An Internet support group for parents of children with neurofibromatosis type 1: a qualitative analysis

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Abstract

Parents of children with neurofibromatosis type 1 (NF1), a rare genetic condition, are at risk for emotional distress. While they may benefit from support groups, they may find it difficult to access support. We conducted an 8-week Internet support group (ISG) with 33 parents (29 mothers, 4 fathers) of children with NF1. Transcripts were evaluated using inductive thematic analysis to determine parental needs and concerns; a process and content theme were identified, with each containing codes and subcodes. In terms of process, parents utilized the ISG to seek out information, share information and experiences, and provide and receive emotional support. Common content codes included medical concerns, psychosocial/cognitive development, and accessing NF1 community resources. These concerns highlight the importance of providing parents with reliable information about their child's condition, providing multidisciplinary support to the children with NF1 and their families, and encouraging involvement in the NF1 community.

Keywords Internet support group · Parents · Neurofibromatosis type 1 · Qualitative analysis

Parents of children with chronic illness are at risk for a variety of psychosocial problems, including social isolation and emotional distress (Chiou and Hsieh 2008; Patino-Fernandez et al. 2008). Difficulty coping with the uncertainty surrounding their child's condition is common (Hinton et al. 2010), particularly when a disease is variable in its presentation. The associated stress can take a toll on numerous aspects of parents' own quality of life, including self-care, marital and other relationships, career and additional life pursuits, and emotional well-being (Tollefson et al. 2017). Moreover, the isolation experienced by these parents may be even more pronounced when their child has a rare condition (Pelentsov et al. 2016; Somanadhan and Larkin 2016), thus narrowing the potential support community of similar others.

Neurofibromatosis type 1 (NF1) is a rare genetic disease that occurs in approximately 1 in 3500 individuals (Tonsgard 2006). While the disease is varied in its presentation across patients, some of the common symptoms of NF1 include café au lait macules, optic nerve gliomas, Lisch nodules, bony abnormalities, and cutaneous neurofibromas. More serious complications include plexiform neurofibromas, malignant nerve sheath tumors, and vasculopathy (Jett and Friedman 2010). These complications often cause visible disfigurement and pain and can at times be life-threatening (Gutmann et al. 2017). Further, learning disabilities and other cognitive problems are prevalent among individuals with NF1 (Gutmann et al. 2017; Levine et al. 2006).

Very little is known about the well-being of parents of children with NF1. However, two studies have identified factors related to parental functioning. First, Reiter-Purtill et al. (2008) found that mothers of children with greater neurological impairment had lower perceptions of social support and higher distress than mothers of children with less neurological involvement. Next, Barke et al. (2016b) documented that parental perceptions of social discomfort and stigma are positively related to the visibility of the child's NF1 symptoms. Finally, in a qualitative study (Barke et al. 2016a), seven parents were interviewed individually about their experiences

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caring for a child with NF1. Common themes included challenges in accessing social support from others who understood their situation and difficulties in obtaining accurate information about the disease.

While parents of children with chronic conditions can benefit from support groups (Korver et al. 2017; Pasold et al. 2010), bringing together these parents can be challenging for numerous reasons, including time constraints, geographical distance, financial barriers, and lack of comfort speaking face-to-face with others about their problems (Creedy et al. 2005; Pelentsov et al. 2016). In recent years, Internet support groups (ISGs) have been able to surmount some of the aforementioned obstacles. For example, ISG users have noted the convenience of having easy, online access to others going through similar challenges, as well as the benefit of being able to discuss personal topics while maintaining some level of anonymity as compared to an in-person group (Malik and Coulson 2008). Moreover, while most of the research on ISGs for parents has been qualitative, a small number of studies have documented quantitative improvements in posttraumatic stress (Sveen et al. 2017), reduced feelings of stigma (Binford Hopf et al. 2013), and increased perceptions of informational and emotional support (Martin et al. 2017). Despite the factors that may make parenting a child with NF1 challenging, including the rarity and varied nature of the disease as well as the myriad of physical, cognitive, and social impairments of affected children, no studies have put forth a qualitative investigation of an ISG for parents of children with NF1.

The purpose of the current study is to provide a qualitative analysis of parental interactions during chat sessions from an 8-week ISG for parents of children with NF1. (The quantitative data from this study was published previously; Martin et al. 2017). In this qualitative paper, we explore both the processes (ways in which parents interacted) and content (topics discussed) from the chat sessions. Through the themes identified, our aim is to determine the unique needs and challenges involved in parenting a child with NF1 that can be used to inform the development of educational and therapeutic interventions. The use of inductive thematic analysis allows the data to come directly from the patients without being influenced by the researcher's preconceived theories or concepts (Braun et al. 2006). This type of qualitative analysis is ideal for the current project, since our knowledge about the concerns and experiences among parents of children with NF1 is limited.

Methods

The Institutional Review Board of the National Cancer Institute approved this study. To be eligible, participants had to be the parent or primary caregiver of, and live in the same household

with, a child with NF1 between the ages 0 and 25 years. Participants also had to be at least 18 years of age, have regular Internet access, and have the ability to read and communicate in English. Parents were excluded if they reported planning to start a new ISG during the 8-week study period, though current, ongoing participation in another ISG was allowed.

Recruitment e-mails were sent to parents with a child enrolled in the NF1 Research Program at the National Cancer Institute and to parents of children enrolled on the NF registry of the Children's Tumor Foundation (CTF). The e-mail included a link to a webpage hosted by CTF that described the study and included an online consent document. The consent contained guidelines governing use of the chat room (e.g., not giving medical advice and being respectful to others), and participants were informed that a mental health professional would monitor communication in the chat room to ensure that these guidelines were followed. Monitors included a licensed psychologist or a psychology staff member (i.e., advanced graduate student, psychology associate) supervised by the psychologist. The monitors did not participate in the discussions or influence the topics of conversation at any point.

Among the 1159 individuals from the CTF NF registry who indicated a willingness to be contacted about research studies and who identified as a parent of a child with NF1 ages 0 to 25 years, 150 names were chosen via a random number generator each week, and e-mails were sent to these groups until a minimum of 30 participants had registered and consented. Online informed consent was obtained from all parents enrolled in the study. A total of 466 e-mails were sent over the course of about 2 months.

Chat sessions were scheduled for one 90-min evening session every week for 8 weeks. The day of the chat, an e-mail reminder was sent to all participants. Users were able to enter written comments or questions on any topics of interest during these sessions. At the conclusion of the 8 weeks, the first, second, and third authors engaged in a sequential process for data analysis. First, the texts from the chats were reviewed by the second and third authors using inductive thematic analysis (Braun et al. 2006). In this approach, the codes are guided by the content of the material rather than by an a priori theory (Braun and Clarke 2014). Initial codes were generated independently by each reviewer and then were compared and reviewed with the first author. This initial review of the data resulted in three codes: information seeking, information sharing, and expressing emotions. A codebook with operational definitions and examples from the transcripts was created. Each transcript was then coded by the first and second authors independently using the codebook. Next, transcripts were compared and any discrepancies were discussed and resolved. If difficulty resolving a discrepancy arose, the third author was consulted. Through this process, full consensus on the codes was reached.

The second step in the data analysis sequence was to enter the coded transcripts in the QSR NVivo Qualitative Analysis Software which aids in review of identified codes. Using NVivo, all excerpts that were placed into the three abovementioned codes were extracted and the first and third authors undertook further qualitative review. During this second review, two larger themes were identified: the process theme (which included the previously identified codes, i.e., how parents interacted with each other) and the content theme (which included descriptions of the topics parents discussed). Both lists were reviewed with the second author. Data within these themes were further separated into codes and subcodes by the first and third authors.

Results

Thirty-three parents (29 mothers and 4 fathers) completed the online consent and enrolled in the study. All reported having one child with NF1, except for one parent who reported having two children with NF1. Thirty-one parents (94%) reported that they did not have a diagnosis of NF1, and two (6%) were unaware of their NF1 status. The NF1-affected children of parent participants ranged in age from 2 to 23 years; age of the children when diagnosed ranged from less than 1 year to 9 years of age (mode = < 1 year). On a single item adapted from Ablon (1996), just over half of parents (52%) rated their child's NF1 as mild, while the remaining parents rated their child's NF1 as moderate (33%) or severe (15%).

Within the qualitative hierarchy, two themes (process and content) were explored. Within the process theme, 3 codes and 9 subcodes were identified, and within the content theme, 4 codes and 11 subcodes were identified (see Table 1).

Process theme codes

Information sharing

Within the information sharing code, the subcodes identified included sharing personal experiences, sharing knowledge and strategies, and providing advice or recommendations.

Sharing personal experiences Participants frequently shared both positive and negative experiences related to parenting a child with NF1. On the positive side, one user noted “My son just applied for his first volunteer job.” Another mother reported that “[the doctor] never made me feel stupid for asking questions or expressing concern about something.” Regarding negative experiences, a user stated “The pediatrician that took

Table 1 Themes, codes, and subcodes

Theme	Code	Subcode
Process	Information sharing	Sharing personal experiences
		Sharing knowledge and strategies
		Providing advice or recommendations
	Information seeking	Asking about personal experiences
		Knowledge seeking
	Expressing emotions	Expressing unpleasant emotions
Content	Health/medical	Offering support
		Expressing appreciation
		NF1 diagnosis
	Cognitive/psychosocial development	NF1 symptoms
		Medical care/treatment/procedures
		Cognitive/academic concerns
		Social functioning
	Family concerns	Mental health
		Transition to adulthood
		Parent coping/self-care
	Resources	Impact on siblings and extended family
		NF community resources
Financial resources/insurance		

over just gave no importance to [my child's] condition or my concerns. I finally changed doctors.”

Sharing knowledge and strategies Users sometimes provided information about aspects of NF1 or strategies they had successfully implemented when dealing with a particular challenge. For instance, in response to a question, one father explained the meaning of “UBOs,” stating that they are “unidentified bright objects” that had been found in his daughter's brain. In terms of personal strategies that were shared, one participant discussed navigating social relationships, which can be difficult for some youth with NF1: “We practice how to ask friends over and how to handle it if they said no.” When discussing how to encourage older children to become more involved in their medical care, one participant shared “I give [my child] a cheat sheet of questions he might want to ask [during doctor visits].”

Providing advice or recommendations Parents in the ISG offered advice about other users' personal struggles in direct and indirect ways. For example, when discussing educational challenges, one participant recommended that a user “have the teachers go to the CTF website for info.” One parent gave advice more indirectly to a mother who said she had not told

extended family members about her daughter's NF1 diagnosis, saying, "Sometimes you can receive a lot of support from others if they know your struggles."

Information seeking

Within the information seeking code, we identified two subcodes: asking about personal experiences and knowledge seeking.

Asking about personal experiences One of the most prevalent subcodes was asking other users in the chat room about their experiences with their children with NF1. These questions crossed a wide range of topics, such as medical procedures, academic accommodations, and various NF1 symptoms. Specific examples included, "Have any of your children had any tumors removed?", "Has anyone had any experience with getting an IEP for a college age student?", and "What made you change doctors?"

Knowledge seeking Participants often sought answers to specific questions in response to a statement made by another participant, often about medical procedures or symptoms. For example, one parent inquired "What's an MRA?" In discussing particular treatments, parents asked questions such as "Are there any other doctors that do this kind of procedure?"

Expressing emotions

Three subcodes identified within the expressing emotions dimension were expressing unpleasant emotions, offering support, and expressing appreciation.

Expressing unpleasant emotions Worry was one of the most frequently expressed emotions among ISG participants. For example, many parents expressed concern about their child's future. One mother said "It does bother me because I do not want him to be lonely in life, and he is an only child." Parents also expressed sadness about their child's disease, with one stating "We feel a lot of heartbreak. No one asked to give our child this disorder." Frustration was another emotion that came up, exemplified in statements such as "I think that is very frustrating that the disorder varies so widely from person to person" and "It drives me crazy!"

Offering support Frequent expressions of support were offered to each other throughout the chat sessions. Some of the supportive comments were akin to cheerleading, such as "Great way to handle that!" and "You're a good parent." Occasionally, parents offered more practical help. One parent stated, "Let me know if I can be of help when you are in DC," and another remarked, "If you thought that would...help your

son manage his depression, I'd be happy to send you my friend's email." In other instances, parents simply validated each other's experiences, as illustrated by statements like "Right, I hear you," and "That's really tough."

Expressing appreciation Many of the participants expressed appreciation and gratitude during the chat sessions. For example, parents shared feeling "grateful that [my child's tumor] has never grown," and "fortunate that my son does not currently suffer physically from NF." Parents also wanted to communicate their appreciation for other ISG users, as illustrated by comments such as, "Thanks for the good information," and "I do appreciate the feedback and encouragement...thank you." Moreover, quite a few parents expressed gratitude specifically for the opportunity to connect with others through the ISG. One mother noted, "This has been good for me, I have never spoken to anyone with older children [with NF1]." Another parent stated that she was enjoying being part of the chat group "because we can all share our experiences and information." Still another parent commented, "It's been great being on this chat! I've really enjoyed getting to know a lot of you."

Content theme codes

Health/medical

Children's health concerns and medical history emerged as one of the most prevalent content codes. The three subcodes identified within this code included the child's NF1 diagnosis, NF1 symptoms, and medical care/treatment/procedures.

NF1 diagnosis Participants frequently discussed their children's NF1 diagnosis, sometimes noting frustration that the diagnosis was missed initially. One parent stated that there were "two developmental pediatricians and a pediatrician [who missed] the NF. It was a pediatric neurologist who diagnosed him in about two minutes." Other parents recalled feeling overwhelmed at the time of diagnosis after learning about all the potential problems that might impact their child in the future. For example, one mother stated, "The pediatrician knew it was NF but scared the heck out of us with all that was going to be wrong." Parents also inquired about other's experiences in communicating with their child about their NF1 diagnosis and its implications, with one mother asking "When did you sit down and explain to your child about NF? How did you first do it?" Additionally, a father in the chat posted that "we haven't told [our daughter] about the possibility of passing NF along yet...have you guys?"

NF1 symptoms Participants often exchanged information about their children's symptoms related to NF1. Some of the symptoms mentioned included Lisch Nodules, café au lait

macules, and plexiform neurofibromas. Parents also described sleep problems, with one parent of a 3-year old with NF1 noting that “it is difficult to get her to bed, and she wakes up in the middle of the night...” Parents occasionally asked questions about particular symptoms, such as “Can you describe leoparding spots?” and “How did you find the plexiform neurofibromas?” Also, some parents of younger children reacted with concern to some of the significant symptoms described by parents of older children. For example, one mother said “My daughter doesn’t seem to be experiencing many of the struggles you’ve all shared. She’s only 6. Should I be waiting for the other shoe to drop?” Another parent expressed concern about the symptoms her child might have in the future, writing “Many times, the more I read, the more I’m scared for her future.”

Medical care/treatment/procedures Children’s medical care, treatment, and procedures made up another commonly discussed subcode. For example, parents asked about others’ experiences with the physicians providing their child’s NF1 care. Additionally, participants inquired about treatments for specific symptoms of NF1, such as migraines and itching. Parents asked questions such as “For those that have NF and migraines, does your typical migraine medicine work?” and “Have you found anything that works well for the itching?” An interest in new treatments for NF1 tumors was expressed as well; one mother asked “Has anyone heard any promising news about possible medications on the horizon? Has anyone tried any?”

Cognitive/psychosocial development

Parents often shared information and asked questions about their children’s cognitive and psychosocial development. Within this broad code, four subcodes were identified, including children’s cognitive/academic functioning, social functioning, mental health, and transition to adulthood.

Cognitive/academic concerns Participants shared about their children’s learning difficulties and academic experiences. For instance, one parent disclosed “So far our hardest NF issues have been related to learning differences.” Parents also showed curiosity about other children’s functioning, asking questions like “Does your son have any cognitive issues?” In addition, questions frequently were asked about how others had obtained support for similar cognitive and academic challenges. Parents inquired about navigating the “educational system and getting services” for younger children as well as “obtaining accommodations [at the] college level.” Beyond inquiries about supportive services, one parent asked about “the best way to educate teachers about NF.”

Social functioning Illustrating another popular subcode, parents often shared about their children’s social challenges. Some parents noted their child’s difficulty making friends, saying, “My son is in two social skills groups and he does not know how to initiate a friendship.” Others shared their children’s experiences of feeling “different” and being socially excluded; for example, one mother stated, “My son...is often hurt by the fact that [his peers] don’t ask him to do things socially.” Additionally, ISG users asked about other parents’ experiences helping their children cope with these types of challenges. For instance, in response to a parent’s disclosure about their child’s struggles, another parent asked “Have you talked to your son about it? Does he want help with social skills?”

Mental health In addition to social difficulties, ISG users discussed concerns about their child’s mental health. In describing emotional challenges, one parent disclosed, “I think my son is having a hard time emotionally although he puts up a tough front” and another shared, “Sometimes I find it difficult to deal with his emotions, he probably is struggling with depression.” One parent described oppositional behavior from her son: “[He is] very defiant, aggressive, sometimes physical.” Participants also inquired about other parents’ insights about their children by asking, “Do you think he’s depressed, or is he sad, frustrated or angry?” They also inquired about how others have coped with their children’s emotional concerns, as exemplified by the question, “Do you currently have a therapist for him to see?”

Transition to adulthood Lastly, the transition to adulthood was a common subcode within the broader code of cognitive/psychosocial development. ISG users asked about others’ thoughts and experiences regarding the transition from high school into college or the workforce, future medical care, and their child’s ability to be self-sufficient and live independently. For example, one mother shared that her son “had a difficult time finding a part time job as his speech can be hard to understand.” Parents described progress as well as limitations in their children’s ability to care for themselves. Specifically, a mother noted, “[My son] has done a good job learning to advocate for himself and I have been forced to let go,” while another remarked that while her son could “cook, do his own laundry, take care of the dog, etc., I don’t think he should drive.” Another parent reported that she was attending seminars on how to support her child’s independence because “he thinks he’s going to live at home until he’s thirty!”

Family concerns

While not as prolific a topic as factors directly affecting their children with NF1, parents also addressed how the disease affects their families more broadly. Two relevant subcodes

included parent coping/self-care and NF1's impact on siblings and extended family.

Parent coping/self-care Questions arose about how other parents practice self-care, such as "...what do you do to take care of yourself when you feel overwhelmed?" Another parent expressed interest in "...hear[ing] how other parents take care of themselves during really tough times." Others shared the importance of self-care, with one parent saying "I think we need to take really good care of ourselves. We do get very worn out."

Impact on siblings and extended family Parents were interested in discussing the impact of their child's NF1 on their other children. Sibling reactions ranged from supportive and caring to ones of frustration, where siblings did not understand their brother's or sister's differences or felt that their sibling with NF1 received extra time and attention from parents. For example, one parent stated that her older (typically developing) daughter "doesn't even really understand it...she has gotten better the past year or so, but she was very resentful for a long time because he was so difficult to get along with." Parents also differed in terms of how much information about their child's condition they shared with others, with one mother sharing that she does not "tell anyone she has it. Not even grandparents know."

Resources

The value of resources available in and for the NF1 community was apparent from many of the comments made by parents in the ISG. Two subcodes that were identified included NF1 community resources and financial resources/insurance.

NF community resources Parents were interested in letting others know about various resources. For example, a mother shared that one NF organization has "patient advocates that can talk" and support parents, and another wanted to share that she had recently "attended the NF Symposium...at Children's in Atlanta." Some participants were curious about others' experiences with fundraising or networking events, such as Cupid's Undie Run and NF walks. The importance of these community resources is underscored by the parents who discussed feeling isolated. One parent stated, "We never told anyone but family and a few close friends [about our child's diagnosis]." Another commented that their family does not know "anyone else with NF1 other than my daughter...I would love to find her a friend who also has it."

Financial resources/insurance Financial concerns were raised a small number of times. For example, one parent asked "Has anyone gotten any sort of removal procedure covered by insurance before?" Another parent shared their experience of their child having "a large part of a plexiform removed by a plastic surgeon and the insurance covered it."

Discussion

This qualitative study is the first to examine the needs and concerns of parents of children with NF1 through an ISG. Parents actively exchanged information in a variety of ways, as highlighted in the process theme. Specifically, the interactions between parents were comprised of posts geared toward asking for information, sharing knowledge and experiences, and expressing support to each other. Understandably, prominent concerns of these parents included their children's health and medical care. Just as notable, however, were the parents' concerns about their children's cognitive, psychosocial, and emotional well-being, as well as the transition of older teenagers to independence. Parents also sought information and shared experiences about various NF1 community resources.

With respect to the content theme, much was revealed about needs and concerns that these parents have, starting around the time of their child's diagnosis. Many parents described frustrating and overwhelming experiences due to pediatricians initially missing the diagnosis or to doctors describing the multitude of possible symptoms that could arise in the future. These comments emphasize the importance of providing emotional support to the families of newly diagnosed children, ideally with a psychologist or counselor working within the multidisciplinary team. While involvement of a mental health practitioner is somewhat common for families of children with more common diseases, such as cancer (Kazak and Noll 2015), more support is needed for families of children with rare conditions, including NF1. The questions that arose about symptoms and current research studies suggest that parents would benefit from being given information about reputable websites on NF1, current clinical trials, and other educational and community resources both at the time of diagnosis and at subsequent clinic visits.

Parents reported concerns about their child's social relationships frequently, indicating the need for psychosocial interventions for these children as well as engagement in the NF1 community. Social skill deficits in NF1 share some features with those seen in attention deficit disorders and, in some cases, with pervasive developmental disorders. However, research has elucidated distinctions between NF1 and these other disorders, both in terms of the social behavioral profile (Plasschaert et al. 2015) and the neurobiological processes linking neurocognition and social functioning (Allen et al. 2016). There is a need for research on the development and implementation of social skills interventions geared specifically toward the unique difficulties in children and adolescents with NF1. Moreover, connecting these children and adolescents to other youth in the NF1 community can offer a source of social engagement with peers who understand some of the challenges inherent in their disease.

Another noteworthy concern revolved around the transition from adolescence to adulthood. Parents expressed

apprehension about whether their adolescents would be able to handle more adult responsibilities. These concerns are shared by parents of children with a variety of health conditions according to a recent review article (Heath et al. 2017). Common themes noted in the review included parental feelings of stress about the child's move to adult health care and uncertainty about how to navigate the process of relinquishing control. Those parents also noted that the process of transitioning to adulthood was linked to developmental considerations, including the child's maturity level, emotional stability, and competence in performing tasks of independent living. In the current qualitative study, several parents mentioned specific resources aimed at helping with this transition period (e.g., independent living programs, vocational schools), and such resources should be shared with parents well before their child prepares to graduate from high school. Additionally, a multitude of NF1 community networks was mentioned, such as websites with chat rooms, fundraising walks, and educational symposiums. Parents spoke highly about their experiences meeting other affected families through these resources, and about using them as a possible means of helping their children to connect with similarly-aged peers with NF1.

Although the question was raised by one participant about how other parents engage in self-care, there were few responses. The fact that this topic was not elaborated upon may suggest that the parents in the ISG were doing well and not in need of additional self-care. However, and potentially more likely, it may be that these parents are not aware of the benefits of even simple self-care routines and/or experience barriers to self-care. Self-care practices include things like healthy eating, getting enough sleep and exercise, accessing social support, and taking time for oneself away from caregiving responsibilities. Research has demonstrated that self-care can play an important role in caregivers of individuals with chronic health conditions. Among caregivers of adult family members with cancer, fewer self-care practices were correlated with higher anxiety and depression scores, and just as importantly, with being less prepared and having lower self-efficacy regarding their caregiving (Dionne-Odom et al. 2017). In a qualitative study of parents of children with eating disorders, parents reported barriers to engaging in self-care that were both psychological (e.g., stress) and informational (e.g., lack of awareness of self-care resources; Patel et al. 2014). Future research should investigate ways to help parents of children with NF1 learn about the importance of self-care and incorporate self-care activities into their routine.

Limitations and future directions

This study should be considered with several limitations in mind. First, our sample size was relatively small, although it allowed for a good (but not overwhelming) amount of

discussion. Nonetheless, a larger sample may have been more representative. Specifically, none of the parents reported having NF1; the needs and concerns of parents with NF1 may be different than those who are unaffected and are areas that need further exploration. Also, most participants were mothers. An ISG with more fathers of children with NF1 may provide more insight into the specific needs of male caregivers. Moreover, to have learned about this study, parents must have been involved in either the CTF registry or had a child enrolled in a research study at the National Cancer Institute. Parents who had sought out contact with these organizations may be different from parents without such involvement, thus further limiting the generalizability.

Another limitation involved the fact that, in order to maximize participation and limit participant burden, we did not collect a lot of personally identifiable information. Examination of more detailed demographic data (e.g., education level of parents) may have provided more context regarding the participant sample and the identified themes. Finally, given that participation in this study was entirely online, we had only the parents' reports of their child's NF1 diagnosis rather than medical documentation of diagnostic criteria being met. While unlikely, we cannot rule out the possibility that some children were misdiagnosed.

Conclusions

This qualitative analysis offers insight into the concerns and needs of parents of children with NF1 that had not been elucidated previously in the literature. This insight can promote the development of clinical services and research studies in these areas of need. The topics of discussion in the chats and the parental needs that were evident underscore the importance of giving parents reliable information about their child's condition and treatment, encouraging involvement in the NF1 community and providing much-needed multidisciplinary support to the children and their families. Connecting parents of children with NF1 with each other through the online group was instrumental in identifying common areas of concern and needs and provided a means of support for the NF1 community.

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Compliance with ethical standards

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 was obtained from all individual participants included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

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