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Children with Facial Morphea Managing Everyday Life: A Qualitative Study

Running Title: Children with Facial Morphea Managing Everyday Life

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What's already known about this topic?

- Facial morphea is a chronic inflammatory skin disorder that can be disfiguring, typically presenting in childhood and adolescence.
- Existing research using quantitative measures indicate that children with facial morphea have a mild to moderate impairment in quality of life.

What does this study add?

- This is the first study to use qualitative methods to explore in-depth the impact of facial morphea on the lives of children and their parents.

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- Children with facial morphea experience significant psychosocial challenges including perceptions of being different, with negative reactions from others, such as intrusive questioning and bullying.
- Management strategies entail normalizing the experience of having facial morphea.
- Treatment effects can be as distressing as the illness itself.

What are the clinical implications of this work?

- Clinicians can support children with facial morphea and their parents by helping them construct explanations in response to intrusive questioning, providing access to resources to manage anxiety and bullying; and connecting children to peer support.
- The potential adverse impact of treatment needs to be considered when developing treatment plans.

SUMMARY

Background: This study explores the everyday experiences of children with facial morphea by examining the psychosocial impact of living with facial morphea and how children and their families manage its impact.

Methods: We used a qualitative, social constructionist approach involving focus groups, in-depth interviews and drawing activities with 10 children with facial morphea 8-17 years of age and 13 parents. Interpretive thematic analysis was utilized to examine the data.

Results: Children and parents reported on the stress of living with facial morphea, which was related to the lack of knowledge about facial morphea and the extent to which they perceived themselves as different from others. Self-perceptions were based on the visibility of the lesion, different phases of life transitions and reactions of others, (e.g. intrusive questioning and bullying). Medication routines and side effects, such as weight gain added to participants' stress. To manage the impact of facial morphea, children and their parents used strategies to normalize the experience by hiding physical signs of the illness, constructing explanations about what 'it' is, and by connecting with their peers.

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Conclusion: Understanding what it is like to live with facial morphea from the perspectives of children and parents is important for devising ways to support children with facial morphea to achieve a better quality of life. Health care providers can help families access resources to manage anxiety, deal with bullying and construct adequate explanations of facial morphea, as well as providing opportunities for peer support.

INTRODUCTION

Juvenile localized scleroderma (JLS) or morphea is a rare chronic, autoimmune, inflammatory disorder resulting in fibrosis of the skin and underlying tissues.[1,2] The estimated annual incidence of morphea is 1 to 3 per 100,000 children[3] and the mean age of onset is 7.3 years of age.[4] The linear type (limb, and/or face/head) is the most common and can have associated seizures, ocular and dental and temporomandibular joint abnormalities with severe cosmetic changes.[4] Facial disfigurement occurring during child and adolescent development might be expected to have a significant impact on self-esteem, psychosocial outcomes and overall quality of life. [5,6] Research on other visible chronic skin conditions among children and young people (e.g. psoriasis and atopic dermatitis), reports lower health related quality of life (HRQoL)[7] and negative impacts on psychosocial functioning.[8,9]

The rarity of morphea poses particular challenges with respect to gaps in knowledge about its etiology, prognosis and treatment [10-12] and also about the HRQoL of individuals with this disorder.[13] To date, little has been written on HRQoL in pediatric patients with morphea, specifically facial subtypes. [5,13,14] A recent study examining the impact of morphea on adults[15] found that morphea affects overall HRQoL, particularly regarding emotional and mental health. Existing studies examining the quality of life in children with morphea reported mild to moderate impact.[13,14,16,17] However, these studies tend to have small patient

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numbers with mixed types of morphea, involving very few cases of facial morphea.[13,17] In addition, the quantitative study measures utilized such as the Child Dermatology Life Quality Index (CLDQI)[18] and the Child Quality of Life Questionnaire (CQOL)[19] are generic instruments that are limited in capturing constructs particular to pediatric patients with facial morphea. The heterogeneity of morphea in terms of the severity and location of lesions and the expansive range of children affected can influence quality of life in varied and complex ways[16] that are not easily translated to standardized categories.

Despite the importance of children's perceptions about the severity and therapeutic outcomes of morphea for clinical decision-making and research, the impact of morphea on children and their families, including the social limitations brought on by the disease[16] are not well understood.[14] We set out to explore the potential psychosocial implications of facial morphea on pediatric patients from the perspectives of children with facial morphea and their parents. Understanding the impact of facial morphea on the everyday lives of children and their families can help health professionals plan and deliver appropriate treatment and support. In addition, findings can inform the development of a quality of life tool to assess the effect of different treatments for children experiencing this illness.

METHODS

To understand the psychosocial experiences of children and their families living with facial morphea, we used a qualitative methodological approach guided by social constructionism. Social constructionism emphasizes how meaning is made, rather than discovered, such that living with and managing a chronic illness, like facial morphea can be understood by examining how culture shapes inter-subjective interpretations of that experience. The emphasis on the 'social' in a constructionist process focuses on the collective, socio-cultural

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generation of meaning.[20] Further, the social construction of reality emphasizes that individual interactions with the world actually shape (or construct) a shared sense of reality (what it means to 'live with' and manage facial morphea).[21] As a key meta-theory for knowledge production in medical sociology, social constructionism has made significant contributions to understanding the social dimensions of illness that are distinct from the biological aspects of disease[22]. These social dimensions are important to the objectives of this study, which are to understand how children construct and manage their illness within the social contexts they occupy.

Setting and Participants

The study was conducted at The Hospital for Sick Children, Toronto, Canada, a tertiary referral centre, between April 2013 and April 2015. Research ethics approval was received from this institution.

Children attending the specialized Morphea Clinic and their parents were invited to participate via a letter from the clinicians associated with the clinic. This letter was followed-up with a telephone call from one of the first two authors who also conducted the group and individual interviews. Parents were the first point of contact as they could best determine whether their child would be comfortable speaking about their experiences. Two parents, from different families, declined to participate stating they felt it might upset their child or themselves at this time. For younger children (under the age of 14) consent was obtained with the parent present and with their assent.

Our sampling approach was purposive [23] with maximum variation to include children of both genders and from a range of ages (8-17), who had been diagnosed with facial morphea for at least six months and parents of children diagnosed with facial morphea. Thirteen families

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(child and/or parent) of 27 potential families agreed to participate in the study. Recruitment ceased when the pool of potential participants had been contacted.

Data Collection

Focus groups (one comprised of children, n=3 and one comprised of parents, n=4) and individual in-depth interviews were conducted in person and via telephone for those who lived outside of the city and were unable to travel. Individual interviews accommodated children and parents who did not feel comfortable speaking about the topic in a group setting or were unavailable to participate in a focus group. Semi-structured interview guidelines were followed in focus groups and individual interviews. Questions were developed from clinicians' experiences and observations of the psychosocial challenges their facial morphea patients experienced, which was explored by asking how living with facial morphea affected children's everyday life in the context of their school, their social activities and family life. Interviews opened with asking participants how they would describe to someone what it was like to live with facial morphea. Closing questions included how they managed the challenges they had identified and what was most or least helpful. Parents were asked to respond to the same questions in regards to their perceptions of their children's lives as well as their own. Individual and group interviews were audiotaped and transcribed into text documents for analysis.

Children and parents who were interviewed in person were asked, following the interview after some rapport was established, to complete a drawing that represented what it was like to live with facial morphea. Drawing as an adjunct method in qualitative research can offer greater portential for studying complex human experiences, particularly within the context of chronic health conditions and involving vulnerable populations and sensitive topics.[24,25] Participants were asked to explain what their drawings meant which generated reflective

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discussion and added insights about their experiences. These interpretations were drawn on in the analysis and used to supplement group and individual data.[26] The images were not analyzed on their own.

Analysis

Data were examined using interpretive thematic analysis because it is compatible with a constructionist qualitative approach that seeks to understand how patterns in the data are socially produced, and actively involves the researcher in explicitly identifying (i.e., interpreting) themes, selecting those of interest and reporting them to the reader. [27] Thematic analysis involves progression from a description of the data—organized to show patterns in the semantic content—to an interpretation of the data, in which underlying ideas, assumptions, and conceptualizations are identified and theorized as shaping and informing the semantic content.[27] This process recognizes the interdependence of conceptual thinking underpinning the research objectives and questions and the data generated from empirical observations developed in situ.[28] A classic set of coding strategies for qualitative thematic analysis, as outlined by Braun and Clarke[27] were followed (Table 1). Analytic and procedural rigor, understood within qualitative methodology as the trustworthiness or quality of the study results,[22] aided verification of findings by employing the following strategies: peer debriefing, thick description, persistent observation and prolonged engagement (Table 2). Social science health researchers (ES and BG) who have extensive experience in qualitative methodology, interviewed participants and analyzed and interpreted the data.

RESULTS

Ten children, ages 8 to 17 years (mean 14 years), participated in the study (N=3 focus group; N= 7 individual interviews), including seven females and three males. Participants had been

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diagnosed with facial morphea for periods between three to 12 years (median 7 years). Thirteen parents of children with facial morphea participated in the study (N=4 focus group; N= 9 individual interviews). Ten were parents to children who were participants in the study. All parents were mothers except for one father. Only one parent per child participated (Table 3).

Our findings are presented in two main themes we identified in the data alongside corresponding sub-themes: 1) The impact of living with facial morphea - experiencing transitions, troubling social interactions, and treatment as disrupting and worse than the illness (Table 4) and 2) Managing the impact of living with facial morphea - managing self-presentation, managing information, and feeling gratitude in connections with "similar others" (Table 5).

Impact of Living with Facial Morphea

Experiencing Transitions: Reaching Puberty and Changing Social Environments

Stress was a dominant feature of living with facial morphea, related to the degree that children felt that their lesions marked them as being different from their peers and intensified by the uncertainty and lack of knowledge about facial morphea. Children's awareness of their physical differences was acute during times of transition related to their age and life stages, such as puberty when, as stated by a young person, "looking matters a lot". Adolescence brought a level of self-consciousness that sometimes resulted in insecurity, a loss of self-esteem and depression. Young people described a heightened attentiveness to others' reactions particularly from the gender they were attracted to. They felt they were "being constantly looked at", which contributed to anxiety and apprehension about their physical and sexual attractiveness.

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Accompanying age and developmental phases that may be entwined with puberty, were transitions that involved moving from elementary to middle and eventually high school. During these times of transition to less familiar contexts, children seemed acutely aware of their perceived difference for the first time. Their previous ease of living with facial differences was attributed to the acceptance of friends who had grown accustomed to their appearance and thus asked fewer questions. In encountering new peers children described feeling abnormal and not accepted "as they are". They had to find ways to fit into a different setting where they and others were not "used to it".

Troubling Social Interactions: Intrusive Questions and Bullying

Children experienced a range of reactions from intrusive questions to name calling and bullying, which impacted their identity and self-worth. They reported being annoyed and upset by "pestering" or "rude" questions, including a particularly harsh example provided by a participant who was asked, "What the 'eff' is wrong with your face, man?" Some children did not talk to anyone about being called names because they feared reprisals that might escalate tensions and "make things worse".

Parents also described observing unwanted stares and annoying questions from others about their child's appearance. They worried this would undermine their efforts to help children feel good about themselves, and add to their child's sense of being different. Although some parents felt they were more affected than their children who seemed better at just "ignoring it". The uncertain nature of facial morphea made it difficult for children and parents to relay the 'right' explanation about facial morphea. For example, young people described the panicked reaction of others if they explained facial morphea simply, as a "skin disease"';

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although another participant expressed annoyance at this reaction responding, "It's not contagious!"

Treatment as Disrupting and worse than the Illness

In cases where the treatment for facial morphea (corticosteroids, methotrexate) involved disruptive medication effects such as weight gain and extreme nausea, as well as intrusive routines (e.g. injections) administered in the home, it was described by children and parents as "worse than the illness". Weight gain further altered children's appearance, sometimes even more than the lesion itself. Such sudden and dramatic changes in physical appearance were very distressing as illustrated by a young woman who described, "crying for hours" when her clothes no longer fit her and she was subject to bullying. For some participants, nausea disrupted family life as parents devised elaborate routines to help their children take the medication and manage the effects. Some parents reported their children as being anxious about meeting with the clinical team because they were "terrified" of being put back on the medications. For children and parents, the uncertainty surrounding the treatment protocol, including the medication's long-term effects added to their stress.

Management Strategies

Managing Self-presentation: Hiding and Disguising

Children and parents described strategies for managing the impact of living with facial morphea that entailed normalizing the experience by minimizing the physical signs. Hiding or disguising the lesions included applying make-up and/or adopting a particular hairstyle, as children illustrated in their drawings (Figure 1). Some children took particular care to position their bodies so others would see only their "best side" in public when, for example, they walked on the street or sat in restaurants. These management techniques relaxed over

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time if children sensed that they and others had "gotten used to it', which involved learning "to ignore it" or "not to take things to heart" about being talked about and bullied. Less commonly, surgery was used as a strategy.

Managing Information: Constructing Explanations

In response to continuous questions posed about their appearance, children and parents constructed explanations they hoped would not set them apart from others. Some explained facial morphea by providing brief truncated facts, as they understood them. More commonly, they avoided experiencing the potential stigma of the illness by describing the lesion as a birthmark, skin allergy or as the result of a fall. Simple answers like, "it's a scar", or "a bruise" were less likely to require further explanations which children felt ill equipped to provide. However, they understood other people were curious, and indicated wanting help to talk about it in ways that did not alienate their peers. Sometimes the struggle to find a suitable explanation evolved over time, as illustrated by a participant who initially explained he was "born with it" but learned to say he didn't know what happened, which halted further questioning. Parents were eager to stem the questioning that might add to their child's self-consciousness, disrupting their sense of being "normal". They wanted more detailed descriptions and explanations of facial morphea so that this might "just shut them up".

Feeling Gratitude: Connections with "Similar Others"

Social relationships and interactions with peers or those deemed to be "similar others" helped children and their parents to normalize their experiences by making comparisons about illness severity or sharing commonalities in their experiences of being different. For example, hospital appointments normalized the experience of facial morphea, enabling children to see it as: "not being the worst thing in the world, and that there are a lot of other things [that I]

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could have had, which are worse". Parents expressed gratitude that facial morphea was not like cancer and at most it was "just like a mark or an indentation" and their lives were "going to be better soon". They also observed their children's perceptions of being lucky, including a mother who described her daughter as feeling fortunate by comparison to others in a camp for children with facial differences because she could use her hair to hide her scar.

Connecting with others who were similar in their differences also helped to normalize children's experiences of living with facial morphea through a process of realizing they were not alone. The daughter who attended the camp described earlier found it comforting to see that she and the other campers with facial differences were the "same as everybody else except they just look different and that's the only thing". Another young woman, who joined an anti-bullying campaign, speaking to girls who shared her experiences of being bullied, expressed gratitude in finding a connection to others via the common human experience of being different. This view is manifested in her drawing where she shows herself as different from the others whose hands she holds in an overall positive picture of social solidarity (Figure 2.).

DISCUSSION

This is the first in-depth qualitative study to explore how children and their parents give meaning to their experiences of living with and managing facial morphea and its impact on their everyday lives. Contrary to previous studies, which report minimal to moderate impact of morphea on children's quality of life,[13,14,16,17] our results indicate that children experienced a range of psychosocial effects, which had to be actively managed. The discrepancy in findings suggests the usefulness of qualitative methodologies to examine the complex, socio-cultural and context bound nature of children's experiences of living with and managing

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chronic illness and its implications.[29] For instance, the effect of facial morphea on face-to-face social interactions, and the resulting perceived stigma, which children and their parents experienced and responded to in order to minimize its impact, can be considered part of the experience associated with being identified as a devalued social group.[30,31] The inclusion of arts-based methods in the form of drawings allowed participants to reflect on their experiences, which helped the participants and the researchers to acquire new insights into the socio-cultural dimensions of this illness experience. [32]

Our findings that children and adolescents with facial morphea experience intrusive questions, perceived stigmatization, feelings of being different and bullying are aligned with those of other studies examining the psychosocial effects on children with other visible chronic skin diseases (eg. psoriasis, Epidermolysis Bullosa),[6,7,33,34] and facial disfigurements such as cleft lip and/or palate.[35,36] Similar to these populations, the effects were especially salient among children in our study during adolescence when physical appearance and peer approval plays an important role.[7,8] However, the rarity, uncertainty and lack of information about facial morphea, brought added challenges to our study participants, exemplified in the distress they experienced around trying to manage the barrage of intrusive questioning about their facial lesions. Without clear understanding about facial morphea, children and parents struggled to provide appropriate answers, heightening their perceptions of being stigmatized. Unlike other skin and facial medical conditions, the mystery surrounding facial morphea, comparable to other stigmatized disorders such as schizophrenia, which have unknown etiologies and prognosis, can bring feelings of loss of control, unpredictability and social distancing.[37]

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A surprising finding in this study is the extent to which children and parents described the deleterious impact that the treatment of facial morphea has on them, including anxiety about the medication's long term effects, and the emotional distress of weight gain, which they viewed as further marking them as being different and socially unacceptable.[38] Other studies have reported that symptoms related to facial lesions, such as fatigue, pain and itching, have negatively impacted children and adult's quality of life and should be duly considered in clinical decision-making.[14,15,39] Our findings suggest that treatment effects must also be taken into account when developing treatment plans. The task of halting the disease course of facial morphea, while reducing symptoms and minimizing the treatment effects as potential determinants of quality of life is challenging for clinicians and requires attention and research.[14] For example, recent initiatives to develop consensus treatment plans for morphea, also need to consider the impact of treatment on children and their families.[2]

To cope with the impact of living with facial morphea, children employed a variety of strategies to normalize the presence of morphea by trying to manage the impressions they made on other people. According to Goffman's [31] analysis of face-to-face social interaction, individuals engage in *mutual monitoring*, whereby the interplay of beliefs and interpretations about a situation shape individuals' attempts to manage how they present themselves and control information in their responses to one another. The imagination and resourcefulness that participants displayed in devising disguises and constructing explanations to manage difficult emotions during social interactions, attests to the social competence children can develop as a result of their illness experience.[40] However, some of these strategies are posited in the disfigurement literature, as useful only as a short-term coping strategy, undermining the potential to develop long-lasting effects.[41] For instance, the strategy of *self-presentation*, which refers to maintaining a sense of acceptability in the face of others' reactions, involves

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hiding or concealing the disfigurement. While this may bring short-term positive outcomes, children may not learn longer–term coping techniques that are rooted in self-acceptance and the rejection of unrealistic beliefs around others' negative perceptions of them. Similarly, *self-protection* strategies used to minimize the sense of being different, by making downward social comparisons with others considered to be worse off, are also short term coping mechanisms. Rather, social support and pro-active strategies to manage intrusive reactions through educating others and assertively confronting negative reactions may mitigate the social impact of disfigurement.[41,42] Children in our study, often with the help of their parents, actively engaged in strategies of informing and sometimes confronting others, but struggled in devising appropriate explanations.

Study limitations include the lack of fathers who participated (n=1). Difficulties in recruiting fathers in pediatric research are well documented. [43]In addition, most children had been diagnosed at least 7 years prior to the study and were past the active phase of their illness. Obtaining the experiences of children in the midst of their illness may have elicited different insights. Recruitment presented challenges with only 13 families (children and/or parents) out of a pool of 27 agreeing to participate. Those who declined may have experienced more visible lesions. The researchers observed that children who participated had less visible lesions, except for two children interviewed by telephone and hence the extent of their lesions was unknown.

In conclusion, this study addresses the lack of knowledge regarding the psychosocial impact of children and their families living with facial morphea. By understanding the challenges that children face, particularly regarding their perceptions of being different and the reactions

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of others, health providers can augment and support children and families in the strategies they are already employing such as: helping them learn how to respond to intrusive queries that are safe and comfortable; developing opportunities for peer support[7,34]; providing access to resources to help with bullying[33]; and attending to the anxiety associated with illness uncertainty and medical treatment. In addition, this new knowledge regarding the psychosocial dimensions of living with facial morphea can inform the development of a quality of life tool and other outcome measures, to aid in treatment planning and clinical decision-making for this pediatric population.

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TABLE 1 Coding Strategies for Qualitative Thematic Analysis

1.	Investigators familiarized themselves with all data, reading and re-reading transcripts, and documenting emerging ideas (extensive memo-writing).
2.	Initial codes were generated by labeling and collating salient features of the data in a systematic fashion across the entire data set.
3.	Themes were developed by further collating coded material into potential groupings.
4.	Groupings were reviewed to establish their consistency with coded extracts (Level 1), and the entire data set (Level 2) thematic 'maps' of the analysis were generated in this process.

Table 2 Analytic and Procedural Rigor Strategies

Peer Debriefing	The use of multiple reviewers at all levels of analysis, including comparison of the transcription process with field notes and tracking of decision-making.
Thick Description	Providing detailed description of the study context, and sample, linked to the data analysis and interpretation put forward.
Participant Observation and Prolonged Engagement	Through reasonable time spent embedded in the substantive literature, with the participants and the research project as a whole.

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TABLE 3 Demographic Characteristics of Participants

Children	n
Gender	
Female	7
Male	3
Age Range	
8 -12	2
13-17	8
Years Diagnosed with facial morphea	
3-6	3
7-11	7
Cultural Background	
European/Canadian	8
Asian	2

Parents	n
Gender	
Female	12
Male	1
Gender of Child	
Female	10
Male	3
Age of Child	
4 -12	3
13-17	10
Years Diagnosed with facial morphea	
6 months – 4 years	5
5 - 12 years	8
Cultural Background	
European/Canadian	10
Asian	2

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TABLE 4 Impact of Living with Facial Morphea

Themes	Quotes - Children and Parents
Puberty and School Transitions	"School was ok, since I went to kindergarten and grew up with the kids, so they accepted me and I was like normal to them. But then when we changed schools that was really hard to do." (young person, age 17*)*
	"So at the age of eleven she started high school with children from the age of eleven to eighteen being in the same school with puberty and all those things going on. It was horrendous for her." (mother)
Intrusive Questions and Bullying	"Like this one friend, she's kind of arrogant, like she's kind of inappropriate. Like she says, 'Is that a hickey on your neck?' (pointing to the facial morphea on her chin and neck area). And I'm like 'That's a little rude.' (young person, age 16)
	"She spent her recesses and her lunches pretty much by herself. She barely had any friends. I mean she had a couple of girls that were actually nice to her, but she says it's probably out of pity." (mother)
	I didn't tell anybody. I just dealt with it and people would just make fun of me and talk about me behind my back, especially my friends as well… I guess I was afraid that if I told someone, then someone would keep doing it even more, and I didn't want to hear it. (young person, age 16)
Treatment as Worse Than the Illness	"It was really just gaining weight that like really got me. Like yesterday I went to the hospital because I've been having like back pain or whatever, and just hearing Prednisone made me cry.... I went from being kind of tall and really skinny to like short and just like really really chubby and like my cheeks were like huge. And so I was bullied a lot for that." (young person, age 17)

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	"And she was sick at least two days every week, because every Friday we'd have to give her methotrexate. And she loathed Fridays. We would have temper tantrums, spitting, scratching, throwing herself on the floor. Me ripping my hair out of my head literally. Begging me not to give her the medication…it was torture for the whole family, for her sisters to see her go through this, for my husband and myself and it just caused a lot of stress and anger in the house". (mother)

Table 5 Managing the Impact of Living with Facial Morphea

Themes	Quotes – Children and Parents
Hiding and Disguising	"I used to just like cover it up with my hair… it kind of looked really awkward like, but then I got used to it." (child, age 13)
	"Like my family, they're the only ones I will ever like put my hair up and let them see my full face… I let my bangs grow long so they're slanted and they hide my forehead right down to my eyes and my hair is long most of the time, people only see one eye and I'm more comfortable with my hair in my face… when there's a wind outside I'm very insecure… I don't like swimming, if I do I don't get my head wet because there's a lot of people and I get very insecure, so I usually just go swimming like with my family, just them. " (young person, age 17)
	"So, I did her make-up for her the one time she was about seven years old and she liked it. I did the concealer and the foundation and I just made this really nice base for her to hide the discolouration and what not. And she looked in the mirror and she had the biggest smile on her face. She was so happy and I just about, I started crying." (mother)
Constructing Explanations	"I said to (daughter): 'Like you need to educate other people about what you have, and if you show them it doesn't bother you and that you're okay explaining what's wrong with you and don't act like you've been in a, you know, traumatic accident or something, well then people will feel more comfortable around you,

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	you know.'" (mother)
	"Some kids were like 'Eew you have a disease.' Like kids are, can be cruel. So she was like, 'Yeah but it's not contagious and I wish it was right now'". (mother, laughing)
	"It gets pretty annoying when you go somewhere and it's pretty visible because everyone's running up an asking you, what is that by your eye? What is that on your face? And then I never have an answer to that. I just say I'm sorry I don't know, or I used to say I was just born with it." (child, age 12)
Connections with Similar Others	"One thing that I found really cool that helped me was by going to a facial difference camp one year. It helped me a lot because I didn't realize how many kids had facial differences, and a lot of them lived with it and showed a lot more than what I have, and that just really helped me to be myself around all these kids." (child, age 14)
	Even though they don't have, you know, the same experience (of bullying), I think everyone goes through it and that's why I realized, you know I'm not alone. And even though I may have this difference in me, like like everyone goes through the same thing, no matter who they are." (young person, age 16)
	"I don't think I'd change anything because I wouldn't be who I am. I wouldn't be doing the things that I am doing right now. So I'm looking to open up my own campaign about anti-bullying so I just want to get the message to everyone that, you know, being kind does get you somewhere, you know. It not only makes yourself happy but others really happy too." (child, age 16)
	"The more she tells her story, the better she feels about it. And she's started to see the glass half full rather than half empty. Because we're constantly pointing out, 'Wow, you know it must be so difficult for that child. Look at, you know, we're so lucky we're here rather than in that situation.' I think she really gets that. (mother)

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Figure 1.

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Figure 2.

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