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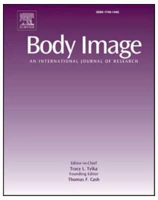

Cross-condition risk and protective factors for psychosocial distress in parents and carers of children and young people with appearance-affecting conditions and injuries

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

[a] *Centre for Appearance Research, University of the West of England, Bristol, UK*
[b] *School of Health and Social Wellbeing, University of the West of England, Bristol, UK*
[c] *Outlook Service, Southmead Hospital, Bristol, UK*

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ABSTRACT

Alongside typical parenting challenges, initial condition-specific research suggests thadifferent experiences and support needs.t parents of children with different visible differences may experience similar psychosocial difficulties. Despite this, large-scale cross-condition research to identify risk and protective factors for parental distress and psychosocial adjustment has been lacking. Two hundred and nine parents and carers of children with a range of visible differences completed an online survey comprised of standardised outcome measures, study-specific measures, and open-ended questions. Multiple regression modelling identified possible risk and protective factors, and data collected via open-ended questions were analysed using content analysis. Findings support themes previously identified in small-scale cross-condition qualitative research with parents of children with visible differences. Risk factors for parental negative affect and stress included parental reports of the noticeability of their child's visible difference and teasing. Protective factors included good parent-child communication, self-compassion, knowledge of their child's condition and satisfaction with treatment. The risk and protective factors identified provide important insight into the experiences of this parent population and indicate possible avenues for psychosocial intervention.

1. Introduction

A wide range of conditions and injuries can result in an appearance that diverges from the "norm" (Rumsey & Harcourt, 2012), often referred to as a visible difference or 'disfigurement', such as craniofacial conditions, skin conditions, burn injuries, limb differences, and scarring. It is estimated that over 1.3 million people in the UK have a significant visible difference which affects their face or body (Changing Faces, 2010). Regardless of the cause of their difference, affected children and young people can struggle with a variety of psychosocial challenges (Waite et al., 2023). This can include social stigma, fear of negative evaluation, negative self-perceptions, low self-esteem, and anxiety (Jenkinson et al., 2015).

Although it is important to note that some parents and carers adapt well to the challenges of having a child with a visible difference (Klein et al., 2006), condition-specific qualitative research has found that parents of children with a wide range of visible differences can experience psychosocial difficulties, which can include psychological distress (e.g., anxiety, low mood, stress, and guilt; Heath et al., 2018; Hlongwa & Rispel, 2018; Oliver et al., 2020). Commonalities and differences experienced by those with different appearance-affecting conditions and injuries and their families remains an ongoing discussion within the field. For example, recent cross-condition quantitative research with adults with a range of conditions has indicated that the timing of their visible difference (whether congenital or acquired) did not predict psychosocial outcomes (Zucchelli et al., 2023). However, currently no quantitative research has explored the association between parental psychosocial outcomes and the timing of their child's visible difference (i.e. congenital or acquired).

Cross-condition qualitative research, with parents of children with a range of appearance-related differences, has also identified themes that detail common concerns and indicate factors that may influence

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* Corresponding author.
E-mail address: maia.thornton@uwe.ac.uk (M. Thornton).

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parental adjustment. Parents and caregivers of children with craniofacial conditions can experience difficulties when communicating with their child about visible difference (Feragen et al., 2021; Zelihić et al., 2021). Thornton et al.'s (2021) research highlighted that some parents of children with a range of conditions and injuries may anticipate and worry about their child encountering appearance-related social difficulties, including exclusion, teasing, and bullying by peers. This can drive them to be overprotective and lead to anxiety about their lack of confidence in how to support and equip their child to manage social challenges independently. While cognisant of the need to speak to their child about their condition or injury - to aid understanding, facilitate an open dialogue about their thoughts and feelings and educate them about diversity more broadly - parents can find these conversations challenging. They worry about how to raise the topic sensitively, what language to use and are concerned about causing distress.

Parental adjustment to their child's visible difference may also be influenced by their own appearance-related thoughts and behaviours. Thornton's qualitative study (Thornton et al., 2021) also highlighted that some parents conceal or alter their child's visible difference (with clothing or hairstyles) to ameliorate their worries about their child appearing noticeably different to others. Such appearance-fixing behaviours are used to resolve parental anxiety by attempting to bring an individual's appearance more in line with society's appearance norms (Cash et al., 2005). However, even in instances where parents were able to conceal or reduce their child's difference through surgical intervention, this did not alleviate their anxieties about social challenges their child might face in the long-term (Alderson et al., 2024).

Several psychosocial factors which may protect against distress in parents of children with a visible difference have been identified in the existing visible difference literature. Quantitative research conducted with adults with a visible difference has highlighted an association between increased psychological flexibility and improved wellbeing outcomes (Dudek et al., 2016). Cross-condition qualitative research with parents of children with a visible difference has also identified that those who demonstrated greater psychological flexibility and self-compassion (acting with kindness towards ourselves, appreciation of our common humanity, and the ability to aware of the present moment; Neff, 2011) in response to actual or anticipated challenges appeared to adjust positively to their child's condition or injury (Thornton et al., 2021). Parents who demonstrated a more positive, optimistic outlook towards anticipated challenges and their child's ability to cope were also less likely to experience anxiety related to their child's condition or injury. Finally, parents who discussed the beneficial role of support from their social networks (e.g., family members, online communities etc.) also appeared to experience less anxiety. Overall, valuable insights from existing research, supported by relevant theory, demonstrates that parents and caregivers of children with visible differences of any sort may benefit from having access to psychosocial support.

Research and theoretical perspectives on adjustment in families with children with long-term health conditions suggests that a range of psychosocial constructs and stressors can have an impact on parental adjustment (Pinquart, 2017; Wallander & Varni, 1998). Furthermore, although parents of children with a visible difference may experience some distinct challenges (e.g., concerns about appearance-related stigma), some of their experiences for example, treatment decision making (Nelson et al., 2012a), attending hospital appointments (Hlongwa & Rispel, 2018), and carrying out treatment regimens (Lewis-Jones, 2006; Rork et al., 2012) may be similar to those of parents of children with other long-term health conditions and may impact adjustment. Parenting theory and literature suggests that parental functioning and child adjustment can also be influenced by additional contextual stresses or support (Belsky, 1984; Jia et al., 2016). Previous visible difference research has identified subjective factors such as perceived noticeability (a subjective judgement that spans across conditions and injuries regardless of cause), is an important contextual factor that can impact adjustment (Zucchelli et al., 2020). Furthermore, child age has also been considered another important variable in parental experiences and psychosocial adjustment (Costa et al., 2019). Overall, the existing theory and literature that addresses the experiences of parents, both within the general population and those parenting children with a visible difference, suggests that parental adjustment is a complex phenomenon which could be influenced by many possible psychosocial factors.

There has been a lack of large-scale cross-condition quantitative research in this field. Identifying factors that influence psychosocial distress and parenting would improve understanding of parental support needs, and potentially inform the development of psychosocial intervention. The aim of this study was to identify psychosocial risk and protective factors associated with distress and stress in caregivers of children and young people with appearance-affecting conditions and injuries.

The research question posed at the outset of the present research was: 'What are the cross-condition risk and protective factors for psychological distress in parents of children with appearance-affecting conditions and injuries?' In addition, the impact of cause (i.e., congenital versus acquired via illness or injury) of a child's visible difference on parental outcomes was also explored.

Based on limited existing literature (e.g., Heath et al., 2018; Nelson et al., 2012a; Stock & Rumsey, 2015; Thornton et al., 2021), it was hypothesised that:

1) Parental assessment of the noticeability of the child's visible difference and experiences of teasing will be positively associated with negative affect, stress frequency, stress difficulty and negatively associated with positive affect.
2) Parental-reported self-compassion, psychological flexibility, knowledge of their child's condition/injury, self-efficacy, perceived social support, optimism, and parent-child communication will be negatively associated with negative affect and stress and positively associated with positive affect.
3) Parental investment in appearance and appearance-fixing behaviours will be positively associated with negative affect, stress frequency, stress difficulty and negatively associated with positive affect.
4) Child age will be negatively associated with stress frequency, stress difficulty, negative affect and positively associated with positive affect.

2. Method

2.1. Design

Quantitative data were collected using standardised psychosocial measures and study specific measures. To increase the generalisability of the findings from existing qualitative research and allow for more robust conclusions to inform intervention development, an online survey was used to collect data from a sample of parents and carers. Within the survey, open-ended questions also gave participants an opportunity to elaborate on their experiences in their own words (Greene et al., 1989). Data were collected between July and October 2020, following the first national COVID-19 lockdown in the UK.

2.2. Recruitment

Any parent/carer (adult with caring or guardianship responsibilities) was eligible to take part if they had a child (aged 0–18 years old) with an appearance-affecting condition or injury, a good understanding of written English sufficient to complete the online survey and were based in the UK. Inclusion criteria were presented as a series of screening questions at the beginning of the online survey. If participants did not meet the inclusion criteria they were thanked for their time and directed out of the survey. More than one parent or carer from the same family unit could take part in the research but whether both parents or multiple carers from the same family took part this was not monitored by the research team.

Eleven national UK-based charitable organisations who support individuals with visible differences were contacted and agreed to advertise the study via their websites, social media platforms and e-newsletters. The study was also advertised on the Centre for Appearance Research social media platforms and details were emailed directly to individuals who had previously registered an interest in the centre's work. Adverts were posted on parent, carer, and family groups on Facebook, relevant Reddit community pages (e.g., r/cleftlip, r/eczema), and webpages of several regional branches of the parenting forum "Mumbler".

2.3. Materials

2.3.1. Outcome measures

2.3.1.1. Parent affect. The Positive and Negative Affect Scale (PANAS; Watson & Tellegen, 1985) is a 20-item scale with two subscales measuring positive (10 items) and negative affect (10 items). Respondents indicated on a five-point scale (very slightly or not at all = 1; extremely = 5) the extent to which they experienced a list of 20 emotions (e.g., proud, scared, excited, upset) over the last week; with higher scores indicating experiencing greater intensity of this emotion. Both PANAS scales demonstrated good internal consistency (Positive affect, α = 0.91; Negative affect, α = 0.88) in this study.

2.3.1.2. Parent stress. The emotional functioning subscale of the Brief Paediatric Inventory for Parents (PIP; Casaña-Granell et al., 2018) assesses the perceived frequency of stress (3 items) and difficulty of managing it (3 items), with higher scores indicating higher stress. Respondents rated both dimensions on a five-point scale (not at all = 1; always =5). Example items include 'Feeling helpless regarding my child's situation' and 'Feeling uncertainty about the future'. Both dimensions demonstrated good internal consistency (Stress frequency, α = .85; Stress difficulty, α = .89).

2.3.1.3. Parental psychological flexibility. The Parent Psychological Flexibility (PPF) questionnaire (Burke & Moore, 2014) is a 19-item scale rated on a seven-point scale (never true = 0; always true = 6), with higher scores indicating greater psychological flexibility. An example item from this scale is "My emotions cause problems in my relationship with my child". This scale demonstrated good internal consistency (α = .88).

2.3.1.4. Self-compassion. The Self-Compassion Scale Short Form (SCS-SF, Raes et al., 2011) is a 12-item measure of self-compassion, rated on a five-point scale (never = 1; almost always = 5), with higher scores indicating greater self-compassion. An example item from this scale is "When something painful happens, I try to take a balanced view of the situation". This scale demonstrated good internal consistency (α = .87).

2.3.1.5. Social confidence. The 3-item Social Situation subscale from the parent version of the CARe Burn Scales (Griffiths et al., 2021) was developed initially for use with parents of children who have had a burn injury. In the current study, it was adapted for a cross-condition sample (reference to "burn injury" changed to "appearance-affecting condition or injury"). Items were rated on a five-point scale (1 = not at all confident; 10 = very confident), with higher scores indicating greater social confidence. This adapted subscale demonstrated good internal consistency in this sample (α = .85).

2.3.1.6. Perceived social support. The Multidimensional Scale of Perceived Social Support (MSPSS, Zimet et al., 1988) is a 12-item scale, rated on a seven-point scale (very strongly disagree = 1; very strongly agree = 7), with higher scores indicating greater perceived social support. An example item from this scale is "I get emotional help and support from my family". The scale demonstrated good internal consistency (α = .93).

2.3.1.7. Optimism. The Life Orientation Test Revised (LOT-R, Scheier et al., 1994) has 10-items assessing generalised expectancies for positive versus negative outcomes, rated on a five-point scale (strongly disagree = 0; strongly agree = 4), with higher scores indicating greater optimism. An example item from this scale is "In uncertain times, I usually expect the best". The scale demonstrated good internal consistency (α = .86).

2.3.1.8. Treatment knowledge and satisfaction. To assess parents' knowledge and satisfaction with treatment, five items from the Clinical Excellence Network Questionnaire (CEN-Q, Stock et al., 2016) were adapted for this study. Example items included: "I have all the information I need about my child's condition" and "I have been involved in the decisions about my child's treatment so far". Items were rated on a five-point scale (never = 0; almost always = 4), with higher scores indicating greater knowledge and satisfaction. This scale demonstrated satisfactory internal consistency (α = .68), given the small number of scale items (<6) and the number of participants (n = 100–300; Ponterotto & Ruckdeschel, 2007).

2.3.1.9. Subjective noticeability of the visible difference. To assess the extent to which participants perceived their child's visible difference to be noticeable to themselves and others, a two-item scale was adapted from previous visible difference literature (Clarke et al., 2014; Zucchelli et al., 2020). The two items, "How noticeable is your child's condition or injury to other people?" and "How noticeable is your child's condition or injury to you?" were rated on a 11-point scale (not at all noticeable = 0; very noticeable = 10).

2.3.1.10. Perceived social challenges. To assess parents' understanding of whether their child was experiencing social challenges related to their visible difference, a three-item scale was adapted from the Project EAT-III Teasing Scale (Neumark-Sztainer et al., 2007) to measure the emotional impact of teasing on the parent and their child. Rated on a six-point scale (never = 0; always = 5), higher scores indicate greater perceived social challenges. An example of an item from this scale is "How often has your child been teased about the way they look?". This scale demonstrated good internal consistency (α = .84).

2.3.1.11. Parent-child communication. To assess communication between parent-and child, four items specific to the experiences of parents of children with visible differences were developed (e.g., "I feel ok answering my child's questions about their difference in appearance" and "I feel ok talking to my child about treatment that will alter their appearance"). These items were constructed to measure the extent to which parents felt able to communicate with their child openly and confidently about their visible difference. Items were answered on a six-point scale (never = 0; always = 5), with higher scores indicating more open and confident parent-child communication. This scale had good internal consistency in the present sample (α = 0.87).

2.3.1.12. Appearance-fixing. To assess the extent to which parents utilised appearance-fixing behaviours to cope with distress related to their child's appearance, four items specific to the experiences of parents of children with visible differences were developed (e.g., "I attempt to cover or hide my child's appearance difference", "I feel uncomfortable in situations where my child's appearance difference might be seen"). Items were based on previous cross-condition qualitative research with parents of children with a visible difference (Thornton et al., 2021) and existing scales of appearance-fixing behaviour for the general population (Cash et al., 2005). Items were answered on a five-point scale (not like me = 0; definitely like me = 4), with higher scores indicating greater appearance-fixing behaviours. This scale demonstrated good internal consistency (α = 0.74).

2.3.1.13. Parent self-efficacy. 11 items were created to form a self-efficacy scale specific to the needs and experiences of parents of children with visible differences (e.g., "I can support my child in telling others about their condition or injury", "I can promote confidence and resilience in my child"). These items were based on findings from previous cross-condition qualitative research with parents of children with a visible difference (Thornton et al., 2021). Items were rated on a six-point scale (not at all confident = 0; very confident = 5), with higher scores indicating greater parent self-efficacy. This scale demonstrated good internal consistency (α = 0.90).

2.3.2. Open-ended questions

Nine open-ended questions (e.g., "Do you have anything else you would like to share related to communication about your child's condition or injury?") enabled participants to elaborate on their experiences, provide context or greater depth to their answers, and raise any issues they felt were not covered elsewhere in the survey (O'Cathain & Thomas, 2004). Parents were also asked about their experiences of caring for a child with an appearance-affecting condition or injury during the COVID-19 outbreak and lockdowns.

2.4. Public involvement and piloting

Three Patient and Public Involvement (PPI) advisors (parents of children with visible differences) completed the full survey and provided feedback on the content and design, which resulted in some changes to formatting. The survey was piloted by an experienced researcher in the field who was external to the research team and the parent of young children. They were able to reflect on the content from both a professional and parenting perspective, and no changes were recommended.

2.5. Participants

In total, 209 parents/carers (186 women; 23 men) took part (*M* age = 36 years, SD = 7.26). Most were married or in a civil partnership (72 %), parenting within a two-parent family structure (89 %) and were White British (71 %). They provided demographic details (see Table 1) about their child; 54 % were girls , 45 % were boys and the mean child age was 6 years old (SD = 4.93, age range 1 month to 18 years old).

2.6. Procedure

Ethical approval was granted by the University of the West of England Research Ethics Committee (Approval code: HAS.19.12.092; 25/12/2020). All data collection procedures were conducted in line with British Psychological Society's code of ethics and conduct (British Psychological Society, 2021). Parents/carers who were interested in taking part were directed to a Qualtrics page (secure online data collection platform) where they read the information sheet, confirmed eligibility, and provided written informed consent. Participants were asked to generate a unique code to facilitate the withdrawal of their data and complete the survey. At the end of the survey, participants were given the opportunity to enter a prize draw (for a chance to win a £50 shopping voucher) and request a summary of the survey results.

2.7. Data analysis

Statistical analyses were conducted using SPSS Version 28. All analyses were conducted using two-side statistical testing. Multiple regression models were used to determine whether potential explanatory variables would be significantly associated with outcome variables. The outcome variables for the four regression models were 1) parent negative affect, 2) parent positive affect, 3) stress frequency, and 4) stress difficulty. Purposeful regression modelling was selected to identify risk and protective factors (Hosmer & Lemeshow, 2000). Purposeful regression modelling is an augmented backwards elimination method in which the analyst makes systematic decisions about variable selection at each stage of the modelling process (Bursac et al., 2008).

Table 1
Demographic information for survey participants (n = 209).

	Mean	SD
Parent age	36	7.26
Child age	6	4.93
	N	%
Parent gender		
Woman	186	89
Man	23	11
Child gender		
Girl	113	54
Boy	94	45
Prefer not to say	2	1
Relationship to child		
Mother	185	88
Father	23	11
Non-parent carer	1	< 1
Marital status		
Married/civil partnership	151	72
Cohabitating	37	18
Single	10	5
Divorced/separated	8	4
Did not report	3	1
Ethnicity		
Asian Other	1	< 1
Black African	3	1
Mixed/Multiple	5	2
South Asian	7	4
White British	149	71
White European	18	9
White Irish	9	4
White Other	16	8
Other	1	< 1
Highest level of qualification		
GCSEs/ISCED 3 C	15	7
A Levels/HND/BTEC/ISCED 3 A	31	15
Bachelor's degree	108	52
Master's degree	36	17
Doctorate degree/PhD	9	4
Did not report	10	5
Child condition/injury		
Abdominal difference	1	< 1
Birthmark	73	35
Burn injury	19	9
Craniofacial condition	75	36
Hair loss	9	4
Limb difference	11	5
Paralysis	4	2
Scarring	2	1
Skin condition	15	7

The purposeful regression modelling protocol includes an initial stage of univariate analysis between the candidate explanatory variables and outcome variables to determine whether explanatory variables met the variable selection criteria to be potentially included in the regression model. The criterion $p < .20$ was used to prevent inadvertent exclusion of important variables (Bendel & Afifi, 1977; Mickey & Greenland, 1989).

Univariate analysis indicated that there were no significant differences between parents of children with congenital or acquired conditions on any outcome variable. As a result, cause of condition was not included in the regression modelling phase.

Model residuals were examined to assess regression assumptions. Inspection of Q-Q plots did not indicate deviations from model assumptions. Multicollinearity was assessed using Tolerance and Variance

Inflation Factor (VIF) values. In all models, VIF values < 4, indicating no multicollinearity.

2.7.1. *Content analysis*

The data from open-ended questions were analysed using deductive content analysis, a systematic and objective means of describing and quantifying data (Sandelowski, 1995) that allows researchers to test theoretical issues and build a conceptual model or system of a phenomena (Elo & Kyngäs, 2008). The pre-existing categorical framework for this content analysis was informed by the psychosocial constructs under investigation in the online survey. All coding was conducted by the first author. Following this the codes and categories were reviewed through peer-debriefing discussions with the co-authors (Richards & Hemphill, 2018). Patient and Public Involvement representatives then acted as member checkers to review the final categories (Lincoln & Guba, 1985).

2.7.2. *Integrating data*

The quantitative and qualitative data were integrated using the "following a thread" method (Moran-Ellis et al., 2006), which involves identifying a theme or question in one data set and following it across to the other data set to enhance understanding. In this study, a theme or question was identified in the quantitative survey data and then followed into the corresponding open-ended questions to provide further detail.

3. Results

3.1. *Multiple regression models*

3.1.1. *Parent negative affect*

The fitted model accounted for 33 % of the variance and comprised of four statistically significant variables ($F(10,158) = 9.31, p < .001$ adj. $R^2 = .331$) as shown in Table 2. Increased parent-reported teasing was positively associated with negative affect scores, whereas increased child age, greater parent-child communication scores, and greater knowledge of condition and satisfaction with treatment were all negatively associated with negative affect scores.

3.1.2. *Parent stress frequency*

The fitted model accounted for 32 % of the variance and was comprised of four statistically significant variables ($F(8160) = 11.23, p < .001$, adj. $R^2 = .328$). Increased parent-reported teasing and greater perceived noticeability to parents were positively associated with stress frequency whereas, greater self-compassion, and greater knowledge of condition and satisfaction with treatment were negatively associated with stress frequency in parents (See Table 2).

3.1.3. *Parent stress difficulty*

The fitted model accounted for 29 % of the variance and was comprised of four statistically significant variables ($F(8160) = 7.77, p < .001$ adj. $R^2 = .294$). Increased parent-reported teasing and increased appearance-fixing behaviours were positively associated with stress difficulty, whereas greater self-compassion and greater parent-child communication scores were negatively associated with stress difficulty (see Table 2).

3.1.4. *Parent positive affect*

The fitted model accounted for 23 % of the variance and was comprised of three statistically significant variables ($F(5167) = 11.32, p < .001$, adj. $R^2 = .231$). Increased parent-reported teasing, greater parent social confidence, and greater parenting self-efficacy were positively associated with positive affect (see Table 2).

Table 2
Final multiple regression models for negative affect, stress frequency, stress difficulty and positive affect outcomes.

Outcome variable	Explanatory variable	β	t	p	Adj. R^2
Parent negative affect	Teasing	.16	2.16	.033*	.33
	Noticeability to parent	.13	1.86	.061	
	Noticeability to others	-.09	-1.31	.192	
	Appearance-fixing	.14	1.83	.069	
	Child age	-.14	-2.01	.046*	
	Self-compassion	-.16	-1.82	.071	
	Parent-child communication	-.17	-2.48	.014*	
	Knowledge and satisfaction with treatment	-.18	-2.28	.014*	
Parent stress frequency	Teasing	.33	4.99	< .001	.33
	Noticeability to parent	.23	3.41	.001**	
	Self-compassion	-.18	-2.11	.036*	
	Parent-child communication	-.10	-1.56	.122	
	Optimism	.05	-1.51	.134	
	Perceived social support	.10	1.41	.159	
	Knowledge and satisfaction with treatment	-.21	-3.08	.002**	
	Parent gender (Female)	.09	1.41	.160	
Parent stress difficulty	Teasing	.24	3.50	.001**	.29
	Noticeability to parent	14	1.97	051	
	Appearance-fixing	.18	2.23	.027*	
	Self-compassion	-.29	-3.46	.001*	
	Parent-child communication	-.17	-2.26	.025*	
	Psychological flexibility	.15	1.67	.096	
	Perceived social support	.10	1.37	.172	
	Knowledge and satisfaction with treatment	-.13	-1.76	.080	
Parent positive affect	Teasing	.21	2.77	.006**	.23
	Social confidence	.17	2.19	.030*	
	Self-efficacy	.33	4.46	< .001**	
	Child gender (Female)	.10	1.45	.148	

[*] p < .05;
[**] p < .001.

3.2. *Content analysis*

In total, 167 participants (80 % of total sample) responded to at least one open-ended question. Six main categories were identified, each with sub-categories (Elo & Kyngäs, 2008). Six a priori categories were included in the original categorisation matrix: parent affect and stress, reactions of other people to their child's visible difference, communication, strategies for coping, self-efficacy in parenting role, impact of COVID-19. Several novel sub-categories were identified within these main categories (e.g., changes in support and social contact due to COVID-19) and integrated. A summary of the frequencies of themes and sub-themes and example quotes can be found in Table 3.

4. Discussion

This study investigated the experiences of parents of children with a visible difference by using a cross-sectional survey design with measures intended to capture psychosocial constructs identified in previous qualitative research and limited existing literature. It also investigated risk and protective factors for parental affect and stress. Parent-reported teasing, noticeability of the child's condition or injury, and appearance-fixing behaviours were associated with increased negative affect and stress. Higher parental self-compassion scores, open and confident

Table 3
Summary of the content analysis of open-ended responses within the survey.

Categories/ Subcategories	Frequency N (%)	Exemplar quotes
Parent affect and stress		
Negative affect	17 (10)	“It took until he was about 10 years old for me to stop wishing it away every single day.”
Positive affect	14 (8)	“I feel proud talking about the surgery he went through and how he coped.”
Anxiety	55 (33)	“The unknown is always scary and with any diagnosis there is at least some aspects that are unknown as each person is different”
Stressful situations	8 (5)	“Exhausting - we have to stick strictly to a daily routine of creams, baths, bandages etc for my daughter and this can be tiring.”
Guilt	20 (12)	“I cannot help but feel guilty at the same time as it makes me think of the accident and our time in hospital.”
Reactions to visible difference		
Lack of public awareness	93 (56)	“It is usually out of ignorance that people make comments. It’s frustrating that there is not better education and subsequently acceptance of facial differences.”
Impact on children	18 (11)	“My child even at only 4 understands that a lot of people point and laugh/make nasty comments. And gets very upset about it and even refuses to wear clothes that reveal to much of his marks.”
Emotional impact on parents	41 (25)	“I feel guilty that people see his inflamed skin and assume I’m doing something wrong, mostly because I feel guilty that I could be doing more for him”
Communication		
Preparing their child	38 (23)	“We teach her everything we know about vitiligo, so that she too can educate those around her as honestly as possible”
Promoting acceptance	15 (9)	“We have brought her up to embrace her difference, however, with her only being 4 this is an ongoing process.”
Child too young	26 (16)	“As he is not yet 3 years old and the birthmark is on his shoulder blade I’m not sure how aware he is of it.”
Coping		
Active coping	13 (8)	“I set up a national support group and charity so people would have the support they needed when their babies were born.”
Psychological resources	23 (14)	“I am really working on trying to be more compassionate with myself and my own failures and not catastrophize as much in uncertain/bad times.”
Social support	24 (14)	“With time, family and friend support and help from the charity I feel much more able to cope and help my daughter now.”
Self-efficacy		
How do I do this?	13 (8)	“I don’t know how to advise her to respond to cruel remarks well enough.”
Weight of responsibility	9 (5)	“I often think as she gets older, I need to be ready to support her for when this happens.”
Confidence in skills and knowledge	22 (13)	“But I am prepared to answer his questions and talk to him and other freely about difficulties he may have or potentially have.”
Impact of COVID-19		
Changes in support	11 (7)	“COVID-19 has really limited the amount of practical help / face to face support that I have been able to ask for.”
Reduced social contact	50 (30)	“I worried during lockdown that not socialising with her friends and going to nursery would set her back in this regard.”
Health concerns	45 (27)	“The COVID-19 pandemic has truly thrown our plans into a tailspin. I’m concerned for her health and my entire family’s health - especially if something were to happen to me or my husband and providing for her once we have passed away.”
Positive experiences	20 (12)	“Lovely to have the children at lunch and supper each day as a family.”

parent-child communication, and greater knowledge of the condition and satisfaction with treatment were associated with reduced negative affect and stress. Higher parent self-efficacy scores and social confidence were associated with increased positive affect. No significant differences were found between parents with a child with a congenital or an acquired visible difference, which indicates that parents can share similar psychosocial experiences and challenges, regardless of the nature or cause of their child’s visible difference. This is supported by existing cross-condition qualitative research exploring the experiences of parents (Thornton et al., 2021), as well as a cross-section survey study with 331 adults with a visible difference which indicates no differences in psychosocial outcomes for those with congenital vs acquired conditions (Zucchelli et al., 2023). The responses from the open-ended questions also provided further clarification and context. Parents most frequently reported on other people’s reactions to their child’s condition, the importance of parent-child communication, and the impact of COVID-19.

4.1. Managing social challenges

As hypothesised, parent-reported teasing was significantly, positively, associated with the majority of affect and stress outcomes, suggesting that parents’ perceptions of teasing can negatively impact their own wellbeing. Data from the open-ended questions suggested that parents struggled with managing the reactions of other people and the emotional burden of coping with stigma or lack of awareness of their child’s condition among members of the public. In line with predictions, increased parent social confidence was also associated with greater positive affect. These findings suggest that social challenges are a salient concern for parents and the skills and confidence to manage social challenges may support improved parent adjustment.

Within the broader general population, parents of children who experience teasing or bullying can also struggle with psychological distress (Harcourt et al., 2014), suggesting that this is an experience which is not specific to parents of children with a visible difference. However, as suggested by the findings of the present research, parents and carers of children with visible differences regularly share concerns about social stigma and exclusion specifically associated with their child’s difference in appearance. For example, a meta-ethnography of 12 studies explored the psychosocial impact of skin conditions on both parents and young people. It found young people reported that teasing was the worst part of living with their condition, and parents also reported fears of appearance-related teasing (Ablett & Thompson, 2016). Ablett and Thompson also identified a broader theme, which captured parental distress at observing their child experiencing condition-related difficulties. Parents of children with craniofacial conditions reported that due to their familiarity with their child’s appearance on a day-to-day basis, the reactions of others often served as a surprising reminder that their child had an appearance difference (Feragen et al., 2021), suggesting that other people’s reactions may reinforce their child’s difference and cause distress.

Parents of children with an appearance-affecting condition also expressed worries about social exclusion for the affected child and the family as a whole. Hlongwa and Rispel (2018) found that South African mothers of children with cleft lip and/or palate (CLP) felt alienated from their communities and were ashamed of other people's reactions to their child's condition. Parents of children with limb differences have also reported observations of their child being excluded from social settings (Oliver et al., 2020). The findings of Oliver et al. (2020) suggested that parents sometimes felt they were caught between feeling distressed by the unwanted attention from others (e.g., staring) and managing reactions through compassionate understandings of staring and comments as acts of curiosity.

Some parents of children with craniofacial conditions reported they adjusted to their child's condition over time, and this led to greater social confidence and ability to cope with social challenges (Feragen et al., 2021). Regarding age, it may be that parents of children with a visible difference may be more likely to experience distress related to social challenges when their child is younger. Other qualitative research has also proposed that the early years of a child's life or period after a child's injury can be most challenging, but as a child grows up and develops cognitively, socially, and emotionally parents become less distressed by their visible difference (Thornton et al., 2021). This suggests support related to managing social challenges may be particularly important for parents of younger children.

A strategy parents have previously reported using to shield their children from social stigma due their appearance difference are appearance-fixing behaviours (Thornton et al., 2021). As predicted, the present study also found that increased parent-reported, child-focused appearance fixing behaviours (e.g., altering their child's appearance to align with societal norms such as, hiding or covering their appearance difference) was associated with greater stress difficulty. This is in line with a qualitative study with 15 adults with visible differences which found that these individuals experienced anxiety when faced with the prospect of disclosing their visible difference to other people (Sharratt et al., 2020). Parents who feel greater anxiety about their child's appearance difference being visible may be more inclined to conceal their child's visible difference, thereby not providing themselves or the child an opportunity to develop strategies to cope with the reactions of others. This can result in parents potentially remaining anxious or stressed when anticipating situations in which their child's condition or injury may become visible to others and invoke unpredictable reactions. This may be important to consider in the context of support development to encourage parents to equip children with psychosocial strategies and skills to manage the reactions of others rather than solely relying on concealment or other appearance altering behaviours.

The findings from existing qualitative research, along with the quantitative findings from the present study, indicate the complexities of managing social challenges and how these difficulties may evolve as the child grows up. This discussion also provides further evidence that parent perceived social challenges can impact the psychological wellbeing of the parent. This may in turn influence how parents interact and care for their child. For example, existing literature suggests that parents of children with a visible difference can respond to perceived social threats to their child by becoming overly restrictive or protective (Horridge et al., 2010), which can impact socioemotional development (Benson et al., 1991). Consequently, it is essential for parents to have access to support to manage their own emotional responses to possible social challenges to promote wellbeing of both the parent and the child.

4.2. *Parent psychosocial resources and strategies*

Several of the variables explored in this study were related to parents' own psychosocial resources and strategies. In line with predictions, feeling knowledgeable about their child's condition or injury and satisfied with the treatment their child had received was associated with reduced negative affect and stress frequency. As hypothesised, parental self-efficacy was also associated with increased positive affect. These findings support results from a survey of 1163 parents of children with CLP which found that knowledge of their child's condition and satisfaction with treatment was significantly associated with greater positive life orientation (Stock et al., 2020). Data from open-ended questions in the present study also alluded to parents' concerns about reduced access to healthcare and dissatisfaction with their child's care. This is in line with a qualitative study which found that, when healthcare and support was limited by lockdown restrictions, anxiety and stress increased in caregivers of children with CLP during the COVID-19 pandemic (Costa et al., 2021). The present study provides further supporting evidence that feeling informed and satisfied with care is important to parental wellbeing.

When parents did experience challenges or encounter difficulties, the findings of the present research indicated that increased self-compassion was associated with reduced parenting stress. This supports previous cross-condition qualitative research which highlights parents' concerns about doing the 'right' thing for their child and worries about negative outcomes should they fail to 'strike the balance' between providing adequate support and allowing their child to self-manage (Thornton et al., 2021). As with the findings of the present study, parents reported how a lack of self-compassion led to self-blame and increased stress. In addition, condition-specific visible difference literature has also begun to identify the important role of self-compassion for caregivers. Hawkins et al. (2019) found that greater self-compassion predicted fewer depressive symptoms in parents of children with burn injuries. Self-compassion explained a greater proportion of the variance in this depression outcome than shame, and guilt was found to no longer be a significant predictor once self-compassion was included in analysis.

Self-compassion was highlighted as an important factor in promoting wellbeing in parents in the general population (Moreira et al., 2015). Self-compassion may help parents develop a calm, accepting, and compassionate approach to their child's behaviour, particularly when children express negative emotions (Neff & Faso, 2015). Mindful parenting, an intervention designed to promote self-compassion, can increase general well-being in parents (Gouveia et al., 2016). These findings from the general population, in addition to those from the present study and existing visible difference literature, suggest that self-compassion could be an important protective factor for parental adjustment and possibly a key target for future intervention development.

Social support from those close to parents is often discussed in the field of visible difference research. Contrary to expectations, perceived social support was not a significant variable in the stress frequency and difficulty regression models. In contrast, previous research with parents of children with a visible difference indicated that access to appropriate levels of social support played an important role in ameliorating distress. For example, in a cross-sectional study of 103 parents of children with CLP, higher levels of social support were associated with less family impact, lower psychological distress, and greater positive adjustment to having a child with a craniofacial condition (Baker et al., 2009). Open-ended question data in this study indicated it was important that the type of social support met the parents' needs, and that inappropriate support may be an additional source of distress. This reinforces the finding that perceived quality of social support is associated with greater psychological wellbeing in individuals with long-term health conditions (Franks et al., 2004). It is also important to acknowledge that the present data were collected following the first COVID lockdown in the UK, which may have significantly affected parents' perceptions of social support. This was reflected in the open-ended qualitative responses in this survey. To improve our understanding of the role of social support for this parent population, future research should consider exploring the factors which promote beneficial social support.

4.3. Parent-child interactions

In line with predictions, good parent-child communication related to their child’s visible difference was associated with reduced negative affect and stress difficulty in parents. Within the open-ended responses, some participants described being cognisant of the need to prepare their child to manage independently and believed this could be achieved by regularly speaking to their child about their condition or injury. These conversations aimed to help their child understand and discuss their appearance difference, as well as difference and diversity more broadly. Parents also reported an awareness of the need to provide a good model to their child about how to communicate with others (e.g., friends, teachers, public).

Evidence from qualitative research with parents of children with a range of visible differences found that parents can find appearance-focussed conversations challenging (Zelihić et al., 2021), particularly around when and where to initiate conversations with fears that they might upset and/or exacerbate their child’s appearance worries. Similarly, in a study of parents of children with craniofacial conditions, almost all participants reported concerns about creating a negative awareness of their condition or distressing their child (Feragen et al., 2021). Parents also acknowledged that this conversation would likely become unavoidable and described an ongoing lack of confidence about how to address the subject. Findings from previous research, alongside those from the present study, indicate that clarity and confidence around open parent-child communication are critical skills for parents, and psychosocial interventions would benefit from an increased focus on this.

4.3.1. Child age

Child age was significantly negatively associated with parent negative affect, which supports previous findings that parents have found adjustment to their child’s visible difference most challenging in the early years of life (Costa et al., 2019; Heath et al., 2018). As mentioned above, some parents of children with visible differences report finding certain challenges less difficult to manage (e.g., social situations) as their child grows up and develops (Feragen et al., 2021; Thornton et al., 2021). Due to long hospital stays and feelings that those around them did not share experiential knowledge, parents of children with burn injuries found the time after their child was injured both psychologically and physically isolating (Heath et al., 2018). Similarly, a review of literature exploring the early experiences of parents of children with CLP identified that early feeding difficulties, challenges with psychological adjustment, and a high burden of treatment (e.g., hospital appointments and surgery) can result in challenging early years for these families (Nelson et al., 2012b). The mean age of children in the present study was six years old, similar to much of the existing literature in the visible difference field. As such, these findings contribute to our understanding of parents and carers of children, rather than those of pre-adolescents or adolescents. This relatively low mean age and the findings indicating that the early years of life are challenging, could be related to the large proportion of parents of children with congenital conditions in the present sample. This suggests that this study may not be able to provide insights into parents of older children with visible differences. Pre-adolescence and adolescence can be vulnerable periods for young people and their parents regarding appearance concerns, including young people with visible differences (Stock et al., 2013). Further research may therefore be required to understand the specific experiences and support needs of parents of pre-adolescents and adolescents with visible differences, including parents of children who have acquired a visible difference later in childhood.

4.4. Limitations

Whilst this study provides novel insights into risk and protective factors for parents of children with visible differences, it is important to recognise its limitations. Despite efforts to broaden the representation of different family structures, most participants were from ‘traditional’ two parent families, thus the findings may not apply to families comprised of non-parent carers or single parents. The broader paediatric literature has noted that the experience of single parents of children with chronic health conditions is underserved by research (Granek et al., 2014). A common limitation of literature within this field is the underrepresentation of fathers and male caregivers. This gender imbalance was reflected in the current sample with most participants being mothers or carers who identified as women. Previous research has found that there are differences in variables which predict adjustment in mothers and fathers of children with CLP (Stock et al., 2020), suggesting that women and men may have different experiences and support needs. As a result, the findings of the present study may not generalise to caregivers of all genders and roles. A large proportion of the appearance-affecting conditions represented in this study were congenital (approx. 75 %), rather than acquired. This sample bias towards congenital conditions could have implications for statistical testing. Consequently, findings should be considered in the context of this limitation.

This research utilised a cross-sectional design and consequently, the findings and conclusions are limited in terms of changes in parental distress over time. This could be particularly pertinent for understanding parent adjustment as children grow up and develop. Given that research with parents of children with a visible difference is still an emerging field, many of the measures utilised in this study have not been specifically validated within a visible difference population, although all have been utilised within the context of paediatric chronic illness or appearance research. Consequently, the findings of the study should be considered with this limitation in mind. In addition, several non-validated measures were developed by the authors for use in this study. These measures were utilised to capture the unique experiences of parents of children with a visible difference. The associations between non-validated and validated measures have been assessed and there no large correlations between variables ($r < .50$) suggesting that all measures assessed distinct constructs. However, the psychometric properties of these measures have not been assessed through a scale validation process.

This is an exploratory study predicated on prior reasoned variables informed by literature and qualitative research related to parental adjustment. The methodology of purposeful variable selection in multivariable regression with multiple predictors and outcomes is prone to identify some relationships which might not replicate. This method was adopted to ensure that no potentially important variables were excluded. We also assessed the significance of variables in the full regression models using the Benjamini-Hochberg False Discovery Rate (FDR) procedure. In common with other exploratory studies, we controlled the FDR at $q = 0.20$. Under this assessment all of the variables in the models presented retained statistical significance. As this is early stage research, we acknowledge that other constructs, not considered in this research, may be included in future research and add to our understanding of parental experiences.

Finally, this study did not employ a comparison group to explore the differences in adjustment between parents of children with or without a visible difference. Previous research has found that parents of children with CLP and infantile haemangioma (a birthmark) report less distress than parents of children without a visible difference (van Dalen et al., 2021). These findings suggest differences between the two parent populations. As this comparison is not available within the present study, it may not be possible to conclude which aspects of the findings are specific to parents of children with a visible difference rather than a result of the typical challenges of parenting.

4.5. Clinical implications

The present research has provided valuable insight into possible risk and protective factors for parental psychosocial wellbeing. This could help practitioners to identify risk factors for poor psychosocial adjustment in the families they are supporting and provide an evidence-base to inform intervention. The findings indicate that actual and anticipated social challenges (e.g., teasing and bullying) can be a major concern for parents. Therefore, it is essential that these concerns are addressed through support which provides practical skills for managing unwanted social stigma and increasing social confidence, as well as psychological strategies to support parents with any associated challenging thoughts and feelings. Interventions may also include equipping parents with the skills to gather high-quality information about their child's condition. Additionally, strategies to support open and transparent parent-child communication, as well as how to manage any difficult thoughts and feelings that may arise in the process of having sensitive conversations should be included in parent support. Finally, encouraging parents to engage in therapeutic activities designed to cultivate self-compassion may also be effective in promoting parental adjustment.

5. Conclusion

By exploring cross-condition risk and protective factors for psychological distress, this study adds to existing knowledge related to the shared experiences of parents and carers of children with a range of visible differences and identifies important considerations when developing psychological support for parents. Self-compassion, good parent-child communication, knowledge of condition and satisfaction with treatment contributed to parent psychosocial wellbeing whereas, perceived social challenges can present difficulties and was associated with psychological distress. This emphasises the importance of support for parents throughout their child's development, with the acknowledgement that there may be particular challenges during the early years of a child's life. Greater understanding of factors which promote wellbeing in parents of children with a range of visible differences can inform therapeutic practice for professionals who deliver care and psychosocial support to these families. For example, findings suggest that interventions that promote self-compassion, support parents to communicate openly with their child, and ensure parents feel informed about their child's condition may improve parental wellbeing.

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CRediT authorship contribution statement

Maia Thornton: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Data curation, Conceptualization. **Paul White:** Writing – review & editing, Formal analysis. **Heidi Williamson:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Conceptualization. **James Kiff:** Writing – review & editing, Writing – original draft, Supervision. **Diana Harcourt:** Writing – review & editing, Writing – original draft, Supervision, Funding acquisition, Conceptualization. **Toity Deave:** Writing – review & editing, Writing – original draft, Supervision, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data that has been used is confidential.

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