

## ORIGINAL ARTICLE

# Older Adults' Experiences of Living With Cleft Lip and Palate: A Qualitative Study Exploring Aging and Appearance

Claire Hamlet, B.Sc., M.Sc., Diana Harcourt, B.Sc., M.Sc., Ph.D.

**Objective:** To explore older adults' experiences of living with cleft lip and/or palate (CL/P), focusing on aging and appearance.

**Design:** An exploratory-descriptive qualitative study.

**Participants:** Individual semi-structured interviews (five via telephone, one face-to-face) conducted with six adults between the ages of 57 and 82 years.

**Results:** Interview transcripts were analyzed using interpretative phenomenological analysis, which resulted in five themes: cleft across the life span, keeping up appearances, being one of a kind, resilience and protection, and cleft in an ever-changing society. A CL/P had an ongoing impact on participants' lives, although its relevance shifted over time and some aspects of life (e.g., romantic relationships, decisions about having children of their own) were particularly affected. Participants seemed at ease living with CL/P as an older adult and considered it an important aspect of their identity, yet they still described feeling isolated at times and had little contact with other people with a cleft. They felt that health care could be more considerate to the needs of older people with a cleft, particularly around dentistry and information provision. Participants thought societal attitudes toward visible differences had changed over the years, but not necessarily for the better. A paradox was evident between reports of being noticed by others because of their cleft and simultaneously feeling invisible or ignored because of their age.

**Conclusions:** These findings have implications for provision of care for older adults with a CL/P and for younger people with a CL/P who will be the older generation of the future.

KEY WORDS: *aging, appearance, cleft lip/palate, older people, qualitative*

A cleft lip and/or palate (CL/P) presents a myriad of challenges to those affected, and the psychosocial impact can be varied and far reaching (Roberts and Mathias, 2012). Reported problems can include appearance-related concerns (Marcusson et al., 2002), low self-esteem (Sarwer et al., 1999), anxiety and depression (Ramstad et al., 1995; Mani et al., 2010; Foo et al 2011; Roberts and Mathias, 2012), and social anxieties stemming from the responses of others, including staring (Rumsey et al., 2004), teasing and bullying (Hunt et al., 2006), and wider social discrimination (Sarwer et al., 1999). Establishing friendships and relationships can prove especially challenging in childhood and adolescence as young people may be teased about their CL/P (Hunt et al., 2006). Some reports suggest that adults living

with a repaired cleft are less likely to marry compared with the normative population or tend to do so later in life (Ramstad et al., 1995; Robert and Mathias, 2012) and that having a cleft oneself, and the increased chance of having a child with a cleft, can influence reproductive decision making (Yttri, 2011; Roberts and Mathias, 2012).

While research in this area has tended to focus on negative outcomes, recent work has shifted attention toward positive outcomes and resilience. Most of those living with a cleft report satisfaction with their overall appearance (Turner et al., 1998), and self-esteem can be higher than that reported by comparison groups without a cleft (Roberts and Mathias, 2012). People living with any kind of visible difference (disfigurement) may attach greater value to aspects of their lives, such as careers and family, rather than focusing on appearance, and this may enable a sense of fulfilment and satisfaction (Strauss and Fenson, 2005; Thompson and Broom, 2009). Many adults with CL/P feel that their cleft does not affect family or marital life and that, once in a relationship, the cleft has no impact whatsoever (Patel and Ross, 2003). People who have a cleft have reported attracting good friends who are not put off or shamed by their appearance (Eiserman, 2001) and positive outcomes such as the development of an inner strength and coping techniques that transfer to other aspects of life (Egan et al., 2011). In essence, those living successfully with

---

Ms. Hamlet is Research Associate at the Centre for Appearance Research, University of the West of England, Bristol, United Kingdom. Professor Harcourt is Professor of Appearance and Health Psychology and Co-Director, Centre for Appearance Research, University of the West of England, Bristol, United Kingdom.

Submitted November 2013; Accepted March 2014.

Address correspondence to: Dr. Diana Harcourt, Centre for Appearance Research, University of the West of England, Coldharbour Lane, Frenchay, Bristol, United Kingdom. E-mail Diana2.Harcourt@uwe.ac.uk.

DOI: 10.1597/13-308

a craniofacial difference may develop confidence in being able to deal with whatever challenges life may bring them (Eiserman, 2001).

However, the psychosocial CL/P literature to date has focused on the experiences of children, young adults, and parents, while the experiences and needs of older adults with a cleft remain unclear (Feragen, 2012). Although no research has specifically investigated older adults' experiences, a small number of studies have incorporated discussion around age effects and suggested that the psychosocial impact could reduce over time, as the individual has time to adjust and incorporate the cleft into his or her self-image (Thompson and Broom, 2009; Mani et al., 2010).

While age-related changes to appearance such as wrinkles, sagging skin, and changes in posture are considered by many to be inevitable, they are rarely seen in a positive light (Rumsey and Harcourt, 2005). Within the broader appearance and body image literature, it is commonly assumed that physical appearance is less important to older adults, resulting in lower levels of appearance concerns compared with younger adults (Harris and Carr, 2001). However, why the importance attached to outward appearance decreases with age remains unclear. It has been suggested that, with age, people's attention shifts from appearance to functional and physical health concerns (Baker and Gringart, 2012). Alternatively, society may have lower expectations of older adults' appearance, so the perceived pressures to attain an ideal image are reduced (Halliwell and Dittmar, 2003), and older people may start to compare themselves to age-appropriate role models rather than younger fashion models or celebrities (Grogan, 2008).

Yet some research suggests that body dissatisfaction in women remains stable across the life span (Tiggeman, 2004) and that older adults do not stop investing in their appearance. The use of appearance-enhancing strategies including hair styling, clothing, and makeup continues (Tiggeman, 2004) in order to mask the signs of aging (Hurd-Clarke and Griffin, 2008), to buffer the impact of age-related changes to appearance (Baker and Gringart, 2009), and to become more socially visible, as many believe that youth is an indication of value in society (Halliwell and Dittmar, 2003). Research suggests that men are deemed more attractive with age while women are not (Halliwell and Dittmar, 2003), and appearance concerns are thought to reduce with age among men who conceptualize their bodies as functional entities (Halliwell and Dittmar, 2003) and identify themselves with money, power, and status rather than appearance (Sinko et al., 2005). However, a growing body of literature suggests that body dissatisfaction among men is increasing (Hargreaves and Tiggeman, 2009; Fawcner, 2012), but this research has paid little attention to older men (Peat et al., 2011), including those living with a visible difference.

Specialist cleft care in the United Kingdom is provided during childhood, adolescence, and early adulthood, so it is

not surprising that most psychosocial cleft research is conducted during this period, when those who are affected are actively engaged in treatment. Yet the challenges associated with a visible difference continue through adulthood, so age-related factors might affect the impact of a cleft and the support and care needed across the life span, including older adulthood.

Improvements in health care and life expectancy mean that increasing numbers of older people are living with a cleft, but without conducting research in this area, we will not know whether they have specific needs and, if so, whether they are being met. In addition, older adults can provide rich reflective data on their past experiences that could benefit not only other older adults living with a cleft but also the younger generation who are yet to experience life as an older person.

Therefore, the current study set out to address the lack of research into older adults' experiences of living with a CL/P, with a focus on aging and appearance. In addition, it explores participants' views of support needs for older adults living with a cleft and identifies areas for future research.

## METHODS

### Research Design

A qualitative methodology was chosen to allow an in-depth exploration of older adults' experiences of living with a CL/P. Given the lack of previous research in this area, an inductive approach was used to allow participants to highlight issues important to them, rather than a quantitative approach driven by the researchers. Interpretative phenomenological analysis (IPA) was chosen as a method of data analysis since it views the participant as the expert and focuses on understanding individual experiences by gaining an insider perspective and exploring how participants make sense of their world (Smith et al., 2009), rather than relying on existing theories. It has previously been used in appearance-related research to explore participants' experiences of changes due to cancer (Wallace et al., 2007), prostheses (Saradjian et al., 2008), amputation (Mathias and Harcourt, 2013), and visible difference (Thompson and Broom, 2009). It also complements the current drive in the U.K.'s National Health Service to take a person-centered approach to health care by listening to the views of service users (Reid et al., 2005).

Approval for this study was granted by the research ethics committee at the University of the West of England, Bristol.

### Participants and Recruitment

The study was promoted through advertisements placed on the Web sites of two U.K. charities: the Cleft

**TABLE 1** Participants' Demographic Information

<i>Pseudonym</i>	<i>Age</i>	<i>Gender</i>	<i>Marital Status</i>	<i>Children</i>	<i>Cleft Lip and/or Palate</i>	<i>Unilateral or Bilateral Cleft?</i>	<i>Family History of a Cleft?</i>
Lynn	69	Female	Divorced	Yes	Cleft lip and palate	Unilateral lip and bilateral palate	No
Jane	57	Female	Single	No	Cleft lip and palate	Unilateral	Yes
John	58	Male	Single	No	Cleft lip and palate	Not known	Yes
Moya	67	Female	Married	Yes	Cleft lip and palate	Unilateral	No
Doris	79	Female	Widowed	Yes	Cleft lip and palate	Unilateral	No
Robert	82	Male	Married	Yes	Cleft lip and palate	Unilateral	No

Lip and Palate Association (CLAPA) and Changing Faces (a charity providing support for anyone affected by disfigurement of any sort). It was also promoted on the researchers' host institution Web site. As the study focused on older adulthood, participants older than 55 years who were willing to talk about their experience of living with a CL/P were sought. Six adults took part, all of whom had either seen the advert on CLAPA's Web site or had been told of the research by family members who had seen the advertisement. All participants (two men and four women with an age range of 57 to 82 years [mean, 69 years]) had a cleft lip and palate. Demographic information is displayed in Table 1. This sample size is deemed appropriate for IPA analysis (Smith et al., 2009).

### Interviews

The researchers designed a semi-structured interview, informed by the existing cleft and visible difference literatures and existing guidance on IPA interviews (Smith and Osborn, 2008). The interview schedule was discussed with an experienced researcher in this field, and her feedback informed the final version used with participants. The schedule was composed of five main topics: experiences of living with a cleft, views on aging and appearance, experiences of coping with the challenges presented by a cleft, support needs, and provision of care. Participants were also encouraged to discuss any other issues they felt were important. They did not receive any financial compensation for taking part.

All interviews were conducted by the first author, a woman in her 20s with no personal experience of cleft, who kept a reflective journal throughout the data collection and analysis. Participants were given a choice of telephone or face-to-face interviews; only one participant chose a face-to-face interview. Interviews lasted 40 to 80 minutes, were digitally audio recorded, and then were transcribed verbatim.

### Data Analysis

Data were analyzed using IPA. To attend to IPA's idiographic commitment, each interview was analyzed

individually before moving onto the next (Smith et al., 2009). Each transcript was read several times to enable the researcher to become familiar with the data. During this close reading, initial thoughts, observations, and first attempts at early interpretations were noted. Development of emergent themes was achieved by clustering related initial themes and searching for connections across them; this was repeated for each interview.

To ensure the validity of the themes generated, the results of the analysis were audited by the second author, who checked the first author's coding against the interview transcripts. Areas of agreement and divergence were discussed by the authors, and a summary of themes and interpretations was agreed on. The summary was sent to all participants, and their feedback was invited. One response was received, and this participant agreed with the generated themes and felt the research was a starting point for people her age living with a cleft and hoped that some benefit and support would come from it.

### RESULTS

Five main themes arose from the data: (1) cleft across the life span, (2) keeping up appearances, (3) being one of a kind, (4) resilience and protection, and (5) cleft in an ever-changing society. The five themes were evident across all of the interviews and are discussed below, illustrated with quotes from participants. Pseudonyms are used throughout (Table 1).

#### Cleft Across the Life Span

It is important to note that medical and surgical care during the participants' childhood was very different from that available to young people today. They described growing up during a war/postwar era that had created a strain on health services and thus the care available to them. Doris spoke of her gratitude that this was an era of innovation in plastic surgery procedures:

I do think I was very fortunate as I was operated on at Great Ormond Street by a famous surgeon who was pioneering cleft repairs . . . apparently I had to go before a board of doctors where he demonstrated me, so I suppose really I am quite

fortunate that it's not too bad considering that was 79 years ago, you know and my speech is very good. (Doris, 79)

Participants' descriptions showed how the impact of living with a cleft had varied over time. Challenges associated with childhood, relationships, marriage, and having children of their own were commonly discussed alongside a greater sense of acceptance of the cleft during adulthood. Talk around romantic relationships, marriage, and children were common in all interviews, despite not being explicit in the interview schedule. Participants spoke about their transition into adulthood as being particularly pertinent due to pressure from their peers and family to get married. Many highlighted the impact their cleft had had on their confidence as a young adult, and the effect this had on building romantic relationships:

I had so much lack of self-confidence, I was very, very shy and getting into the teenage years of course, I didn't have boyfriends, I had quite a few girlfriends but they drifted off into relationships and I didn't. (Doris, 79)

Robert indicated that his CL/P still affected his confidence at the age of 82:

I think for a young man with the appearance I had before a denture, that was embarrassing in the company of girls and I suppose to some extent even today. (Robert, 82)

Participants grew up in an era in which marriage was considered a rite of passage, and five of the participants spoke of the challenge of finding a life partner. It was perhaps a reflection of this concern and external pressure that Jane spoke about marriage being a high point in her life:

Yes, a particular high was when I met [name]. I always used to have this hang up when people used to say "ooh, are you courting yet?" because everybody asks everybody that, but I felt like I had to prove something. (Jane, 57)

Two participants made a decision not to have children of their own because of their family history of CL/P. John spoke about the impact his decision had on developing and pursuing romantic relationships:

This is why I am single, never to have children, as my grandfather had just a hare lip . . . I had 10 operations, that's quite a lot and I thought if my wife gave birth and I knowingly knew that there was a chance, especially if it was a girl, I would never forgive myself. But that was another sort of influence, I didn't push serious relationships. (John, 58)

Participants spoke of their increased acceptance of their cleft and their aging appearance. They conveyed a sense that the worst was over regarding the impact of the cleft on their lives, and they seemed relatively at ease living with it as an older adult. Doris feels that she is now similar to people her age in relation to appearance:

I feel now that everybody is the same, we are all wrinkly and old and we haven't got our good looks and we are not trying to attract the opposite sex, etc. (Doris, 79)

Many struggled to even comprehend life without a cleft, particularly as they had not known any different:

Now whether it would have made a difference had I not had a cleft, I don't know, it is difficult to compare; well you can't compare, you know? If I had had a head injury in adulthood, I could compare before and after, but with a cleft you can't, because there isn't any before. (Lynn, 69)

Participants described having now accepted their cleft after having been on a personal journey of adjustment and problem solving. Four participants felt that if people were not able to manage the challenges of living with a cleft before reaching older adulthood, then they may never be able to:

But no in a sense, the fact I've got a cleft is, so what if I haven't learnt to live with it by now and if other people can't accept it? I've found other things to mither about. (Jane, 57)

Yet, despite living with a cleft since birth, five of the participants still wanted to know more about it. For example, John wanted to know what the future could hold when aging with a cleft, particularly in relation to physical function:

I would like to know more about the aging process, what will happen with this [points to obturator, which is a dental plate in the mouth] they just make the obturator and are like, "thank you, next." . . . It would be nice to say, "well actually, there won't be a problem as these are the kinds of thing that happen, this is what we will do, or what they should do, as far as general aging you shouldn't have any more problems with infections than anyone else." . . . I'm beginning to find I need a little bit of reassurance on that sort of thing, the function side. (John, 58)

### Keeping up Appearances

Participants spoke about the importance of the face in social interactions and how people with a cleft were noticeable because of their appearance:

You will stand out as different, because that's the first place people look, they look straight into your face. (Lynn, 69)

They were keen to manage the image they presented to others and particularly the impression portrayed by both their physical appearance and their voice. Despite seeming to have accepted both living with their cleft and the effects of age on their appearance, they had not given up managing their outward appearance, for example, by maintaining their hair and applying makeup. Lynn described how she still used makeup in an attempt to alter her appearance and divert attention away from features she was unhappy with:

I'm no Elizabeth Taylor by any means, but I'm reasonable and it's not worth hiding. When I was younger I used a covering cream . . . but I haven't bothered for years, I will just make up the eyes a bit, you know that takes the attention away from the mouth, bit of diversionary tactics. (Lynn, 69)

The importance of good, clear speech was mentioned by all six participants, providing further support for the

notion of keeping up appearances and managing the impression others have of them. Some participants described having endured intense periods of speech therapy as a child and constantly having their speech corrected. This seemed to have created a sense of pride in their speech, which they were keen to maintain:

I have realized that as you get older, your voice changes and things like that, and again with the dental work in your mouth, that if you want people to understand what you are talking about and getting older, you need to take charge of that area in your life, more than you would have done if you had been more normal. (Moya, 67)

Moya also highlighted the importance of good dentistry for older people living with a cleft in relation to both function and esthetics:

It's very important as you have to eat and it has an impact on how you talk and look, anytime you open your mouth, your teeth are visible, if they are wonky or missing or whatever and if you can't eat properly, it makes you feel ill. It's very, very important and of course if you can't speak, you have got three things all rolled into one. (Moya, 67)

Five participants spoke about the need to maintain oral and dental health, especially in relation to maintaining the shape of the mouth and palate. Some talked about the importance of good dentistry for older people living with a cleft and had sought private dentistry to ensure their dental needs were met:

The only problem I think is dental work. . . . If my top teeth are not there, the palate collapses, but in order to make sure my teeth are secure when they're crowned, or whatever, I have to pay for that and that's really quite expensive, it's a credit card-type job, and you have to go to a pretty good private dentist for it. (Lynn, 69).

## Resilience and Protection

Participants seemed to have developed resilience to the challenges they had faced in the past as a result of having a cleft and any they were still facing now. This resilience was evident through their focus on positive aspects and outcomes associated with their cleft and how their experiences of living with a cleft had helped them in other areas of their lives. For example, Doris spoke of how the resilience and independence she developed as a child was still helping her cope today:

Because I lived a very lonely life really in my younger years, I learnt to be very independent which in itself has helped me cope with this I am sure. (Doris, 79)

Robert felt that focusing on aspects other than his appearance, such as his intelligence and career, had developed his self-confidence, which had been significant in helping him deal with his cleft:

If I were to think about it, my personality was significant and also without wanting to boast at all, I was relatively clever and therefore that helped me with my self-confidence . . . self-

confidence I think in my condition is very important. (Robert, 82)

Participants' descriptions of the importance they placed on their cleft, and appearance in general, demonstrated a shift in focus away from concerns about how they looked to concerns about protecting and maintaining the function of one's body:

No, I've got too many other troubles I'm afraid, nothing to do with the cleft, oh dear, I'm afraid its arthritis and in fact I have got lymphoma as well, it's being treated . . . but high blood pressure, all the usual things you get with old age. (Doris, 79)

John felt this shift in the value he placed on appearance was partly due to not feeling the need to impress people anymore:

No, it's rather the function that worries me, I suppose, than appearance. I'm not a peacock with his feathers showing, I have gone past that. (John, 58)

But as with many of the issues they discussed in these interviews, participants realized that it was hard to determine whether they would have been different if they had not been born with a cleft:

I'm quite independent, I'm a quick thinker, I'm impatient, um, I don't suffer fools gladly, but I have empathy, but I don't know if I would be like that if I hadn't had a cleft. (Lynn, 69)

## Being One of a Kind

Participants described feeling, throughout their lives, as if they were the only person living with a cleft. Despite feeling that society was increasingly accepting of visible differences, they still felt somewhat isolated today. Most had never met or spoken to someone with a cleft (outside of any family history of the condition).

So that's how rare it is, I'm like "ooh there's one there." It's not like every other person I'm like "ooh he's like me." . . . I can't say I've met that many people at all. (John, 58)

This sense of feeling "one of a kind" was confounded further by the elephant in the room of having a cleft, with participants describing how either they or others were reluctant to bring up the subject. This was illustrated in the following extract from Doris' interview:

Doris: So I think more people are aware of it, but nobody ever brings up the subject and mentions it.

Interviewer: And if someone did bring up the subject, would you mind?

Doris: No, no, I wouldn't mind at all, not now, I don't know what I would have been like years ago, but now no, I would only be too glad to fill them in and let them know what it's like and ask them really to support the younger babies that are born now. (Doris, 79)

The sense of being unusual or different continued when encountering health care services, with partici-

pants expressing concern and frustration when health professionals were not familiar with clefts. John described a sense of exasperation with medical students wanting to sit in on his consultations because of the rarity of his condition:

But my mother did set up an appointment with Dr [name] . . . then about 6 million students came in to have a look and I was like, "oh, God, here we go again." It's the same when I go to the dental hospital for my obturator, you know, there always seems to be a student there because it's slightly unusual. (John, 58)

### **An Ever-Changing Society**

Participants described how societal attitudes toward visible differences had shifted over the years, yet this had not necessarily made things easier for them. They spoke of living in a modern society that simultaneously accepts people who look different while placing more emphasis on appearance than ever before:

I think things are getting worse, this image is everything its valued more than intelligence, which I find really sad . . . it doesn't make life easy for anyone who has got an image problem to start with. (Jane, 57)

John highlighted changes in societal attitudes toward people with visible differences when he described how younger people stared at him less than people his own age did. He attributed this to a culture in which being different is desirable:

I suppose being gay, cross dressers . . . all these sorts of things, were absolutely "arrgghh" in those days . . . whereas now, the younger generation are like "ooh cool": it's all not a problem, you know, so perhaps they are more relaxed about different people? (John, 58)

## **DISCUSSION**

This study sought to gain an insight into older adults' experiences of living with a cleft, an age group that has been overlooked in the literature to date. It was hoped that exploring participants' experiences could help to understand any support needs for older adults living with CL/P and highlight areas warranting further exploration.

Contrary to previous research (Macgregor, 1990; Berk et al., 2001; Marcusson et al., 2002), outside of the formation of romantic relationships, participants in this study did not indicate that their cleft had negatively affected their social relationships. Most appeared to have good social networks and reported no concerns about their social lives, congruent with the qualitative study by Patel and Ross (2002). All participants had experienced difficulties around their cleft at some point in their lives, but they now seemed to be at ease with it. Time seems to have had a positive effect, enabling them to incorporate their cleft into their image and identity (Thompson and Broom, 2009; Mani et al., 2010).

Talk around romantic relationships and childbearing formed a significant part of each interview. It was evident that living with a cleft had influenced the participants' experiences of forming romantic relationships as younger adults, a finding that is supported in the broader literature on visible difference (Sarwer et al., 1999). Participants felt that relationship difficulties, including fewer interactions with the opposite sex, had been affected by their own low self-esteem stemming from the cleft, rather than from any discrimination by others. One participant spoke of noticing that they entered relationships and got married later in life than their peers without a cleft, supporting previous research (Ramstad et al., 1995; Robert and Mathias, 2012). The importance placed on marriage was evident in the current study; however, it should be noted that these participants were young adults in an era when pressure to marry and have children was perhaps greater than it is today. Participants spoke of having had concerns about having children of their own. Two indicated that a family history of a cleft was an influencing factor in their decision not to have children, illustrating the personal impact of childlessness among those with a cleft (see also Yttri, 2011; Robert and Mathias, 2012). Whether these issues are a concern for today's young adults living with a cleft remains to be seen.

Participants' talk of the importance of the face in everyday interactions and the significance of this for someone with a facial difference concurs with other literature on aging and visible difference (Tiggeman, 2004; Hurd-Clarke and Griffin, 2008). Despite reporting being at ease with their appearance, female participants still used makeup to increase feelings of confidence and to distract attention away from their repaired cleft. Research suggests that women with or without a cleft use beauty-enhancing practices, such as makeup, to mask the signs of aging and become more visible in society (Hurd-Clarke and Griffin, 2008). However, participants in the current study used makeup to become less noticeable by using it to draw attention away from aspects of their appearance they did not like. This illustrates a contrast in the experiences and views of older people with and without a cleft: People with a cleft often report feeling that they stand out in a crowd and use strategies to try to blend into the crowd, while older people in general often describe feeling ignored and being less visible in society than they were when they were younger.

In keeping with other research on people with visible difference, participants discussed the importance of speech as an aspect of self-presentation (Eiserman, 2001). They spoke with clarity and confidence, and some described how their speech was corrected by their mothers during childhood, which is concurrent with research by Havstam (2011), who reported that family members had a significant impact on a child's speech.

Participants described feeling isolated, and four participants spoke of having never known anyone with a cleft,

other than their own family members or Internet acquaintances. Participants reported that they and other people rarely raised the subject of a cleft. This supports reports that a cleft can be a taboo subject and something that people are reluctant to talk about (Patel and Ross, 2003) and that people avoid conversations about a visible difference because they are inexperienced, embarrassed, or unsure how to behave (Robinson et al., 1996). However, participants in the current study were happy to talk about their cleft and wanted to raise awareness of the condition and reduce older adults' sense of isolation.

Participants placed more importance on bodily function than esthetics, supporting existing literature on aging (Baker and Gringart, 2012). Yet functionality was salient for both men and women, contrary to suggestions that this is more of a concern for men than women (Halliwell and Dittmar, 2003). In particular, participants emphasized the importance of their teeth in relation to the function and structure of the palate and facial appearance. Older people without a cleft are also known to worry about losing their teeth and, when this does occur, perceptions of body image change for the worse (Niesten et al., 2012). Participants in the current study reported having to find their own way of managing their dentistry and felt they needed more information, support, and advice in this area.

Interestingly, participants seemed to have developed resilience toward pressures to meet societal norms about appearance. On the whole, they reported few appearance-related concerns as an older adult and attached greater value to other areas of their lives such as their families, education, and career. This seems to have buffered the impact of the cleft beyond early adulthood and supports other qualitative research (Strauss and Fenson, 2005; Thompson and Broom, 2009) into resilience to visible difference.

Among the most commonly reported challenges facing people with a visible difference are the reactions of the general public, such as staring and inappropriate questioning (Rumsey et al., 2004). While one of the participants in the current study (John) reported being stared at by people his own age, others had noticed that children tended to stare at them less than they had in the past. Participants talked of witnessing a positive change in societal attitudes toward people with visible differences over the years, but this had not necessarily made things easier for them. They expressed concern that modern society's apparent obsession with appearance could be particularly challenging for younger people living with a cleft. It is possible that, with age, people with a cleft feel that their appearance blends in more with societal norms about appearance in older people (i.e., that older people are not expected to meet the ideals of beauty expected of younger people). However, we cannot generalize any of our findings on the basis of this small sample and would not want to imply that all older people living with a cleft are as well adjusted as those who chose to take

part in this study seemed to be. The experiences of those who chose not to participate may be quite different.

Some consideration should be given to the limitations of this study. First, participants' ages spanned 25 years, so although they all had experience of being an adult with a cleft, they grew up in different eras, and as a consequence, their treatment and experiences could vary considerably. As a result, we should be cautious in generalizing these results to others over the age of 55 years living with a cleft. In addition, the participants who took part in the study were recruited via the charity CLAPA, and people who actively view this Web site may have different attitudes and experiences than individuals who do not have this source of support. The sample size of six may seem small, but this is in line with recommendations for IPA research looking to gain an in-depth understanding of participants' lived experiences (Smith et al., 2009).

Because of the geographical dispersion of the participants, telephone interviews were conducted rather than face-to-face interviews. It has previously been suggested (Turner et al., 2002; Novick, 2008) that telephone interviews can hinder the establishment and maintenance of rapport between an interviewer and interviewee and prevent the researcher from attending to nonverbal communication, but our positive experience of using telephone interviews in this study is in line with previous reports of their suitability for appearance research (Egan et al., 2011).

Despite these limitations, this study is, to the best of our knowledge, the first to focus specifically on the experiences of older adults living with a cleft. As such, it paves the way for future research with this population. The findings from this qualitative study could usefully inform future quantitative research to examine the extent to which these issues are also pertinent to a larger, more representative sample of older adults with a cleft. It would also be useful to survey the views of health professionals working with older adults living with a cleft, to investigate their experiences and perceptions of the support needs of this group. It is also important to explore the needs of older people from different ethnic groups (all of the participants in this study were white and living in the United Kingdom) and those who for any reason do not have a fluent understanding of English. This study also adds to a very small literature about older people and appearance; so far as we are aware, this is the first study to explore the lived experiences of older people who have a visible difference of any kind. Future research should explore the experiences and support needs of older adults living with acquired (e.g., burn injuries or amputations) rather than congenital differences.

This study highlights the importance of appropriate support and information across the life span, in order to meet the needs of older adults living with a cleft and younger people who are the older generation of the future. Although the six participants in this study did not feel the need for psychosocial support themselves, they recognized

that it could be beneficial for other older people with a cleft. Their accounts of feeling isolated suggest that opportunities for contact with others with a cleft might be useful and, since they all responded to an advert for participants that was placed on the Internet, it is possible that online support might be acceptable and useful for some older adults, just as it is for some young people. Participants all expressed a desire for more information about their cleft, particularly about what might happen to their teeth with age, but were unsure as to how they could gain this information and described some frustrations with current health and dental care services. These frustrations suggest that more consideration may need to be given to developing health services in the United Kingdom that are more attentive to the needs of the older adult population.

### CONCLUSION

In summary, this is the first study to specifically explore older people's experiences of living with a cleft lip and/or palate. We hope it will encourage other researchers and health professionals working with this group to consider their specific needs and to ensure that appropriate care and information is provided.

---

*Acknowledgments.* We would like to thank all the participants who kindly took the time to share their experiences with us and CLAPA and Changing Faces for their help in promoting this study.

### REFERENCES

- Baker L, Gringart E. Appearance in later life. In: Rumsey N, Harcourt D, eds. *The Oxford Handbook of the Psychology of Appearance*. Oxford, UK: Oxford University Press; 2012:160–171.
- Baker L, Gringart E. Body image and self-esteem in older adulthood. *Age Soc*. 2009;29:977–995.
- Berk N, Cooper M, Liu Y, Marazita M. Social anxiety in Chinese adults with oral-facial clefts. *Cleft Palate Craniofac J*. 2001;38:126–133.
- Egan K, Harcourt D, Rumsey N; The Appearance Research Collaboration. A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference. *J Health Psychol*. 2011;16:739–749.
- Eiserman W. Unique outcomes and positive contributions associated with facial difference: expanding research and practice. *Cleft Palate Craniofac J*. 2001;38:236–244.
- Fawkner H. Gender. In: Rumsey N, Harcourt D, eds. *The Oxford Handbook of the Psychology of Appearance*. Oxford, UK: Oxford University Press; 2012:175–190.
- Feragen KB. Congenital conditions. In: Rumsey N, Harcourt D, eds. *The Oxford Handbook of the Psychology of Appearance*. Oxford, UK: Oxford University Press; 2012:353–371.
- Foo P, Sampson W, Roberts R, Jamieson L, David D. General health-related quality of life and oral health impact among Australians with cleft compared with population norms: age and gender differences. *Cleft Palate Craniofac J*. 2011;49:406–413.
- Grogan S. *Body Image: Understanding Body Dissatisfaction in Men, Women and Children*. 2nd ed. East Sussex, UK: Routledge; 2008.
- Halliwell E, Dittmar H. A qualitative investigation of women's and men's body image and their attitudes towards ageing. *Sex Role*. 2003;49:675–684.
- Hargreaves D, Tiggeman M. Muscular ideal media images and men's body image: social comparison processing and individual vulnerability. *Psychol Men Masculin*. 2009;10:109–119.
- Harris DL, Carr AT. Prevalence of concern about physical appearance in the general population. *Br J Plast Surg*. 2001;54:223–226.
- Havstam C. Taking charge of communication: adults' descriptions of growing up with a cleft-related speech impairment. *Cleft Palate Craniofac J*. 2011;48:717–726.
- Hunt O, Burden D, Hepper P, Stevenson M, Johnston C. Self-reports of psychosocial functioning among children and young adults with cleft lip and palate. *Cleft Palate Craniofac J*. 2006;43:598–605.
- Hurd-Clarke L, Griffin M. Visible and invisible ageing: beauty work as a response to ageism. *Age Soc*. 2008;28:653–674.
- Macgregor FC. Facial disfigurement: problems and management of social interaction and implications for mental health. *Aesthet Plast Surg*. 1990;14:249–257.
- Mani M, Carlsson M, Marcusson A. Quality of life varies with gender and age among adults treated for unilateral cleft lip and palate. *Cleft Palate Craniofac J*. 2010;47:491–498.
- Marcusson A, Paulin G, Ostrup L. Facial appearance in adults who had cleft lip and palate treated in childhood. *Scand J Plast Reconstr Surg*. 2002;36:16–23.
- Mathias Z, Harcourt D. Dating and intimate relationships of women with below-knee amputation: an exploratory study. *Disabil Rehabil*. 2014;36:395–402.
- Nielsen D, Mourik K, van der Sanden W. The impact of having natural teeth on the QoL of frail dentulous older people: a qualitative study. *BMC Public Health*. 2012;12:839–861.
- Novick G. Is there bias against telephone interviews in qualitative research? *Res Nurs Health*. 2008;31:391–398.
- Patel Z, Ross E. Reflections on the cleft experience by South African adults: use of qualitative methodology. *Cleft Palate Craniofac J*. 2003;40:471–480.
- Peat CM, Peyerl NL, Ferraro FR, Butler M. Age and body image in Caucasian men. *Psychol Men Masculin*. 2011;12:195–200.
- Ramstad T, Ottem E, Shaw WC. Psychosocial adjustment in Norwegian adults who had undergone standardized treatment of complete cleft lip and palate: education, employment and marriage. *Scand J Plast Reconstr Surg Hand Surg*. 1995;29:251–257.
- Reid K, Flowers P, Larkin M. Exploring lived experience: an introduction to interpretative phenomenological analysis. *Psychologist*. 2005;18:20–23.
- Roberts RM, Mathias JL. Psychosocial functioning in adults with congenital craniofacial conditions. *Cleft Palate Craniofac J*. 2012;49:276–285.
- Robinson E, Rumsey N, Partridge J. An evaluation of the impact of social interaction skills training for facially disfigured people. *Br J Plast Surg*. 1996;49:281–289.
- Rumsey N, Clarke A, White P, Wyn-Williams M, Garlick W. Altered body image: appearance-related concerns of people with visible disfigurement. *J Adv Nurs*. 2004;48:443–453.
- Rumsey N, Harcourt D. *The Psychology of Appearance*. Maidenhead, UK: Open University Press; 2005.
- Saradjian A, Thompson AR, Datta D. The experience of men using an upper limb prosthesis following amputation: positive coping and minimizing feeling different. *Disabil Rehabil*. 2008;30:871–883.
- Sarwer D, Barlett S, Whitaker L, Paige K, Pertschuk M, Wadden T. Psychological functioning of individuals born with craniofacial anomalies. *Plast Reconstr Surg*. 1999;103:412–418.
- Sinko K, Jagsch R, Precht V, Watzinger F, Hollmann K, Baumann A. Evaluation of aesthetic, functional, and quality-of-life outcome in

- adult cleft lip and palate patients. *Cleft Palate Craniofac J*. 2005;42:355–361.
- Smith J, Flower P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage; 2009.
- Smith J, Osborn M. Interpretative phenomenological analysis. In: Smith JA, ed. *Qualitative Psychology*. London: Sage; 2008:53–81.
- Strauss R, Fenson C. Experiencing the “good life”: literary views of craniofacial conditions and quality of life. *Cleft Palate Craniofac J*. 2005;42:14–18.
- Thompson A, Broom L. Positively managing intrusive reactions to disfigurement: an interpretative phenomenological analysis of naturalistic coping. *Diversity in Health and Care*. 2009;6:171–180.
- Tiggeman M. Body image across the adult life span: stability and change. *Body Image*. 2004;1:29–41.
- Turner A, Barlow J, Ilbery B. Play hurt, live hurt: living with and managing osteoarthritis from the perspective of ex-professional footballers. *J Health Psychol*. 2002;7:285–301.
- Turner S, Rumsey N, Sandy J. Psychological aspects of cleft lip and palate. *Eur J Orthod*. 1998;20:407–415.
- Wallace M, Harcourt D, Rumsey N. Managing appearance changes resulting from cancer treatment: resilience in adolescent females. *Psycho Oncol*. 2007;16:1019–1027.
- Yttri J. Reproductive patterns among Danish women with oral clefts. *Cleft Palate Craniofac J*. 2011;48:601–607.