young, parents are more often their advocates, conducting this study gives these parents a platform to be heard (Lippe et al., 2017).

Participants

The recruitment strategy applied the methods of purposive sampling due to having prior access to the identified sample universe through Childhood Tumour Trust (CTT) and the associated families (Robinson, 2014). Participants expressed interest through email to the researcher and were further contacted with all study information to allow them to decide to participate. Furthermore, the sample had a degree of homogeneity to explore convergence and divergence between participants (Pietkiewicz and Smith, 2014).

Following a strict inclusion and exclusion criteria ensured the right participants for the study were identified through a gatekeeper. Including parents who had a child with a medical diagnosis of NF1 and accessing SEN support, with children under the age of 16 and a prior diagnosis of learning disabilities such as ASD/ADHD. Carefully allowing the exclusion of participants who did not have access to an active internet connection, as all interviews were conducted through video conferencing (Microsoft Teams) and where English was not their first language (Robinson, 2014).

Data collection

As the research took an idiographic approach, a small sample utilising semi structured interviews allowed for participants to have a locatable voice (Robinson, 2014), this encouraged a free-flowing conversation, meaning the researcher followed up on responses that deviated but were not applicable to the questions (Smith et al., 2009). An interview schedule was developed (Appendix A), beginning with an informal open question to build rapport and trust with the participant (Smith et al., 2009). Subsequently, prior to

the interviews, an email exchange with the participant to organise an interview time and to answer any questions took place to further build rapport. The questions related to experiences of accessing SEN support, any notable differences in multiple education settings, if applicable and finally asking the parents to reflect on their own experiences. This further reiterated the idiographic nature of the study.

Data Analysis

An IPA was chosen for this research due to no current research delving into parental experiences of SEN support (Pelentsov et al., 2016). This analysis is best suited to a research study that invites participants to offer rich, in-depth detailed accounts of their first-hand experiences (Smith et al., 2009). Whilst also capturing the philosophical position of the study as it follows hermeneutics, phenomenology and idiography (Smith and Osborn, 2015). The data analysis followed the steps outlined by Smith et al. (2009) as a guide to a successful IPA.

Firstly, verbatim transcripts were read following the philosophy of a double hermeneutic cycle, with the left side of the transcript containing the participants' interpretations of their experiences and the right side containing the researchers' interpretations of the parents' experiences (Appendix B). A master table of themes was constructed for each participant (Appendix C). Common themes were identified in all transcripts (Appendix D), comparing these with each transcript searching for convergence and divergence between the participants (Appendix E). These was then presented in tables including all the identified themes, with relevant codes and quotes (Appendix F).

Rigour

Throughout qualitative research it is imperative to consider rigour in research (Shenton, 2004). Firstly, establishing credibility by using the study to investigate the topic in question of the lived experiences of NF1 and SEN support to ensure trustworthiness of the study. Transferability can be challenging when researching a rare condition such as NF1, by summarising findings succinctly and providing credible analysis it is left to the reviewer to consider transferable inferences (Lincoln and Guba, 1985; Shenton, 2004). By addressing implementation, data collection and reflexivity within this paper, enables a degree of dependability to be established. Finally, confirmability will be established through

highlighting each participant's experiences to inform the outcomes of the research without any bias from the researcher.

Ethical Considerations

Ethical approval was gained from Manchester Metropolitan University (MMU) ethics committee (Reference: 42561: Appendix G). Participants gave full informed consent via video recording before their interview commenced, with a debrief at the end of the interview allowing participants to ask questions and seek further support if necessary, following the MMU distress protocol (Haigh and Witham, 2015). In line with the British Psychological Society (BPS, 2018) ethical guidelines, the researcher showed respect to the participants, expressing sympathy and empathy where necessary whilst also maintaining the structure of the interview. The researcher did not hold any bias and had competence in the appropriate research area to uphold sensitivity towards the participant.

RESULTS

After conducting an IPA analysis there were three emergent themes: 'Educating communities and Systems', 'Finding strength amidst adversity' and 'A fight to be heard'. The convergence and divergence between participants are illustrated in table one.

Table 1. Showing convergence and divergence across participants

Theme	**Participant**							
	Abby	Sarah	John	Lucy	Emma	Gwen	Mollie	Erin
Educating communities & Systems	**X**			**X**	**X**	**X**		**X**
Finding strength amidst adversity	**X**	**X**			**X**	**X**	**X**	
A fight to be heard	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**

Educating Communities and Systems

The first theme resonated with many of the participants, highlighting how the education and the knowledge surrounding NF1 comes from the parents, to schools, communities, and medical professionals. Parents often alluded to having to educate their

schools on what is best for their child, and how their learning is not the same as everyone else:

> '*The first experience was me giving a teaching and a load of paperwork about NF1 and saying what it comes with and that was met with, I don't want to say resistance, but almost dismissive of erm, he's doing fine, he's ok...and so it was again, it was me challenging the education setting on that.'* (Abby)

Abby spoke about her anger and frustration with her child's school, as her child is yet to have a diagnosis of ADHD and they believe there is an overlap with autism too. Abby made sense of this experience in a negative way, living in an environment where her child's education is central to her world but not to that of the school. When discussing this with Abby, my view of her experience was constant dismissal and a powerful voice not being heard. Often in literature surrounding rare conditions these are the key poignant outcomes, it has been demonstrated in many studies how the 'expert parent' is disregarded in both healthcare and education (Lippe et al., 2017; Baumbusch et al., 2018). Further on in my discussion with Abby, it was clear to see the school is not the only place NF1 is unheard of:

> '*I don't think it's called dyspraxia anymore…there's no, even with the local authority there's half a page of information on it, so that's not understood, heard of in a school setting…so my SENCO had to learn what dyspraxia was, because they've never come across it.'* (Abby)

When speaking about the lack of knowledge in the schools and local authority, Abby was disappointed and angry that there was so little understanding not just of NF1 but also learning difficulties such as dyspraxia. Abby again has experienced the world in a negative way, with the burden of NF1 education on her shoulders. This was further interpreted as a lack of awareness of NF1 and associated comorbidities with parents at the front of the education system. Subsequently, this has been demonstrated in online surveys by Pelentsov et al. (2016), where parents were dissatisfied with the knowledge of professionals regarding rare conditions along with the impact this has on the access to the right care and education they require. Comparatively to Abby, Sarah spoke with more acceptance of how some children do fly under the radar and she has become accustomed to writing reports:

> '*I usually write a summary for the teacher of the year he's going into to say 'this is Adam's requirements, this is what the NF1 is' because there is a report they will write, and they would make sure the letter say's Adam.'* (Sarah)

Sarah had a lot of conflict in her interview, she was torn between who should be supporting both her and her son. It was clear how Sarah's interactions with the world regarding her own experience of NF1, and now her sons, have shaped her conflicted view on who and where the support should be coming from. Despite this, Sarah still takes it upon herself to provide updates to the teachers yearly. When consolidating this statement, it was apparent to myself that the school should be taking responsibility, but the onus is still with the parent. Nevertheless, this has been shown in interviews by Paz-Lourido et al. (2020) as the lack of knowledge within the education system of rare conditions such as NF1 can often impact the support provided by the teachers, putting more strain on the parents to educate. Emma also spoke of how disability is largely unknown in her community:

> *'he's never going to get better, better is now. And that's where, so it's trying to explain that to people, and again I think that again it's just around disability in our community and stuff, you know a lot of people just don't get it.'* (Emma)

When Emma spoke of the work she does for the school, she spoke with confusion about how she had to provide yearly updates to the school when this communication should happen in the school already to ensure continuity of educational standards. She did however have empathy for how busy teachers must be and how they might not have time for every child in their class. It is clear to me Emma has made sense of her experiences in both a positive and negative way, having conflict within her communication. Through interpretation it is obvious it is the parents' responsibility to be the educator for NF1, with little to no responsibility in the school. This is replicated in analysis by Paz-Lourido et al. (2020) as they summarised how the educational sector needs more awareness of rare conditions and respect to be given to the children to incorporate them into their education.

Finding Strength amidst Adversity

This theme was expressed through parents speaking of how their child's differences and unique characteristics is a strength that should be celebrated and built upon throughout their time in education. Five out of eight participants spoke about how celebrations should

be made for the achievements their child makes which will be different to their peers, to ensure the child feels supported in school:

> '*They are told they're not good at this, they're not good enough, they're rubbish at that, they can't play sport, but they're not being told, but actually like your knowledge and understanding, you understand the periodic table and you're 10 years old.'* (Abby)

Abby spoke with sadness as to how her child is not celebrated, focussing on how the school system is not holistically driven to those with NF1. Abby also alluded to how positive reinforcement is key especially for children who have SEN, like her son, to ensure they learn how to harness their differences and experience the world in a positive way. When listening to Abby, it became apparent to me how she wanted her child to be viewed beyond NF1. This is often seen in children with rare conditions as they are not embracing their skills and are often overlooked in the school system (Verger et al., 2020). Similarly, Gwen echoed how they should be celebrated and for educators and communities to look past the diagnosis:

> '*…something about each child that you can, get away from that box and just go, 'oh my gosh', she's done this, he's done that and just see them for who they are. And that's all you ever want, to see your child for who they are, not the diagnosis and I've always said this you know he is more than a label.'* (Gwen)

Gwen spoke with hope and optimism when she described her interactions with the school and their handling of Sean's disability. Seeing the world in a positive way was important to Gwen. She wants the school and community to see him just as they would any other child. It was clear to me Gwen wants all children to be seen as more than their disability and accepted for who they are. Gwen's voice has been echoed in past research when considering Phenylketonuria as parents wanted to see their child develop and do the things all other children were doing such as sports or going to a restaurant (Carpenter et al., 2018). When speaking with Mollie, she received an enlightening experience through their doctor when speaking to her daughter:

> '*But he was fantastic with Lauren, you know explaining how her brain works, explaining the positives of being different. Who wants to be neurotypical anyway? And all the things that people who think differently and in a similar way to her have*

> *achieved. So he was, she came away flying and has really embraced, I understand why I'm different now.'* (Mollie)

Mollies' interactions with the world around her have helped her to make sense of her positive experience with a medical professional who encouraged Lauren to have a positive view on herself by showing her the strengths she has. This helped Mollie to speak with joy and hope for her daughter to overcome any adversities she may face throughout her childhood and harness her unique way of thinking. When listening to Mollie speak of this, it was clear the positive look the doctor gave to Lauren helped Mollie to embrace her differences. This is a unique finding within rare conditions, as many parents don't always find positive experiences with healthcare professionals (Lippe et al., 2017), although Carpenter et al. (2018) demonstrated this as something parents want to hear.

A fight to be heard

The final theme was highlighted through the battle and the sacrifice parents have made to get their child understood, NF1 acknowledged, and for the SEN support to be in place. Parents continued to make sense of their experiences with frustration, sadness and anger:

> '*Why is it me that has to go: where are you with Adam? Why? Where's his dyslexia report? Where's his SEN? Where's the review? Have you done this appointment? Where is this? Right now, it is the parent that has to do it rather than the educational system.'* (Sarah)

Sarah was angry and frustrated at the educational system for putting the onus onto her to ensure her child's education is at the centre when the system is supposed to be trusted to look after and harness children's potential. It was clear to me how disappointing and time consuming this was for Sarah, illuminating how the school did not have processes in place to support Adam and the sacrifice Sarah must make daily to ensure Adam is receiving the best possible education. Paz-Lourido et al. (2020) also summarised how there needs to be a distinct relationship between schools, medical professionals and parents to ensure the child is given the support they require, taking some responsibility from the parent and encouraging child-centred holistic care. Abby also spoke of the sacrifice she has had to make:

> '*I'm a proactive parent and I've had to actually change my work and change my job to support Lucas, that's it, that's what I had to do…and I give up the majority of my life giving that support and that's my job as a parent.'* (Abby)

Abby made sense of the journey she's been through with sadness for the sacrifice she has had to make due to the lack of support for her and Lucas. When speaking of the support available, the environment around her has not provided the support needed and she was disappointed in what little is available to her. It was clear to me that Abby had lost faith in the support provided to her and had to sacrifice more than parents of children without rare conditions would. This is supported in one systematic review by Lippe et al. (2017), emphasising how Abby's voice is not unique and is heard across a significant body of research. Abby's sacrifice, loneliness and constant battle was echoed by Lucy:

> '*I just don't get it and I haven't got time for it, and I haven't got energy for anything you know I'm, I've lost friends over it, it's isolating and, like I said before, you're battling a system that set you up to fail. And you've constantly getting trodden on and beaten down'* (Lucy)

Lucy spoke with exhaustion; it was apparent that the toll this has taken on both her life and social circles is immense. Lucy has made sense of this as being both mentally and physically exhausting through the isolation she faces. When I heard Lucy speak it demonstrated how the system is not built to support her and how easy it is to lose support when trying to ensure your child is getting the best from both their education and community. Commonly, isolation is seen across the literature of rare conditions, Pelentsov et al. (2016) saw 58% of parents having lost friends, like Lucy, because of having a child with a rare condition. Isolation and sacrifice were spoken of throughout many interviews, Mollie spoke in depth about the burden it has had on her family:

> *'I feel that we're very alone in this battle. And it does feel like a battle, and because everything that you want, you have to fight for and be able to put the hours in and be able to pay for. Up until now we've been able to do that but once I'm not working that might not be so easy to do.'* (Mollie)

Mollie spoke in depth about not just the emotional battle she has had to face but also the financial battle to ensure Lauren gets the support she needs, speaking of the

potentially limited time they may have left to be able to fully support Lauren. This shows a burden that should not be on parents if the support from education is in place for every child and is tailored to their needs and unique abilities. The isolation Mollie has experienced led to my consideration of a support system for parents of children with rare conditions, something that has been demonstrated in research for CP. Parents have spoken about how specialised community programs provided opportunities for networking with other families to share information for specific CP issues and help to build a community of support (Reid et al., 2011).

CONCLUSION

This research endeavoured to establish how parents made sense of their lived experience of accessing SEN support for their child with NF1. Through an IPA analysis, there were three emergent themes that shone a light on parent's sense making. The first theme titled 'Educating communities and systems' gave light to the work parents do for their child's school, medical professionals, and community to understand NF1 and their child's needs. Parents spoke of the difficulty they have gaining accurate information whilst also taking on the role of an educator. The 'expert parent' has been recognised throughout research both quantitatively (Pelentsov et al., 2016) and qualitatively (Lippe et al., 2017).

The second theme, 'Finding strength amidst adversity', highlights the strength parents witness in their children, looking past the diagnosis and shining a light on the strengths they do have rather than teachers talking of their child's weaknesses. Participants made sense of this with a mix of emotions, some experienced positive attitudes from medical professionals, whilst others did not experience holistic child-centred education and wanted this to change. (Verger et al., 2020) concluded that parents often felt their child was overlooked and not celebrated for their differences, Carpenter et al. (2018) also demonstrated how parents want their child to be included in the activities that children without rare conditions were doing, like the present study.

The final theme emerging from the data was 'a fight to be heard'. This theme demonstrated how parents experience a lengthy battle and sacrifice to be listened to and believed by medical professionals and educators. Parents spoke with frustration, isolation and anger when discussing the battles they have endured to get their children the necessary

support. It was reiterated by participants the loneliness they encounter because of a loss of social support structure, whilst also carrying the 'second job' of ensuring their child is receiving the most bespoke education possible. This informed the research question as parents spoke of the negative experiences they have socially, physically and in some cases; financially endured. It is apparent the sacrifice parents make is not unique to NF1 and is echoed by Lippe et al. (2017) and Carpenter et al. (2018).

Strengths & Limitations

Currently, there is no other qualitative study focusing on parental experiences and sense-making of SEN support in NF1 (Barke et al., 2015). The use of an IPA allows for the parent's voice to be given a platform and delves further than face value into how parents have made sense of their lived experience (Pietkiewicz and Smith, 2014; Carpenter et al., 2018). Previous research has lacked the insight an IPA can bring, with the present study providing grounded knowledge (Pelentsov et al., 2016). Parents experienced isolation and loss of social groups due to friends not understanding the sacrifice needed to support their children, which is not a unique finding (Carpenter et al., 2018).

Despite the strengths and insights an IPA study brings, it is not without limitations. When recruiting for this study, there was an overwhelming response, however, only one father volunteered to take part in the study. Previous research by Paz-Lourido et al. (2020) looked to consider both the teachers and the parents yet did not specify the gender of the parents, giving no insight into any varying experiences. This limits the knowledge, both from the present study, and previous research, due to it being unclear as to whether fathers share the same views and if they have also had a platform for their voices to be heard. Subsequently, as the present study was recruited through the CTT, this may have led to parents who are not as proactive or forthcoming about their struggles not having the opportunity to participate (Robinson, 2014).

Implications and Applications

The findings from the present study suggest more knowledge must be provided to both educators and medical professionals. It was unanimous across the interviews conducted and previous research regarding rare conditions that there is a common lack of knowledge in education systems. Resultantly, this could inform the development of

interventions involving both teachers and parents to discuss any requirements or adjustments their child needs. It would be useful for this to be utilised throughout their education as it allows for a child-centred holistic view within their school time, putting their needs at the centre of plans. As shown by Carpenter et al. (2018) parents want their child to be viewed the same as other children and to partake in the same activities.

Interestingly, throughout this study the knowledge of NF1 from medical professionals was sparse. Previously, research has found that medical professionals feel they have insufficient knowledge and training in delivering bad news to parents (Finan et al., 2015) which may subsequently lead to delays in diagnosis and appear as having a lack of knowledge about a rare condition. However, given the prevalence of NF1 in society (NHS, 2021) it is vital they undergo training to recognise NF1 early to ensure children are benefiting as early as possible from the right interventions to support their development. Furthermore, it would be beneficial to have a linked approach with educators, medical professionals, and parents to enable child centred interventions to be in place quicker which has been echoed throughout the present study.

Reflexivity

When approaching this research question, it was difficult to predict the response I would receive for participation as NF1 was an unknown condition to me. However, with the support of CTT I was able to provide a platform for parents to have a voice for their experiences with SEN support when they may have never had this before. To obtain eight participants and have initial conversations (not leading to an interview) with 15 others was overwhelming and an extremely positive outcome for the study before it had begun. Before conducting my first interview I felt anxious about making a connection with my participants, however, after the first interview and reflecting with my supervisor it became apparent that these participants want their voices to be heard. As I have found in previous research, parents want a platform for their voices and feel this is the only way for them to be heard. Despite not going through an experience like this myself, I found it easy to build rapport as the interviews were conducted over Microsoft Teams, which takes away some formality and likening to a conversation between friends.

Throughout this project, reflection was fluid in conversations with my supervisor about my experiences and difficulties I faced. This gave me an opportunity to rephrase some

questions for different participants, for example, if I knew they had a secondary school aged child I would ask about the transition between schools and their experiences. Likewise, if they had multiple children, it was key for me to understand the dynamic within the family and how NF1 affects them. This led to a richer interview, with more contextual in-depth conversations. One difficulty I encountered within this research was understanding the double hermeneutic cycle and giving a platform for my voice as a researcher to be heard. I have learnt that the researcher's voice is as important as the participants, as this sense-making helps to delve deeper into the participants words and their meaning behind the way they have spoken.

Where next?

The findings from this research illuminated a crucial aspect of support that is missing for parents. By having to sacrifice their social circles and in some cases change their employment, it is clear more support medically, locally and through their child's school must be provided (Carpenter et al., 2018; Verger et al., 2020)

Most importantly, research and education are needed to support the development of cohesive child-centred education plans which are beneficial to a child with NF1. As this research has shown that every child with NF1 is unique, it is crucial to get parental involvement in an education plan to ensure the parent is happy with the level of support given to their child throughout primary and secondary education. This was not captured within the present study but was alluded to in interviews. Additionally, there needs to be holistic involvement from medical teams to allow for accurate, flowing conversations to ensure all sensory and physical adjustments are in place for each child. Finally, it has been demonstrated across this study and others (Finan et al., 2015; Baumbusch et al., 2018) that medical professionals have little to no knowledge of NF1. Given its growing commonality amongst the population, further education and training must be provided to aid accurate and fast diagnosis.

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SECTION TWO: Clinical Recommendations Paper

Word Count: *2,000*

Introduction

The lived experience of parents accessing special educational needs (SEN) support for their child with Neurofibromatosis type 1 (NF1) is unknown despite their being a clear need for a deeper understanding (Barke et al., 2015; Pelentsov et al., 2016; Rietman et al., 2018). To give a platform for these parent's voices to be heard and investigate this research question eight parents of children under the age of 16 with NF1 accessing SEN support through their schools were interviewed. Verbatim transcripts were analysed using Interpretative Phenomenological Analysis following a hermeneutic epistemology (Robinson, 2014).

Through this analysis, three themes emerged from the data; (1) Educating systems and communities (2) Finding strength amidst adversity (3) A fight to be heard. Parents spoke widely of the challenges, battles, and isolation they have experienced whilst trying to get the right support for their child and to have their education put first. For some parents, just getting an NF1 diagnosis took over ten years, and they are still now fighting for the education system to have child centred holistic support to make sure they have the best education possible. These findings suggest that there is a lack of knowledge for NF1 itself and the support needed for the child and their parent both medically and within the education setting (Baumbusch et al., 2018)

Based on these findings, the following recommendations aim to provide support to teachers to ensure child centred holistic education is a priority to a child with NF1. Firstly, due to every child's unique needs with an NF1 diagnosis it is recommended parents provide a 'get to know my child' poster. A lack of knowledge of NF1 within the education setting enhanced the requirement for a resource like this to be developed. This is congruent with previous research by Baumbusch et al. (2018) as parents often must actively seek out information on their child's disorder, showing how a resource like this would give a voice to the 'expert parent'. Lippe et al. (2017) also spoke of how parents took the responsibility to educate themselves through the internet to further gain knowledge on the rare condition.

Parents spoke of how the teaching staff had a lack of understanding in the varying SEN requirements of children with NF1. Maximising the availability of information for schools has been discussed in prior research by Lippe et al. (2017). Behaviour change

techniques (BCT) will be utilised to support teachers in developing a holistic child-centric classroom (Michie et al., 2014). To implement evidence-based research it is imperative to use BCT's to promote optimal behaviour in a population, this will aim to improve communication between teachers and parents (Michie et al., 2011).

RECOMMENDATION ONE: 'GET TO KNOW MY CHILD'

Parents in the current study spoke of having to give monthly updates, sometimes yearly, of their child's condition and needs to the teachers which became a burden for them and in some cases was not followed. Therefore, by making a 'get to know my child' poster at the start of the year utilising the suggested template (Appendix H) will allow for a collaboration between parents, their child and the teachers. When educating a child with NF1 or another rare condition inclusive schooling is important for the child's development and obtaining interdisciplinary care that is sensitive to each life stage of the child (Verger et al., 2020; Verger et al., 2021). Involving the parent allows for sensitive development of the curriculum and making any reasonable adjustments necessary for the child. It has already been seen that schools are adapting to consider children with rare conditions, and by making a poster that can be widely used throughout schools will draw more education and understanding for NF1, which will benefit parents, teachers, and children (Verger et al., 2021).

How will this be beneficial?

By working collaboratively, parents and teachers will be able to develop meaningful lesson plans that are child centred and enable a child to fully participate in their education. The poster will contain sensory requirements and reasonable adjustments which parents are then able to outline the differences with their needs, as it has been highlighted from this study and existing literature that children with NF1 have individual needs (Plasschaert et al., 2016). Including sensory requirements is imperative as research has shown ADHD characteristics are unique to each child and may present subtly (Garg et al., 2013; Plasschaert et al., 2016). Through the development of this, it will allow teachers to make the necessary adjustments and provide support to the children in a holistic way. Enabling this will reduce the stress for parents which has previously been shown as a factor influencing

parents' distrust and lack of faith in the educational system (Lippe et al., 2017; Baumbusch et al., 2018).

Teachers also have fears when they have a child with a rare condition in their classroom as some believe they do not have the correct training (Verger et al., 2021). The poster will also include details about NF1 and how it affects each child uniquely, this will help to benefit teachers by providing insight to their needs. Tips for the classroom will also be included to help teachers understand more about how the child may learn differently to other children in the classroom as some parents spoke of their child needing extra time or explanations in subjects such as maths. This will ensure teachers are appropriately prepared to give children more support or teach in a slightly different way, which is supported by (Lippe et al., 2017).

The poster will give parents the opportunity to also outline any activities their child may struggle with or enjoy, as in the present study, many spoke of how their child couldn't do many physical exercises but for some they still enjoyed football. This can help to inform lesson plans for different subjects as within some SEN schools they may be merged with mainstream education and the poster can help inform teachers who may not have direct experience with NF1 or SEN requirements. Again, being supported within previous research for multiple rare conditions as SEN schools are often only an option for students, showing the versatility of this resource (Garg et al., 2013; Cleary et al., 2019).

How can this be implemented?

When considering implementing this in schools' parents may be able to access this tool through charities such as Childhood Tumour Trust to help support conversations when enrolling their child, whilst also making use of readily available connections (Barker et al., 2016). This could also be made available through SEN schools by giving this to parents before their child starts the new academic year to be able to have the support in place. By having many different modes of delivery this allows the poster to be accessed by all parents of children with NF1 regardless of location. Consequently, this will improve parent and teacher relationships when discussing the SEN requirements of a child with NF1, as it helps take some obligation away from the teacher and allows for collaboration (Broomhead, 2013).

RECOMMENDATION TWO: BCT's FOR EDUCATORS

Introduction

Throughout the present study and previous research, the knowledge teachers have on the right support needed for children with NF1 and other rare conditions such as Cerebral Palsy is very limited (Baumbusch et al., 2018; Cleary et al., 2019). Parents spoke of the frustration they have when educating teachers on NF1 and showing how best to educate their child. It was summarised within the present study that teachers need to have more preparation, education and support when teaching children with NF1 to improve their knowledge of different SEN requirements. Often, additional learning requirements such as dyscalculia are unknown by teachers when this can be a common comorbidity of NF1 which teachers would need to accommodate for (Johansson et al., 2021). Parent-teacher collaboration has had mixed support within research, as it is largely related to socio-economic status (Syriopoulou-Deli and Polychronopoulou, 2019).

To target the lack of knowledge within the education system surrounding NF1 and its associated comorbidities, BCT's will be used to encourage teachers to engage with parents and improve their relationships. It is well established that when managing rare conditions, the 'expert parent' is disregarded and not considered by teachers when it can improve the child's education (Lippe et al., 2017; Baumbusch et al., 2018). Often, teachers are unaware of the stress parents face when they have a child with NF1 and multiple SEN needs which has been echoed throughout research (Broomhead, 2013; Carpenter et al., 2018). This recommendation will improve teachers' conversations with parents, and subsequently their overall teaching style to those with NF1.

Firstly, one BCT will be utilised in the education setting to encourage teachers to speak with parents regularly. At the start of the academic year, teachers will produce a plan with parents to speak with them monthly, this can be altered to suit both the parents and teachers needs and schedules (BCT 1.4 Action Planning; Michie et al., 2013). By engaging regularly, this will harbour meaningful conversations and encourage teachers to have an open mind and respect that a parent of a child with NF1 and SEN requirements may know more than they do about the child's condition and needs (Baumbusch et al., 2018). Teachers will then be able to modify learning and create lesson plans with the parents' support. With these meetings occurring at regularly scheduled intervals, it allows the teachers to remain

up to date with the child's progress and any changes that may have occurred which can be supported through the classroom.

Furthermore, to improve learning and relationships within the school, teachers will share their learning between their colleagues in quarterly meetings (BCT 12.1 Restructuring the physical environment; Michie et al., 2013). This will enable teachers to share different techniques they have implemented for educating a child with NF1 which may include changes in the physical classroom environment or changes in their teaching style to allow for the child with NF1 to benefit more from their education. Teachers can also discuss any NF1 comorbidities or learning difficulties they have encountered and share experiences as well as knowledge. Within the present study, parents spoke of how dyscalculia and dyspraxia (developmental coordination disorder; DCD) were unknown in their schools. This recommendation will encourage teachers to support one another if they are struggling with making lesson plans or developing ways to improve their classroom (BCT 3.2 Social Support; Michie et al., 2013).

How will this be implemented?

Consequently, to implement these BCT's into the education setting a 'teacher training pack' may be developed to inform teachers on how to have meaningful conversations with parents and how to get the most from these conversations. This pack can be distributed to both SEN and mainstream schools as from the present study children with NF1 are often placed in either of these settings. Furthermore, teachers are often attending training courses for SEN (Morrier et al., 2011) and this presents an opportunity to implement this recommendation as an additional module. Showing teachers how to benefit from conversations with parents for SEN requirements and NF1 will allow for better relationships and encourage more empathy between teachers and parents (Broomhead, 2013).

Conclusion

These recommendations are essential for managing parent-teacher relationships and helping to listen to parents' voices when discussing their child's education. Additionally, these recommendations are feasible to implement within the education setting and through parents' supporting charity. The first recommendation can be utilised through NF1

organisations and promoted through their web pages or in person meetings, where applicable, to help parents have meaningful conversations with teachers and allow them to acknowledge and highlight all their child's requirements. The second recommendation makes use of the well-established 'teaching training packs' and in-person meetings to educate teachers to get the most out of conversations with parents. The recommendations can improve children's education by supporting teachers to improve their knowledge on NF1 and have meaningful relationships with parents. These recommendations should be widely promoted throughout the education setting to ensure all children and their parents are best supported with no voice going unheard.

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SECTION THREE: APPENDICES

Appendix A: Interview Schedule

Question to build rapport

Question 1: I would be keen to understand your family dynamic and get to know a little about you and your family. Could you please give me some information about your dynamic?

SEN Understanding and Access

Question 2: What is your understanding of Special Educational Needs?

Question 3: What did the period of knowing your child needs SEN support, to getting the support look like?

Question 4: Can you talk me through your first experience of accessing SEN support for your child?

Overall Support system

Question 5: What are the broad challenges you have faced?

Question 6: How did the length of time the process took impact your faith in the support offered?

Question 7: Where and who has most of your support come from?

Impact of the experience on the parent

Question 8: How has this experience impacted you?

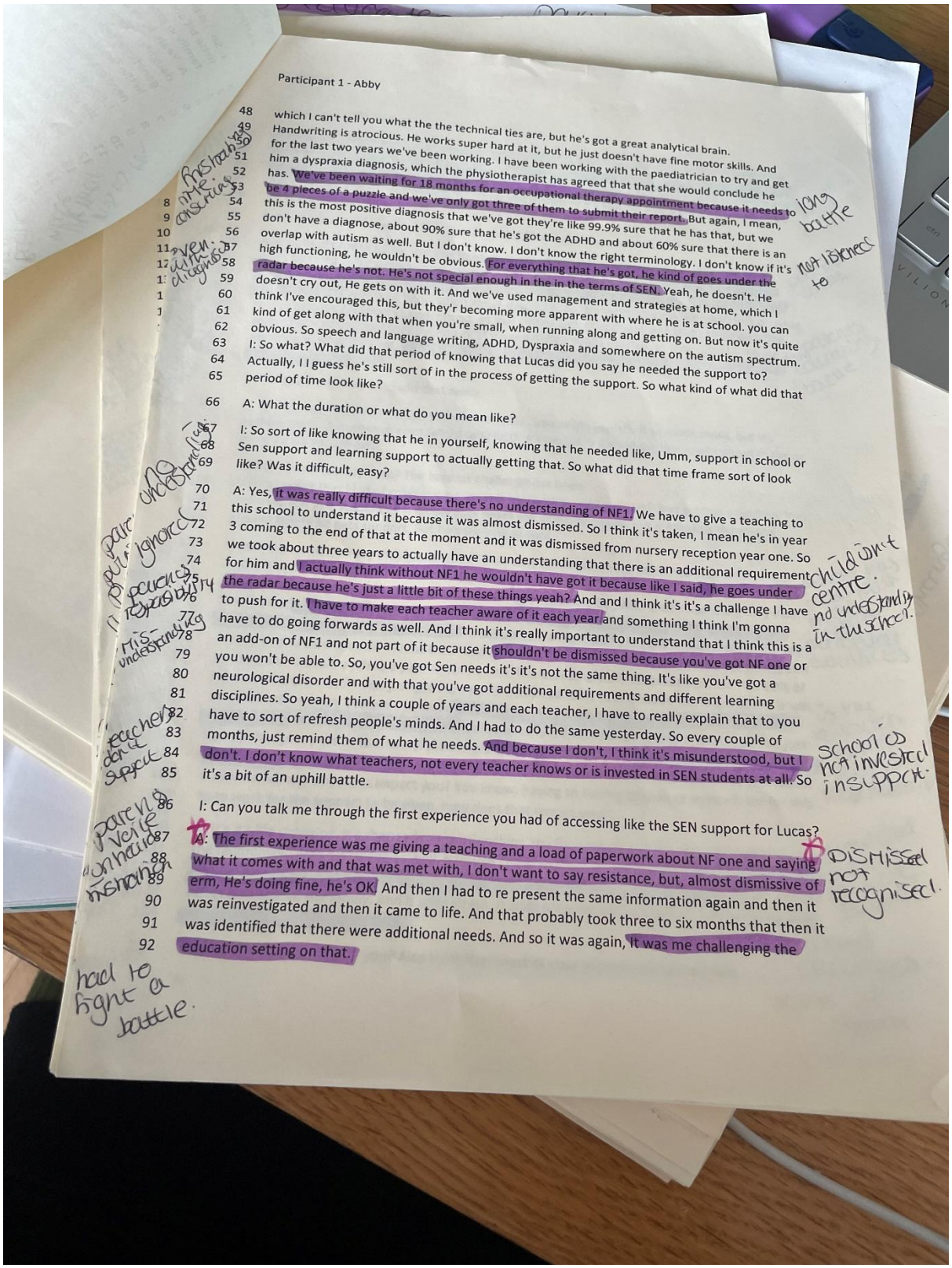
Question 9: How has this experience changed how you perceive the environment and world around you?

Ownership of the interview given to the parent to reflect

Question 10: If you could sum up your experience in three words, what would they be and why?

Question 11: Is there anything you would like to discuss that we have not spoken about yet?

Appendix B: Initial notes and transcript example



Participant 1 - Abby

which I can't tell you what the the technical ties are, but he's got a great analytical brain. Handwriting is atrocious. He works super hard at it, but he just doesn't have fine motor skills. And for the last two years we've been working. I have been working with the paediatrician to try and get him a dyspraxia diagnosis, which the physiotherapist has agreed that that she would conclude he has. We've been waiting for 18 months for an occupational therapy appointment because it needs to be 4 pieces of a puzzle and we've only got three of them to submit their report. But again, I mean, this is the most positive diagnosis that we've got they're like 99.9% sure that he has that, but we don't have a diagnose, about 90% sure that he's got the ADHD and about 60% sure that there is an overlap with autism as well. But I don't know. I don't know the right terminology. I don't know if it's high functioning, he wouldn't be obvious. For everything that he's got, he kind of goes under the radar because he's not. He's not special enough in the in the terms of SEN. Yeah, he doesn't. He doesn't cry out, He gets on with it. And we've used management and strategies at home, which I think I've encouraged this, but they'r becoming more apparent with where he is at school. you can kind of get along with that when you're small, when running along and getting on. But now it's quite obvious. So speech and language writing, ADHD, Dyspraxia and somewhere on the autism spectrum.

I: So what? What did that period of knowing that Lucas did you say he needed the support to? Actually, I I guess he's still sort of in the process of getting the support. So what kind of what did that period of time look like?

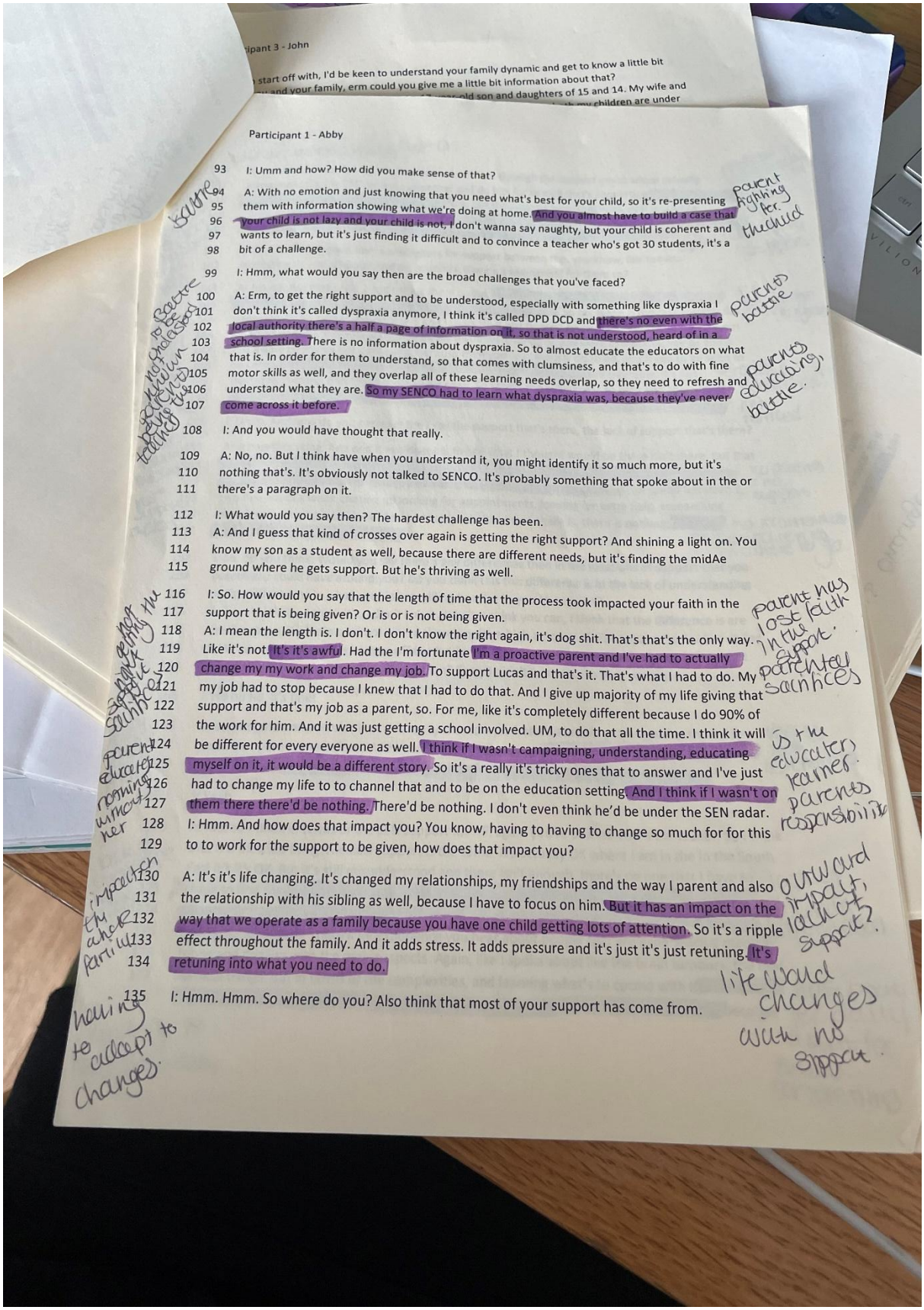
A: What the duration or what do you mean like?

I: So sort of like knowing that he in yourself, knowing that he needed like, Umm, support in school or Sen support and learning support to actually getting that. So what did that time frame sort of look like? Was it difficult, easy?

A: Yes, it was really difficult because there's no understanding of NF1. We have to give a teaching to this school to understand it because it was almost dismissed. So I think it's taken, I mean he's in year 3 coming to the end of that at the moment and it was dismissed from nursery reception year one. So we took about three years to actually have an understanding that there is an additional requirement for him and I actually think without NF1 he wouldn't have got it because like I said, he goes under the radar because he's just a little bit of these things yeah? And and I think it's it's a challenge I have to push for it. I have to make each teacher aware of it each year and something I think I'm gonna have to do going forwards as well. And I think it's really important to understand that I think this is a an add-on of NF1 and not part of it because it shouldn't be dismissed because you've got NF one or you won't be able to. So, you've got Sen needs it's it's not the same thing. It's like you've got a neurological disorder and with that you've got additional requirements and different learning disciplines. So yeah, I think a couple of years and each teacher, I have to really explain that to you have to sort of refresh people's minds. And I had to do the same yesterday. So every couple of months, just remind them of what he needs. And because I don't, I think it's misunderstood, but I don't. I don't know what teachers, not every teacher knows or is invested in SEN students at all. So it's a bit of an uphill battle.

I: Can you talk me through the first experience you had of accessing like the SEN support for Lucas?

A: The first experience was me giving a teaching and a load of paperwork about NF one and saying what it comes with and that was met with, I don't want to say resistance, but, almost dismissive of erm, He's doing fine, he's OK. And then I had to re present the same information again and then it was reinvestigated and then it came to life. And that probably took three to six months that then it was identified that there were additional needs. And so it was again, It was me challenging the education setting on that.



ipant 3 - John

start off with, I'd be keen to understand your family dynamic and get to know a little bit
and your family, erm could you give me a little bit information about that?
old son and daughters of 15 and 14. My wife and
children are under

Participant 1 - Abby

93 I: Umm and how? How did you make sense of that?

94 A: With no emotion and just knowing that you need what's best for your child, so it's re-presenting
95 them with information showing what we're doing at home. And you almost have to build a case that
96 your child is not lazy and your child is not, I don't wanna say naughty, but your child is coherent and
97 wants to learn, but it's just finding it difficult and to convince a teacher who's got 30 students, it's a
98 bit of a challenge.

99 I: Hmm, what would you say then are the broad challenges that you've faced?

100 A: Erm, to get the right support and to be understood, especially with something like dyspraxia I
101 don't think it's called dyspraxia anymore, I think it's called DPD DCD and there's no even with the
102 local authority there's a half a page of information on it, so that is not understood, heard of in a
103 school setting. There is no information about dyspraxia. So to almost educate the educators on what
104 that is. In order for them to understand, so that comes with clumsiness, and that's to do with fine
105 motor skills as well, and they overlap all of these learning needs overlap, so they need to refresh and
106 understand what they are. So my SENCO had to learn what dyspraxia was, because they've never
107 come across it before.

108 I: And you would have thought that really.

109 A: No, no. But I think have when you understand it, you might identify it so much more, but it's
110 nothing that's. It's obviously not talked to SENCO. It's probably something that spoke about in the or
111 there's a paragraph on it.

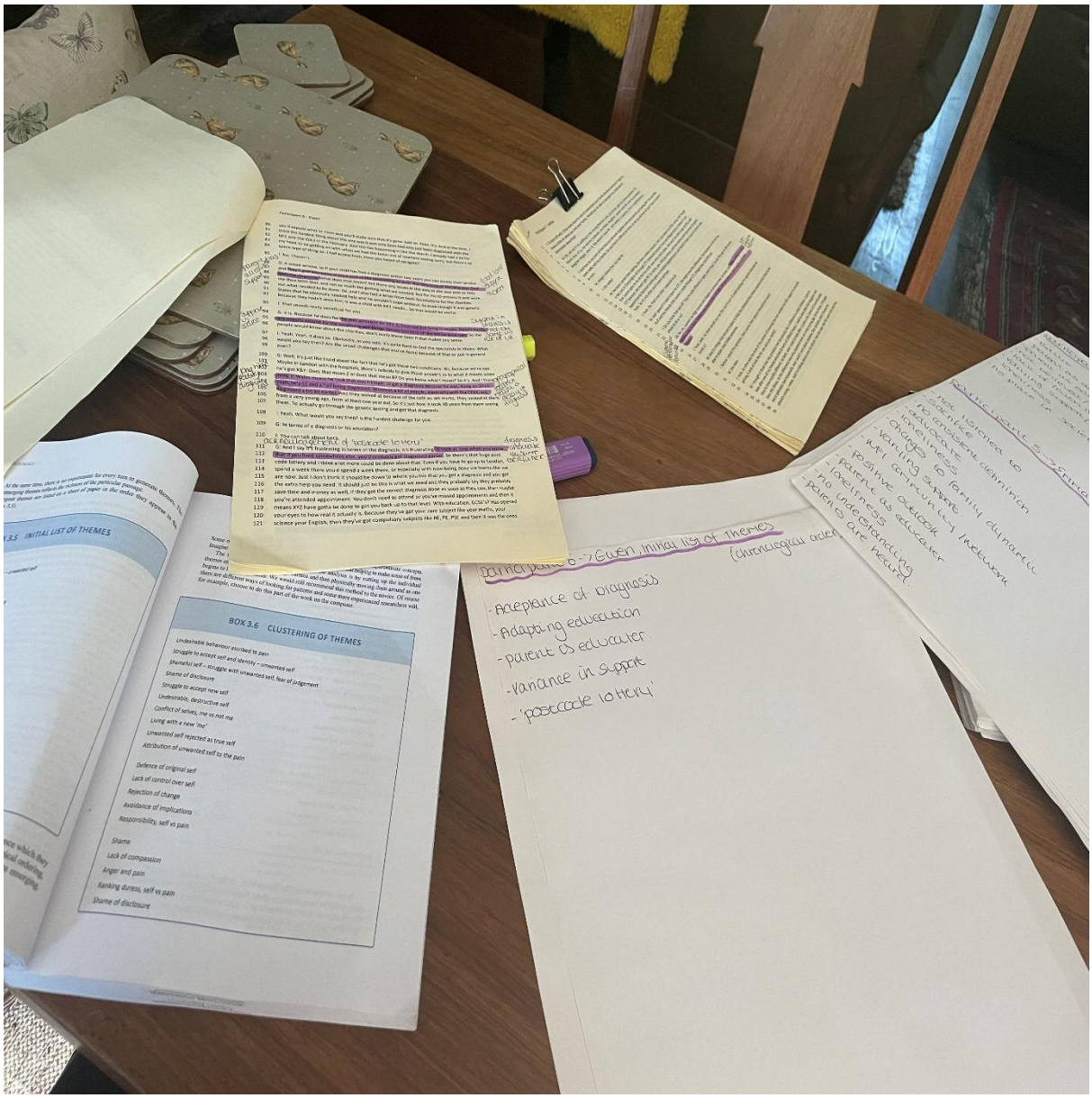
112 I: What would you say then? The hardest challenge has been.
113 A: And I guess that kind of crosses over again is getting the right support? And shining a light on. You
114 know my son as a student as well, because there are different needs, but it's finding the midAe
115 ground where he gets support. But he's thriving as well.

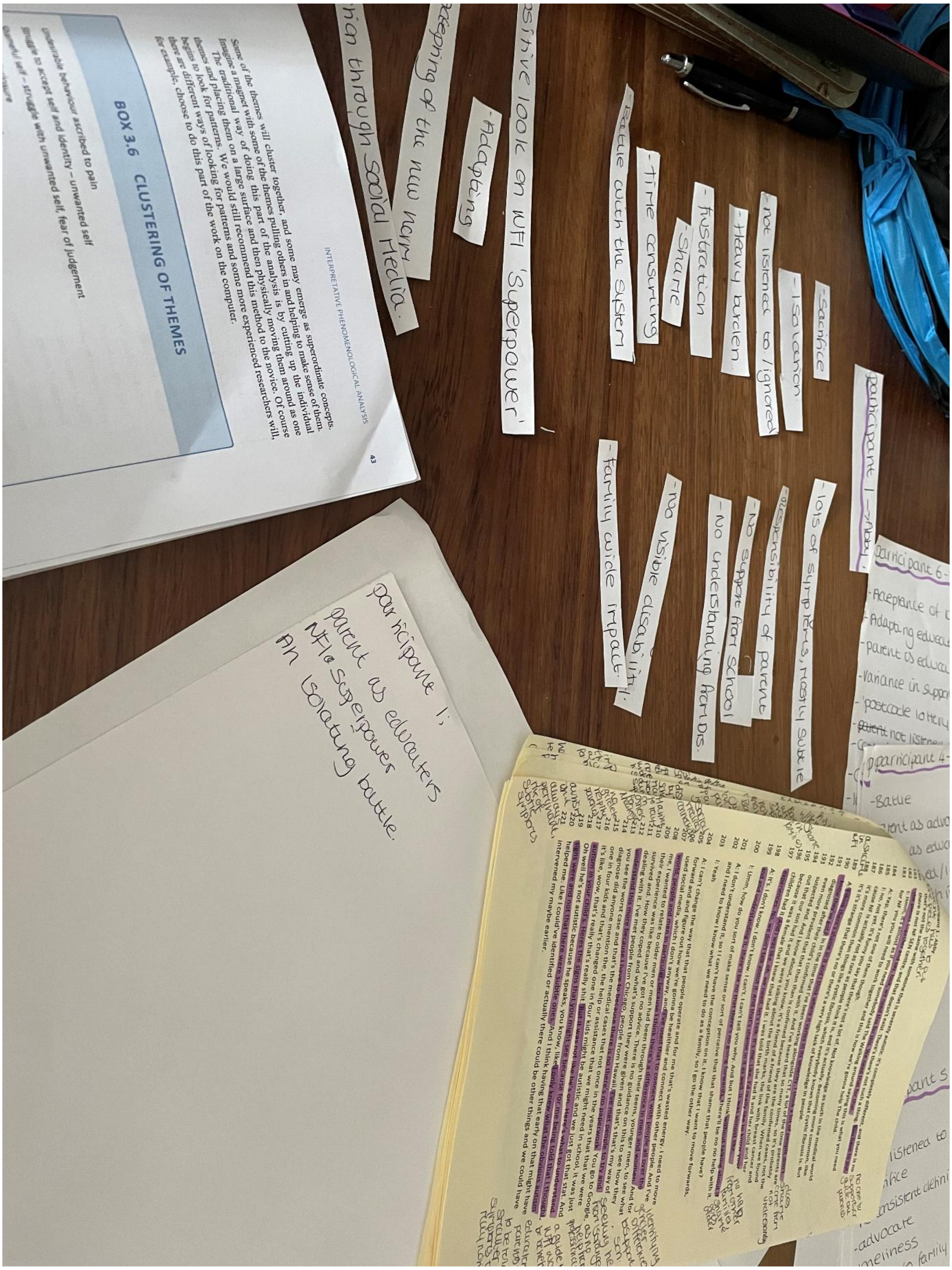
116 I: So. How would you say that the length of time that the process took impacted your faith in the
117 support that is being given? Or is or is not being given.
118 A: I mean the length is. I don't. I don't know the right again, it's dog shit. That's that's the only way.
119 Like it's not. It's it's awful. Had the I'm fortunate I'm a proactive parent and I've had to actually
120 change my my work and change my job. To support Lucas and that's it. That's what I had to do. My
121 my job had to stop because I knew that I had to do that. And I give up majority of my life giving that
122 support and that's my job as a parent, so. For me, like it's completely different because I do 90% of
123 the work for him. And it was just getting a school involved. UM, to do that all the time. I think it will
124 be different for every everyone as well. I think if I wasn't campaigning, understanding, educating
125 myself on it, it would be a different story. So it's a really it's tricky ones that to answer and I've just
126 had to change my life to to channel that and to be on the education setting. And I think if I wasn't on
127 them there there'd be nothing. There'd be nothing. I don't even think he'd be under the SEN radar.
128 I: Hmm. And how does that impact you? You know, having to having to change so much for for this
129 to to work for the support to be given, how does that impact you?

130 A: It's it's life changing. It's changed my relationships, my friendships and the way I parent and also
131 the relationship with his sibling as well, because I have to focus on him. But it has an impact on the
132 way that we operate as a family because you have one child getting lots of attention. So it's a ripple
133 effect throughout the family. And it adds stress. It adds pressure and it's just it's just retuning. It's
134 retuning into what you need to do.

135 I: Hmm. Hmm. So where do you? Also think that most of your support has come from.

Appendix C: Process of theme clustering and emergence of themes




BOX 3.6 CLUSTERING OF THEMES
participant 1;
parent as educaters
NFI a superpower
An isolating battle
- Sacrifice
- Isolation
- Heavy burden
- frustration
- Shame
- Time consuming
- Battle with the system
- Adapting
- family wide impact
- No visible disability
- No understanding from Drs.
- No support from school

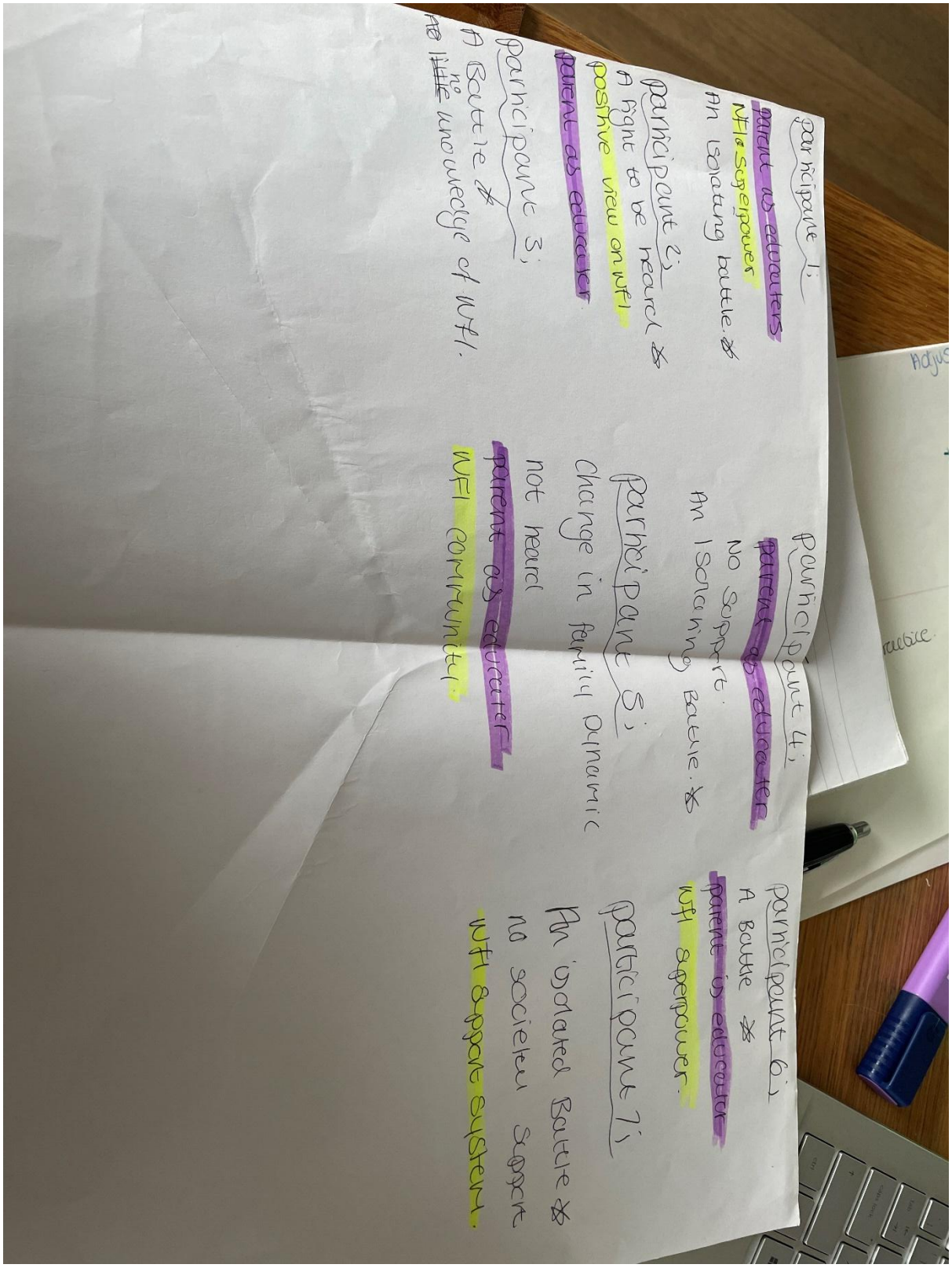
participant 1 -> Abby.
- lots of symptoms, mostly subtle
- battle with the system
- responsibility of parent
- No support from school
- No understanding from DIS.
- No visible disability.
- family wide impact.
- Sacrifice
- Isolation.
- not listened to / ignored
- Heavy burden.
- frustration
- Shame
- time consuming
- Adapting
- positive look on WFH 'Superpower'
- Keeping up the new norm
- Connection through Social Media.

Appendix D: Master table of themes (example)

Table of Themes - Sarah	
1. Parent as educator - Parent is educator - System has failed them - Second job - Sacrifice	'I usually write a summary for the teacher of the year he's going into to say this is Adam's requirements. This is what the NF because there is, there is a report that they will write, and they would actually make sure that the letter says Adam.' (66) 'I mean, once they see an NF letter to take this child has NF. There should be a processed triggered, that would be what I think as a school should do to say, ok, I have this child, the child has NF, these are the processes I need to do.' (95) 'I'm almost like you're doing your job and the job of yeah, of like, a person who was hired to manage your child or something like that. But it's a job in itself yeah.' (123) 'Yeah, so it's difficult. I have a day job so going full speed into how does a child learn? It's another job kind of thing.' (148) 'So instead of having to wait for me to remember to chase up SEN, have you done the EHCP? They should actually have a calendar to say in three months' time, we're gonna do a review.' (220) 'Exhausting, frustrating inappropriate, maybe inappropriate because the educational system doesn't have the process that supports my son…Like for example, I can't book a holiday cause the hospital might say ok your appointment is in…' (269)
	'Being told that, oh we don't need to worry about doing a dyslexia test until he is seven, I'm like well I already know that he has issues because of NF, I don't need you to wait for him to be 7.' (83) 'why is it me that has to go; where are you with Adam? Why? Where's his dyslexia report? Where's his SEN? Where's the review? Have you done the appointment? Where is this? Yeah, it's not, but right now it is the parent that has to do it rather than the educational system, so they should be responsible.' (236)

2. A fight to be heard - Conflicting responsibility - Dismissal of parent and child - No recognition of NF1 **3. Positive view on NF1** - Early intervention - Positive outlook	'And so, I'm very aware of trying to make sure that he doesn't have to go through the same. And early intervention, I think, especially when it comes to child education, is key so that's my focus.' (53) 'I think I'm more proactive than reactive. Again, I know how I can control myself and I can impact Jaden's perception, so I focus more on that.' (261)

Appendix E – Process of searching for convergence and divergence across participants



Appendix F: IPA table demonstrating extracts supporting each theme across participants

(Highlighted extracts were used in the journal report)

Theme	Extract	Code	Interpretation
Educating communities and Systems	'The first experience was me giving a teaching and a load of paperwork about NF1 and saying what it comes with and that was met with, I don't want to say resistance, but almost dismissive of erm, he's doing fine, he's ok' (Abby)	No knowledge of NF1. Parent not believed.	The parent was not heard, despite them being the expert in their child, they were dismissed and not recognised.
	'I usually write a summary for the teacher of the year he's going into to say this is Adam's requirements, this is what the NF1 is because there is a report that they will write, and they would make sure the letter says Adam' (Sarah)	Parent is telling the school what to do.	It is the parents' responsibility to educate the teacher and the school on NF1, when it should be the school ensuring support is in place.
	'I think it's still that constant fight and the jumping through the hoops, erm, and the, you're still just treated as the parent and actually we're the expert in our kids' (Lucy)	Battle. Parent is the expert.	The parent is the expert in her child, with lived experience of the support that is needed, but it's still a battle to be heard.
	'he's never going to get better, better is now. And that's where, so it's trying to explain that to people, and again I think that again it's just around disability in our community and stuff, you know a lot of people just don't get it' (Emma)	Parent is educating. Disability and NF1 are misunderstood.	The parent is having to educated others on NF1, there is a lack of knowledge of NF1 and what it means to be a child with NF1.
	'I'm the kind of parent that the new teacher likes because she said I can put anybody in touch with you and you'll explain what to them and you'll make sure that it's done' (Gwen)	Parent is the expert and the educator.	The parent is educating the teacher on what their child needs, and what additional things they need in place, the parent is able to do this because they are the expert in their child.
	'I don't think it's called dyspraxia anymore…there's no, even with the local authority there's half a page of information on it, so that's not understood, heard of in a school setting…So my SENCO had to learn what dyspraxia was, because they've never come across it.' (Abby)	No knowledge of NF1 and comorbidities. Parent is educator.	If school does not know the condition, how do they create lessons suited to the child.
Finding Strength amist adversity	'What it's helped me understand is that if I can harness my sons' requirements now, and understand them in the right way they can actually be used as a superpower for him' (Abby)	NF1 is used as a superpower	The parent is highlighting how to use their child's differences to benefit them.

	'I started a table with other people that are in his class to find two other NF1 children, and that was a breakthrough for all of us because we all through we were on our own and now we're a little community, so we help each other out.' (Emma)	An NF1 support community	There is a strong NF1 support system, with other parents, they have found an NF1 community. They are now able to rely on people experiencing similar things.
	'Get away from that box and just go, oh my gosh, she's done this, he's done that, and just see them for who they are. And that's all you ever want to see your child for who they are. Not the diagnosis, and I've always said this you know, he is more than a label' (Gwen)	Celebrating differences	The parent wants everyone to see past the diagnosis, see the child for who they are, the child is more then NF1 and SEN, wanting to celebrate them for who they are.
	'They are told they're not good as this, they're not good enough, they're rubbish at that, they can't play sport, but they're not been told. But actually, like your knowledge and understanding, you understand the periodic table and you're 10 years old.' (Abby)	Harnessing child's differences	The parent believes the school do not recognise each child's strengths, should be harnessing their differences.
	'You know, explaining how her brain works, explaining the positives of being different. Who want's to be neurotypical anyway? And all the things that people who think differently and in a similar way to her have achieved…she came away flying and really embraced it.' (Mollie)	Embracing differences	Discussion led to a positive view on NF1 from the medical professional, often unseen.
A fight to be heard	'I'm a proactive parent and I've had to actually change my work and change my job to support Lucas, that's it, that's what I had to do…and I give up the majority of my life giving that support and that's my job as a parent' (Abby)	Parental sacrifice	Parent has lost faith in the support, making sacrifices for their child because the support if not there.
	'Why is it me that has to go: where are you with Adam? Why? Where's his dyslexia report? Where's his SEN? Where's the review? Have you done this appointment? Where is this? Right now, it is the parent that has to do it rather than the educational system (Sarah)	Parent battling to have child's needs at the centre	The school should take the responsibility, it shouldn't be on the parent, an element of support should be given through the school.
	'They help themselves not other people, and in the case of Holly's school, I would say they're a lot more interested in profit than they are care to put it bluntly' (John)	Not child centred	The education setting is not child centred; the child's needs are not a priority to the school; the parent is not getting the support they need.
	'I've lost friends over it, it's isolating and, like I said before, you're battling a system that set you up to fail. And you're constantly getting trodden on and beaten down and, yeah' (Lucy)	Isolation	The parent discusses how it is isolating in their social life, having to fight a constant battle whilst losing support.
	'I say it's frustrating in terms of the diagnosis, it's frustrating it took so long when you know if you lived somewhere else, you'd probably get diagnosed earlier' (Gwen)	Battle to get child noticed	The parent has acknowledged a 'post code lottery', having to fight to get their child the support they need, when a diagnosis

			should be the same everywhere.
	'I feel that we're very alone in this battle. And it does feel like a battle. And because everything that you want, you have to fight for and be able to put hours in and be able to pay for.' (Mollie)	Isolating fight, financial sacrifice	The parent is isolated and has acknowledged how much of a financial burden this is, there are multiple ways this parent is battling the system for their child.

Appendix G: Ethical approval for the current study

Manchester Metropolitan University

Date: 14/05/2022

Project Title: Parental experience of accessing SEN support for children with NF1
PsychREC Ref No.: 42561

Subject: Letter of Approval of research study

Dear Kathryn Booth ,

I am writing to you as the Principal investigator of the project titled "Parental experience of accessing SEN support for children with NF1 " on behalf of the Department of Psychology Research Ethics Committee (PsychREC) to inform you about the outcome of the review of your ethics application. This approval is subject to the following change required: In your PIS, under 'who has reviewed this study?' please put your supervisor's full name and title for clarity (i.e. Dr Joe Keenan).

Document Type	File Name	Date	Version
Additional Documentation	Interview Schedule v1.0	26/03/2022	1
Project Protocol	V3 NF1_SEN Protocol	26/03/2022	3
Additional Documentation	Letter to gatekeeper v1.0	26/03/2022	1
Recruitment Media	Social Media Advert v1	26/03/2022	1
Additional Documentation	Consent-form V0.1	26/03/2022	1
Additional Documentation	Participant-Information-Sheet v1	26/03/2022	1
Additional Documentation	Debrief Sheet template v0.1	26/03/2022	1

I am glad to let you know that PsychREC has granted you favourable opinion for the project to commence (PsychREC Ref No.: 42561 42561).

Please note that the opinion is provided on the grounds that you will comply with all regulations outlined in the application. Any changes to the documentation or study procedures outlined in your application will require the submission of an amendment and approval by PsychREC.

If you have any further questions, feel free to contact me.

Yours Sincerely,

Dr Jasmine Hearn

For help with this application, please first contact your Faculty Research Officer. Their details can be found here

Appendix H: 'Get to know my child' template