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"Have We Done Enough?" A Cross-condition Exploration of the Experiences of Parents Caring for A Child with an Appearance-affecting Condition or Injury

Maia Thornton [a], Diana Harcourt [a], Toity Deave [b], James Kiff [c], and Heidi Williamson [a]

[a]Centre for Appearance Research, Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK; [b]Nursing and Midwifery, Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK; [c]Outlook Service, Southmead Hospital, Bristol, UK

ABSTRACT

Children and young people (CYP) with appearance-affecting conditions/injuries report common pervasive psychosocial difficulties, regardless of cause, nature or extent of their visible differences. Parents or carers can also experience psychosocial difficulties and challenges specific to having CYP with a visible difference. Current literature is confined to exploring condition-specific concerns of parents, typically in more prevalent appearance-affecting conditions/injuries, whilst the experiences of parents of CYP with other visible differences are unknown. Thirty-one interviews (parents n = 20, health and support professionals n = 11) and 4 parent focus groups (n = 25) were conducted. Three overarching themes were constructed: "Appearance does(n't) matter" describes the impact of having a child with a socially undesirable appearance; "Being 'battle' ready" reflects parents' desire to arm their child with resources to manage challenges, whilst "Walking the tightrope" reflects parents' lack of clarity about how best to approach this. Findings highlight shared and common cross-condition psychosocial difficulties among parents and carers.

Introduction

Multiple conditions and injuries can result in an appearance that is different from the "norm",[1] often referred to as a visible difference (or "disfigurement"). It is estimated that over 1.3 million people in the UK have a significant visible difference to their face or body due to, for example, craniofacial and skin conditions, burn injuries, limb loss or birthmarks.[2] In an appearance-focused society, an attractive external appearance which adheres to narrow appearance norms, is considered the ideal; as illustrated through the cultural narrative of "beauty is good".[3] Therefore, it is unsurprising that children and young people (CYP) affected by a visible difference, whatever the cause, can experience common, pervasive psychosocial difficulties, such as negative self-perceptions, teasing and bullying, low self-esteem, depression and generalized and social anxiety.[4]

It is important to recognize that some parents and carers adapt well to the challenges of having a child with a visible difference. They may report experiencing positive psychosocial adjustment, such as increased resilience and being able to focus more on meaning and purpose in life[5,6] whilst others can struggle. Evidence suggests that caring for a child with a visible difference can negatively affect parental quality of life across multiple domains. Qualitative studies with parents have identified that a prenatal or antenatal diagnosis of cleft lip and/or palate (CLP) can be distressing[7] and parents of children with burn injuries have reported stress, anger, anxiety and depression.[8] Parental distress can also persist as their child grows up, with reports of guilt,[9,10] psychological isolation[8] and concerns around social stigma.[11]

In typical child development, CYP will often observe, imitate and model behaviors exhibited by caregivers.[12] As a result, parental reactions and adjustment to their child's visible difference can also affect children within the family. Parents of children with a visible difference can be overprotective and discourage their child's independence.[13] Studies with parents who have a chronically ill child (including those with appearance-affecting conditions) also report that parenting distress, stress[14] and overprotection (protective behavior exhibited by parents which is excessive given the child's developmental stage[15,16]) can affect their child's cognitive and social development. Research with siblings of children with CLP and burn injuries has also found that a disproportionate focus on the affected child, plus parental protective behaviors, can limit the social and emotional development of non-affected siblings.[16,17] Consequently, understanding the challenges faced by parents and carers of CYP with visible differences may be beneficial when considering the needs of the whole family.

Existing research in this field is limited to specific conditions, mostly CLP and burn injuries. Although this literature has utility by drawing attention to the challenges faced by these parents, the findings may not be wholly generalizable to other appearance-affecting conditions. Within condition specific research, study samples remain selective, often representing subgroups within a condition.[8] Given the wide variety of appearance-affecting conditions and injuries that cause visible differences among CYP, this limitation has resulted in a large parent population whose experiences and support needs have not been explored or addressed via research. A cross-condition exploration will not only

increase knowledge of the experiences and support needs of parents and carers of children with under researched conditions, but may also underpin the development of cost-effective, cross-condition intervention materials suitable for parents of children with any appearance-affecting condition or injury.

Often, when families have a concern about their child's condition, they approach their healthcare team for advice or support. As a result, healthcare and support professionals typically have a unique and valuable insight into parental experiences.[18] CLP psychosocial research has found that incorporating the health professional voice has helped to identify common individual and family concerns.[19] However, research with health professionals who work with families affected by visible differences remains sparse, limited to certain conditions (e.g. CLP) and selective professions (e.g. Clinical Psychologists and Clinical Nurse Specialists). Further exploration of the experiences of multidisciplinary health and support professionals who work with families will increase understanding of potential cross-condition issues.

The aim of this study was to utilize both the parent/carer and professional perspectives to, 1) explore cross-condition experiences and support needs of parents of children with visible differences, 2) identify any cross-condition risk and protective factors for psychosocial adjustment in parents of children with visible differences.

Materials and Methods

Ethical Approval

Ethical approval was obtained from the University of the West of England Research Ethics Committee (approval code: HAS.12.03.145).

Design

A critical realist perspective underpinned the study design. Critical realism proposes that there is an authentic reality, which is socially influenced, but can be accessed via research[19,20] in order to bring about change. To identify parental support needs, the research was designed to focus on the real-world impact on daily lives. Critical realism acknowledges interactions between biological and functional aspects of health conditions and the social systems within society, healthcare and the family and, therefore, is a useful lens when conducting applied health research with families.[21] Viewing the research through these theoretical lenses allows the researcher to appreciate the applications and limitations of their activities.

Given the limited evidence-base, a qualitative approach was selected using semi-structured interviews and focus groups to collect data. Semi-structured interviews provided a basis for a systematic exploration of topics using pre-set open-ended questions[22] which allowed for participant-led exploration, whilst remaining focussed on the key topic. Focus groups contributed an additional perspective via the inclusion of parent dyads that facilitated social interactions between parents, including questioning and challenging each other; an interactive element that can increase the depth of inquiry.[23]

Recruitment and Participants

To capture as many aspects of parental experiences as possible and to facilitate the identification of cross-condition themes, purposive sampling was utilized to increase variation in appearance-affecting conditions and injuries.[24] The study was advertised via social media and other online platforms hosted by charitable organizations who support individuals with appearance-affecting conditions and injuries, on the social media pages and website of the Center for Appearance Research, and invitations were emailed directly to individuals who had registered an interest in the center's work. Health and support professionals were purposively recruited to understand the experiences and perspectives of professionals who are familiar with common issues faced by families of a child with an appearance-affecting condition/injury. Existing research has previously explored the experiences of nonspecialists[25]; thus, this group was not targeted in the present research.

Focus group participants were recruited during a conference run by the Caring Matters Now charity (https://www.caringmattersnow.co.uk/), who support individuals and families affected by a rare skin condition called Congenital Melanocytic Nevus (CMN). The focus groups were advertised within the conference schedule, three months prior to the event.

In total, 20 parents (16 mothers and four fathers, M age 38 years (SD = 6.1)) and a multidisciplinary mix of 11 health and support professionals were interviewed (all female, mean age 39 years (SD = 8.85)). A sample size of 15–30 interviewees is typical for studies that aim to identify patterns across data.[26] Saturation was noted in both parent and professional groups, as no new information was being generated by additional interviews.[27] The sample size included a range of eight conditions and injuries including congenital conditions, acquired conditions, skin conditions, and limb differences. In total, 25 parents (18 mothers, M age 46 years (SD = 6.43)) attended the focus groups. Seventeen of the children of these parents who had CMN were female and three were male with a M age 12 years (SD = 6.01). Focus groups had between six and eight participants to encourage rich discussion.[26] Further demographic data are presented in table 1, 2, 3,4.

Materials

A public involvement advisory group (parents and health professionals) and existing literature[4,7,8,28] informed the choice of demographic questions about family context and the development of the interview schedule and focus group topic guide. The advisory group reviewed all study materials, which resulted in minor changes. See table 5 for examples of questions and prompts used in the interviews and focus groups.

Procedure

Interviews

Parents and professionals interested in participating contacted the researcher (lead author) by e-mail or left contact details via Qualtrics (an online data collection tool). The researcher then

Table 1. Demographic information of 20 parent interview participants.

	Mean	SD
Age	38	6.1
	N	%
Gender		
Female	16	80
Male	4	20
Relationship to child		
Mother	16	80
Father	4	20
Ethnicity		
Asian other	1	5
White British	16	80
White European	1	5
White other	1	5
White Scottish	1	5
Marital Status		
Single	2	10
Married	17	85
Divorced	1	5
Highest level of qualification		
GCSEs	2	10
A Levels/HND/BTEC/	7	35
Bachelor's degree	7	35
Master's degree	2	10
Doctorate degree/PhD	2	10

Table 2. Demographic information of children of interviewed parents.

	Mean	SD
Age	7	4.17
	N	%
Child gender		
Female	8	40
Male	12	60
Child condition/injury		
Alopecia	4	20
Amputee (Meningitis)	3	15
Cleft lip and palate	1	5
Congenital upper limb difference	5	25
Eczema	3	15
Facial Palsy	2	10
Microtia	2	10
Vitiligo	1	5

Table 3. Demographic information for 11 health and support professional interview participants.

	Mean	SD
Age	39	8.85
	N	%
Gender		
Female	11	100
Male	0	0
Ethnicity		
White British	7	64
White Irish	3	27
White Scottish	1	9
Highest level of qualification		
A Levels	1	9
Bachelor's Degree	3	27
Master's degree	3	27
Doctorate degree	4	37
Job role		
Administrative & support	1	9
Charity managerial & support	3	27
Dental Surgeon	1	9
Family support worker	2	18
Psychologist	4	37

emailed them a study information sheet and a consent form, before arranging a mutually convenient time for the interview.

Table 4. Demographic information of 25 focus group participants.

	Mean	SD
Age	46	6.43
	N	%
Gender		
Female	18	72
Male	7	28
Ethnicity		
White British	17	68
White European	5	20
White Irish	2	8
Not specified	1	4
Highest level of qualification		
GCSEs	2	8
A Levels/HND/BTEC	5	20
Bachelor's degree	9	36
Master's degree	7	28
Not specified	2	8
Relationship to child		
Mother	17	68
Father	8	32
Gender of child		
Female	17	68
Male	3	12
	Mean	SD
Age of child	12	6.01

Participants could participate in a face-to-face, Skype or telephone interview; offering this flexibility can improve accessibility of research for participants, as well recruitment and response-rate.[29] All participants selected telephone interviews, and these were audio-recorded and transcribed verbatim. Verbal informed consent was given by participants at the start of each interview.

Parent Focus Groups

The CMN charity directors advertised the focus groups to parents who were planning to attend their conference. Parents provided written informed consent upon arrival and were split into three focus groups based on the age of their child (0–9, 10–13, or 14–18 years). These groups were led by the lead author and two experienced researchers.

Data Analysis

As the lead author has clinical experience in the area and is familiar with the existing condition-specific literature with parents or children, a template analysis approach was utilized. This allowed for both inductive and deductive coding. Template analysis uses the structure of a coding template constructed from preexisting ideas, whilst having the ability to remain flexible.[30] The present study followed the template analysis procedure as described by Brooks et al.[30] Preliminary coding was carried out separately on a sub-set of each data set (parent interviews, professional interviews and parent focus groups). The aim was to develop latent codes that go beyond the explicit meanings of the data and attempt to understand parent experiences at a more interpretative level.[31] Themes within each data set were grouped into clusters and used to develop initial coding templates. The coding template was applied to the remaining data sets and modified as new

Table 5. Example questions and prompts from interviews and focus groups.

Example parent interview questions	Example parent focus group questions	Example professional interview questions
As a parent, what has your experience of your child's condition/injury been like so far? **Example prompts**: *Have there been any particular times when things have been more challenging?* *Can you tell me about any positive experiences that you may have had as a result of your child having an appearance altering condition/injury?*	What have been some of the challenges and experiences that have arisen as a result of your child having a visible difference? **Example prompts**: *How did that affect you as a parent/as a family?* *Can you say a bit more about that?* *Can you explain what you mean by . . . ?* *Why do think that experience had that impact on you/your family?* *Why do you think that was particularly challenging?*	Can you describe for me what you feel the support needs of parents with a child with an appearance-altering condition/injury are? **Example prompts**: *What concerns/problems/challenges are coming to you with?* *What are the key time points for support on the patient/service user journey?*
Can you tell me about any support that you have received as a parent? **Example prompts**: *What has made it easier/harder for you to access support?* *Who has that support been from?* *If any, what additional support would you like/would have liked?* *How was that/would that be beneficial for?*	What support have you received as a parent of a child with a visible difference? **Example prompts**: *What did that support include?* *Who provided this support to you?/What was the source of this support?* *Can you explain why you found that support helpful/unhelpful?* *What impact did this support have on you/your family?* *Why do you think that might be/might have been helpful?/How do you think that support would benefit your family?*	What interventions/support do you provide/are you aware of for parents of children with an appearance altering condition/injury? **Example prompts**: *Give examples e.g. online information, leaflets, groups etc.*

information arose. Using this iterative process, a final template was constructed and applied to the full data set to ensure no information was missed. An existing triangulation protocol[32] utilizing convergence coding (identifying agreement and dissonance across data sources) on dimensions of meaning and prominence of the themes was applied to combine the interview and focus group findings. Only themes that appeared across all conditions were integrated at this stage of the analysis.

To increase credibility of the analysis[33] a second coder reviewed a selection of transcripts and used the coding template to code these independently. Coding discrepancies were discussed with the lead author until a consensus was reached. To ensure rigor, a model of conducting transparent and systematic qualitative research[34] was followed throughout the design, data collection and analysis process.

Results

Parents described their experiences of caring for their child with a particular focus on the appearance-affecting aspects of the condition or injury. Given the cross-condition aims of the study, all themes discussed were present across all conditions and injuries within the data. Although not discussed here in detail, some parents discussed condition specific experiences that have been reported in the literature.[35,36] These included concerns related to specific physical and developmental impairments caused by their child's condition or injury (e.g. difficulties with mobility in children with limb differences, problems with feeding and speech in children with facial differences). Parents did not report any concerns regarding intellectual impairments. Although these themes did not appear across all conditions, these condition specific issues do provide context and shaped parents' experiences of the broader themes discussed below.

Three cross-condition themes were constructed from the three data sets: 1) Appearance does(n't) matter, 2) Being "battle" ready, and 3) Walking the tightrope. These are discussed in turn and in some cases sub-themes further elucidate key aspects of the main themes. Some parents discussed that they found the interview process cathartic and an opportunity to discuss and explore topics they had rarely or never spoken about before. Participant quotes are presented with pseudonyms to preserve anonymity.

Appearance Does(n't) Matter

Parents discussed the psychological impact of having a child with a visible difference. As they reflected on this, it was evident that their responses were influenced by the degree to which they themselves valued appearance as an attribute. Many parents were initially distressed by their child's difference, but for some this changed over time after a period of adjustment. For others, the distress about the difference in appearance persisted. Some parents seemed less concerned about their child's appearance and did not struggle in the same way. Professionals also reflected on parental communication about, and attitudes toward, appearance. When providing support they found it useful to determine how salient this domain was for the parent.

"It Broke Me"

Parents talked about the distress they experienced related to their child's visible difference. More specifically, parents discussed initial feelings of shock, anxiety and low mood in response to seeing the impact of the condition or injury on their child's appearance. For example, Holly described her experience of her 8-year-old daughter losing her hair due to Alopecia: *"I kind of have this hope that the first time was the worst time, the real big shell shock, it broke me for about 2 weeks, completely couldn't think about anything else, I was worried*

about it all the time, I was picking up the hairs off the floor and like examining them all".

Bella, Clinical Psychologist working with congenital conditions, reflected on a similar parental experience: *"I so admired the mother who I think was incredibly open about how they were feeling repulsed and shocked by their child's appearance'.*

Many parents equated this experience with feeling "broken". For some, this was a short-term reaction to the initial shock of their child's visible difference. However, for others these feelings persisted for years: *"I find it very difficult; I still have some sleepless nights about it because I can just see, it is a horrible thing to deal with"* (Ellen, mother of 16-year-old daughter with Alopecia).

Parents reflected on how their child's unusual appearance challenged their hopes and dreams of having a "perfect" child, which included them having a conventionally attractive appearance. This often led to feelings of sadness and disappointment and, as Grace (mother of 19-month-old daughter with facial palsy) described, this was often followed by shame and feelings of disloyalty: *"yeah so I just found it hard that you expect your baby to look a bit of a certain way and obviously she doesn't and it's awful to say, and I feel ashamed to admit it, but I found that quite hard because she didn't visually look as I expected".*

Professionals also reflected on parents' feelings of loss related to their child's appearance. *"I've heard parents before saying 'this isn't what I wanted for my child', 'I imagine my little girl having beautiful plaited hair' or whatever so sort of feeling, and then they feeling guilty for feeling like that and actually their child is still the same child, it's just maybe what they thought life was going to be like has twisted on its head"* (Tara, charity worker, working with families affected by an acquired condition).

Parents also spoke frequently about feelings of guilt associated with their child's visible difference. For example, Charlotte (mother of a daughter with CMN, 0-9-year-old focus group) blamed herself for her daughter looking different: *"I'd done something wrong, my body had failed my little girl".*

"They Become so Much More"

Despite feeling initially shocked or distressed by their child's visible difference, some parents reported these concerns faded into the background of family life. Others reflected that, ultimately, appearance was not a particularly important aspect of their child's identity. Parents described this as either being able to look past the visible difference, seeing the child as a whole, or not considering the difference to be a significant issue for their child in the first place. Some parents perceived there to be nothing wrong with their child and did not feel the need to alter anything about them. For example, Nina (mother of 10-year-old son with Alopecia) reported: *"there was no sort of drive inside me to find a cure or anything like that I wasn't, there wasn't something missing that I needed to fix in that way".*

Others described how their view of their child's visible difference changed over time. Some parents who initially might have felt "broken" were able to rebuild and adjust to the new normal: *"when the child is born there's quite a lot of sadness or grief about, you know, the fact that their child has a visible difference but over the course of the following years they*

come to terms with it" (Lisa, Clinical Psychologist working with families affected by congenital conditions).

Mollie (mother of 9-year-old son with an upper limb difference) described how her child's ability to cope fueled this healing process: *"Initially when I first had him, and I think it's the same for a lot of the other parents with children with limb differences, you worry about how they will manage and you really quickly learn that they cope amazingly, those kind of worries had kind of disappeared within the first 3 years probably".*

As children grew and developed into a young person with likes, dislikes and a distinct personality, they became defined by multiple attributes rather than just their appearance: *"when they're born you feel like they're just a birthmark on a child and then they just become their name and that child and then that funny person and the one that only eats fish fingers and they become so much more, there are just other things that takeover"* (Rachel, mother of daughter with CMN; 14–18-year-old focus group).

Professionals observed that parents vary in their judgments of the importance of appearance and felt that this affected how parents viewed their child's visible difference. Sarah (charity worker, working with people with an acquired condition) observed that, *"parents who cope well are the ones that kind of embrace it in a way and give lots of reassurance to their child that it doesn't matter what they look like".*

Some parents also described broader positive outcomes associated with their experience of having a child with a visible difference. These included appreciating that they now had greater acceptance of appearance diversity, empathy for those who are different and awareness of their own, and their family's, resilience. For example, Caitlin (mother of 4-year-old son with Microtia; a congenital condition which affects the development of the external ear) reported that: *"it's certainly made my husband and I more, maybe accepting and trying to be more understanding of differences and I think it helps us to teach both of our kids to look beyond outer experiences and accept that people have differences and differences are good".*

Being "Battle" Ready

Parents vocalized their concerns about their child coping with their difference, drawing on various social situations they have experienced and framing these as potential threats or barriers that their child would need to overcome. Parents were cognizant of the need for children to manage social challenges associated with their visible difference independently (e.g. addressing comments made about their appearance). However, after shielding their child and feeling responsible for managing the impact of the visible difference, parents reflected on having to "let go", to allow their maturing child to manage on their own. Regardless, parents felt a strong sense of responsibility to ensure that their child is prepared and "battle" ready.

Identify the Threats

When discussing the challenges that their child might face, many parents worried most about the social impact of the child's visible difference. Parents were concerned about children socializing within their own circles (e.g. at school or with

friends), as well as interacting with the public. They worried that their child might experience social stigma or discrimination and were fearful about the negative impact this might have on their child's well-being. Jade was worried her 6-year-old son with Vitiligo would be a target: *"kids will be kids and kids don't really need an excuse to have a target of other children for bullying and things like that, I'm worried that he's going to become a target"*. Mollie (mother of 9-year-old son with an upper limb difference) summarized a common occurrence experienced by many parents: *"you get a lot of double takes shall we say, a lot of staring, people tend to fall into two categories of staring and not saying anything or just being really forward and saying, 'what happened to him?'"* .

Professionals also shared examples of parents' concerns about the potential negative social impact of their child's appearance. Professionals and parents also described how parents often anticipate future, sometimes unknown, threats (e.g. teasing at school). Professionals highlighted that these fears can underpin parents' drive to seek appearance-altering treatments: *"they're concerned that when these children go to preschool and when they start in big school that they're going to get teased or bullied or whatever and so they're keen sometimes to try and get more normal looking dentition in advance of that"* (Ruth, Pediatric dentist working with congenital conditions).

Several parents also discussed gender differences, asserting that appearance is more salient for girls, and reaffirming societal expectations that appearance is closely tied to worth and value for girls/women and less so for boys/men. As a result, parents of girls appeared more concerned about the potential social impact of their child's visible difference.

"I'm just worried it may damage her self-esteem and I suppose in so far as being female as well, because I just know that perhaps unfortunately there is a greater emphasis on physical appearances in that respect and maybe she'll be ridiculed more" (Sam, father of 10-month-old daughter with an upper limb difference).

Shielding My Child

Some parents considered attempts to shield their child from potential threats by altering their child's appearance to fit with appearance norms, for example, by concealing or hiding the visible difference from others: *"I am a bit more conscious of it and trying to make sure he keeps covered up but then there are times when we are away, just in a swimming pool, he's quite exposed"* (Jade, mother of 6-year-old son with Vitiligo). Others stepped into social interactions between their child and others, to offer protection. In some situations, the parents who took actions to conceal their child's visible difference were the ones who expressed negative perceptions of their child's appearance. For example, Ellen (mother of 16-year-old daughter with Alopecia) stated her concerns about her daughter's "unattractive" appearance: *"I can't lie to her and say she looks attractive without a wig because she doesn't, I think it is particularly unattractive because it's patchy"*.

Of these parents, some reflected that perhaps they were shielding their children too much, but still found it difficult to let go of protective behaviors. Martin (father of daughter with CMN, 14–18-year old focus group) articulates this challenge: *"I find as well sometimes you can step in too quickly, at*

the swimming pool you have kids coming up to her saying, 'what are the spots on your skin?' And I'd be stepping in and saying something and actually it's better to let her say something so I had to learn to step away".

Professionals reflected, in more depth than did parents themselves, on parental motivations to conceal differences. This suggests that parents might also choose concealment as a strategy to manage their own sense of vulnerability about their child's visible difference: *"I can see that the mother has used a wig as a way of almost to protect herself basically from her own feelings around the child's hair loss"* (Alice, charity worker working with families affected by acquired condition).

Arming My Child

Parents talked about the need to arm their child with psychosocial tools to self-manage challenges. They discussed the process of equipping their child with these tools, either as a strategy in addition to concealing the visible difference, or as a lone strategy. They wanted to build confidence and resilience in their children in order to protect them from difficult social situations, and described coping skills they wanted to nurture or instill: *"it's trying to arm him with enough mental fortitude around it to be able to deal with those questions and understand that people will have questions"* (Robert, father of 6-year-old son with an upper limb difference). There was also an underlying uncertainty felt by parents who queried whether they had done enough: *"have we done enough confidence wise to get them through?"* (Stuart, father of son with CMN, 10–13-year old focus group).

Many parents also raised the issue of communication with their child about their visible difference and acceptance of human diversity more generally. They expressed a sense of responsibility for ensuring these conversations informed their child's understanding of their own difference. For example, Robert (father of a 6-year-old son with an upper limb difference) said *"really tried to make him aware of the fact that he has got a little arm, differences are good, everybody's different, daddy is a diabetic and injects himself, mummy's got blonde hair, and you can see differences in everybody"*.

Parents also talked about the importance of modeling adaptive responses to their child's visible difference (e.g. answering questions from others in a positive and calm manner). They hoped that providing their child with a model of behavior allowed them to learn strategies to manage challenges that they may face. Professionals concurred, and suggested that parents who exemplify the use of adaptive approaches to manage challenging situations provided children with behavior to observe, model and imitate as they begin to interact and socialize independently. *"if the parent was able to say 'oh it's a birthmark' or whatever the condition was 'she's not in pain' and then sort of move the conversation along then often the child then learnt oh well that's how my mum fields these questions and I can deal with that too and they seem to be the ones that are more confident and were less concerned about their appearance"* (Bella, clinical psychologist working with families affected by congenital conditions).

Walking the Tightrope

Parents were concerned about how to protect their children from perceived threats and how much attention to focus on their child's visible difference. Parents considered whether they

should try to minimize the impact of the difference and worried that talking about it too much might create a problem where one did not exist. On the other hand, if they avoided the issue then children would lack observable behavior to model, preventing them from developing their own narratives. Participants described walking a fine line in attempts to "get it right" whilst also being unsure about where that line lay. Getting it wrong was regarded as potentially disastrous because their child's mental health was at stake.

"Messing about in the Dark"

Many parents felt lost regarding the best way to support their child and reported very little guidance being available: *"It's like everybody is just messing about in the dark, hoping that these things are going to work"*, Holly (mother of 8-year-old daughter with Alopecia). Conversations about appearance were particularly difficult for parents, who lacked confidence in their ability to effectively support their child: *"it's difficult to use the right words that don't come across as making a judgment about the way he looks or the way he, his abilities are"* (Caitlin, mother of 4-year-old son with Microtia). Striking the right balance between too much and too little appearance talk was also challenging: *"I don't know whether I do dismiss it a bit too much, you know do you underplay it a bit too much"* (Erica, mother of 12-year-old son with an upper limb difference).

This lack of clarity and confidence was also witnessed by professionals: *"I think that's the kind of things that parents worry about like is what I'm saying doing more harm or more good? They're not really sure, should they be encouraging them to cover it or should they be encouraging them to embrace it, those are the questions that we hear from parents"* (Tara, charity worker working with families affected by acquired conditions).

The Double-edged Sword of Support

Parents described their mixed experiences of reaching out to those they perceived as experts (e.g. professionals or others with experience of the condition) when they required information, reassurance or support. Although some experiences were positive, parents were often disappointed. For example, Ellen (mother of 16-year-old daughter with Alopecia) spoke about the appointment during which her daughter was diagnosed. She felt that her information and support needs were not met: *'to this day I remember what she said because we went and we got diagnosed through the GP with a dermatologist, actually at hospital and as when left I sort of said "what can I do?" and they said "there's nothing you can do, it won't kill her"'*. Professionals also talked about a lack of confidence when working with those affected by appearance-affecting conditions; they too were unsure about how to address appearance concerns: *"They're [staff] nervous that they don't want to get too involved"* (Ruth, pediatric dental surgeon).

Parents also sought information via charity websites and social media, but again with mixed results. Peer support platforms were useful to share experiences and reduce feelings of isolation: *"it's nice to see that other people on these Facebook pages, there's no negativity, there's no like 'well you shouldn't be doing things, you shouldn't be doing that', everyone seems to be really positive about it all, like sharing opinions"* (Marie, mother of 2-year-old son with Microtia). However, both parents and professionals recognized that peer support could also fuel anxiety, exposing parents to worse case scenarios and stories about previously unknown threats or future challenges, further confirming their need to equip their child with coping strategies but with no more knowledge of how to do so. *"I sort of read a lot of the conversations in there, some of that is really scary because you get all the worst-case scenarios where people go on to lose all their hair so in my head I was preparing for her to lose all her hair"* (Holly mother of 8-year-old daughter with Alopecia).

"On the Edge of a Big Black Hole"

Parents felt fully responsible for their child's ability to cope with challenging situations and carried the guilt if their child struggled to adjust. Their primary concern was that living with a visible difference would affect their child's wellbeing and mental health: *"I do obviously worry about his emotional state and mainly teenage years are my biggest worry and he has over the last 4 years, had problems with anxiety and kind of angry melt downs that kind of thing"* (Mollie, mother of 9-year-old son with limb difference).

Health professionals also witnessed parents expressing guilt when their child struggled to manage challenges resulting from looking different. The weight of this responsibility and the severity of the perceived consequences for their child sometimes had a detrimental effect on the psychological wellbeing of the parent. Paige spoke about a mother who was struggling to cope with her child being bullied about their appearance: *"she described it as she just has to hold it together and she describes herself as being on the edge of like a big black hole and she knows she is right on the edge but she is determined, she also knows that she can't fall into it because if she falls into it then everything will fall apart"* (Paige, charity worker working with families affect by acquired conditions).

Discussion

This study aimed to explore cross-condition experiences and the support needs of parents and carers of CYP with appearance-affecting conditions or injuries, and risk and protective factors for parental psychosocial adjustment. Three main cross-condition themes were constructed from the data collected via interviews (n = 20) and focus groups (n = 25) with parents of a child with a range of appearance-affecting conditions and interviews with professionals with relevant experience of supporting parents and affected children (n = 11). "Appearance does(n't) matter" describes how parents' attitudes toward the importance of appearance influenced the way they perceive and cope with their child's visible difference. "Being 'battle' ready", describes parents' anticipation of threats to their child's wellbeing, as a result of their visible difference. Finally, "Walking the tightrope" describes the balancing act of supporting a child with a visible difference and the lack of confidence and clarity about how to do so successfully, as well as the fear of the consequences of failing to achieve a balance by providing their child with enough support whilst not overemphasizing the impact of the visible difference.

Initial reactions of shock and distress to their child's visible difference were common across parents of CYP with a variety of conditions and injuries. Consistent with these findings, both

qualitative and quantitative research with parents of children with CLP[37,38] and burn injuries[8,28] have reported shock, distress and anxiety following their child's diagnosis or injury. Some parents in this sample were able to adjust, and for them this initial reaction was only temporary as distress passed or lessened. For others, psychological distress endured. For some parents, this meant they struggled even when children were in their mid to late adolescence. To date, the existing evidence base does not represent the voices of parents with children in mid and late adolescence.[7,8] The present research therefore builds on the current evidence by beginning to provide a narrative about the experiences of parents of older children. The psychological distress experienced by parents of children with visible differences indicates an unmet psychological support need in these parents, which should be further explored in order to provide recommendations to address these needs in practice.

The findings also highlight that it is common for parents of CYP with any visible difference to experience guilt, often associated with the cause of the difference (e.g. the injury event or prenatal development). For some parents, guilt persisted as their child grew up, leading to ongoing distress. Feeling guilty about the cause of their child's visible difference has previously been reported in studies with parents of young children with CLP and burns. Whilst feelings of guilt were reported by both mothers and fathers in the present study, they were particularly felt by the mothers in previous studies. For example, a study investigating causal beliefs in parents of children with CLP found that self-blame had a greater association with anxiety and stress when fathers were excluded from the analysis.[10] This was thought to be due to the causes of CLP being linked to the mother due to pre-natal behaviors and events.[10]

Self-blame is clearly a pervasive issue for these parents, irrespective of their child's condition. Although the present research provides an insight into the experience of self-blame, not all parents in this sample felt this way. Existing research with parents has indicated that self-compassion and mindful parenting (a set of parental practices that seek to enhance moment-to-moment awareness in the parent-child relationship) is associated with lower levels of parenting stress.[39] Therefore, increased self-compassion may also be beneficial in reducing self-blame in this parent population. Further research is needed to better understand the reasons that some parents report experiencing self-blame, whereas others do not. A clearer understanding of the factors contributing to the experience of self-blame in parents could have important implications for guiding clinical practice and support for parents with children of visible differences, as well as other chronic conditions.

Parents' beliefs about the importance of appearance seemed to influence their perceptions of their child's visible difference. Appearance investment is the importance, meaning and influence of physical appearance in one's life.[40] Existing theory and literature around body image disturbance suggests that parental attitudes about appearance may also impact their child's body image. The Tripartite model of body image disturbance[41,42] suggests that parents influence the way their children think and feel about their bodies and appearance. Existing research has demonstrated that direct parental influence (e.g. appearance-related comments) and modeling of dieting and other related behaviors were significantly related to body image and eating disturbance in both male and female adolescents,[43–46] showing that parental attitudes can influence child appearance satisfaction. Investigating parental attitudes toward appearance in a visible difference population is important in order to understand how parents might influence the psychosocial adjustment of young people whose appearance diverges from the norm.

Many parents in the present study reported their concerns about the potential impact that their parenting behaviors would have upon their child's adjustment. Existing pediatric health literature has highlighted the importance of acknowledging the role of the family system and interactions between family members, when considering the contributing factors to child adjustment.[47] A research study of 272 children with asthma and their primary caregivers found evidence for both direct and indirect pathways between parenting emotional expressiveness and child anxiety, depression and physical health.[48] This emphasizes the need to reflect on parent-child interactions when exploring parent adjustment to their child's condition. Interventions which include both parent and child have been found to have positive outcomes.[49] Therefore, it is important to include considerations of the parent-child dyad in future intervention development.

Parents exhibited a deep-rooted drive to protect their child from threats to their wellbeing as a result of their unusual appearance. They engaged in protective behaviors (e.g. attempting to conceal a visible difference, taking the lead in social situations) and experienced anxiety about possible threats (e.g. concerns about or anticipation of bullying). Social situations were regarded as particularly threatening, which echoes concerns reported by parents of children with CLP and burn injuries.[6,] Given evidence that appearance and attractiveness are increasingly important in youth culture and appearance-related attributes are highly valued,[50,51] it is not surprising that parents of CYP with visible differences anxiously anticipate their child's increased social independence. As a result, a lack of confidence or low self-efficacy in how to prepare their child for challenging social situations may be a risk factor for increased parental anxiety and stress.

High levels of anxiety are not only distressing for the parents but are also a risk factor for overly protective parental behaviors that may negatively impact child development. Research with parents of children with burn injuries or craniofacial conditions has illustrated that the desire to protect their children can result in the restriction of social activities outside of the home and educational opportunities that parents perceive as threatening.[12,52] Siblings of burn-injured children have also reported less involvement in school activities and lower social competence when compared to a normative sample.[53] Therefore, it is important to consider the potential impact of a parent's increased desire to protect their children, in terms of their child's social and emotional development. Being protective of their children is a widely experienced parenting instinct, but may be heightened in parents of children with appearance-affecting conditions or injuries and chronic conditions more broadly.

Parents were aware that CYP model their behavior on them and were anxious to provide a good example of how to manage appearance-related questions or comments. Theoretical and empirical evidence underpins this parental concern. Social Learning Theory outlines that children engage in observational learning, wherein they observe, imitate and model the behavior of people they identify with, such as their parents.[13] Observations described by health professionals in this study also suggested that children imitate their parents' attitudes and approach to their visible difference. Many parents in the current study lacked confidence in their ability to communicate with their child about their visible difference and model adaptive behavior. Increasing parental confidence and skills in these areas may protect against parent distress and consequently benefit their children.

Parental anxiety and anticipation of oncoming challenges and concerns about how to best prepare their child suggests a greater need for support for parents in how to manage these difficulties. A recommendation for clinical practice from these findings is that support for parents needs to include guidance on how to build confidence and resilience in their child. Alongside this there should be guidance on specific challenges in the parenting role such as communication about their child's visible difference. This also supports previous recommendations for healthcare professionals supporting parents of children with craniofacial conditions.[54]

Some parents felt that healthcare professionals did not adequately address their appearance-related concerns. Lack of support can result in parental distress. Recent qualitative research by Gee et al.[19] has identified that healthcare professionals can lack confidence in discussing appearance-related issues and associated distress; professionals fear causing harm to patients and want to avoid making assumptions about the source of a patient's worry. However, a large proportion of the same sample also identified positive aspects of their management of appearance-related concerns, and the importance of validating feelings and providing reassurance.[19] This suggests that, whilst professionals want to provide sympathetic care, they can (like parents) lack confidence in how to approach the topic of appearance and provide support for appearance-related distress. Healthcare satisfaction has been associated with reduced stress, anxiety and depression scores and improved quality of life in parents of children with CLP.[55] Therefore, it is important that healthcare professionals are aware of challenges faced by parents and carers and are able to provide support to those who lack confidence in how to best support their child. In line with existing literature, these findings provide evidence of a need for further training around appearance-specific support for families and the normalization of appearance talk with parents and carers in healthcare settings

Strengths and Limitations

A strength of the present study was the inclusion of many different conditions and injuries within the sample. This is novel, as existing research with parents and carers has focused on a single condition or group of conditions with similar presentations (e.g. craniofacial conditions.[6]) This study identified shared difficulties and experiences of parents and carers of CYP with various visible differences, which cut across conditions and injuries. Understanding the nature of these difficulties has implications for identifying unmet support needs of this parent population that could be targeted by intervention. Whilst representing a range of conditions and injuries, the sample remained selective, comprised of parents who were receiving support or engaged in charitable organizations. Some small differences have been reported in preferences for the delivery of psychological support, when comparing samples from charities and hospital sites.[56] Future work in this area should include parents of CYP with visible difference who are not engaged in support from charitable organizations.

Despite attempting to recruit from a range of backgrounds, it should be noted that the sample was comprised of parents who were mostly highly educated, which can be indicative of higher socioeconomic status (SES). Although a sample bias toward higher SES is not uncommon in psychological research,[57] it is important to acknowledge that parents in this sample may have access to resources (e.g. financial support) that could facilitate coping with challenges related to their child's condition or injury, which individuals from lower SES backgrounds may not. This may limit the transferability of these findings to the broader parent population.

A sample of health and support professional specialist staff with regular contact with this population was purposively recruited to capture the perspectives of professionals working with a range of conditions and injuries. Parents of children with visible differences are likely to have ongoing contact with non-specialist health professionals. Condition specific research with nonspecialist health professionals found that nonspecialists experience challenges in delivering care and support to these families and have a range of unmet training needs[26] (e.g. lack of confidence engaging in discussions related to their patient's appearance). Future research including nonspecialists may provide further insight in how to support these training needs.

Lastly, due to their opportunistic nature, the focus groups were only conducted with parents of children with a single condition (CMN). Nonetheless, these focus groups were valuable because they provided an opportunity to better understand the experiences of parents of children with a rare appearance-affecting conditions and contribute to the broader cross-condition themes. Findings from these focus groups will be beneficial in understanding the experience of appearance-affecting conditions broadly and provide a basis for including parent dyads in future research of this kind.

Conclusion

Parents of CYP with a wide range of visible differences experience similar psychosocial difficulties, regardless of the cause or nature of their child's condition or injury. Parents can be preoccupied with potential future challenges related to their child's visible difference and concerned about how to prepare them to manage these effectively and independently. Some parents felt that when reaching out for support to help their child, their needs were unmet. The experiences described in this paper highlight a need for further parental support with regard to understanding their own reaction to their child's

visible difference, preparing their child to understand, communicate and manage appearance-relate challenges independently. Further research, informed by the present findings, needs to examine possible risk and protective factors for distress in these parents, to identify possible psychosocial targets for intervention.

These findings demonstrate the commonalities across the experiences of parents of children with appearance-affecting conditions and injuries. These experiences may also be present amongst parents of children with a wider variety of chronic conditions. An understanding of these experiences and further exploration of risk and protective factors would have important implications within the visible difference field, as well as for parents and families of children with health conditions and injuries more broadly.

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ORCID

Maia Thornton http://orcid.org/0000-0003-3547-8840
Diana Harcourt http://orcid.org/0000-0002-4285-5678
Toity Deave http://orcid.org/0000-0001-9966-8948
James Kiff http://orcid.org/0000-0002-6105-5887
Heidi Williamson http://orcid.org/0000-0003-0189-4803

Declaration of interest

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