Abstract

Many children and young people struggle adjusting to the psychosocial consequences (e.g., body dissatisfaction, social anxiety, and stigmatisation) of visible differences (or disfigurement). As appearance-affecting conditions often require specialist multidisciplinary team care, health professionals are in a unique position to offer psychosocial support and intervention. However, there is a dearth of literature on how appearance-related concerns are managed in pediatric hospital settings. Sixteen Australian specialist health professionals participated in semi-structured qualitative interviews to address this gap. Interviews explored current appearance-related psychosocial service provision, barriers in accessing appearance-related care, and perceptions of online platforms to deliver specialist support and intervention. Thematic analysis demonstrated four themes: *We can do it better*, *Capability versus availability*, *Online generation*, *and Putting appearance on the agenda.* This research highlighted the potential value of online platforms to increase accessibility to specialist appearance-related care, the need for more psychosocial resources to be integrated into appearance-related specialities, prioritising the development of low to medium appearance-related support and intervention, increasing the appearance-related knowledge of health professionals and families, and the need for more holistic approaches in routine care.

Key Words

children; young people; appearance-related care; online interventions; health professionals; visible difference

1. Introduction

Conditions or injuries that alter a child's skin, body, or face can cause a myriad of psychological and social struggles. Although some children and young people (CYP) can adjust positively to living with a permanently altered appearance (e.g., visible difference), long-term negative outcomes such as stigmatisation, social anxiety, body dissatisfaction, and poor self-esteem are commonly documented (Rumsey & Harcourt, 2007). Associated with feeling and looking different from the 'norm' (Rumsey & Harcourt, 2012a), CYP who live with a visible difference due to congenital conditions (e.g., craniofacial condition), injury (e.g., burns), or disease (e.g., vitiligo) often struggle managing the response of others, such as staring and unwanted attention (Masnari et al., 2012). In a world that increasingly promotes unhealthy beauty standards (Halliwell & Diedrichs, 2012), CYP who live with visible differences often feel isolated in their experience.

A wide range of individual and group therapeutic interventions (e.g., camps, wellness programs, cognitive behavioural therapy, social skills training) have been tested on CYP to improve their adjustment to visible differences; however, their effectiveness in enhancing psychosocial outcomes has been poor (Jenkinson, Williamson, Byron-Daniel, & Moss, 2015). The growth of technology and the Internet has also seen interventions to target appearance-related distress delivered online. Although still in their infancy, using online platforms to ameliorate the psychosocial consequences of visible difference appears promising.

Delivering therapeutic support online (e.g., Face IT: http://www.faceitonline.org.uk/Home/About (Bessell, Clarke, Harcourt, Moss, & Rumsey, 2010)) has been found to be equally effective as face-to-face therapy at reducing anxiety, depression, and fear of negative evaluation in adults living with a range of appearance-affecting conditions (Bessell, Brough, et al., 2012). Face IT has now been adapted to support adolescents with appearance-related distress associated with visible difference. Patients, parents, and health professionals have found the adolescent version (e.g., Young People's Face IT, known as YP Face IT: https://www.ypfaceit.co.uk/default.aspx) acceptable, believing it can overcome barriers associated with accessibility to specialist support (Williamson, Griffiths, & Harcourt, 2015). However, testing is still ongoing (Williamson et al., 2016), so its effectiveness remains unclear. Due to the time and process required to develop online interventions and the potential ethical issues surrounding their implementation, it is important that research continues to explore their suitability (Bessell, 2012). Irrespective of mode of delivery, additional research is also needed to ensure that future specialist support and intervention not only remains clinically relevant, but targets the appearance-related needs and experiences of pediatric patients (Jenkinson et al., 2015).

Due to the enduring nature of appearance-affecting conditions or injuries, many CYP face years of specialist treatment in healthcare settings. However, psychosocial service provision for appearance-related issues remains unclear. Of the scant literature available, evidence suggests appearance-related concerns are typically managed through the lens of a biomedical model (Bessell, Dures, Semple, & Jackson, 2012), are handled reactively (Centre for Appearance Research, 2015), and are considered 'low priority' (Bessell, 2012). There are also concerns that health professionals lack appearance-related knowledge (Williamson et al., 2018) and rely on objective assessments of the severity of visible differences to predict appearance-related distress (Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). This is despite evidence suggesting an individual's subjective assessment of the severity and visibility of their difference is a more useful predictor of adjustment (Moss, 2005).

In a recent study exploring health professionals' perspectives of appearance-related care for adolescent cancer patients, 70% of participants surveyed felt current support fails to meet patient needs (Williamson & Rumsey, 2017). A range of personal and organisational barriers that prevent optimum delivery were reported such as avoidance of appearance-related talk, lack of coordinated care, and limited access to specialist support. Burns literature also suggests that psychosocial service provision can be highly variable, dependant on global location (Lawrence, Qadri, Cadogan, & Harcourt, 2016), and type and availability of specialist psychosocial resources (Guest, Griffiths, & Harcourt, 2018). Funding, national standards of care and structure of health care systems are also thought to contribute to how well appearance-related psychosocial care is delivered in healthcare settings (Harcourt et al., 2018). Appearance-related psychosocial service provision is also thought to be influenced by health professionals' attitudes and values (Konradsen, Kirkevold, & Zoffmann, 2009; Williamson & Rumsey, 2017).

Despite their valid contribution, recent studies that have investigated appearance-related care have been primarily conducted in Europe, particularly resource rich countries, and exclusively investigated specific conditions. This makes it difficult to extrapolate findings cross-culturally and across appearance-related specialities. In addition, research has also found that non-psychosocial specialists are often forced to manage the psychosocial care of patients with visible differences (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014), potentially contributing to appearance-related issues being overlooked and therefore harder to treat in the long-term (Guest et al., 2018). However, of the small number of studies that have specifically focused on appearance-related care, many have only sought the perspectives of psychosocial specialists. Hence, it is vital to gain the perspectives of health professionals across a wide range of multidisciplinary team roles. In addition, limited perspectives have been obtained from specialist health professionals that work primarily in a tertiary pediatric hospital setting. Deeper exploration will help elucidate current practices and challenges in appearance-related psychosocial service provision and offer insight as to how appearance-related care can be optimised for pediatric patients with visible differences.

1.1. Aims of the Current Study

To the authors’ knowledge, no qualitative study has explored the perspectives of health professionals who work primarily in a specialist hospital and treat pediatric patients with a wide range of visible differences. There is also a dearth of literature in this area in Australia. Given this gap in evidence-base, qualitative research was perceived to be the best methodological approach to address this under-researched area.

Qualitative research methods uniquely capture the beliefs, feelings, and motivations that underline an individual’s behaviours and perspectives, and are therefore, best suited to studies exploring how participant’s ascribe meaning to lived experiences, sociocultural practices, and phenomena (Moen & Middelthon, 2015). More specifically, applying qualitative approaches to health research can help elucidate the role of psychosocial factors in health and illness, enhance the understanding of patient-health professional therapeutic relationships and establish solutions on how to improve service provision (Green & Thorogood, 2013).

This study forms part of a larger body of research exploring the psychosocial support and care needs of Australian CYP living with visible differences. The purposes of this study were to: (a) explore current practice in the management of appearance-related psychosocial issues in a specialist pediatric hospital, including gaps and barriers in the delivery of and accessibility to appearance-related psychosocial care; (b) explore health professionals’ perceptions of the suitability of online platforms to deliver specialist appearance-related support and intervention. Recommendations on how to improve current appearance-related care were also sought.

2. Method

2.1. Ethics Approval

Ethics approval for the project was obtained from the Human Ethics Research Committees of Children’s Health Queensland (HREC/16/QRCH/101) and The University of Queensland (#2016000850). Site specific approval was also obtained from Children’s Health Queensland Research Governance (SSA/16/QRCH/211).

2.2. Research Team

The research team includes the first author, who is a PhD candidate with an undergraduate psychology degree and over five years of counselling experience. The first author also undertook qualitative research training during the project. The last author is an expert in health psychology, visible difference, and has over 10 years of experience supervising and conducting qualitative research. The second author is an expert in burn scar research, has worked in acute health care as a social worker for over 15 years, and has 10 years of experience conducting qualitative research. The third author is an associate professor in developmental psychology, with expertise in quality of life and chronic illness. The fourth author has been a professor in burns research for over 10 years. The third and fourth author have a combined 15 years of experience supervising qualitative research.

2.3. Interpretative Framework

The study design and interview guide were underpinned by social constructivism. Social constructivism is an interpretative framework which claims that the way in which an individual sees and views the world is socially constructed (Creswell & Poth, 2018). All individuals’ experiences and perspectives are perceived to be valid (Mertens, 2015), because knowledge is inductively derived from the contexts and environments in which people live and the interactions they have with their social and cultural worlds (Creswell, 2007).

Social constructivists believe reality is co-constructed by the researcher and the researched, as each individual influences the other (Creswell & Poth, 2018). Therefore, the role of the researcher is to remain open and flexible to participants' experiences so there can be equal engagement and co-creation of a shared reality.

Methodological beliefs of social constructivism applied to this study included the use of qualitative interviews (Creswell, 2007), purposeful sampling to obtain a variety of health professionals' perspectives, in depth detail of participants' backgrounds, asking participants open-ended questions and using flexible analysis techniques (e.g., thematic analysis) (Creswell & Poth, 2018; Mertens, 2015). Specific to this study, methodological approaches such as these allowed specialist health professionals to freely share their lived experiences of providing psychosocial care to visible difference populations and perspectives of pediatric appearance-related psychosocial service provision.

2.4. Participants and Recruitment

Participants were recruited from a large Australian pediatric specialist hospital. Sixteen health professionals, including 12 women and four men, were recruited. Participants were aged between 30 and 58 with an average age of 40.13 years (*SD* = 7.05). A wide range of multidisciplinary team professions were represented, 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. Participants were required to have sufficient English proficiency and work in a role that cared for CYP with visible differences. On average, participants had been in their profession for nearly 15 years

(*M* = 14.97 years, *SD* = 7.82), ranging between 5-30 years. Six invited health professionals declined to participate due to high workloads, insufficient time, or did not respond.

Health professionals were purposively sampled from a broad range of appearance-related specialities including dermatology, vascular malformations, burns, trauma, child, youth and mental health, cleft, craniofacial, epidermolysis bullosa, and surgical departments such as general pediatric, plastics, reconstructive, oral, and maxillofacial. The first author invited participants face-to-face or via email.

All participants provided written consent prior to their participation. Once consent was obtained, participants took part in a single face-to-face semi-structured interview (40 – 100 min., *M* = 43.14 min.) with the first author. Interviews were audio-recorded and conducted in a private room at the hospital or research centre.

2.5. Interviews

After reviewing past literature, a series of draft questions were developed that focused on appearance-related psychosocial service provision. Questions explored gaps and barriers in appearance-related care, perceptions of online platforms to deliver specialist support, and recommendations to improve appearance-related psychosocial service provision. The interview guide was reviewed and refined by four authors to ensure questions met project aims. A list of questions can be found in Table 1.

Interviews were conducted by the first author who has extensive counselling experience and undertook qualitative research training. Interview questions were used flexibly within each interview to allow participants to raise new topics and voice pertinent issues.

The number of participants recruited met guidelines for a medium thematic analysis project (Braun & Clarke, 2013). Recruitment concluded after the 16th interview, as data saturation was believed to be reached. This decision was made by the research team as no new ideas were emerging from the data and the existing data were deemed comprehensive and rich.

2.6. Data Analysis

Qualitative data were analysed using thematic analysis. Analysis followed Braun and Clarke (2013) six phase process. Thematic analysis was inductively driven, whereby coding and theme development were grounded in the data, rather than fitting into pre-existing coding (Braun & Clarke, 2006). All transcripts were transcribed verbatim and completely coded; all data relevant to the research aims were coded.

The transcripts were initially coded by hand and with the assistance of the Nvivo qualitative software program. Initial coding focused on identifying recurring patterns and interesting features of the dataset, particularly in relation to answering the research question. The first, second, and last author completely coded the first four transcripts independently. The first author then met individually with the second and last author to corroborate coding decisions and discuss initial theme ideas. Coding and theme discussion was conducted over the phone, Skype, and email. This collaborative process allowed experienced researchers in the team to assist the first author to reflect on the coding process and the assumptions being made about the data. It also ensured the first author’s coding was grounded in the data and participants’ experiences. The remaining transcripts were then completely coded by the first author. At least three coding sweeps were conducted on interview transcripts to ensure each data item was given equal attention.

Once all interview transcripts were coded, theme development began (Phase 3). This process involved collating codes, grouping under initial themes, looking at the relationship between codes, potential themes, and sub-themes. Mind maps were used to assist in this stage of analysis (Braun & Clarke, 2006).

During Phases 4 and 5 of analysis, a list of themes, sub-themes, and theme definitions were generated from the coded data. This was sent to all authors for further discussion. Upon reviewing themes, there was some disagreement between authors in relation to the labelling, strength, and clarity of some sub-themes. As a result, some sub-theme labels were modified for clearer operationalisation, and some sub-themes were changed or condensed. Refinement of themes involved re-reviewing interview transcripts to ensure the data still remained grounded in participants' responses. All authors agreed on the final four themes and sub-themes.

To ensure credibility of the analysis (Elliott, Fischer, & Rennie, 1999), a summary of findings were sent to all participants for review. Three participants responded, however, no further feedback was provided.

3. Results

A total of four themes were generated from the final data analysis. Themes represent health professionals' perceptions of current appearance-related psychosocial service provision including barriers and gaps, online platforms delivering specialist appearance-related support to CYP and recommendations to improve appearance-related psychosocial care. The themes include: (1) *We can do it better*, (2) *Capability versus availability*, (3) *Online generation*, and (4) *Putting appearance on the agenda*.

In line with qualitative publication guidelines (Elliott et al., 1999), participant quotes are included in narratives to illustrate grounded examples. Some quotes have been edited to ease readability. Pseudonyms have been used to protect participants' identities.

3.1. We Can Do It Better

This theme captures health professionals’ beliefs that current appearance-related psychosocial service provision is poorly managed and often fails to support the complex and psychosocial needs of CYP living with visible differences.

3.1.1. You’d think we’d have it more together.

Twelve of the 16 participants communicated concern that the management of appearance-related psychosocial issues for CYP with visible differences was reactive and “ad hoc.” Jack’s (Oral Health) testament, “[we are not] even scratching the surface of some of the issues that some of the kids have to deal with” was commonly reflected. Despite being a large specialist children’s hospital, participants felt psychosocial service provision “is certainly an area that’s kind of missing” (Esther, Nurse). In particular, appearance-related concerns were felt to be poorly addressed: “I don't feel like the [appearance] needs are necessarily being very well met at any of the phases” (Jackie, Speech Pathologist).

Although many participants felt that they can acknowledge when their patients are struggling with appearance-related issues, a lack of follow-up, resulted in families being sent home to manage appearance-related distress without support: “Sometimes they’re identified but not always actioned upon… the discussion has been oh god, that kid’s not doing very well, but we’ll see them again in 3 months…” (Carol, Nurse). As Michael (Oral Health) discussed, feedback from families reflects how poorly the psychosocial support needs of this patient group are managed: “Just chatting and listening to parents, you know we’re not doing it, well we’re doing it, but we’re not doing it how they would probably want it done.”

3.1.2. Biomedical focus.

Thirteen participants described the predominant use of biomedical approaches in their clinical practice. Service provision strongly focused on “what are we going to do….not so much about how this person manages” (Sally, Speech Pathologist). Triaging clinical work involved health professionals asking physically focused questions: “I’d say well let’s look at it from function, is this is a problem? Has it achieved its surgical aim?” (Julie, Nurse) or using the severity of a patient’s visible difference to assess their psychosocial distress. Health professionals also described how physical and surgical goals were prioritised: “We're very outcomes focused... perhaps we're so focused on that physical outcome we sometimes [don't] give the appearance side of it as much credit” (Kate, Physiotherapist).

Participants described their patients as having “deformities” and “abnormalities,” with some health professionals expressing their role was to help “fix” or normalise a child’s visible difference. The lack of psychosocial staff dedicated to appearance-related specialities was also acknowledged: “In all of the clinics that I'm involved with there's no….very little social worker support, very little psychological support ….” (Jack, Oral Health).

3.1.3. Avoidance of appearance-related discussion.

Initiating appearance talk was identified as a common challenge by 14 of the 16 participants. In lieu of initiating appearance-related conversation, participants relied on the body language of patients or waited for families to raise concerns: “Unless a child or family is clearly articulating and expressing that there is a concern, we don’t necessarily delve into it…we can’t assume that every child has [problems]” (Alison, Occupational Therapist). Families prepared to discuss appearance-related concerns alleviated pressure on health professionals to initiate appearance talk: “There’s a bit of relief when the parents or the kids have already talked about it and they come in and they say, I'm really bothered by this…" (Phillip, Surgeon).

Health professionals discussed how clinicians often use cursory or assumptive questioning, which also prevents appearance-related exploration: "[They] phrase the question… 'so all's going well at school then?' You know, it's that statement of…and you're like 'no no, you need to ask more detailed questions' …." (Jackie, Speech Pathologist).

3.1.4. Awareness of support options.

Half of the participants were able to identify an appropriate psychosocial option for CYP and/or families impacted by visible differences. However, understanding of these options was limited, and few participants were able to name more than one or two support options. Within the hospital, most health professionals discussed relying heavily on occupational therapists or social workers to deliver psychosocial care because of poorly resourced psychology, child and youth mental health services: "Occupational therapists go above what their role really is and they need a psychology degree added onto their degree" (Julie, Nurse). Some health professionals admitted to rarely referring patients onto psychosocial support.

Participants identified various sources of support within the community: General practitioners to access mental health plans for private psychological support; school counsellors; psychology graduate programs at universities; Headspace (https://headspace.org.au/); parenting programs (https://www.triplep-parenting.net.au/qld-uken/triple-p/); condition-specific support groups and camp programs (e.g., burns). With regards to specialist appearance-related support, participants identified Young People's Face IT (https://www.ypfaceit.co.uk/index.aspx) and Microskin (cosmetic camouflage). Nurse-led education for teachers and a national family support officer were also identified specifically for patients with epidermolysis bullosa.

3.1.5. Psychosocial awareness.

Despite perceptions that appearance-related care is poorly addressed, 11 of the 16 participants discussed the importance and value of psychosocial awareness: “Even though what I do is physical with the kids, the psychosocial stuff has a real impact on that physical stuff” (Kate, Physiotherapist). Psychosocial awareness was regarded as particularly pertinent to help time surgical intervention, build relationships with families, make treatment decisions, and advocate for patients: “If they’re really struggling and I don’t think they’d really cope with a surgery …we wouldn’t do it….you wouldn’t subject that child to having surgery if they’re not in a good headspace” (Katie, Surgeon).

3.1.6. Perceived positives.

Despite acknowledging the need for improvement, 10 of the 16 participants reported positive aspects related to their current management of appearance-related concerns. Some participants even felt, compared to the past, health professionals respond more sensitively. Health professionals discussed how they “normalise” appearance-related concerns, “validate feelings,” as well as provide “education” and “reassurance.” In general, health professionals also felt CYP were given autonomy in their treatment, time to ask questions and consider options: “I don’t know if there are unrealistic expectations because we try and counsel from the very first meeting, we tell them what the timeframe will look like over the next 18 years…” (Jackie, Speech Pathologist).

Participants who felt their speciality area managed appearance-related concerns more confidently attributed it to a “team approach.” Strong leadership, sharing of psychosocial information and regular psychosocial meetings were all factors believed to enhance patients' psychosocial outcomes.

3.2. Capability versus Availability

This theme reflects health professionals' perceptions that they are capable of delivering appearance-related care, but feel there are a wide range of personal, organisational and external barriers that prevent this (Table 2). A summary of perceived personal and practical barriers that prevent CYP and their families accessing appearance-related care are also presented in Table 3.

3.2.1. Personal barriers – Health professionals.

The most commonly reported personal barriers for health professionals were related to gaps in appearance-related knowledge, which led to participants worrying about "opening Pandora's box," feeling "underqualified," and lacking in "confidence." These personal barriers caused health professionals to avoid discussing appearance with patients: "We don't know how to ask the question….or if we ask the question and we get the answer, what to do with it…. maybe we're all too scared…" (Michael, Oral Health). An overriding fear of causing harm to patients, making "the problem worse" or saying something which will "devastate the young person and they won't be able to recover" (Eve, Psychologist) were also discussed. Avoiding appearance-related discussion also led health professionals to make personal assumptions about the source of worry for a patient, which was sometimes in contrast to patient/family perspectives: "What we see as being an issue maybe nothing to them and what they see as an issue is maybe nothing to us" (Jackie, Speech Pathologist).

Repeatedly, participants felt they were not adequately trained to deal with the complexity of appearance-related concerns: "Psychosocial, it's a really hard issue….it's important in healthcare and health professionals are not educated in it well at all…" (Jack, Oral Health). Due to a lack of training, some health professionals discussed reliance on experiential learning to help them manage appearance-related psychosocial issues: "You don't have formal training, so I tend to fall back on just my personal values and my personal experience " (Sally, Speech Pathologist).

Participants expressed low confidence in managing patients with appearance-related distress. Confidence was most commonly associated with feeling there was "nothing to offer" or not knowing where to refer to. Health professionals commonly reflected that "everyone's a bit lost" about support options, referral pathways and therapeutic interventions to manage appearance-related distress attributed to visible differences.

Health professionals who were more confident in initiating appearance-related conversation described various factors that helped. Utilising "scar assessments," offering disclosure "across different mediums" (e.g., drawings, email), identifying an alternative "safe person" or "team member" or unique environments (e.g., burns camps) were all reported. Years of professional experience, time available, and level of rapport with a patient also increased health professionals' confidence to explore appearance-related subject matter.

Role delineation was another common barrier raised. Participants queried whether it was their "role" to manage appearance-related concerns, expressing worry about "encroaching on boundaries." Only one non-psychosocial specialist, Speech Pathologist Jackie, discussed providing direct psychosocial support (e.g., social skills training, mindfulness) to a patient, albeit with some limitations: "It fits in well with her sessions that she does with her psychologist… but if she wasn't seeing a psych, I would be pretty worried and I would be referring on pretty quickly." There were conflicting views as to who should bear responsibility for psychosocial care. Outside of psychosocial specialists, some participants felt doctors and surgeons need to take more lead, whilst others felt responsibility should fall on all multidisciplinary team staff.

3.2.2. Organisational barriers – Health professionals.

In addition to prevailing biomedical approaches in service provision, significant gaps in hospital resources (e.g., funding, facilities, staffing) also contributed to poor appearance-related care. Participants discussed barriers related to insufficient time, high caseloads, poorly coordinated care, and lack of privacy. High clinical demands limited time to devote to patients and affected health professionals' ability to source support and implement intervention: "Honestly, it's about finding the time…to find these resources to then implement them... being the only social worker, I would love to have some time to find resources that would benefit these kids" (Alexandra, Social Worker).

Limited capacity to offer a safe space for families to discuss a sensitive topic such as appearance was also a significant barrier. Multidisciplinary clinics were described as "intimidating" and "overwhelming" for families:

> If I was going to a clinic with a child and you've got 12 or 14 people and all of a sudden [an appearance] question is asked at you in front of those people, I think we're really silly as health professionals dreaming that we're going to get the answer that they want to give us (Michael, Oral Health)

Poor continuity of care was another significant organisational barrier. Where possible, health professionals strove to maintain "consistency of people" for families, but this was often impossible because of the way specialist tertiary hospitals were staffed. Many health professionals reflected that, for a sensitive population, having “someone different every time [could be] demoralising for the kid and the parents” (Jack, Oral Health).

The timing and frequency of appointments was also a factor. Health professionals felt inpatients were prioritised over outpatients. Particularly after acute phases, regular clinical reviews became less frequent and thus some patients “fall off the radar.” As a result, health professionals felt there was a higher likelihood of psychosocial issues being missed due to long periods between appointments. Some health professionals even admitted to avoiding psychosocial discussion with long-term patients, especially if they have always appeared to be well-adjusted.

Even if appearance-related distress was acknowledged, participants discussed significant organisational barriers in accessing internal specialist psychosocial support. CYP not meeting stringent criteria for referral, limited psychosocial resources, and poor coordination of care were discussed in depth. One of the major barriers was the current lack of mid-range psychological services within the hospital:

> Where the person doesn’t have a severe and complex problem so they’re adjusting, but they do have some say disfigurement….they might have some mild social anxiety, sleep disturbance but not as part of a depression, they might not meet the criteria for child youth mental health services…(Eve, Psychologist)

3.2.3. External barriers – Health professionals.

Health professionals also identified external barriers that impact access to appearance-related care for CYP and their families. Due to limited options within the hospital, health professionals raised fears about referring to “unreliable” community supports. Concerns about general practitioners not knowing “good options” and high variability in quality support groups were mentioned. Whilst the “sharing of experiences” was viewed as positive, concern about support groups being reliant on “who you talk to” and “no formalised training” were evident. Participants also felt that patients with particular conditions or injuries had access to more support than others.

Health professionals also discussed that psychosocial specialists within the hospital also often instruct them to tell families to seek out more support at school. However, participants expressed concern about the reliability of psychosocial support in school settings:

> They’re like, ‘well you just need to try and get the school involved,’ and a lot of the parents find that really frustrating, cause there’s not really a lot of feedback from the teachers…from the schools. The kids still come home unhappy… (Katie, Surgeon)

3.2.4. Personal barriers - Patients and families.

Participants identified numerous personal barriers that impede families accessing appearance-related care. Patients and their families’ reluctance to discuss appearance-related concerns, parents exerting control over their child’s care, and unrealistic expectations of surgery/treatment were all reported. Intimidating multidisciplinary clinics, CYP feeling “embarrassed,” “in denial,” worried about the stigma of accessing help, or discussing concerns in front of their parents were all considered contributing factors in the reluctance to disclose. Debbie (Occupational Therapist) also felt families may not feel comfortable raising concerns for fear of “complaining [to] people who have actually helped them.”

Parental efficacy was also commonly discussed, as health professionals felt parents significantly influence whether a child will receive psychosocial support for their appearance-related concerns: “We have a catchment that are recurrent failure to attendance. And I think, well geez, if you're not going to bring them for a wound dressing, are you going to take them to get their thoughts sorted...” (Julie, Nurse).

In addition, the health literacy of a parent/caregiver was also a perceived factor as to whether a child will have their appearance-related psychosocial needs met:

> I think you get the parents that you know are really proactive and have a really healthy positive outlook and approach to managing the visible difference and then I think you have some parents who just don't have the capacity or the skills to even know where to start or how to do that… (Alison, Occupational Therapist)

Like health professionals, parents were also perceived to have poor awareness of specialist support options for appearance-related distress associated with visible difference.

3.2.5. Practical barriers – Patients and families.

Burden of care, travel, and associated financial costs were also common practical barriers for families. Health professionals reflected on the logistical difficulties of running state-wide services that require families to travel long distances to receive specialist care. Inner-city hospitals also required families to pay significant fees for onsite hospital parking. In order to attend appointments, taking time off school, work, and organising child-care for siblings also created additional barriers. Due to limited psychosocial support within the hospital, health professionals also drew attention to the expense associated with seeking out private psychological support and potential long wait times:

> You know there are many families that can pay to get the [private] psych [but] there are many many more families that can’t and need to have something that is accessible that won’t take too long….that’s one of the big problems (Jackie, Speech Pathologist)

Patients living in rural or regional locations were also perceived to be particularly impacted, as many remote areas lack specialist mental health services.

3.3. Online Generation

The theme online generation represents health professionals’ perceptions that the future of appearance-related support and intervention needs to reflect a growing online and technological world. However, participants also recognised the importance of maintaining human connection in specialist therapeutic treatment, to counteract issues associated with safety, self-efficacy, application, and tailoring.

3.3.1. Online world.

By offering more online appearance-related support options, 15 of the 16 participants felt this would meet the needs of a generation who “spend so much time online” (Kate, Physiotherapist) and match the “huge move in mental health apps” (Eve, Psychologist). Most participants expressed that online support was a way to break down barriers currently associated with “accessibility” to appearance-related care. Online platforms that could be easily accessed anytime and anywhere, were seen as particularly advantageous for many of the “rural and remote” patients that participants currently treated.

Offering appearance-related support and intervention via online platforms was considered appealing to both children and teenagers. For young children, being able to offer "games" and "interactive" elements was favoured. For "normally quite introverted" teenagers with visible difference, online platforms offered convenience and privacy:

> My hours are obviously very limited. I would imagine they would feel more comfortable in accessing something themselves rather than calling me or telling their parents so they can make an appointment to then come in and there's a wait time… (Alexandra, Social Worker)

Online interventions were also perceived to offer a platform for CYP to disclose their appearance-related concerns more freely and reduce embarrassment: "It's more difficult to interact face-to-face. They may not be willing to display or show their concerns…if it's online, their feelings come out a whole lot more…as long as they know it's going somewhere secure" (David, Surgeon).

3.3.2. Human connection is critical.

Despite many perceived benefits of online appearance-related support and intervention, 10 of the 16 participants acknowledged that face-to-face is still critical. Deeper exploration of appearance-related distress, ability to build rapport, and monitoring of high risk patients were perceived as the main benefits of face-to-face support: "Your biggest fear, would be you know depression and suicidal tendencies. I suppose online you wouldn't be able to stop something like that, whereas face-to-face you've got more of a chance to harness it and try and fix it" (Sarah, Nurse).

As reflected by Jack (Oral Health), although online appearance-related support and intervention offered many advantages, he believed it could not replace what human connection could provide: "There's nothing better than having a good talk to someone and getting that direct empathy. Computers are a cold, sterile, sort of environment…you know, we're social beings."

3.3.3. Online intervention considerations.

Fifteen of the 16 participants highlighted some important considerations in relation to the design and delivery of online support and intervention for appearance-related distress attributed to visible differences. Issues such as self-efficacy and safety were commonly mentioned. Knowing that CYP are both motivated to complete and retain therapeutic skills were important factors: "Identification of appearance-related concerns as a stressor might not be anyway correlated with motivation to do anything about that, particularly for teenagers…trying to get them to do something about it is a challenge…." (Eve, Psychologist).

CYP accessing information on their own was considered potentially problematic. Concerns about "cyberbullying" and "chat forums" were referenced by numerous participants: "I feel like if there is an online chat type room, who actually has access to it, yeah, that would be my only concern" (Alexandra, Social Worker). Health professionals also raised concerns about CYP being exposed to "sharing of negative experiences," "misdiagnosing," and information that was "not specific" or "wrong."

The importance of safe, trustworthy, and reliable online appearance-related support and intervention was stressed, including options that instruct CYP when "you should talk to someone." The majority of participants also discussed the importance of incorporating elements of "control" and "monitoring." As it can be difficult to tailor online support to specific needs, guidance and structure were emphasised: "It's got to be a good enough resource to make sure that, they're being directed to the right part that is affecting you in your life at that point…" (Michael, Oral Health).

There was mixed opinion as to the most appropriate figure to supervise online activity for CYP. Whilst some participants believed parents should play a role, others felt health professionals were more appropriate:

> I don't think [parents] always know the answers. I think they'd like to think they do but health professional wise, there not always going to know. We might just go, that's easy, do this, [whereas parents might be] throwing their arms up in the air, oh it's hopeless, can't do anything about that. But we might have the answer or know someone that would (Julie, Nurse)

However, the capacity and availability of health professionals was also flagged, as high clinical demands would need to be factored into any supervisory role: “ It would just be a time factor…It really varies on how busy we are in the unit, this week would be a good week. I would be able to provide some of that supervisory support. This time last year, horrendous” (Kate, Physiotherapist).

3.4. Putting Appearance on the Agenda - Recommendations

This theme summarises a range of recommendations that participants offered to optimise appearance-related care. Most commonly, integrating psychological support into appearance-related specialities, education, preventative practices, and “bringing [appearance] back to people’s awareness” (Kate, Physiotherapist) were discussed.

3.4.1. Education.

Thirteen of the 16 participants felt health professionals would benefit from better education and training around the subtleties of appearance-related distress and approaches to managing common difficulties associated with visible differences. Education was perceived as particularly important for health professionals so they can “guide people in the right direction, how to manage and provide support when it’s raised with us” (Sally, Speech Pathologist). Strategies to help initiate sensitive appearance-related talk and when to escalate referral were particularly stressed: “What's the right way to go about it, prompt wise…what questions would we need to be asking to see how severe their concerns are” (Julie, Nurse).

Clear “criteria” regarding how much support a health professional could provide versus when “a referral is warranted” (Esther, Nurse), as well as appearance-related distress “red flags [for] different age groups” (Jackie, Speech Pathologist) were requested. In addition to “ongoing” multidisciplinary team training, education specifically pitched at “junior staff” was also perceived as particularly important.

Especially due to the clinical demands of specialist health professionals, participants stressed that training needs to cater to different learning styles, offer “variety” and accessibility. Suggestions for training platforms for health professionals included a “website,” “online seminars,” “orientation packages,” or face-to-face group settings such as multidisciplinary team meetings.

Fourteen of the 16 participants felt parents also need additional skills to support and manage parenting a child with a visible difference: “They need a little handbook of what they can do or what they can access. Sometimes parents feel at a loss as to what to say and when to act. You know, when is it you escalate something?” (Katie, Plastic Surgeon). Commonly, health professionals discussed that parents specifically need “practical resources” to manage “how to have the conversation about your child’s appearance,” “[appearance-related] bullying,” “coping mechanisms that they can [teach] their child,” and “how they get support for their kid.” Teaching parents skills to nurture and instil resilience during early “childhood years” was seen as particularly vital.

Parent education was recommended to be delivered “online,” through “webinars,” “support groups,” or displayed on electronic screens in hospital waiting rooms. To ensure families retain information, Esther (Nurse) felt “drip feeding [education] is really important.”

3.4.2. New processes.

Twelve of the 16 participants recommended new processes that could help improve appearance-related psychosocial service provision. A general review of the design of specialist multidisciplinary clinics was advocated. Participants suggested reviewing the time allocated for appointments, the number of health professionals present during clinics and offering more one-on-one support to patients in psychosocial distress. Offering “similar age group” clinics, particularly as children grow into adolescence, was perceived to help health professionals focus on age-appropriate physical and emotional concerns. To foster independence for adolescent patients, offering consultation without parents was also suggested.

Debbie (Occupational Therapist) recommended a member of the multidisciplinary team offer a “phone call,” “Skype” session, or “online chat” to families prior to coming to review appointments, so that they can discuss psychosocial concerns in their own home environment. Esther (Nurse) also suggested a team member engaging in a “follow-up” telephone call to families if psychosocial distress is observed during multidisciplinary clinics.

3.4.3. New resources.

All participants recommended a range of new resources that they felt could improve the psychosocial care of CYP living with visible differences. Participants stressed the need for more funding to be allocated to hiring psychosocial specialists as well as more psychosocial support to be embedded into appearance-related specialities: “If psychology were just part of the team, and be like a clinical photographer, everybody checks in, maybe that's a better way cause then everybody gets it, you know it's just offered” (Sally, Speech Pathologist). The benefits of integrating a psychosocial specialist into multidisciplinary teams were that “[issues] can get picked up,” support can be offered more timely and families may feel more comfortable to “open up” about appearance-related concerns during specialist clinics.

Health professionals also perceived value in the development of a psychosocial screening tool, a pre-clinic questionnaire or survey, that could assist in screening patients for appearance-related distress. Developing a “universal” set of psychosocial questions and “red flag check-in points” for appearance-related concerns were also emphasised. However, health professionals also reiterated that by asking more questions and screening patients, a supplementary protocol or flowchart that directs patients to support that matches their level of appearance-related distress was essential. Utilising patient-reported tools and collecting longitudinal data on patients’ psychosocial well-being were also encouraged.

Health professionals stressed the value of a reliable directory of referral options and resources to support anyone impacted by appearance-related psychosocial issues. A directory that includes internal, external services, resources, clear referral, and financial criteria were emphasised.

“Fact sheets” or “brochures” for patients and families that normalise common appearance-related concerns, recommend coping strategies, and offer psychoeducation were also suggested. A more comprehensive handbook, program or website was also recommended.

Michael (Oral Health) also suggested the implementation of “outreach clinics” to reduce practical barriers (e.g., financial cost of travel) for families from rural and regional areas and increase the training opportunities of health professionals who live in their areas. Implementing support groups within the hospital was also considered beneficial.

3.4.4. Mindset.

Ten out of the 16 participants reflected that in order to improve current appearance-related care, health professionals need to reassess their mindset and clinical practice. As Kate (Physiotherapist) discussed, health professionals need to be reminded that “appearance is a thing that’s worthwhile paying attention to.” Shifting perspectives away from a biomedical culture of care and towards more holistic and strength-based approaches was strongly reflected: “I think we actually need to get better at not seeing the physical and psychosocial as these two different entities because the research is clearly telling us that this is an area that one influences the other” (Debbie, Occupational Therapist). Michael (Oral Health) also stressed the importance of health professionals advocating for change and challenging current clinical practices: “We’ve never sat down and put the question, how can we do this better? No one [has] ever challenged: should we do it better, should we do it differently?”

4. Discussion

Participants from a wide range of multidisciplinary team specialist roles that treat CYP with visible differences offered perspectives on appearance-related psychosocial service provision in an Australian pediatric tertiary hospital. Despite acknowledgement of some perceived positives, most participants reflected that current appearance-related care fails to address patient needs. As past research has primarily focused on condition specific care (Guest et al., 2018; Nicholls et al., 2017; Williamson & Rumsey, 2017), results extend previous literature and suggest that, irrespective of global location, speciality area, and profession, health professionals face similar challenges when supporting pediatric patients living with visible differences.

There is now increasing evidence to indicate that multidisciplinary team health professionals without specialist training are required to triage appearance-related psychosocial concerns. As a result, CYP with appearance-related distress are not adequately supported to counteract long-term negative outcomes. As discussed in Harcourt et al. (2018), increasing the number of psychosocial specialists trained in appearance-related issues is advocated by professionals working in the area. As this change in resourcing may rely on the funds available to individual healthcare settings, broader solutions need to be established.

Due to the increasing demand for psychosocial support for this population, it seems the wider multidisciplinary health professionals who work in appearance-related specialities need to be better trained to support patients. However, as reported here, many health professionals lack confidence in managing appearance-related distress and would welcome further training. This was also found in a large European study of 718 health professionals working in appearance-related specialities (Williamson et al., 2018). Online training has been developed to support this need (see www.whenlooks.eu or www.facevalue.cc). However, as evidenced in this study, organisational barriers such as high clinical demands and time may impede health professionals opportunity to access online module-type training. Relying on health professionals to access training in their own time is also another factor that needs to be considered. As recommended by our participants, ease and access to training is crucial for healthcare workers and needs to be explored further to ensure effective implementation.

Health professionals welcomed the use of online platforms to deliver specialist support and intervention for patients and their families as well as for their own training purposes. In particular, the ease and accessibility of smartphone friendly Apps was discussed. Due to the wide range of identified barriers that currently prevent patients and their families accessing appearance-related care, an evidence-based App may offer some solution to these. As there is increasing evidence to suggest the lack of specialist support for low to mid-range appearance-related concerns (Rumsey & Harcourt, 2012b), an online intervention maybe a safe option to target this type of distress. However, as raised by participants, the safety and regulation of Apps, particularly as a therapeutic option for CYP, is an area that still requires careful consideration.

Online platforms were also perceived to be beneficial for health professionals in need of further training and education. In addition to face-to-face training, it also seems worthwhile considering the development of an evidence-based App or smartphone friendly website for health professionals. Mobile device Apps for health professionals are argued to not only be convenient but can increase the efficiency of clinical practice (Ventola, 2014). The utility of an evidence-based app for health professionals that incorporates appearance-related education specifically requested by our sample such as practical strategies, red flags to indicate the need for specialist support, conversation starters, directory of services and referral guidelines is worthy to explore in a growing online educational landscape.

Attitudes of health professionals and their speciality team may also impact the delivery of appearance-related care. These results support previous findings (Williamson & Rumsey, 2017) that suggest some health professionals rely on a biomedical framework, where reactive and ad hoc approaches to managing appearance-related psychosocial concerns are common. It was also clear that due to a lack of perceived training, many health professionals rely on experiential learning to guide their delivery of care. Despite all participants acknowledging the value of psychosocial awareness, there was limited evidence that these attitudes informed clinical practice. This may in part be due to the wide range of personal, organisational, and external barriers discussed in the data. Irrespective of this, research suggests that psychosocial adjustment to visible differences is more strongly predicted by psychological and social factors, rather than aesthetics or function (Clarke et al., 2014). Therefore, it is vital that health professionals adopt more holistic approaches in order to enhance positive outcomes for CYP with visible differences. Not only does this require improved resourcing and the implementation of training, but also relies on health professionals and broader health care settings adopting biopsychosocial attitudes towards care delivery.

As recommended by participants, various new resources and processes were suggested that may improve current appearance-related care. To counteract issues associated with determining whose role it is to lead psychosocial discussion or fears of burdening allied health teams, training all multidisciplinary staff to routinely ask sensitive psychosocial questions and be aware of appropriate psychosocial referral pathways is essential. This is particularly pertinent when speciality teams have limited or no access to psychosocial specialists. To avoid patients “falling off the radar,” implementing more structured and regular screening tools may also encourage preventative intervention. As standardised measures have been criticised for being unsuitable in busy clinics (Rumsey & Harcourt, 2012b) and self-report measures have been found to under-report appearance-related distress (Kish & Lansdown, 2000), a psychosocial screening tool might be more suitable. Incorporating a structured but brief screening tool into routine practice that focuses on both psychosocial and physical factors may also alleviate the embarrassment, discomfort, and anxiety associated with talking about appearance for families and health professionals. Clinicians working in the visible difference area suggest being able to offer the most appropriate psychosocial support at the most appropriate time reduces the likelihood of patients developing long-term negative outcomes (Spalding, 2017). Developing an online version would also make it more suitable for use in busy clinical settings and easier for families to access beyond acute phases of care. Conducting regular psychosocial screening would also allow health professionals to track patient needs over time and reduce the risk of appearance-related distress being missed or forgotten.

Given that there is growing evidence to suggest family factors influence how a child adjusts to visible difference (Bellew, 2012), a screening tool such as the Psychosocial Assessment Tool (PAT) (Kazak et al., 2001) might be a good example to follow. The PAT was originally developed to assess psychosocial risk in families of children newly diagnosed with cancer. It explores a broad range of stressors for the child, family, and broader systems such as: Family functioning, resources and support networks, knowledge and education, psychosocial concerns and maturity, family beliefs/values, and other stressors. The PAT is based on the Paediatric Psychosocial Preventative Health Model (PPPHM), a framework which aims to match families to varying levels of psychosocial risk and appropriate intervention. The goal of the PAT is to screen families early in the treatment process so that their scores can inform the direction of evidence-based psychosocial care (Kazak, Schneider, Didonato, & Pai, 2015). Given its socioecological approach to psychosocial risk, replicating a tool like the PAT for patients with visible difference is a worthwhile area for future research.

Undoubtedly, if health professionals begin to incorporate more preventative and holistic approaches to their practice, this will significantly increase demand for specialist appearance-related support and intervention. However, without appropriate financing and unless psychosocial resources are prioritised, appearance-related care will continue to fail to meet patient needs. This may be especially pertinent for low to middle-income countries, where access to finances to fund specialist services may be even more limited. Therefore, it is essential that all visible difference research includes health economic analysis. This may help governments and health policy makers recognise the value of integrating psychological services into pediatric healthcare settings and the potential reduction in costs on adult mental health services.

Looking to the future, health professionals and researchers need to replicate work being conducted in the United Kingdom (UK), a country that is forging new ground in appearance-related support services. For example, as part of the centralisation of cleft services in the UK, a psychologist is now integrated into every specialist cleft team (Sandy et al., 1998). In a survey conducted with UK adults who had previously accessed care prior to and after the centralisation of cleft services, one of the most positive changes to delivery was the integration of clinical psychologists into routine care (Stock, Anwar, Sandy, & Rumsey, 2018). The inclusion of psychological support was not only seen to improve emotional support but encourage patient advocacy.

More recently, in collaboration with the charity Changing Faces and the National Health Service (NHS), a new pediatric service at the Royal Hospital for Children in Glasgow, Scotland will become one of the first to offer specialist psychological support for children living with visible differences (McArdle, 2018). This pioneering initiative sees the first Changing Faces Practitioner, a professional role which will offer specialist and tailored disfigurement-related support to CYP, families and schools. Working alongside health professionals, the Changing Faces Practitioner aims to help patients feel more understood and body confident by providing emotional support, practical advice, and therapeutic intervention.

The UK also has the first and only NHS-funded hospital-based disfigurement support unit called Outlook (Maddern, Cadogan, & Emerson, 2006). Located in Bristol, Outlook offers psychological support to individuals struggling with the psychosocial consequences of an appearance-affecting condition or injury. Outlook staff are psychologists who provide psychotherapeutic intervention such as cognitive behavioural therapy, acceptance and commitment therapy, and social skills training. Roles such as the Changing Faces Practitioner and services such as Outlook need to be more broadly recognised and strongly advocated for implementation across the globe. Not only do initiatives like this equip patients with ‘appearance-specific life skills,’ but they also reduce the burden on hospital health professionals and mental health services (Spalding, 2017).

Prioritising the development of psychosocial standards of care for patients living with visible differences is also important. This has recently been achieved in pediatric cancer care. The Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) saw a group of pediatric oncology psychosocial experts and stakeholders collaborate to produce evidence-based standards for pediatric psycho-oncology service provision (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). A similar project that focuses on pediatric patients living with visible differences may help children and their families receive more standardised psychosocial care in the future. However, successful implementation of standards of care requires health professionals to be appropriately trained, adequate resources, and the backing of relevant policy makers and leadership teams (Harcourt et al., 2018).

Despite the wide range of multidisciplinary team specialist roles sampled in this study, findings would have been strengthened by a larger sample size. However, it was difficult to conduct in-depth interviews with hospital health professionals due to high clinical caseloads and time pressures. Transcripts were sent out to participants but no further feedback was provided to authors.

To validate the current findings, it would also be important to consider the perspectives of patients and their families in relation to appearance-related psychosocial service provision in an Australian pediatric tertiary hospital. Follow-up studies exploring both adolescent and children perspectives are currently being conducted by the authors to triangulate findings. Irrespective of this, to the authors’ knowledge, this is still the first qualitative exploration of health professionals’ perspectives of pediatric appearance-related psychosocial service provision, drawing participants from a wide range of speciality areas who work specifically in a tertiary hospital setting.

As suggested by Harcourt et al. (2018) and supported by our findings, increasing networks across the globe, encouraging the sharing of resources and experiences between health professionals in this field is a useful consideration for the future. It appears that irrespective of global location, condition or profession, appearance-related psychosocial service provision is facing very similar challenges in respect to lack of specialist appearance-related support, education, and resources. However, it is important to acknowledge that findings may not necessarily reflect appearance-related care in low and middle income countries. As this study and most past research has been conducted in high income countries, deeper exploration is required to determine the provision of support in less resourced healthcare systems and any additional barriers that health professionals face in these countries.

The priority of future research should be developing low to medium range appearance-related support services and resources for health professionals, patients, and their families. This should involve focusing on more practical and innovative training opportunities for all health professionals who work in appearance-related specialities. More importantly, the delivery of training needs to overcome barriers associated with busy hospital settings. Appearance-related education and support for patients and families also needs to reflect current online trends and be easily accessible. More dedicated efforts to bring attention to the importance of psychological services and need for more holistic approaches to appearance-related care are also crucial.

4.1. Conclusion

This study has provided insight into a range of specialist multidisciplinary health professionals' experiences and perceptions of appearance-related psychosocial service provision in an Australian pediatric tertiary hospital. It offers perceptions of perceived positives in current practice as well as organisational, personal, external, and practical barriers that prevent optimal delivery of and accessibility to appearance-related care. Results indicate that future training, resources, and therapeutic support needs to adapt to a growing online world, with appropriate safeguarding. Prioritising low to medium specialist appearance-related support and intervention, integrating psychological services into routine care, and developing evidence-based psychosocial standards of care for patients with visible differences were emphasised. A wide range of recommendations across education, process and resources have been offered that can inform future appearance-related psychosocial service provision.

Declarations of interest

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Table 1. *Semi-Structured Interview Guide Questions*

Questions
How well are the psychosocial needs of CYP with visible differences being met (e.g., acute, post-acute, discharge)?
How would you manage a patient who was presenting with appearance-related distress associated with their visible difference?
What interventions, resources, support are you aware of to help CYP living with appearance-related psychosocial difficulties?
What difficulties do you encounter as a health professional in relation to discussing and managing appearance-related psychosocial issues?
What are some of the barriers for CYP and their families in relation to accessing appearance-related psychosocial support?
Can you offer any suggestions, ideas or strategies on how to improve care and service provision for CYP with visible differences?
How suitable do you think online support and intervention is to help CYP living with appearance-related psychosocial difficulties? What concerns would you have?

Note. CYP = children and young people.

Table 2 *A Summary of Health Professionals' Perspectives on Personal, Organisational, and Community Barriers that Inhibit the Delivery of Appearance-Related Care For Children and Young People with Visible Differences*

Type of Barrier	**Examples**	***n***
Personal Barriers	• Avoidance of appearance-related discussion	14
	• Poor awareness and understanding of appearance-related support and intervention options	13
	• Confusion and doubt as to whose "role" it is to deliver appearance-related psychosocial care	12
	• Fear of being underqualified/lack of appearance-specific training	11
	• Lack of confidence to deliver psychosocial care	9
	• Fear of causing harm/opening Pandora's box	8
	• Management of patients guided by incorrect personal assumptions/beliefs	7
	• Perceive that cannot offer anything to support appearance-related distress	6
Organisational Barriers	• Biomedical approaches predominantly utilised in clinical care	13
	• Psychosocial care is ad hoc and/or reactively delivered	12
	• Limited psychosocial specialist services and resources	11
	• Lack of time/high clinical caseloads	10
	• Lack of coordinated care/referral pathways	10
	• Lack of safe space for private, sensitive discussion with patients and families	9
	• Inpatients prioritised over outpatients	8
	• Poor continuity care/difficulty establishing rapport with patient and families	8
	• Children do not meet extensive criteria for psychosocial specialist services	7
External Barriers	• Lack of evidence-base/formalised training underpinning support groups	4
	• Lack of and/or high variability in specialist disfigurement-related support services	3
	• Psychosocial support at school is unreliable and variable	3
	• General practitioners have poor awareness of appearance-related issues and support	2

**n* indicates number of participants that contributed to this sub-theme.

Table 3 *A Summary of Health Professionals' Perspectives on Personal and Practical Barriers For Children, Young People, and their Families Accessing Appearance-Related Care*

Type of Barrier	**Examples**	***n***
Personal Barriers	• Reluctance to discuss appearance-related concerns • Parent exerting control over child's care/Lack of patient voice in decision-making • Intimidating multidisciplinary clinics prevent disclosure of appearance-related concerns • Low parental self-efficacy • Unrealistic expectations of surgery/medical treatment • Poor awareness of specialist appearance-related support options • Poor parental health literacy • Discomfort raising appearance-related concerns in front of parents • Embarrassment and/or in denial about appearance-related concerns • Male less inclined to raise appearance-related concerns • Stigma/fear associated with help-seeking for appearance-related distress • Fear appearance-related concerns will be minimised or perceived as "vain" • Fear of being perceived as "complaining" to health professionals who have helped them	12 11 6 6 5 4 3 3 2 2 2 2 1 1
Practical Barriers	• Long-distance travel and time associated with accessing care • Financial costs related to accessing care (e.g., travel, parking costs) • Lack of specialist psychosocial support in rural and regional areas • Financial cost associated with accessing private psychological support • Taking time off school/work in order to access care • Long wait times for private specialist support • Organising child care for siblings in order to access care • Long wait times at the hospital in order to access care	5 5 5 4 3 1 1 1

**n* indicates number of participants that contributed to this sub-theme.