

## **Abstract**

Living with a visible difference (e.g., disfigurement) can compromise a child's psychological wellbeing. Although some children can adjust well, others can develop a range of appearance-related issues such as social anxiety, low self-esteem, and body dissatisfaction. However, current research fails to confirm what factors contribute to appearance-related distress, and what factors buffer the consequences of living with a visible difference. Semi-structured qualitative interviews were conducted with 16 Australian specialist health professionals who care for children with visible differences. Interviews explored the type of appearance-related psychosocial concerns presented to a pediatric hospital, perspectives on the impact of appearance-related distress, as well as factors and processes that health professionals perceive influence adjustment. Data were subjected to inductive thematic analysis. Rich evidence was offered by health professionals, which demonstrated deep understanding of the psychological wellbeing of their patients. Three themes were identified: *Mind, Body, and Soul*; *Stages of Life*; and *Individual Differences*. Findings highlighted the complexity of appearance-related distress, with individual differences in adjustment, and the powerful impact it can have on a child's short and long-term psychosocial wellbeing. The importance of reaching consensus in the conceptualisation and measurement of psychological wellbeing is stressed, and key domains associated with adjustment are proposed.

## **Keywords**

children; young people; appearance-related distress; psychosocial adjustment; health professionals; visible difference

## 1. Introduction

Permanent or temporary visible differences (e.g., disfigurement) can be caused by congenital conditions (e.g., cleft lip), acquired injuries such as burns and traumatic accidents (e.g., scarring, limb loss), birthmarks, skin conditions (e.g., vitiligo or psoriasis) or treatments for disease (e.g., chemotherapy). Whether evident at birth or acquired later in life, adjustment to both the physical and aesthetic consequences of appearance-affecting conditions or injuries can be stressful and enduring for children and young people (CYP) (Attoe & Pounds-Cornish, 2015; Rumsey, 2018; Stock & Feragen, 2016). Although CYP can endure challenges specific to their condition or injury, it appears psychosocial challenges that cause the most impact for CYP are relatively common. Whilst some CYP with visible differences report a range of daily struggles such as staring, social exclusion, depression, anxiety, bullying, and suicidal ideation, others can adjust well, using their unusual appearance to good advantage (Changing Faces, 2018b; Partridge, 1990; Rumsey & Harcourt, 2004). Research suggests approximately a third of individuals affected by a visible difference are vulnerable to psychosocial challenges, resulting in poor mental health (Rumsey, Clarke, & White, 2003). However, despite increasing research documenting the long-term psychosocial consequences associated with a visible difference, research exploring what factors and processes differentiate CYP who adjust well from those who struggle is lacking.

To date, there is agreement from researchers and clinicians in the field that adjustment to a visible difference is complex, influenced by a range of physical, developmental, cultural, treatment, psychological, and social factors (Rumsey & Harcourt, 2004, 2005; Thompson & Kent, 2001). Adjustment is also highly variable (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014). At present, psychological and social variables are believed to more strongly predict an individual's adjustment, over factors such as etiology, severity, age, and gender (Clarke et al., 2014). As a result, utilising psychosocial support and intervention to target

appearance-related distress has gained increasing attention. However, caution is needed, as evidence underpinning intervention has been primarily drawn from research conducted on adults with visible differences. A limited evidence base exists confirming the effectiveness of psychosocial support and intervention, as well as clear factors and processes that exacerbate and ameliorate appearance-related distress for pediatric populations (Jenkinson, Williamson, Byron-Daniel, & Moss, 2015).

It is presumed that CYP are particularly vulnerable to appearance-related distress because a visible difference is an underlying stressor, exacerbated by developmental and sociocultural pressures across the lifespan (Lansdown, Lloyd, & Hunter, 1991). For example, CYP who look 'different' are forced to grow up in a sociocultural landscape increasingly saturated with images of unrealistic beauty stereotypes, physical perfectionism and active encouragement of appearance-altering intervention (Smolak, 2012). Adjustment is also thought to be compromised, because adolescence is a period typically characterised by increased value and investment in body image, greater social comparison and sexual interest amongst peers (Stock, Whale, Jenkinson, Rumsey, & Fox, 2013). In the context of pediatric populations, the role family and peers play in adjustment is also thought to be significant. However, little research has been conducted to discern their impact and how they influence a child's appearance-related values, attitudes and behaviours (Bellew, 2012; Ricciardelli & Mellor, 2012). Hence, for CYP, adjustment to a visible difference is complicated, requiring consideration of sociocultural and developmental pressures, unique to childhood and adolescence.

Currently, no one model or framework explains psychosocial adjustment to a visible difference. Instead, there are a range of different models that uniquely contribute to our current understanding. Living with an unusual appearance is perceived to have a negative impact on an individual's self perceptions, which can contribute to lower levels of self-

esteem (Wisley & Gaskell, 2012), especially if there is high investment and value placed on appearance-related information stored within an individual's self-concept (Moss & Rosser, 2012). Body image disturbance models also propose that individuals who look 'different' are more vulnerable to appearance-related distress, because they may feel their disfigurement does not meet sociocultural norms of physical attraction (Cash, 1996). Failing to meet sociocultural informed standards of attractiveness is also posited by Goffman's Stigma Model (1963) as a risk factor for affected individual's fearing rejection, exclusion or discredit by others. In turn, this can lead to increased social anxiety or isolation to protect against the perceived threat of and/or actual experiences of social exclusion or rejection (Newell, 1999). Additionally, social skills models suggest one's own fixation on appearance and the fear of being negatively judged contributes to poor social behaviours, which ultimately creates discomfort and vulnerability in social interactions (Partridge, 1990; Rumsey, Bull, & Gahagan, 1986). Whilst all models explain individual facets of adjustment, no single model captures the full experience of living with a visible difference although, Kent (2000) made progress by proposing The Integrated Model, combining psychological theories of body image, social anxiety, social skills, and stigma. However, despite this, all theoretical explanations remain primarily drawn from adult literature and research, limiting their application to CYP. To date, there has been no systematic exploration of factors and processes affecting adjustment amongst CYP with visible differences.

Poor conceptualisation of psychosocial adjustment is a significant issue within current pediatric visible difference research. There is no definition of successful adjustment to a visible difference and no single conceptual framework exists that can explain a child's adjustment. In addition, existing measurement tools fail to capture important aspects of the lived patient experience (Jenkinson et al., 2015). Instead, there is high variability of constructs and subsequent measurement tools being used to assess the psychological

wellbeing of CYP with visible differences (Rumsey & Harcourt, 2012). For example, up to 40 different measures evaluate a child's psychosocial adjustment and/or quality of life across different appearance-related sub specialities (Griffiths et al., 2015; Klassen et al., 2012). Further complication arises when researchers assess different dimensions of the same construct (Szabo, Ferris, Urso, Aballay, & Duncan, 2017). Poor conceptualisation and inconsistent measurement of psychosocial adjustment not only makes it impossible to compare studies and derive solid conclusions, it impacts effective evaluation and compromises research quality. It also has significant implications for appearance-related psychosocial service provision, because both researchers and clinicians have no solid evidence base to guide intervention to target the psychosocial consequences of a visible difference. This is evidenced by recent research confirming that health professionals working in appearance-related specialities lack confidence to support the psychosocial needs of patients with a range of visible differences (Gee, Maskell, Newcombe, Kimble, & Williamson, 2019; Harcourt et al., 2018).

In order to progress the conceptualisation of psychosocial adjustment for pediatric visible difference populations, it is important to enrich our understanding of the experiences, factors and processes that enhance psychological wellbeing and exacerbate appearance-related distress amongst this population (Rumsey, 2018). By doing this, researchers and health professionals will have better evidence to guide decision-making, which in turn could progress consensus of key constructs, definitions and outcome measures associated with adjustment to a visible difference. As CYP with visible differences often develop strong, long-term relationships with those who treat them (Ramini, Brown, & Buckner, 2008), health professionals are well placed to provide perspectives on their patients' psychosocial adjustment. Increasingly, irrespective of profession, specialist health professionals in a multidisciplinary team are expected to identify and address a wide range of complex and

unique psychosocial issues associated with appearance-affecting conditions or injuries (Williamson et al., 2018). Despite this, past research conducted with health professionals has been limited to specific clinical populations (e.g., those with cancer and burns) (Guest, Griffiths, & Harcourt, 2018; Williamson & Rumsey, 2016) or been primarily focused on the opinions of psychosocial specialists (Harcourt et al., 2018). With increasing evidence confirming how commonplace it is for non-psychosocial specialists to manage the psychosocial care of patients with visible differences, and CYP experience similar psychosocial challenges irrespective of the type of condition or injury (Clarke et al., 2014), there is significant value in exploring a wide range of multidisciplinary health professional perspectives, from a broader range of appearance-related specialities. Given health professionals unique position and regular exposure to the target population, means their perspectives of patients, including factors and processes that contribute to psychological wellbeing and appearance-related distress are essential for richer and clearer conceptualisation of appearance adjustment for CYP.

### **1.1 Aims of the Current Study**

To our knowledge, no qualitative study has explored the perspectives of Australian multidisciplinary health professionals working across a broad range of appearance-related speciality areas in a pediatric setting. Furthermore, general research related to CYP's adjustment to visible difference has never been conducted in Australia. The bulk of existing literature is confined to Northern European and American healthcare contexts and primarily quantitative studies, which fail to adequately capture the essence of a lived experience. Australia is a unique contextual setting, due to its warm climate, outdoor living, large rural areas, different healthcare systems, multicultural and multiracial population (Australian Government, n.d.), all factors which may influence how Australian CYP adjust to a visible

difference. Hence, an opportunity to explore factors and processes that influence Australian CYP's adjustment to visible differences offers a novel contribution to the literature.

This study was part of a larger research program exploring the appearance-related psychosocial care and support needs of Australian children living with visible differences. However, the purpose of this specific study was to explore Australian health professional perspectives on appearance-related psychosocial issues observed in Australian CYP as well as factors and processes that they believe influence psychological wellbeing and appearance-related distress for CYP with visible differences. Overall study findings aim to progress current conceptualisation of psychosocial adjustment to visible difference for pediatric populations.

## **2. Method**

### **2.1 Ethical Approval**

Ethical approval was granted by the Children's Health Queensland Human Research Ethics Committee (HREC/16/QRCH/101), Research Governance (SSA/16/QRCH/211) and the Human Ethics Research Committee of the University of Queensland (#2016000850).

### **2.2 Research Team**

The first author is a PhD candidate with a psychology background, nearly 6 years of counselling experience, who has undertaken qualitative research training. The last author is an expert in health psychology, visible difference and has over 10 years conducting, collaborating and supervising qualitative research. The second author has worked in acute clinical health care as a social worker for over 15 years, is an expert in burn scarring and has had 10 years of experience conducting qualitative research. The third author is an associate professor in developmental psychology, with extensive experience in quality of life and chronic illness. The fourth author has been a professor in burns research for over 10 years.

Both the third and fourth author have a combined 15 years' experience supervising qualitative research.

### **2.3 Interpretive Framework**

This program of research was guided by social constructivism. Proponents of social constructivism believe that the way an individual sees and views the world is socially constructed, derived from the contexts, environments, and interactions in which people live and work (Creswell, 2007). Social constructivism was perceived to be an appropriate theoretical fit for this research study as health professionals' understanding and perspectives of psychosocial adjustment and appearance-related distress is assumed to be heavily influenced by their personal values, experiences, and training. The social constructivist framework posits that there is no single truth, but multiple constructed realities (Creswell & Poth, 2018; Mertens, 2015). For this reason, research is believed to be co-constructed by the researcher and the researched, as each other's experiences and backgrounds influence the other (Creswell & Poth, 2018). Social constructivism promotes flexible yet exploratory methodological designs such as qualitative interviews, with open ended questions, purposive sampling, inductive and interpretative approaches to data analysis (Creswell & Poth, 2018).

Given the limited evidence-base in this research area, qualitative methodology was deemed the more suitable approach to address this topic. Utilising qualitative approaches in health research has been shown to enhance understanding of patient-health relationships, explain the role of psychosocial variables in health and illness and ascertain solutions to improve service provision (Green & Thorogood, 2004).

Researcher reflexivity is also an important component of qualitative research, especially social constructivism. Reflexivity promotes researchers to be self-aware and transparent regarding their motivations, assumptions, perspectives on the research topic and



participants, so as to allow readers to interpret findings with contextual understanding (Begoray & Banister, 2010; Yardley, 2000).

## **2.4 Participants and Recruitment**

Participants were purposively sampled from a large Australian pediatric specialist hospital. Recruitment targeted professions that would typically feature in a specialist multidisciplinary team who provide care and treatment to CYP with a range of visible differences. All efforts were made to ensure a range of medical, psychosocial, and allied health professionals were included from a wide range of appearance-related specialities. The first author purposively approached clinicians from ethics approved speciality areas: plastics and reconstructive surgery (including oral and maxillofacial specialists); cleft and craniofacial teams; burns and trauma; paediatric surgery (including vascular malformations); child, youth, and mental health; and dermatology. Participants were excluded if they had inadequate English proficiency to participate in an interview.

A total of 16 participants (12 female, *M* age = 40.13 years) were recruited, representing a wide range of multidisciplinary roles including four nurses, three surgeons, two occupational therapists, two speech pathologists, one orthodontist, one oral health therapist, one psychologist, one social worker, and one physiotherapist. Whilst the majority of clinicians worked within one speciality, others worked across multiple appearance-related specialities. Health professionals had worked in their profession an average of 14.97 years. Six declined to participate due to clinical demands, time factors, or did not respond. See Table 1 for participant characteristics. To preserve participant anonymity, only pseudonyms, profession, and years of training are detailed. Sample size was guided by Braun and Clarke's (2013) guidelines for a medium thematic analysis project (e.g., 10 -20 participants).

The first author invited participants in person or via email and provided them with study information sheets. Once consent was obtained, health professionals participated in a single, face-to-face, semi-structured interview in a private room within the hospital or adjoining research centre. All interviews were audio-recorded.

Prior to beginning this research, the first author spent time observing specialist consultations at the recruitment site. During observation periods, the first author professionally interacted with some participants recruited for this study. However, these interactions were brief and discussions were minimal. Participants were unaware of the content and nature of this research project until they were approached to participate. Hence, any participant bias is perceived to be minimal.

## **2.5 Interviews**

The semi-structured interview schedule covered topics and probes relevant to psychosocial adjustment and appearance-related distress for pediatric visible difference populations. Interview questions primarily focused on the following areas: (1) What appearance-related psychosocial issues do you see in your work with CYP with visible differences? (2) What differentiates CYP who adjust well from those who struggle with visible differences? (including influences that promote or exacerbate appearance-related distress) (3) What long-term impact do visible differences have on a CYP's quality of life and psychosocial adjustment? The interview schedule was used flexibly, to allow participants to respond and expand on topics which they felt to be important.

Interviews were conducted by the first author, ranging from 40 to 100 minutes, but lasting an average of 43.14 minutes.

## **2.6 Data Analysis**

Data were transcribed verbatim and analysed using thematic analysis (TA). The analysis followed an inductive and data-driven approach using Braun and Clarke (2013) six-phase process. Coding was completed by hand-writing on transcripts, utilising Nvivo and Microsoft Excel software programs. The first four transcripts were completely coded by the first, second, and last author independently. The first author met with the second and last author separately to discuss each of the four transcripts in depth, to verify coding decisions and develop initial themes. Communication regarding coding was also conducted across Skype, phone, and email. The remaining transcripts were completely coded by the first author, ensuring anything relevant to the research question was coded (Braun & Clarke, 2013).

Mind maps were constructed to conceptualise and refine themes from codes. Once themes were identified, theme definitions were generated and sent to coders for further review. Whilst coding was generally consistent across coders, there was some initial disagreement in relation to the labelling of some themes, sub-themes, and around the clarity and strength of some sub-themes. Theme and sub-theme labels that were considered ambiguous were changed for clearer operationalisation. The strength and clarity of some sub-themes were debated, and as a result some were consequently removed or collapsed. This process involved re-reviewing transcripts to ensure analysis remained grounded in the data. Disagreement between coders was resolved by in-depth verbal discussion until consensus was reached. Discussion continued through to the final write up stage to ensure coherence and final consensus across all co-authors. To increase credibility of the data analysis (Tracy, 2010), a summary of findings was sent to all participants for further feedback. Three participants responded and supported the analysis, and thus no changes were made.

Once all themes and sub-themes were finalised, further thematic analysis of the data was conducted. The aim of this process was to produce key domains of adjustment, to address overall study aims (detailed above). Therefore, a more deductive and latent analysis was specifically conducted on final themes and sub-themes. To gain a broader and more tangible conceptualisation of psychosocial adjustment, this deeper analysis focused on identifying concepts and assumptions underpinning final themes and sub-themes (Braun & Clarke, 2013). In line with social constructivism framework, this process aimed to represent the co-creation of research between the researcher and the researched (Creswell & Poth, 2018).

Sample size met guidelines for a medium TA project (Braun & Clarke, 2013). After 16 interviews, recruitment ceased. At this time, data saturation was believed to be reached as the data collected were deemed comprehensive and rich, participants had been consistently communicating similar ideas and topics, and no new ideas were emerging (Fusch & Ness, 2015).

To maintain quality qualitative publication, Elliott, Fischer, and Rennie (1999) guidelines were followed. Strategies included reporting theoretical orientations (e.g., owning one's perspective), providing demographic data of participants (e.g., situating the sample), careful selection of participant quotes (e.g., grounding examples), member checking (e.g., credibility checks), and a visual framework of findings (e.g., coherence).

### **3. Results**

Three main themes captured Australian health professionals' perspectives regarding psychosocial adjustment to visible difference for pediatric populations: (1) *Mind, Body, and Soul*; (2) *Stages of Life* and (3) *Individual Differences*. Each of these themes is discussed in turn and sub-themes further elucidate key aspects of each theme.

Findings focus on patterned meaning drawn across the entire dataset, however, individual participant quotes have been included to illustrate grounded examples (Elliott et al., 1999). Pseudonyms are represented in brackets as well as profession and years of experience in role. Quotes have been edited to aid readability and comprehension (i.e., removing false starts, hesitation, adding punctuation).

In line with overall study aims, further deductive and latent analysis of final themes and sub-themes was conducted to advance current conceptualisation of psychosocial adjustment to a visible difference. Hence, Figure 1 illustrates broader conceptual understanding of overall study findings, proposing key domains and influences central to a child's psychosocial adjustment to a visible difference, based on Australian health professional perspectives.

### **3.1 Mind, Body, and Soul**

This theme represents the significant impact living with a visible difference can have on CYPs' mind, body, and soul. The sub-themes encapsulate health professionals' perceptions that a child's psychological, social, and physical self is challenged by persistent and complex issues that impact on their quality of life and long-term psychosocial adjustment.

#### **3.1.1 Life of difference.**

This sub-theme was discussed by 13 of the 16 participants, revealing CYP's struggle with a life characterised by difference: "anything that's different is difficult...the idea of having something labelled [as different] ...is something that a lot of young people struggle with..." (Eve, Psychologist, 15 years). Alison (Occupational Therapist, 12 years) shared a young patient's distress associated with feeling and looking different: "I look like a freak, it looks so weird, so odd." Additionally, it had been observed that even parents struggled with a

life of difference: “Mum kept saying, I just want her to look normal, you just have to make her look normal” (Sarah, Nurse, 17 years). The concept of difference extended far beyond physical appearance and was connected to “a fear associated with being different” (David, Surgeon, 8 years) in one’s own social world. Appearance-related distress was fuelled by how differently a child felt in their present world and from others. The difference associated with having to care for an appearance-affecting condition or injury (e.g., wearing a pressure garment for a burn), having different routines from peers (e.g., missing school due to treatment/surgery) and/or having different physical capabilities (e.g., restricted movement due to functional limitations) further illustrated a life characterised by difference.

### **3.1.2 Loss of social anonymity.**

Thirteen of the 16 participants detailed CYP’s discomfort associated with a loss of social anonymity: “[when] they’re in the public arena, a school thing or a shopping centre, somebody will come up and ask questions, it’s like your public property just because you’ve got this injury...” (Alison, Occupational Therapist, 12 years). Constant unwanted attention, fielding curiosity and persistent questioning: “because [their appearance is] outside the standard deviation of normal” (Katie, Surgeon, 10 years) was perceived to exacerbate a child’s appearance-related distress. Jackie (Speech Pathologist, 18 years) discussed how parents also struggle fielding questions about their child’s appearance, for example people often ask “what’s wrong [with your child],” rather than asking questions “that everybody [typically] gets [about their child].”

The adoption of safety behaviours (e.g., concealment, disguising, and avoidance of activities) provided CYP reprieve from staring, reduced personal fear of exposure, and discomfort to others. However, having to evaluate and assess all social behaviours and interactions was believed to significantly disrupt CYP’s social functioning: “do they cover

that up, do they tell people, how do they manage if people say ‘what's that on your arm, why do you have those scars?’” (Eve, Psychologist, 15 years).

### **3.1.3 Stigma.**

Stigmatisation by others was commonly reported by 13 of the 16 participants, as one of the most significant challenges for CYP affected by visible differences. It was commonplace for health professionals to hear testimonials from families regarding CYP being subjected to bullying and teasing because of their altered appearance and/or limited functional capacity:

I remember working with a boy, he was 3 or 4 and he had been bullied in [kindergarten] by a peer; he said something about the fact that his mum was obviously a drunk because she had a child with a cleft... (Jackie, Speech Pathologist, 18 years)

Social stigma was also thought to be linked to mistaken beliefs about disease origins, contagion, and/or poor understanding appearance-affecting conditions and injuries:

People will see their skin condition and not want to be friends with them, because they think they're infectious...or dirty...or [have] poor hygiene...people assume if you've got bad skin...maybe you've got poor hygiene” (Carol, Nurse, 6.5 years)

Being the subject of negative attention and misconceptions regarding the nature and cause of one's visible difference was observed by health professionals to contribute to poor psychosocial outcomes. Participants described patients becoming socially isolated because of purposeful withdrawal or avoidance and/or other children refusing to play with them. Health professionals spoke of examples of appearance-related bullying and teasing leading some parents to change their child's school or had discouraged CYP from seeking employment, which some health professionals raised had significant impacts on a child's education, friendships and career prospects.

### **3.1.4 A life less engaged.**

Ten of the 16 participants perceived CYP often lived a restricted life because of a visible difference. Poor life engagement was believed to be a direct consequence of CYP's need to shield themselves from unwanted attention, stigmatisation, manage symptom burden and/or functional limitations. As Katie (Surgeon, 10 years) described, "[CYP] limit their life because they don't want to get made fun of, or mocked."

Participants shared that they had witnessed CYP miss out and/or experience reduced enjoyment in preferred activities, school absenteeism, restriction in pursuing employment or romantic relationships. Alison (Occupational Therapist, 12 years) had observed CYP "not wanting to play certain sports because you have to wear that uniform which would then expose the visible difference." Perceived restriction and reduced enjoyment in day-to-day activities was believed to significantly impact CYP's ability to live a full, happy and engaged life. For example, Alexandra (Social Worker, 5 years) described how living with disfigurement places significant strain and stress on everyday ordinary experiences: "[they have] troubles at school, troubles with employment, [they] question whether it will impact them at work, even right through to, [worrying about] appearance at a school formal or [on a] partner... relationship...having kids and explaining it to kids."

### **3.1.5 Impact on long term mental health.**

Thirteen of the 16 participants emphasised the psychosocial complexity of living with a visible difference and the negative impact it can have on a child's long term mental health. Health professionals had observed their patients develop low self-confidence, poor self-esteem, suicidal ideation, depression, anxiety, post-traumatic stress, and social withdrawal. Even after surgical intervention, the impact of disfigurement and the social consequences of an unusual appearance had lasting effects on CYP's psychosocial wellbeing and confidence:



this kid said [to me]....I want to be normal, I want to look normal, [he] was so distressed....his confidence had gone right down again....[he had asked] one of the prettiest girls in school out and she said yes....but her father said “what, you’re not going with him....he has a cleft”....I don’t know how you get around it ...this kid did have a shorter lip and lip asymmetry... he wasn’t bad, but it was just devastating to him...and even after he had the lip done, he wasn’t the same...they’ve gone through all their surgery .....they look fantastic, but they’re still damaged on the inside (Jack, Oral Health, 30 years)

Alison (Occupational Therapist, 12 years) discussed a time when a parent emailed her seeking support, as her daughter had been contemplating suicide because of the distress of her physical appearance: “[Mum] found a note that her daughter had written about wanting to commit suicide....she [was] reporting wanting to do things to end her life because of the impact of how she looks.” David (Surgeon, 8 years) also reflected on the trauma associated with visible differences: “every time they see it, they’re reminded of the injury, so all of the post-traumatic stress may continue to develop [if] keeps being brought up.”

### **3.2 Stages of Life**

The theme, stages of life is presented in Table 2. Table 2 summarises health professionals’ perspectives of appearance-related issues characteristic to different developmental time points and transitional periods in a child’s life and offers exemplary quotes. Collectively, participants reiterated the importance of CYP receiving specialist appearance-related psychosocial support and intervention during these specific stages of life.

### **3.3 Individual Differences**

The theme individual differences reflected participants’ collective beliefs that for a child, adjustment to a visible difference is highly variable, complex, and dynamic, due to a

range of multifaceted factors and processes: “it's amazing, some kids just go through life and just never have any problems, but we also have kids...[and] they're traumatised...” (Jack, Oral Health, 30 years). Sub themes illustrate the wide range of predisposing, personal, family, sociocultural, care, and treatment factors perceived to positively and negatively influence their psychosocial adjustment.

### **3.3.1 Predisposing factors.**

Fourteen of the 16 participants referred to innate factors such as disposition, resilience and personality that they perceived significantly influenced a child's adjustment to their visible difference: “those who are resilient with their deformity, they're resilient in the rest of life...if they're not coping with the deformity, they generally don't cope with life” (Katie, Surgeon, 10 years). CYP who inherently displayed “personality and inner confidence to be able to stand up and say, this is me...love me or hate me [as I am]” (Jackie, Speech Pathologist, 18 years) often demonstrated better adjustment when compared with “the quieter kids...[whose] self-esteem is down a little bit anyway or they're a little bit unsure of themselves” (Jack, Oral Health, 30 years).

Age of injury was also perceived to be a factor in adjustment, generating contemplation as to the developmental age a child can integrate their condition or injury into their self-concept or self-identity. David, (Surgeon, 8 years) believed that CYP who acquire their condition or injury during early childhood “grow up thinking ‘this is normal’ and may naturally feel this makes me who I am”. Whereas, Debbie (Occupational Therapist, 20 years) pointed out the significance of acquiring a condition or injury during a critical junction such as adolescence, “when you're already dealing with change and not wanting to be different.”

The noticeability or visibility of a child's visible difference was also perceived a factor in their adjustment. A highly visible or noticeable condition or injury was believed to

invite intense public scrutiny and negative attention, which was challenging for many CYP: “if a child only has scarring on their chest and tummy as opposed to on their arms, where it’s potentially in open view all the time, there’s a difference with that” (Kate, Physiotherapist, 10 years). Although visibility was not considered a defining factor in adjustment, higher appearance-related distress had been seen in CYP living with highly noticeable appearance-affecting conditions or injuries: “so the kids that had external fixation as opposed to internal fixation, with internal being a surgical scar on their leg, you can’t see the device fixing the structure, whereas external fixation, there was a lot more psychosocial issues reported....” (Alison, Occupational Therapist, 12 years).

### **3.3.2 Influence of significant others.**

All sixteen participants described how a child’s psychosocial adjustment can be strongly influenced by the appearance-related beliefs and attitudes of significant others. It was widely observed that parents who struggle with their own mental health (potentially associated with guilt about their child’s visible difference), often transfer that distress onto their child:

Absolutely depends on the family... a mother might be completely anxious personality, and that's everything to them, and the child might have the deposition of the father and, it's all okay for them.....but it becomes a problem because it's a problem for the mother..... (Julie, Nurse, 22 years)

Significant others who modelled negative appearance-related beliefs and attitudes were perceived to be particularly harmful: “if the parents keep, or people keep, pushing the point [that] this is a problem, they grow up thinking this is a problem” (David, Surgeon, 8 years). Consequently, Michael (Oral Health, 28 years) felt “I’d be really pushed to say that the [appearance] worry comes initially from the child...I think you’ve got this adult figure

that's raising the issue." In some cases, Debbie (Occupational Therapist, 20 years) believed that parents can unconsciously transfer distress onto their child, simply in how they approach their treatment and care:

they're catching a flight because their local burns service is saying, there is nothing more we can offer....on the surface of it, it's this tiny little [scar], but this family was travelling 2000kms because they just want [the scar] to go away...[so] that's the message they inadvertently give to their child as well.

High parental salience (i.e., significance ascribed to appearance) and valence (i.e., investment in appearance) in appearance had also been observed to negatively impact a child's psychosocial adjustment. Sarah (Nurse, 17 years) suggested there was a strong relationship between an individual's investment in appearance and their vulnerability to appearance-related distress:

You know mum is all done up gorgeous, wearing everything, and they're very very worried about the appearance of their children and then you see another family coming in and they're a bit more casual and they're not so much worried about the appearance of their child...

High salience and valence in appearance was also perceived to drive unrealistic expectations and attitudes towards surgical intervention. Katie (Surgeon, 10 years) spoke about the challenges of managing parent perceptions of appearance-altering surgery:

...some parents really push surgery...which you know is not in the best interests of the child and the mother thinks it will be a panacea for their [child's] problem...and sometimes they really look to surgery to be the be all and end all of the problems...and it's not...

On the contrary, positive role modelling and parental acceptance of a visible difference was perceived to help CYP adjust better: “so one particular patient.....her parents have done a lot of focus on building up her self-esteem and you know, focusing on her positives.....that family has gone and sought psychological help and are very involved with the psychology side of things....” (Esther, Nurse, 10 years).

The appearance-related beliefs and attitudes of significant others were also perceived to potentially differentiate how males and females adjust to their visible difference. Despite acknowledgment that male patients report appearance-related distress, the majority of participants believed females express higher distress levels. Alison (Occupational Therapist, 12 years) had noticed fathers project greater appearance-related concern for their daughters: “I’ve had lots of Dads say to me...what’s it going to be like when she wants to wear a bikini on the beach...they’re really conscious of it...it seems emotionally different to a mother saying the same thing...”. This was in contrast to the level of appearance-related concern expressed by both mothers and fathers for their sons: “...[a boy] had a big port wine stain down the leg...the dad said ‘chicks dig scars don’t they?’” (Carol, Nurse, 6.5 years). Carol went onto comment further that health professionals too can be prone to making assumptions that “he’s a boy....so that won’t probably worry him too much.” This specific influence was perceived to contribute to lower levels of appearance-related distress being reported by males, potentially associated with them feeling that it is not culturally acceptable to discuss or be open about their aesthetic concerns: “...it’s not cool [for boys to say]...that I am worried about how I look...” (Katie, Surgeon, 10 years).

### **3.3.3 Support networks.**

Twelve of the 16 participants described how support networks typically influence a child’s psychosocial adjustment to their visible difference. Support networks were wide and varied but included family, school, peer, hospital, community, and exposure to individuals

living with similar conditions or injuries. Kate (Physiotherapist, 10 years) reiterated the importance of CYP needing a supportive family behind them, particularly during those early formative years:

I think the family support and the ability of the parents and the family around them to take it in their stride and try and help normalise....I think that really helps. The kids that don't adapt, they've got a family environment that isn't so supportive or isn't able to deal with trauma.

Many participants also stressed "positive peer relationships" and "strong friendship groups" protect CYP from poor psychosocial adjustment: "the negative stuff comes up when they don't have a good support network within their peers" (Alexandra, Social Worker, 5 years).

A couple of participants mentioned the positive impact a supportive school community can have on a child's psychosocial adjustment: "[having a] school really embrace [a child's visible difference] and support [them]... I think the culture of the school is something, the teachers are mindful.... it makes a massive difference" (Eve, Psychologist, 15 years). In support of this observation, Sarah (Nurse, 17 years) reported that bullying among patient groups that she works with (e.g., those with rarer conditions) was unusual, because her role involved educating schools and facilitating community support.

Exposure to individuals living with similar conditions or injuries was also perceived to be a powerful protective factor that supported positive adjustment to a visible difference. Due to the often isolating experiences connected to life with a visible difference, being afforded opportunities to meet other individuals with appearance-affecting conditions or injuries was seen to offer normalisation and validation: "the more people you meet, the more

you find out that, there are lots of people that have [different] things...it normalises it, that everybody has a struggle” (Katie, Surgeon, 10 years).

### **3.3.4 Sociocultural factors.**

Fourteen of the 16 participants described various sociocultural factors that influence a child’s adjustment to their visible difference. Societal pressures and expectations in relation to physical appearance, reinforced by mass media were considered detrimental in perpetuating appearance-related distress amongst this population. In particular, sociocultural messages that feed the association between “looking good and more success and happiness” (Sally, Speech Pathologist, 22 years). Michael (Oral Health, 28 years) described an example of how social media can negatively influence how CYP with visible differences are perceived, which can consequently damage their own self-esteem:

It's interesting [with] the recent snapchats.....the pressure [because of] the faces you can get on snapchat...they're so mean, because we treat patients that look like this....that all of a sudden will start changing the way people think about appearance...I'm sure that person wouldn't want to then look like that person [with the upside smile]....

The increase in sociocultural messages that endorse surgical intervention and growing public acceptance of cosmetic surgery were also thought to feed patients and families heavy investment in surgery as a way to fix appearance-related distress. This point was reiterated by Katie (Surgeon, 10 years):

.... there's just a bit of a blazay attitude towards surgery now. I'll just go and have that operated on. And I don't think they quite realise, that you're still having surgery....we will give you pain, we will give you [another] scar, we will give you tissue damage. I think it's a very societal thing...

The influence of culture on adjustment was also discussed widely by participants. Higher levels of appearance-related distress had been observed in Asian families, with specific references to Chinese, Indian, Pacific Islander, Vietnamese, and Japanese cultures, groups commonly found in the Australian population. Carol (Nurse, 6.5 years) discussed how families from Asian cultures “are often the more worried ones about skin appearance even if it’s really mild, they get really worked up over really mild cases, they sort of nick pick about the small...”. Asian families were also perceived to struggle with accepting clinical advice: “they’re often quite hyper vigilant about reporting it and wanting to keep interventions going longer than what is clinically indicated..., they’ll end up doing their own thing regardless of what you suggest...” (Alison, Occupational Therapist, 12 years). Higher levels of appearance-related anxiety within Asian cultures was perceived to be largely related to the fact that this population often “physiologically scar differently, so they’re often at greater risk of [a] visible difference” (Alison, Occupational Therapist, 12 years) and they “already have features” that are anatomically different to their Caucasian peers (Phillip, Surgeon, 6 years).

A child’s locality was also mentioned as an influential factor in adjustment. Two participants specifically commented that CYP who lived in the country (e.g., regional and rural areas) appeared to adjust more positively than those living in more urban/city areas. Sarah (Nurse, 17 years) believed:

I find the country children, so the ones that travel from out of town are a little bit more accepting of their condition or injury and they don’t seem to be as worried about [appearance] as much...in the country, there is a small community and that’s how so and so has always been... you kinda do see a little difference between that...”

David (Surgeon, 8 years), supported this observation and went on to explain how country families approach appearance-related care and treatment:



People out in the country, who just have to get on with life, I find that they're a bit more grateful, they're not the ones to complain and they just get on with treatment. Whereas, the inner city, first world (laughs) type people are much more finicky about little things.

### **3.3.5 Treatment/care factors.**

Seven participants spoke about how treatment/care perceptions and experiences appeared to impact a child's adjustment to visible differences. Given many affected CYP spend years engaged in multidisciplinary specialist care, general care/treatment experiences, including the predictability of future treatment outcomes and treatment expectations were perceived to shape overall adjustment. Katie (Surgeon, 10 years) spoke about how challenging it can be for CYP when there is a mismatch between expectations and patient satisfaction with outcomes: "I had one patient who went into a depression after her facial surgery, basically because she looked so different...aesthetically it looked better...but because it was such a change from what it had been before, she really struggled."

Unrealistic patient expectations that surgery will normalise a visible difference was seen as particularly problematic, especially if delays in surgical intervention are needed to ensure full developmental growth: "when the teenagers come in and they find out they've got to wait a certain length of time.....when they just want to look 'normal' ...they take that really hard, they just want it fixed now" (Esther, Nurse, 10 years). This was further reiterated by Sally (Speech Pathologist, 22 years): "there is this perception that I'm going to have these big operations at 16, 17,18 and that's going to change it all.....I do believe they hold a lot of stead in that there's a big surgery coming..."

Timing, access, and satisfaction with specialist care/treatment were also raised as complicating, but influential factors in adjustment. Sarah (Nurse, 17 years) believed that "if

they come as an infant, it's sort of made more normal, I think when they present late, they struggle a bit more, families aren't as educated." David (Surgeon, 8 years) also raised the potential impact on a child and their family if care/treatment experiences are perceived negatively: "they'd be fearful of coming to the hospital, this is where all the bad things happened."

### **3.3.6 Protective factors.**

Eleven of the 16 participants discussed a range of factors that they believed positively influenced a child's psychosocial adjustment to visible differences. CYP who had a strong sense of identity, influenced by non-appearance based attributes, were more likely to adjust positively:

a lot of kids that have an outside interest seem to cope better, like whether it's sporting or cultural....[if they] have a very clear direction of what they like and kind of want to get out of school and things outside school, those kids just seem to be less... bothered by specifics of how they look... (Phillip, Surgeon, 6 years)

Being able to affirm personal strengths and embrace achievements also had a positive impact on a child's long-term psychosocial wellbeing:

[if they have] success in other parts of their lives, so whether that be, I'm a really good music player, I'm really good at art, I'm really great at playing netball.....something like that, they have a sense of success and achievement in other parts of life (Alison, Occupational Therapist, 12 years)

CYP able to experience and attribute personal growth to their appearance-affecting condition or injury was also considered another protective factor. Participants spoke about patients who had shared that their visible difference "makes [them] stronger and helps remind them that they are brave for what they been through" or "proud" (Kate, Physiotherapist, 10

years). As discussed by Eve (Psychologist, 15 years), if CYP are able to depend less on appearance for their own self-identity and focus on other positive attributes, it can help them utilise more strength-based coping mechanisms to adjust more positively:

This case... severe leg fracture (associated with a very traumatic experience)..... he had quite a significant scar, he very willing showed us his scar, he had some ongoing pain, [but] got back out there, his identity was very much connected to his work, and so he went back to it. And he didn't worry about the change in physical appearance, so I think probably he was a very resilient person pre-morbidly. Um, he had survived, he interpreted as, I've got through this, this is a strength, rather than, oh my god, I nearly died, the world's terrible.

Collectively, participants commented on the importance of CYP being able to adopt positive coping strategies to buffer the negative consequences of visible differences. CYP who displayed positive adjustment to their visible differences had typically developed coping mechanisms; that promote acceptance of their condition or injury (e.g., self-compassion techniques such as “love themselves”), to manage challenging social situations (e.g., have prepared responses such as “little comebacks”) and that enable them to keep their differences private (e.g., safety behaviours such as “cosmetic camouflage”). Having the ability to disguise or conceal a visible difference was also observed to help CYP feel safe and in control of their life.

#### **4. Discussion**

Drawing on the experience of participants from a wide range of multidisciplinary professions and appearance-related speciality areas, this study is one of the first qualitative explorations to document health professionals' perspectives on appearance-related distress and psychosocial adjustment in pediatric visible difference populations. Current evidence

highlighted, as children navigate typical life events and transitional periods, irrespective of the cause or nature of their visible difference, appearance-related distress can have a powerful impact on how they live their lives. Although more in-depth investigation is required to advance the conceptualisation of psychosocial adjustment to visible difference, current findings provide foundation as to factors and processes that discern well-adjusted CYP from those that struggle.

Many of the factors and processes identified to contribute to a child's psychosocial adjustment were found in a project conducted by the Appearance Research Collaboration (ARC) (Clarke et al., 2014). The ARC project was a multicentre, mixed methods study of over 1200 adults with a variety of appearance-affecting conditions, ages, and backgrounds, which led to a working framework for understanding adjustment to a visible difference among adults (see Figure 2). ARC findings demonstrated the dynamic nature of psychosocial adjustment over time, and how socio-cognitive processes (e.g., fear of negative evaluation), appearance-specific cognitions (e.g., social comparison), and dispositional style (e.g., optimism) shape an individual's psychological wellbeing. A replication of the ARC project with pediatric populations has yet to be conducted, but is needed. Despite this, similar to the adult ARC project, current evidence suggests the extent to which CYP perceive and socially compare themselves to their peers, how they are treated in social contexts, the degree to which they are accepted by others, and the level of social support they receive are socio-cognitive processes that play a role in adjustment. In addition, appearance-specific cognitions, such as salience (i.e., level of importance attributed to aesthetics), valence (i.e., evaluation of the self in relation to appearance), how noticeable or easily disguisable one perceives their visible difference to be (i.e., subjective visibility), disposition (e.g., optimism) and personality (e.g., resilience) are also variables that influence a child's core beliefs and assumptions about disfigurement and its subsequent impact. Given current findings overlap

those in the ARC project, a stepped care approach, which targets unhelpful appearance-specific cognitions and behaviours through psychosocial intervention may be most effective in promoting positive adjustment (Clarke et al., 2014).

As highlighted in recent systematic reviews for both adults and CYP with visible differences, the biggest issue plaguing current research is the lack of evidence base on which to develop effective intervention (Bessell & Moss, 2007; Jenkinson et al., 2015; Norman & Moss, 2015). Undoubtedly, this issue is the result of discord amongst the field in regards to the conceptualisation and measurement of psychological wellbeing for this population. Without a common framework, which outlines key domains of adjustment, outcomes and subsequent measurement tools, research and intervention development will fail to progress. Whilst it is clear more extensive investigation is still required, rich perspectives derived from health professionals sampled in this study offers foundational evidence that can be further validated and examined in the future.

As illustrated in Figure 1, key domains of adjustment proposed by this current exploration include: (1) Psychological wellbeing, (2) Social experiences, (3) Life engagement, (4) Appearance evaluation, and (5) Treatment/Care. Whilst many of these constructs are already referenced across CYP visible difference literature (Ablett & Thompson, 2016; Feragen, 2012; Rumsey & Harcourt, 2007; Stock et al., 2015; Wisley & Gaskell, 2012), life engagement is a behavioural domain that has attracted recent attention. Evidence that many CYP experience reduced life engagement to protect themselves from social intrusion, physical and/or symptom burden, implies both aesthetic and functional consequences of appearance-affecting conditions or injuries impact adjustment. Our study found functional limitation was especially significant for children in their early school years, because it restricted them from engaging in preferred hobbies and activities. It could also be argued that children of this age may also lack the maturity to comprehend the full aesthetic

impact of a visible difference. Scant adult literature supports this finding, indicating functional limitation can be of great importance and can contribute to feelings of appearance-related social anxiety (Clarke et al., 2014). Our study also found restricted engagement in important and preferred life areas such as education, physical activity, relationships and vocation also caused significant distress for older CYP. Hence, assessing the extent to which a visible difference prevents children from engaging in life activities due to both aesthetic and functional factors warrants further exploration. Compared with a construct such as Quality of Life (QOL), which is often queried for its utility (Rumsey, 2018), life engagement maybe a more appropriate domain to explain adjustment, particularly for pediatric populations. A measure that assesses the extent to which negative feelings about appearance prevents life engagement has shown some promise in general body image work; however, further psychometric validation is still required (Diedrichs et al., 2015; Diedrichs et al., 2016).

Current findings also draw attention to the influence of significant others and sociocultural factors in shaping a child's adjustment to a visible difference. Within the adult ARC framework (see Figure 2), these influences are viewed as less amenable to intervention and are regarded as 'predisposing' factors (Clarke et al., 2014). However, we suggest this supposition may need to be reconsidered for pediatric populations. In particular, our findings highlight how parental appearance-related attitudes, values, and beliefs appear to exacerbate or ameliorate appearance-related distress for a child. These results suggest provision of support and intervention for CYP needs to consider ways to strengthen and promote positive parental influence, and counteract negative role-modelling. As suggested by current evidence, supporting parents to affirm their child's strengths and achievements, encourage involvement in activities that promote self-identity outside of disfigurement, expose their child to peer support, and maintain inclusive support networks are possible strategies that may buffer the onset of appearance-related distress (Changing Faces, 2018a; Frisé, Lunde, & Berg, 2015;

Öster, Hensing, Löjdström, Sjöberg, & Willebrand, 2014). In addition, targeted parental psychoeducation that promotes healthy attitudes about appearance and surgery, teaches strategies to manage negative attention, and reduces gender appearance-related stereotypes would also be vital (Barke, Coad, & Harcourt, 2016; Nelson, Kirk, Caress, & Glenney, 2012). The timing of parental intervention is also salient, as our evidence suggests early childhood is a time characterised by appearance-related worry by parents. These results suggest, to ensure the construction of positive appearance-related values, beliefs and behaviours is fostered in children from a young age, early intervention which includes significant others is crucial. A recent report called 'Looking Different' (Changing Faces, 2018b), which investigated the perspectives of school-aged young people with and without a visible difference, supports this notion. The report recognised the need for early intervention so that all young children can learn the value of difference.

Study findings revealed higher levels of appearance-related distress amongst Asian families, a common cultural group in Australian society. Whilst health professionals did acknowledge that Asian complexions tend to be more susceptible to scarring, beliefs as to why this cultural group are more prone to poor adjustment and highly invested in their physical appearance remains unclear. Past adult studies that have explored South Asian perspectives suggest disfigurement is often a source of stigmatisation due to traditional and cultural beliefs blaming causation on past sins (Hughes et al., 2009) and the strong association of physical appearance with status (Thompson, Clarke, Newell, & Gawkrödger, 2010). Hence, the role of ethnicity and culture requires further exploration in order to elicit the health belief systems and the subsequent influences on adjustment for this group. As older generations of Asian cultures have been found to be more critical of disfigurement (Thompson et al., 2010), it may be useful to explore whether Asian parents are the primary drivers of appearance-related distress and the extent to which Asian children share or offer

conflicting perspectives. For example, future studies could consider conducting qualitative interviews with Asian parent-child dyads, and also compare these to Caucasian groupings.

Another sociocultural factor identified to influence a child's adjustment was locality, with references to city-based children being more prone to appearance-related distress. In line with the social constructivist paradigm, community context may indeed shape how children perceive and adjust to a health condition. Children in the country may live in more closely connected circles (Edwards & Baxter, 2013) with less exposure to strangers, which may result in less social intrusion. Whereas, children who live in the city may be more saturated with mass media that promote unrealistic beauty stereotypes, which could increase vulnerability to body image disturbance (Herbozo, Tantleff-Dunn, Gokee-Larose, & Thompson, 2004). However, if country children do experience poor psychosocial adjustment, the impact may be more significant. Children from rural and remote areas are less likely to have access to mental health services (Judd et al., 2002) and if they do experience challenges with socialisation and stigmatisation, it may be more difficult to cope if confined to a small community. Further exploration of the lived experiences of children with a visible difference from rural and regional areas may help elucidate more factors that promote positive adjustment. To establish whether these findings are unique to Australian communities, exploring country areas in different continents may also be important.

Observable and experienced effects of appearance-related distress such as suicidal ideation, depression, anxiety, low self-esteem, and withdrawal witnessed in CYP with visible differences also overlap adult literature (Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). These findings highlight how important it is for CYP to have access to effective psychosocial intervention and the need for standardised screening in routine clinical care; particularly important given evidence here that appearance-related issues can differ with life stage. Regular screening and assessment to ensure CYP are assessed at key developmental



and contextual time points would ensure ‘at risk’ patients are promptly identified and directed to suitable support. However, in order to advance appearance-related psychosocial service provision, clearer conceptualisation of adjustment, and firmer confirmation of predictors of appearance-related distress are urgently needed.

In order to advance current empirical research, it is critical to develop a conceptual framework of adjustment for CYP. This will enable those within the field to work within and test the utility of a common framework, whilst, also ultimately progressing intervention development (Rumsey & Harcourt, 2012). Whilst conceptualisation is still in its infancy, current evidence highlights some important considerations for a framework for CYP. Our findings and past work (Rumsey & Harcourt, 2004) demonstrate that CYP experience similar appearance-related psychosocial issues regardless of the cause of their visible difference. Therefore, it appears feasible to develop a conceptual framework generalizable to different appearance-affecting conditions and injuries. Additionally, current evidence revealed different life stages and developmental events can exacerbate different types of appearance-related psychosocial issues, yet some CYP persistently experience appearance-related distress. Past findings also support this notion (Clarke et al., 2014; Rumsey & Harcourt, 2007; Williamson & Rumsey, 2016), implying, adjustment can and does fluctuate over time. Overall, this evidence highlights the importance of biopsychosocial and developmental factors underpinning a conceptual framework (Williamson & Rumsey, 2017), and the benefit of pinpointing age-specific risk and protective factors. Researchers and health professionals in the field should follow the lead of those working in cleft lip and palate care. The Cleft Collective has seen a group of experts collaborate to develop a conceptual framework that includes age-specific risk, protective factors and agreed outcomes to measure psychological adjustment to cleft lip and/or palate (Stock et al., 2015).

## **4.1 Reflexive Analysis**

In line with the social constructivist paradigm, the research team's personal values, background, and experience needs to be recognised as shaping how meaning has been constructed from participant accounts (Creswell & Poth, 2018). For the lead author, who conducted all of the interviews, completed the majority of the data analysis and write-up, it was crucial to engage in regular reflexivity throughout the duration of the study.

The first author, a PhD student, came into the study with training in psychology and counselling, significant experience in family relationships and working with CYP from vulnerable backgrounds. Prior to conducting interviews, as well as immersing herself in academic literature on visible difference, the first author also spent a significant time observing appearance-related speciality consultations at the recruitment site. This period of time was designed to be purely observational, to gain contextual understanding of the recruitment site and the inter-relationships between health professionals and families impacted by a visible difference. The first author did briefly interact with some recruited participants during the observation period, but this was prior to them knowing about the current study. This brief professional interaction was actually considered beneficial, as it was believed to assist with purposive sampling once recruitment began, built trust and investment in the study, as well as increase rapport and engagement once interviews were conducted. Although the first author had never conducted research interviews prior to the study commencing, her background and experience undoubtedly shaped how she conducted interviews and contextualised participant perspectives.

The first author also notes that as a young woman, one's own appearance-related attitudes, values and behaviours may have influenced the research process. Upon reflection, the first author recognises that she herself has (albeit minor) and those close to her have lived with visible differences. Hence, this history and experience gave her an opportunity to fulfil

different roles during the study. Not only did she play the role of an ‘outside’ researcher looking in, but she also had an ‘insider’ perspective of the target population with which the study was examining (Hellowell, 2006). As posited by the founders of thematic analysis, researcher subjectivity (or perhaps an insider approach) should be understood and appreciated as a resource, rather than a threat to knowledge production (Braun & Clarke, 2019).

Upon reflection of the interview process, the first author recognises that when discussing factors that influence adjustment, health professionals were sometimes contradictory, suggesting that successful adjustment was related to innate factors, such as personal disposition, whilst still emphasizing the role of parental modelling and other sociocultural factors. This conflict reflects a wider debate around the stability of traits and the influence of social learning (Bandura, 1977). Undoubtedly, current evidence highlights how any conceptual framework of adjustment for pediatric visible difference populations needs to recognise the impact of external influences and how they shape a child’s appearance-related beliefs, values, and behaviours from early childhood to adulthood. Additionally, psychosocial support and intervention needs to be able to target complex, multifactorial influences across a child’s inner and outer network. These findings support intervention being underpinned by social learning theory, as well as combined individual, group and societal approaches.

In addition, when discussing the term ‘adjustment,’ the first author recognises that participants’ interpretation and understanding of this construct may have varied and impacted their responses to interview questions. For example, some may have interpreted adjustment as the absence of psychological symptoms (e.g., depression, anxiety), whilst others may assume successful adjustment is a child who has challenges but has adopted coping strategies, or who does not experience difficulties at all. This highlights potentially rich variation in the social realities, experiences and backgrounds of the sample, a characteristic appreciated by the theoretical framework underpinning this study. However, it also emphasizes the complexities

associated with developing a common definition for 'adjustment' for use in research and clinical practice.

## **4.2 Limitations**

Findings from this study would have been enhanced with participants from appearance-related specialities not featured in the current sample, such as cancer, as well as more representative samples of certain professions (e.g., psychology, social work, and physiotherapists). Participants also had spent a significant time in their specialist areas, averaging nearly 15 years each (ranging 5 to 30 years), therefore, offering perspectives based on high levels of expertise and experience. However, the research may have also benefited from including more junior participants, who may have been able to offer alternative perspectives. Despite this, a wide range of multidisciplinary professions and specialities were represented and participants were directly recruited from a large tertiary pediatric hospital, which more recent studies have not done. Lastly, this study would have also benefited from exploring patient and parent perspectives alongside health professionals to be able to compare and contrast divergent findings across groups.

## **4.3 Conclusion and Future Directions**

Findings from the present study revealed that living with a visible difference requires CYP to adapt to multiple, interrelated psychosocial demands shaped by self-perceptions, social experiences, psychological wellbeing, life engagement, appearance, and treatment/care factors. In addition, for CYP, successful adjustment to a visible difference is a dynamic and complex process, also complicated by developmental life stage and external influences such as the family and sociocultural environment within which they exist.

Albeit our research offers some better understanding of adjustment to a visible difference for pediatric populations, future research should prioritise further investigation and

validation of proposed domains, factors and processes, and incorporate direct qualitative feedback from pediatric patients and their parents. Designing a similar project like ARC, but for CYP may help us achieve this. The project could include an international multi-site study establishing psychosocial factors and processes associated with positive adjustment and distress, as well as quantitative and qualitative longitudinal studies that explore the progression of psychosocial adjustment from childhood through till adulthood. In addition, qualitative studies using parent-child dyads to explore the onset of appearance-related distress and influential sociocultural factors would be crucial in order to further examine the role family, culture, and locality play in a child's psychosocial adjustment. These type of studies may help those working in the field finalise key measures to assess psychological wellbeing, and offer evidence-base with which more effective intervention and support can be built and delivered so CYP with visible differences can lead a happier and more fulfilled lives.

#### **Declarations of Interest**

None.

#### **Funding**

This work was supported by a program grant by the Children's Hospital Foundation, Brisbane, Australia [Scholarship Number: 2155294].

#### **Acknowledgements**

We would like to thank everyone who participated in the study.

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Table 1

*Participant Characteristics*

<b>Participant*</b>	<b>Profession</b>	<b>Years of Experience</b>
Julie	Nurse	22
Sally	Speech Pathologist	22
Kate	Physiotherapist	10
Eve	Psychologist	15
Debbie	Occupational Therapist	20
Jackie	Speech Pathologist	18
Alexandra	Social Worker	5
Esther	Nurse	10
Alison	Occupational Therapist	12
Sarah	Nurse	17
Michael	Oral Health	28
Jack	Oral Health	30
Phillip	Surgeon	6
Carol	Nurse	6.5
David	Surgeon	8
Katie	Surgeon	10

**\*Note.** Participant names are pseudonyms

Table 2

Theme –Stages of Life: Health Professionals’ Perspectives of Appearance-related Issues Characteristic to Different Developmental Life Stages and Transitional Periods

Stages of Life Sub-Themes and Exemplary Quotes			
Early Childhood (7)*	Primary School Years (9)*	Adolescence (8)*	Key Events (6)*
<p><b>Appearance-related distress is observed in early childhood.</b>                      “We’re all really quick to think about the teenagers that sit there with their head down but [appearance-related worry] starts from such an early age...[we need] to get [preschools] on board”  <i>Esther, Nurse, 10 years</i></p> <p><b>Recognition of ‘difference’ occurs at a young age.</b>                      “3 or 4 year olds are talking about...that kiddie’s different...they’re noticing things...it starts so early and that’s paving the way to what can then happen”  <i>Debbie, Occupational Therapist, 20 years</i></p> <p><b>Parents commonly report appearance-related distress during their child’s infant years.</b>                      “babies...[parents say] ‘it doesn’t look right, the pigmentation isn’t, it hasn’t come back to normal’, especially with donor sites”  <i>David, Surgeon, 8 years</i></p> <p><b>Parents put pressure on health professionals to perform surgery in hopes that it will prevent appearance-related distress.</b>                      “...they’ve only got an 18 month old...and she’s like so when will the ears get done?... it’s really difficult to say look, this isn’t really necessarily in the best interests of your child....it may not significantly change things....and it may not make things better...”  <i>Katie, Surgeon, 10 years</i></p>	<p><b>Increased self-awareness of one’s own visible difference causes rumination and questioning of identity.</b>                      “I would say primary school age...they can see that they’re different, because other kids ask them ‘what’s that’, they then start to ask questions about why do I have this? Is this going away?”  <i>Alison, Occupational Therapist, 12 years</i></p> <p><b>Evidence of appearance-related psychosocial issues impacting a child’s mental health.</b>                      “We have a patient at the moment, who is not coping, he’s just 6 and he has terrible self-esteem issues, body issues and everything...”  <i>Carol, Nurse, 6.5 years</i></p> <p><b>Increased socialisation coincides with incidences of appearance-related bullying, teasing and questioning.</b>                      “In the early school years, people will raise bullying concerns...often asking questions like how to manage that or seeking support for that”  <i>Sally, Speech Pathologist, 22 years</i></p> <p><b>Children begin to question their capacity and capability.</b>                      “The younger ones [ask], can I go horse-riding, can I go swimming, how come my brother gets to do this, how come [I’m] missing out...it’s not fair, why won’t you just let me...”  <i>Eve, Psychologist, 15 years</i></p> <p><b>It can be difficult to establish the true origin of appearance-related distress: the parent or the child.</b>                      “Earlier on, it tends to be parents that drive it, even at 7 to 8...[children] still don’t carefully articulate things...it’s only really when they get through to adolescence where they can quite definitely pick things they’re unhappy with...”  <i>Phillip, Surgeon, 6 years</i></p>	<p><b>Adolescents have high salience in appearance.</b>                      “Aesthetics are most important for the teenager, that 12, 13, 14, 15 age group”  <i>Jackie, Speech Pathologist, 18 years</i></p> <p><b>Adolescents strive for normality.</b>                      “Appearance [can be a] daily preoccupation for someone that looks different, or perceives that they look terribly different or even a bit different, it creates a whole lot of anxiety, that’s what adolescence is about, they [need to] fit in, at no times in our lives are the opinions of our peers more important than adolescence”  <i>Eve, Psychologist, 15 years</i></p> <p><b>Adolescence sees an increase in some appearance-affecting conditions.</b>                      “Probably acne we see a lot in the teenage group...we’ve seen quite a few boys lately who are quite self-conscious about [their appearance]...[they say] ‘my face is ugly””  <i>Carol, Nurse, 6.5 years</i></p> <p><b>Events that focus on appearance commonly occur during adolescence.</b>                      “Teenage girls are using cosmetic camouflage for like their formals and stuff because that’s a big thing for them, especially there has been a couple where it’s been on their face so it’s trying to cover that”  <i>Alexandra, Social Worker, 5 years</i></p> <p><b>Appearance-related bullying/teasing peaks.</b>                      “I would say the teenagers would be the biggest group that get teased and bullied”  <i>Michael, Oral Health, 28 years</i></p>	<p><b>Returning to school after hospitalisation/treatment.</b>                      “I think returning to school is a big one....trying to prepare kids to return to school and educating the school as much as we can...”  <i>Alexandra, Social Worker, 5 years</i></p> <p><b>Transitioning to a new school.</b>                      “Starting school....changing schools...”  <i>Debbie, Occupational Therapist, 20 years</i></p> <p>“Primary to secondary school, where they change peer groups, and then it becomes something that kids start commenting on again...they’re not in familiar circles”  <i>Phillip, Surgeon, 6 years</i></p> <p><b>Activities that increase exposure of a visible difference.</b>                      “[They] want to be able to go to the beach and wear bikinis or be confident in their [swimmers]...not wanting to play certain sports because you have to wear that uniform which would then expose the visible difference”  <i>Alison, Occupational Therapist, 12 years</i></p> <p>“When there is public speaking that has to be done”  <i>Phillip, Surgeon, 6 years</i></p> <p><b>Transitioning into romantic relationships.</b>                      “We start to talk about relationships and that type of stuff...what it’s like around having kids and explaining it to kids and that type of stuff...”  <i>Alexandra, Social Worker, 5 years</i></p> <p><b>Starting a family.</b>                      “The parent’s bring it up for genetic reasons, like what’s going to happen if he has kids and this and this....but it’s more they’re thinking of genetics and passing it on...”  <i>Sarah, Nurse, 17 years</i></p> <p><b>Transitioning into employment.</b>                      “We had a teenage boy, he got a job at Coles which was great, but they didn’t understand...the work environment was quite difficult, so he couldn’t maintain that job, so then he had to find another little job more accepting of his condition...”  <i>Sarah, Nurse, 17 years</i></p>