Understanding Appearance Concerns in Young People with Cleft Lip +/- Palate: A Photo Elicitation Study

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Running title: Appearance perceptions of young adolescents born with cleft

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Objective:

Young people (YP) with a cleft lip with or without cleft palate have expressed concerns about their appearance and image-sharing on social media. This study aimed to explore and understand YP's concerns, views, and experiences regarding photographs of themselves.

Design:

This was an exploratory qualitative study using photo-elicitation during semi-structured interviews conducted virtually. YP provided three photographs of themselves they liked and three they did not, which were used to facilitate discussion of their appearance, thoughts, and feelings about their photographs, and social media. Interviews were transcribed and analysed using Reflexive Thematic Analysis.

Patients/Participants:

Thirteen YP aged 16–20 years (mean = 17.8), ten females and three males, were recruited via a UK cleft charity. Two had cleft lip only, nine had unilateral cleft lip and palate, and two had bilateral cleft lip and palate.

Results:

Four themes were developed: (1) Symmetry equals beauty, (2) Controlling and curating the image presented to others, (3) Acceptance with maturity, and (4) Connections can promote empowerment.

Conclusions:

The themes highlight the concerns that YP have with their appearance, how they present their

self-image to others and how they can become empowered to embrace their cleft condition and support others. Results suggest cleft services should integrate psychosocial screening, peer support, and appearance-focused interventions to promote confidence and resilience in young people.

Key Words: Cleft Lip; Cleft lip and palate; Patient Satisfaction; Psychosocial adjustment; Quality of Life; Young adults; Photo-elicitation

Introduction

Over one thousand babies each year in the United Kingdom (UK) are born with a cleft of the lip and/or palate (CL/P), which makes cleft conditions the most common congenital anomaly affecting the face.[1] Surgeries for cleft lip can result in scarring and, for some individuals, asymmetry of the lips and/or nose, both of which can be visible differences.[2] Children born with a cleft condition often require a programme of staged surgical interventions throughout childhood and adolescence, aimed at improving function and appearance.[3] The presence of a visible difference has been linked to an increased risk of YP experiencing difficulties with their well-being and self-esteem.[4] Social acceptance during adolescence has been linked with physical appearance,[5] and it is suggested that this is due to societal beauty standards and the tendency to form judgments based on appearance. Therefore, it is possible that YP with cleft conditions may be disadvantaged by sociocultural expectations to conform to often unattainable standards of physical appearance.[6]

Appearance satisfaction and concerns play an important role in the psychosocial adjustment of young people (YP) with cleft conditions, as lower satisfaction has been associated with emotional and social difficulties and can influence self-perception and adjustment.[7,8] Dissatisfaction with facial appearance may contribute to psychological distress, including anxiety and depression, particularly when the difference is visible.[7,9,10]

Conversely, positive body image, characterised by body appreciation and self-acceptance, is associated with protective factors such as adaptive eating behaviours and reduced engagement in harmful health behaviours.[11] Therefore, fostering positive body perceptions in YP with cleft conditions can be important for ensuring well-being.[12]

Several studies, both qualitative and quantitative, have looked at cleft conditions and satisfaction with appearance. They found that there is a relationship between satisfaction with appearance and psychosocial adjustment,[7,13] and that psychosocial adjustment can fluctuate.[13] These psychosocial challenges can continue to cause distress into adulthood. Specifically, adolescents with cleft lip with or without cleft palate (CL±P) who demonstrate less realistic self-perceptions may experience poorer psychological adjustment.[7,13]

YP with cleft conditions often experience a range of emotional and psychosocial factors related to their condition. These can include lowered self-esteem, social anxiety, and heightened self-consciousness, often observed to intensify in adolescence in certain studies.[7,13] Age plays a significant role in shaping these experiences, with older adolescents often reporting increased emotional distress.[7,13] Higher dissatisfaction with appearance has been associated with greater difficulties in social functioning and self-image.[14] Coping and adjustment can also be influenced by the visibility of the cleft, the number and outcomes of surgical interventions, and the perceived reactions of peers and the broader social environment.[7,14]

In a recent focus group study YP with cleft conditions, aged 16-20 years, highlighted dissatisfaction with their appearance and a concern about taking photographs and, in particular, sharing these on social media.[15] These concerns led to the YP becoming increasingly anxious about sharing their image with others for fear of negative comments from their peers.[15] This illustrates that concerns and anxiety exist, however more needs to be understood regarding the source of this anxiety, and what it is about particular photographs or elements of appearance that leads YP to be fearful about sharing their image with others.

One approach that could be well suited to exploring this in detail is photo-elicitation, a method that uses photographs to facilitate participant-led conversation during an interview.[16-19]

Although some of the cited studies include adults rather than adolescents, drawing on literature across the lifespan provides valuable insight into long-term psychosocial adjustment. However, age-related differences should be considered when interpreting these findings, as experiences and coping strategies may vary between younger and older individuals. Developing an understanding of the features of photographs and elements of appearance that are of greatest concern to YP with cleft conditions could inform discussions regarding potential appearance-based causes of anxiety or depression,[7,13,14] or challenges with socialising,[7,14] and improve health care professionals' ability to communicate with and show understanding of YP with cleft conditions. This could then offer a potential route to intervention to enhance self-esteem and confidence, particularly when faced with negative comments on social media, which has been raised as a concern for this group.[15,20] In turn, this could help build resilience when encountering negative comments from others. This study therefore aims to use photo-elicitation to provide YP with CL±P an opportunity to talk about their appearance-related experiences and concerns to address the research question: "What do YP with CL±P think about their appearance?"

Method

Design

A qualitative design was used with virtual, one-to-one, semi-structured interviews.[21] To supplement the interview, photo-elicitation[22] was used, where the YP provided photographs of themselves to facilitate participant-led in-depth discussion about their appearance and reflection on any potential issues that may be affecting them.[16] "The use of photographs to support discussion aimed to reduce the power imbalance often associated with researcher-led interview schedules[23] and to ensure that the knowledge generated remained grounded in the YP's lived

experiences.[3] In addition, photographs are effective tools for eliciting detail about an individual's world and can be less threatening than reflection on direct experience therefore helping to establish a safe and comfortable space for self-disclosure.[24] Participants and researchers mutually agreed that the images would only be used during the interview and not shared outside the study team.

Participants

Following ethical approval from **blinded for review**, YP were recruited through a UK based charity, the Cleft Lip and Palate Association (CLAPA), via their website and social media sites. Inclusion criteria were individuals born with a CL±P, English speaking, and aged 16-20 years. This age range was chosen as it followed previous research where YP expressed concerns about their image and sharing it particularly on social media.[15] Sixteen is the age when consent can be given by the YP themselves and the limit of twenty years is often the end of the specialist care pathway for YP with a cleft condition in the UK.[25]

Thirteen participants were recruited, aged 16 -20 years (mean=17.8 years), all participants were white and English speaking. Braun and Clarke[26] report that the determination of sample size should be guided by the research question and the goals of the study, rather than adhering to a rigid or predetermined sample size. Therefore, the researchers in this project considered 13 participants an acceptable number for the analysis to show similarities and generate themes. Ten were female and three were male, and cleft types represented included: 2 Cleft Lip only (CL), 9 Unilateral Cleft Lip and Palate (UCLP) and 2 Bilateral Cleft Lip and Palate (BCLP) (YP characteristics and a written description of the photographs discussed are detailed in Supplemental Table 1).

Procedure and materials

To gauge interest the lead researcher attended a virtual CLAPA YP's meeting open to all members of CLAPA's YP group. There were ten YP present, ages ranging from 15-20 years. The research idea was discussed with the YP, and it was agreed that this would be a beneficial area to be explored. The YP were informed that the study would be advertised on social media and CLAPA's website. The advert briefly introduced the study and provided email contact details for more information.

On responding to the advert, YP were emailed a participant information sheet and consent form link via Qualtrics.[27] Upon receiving consent, the YP were asked, via email, to take photographs of themselves with their smartphones or collect recent photographs taken within the last six months. Recent photographs were used to ensure that participants' recollections were current and after primary cleft surgeries were completed. They then chose six from these recent photographs to replicate previous research using photo-elicitation interviews.[16,19,28] The YP were asked to identify three photographs where they liked their appearance and three where they did not, to explore both positive and negative perceptions of self-image. It is only possible to gain an in-depth understanding of what YP dislike, and their reasons for discomfort sharing their image on social media[15] by attending to disliked images, therefore it was important to attend to both negatively and positively evaluated photographs. To minimise potential discomfort, participants were reminded they could pause or stop the interview at any time and were provided with a debrief sheet listing support services.

Semi-structured, photo-elicitation interviews took place virtually with the first author and lasted 45 to 90 minutes. It was considered important that the interview take place in a secure and safe place so that the YP felt comfortable to share potentially sensitive information.[29] A semi-

structured interview schedule was developed to ensure that the unique experiences and beliefs of the YP were captured, whilst making sure that the main topics of the study were explored. The interview schedule was developed following a focus group with YP looking at the end of care pathway, where they raised that they were having concerns about their appearance and spoke about posting photographs on social media. It was also shaped by existing literature on photo elicitation methodology.[19,28] The interview schedule was then finalised by the first and third authors and refined based on these sources. Interviews began with the interviewer and YP introducing themselves and the YP was asked to tell the researcher about themselves and about their appearance (Full Interview Schedule can be found in Supplemental Table 2).

The YP and the interviewer then looked at the photographs one-by-one together, with the YP deciding in which order they should be discussed. The same questions about their appearance and feelings about their images were asked from the interview schedule about each photograph, which remained visible throughout the interviews thereby following previous photo-elicitation research.[16,19,28] Follow-up questions explored the sharing of photographs on social media.[15] The interview ended with the YP being asked if they had anything else they would like to share. Following the interview, a debrief information sheet was emailed to the YP with details of support services and how they could withdraw their data from the study. Interviews were transcribed with pseudonyms chosen by the YP or by the first author.

Ethics and Safeguarding

This study was approved by the [University Research Ethics Committee (reference number: removed for anonymity)]. All participants, who were aged 16 years or older, provided written informed consent prior to participation. A parent/guardian information leaflet and contact

details were provided in case participants wished to share information with their families or seek guidance.

Researcher Reflexivity

The interviewer's background is speech and language therapy with a specialism in cleft conditions. Training in conducting qualitative research included formal teaching and supervision from an experienced qualitative health researcher. A reflexive diary was therefore completed throughout the study to reflect on any personal experiences that may influence the study[30] and to ensure quality qualitative analysis.[31] Supervision discussions also took place between the first author/interviewer and the third author, a health psychologist and qualitative methodologist without specialist knowledge of cleft care, to reflect on the interviews and discuss possible themes to be considered.[32] Supervision also addressed ensuring any discomfort experienced by participants was identified and appropriately addressed. The authors reflected on their positionality throughout the study, considering clinical experience, connections to cleft research, and supervision discussions. No personal self-disclosures were made in interviews. The interviewer had not provided speech and language therapy to any participants, although brief professional contact occurred with three during multidisciplinary clinics. Any potential influence of prior contact was considered during reflexive supervision.

Analytic Strategy

Reflexive Thematic Analysis (RTA) was used to analyse the data as this is an effective way of identifying themes in an information-rich set of data.[26] It has also been used in qualitative cleft condition research[13,33] and photo-elicitation research.[34,35] A critical-realist epistemological position enables the analyst to interpret the YP's perceived reality and views of their appearance,

in order to develop an understanding of their experiences.[36,37] A phenomenological experiential approach to RTA by the first author was taken to explore the lived experiences and views of the YP with cleft conditions.[26,38] Analysis was inductive, and the analyst followed a six-stage process, in accordance with Braun & Clarke's[26] guidelines. Firstly, becoming fully acquainted with the data, secondly, coding of the data for both semantic and latent content, thirdly, identification of themes, fourthly, the reviewing of themes to confirm accuracy, fifthly, defining and naming of themes and finally, production of a report.[26] Stages three-to-five were conducted in an iterative manner.

Following theme development, the authors invited the participants to a meeting to discuss the themes developed. Three participants attended this session in person and two attended online. The proposed themes were presented to the group and discussed, and the participants agreed that the themes captured their experiences.

Results

Four distinct but overlapping themes were developed: Theme 1: Symmetry equals beauty, Theme 2: Controlling and curating the image presented to others, Theme 3: Acceptance with maturity, and Theme 4: Connections can promote empowerment. The themes explore how YP control how others see their self-image, their acceptance of their cleft condition, and the ways that they have learnt to feel empowered to share their journey both in-person and online. Quotes have been taken from the interview transcripts to convey the YP's experiences.

Symmetry equals beauty

All of the YP expressed a preference for symmetry in their appearance and reported disliking images of themselves when they noticed asymmetry, *"I don't like the asymmetry of it in*

my face…and the scar on my lip."(Sally) Sarah highlighted how facial asymmetry disrupted the overall balance of her features, *"When things are not symmetrical it just looks a bit like disorganised."* Summer who had a BCLP described herself as 'lucky,' *"Having the bilateral [cleft]…I think it definitely makes it slightly easier to deal with because my face is symmetrical…it looks slightly more normal."*

Comparing their image with their non-cleft peers was also mentioned in relation to symmetry, with Sarah saying, *"Every one of my friends…they all have quite symmetrical faces."* Sarah explained that this particularly upset her when getting ready to go out as she felt she had to spend a lot more time making her face and lips "*even*," so that she felt good about how she looked. This awareness of asymmetry and its effect on self-perception provides context for the next theme, which explores how YP actively manage and present their image to others.

Controlling and curating the image presented to others.

Taking action to control and curate how they appeared to others was a consistent theme throughout the YP's narratives. This included strategies to highlight features they felt positive about and to manage how photographs were taken and shared. Some YP described focussing on parts of their appearance they liked, using these to draw attention away from the cleft asymmetry. For example, two of the male participants spoke about how going to the gym and developing a muscular build gave them something positive to emphasise in photographs, Peter stated, *"I can see my muscles looking a little bit nicer and I think that looks nice,"* and Tommy said, *"I like this one because my arms look very big."*

In addition, others used filters or make-up to conceal the asymmetry,

"So, there's filters that will put like a full face of makeup on you and that will completely

smooth your skin. Make your face look a bit more symmetrical without you even

realising it…I usually do use one of them ... just so that I don't have to try and look

nice." (Linda)

In addition to filters, there was a pattern for some female participants selecting preferred photographs where they were wearing make-up. In this way, highlighting features they were proud of or using tools to modify their appearance enabled YP to share images in which they felt confident.

Participants also took an active role in controlling how photographs were composed, aiming to capture what they considered the most aesthetically pleasing image of themselves. One approach was to control the way they positioned their body when taking a photograph. They did this in several ways, for example, Sarah favoured a full body photograph, *"I much prefer, like, a full body photo because I'm like jazz the outfit up and no one's gonna notice your face."* While others controlled the way they angled their head and camera when taking selfies as they felt this improved the photograph taken of them, Maria said, *"I like the angle of [this photograph] …it like makes my nose look better than usual,"* and Evelyn stated, *"[I like] the angle I've taken [the photograph] because I had control over that…made my face look good."*

Several YP preferred taking photographs in a mirror, which may reflect a sense of familiarity and comfort with the image they see every day, as Amy said, *"When I look at myself in a mirror…I don't mind it…but I think that's because I've gotten so used to seeing it on my face."* In addition, Peter described using a mirror as a way to control his image, as this approach allowed him to partially hide his face, *"In a mirror photo you can hide your face quite well… you can't look straight at the mirror; you have to look at the phone."*

Group photographs were often perceived as less anxiety-inducing because attention was not drawn to any one individual. However, these photographs were still carefully managed, with YP positioning themselves to minimise how visible their cleft condition might be, as Sarah explained, *"I always make sure that if I'm in a group photo…hang on I need to be on the right because my cleft side is my left side."* Similarly, Jenny often took photographs with other people or with her horse, so that the focus was drawn away from her face. This strategy helped her manage anxiety about being photographed, *"I look nice in the picture with the horse…no one's going to be looking at that picture and be proper taking in my face."*

All participants spoke initially about not minding others posting photographs of them on social media because they did not need to look at the comments, however, on further discussion Maria spoke about it making her feel uneasy, *"But like if that got posted…probably would be a wee bit like on edge,"* and Faye spoke about not liking the lack of control when others posted her image, *"I don't find it easy when a friend posts because I don't have that sort of power and that control."* Some managed this by orchestrating it so that their phone was used to take photographs, facilitating control over the photographs shared, such as: *"A lot of the time I'm the person who has all the photos…they're like, let's take photos, so I'm like yeah, here's my phone…and I'll just send them the ones that I like." (Sarah)*

Another way to control social media postings was by making their accounts private so only their close friends could see, *"My Instagram it's private and I only have people on-there that I actually know, my circle of trust."(Sarah)* Keeping accounts private was because they were *"wary" (Tommy)* of being on social media for fear of being "*judged" (Tommy).* Some spoke about having two accounts, one that they posted their image on, which only went to close friends and family, and another more open account where they posted photographs of places they had

visited, but not their image, *"I have two accounts, one where it is just my close circle of friends and that is the one, I would post my face on." (Faye)* This careful management of image and presentation provides the context for the next theme, which explores how YP's growing maturity influenced their acceptance of their cleft condition.

Acceptance with maturity

In addition to direct discussion of their appearance, many of the YP used their photographs as a catalyst to explain how maturity had enabled them to accept their cleft conditions. Most found having a cleft condition during their childhood and early teenage years distressing. The YP described difficult school experiences with memories of bullying, *"At school, especially secondary school…I got a lot of bullying around that time." (Evelyn)* The bullying was sometimes so severe that one YP felt the need to move to a different school to escape these negative experiences, *"In year seven and eight I left that school and moved to a different one…because of all these comments." (Jenny)* These experiences led to isolation for some, for example through the choice not to engage with others, *"I didn't have many friends, you know, I didn't really interact with anyone at school, and that was the same through sixth form [education during 16-18 years]." (Amy)*

In comparison, others felt their personalities protected them in some ways from this isolation, with Tim also resorting to name calling as a response and protective strategy to negative comments, *"I think people just like me, so they don't really comment on anything…if someone did make a dig, if they were a bit bigger, I'd call them maybe fat or something."* The YP described how getting older had made things a little easier, *"What I thought when I was sixteen to what I thought when I was nineteen/twenty is completely different." (Sarah)* and many

described this road to acceptance of their cleft condition as a journey, as Evelyn stated, "*I've gone through quite a journey of self-acceptance,*" and Becky said, *"I'm going to appreciate my lip and love the story it tells."*

Discharge from the adolescent cleft team was an important transition point in this journey for some YP which helped them to move forward with acceptance. For example, for Sarah this represented a new phase, *"You're kind of out of that and you're stopping getting that scrutinisation, I think then [when you have been discharged] you can actually start to…accept how you look." (Sarah)* This sense of acceptance was reflected in participants' acknowledgement of their cleft condition as an integral part of their identity. Many expressed pride and described their cleft condition as a symbol of personal growth and a unique aspect of their journey, as Evelyn stated, *"My smile…it's been through a lot of work and to say from where it's come from, I feel it makes me like it more,"* and Peter expressed, *"I think if I got to choose between a version of me without a cleft, a version of me with a cleft… I would choose a version with my cleft, as I think it adds a little more."*

While participants described strategies to manage how they were perceived in earlier themes, many in this theme also expressed pride and acceptance of their cleft condition. This illustrates a subtle balance between managing how others see them and embracing their identity over time. The next theme demonstrates how the maturity outlined in the previous theme can be further strengthened through connections with others who share similar experiences, supporting confidence and empowerment.

Connections can promote empowerment.

Reflecting on past experiences, the YP highlighted the importance and benefits of connecting with others who shared similar experiences. When discussing the photographs, this

connection with others was highlighted as something that empowered YP to accept and feel confident about their appearance.

Those who were members of CLAPA spoke about the benefits of knowing others with a cleft condition as it meant they did not feel alone, *"Having the friends, I've made from, like being involved with CLAPA from a young age, always reminds yourself that there are people there." (Amy)*. These connections enabled the YP to observe the confidence of others which in turn encouraged them to develop their own, *"I started becoming quite involved with the cleft community…which helped massively…if these people can be very confident in who they are and how they look then…why can't I?" (Evelyn)* Amy described how relaxing it was to spend time with a group of peers who also had a cleft condition, perhaps because, unlike during her school years when she had felt the need to isolate herself and push others away (as discussed in the previous theme), she no longer felt alone, *"If I'm surrounded by everyone who has a cleft, I really don't care…I'm like oh its fine."*

There was also a sense that participants wanted to pass on the benefits they had received from these connections by supporting younger members of CLAPA, *"I'd like to keep up with CLAPA…because I feel like my experiences can you know help them…it's all worth it when you have a positive influence on a couple of young people."(Sarah)*. Reflecting on her own journey, Amy also expressed a broader sense of personal empowerment and pride in her identity, illustrating how growing confidence enabled her to share her experiences more openly, *"I thought now I'm gonna own it…I'm very proud of having a cleft…I'll always do what I can to promote it."*

Another avenue to connect with others with visible difference was through social media. Many chose to follow accounts that helped them see their cleft condition in a more positive light,

as Becky noted, *"I've gotten into following people who have cleft lip and palate with cool stories…"* and Sarah similarly expressed, *"I actually follow a lot of like models who have like got disfigurements… they've got something a bit different about them… watching them then encourages you to just be yourself and post what you want."* Several of the YP had been empowered by these accounts and had chosen to share their own journey through posting self-images online to educate and support others, Sarah said, *"I post every year on Cleft Awareness week, and I'll put up photos of when I was a baby and my surgeries and I'll be like, this is my journey,"* and Becky explained, *"I decided to make a short video on living with a cleft lip and palate, just because I wanted to normalise it, and introduce the condition to my friends who hadn't heard of it before."*

However, these actions were also sometimes perceived to be a risk. For example, Evelyn spoke about receiving a particularly difficult negative comment on social media when posting her cleft journey, *"I've had a couple of negative comments like, people with clefts are gonna just live alone and die alone."* Peter posted his image regularly in open forums online. However, he received several negative comments about his appearance and therefore controlled this situation by no longer using his image, just his voice on his posts, *"I want to still create…I just don't want my face to be on it now."* These comments could have major impacts on self-perception and one participant reported becoming so self-conscious about their appearance after receiving negative comments online that they were planning further revisional surgery at the time of data collection.

These findings highlight how connections, with peers in person and online, can support YP's confidence, self-acceptance, and willingness to share their experiences, while also showing that negative feedback can affect how they present themselves.

Participant Feedback on Themes

In a follow-up discussion, participants confirmed that the themes reflected their experiences and clarified that concealment versus pride was about choice, wanting flexibility to hide or share their cleft condition.

The discussion considers how these processes interact and their implications for supporting YP with cleft conditions.

Discussion

This study sought to explore what YP with cleft conditions think about their appearance. Using semi structured photo-elicitation interviews and RTA, four themes were developed: symmetry equals beauty, controlling and curating the image presented to others, acceptance with maturity, and connections can promote empowerment. As with previous research, the accounts illustrated the challenges of living with a visible difference such as a cleft condition[39] but also highlighted positive experiences and the influences these could have on how YP think about their appearance.

The participants spoke about how satisfaction with their own appearance in photographs was tied to presenting a symmetrical image. Satisfaction with appearance is a concern found with many YP in the general population[40] along with attractiveness being related to facial symmetry.[8,41] However, the participants with cleft conditions discussed symmetry in the context of their surgeries, expressing dissatisfaction with their appearance due to the perceived lack of symmetry in the results.[43] Dissatisfaction is often due to the appearance of their nose, lips, teeth, and surgical scars.[14] Satisfaction with appearance is complex for YP with cleft conditions,[10] and although adolescence is often a difficult time for all YP, this study shows that living with a

visible difference adds challenges, reflected in participants' accounts of managing asymmetry and social comparisons.

The participants managed their appearance carefully to present an image that they felt represented this symmetrical 'ideal.' The participants spoke about several strategies that they used to control the way they looked in photographs so that the eye was drawn away from the cleft condition. For example, several participants shared mirror selfies, as they were more familiar with this type of image, and it allowed them to partially conceal their face by looking at their phone rather than directly into the mirror. All participants would often take a photograph from a certain angle or direction, with those who had a UCLP often taking the photograph from the non-cleft side whilst others particularly those with a BCLP liking front facing photographs. The perceived need to conceal a visible difference or control their appearance may be influenced by how they believe peers perceive them and prompting them to adjust their behaviour to hide their cleft condition.[42]

The use of make-up[43] and filters[44] is described in the literature as "selfie-editing," and was discussed in detail across most interviews. It refers to the improvement of photographs, the removal of blemishes, and in the case of the participants in this study, the removal of scars, using makeup and/or smartphone applications. Most social media platforms, for example Instagram and Snapchat, offer this self-editing option.[45] There is evidence to suggest that selfie-editing may have both positive and negative effects on well-being within the general population. From a classical conditioning perspective, continued exposure to idealised appearance norms and sociocultural pressures to conform may act as a form of negative reinforcement, increasing appearance dissatisfaction.[46,47] Similarly, in this study, several participants described anxiety about posting images and reported that negative comments online led them to avoid sharing

photographs or even consider further surgery. Conversely, receiving positive feedback from peers or family following the sharing of edited selfies may serve as positive reinforcement. While such feedback may offer short-term relief or validation, it can ultimately reinforce maladaptive self-perceptions by strengthening the association between appearance modification and approval from other people.[48,49]

The use of makeup to enhance their image can also result in an improvement in confidence.[50] It has also been suggested in the literature that selfie-editing can increase social engagement,[51] and can help those with a visible difference as it allows them to minimise concerns about their appearance.[52] The use of camouflage make-up services within the cleft service, where YP are shown how to use make-up to hide scars is also available.[5] Organisations such as Changing Faces[53] have previously provided make-up support sessions for YP with visible differences, which demonstrate the value of practical, confidence-building interventions. Expanding access to such services could represent an important area for development and advocacy within cleft care and psychosocial support more broadly. Although make-up can be a useful coping strategy it may be over-relied upon[5] and does not address the YP's anxiety with their appearance.[54] This approach may further reinforce the notion that a person's quality of life may improve with an improvement in their appearance.[5]

Participants described maturity, both getting older and developing emotional resilience, as improving satisfaction with appearance. This finding is seen in the general population[55] and those with cleft conditions.[56] All the participants reported that their cleft condition had affected their lives negatively whilst growing up, particularly during their time at school, but that as young adults it had become easier, with some saying they were proud of their cleft condition. This process reflects growing resilience and acceptance over time, which has been linked to

improved coping with other stressful life-events in earlier literature.[57,58] Whilst also being proud of and accepting their visible difference, their ongoing efforts to minimise attention to their cleft, were explained as being about choice. They wanted the option to wear makeup, edit their photographs, and conceal their cleft condition if they wished, similar to how their peers might use makeup to enhance their appearance. At the same time, they also wanted to feel comfortable sharing unedited images that included their cleft condition without fear of negative comments.

Being accepted, having a friendship group and 'fitting in' at this at school is important for a YP's psychological well-being.[59] In this study the majority of the participants discussed being teased or bullied at school. How they managed this teasing was different, with some becoming more anxious and withdrawn. Others sought further surgery to improve the way they looked. One highlighted areas of difference in the person teasing them to deflect attention away from them. The use of different coping strategies has been recognised previously in the literature,[58,60] and has been linked with emotional resilience.[61]

The relationship between being able to cope with teasing and having a supportive friendship group was also discussed by the participants in this study and has been mentioned previously in the literature.[58] However, unfortunately not all the participants in this study had a secure friendship group, while being socially confident appeared to be a successful strategy for some in the group. YP have been reported to be viewed more positively if they had strong social-emotional skills, such as empathy, cooperation, sociability, and emotional regulation[62] and so interventions may focus on providing YP with these skills and promoting individual strengths and abilities.[58] It is important to acknowledge that the evidence base for psychosocial interventions in the context of cleft conditions is currently limited and inconsistent, highlighting the need for further research to identify and evaluate effective therapeutic approaches. The *YP*

Face It studies explore the complex psychosocial experiences of YP living with visible difference conditions, including cleft conditions[63,64] The research emphasised the need for tailored psychosocial support to address the unique experiences of YP with cleft conditions, to improve their emotional well-being and social confidence.[63,64] As previously reported, the participants that were involved with CLAPA reported the benefits of knowing others with a cleft condition and how this had supported them through difficult times at school.[57] They also mentioned how empowering they found helping other younger members through sharing their experiences. Therefore, it is recommended that cleft professionals continue to seek opportunities to promote peer support, such as signposting families to CLAPA in the UK or equivalent services internationally, during clinic visits, as the value of peer support should not be underestimated.

The sharing of images and the posting of "selfies"[65] on social media platforms has become increasingly popular with teenagers and young adults, with 90% of 16–24-year-olds in the United Kingdom using Instagram, Snapchat, and TikTok.[66] The participants in this study were no different, with all posting, to greater or lesser extents, on one or more platforms. Many of the participants with cleft conditions made their accounts private. Several participants who posted their image publicly, online, experienced online bullying with negative comments targeting their appearance. For one participant this experience prompted a decision to pursue further surgery and to engage online through voice-only formats. They described increased anxiety and dissatisfaction with their appearance, responses that are consistent with existing literature on the psychological effects of cyberbullying.[67,68]

Education and promotion of 'body positive social media' and negation of the ideal,[69,70] may address bullying that occurs in person and online by emphasising bullying is a negative

experience that needs to be eliminated.[68,71,72] It is an opportunity to normalise the visible difference whilst positively highlighting the YP's personality and personal qualities rather than just concentrating on their appearance.[73] Previous research has shown that school aged children react well to learning about issues around appearance[74] and whilst this often raises curiosity it normalises the visible difference and leads to increased acceptance.[71] Discussion with their peers, teachers and parents about their facial appearance is also reported to build resilience and develop coping strategies.[75]

The participants in this study found it empowering to educate peers online through positively promoting their cleft condition and sharing their 'cleft journey.' The literature supports this empowerment and reports the benefits of posting videos on YouTube, Facebook, and Instagram, and openly talking about their cleft condition.[76] It is through openly talking about their cleft condition that the YP may embrace their visible difference which in-turn promotes acceptance. This active use of posting and interacting with peers online can also result in improved well-being and less instances of depression,[77,78] as the YP find that when posting their own content, they generally received positive feedback from their peers.[78] However, participants also described circumstances in which negative online feedback could be harmful to their wellbeing, suggesting that strategies are needed both to reduce this harm and to support YP with cleft conditions in coping with such situations.

Participants' experiences resonate with broader psychosocial models of visible difference and may offer potential directions for psychological support. For example, cognitive-behavioural therapy (CBT) approaches that specifically address appearance-related self-consciousness could be trialled in YP with CL±P. Existing initiatives such as YP-FACE IT, which uses CBT-informed self-help, have already shown promise for YP with visible

differences.[63] Peer support interventions, such as those facilitated by CLAPA's Children and Young People's Council (CYPC) in the UK, may also help to normalise difference and reduce isolation. In the UK, survey evidence indicates that many individuals with visible differences would like more support focussed on appearance acceptance and self-esteem.[79] Given that our participants voiced similar needs, psychological approaches such as self-help CBT tools [80,81] or peer support groups may be particularly useful to reduce appearance-related distress.

Beyond clinical interventions, the data also highlight the importance of community-level and cultural strategies to promote appearance diversity. Media campaigns that feature individuals with CL±P in positive and non-stigmatising ways may help to counteract stereotypes and challenge narrow beauty norms. School-based initiatives on body image and appearance diversity may provide additional avenues for prevention and early support, particularly given the centrality of peer relationships during adolescence. Future research could explore the acceptability and effectiveness of such interventions, as well as co-produce resources with YP themselves to ensure relevance.

The study findings highlight the experiences YP with a cleft condition face in relation to their appearance, identity, and social comparisons, with the additional factor of social media. The themes have a strong alignment with the Appearance Research Collaboration Framework of Adjustment to Visible Difference.[81,82] This framework conceptualises adjustment as a dynamic and socio-cognitive process, influenced by factors such as social comparison, fear of negative evaluation, and the availability of social support, all of which emerged as salient in our participants' accounts. It also highlights how adjustment varies across the life course, which resonates with the developmental nuances seen in the data.

These insights emphasise the importance for cleft services to take a holistic approach to psychosocial support. In clinical practice, this could inform targeted psychosocial interventions during key transition points, such as around adolescence or before surgeries, where body image and peer comparison may be more pronounced. Multidisciplinary cleft teams at tertiary hospitals, who often follow patients at protocol-driven review ages, are well positioned to provide guidance and support around appearance-related concerns. Routine psychosocial screening should include asking YP questions about their social media use, body image, and peer relationships, as well as conversations during appointments to normalise concerns about appearance.

Future Research

Instagram posts of people with visible difference can reduce stigma[83] and social media can have a positive influence in other areas, such as obesity.[84] Therefore, ensuring that images of YP with cleft conditions are available on these platforms is important, ideally through campaigns led by trusted organisations and media outlets rather than placing the responsibility on individuals. Future research can focus on appropriate mechanisms for images to be shared with supports in place.

Future research should also involve YP with cleft conditions as co-researchers who shape and guide the solutions to these issues, consistent with co-production principles outlined by Bates et al.[85] The present study has shown that this population have strategies that can help them. Research guided by the YP themselves and focussed on validating the experiences of others, and sharing their stories, has potential to both empower improved self-image and educate the wider population and healthcare professionals about these experiences and the challenges faced.

Limitations

Recruitment of participants was via CLAPA and its social media sites. Therefore, it cannot be assumed that this group of YP are representative of the general UK cleft population. This includes potential underrepresentation of minoritised ethnic groups, as social media recruitment often disproportionately reaches White participants. Participants in this study predominantly identified as White British, and cleft conditions occur worldwide, so cultural differences should be explored in future research. Strategies to engage diverse communities and include a representative sample are needed to fully capture the range of experiences of YP with cleft conditions. The cohort of participants were all self-selecting, so there is a possibility that they chose to participate because they had a particular negative or positive experience to share. However, this did not appear to be the case as there were a wide range of experiences reported. The YP who chose to participate may have been more psychologically resilient or more comfortable reflecting on and discussing their appearance than those who did not opt in. This may have influenced the themes that were developed, particularly around coping and adjustment. Additionally, the gender imbalance in the sample, with 10 females and only 3 males, may reflect broader gendered differences in willingness to engage with discussions about appearance[5].

Additionally, the study required participants to submit photographs which may have deterred some YP who do not like photographing themselves, this may have led to an over emphasis on feelings of empowerment and positivity evident in some of the themes, which may not be representative of the wider community. It also asked them to submit photographs that they did not like of themselves, which may have discouraged individuals that are negatively impacted by their own appearance. Another limitation relates to the potential for participant self-censorship in the selection of disliked photographs as it is possible that they chose to share

photographs that felt 'safe' to disclose to a researcher, rather than those that evoked the strongest discomfort or distress. This may in part explain why no participants expressed visible distress during interviews, despite the sensitive focus of the task. As such, our findings may represent a moderated account of experiences with disliked images, shaped by what participants felt appropriate to disclose in a research context. Future research could ask participants to submit images and descriptions anonymously online, without the need for further discussion about them.

Conclusion

The research explored how YP navigate challenges with appearance both in person and online, revealing a desire for autonomy in how they manage their appearance. Specifically, they expressed a need for choice, whether to conceal their scars to align with peers or to openly share their 'cleft journey' on social media as a means of educating others and empowering those with a visible difference. The YP wished to do so without fear of negative judgment, in a society that accepts and understands visible differences. Supporting YP in achieving this goal is a shared responsibility that lies with families, peers, healthcare professionals, and educators.

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Pseudonym	Age	Gender	Cleft Type	Photo ID	Frame Type	Selfie	Lighting	Expression	Effort to minimise cleft	Attire	Make up	Other notes
Sarah	20	Female	UCLP	Liked 1	Side-profile	No	Bright	Smiling	Face angled away from cleft side	Formal	No	Background clearly focused
				Liked 2	Front-facing	No	Bright	Smiling	Hair down, facing camera	Formal	No	—
				Liked 3	Side-profile	No	Bright	Smiling	Hair scraped back, wearing makeup	Formal	Yes	—
				Disliked 1	Close-up	Yes	Bright	Smiling	None	Casual	No	Looking up at camera
				Disliked 2	Side-on	No	Bright	Smiling	None	Casual	No	—
				Disliked 3	Full-face selfie	Yes	Bright	Smiling	None	Casual	No	—
Amy	19	Female	UCLP	Liked 1	Mirror selfie	Yes	Bright	Neutral	Head tilted to conceal cleft	Casual	Yes	—
				Liked 2	Front-facing	No	Bright	Smiling	None	Work	Yes	Seated at desk
				Liked 3	Front-facing	No	Bright	Smiling	Head tilt, full makeup	Casual	Yes	Confident pose
				Disliked 1	Side-facing	No	Bright	Relaxed	None	Casual	No	—
				Disliked 2	Front-facing	No	Bright	Neutral	None	Formal	No	—
				Disliked 3	Side-facing	No	Bright	Playful (tongue out)	None	Formal	No	—
Faye	16	Female	CP	Liked 1	Side-on	No	Blurry	Smiling	None	Casual	No	—
				Liked 2	Close-up	Yes	Bright	Neutral	None	Casual	No	Direct gaze
				Liked 3	Side-on	No	Dark	Neutral	None	Casual	No	—

Name	Age	Gender	Group		Angle		Lighting	Expression	Obstruction	Dress		Notes
				Disliked 1	Close-up	No	Bright	Neutral	None	Casual	No	Wearing glasses
				Disliked 2	Front-facing	No	Bright	Neutral	None	Casual	No	—
				Disliked 3	Side-on	No	Bright	Slight smile	None	Casual	No	—
Maria	16	Female	UCLP	Liked 1	Front-facing	Yes	Bright	Smiling	None	Casual	Yes	Full face visible
				Liked 2	Side-angle	No	Bright	Smiling	None	Casual	Yes	Glancing sideways
				Liked 3	Side-angle	No	Bright	Smiling	None	Casual	Yes	Taken from slight distance
				Disliked 1	Side-angle	No	Dim	Smiling	None	Casual	Yes	Low lighting
				Disliked 2	Side-profile	No	Natural	Neutral	Hood partially obscuring face	Casual	No	Outdoor setting
				Disliked 3	Over-shoulder	No	Bright	Neutral	Hair styled, face angled	Formal	Yes	Formal outfit
Peter	17	Male	UCLP	Liked 1	Mirror selfie	Yes	Bright	Neutral	Side-on angle	Casual	No	Taken from distance
				Liked 2	Full body	No	Backlit	Neutral	Shadow across face	Casual	No	Arms folded
				Liked 3	Front-facing	No	Bright	Smiling	None	Formal	No	Direct gaze
				Disliked 1	Full body	No	Bright	Smiling	None	Casual	No	Holding a glass
				Disliked 2	Portrait-style	No	Bright	Smiling	None	Casual	No	Captured by another person
				Disliked 3	Action shot	No	Bright	Neutral	Card partially obscuring face	Casual	No	Standing by car
Evelyn	18	Female	BCLP	Liked 1	Full body	No	Bright	Smiling	Glasses, medal	Casual	No	Post-charity run

				Liked 2	Front-facing	No	Bright	Smiling	Full makeup	Casual	Yes	Confident pose
				Liked 3	Front-facing	No	Bright	Neutral	Glasses, full makeup	Casual	Yes	Head slightly tilted
				Disliked 1	Front-facing	No	Bright	Neutral	Hair pulled back, no makeup	Casual	No	Wearing pyjamas
				Disliked 2	Close-up	No	Bright	Smiling	Wearing makeup	Casual	Yes	—
				Disliked 3	Close-up	No	Bright	Smiling	None	Casual	Yes	Taken by another person
Summer	17	Female	BCLP	Liked 1	Full body	No	Dim	Smiling	None	Casual	No	Slightly out of focus
				Liked 2	Group seated	No	Bright	Smiling	Slight turn toward camera	Casual	No	With family
				Liked 3	Arm's-length selfie	Yes	Bright	Neutral	Hair softly framing face	Casual	No	—
				Disliked 1	Close-up	Yes	Bright	Neutral	None	Casual	No	Leaning in toward camera
				Disliked 2	Group photo	No	Bright	Smiling	Sister is main focus	Casual	No	—
				Disliked 3	Close-up selfie	Yes	Bright	Neutral	None	Casual	No	—
Tommy	16	Male	UCLP	Liked 1	Close-up (from below)	No	Bright	Neutral	Lips closed, looking down	Casual	No	—
				Liked 2	Close-up (from below)	No	Bright	Neutral	Eyes glancing sideways	Casual	No	—
				Liked 3	Full-body side profile	No	Bright	Neutral	Muscular pose, cleft side away	Gym wear	No	Working out

				Disliked 1	Extreme close-up	No	Dim	Neutral	Only lips/chin/nose visible	Casual	No	Looking into distance
				Disliked 2	Close-up	No	Bright	Neutral	With friend, lips pursed	Casual	No	—
				Disliked 3	Close-up	No	Blue-lit	Neutral	Looking down	Casual	No	—
Tim	18	Male	UCLP	Liked 1	Close-up	No	Dim	Smiling	None	Casual	No	Low-light setting
				Liked 2	Group photo	No	Dim	Smiling	None	Casual	No	In bar with friend
				Liked 3	Full body	No	Bright	Neutral	None	Formal	No	Shirt and tie
				Disliked 1	Close-up candid	No	Bright	Neutral	None	Casual	No	—
				Disliked 2	Close-up	No	Bright	Smiling	None	Casual	No	With friend
				Disliked 3	Full body	No	Bright	Neutral	None	Casual	No	Backpacking, windy day
Becky	18	Female	UCLP	Liked 1	Side-on	No	Bright	Smiling	Hair covering cleft side	Casual	No	With friend
				Liked 2	Close-up (from above)	No	Bright	Smiling	Head tilted	Casual	No	—
				Liked 3	Side-on (from above)	No	Bright	Smiling	Hair covering one side	Casual	No	—
				Disliked 1	Close-up (from above)	No	Bright	Smiling	None	Casual	No	Different angle
				Disliked 2	Side-profile	No	Bright	Surprised	None	Casual	No	—
				Disliked 3	Group photo	No	Bright	Smiling	None	Casual	No	Seated with siblings
Sally	20	Female	UCLP	Liked 1	Side-on	No	Dim	Smiling	Slight blur	Casual	Yes	With partner

				Liked 2	Close-up	No	Dim	Neutral	Full makeup	Casual	Yes	Same angle as Liked 1
				Liked 3	Close-up	No	Soft focus	Neutral	Glamorous wig, full makeup	Casual	Yes	—
				Disliked 1	Overhead close-up	No	Bright	Neutral	Full makeup	Casual	Yes	Looking directly at camera
				Disliked 2	Front-facing	No	Bright	Smiling	Hair tied back	Casual	No	—
				Disliked 3	Close-up	No	Bright	Neutral	Natural light from side	Casual	No	Inside car
Jenny	17	Female	UCLP	Liked 1	Full body	No	Bright	Neutral	Facing away	Casual	No	Corner of room
				Liked 2	Side-on	No	Bright	Smiling	Riding hat casting shadow	Casual	No	With horse
				Liked 3	Close-up	No	Bright	Smiling	Head tilted	Casual	No	With father
				Disliked 1	Front-facing	No	Bright	Neutral	Mouth closed	Casual	No	Arms folded
				Disliked 2	Front-facing	No	Bright	Smiling	None	Casual	No	With father
				Disliked 3	Close-up	No	Bright	Smiling	Head resting in hands	Casual	No	—
Linda	19	Female	CL	Liked 1	Close-up	Unclear	Bright	Neutral	Hair framing face, makeup	Casual	Yes	Subtle lipstick
				Liked 2	Close-up	Unclear	Bright	Subtle smile	Head tilt	Casual	Yes	Looking past the camera
				Liked 3	Close-up	Unclear	Bright	Neutral	Full makeup, hand to face, styled hair	Casual	Yes	Good lighting
				Disliked 1	Close-up	No	Bright	Laughing/smiling	None	Formal	Yes	With partner
				Disliked 2	Close-up	Unclear	Bright	Neutral	Head in hands, full makeup	Casual	Yes	Dark lipstick

				Disliked 3	Close-up	Unclear	Bright	Neutral	None	Casual	No	Looking straight at camera

Opening Questions

Tell me about your cleft?

How do you feel about your appearance?

What do you like about your appearance?

Is there anything that you don't like about your appearance?

If you could change one thing about your appearance, what would it be?

Photo-Elicitation Questions

Can you tell me why you chose this photograph?

Can you tell me the reason this photograph is important to you?

How do you feel about your appearance in this photograph?

How did you feel when you were taking this photograph/it was taken of you?

Would you have ever shared this photograph with anyone/have you shared it?'

Follow-up Social Media Questions

Do you use social media?

Do you post photographs of yourself on social media?

Have you had any good/ bad experiences of posting on social media?

How do you feel about others sharing your image on social media?