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# 'Your face freezes and so does your life': A qualitative exploration of adults' psychosocial experiences of living with acquired facial palsy

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**Objectives.** Facial palsy (FP) is a highly visible appearance-affecting condition and can have a significant impact on facial function. Qualitative research focussing on adults' experiences of living with acquired FP is limited. This study aimed to explore the psychosocial impact of acquired FP and to gain a greater understanding of patients' experiences of treatment and care in the United Kingdom.

**Design.** A qualitative interview study with individuals living with acquired FP.

**Methods.** Ten adults with acquired FP were recruited. Their experiences were explored using semi-structured telephone interviews. Data were analysed using thematic analysis.

**Results.** Five master themes were identified through the thematic analysis: 1) grappling with a new identity, 2) the psychosocial impact of living with facial palsy, 3) isolation: dealing with 'one hell of a problem on your own', 4) a life on hold, 5) coping strategies. Findings indicated high levels of distress and significant challenges in managing the functional and psychosocial changes associated with acquiring FP. Participants expressed grief for their former appearance and identity, with photographs and mirrors acting as agonizing reminders. Many reported a sense of abandonment due to uncoordinated care and, as a result, engaged in an endless and often fruitless pursuit to gain control over FP by experimenting with their own treatment. Many reported the negative impact of their altered facial expressions on social interactions and a fear of being negatively evaluated.

**Conclusions.** This study highlights a pressing need to review how FP is managed in the UK. To improve patient well-being, health care professionals could benefit from FP education, and patients from timely access to psychological support and clearer standards of care following diagnosis.

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## Statements of contribution

### *What is already known on this subject?*

- Facial palsy (FP) significantly changes facial appearance and function, and quantitative research indicates individuals with FP can experience notable psychosocial difficulties.

### *What does this study add?*

- The inability to smile and effectively express emotion was one of the most distressing aspects of acquiring FP. This not only affected how participants related to others, but how they related to themselves.
- Resolving and managing the impact of FP appeared to have consumed many of the participants' lives. The Common-Sense Model of Self-Regulation could be a useful framework to understand the complexity of adjustment to FP and warrants further research.
- FP patients in the UK appear to be experiencing inadequate access to specialist services, indicating a need to review how FP is managed across primary care and secondary care.
- Patients want, and may benefit from, increased access to psychosocial support, regardless of the permanency of their FP.

## Background

Facial palsy (FP) is a term used to describe facial disfigurement resulting from a weakness of the facial muscles due to temporary or permanent damage to the facial nerve. Approximately half of all cases of FP are caused by Bell's Palsy, which affects around 20.2 people per 100,000 in the UK (Rowlands, Hooper, Hughes, & Burney, 2002). Whilst many with Bell's Palsy will make a full recovery, around 30% will not (Peitersen, 2002). Other acquired causes of FP include trauma to the facial nerve (e.g. surgery, accidents, brain tumours) or conditions such as Ramsay Hunt Syndrome (a complication of shingles). Finally, some FP cases are due to congenital conditions, such as Moebius syndrome.

Facial palsy is a highly visible appearance-affecting condition and can significantly change facial function. Verbal and non-verbal communication are often affected due to a lack of facial animation (Keillor, Barrett, Crucian, Kortenkamp, & Heilman, 2002). Other difficulties can include dry eyes, drooling, hemi-facial spasms and problems eating and drinking due to muscle weakness (Benecke, 2002). Those with FP can experience notable psychosocial difficulties, such as anxiety and depression, regardless of the objective severity of physical symptoms (Hotton et al., 2020). For example, Cross, Sheard, Garrud, Nikolopoulos, and O'Donoghue (2000) assessed psychological distress (e.g. negative self-concept, self-consciousness) due to appearance, ways of coping, and self-esteem amongst 32 men and 71 women living with FP after acoustic neuroma surgery in the UK. They reported widespread psychological distress and maladaptive coping that was higher among women and younger patients, in addition to low self-esteem across the sample. The severity of FP did not predict the level of distress. Fu, Bundy, and Sadiq (2011) found that 32.7 and 31.3% of 168 patients attending a UK FP clinic had significant levels of anxiety and depression, respectively, as measured by the Hospital Anxiety and Depression Scale (HADS). Walker, Hallam, Ni Mhurchadha, McCabe, and Nduka (2012), who also used the HADs, found that 60% of 126 patients referred to a UK FP specialist centre showed symptoms suggestive of anxiety and/or depression, which again was higher among women than men.

Whilst these findings indicate FP can have a significant impact on psychosocial well-being, they focus on patients drawn from surgical settings, resulting in samples biased towards receiving physical treatment for their FP. Current FP treatments are wide-ranging

and include nerve grafts, brow lifts, and botulinum injections, in addition to non-invasive treatment such as facial physiotherapy (Ho et al., 2012). However, in the UK, a high proportion of patients are unable to access specialist FP treatments, and thus, the voices of this group remain unheard. Recent reports indicate only 13% of health care clinical commissioning groups routinely fund treatment, with General Practitioners (GPs) and commissioners often designating FP an appearance-related or 'cosmetic' issue rather than acknowledging the functional deficits (Jing, Thomas, & Nduka, 2014; Kilshaw, Holmes, & Matteucci, 2016). A recent UK Delphi study to identify research priorities reinforced the current inadequacy of care for people affected by FP (Hamlet, Rumsey, Williamson, Johnson, & Nduka, 2018).

Whilst the cross-sectional quantitative designs of existing FP studies have highlighted that psychological distress is prevalent in those with FP, they do not facilitate a detailed exploration of its source. Two qualitative studies in the UK have sought to understand the nuanced experience of living with FP amongst patients drawn from medical settings. Norris et al. (2019) interviewed 14 patients (5 men) who had attended a Facial Palsy clinic in Oxford to develop a FP-specific Patient-Reported Outcome Measure. As a result, they identified five measurable domains that related to patient experience: facial function and symptoms; facial appearance; psychological and social function; and experience of health care. Pattinson et al. (2021) interviewed 14 females and 6 males attending a specialist facial function clinic about their illness beliefs, emotions, and behaviours in relation to their FP, and to understand how their distress was experienced. They reported that the burden of managing a long-term condition, altered self-perception, and social anxiety and isolation were key drivers of distress (e.g. anxiety, depression and suicidal ideation).

It is evident there is a pressing need to understand more about psychosocial impact of FP by speaking directly to those with FP, outside of surgical settings. This study qualitatively explored the lived experiences of people with acquired FP. The main objectives were (1) to gain an in-depth understanding of the psychosocial impact of acquired FP and (2) to gain insight into individuals' experiences of treatment and care. This research focussed specifically on those with acquired FP (the most representative sample of the FP population) in UK community settings to understand the particular needs of this group.

## Method

Ethical approval was obtained from the first authors' host institution. Recruitment was facilitated by the charity Facial Palsy UK and the Centre for Appearance Research, who advertised the study via their social media channels. Those interested in participating ( $n = 14$ ) were advised to contact the lead researcher, who provided a detailed study information sheet and answered any questions prior to arranging an interview. Audio-recorded verbal consent was taken at the start of each interview. It was decided a priori that recruitment would continue until data saturation was reached, defined as the point at which no new themes emerged in the interviews (Fusch & Ness, 2015).

This study used one-to-one semi-structured telephone interviews. Telephone interviews were selected, firstly because of the likelihood that the sample would be geographically disperse and secondly because this medium may be preferable to face-to-face interviews for those who are socially self-conscious (Coulson, 2012). Interviews were semi-structured to facilitate comparisons across interviews on key topics whilst permitting interviewees freedom to share views and delve deeply into personal and

sometimes sensitive issues. The interview schedule included open questions regarding participants' experiences of living with FP and their experiences of support and treatment (interview schedule available as Appendix S1). An individual with lived experience of FP and a FP surgeon reviewed and approved the final interview schedule. All interviews were conducted by the first author (CH), a health psychologist of White British origin with academic knowledge of FP, but no lived experience, and prior experience of conducting qualitative research with those living with a visible difference. CH did not personally or professionally know the participants. At the end of interviews, the interviewer checked to ensure participants were not distressed and were comfortable ending the call. Participants were reminded of the support offered by Facial Palsy UK and advised to talk to their GP if they felt they required additional psychological support. This advice was also available in the information sheet. Reflexive notes were written after each interview to aid the analysis. CH sought supervision from HW after interviews to reflect on the emotional challenges of carrying out interviews with participants expressing distress. Interviews were recorded and then transcribed verbatim.

### **Analysis**

Data were subject to contextualist thematic analysis, which acknowledges the authors' commitment to report participants' individual experiences and the meanings they attach to them, whilst considering the broader influence of society on these experiences and how they are interpreted (Braun & Clarke, 2006). The data were explored using the six steps outlined by Braun and Clarke (2006). Firstly, to achieve familiarization with the data, CH listened to and read the transcribed interviews repeatedly. Transcripts were analysed initially by CH through coding transcripts and then identifying preliminary master themes and subthemes. After this stage, other members of the research team (HW – a health psychologist experienced in visible difference research and MH – a clinical psychologist working in an NHS facial palsy centre) were involved in discussions around the data. The preliminary master themes and subthemes were reviewed against the transcripts to ensure they were founded in the data and were then modified and discussed iteratively amongst the team before they were finalized.

Ten adults (7 females) aged between 35 and 62 years took part. Causes of FP included Bell's Palsy ( $n = 6$ ), acoustic neuroma ( $n = 2$ ), operation trauma ( $n = 1$ ), and unknown cause ( $n = 1$ ). Interviews lasted between 38 and 89 minutes (Table 1).

**Table 1.** Participant demographics

Pseudonym	Gender	Cause of FP	Current age	Age of FP onset	UK location
Ursula	Female	Unknown origin	62	61	South East
Katey	Female	Bell's Palsy	53	53	North East
Aran	Female	Bell's Palsy	56	55	Yorkshire and Humber
Sian	Female	Bell's Palsy (twice)	55	34	London
Kathy	Female	Bell's Palsy	56	42	North West
Robert	Male	Acoustic Neuroma	47	37	South East
Paul	Male	Acoustic neuroma	47	37	South East
Helen	Female	Bell's Palsy	50	38	South East
Amy	Female	Trauma ear operation	53	11	South East
Craig	Male	Bell's Palsy	35	32	Yorkshire and Humber

**Table 2.** Master themes and subthemes

Theme	Subtheme
1. Grappling with a new identity	
2. 'The psychosocial impact of living with facial palsy	2.1. Importance of the face in social interactions 2.2. Appearance-related distress 2.3. Anxiety in public 2.4. Impact on romantic relationships
3. Isolation: 'Dealing with 'one hell of a problem on your own'	
4. A life on hold	4.1. Searching for answers 4.2. Trying to gain control
5. Coping strategies	5.1. Downward comparisons 5.2. Acceptance 5.3. Humour 5.4. Health professional support

## Results

Five master themes and ten subthemes were identified through the thematic analysis: 1) grappling with a new identity, 2) the psychosocial impact of living with facial palsy, 3) isolation: dealing with 'one hell of a problem on your own', 4) a life on hold, 5) coping strategies. These are outlined in Table 2.

### ***Grappling with a new identity***

It was evident that facial appearance was a central part of participants' self-identity. This theme encompasses the impact of FP, particularly lack of facial expression, on their sense of identity. Many participants experienced a sense of loss or grieving for their former face:

And as much as I'm grateful I haven't had a brain tumour. . . or any of those horrible cancers that all those consultants were looking for. . . the bottom line my face is not my face anymore. (Helen, 50)

Some participants spoke about themselves in the third person, indicating they no longer identified with their former self:

It feels as if part of you has died or, if not, you've died as a person. You're no longer the same person you were when you could smile. . . it's like a grieving process. . . You want that person back and, for some people, you'll never get that person back. . . that person is gone until maybe magically you wake up one morning and their back. (Craig, 35)

Participants lamented their face's ability to communicate and reflect their real emotions, which they found frustrating and upsetting. Some responded by actively trying to avoid looking at themselves in mirrors or pictures:

I try and avoid them [photos/videos] but then I'm missing out on . . . all the previous moments like with your children and when you get married and all that. . . there's photos of me but I'm

never smiling or I'm never showing my real emotions. You know, like if I feel happy I can't show it. (Amy, 53)

They also found that encountering mirrors and photographs and noticing looks from strangers acted as stark reminders of their new appearance:

When you're looking out of your own eyes you don't see your face and you do forget for a little bit until you get a funny look. . . or you just catch a glimpse of yourself when you're in town in a mirror . . . then you feel like a kick in the stomach like 'Oh God I forgot about that'. (Robert, 47)

### ***The psychosocial impact of living with facial palsy***

This theme represents participants' social and psychological experiences of living with FP, including the impact that their unusual appearance and inability to smile had on their social interactions and self-confidence.

#### *Importance of the face in social interactions*

Many reflected on the importance of the face in social interactions and communication, and the frustrations and distress of not being able to smile and express themselves. Some recalled particular incidents where the impact of their facial difference on others became acutely apparent:

I know it sounds daft but there was an acquaintance who picked me up from the hospital, he went and apologised to the nurse and said 'Oh don't worry, she doesn't normally look like this, she's normally a very happy person.' That's the first time I've actually realised that I looked like this glum zombie. You don't realise how important it is to be able to smile until you've lost it. . . one of the biggest difficulties is communicating and interacting. (Ursula, 62)

A [term for homeless person] at the side of the road, said 'Cheer up mate, it might never happen.' Which kind of makes you . . . firstly a bit shocked, then you have a bit of a chuckle to yourself thinking you must look bad! (Robert, 47)

#### *Appearance-related distress*

Both male and female participants spoke about the negative impact of FP on their appearance confidence, something which they still struggled to come to terms with and that had implications for their mental health:

You know, I was never ugly. . . . I used to be really attractive, I'm not attractive anymore. One side of my face is very 'liney' and the other side of my face is stuck and I can't smile properly and I haven't been able to for years. . . you can get very, very down about it all. (Helen, 50)

#### *Anxiety in public*

When in public settings, participants reported how strangers stared at them and how they worried about they thought of them. Some felt that unwanted attention was because there was a lack of public awareness of FP, which meant people did not understand why they looked different. As such, some felt more comfortable when they made the cause of their visible difference more explicable to others.

You see them look at your face and you think 'Oh God. . . they're judging you' or whatever. So I've got a metal screw at the side of my head [hearing loss], and I see people look at that all the

time but that doesn't bother me so much because... there's a reason for it... if I had a big scar visible it's almost sort of telling a story if you know what I mean? But if they just see the face then they're thinking 'Oh what's wrong with him, there's something not right'. (Robert, 47)

You become aware of people staring at you before you've even seen them... you find people giving you a real good gawk. The eye plaster helps give me confidence because it makes it absolutely obvious that there's something going on. (Katey, 53)

Many reported their FP often became the 'elephant in the room', which led them to wonder whether it would help to openly and verbally disclose their condition to people they met:

When you meet somebody new and they look at you, the first thing you think is 'Are they noticing that my face doesn't quite work how everybody else's does?' and you don't know whether you should explain to them that you've had it or do you just not say anything or it's really, really difficult. New situations, new people, because people don't understand it. They don't understand what it feels like. They'll say 'Well you look alright to me.' And you can't explain 'Well actually I don't feel alright because, as I'm talking, I feel like my eyes are twitching and my mouth feels stiff and I can't smile properly'. (Kathy, 56)

For years, if I'd meet somebody new I wouldn't say 'Oh hi, I've got Bell's Palsy'... I was probably embarrassed, but now I don't really care... but they [strangers] don't acknowledge it or they don't ask me, and I don't know why that is. (Sian, 55)

#### *Impact on romantic relationships*

Whether single or in a partnership, some participants reported how their FP had impacted on their romantic relationships, primarily due to reduced appearance confidence:

I've been single for a lot of years now and I think the majority of the reason for that is because of my face. It's not because I wouldn't like to meet somebody to share my life with but I am very conscious of it... And with dating it is very much appearances matter don't they? (Kathy, 56)

#### ***Isolation: 'Dealing with one hell of a problem on your own'***

This theme represents participants' frustrations with the lack of understanding and support for FP exhibited by some medical professionals, which resulted in them feeling alone in managing it. Many reported that on the whole, the NHS failed to offer appropriate treatment. For example, some received no follow-up care after diagnosis, leaving participants to navigate the condition alone. This was particularly frightening in the early days after the condition first presented and when they felt uncertain about recovery:

They can't tell you how long you've got it for. They can't tell you if you're going to recover. They can't tell you how you're going to feel. You just feel like you're walking home to deal with one hell of a huge problem on your own and there's not many other conditions, I don't think, that that would happen with. Even if you were suffering from depression they would say 'I want to see you in two weeks.' But this, your face is paralysed and you're sent home to deal with it. (Kathy, 56)

I think partly it's because it's such a rare thing they didn't know what to do with me. If I'd had a stroke there would be a procedure, a protocol, they would know what to do with you... because I didn't fit any common problem there's no solution, there's no pathway, there's nothing. (Ursula, 62)

Due to a lack of understanding about FP, some participants reported that GPs failed to make timely and appropriate referrals for FP treatment. For some, this meant missing the crucial treatment window for medication:

It was now the sixth day that I actually got to see somebody who could treat the Bell's Palsy. And, as you know, it's a 72 hour window that you're supposed to get the steroids (Kathy, 56)

For others, this meant being referred to health professionals with no experience of FP, which was emotionally exhausting when they were desperate for help:

I did get referred to one of the physios in [UK town] after I'd badgered for it. Unfortunately, the physio that I saw, ultimately, by his own admission, didn't have any experience with facial palsy. And I knew that, I'd kind of go along to these sessions and I was absolutely desperate because my face was changing . . . it was a real struggle emotionally and then I found that there were specialist physios dotted around the country. I asked for a referral to the specialist physio in [UK town]. (Aran, 56)

Many felt they were not listened to or treated with compassion due to a general lack awareness around the physical and psychosocial impact of FP, particularly amongst GPs. Some believed this was due to the perception that FP only has 'cosmetic' consequences:

I think because people aren't kind of aware of the problems that it causes and how difficult it is to live with, if they think 'Oh it's nothing, it'll go' then they're never going to put any money into it are they? Because it isn't such a big problem and 'Oh yeah, you're just not quite happy with your face so it's a bit cosmetic that you want doing', you know? It's kind of that attitude isn't it? (Kathy, 56)

In addition to expressing the psychosocial challenges of living with an altered appearance, participants also highlighted a need for medical attention to address the functional challenges associated with FP. Those that were most concerning were eye problems (e.g. watering) and a potential loss of eyesight, synkinesis (when a voluntary facial movement causes an involuntary one in another part of the face), and problems eating and drinking.

The wiring is misconnected is the best way of putting it. And I said to him 'Well what do you do about that?' and he said 'Well we give botox injections.' Well that's the last thing I want. . . I think a lot of what the rehab people are working towards is just to make people look a bit more balanced and normal, whereas what I want is more functionality. (Ursula, 62)

Experiences of receiving FP treatment, from the point of diagnosis through to the present day, featured heavily in participants' account and thus warrant reporting in a separate paper.

### ***A life on hold***

This theme refers to a sense that participants' lives were on hold due to the presence of FP, and the constant struggle they faced in trying to understand its cause, as well as obtain a sense of personal agency over it.



### *Searching for answers*

Despite having a label of Bell's Palsy, many struggled with the uncertainty around what exactly brought it on and described feeling in a state of 'limbo' as a result:

My GP, as lovely, and as talented as he is, he just kept saying 'I don't know Helen. I don't know why it keeps happening. . . and the thing is, because you're on this journey of trying to find out why, you're not really living because you feel like everything's on pause . . . which is what your face does. Your face freezes, and so does your life. (Helen, 50)

Some questioned whether their past life events had contributed to its development (e.g. stress, trauma). Craig reflects on how this makes FP different to unambiguous health conditions:

What even causes it is another thing. . . they don't know if it's stress . . . I've heard travelling on an airplane and pressure . . . other people have said dentists causes it . . . it's not like breaking your leg, you've done it and you've caused it by doing this. (Craig, 35)

### *Trying to gain control*

With participants' feeling that their life was on hold due to FP, many seemed to be consumed with trying to regain some sense of control. For example, many were engaged in an endless pursuit of researching FP and potential treatments to try. These efforts were often pursued without medical guidance and were thus funded by the patients themselves:

I've spent hours on the internet looking at stuff to make myself feel better by knowing there's things out there that I could buy or have. I'm basically hitting everything I can possibly think of to try and make it go away. (Katey, 53)

The speech and language therapist showed me some exercises. . . I wasn't referred for anything else, but I went to the States and I could see they took an interest. . . this led me to find a private clinic in Manchester, her method was facial therapy and electrical stimulation. . . I had follow-ups until I felt I wasn't making any more progress (I paid for that). Then had some acupuncture and there was a slight improvement in my mouth but, again, after a couple of sessions (I paid for that) nothing else happened there so I stopped there. Then it was started coming out about botox. . . although he [GP] didn't want to send me, we had to badger him. I went there for about 10 years until varying degrees of success, but I felt I looked better. (Sian, 55)

### ***Coping strategies***

Whilst FP did have a significant impact on participants' lives, some spoke of strategies and experiences with health care professionals that helped them manage its challenges.

### *Downward comparisons*

Whilst many participants wanted to gain control of their FP and were heavily engaged in searching and fighting for appropriate treatment, some reported that these endeavours resulted in negative feelings of vanity and guilt, as other people experience conditions with impacts that could be perceived as being far worse. Some found making downward social comparisons (Festinger, 1954) helpful. Helen highlights the complex nature of this struggle:

You feel guilty because you think 'Oh my goodness, I'm being so vain and here's all these other people that have got brain tumours' and also during this period I've lost four different people in my life. . . you feel guilty that you're feeling sad because your face isn't quite normal and here they are a long time dead. So you kind of grab yourself and go 'Right, come on, you've got to get on with this girl, this is just the way it is and accept you have a wonky face' and some days I'm ok with it and other days I can't go out. (Helen, 50)

### *Acceptance*

Some participants reported accepting that FP would be with them for life, although they still hoped this would not be the case:

I'm just one of the unfortunate ones, I suppose, who's probably got it for the rest of my life. There's always a chance I might wake up tomorrow and it might be gone but I'm resigned to the fact I've got it now. (Craig, 35)

### *Humour*

Some participants' believed it was their humour and optimism that had got them through the tough times:

Right from the beginning of when all this started I've always been positive you know? . . . it's never really got me down, ever, which is quite something to say now when you think what . . . what I actually went through. (Paul, 47)

It's my saving grace. If I didn't have a sense of humour I think I'd been in bits. (Katey, 53)

### *Health professional support*

Whilst there were clearly challenges in receiving medical treatment for their FP, when this was received (e.g. facial therapy, Botox, surgery), patients described both physical and psychological benefits:

I had to wait. . . but I've had two [sessions with a specialist FP physiotherapist] what a difference to me psychologically but actually, as it happens, it's also made a difference to my face. (Aran, 56)

My facial physiotherapist has been fantastic. I mean, she's . . . she has listened to me sobbing over the last couple of years and she's been so helpful and so supportive. (Kathy, 56)

Only two participants reported receiving formal psychosocial support from the NHS (counselling or a referral to a hospital support group), but expressed how beneficial this was:

Just talking to someone about the illness has absolutely helped no end. Because it's ok talking to family from time to time but, again, you don't want to burden them with your problems as such. (Craig, 35)

Many reflected on the significance of being able to talk to others living with FP. This enabled them to share experiences and feel less alone, as well as share hints and tips for the management of their FP.

I think I'd have gone completely batty if I hadn't found that [Facial Palsy UK] . . . they put me in touch with [name] he had bodily paralysis as well as facial . . . talking to him was one of the most beneficial things in that early period. (Ursula, 62)

## Discussion

In this study, we explored the psychosocial impact of living with acquired FP and gained a greater understanding of patients' experiences of treatment and care in the UK. In addition to the functional challenges reported by participants, this study has identified a number of associated psychosocial challenges.

Undoubtedly, the face plays a major role during our social interactions (Frith, 2009), and thus, it is perhaps no surprise that the inability to smile and effectively express emotion was one of the most distressing aspects of acquiring FP. The impact of this change on the participants' social interaction experiences and on how others perceived them was reported as a regular source of worry. This is not an unexpected finding, as the functional and cosmetic changes associated with FP disrupt facial communication with others. This can result in both parties feeling misunderstood during social interactions (Bogart, 2019). Further, the fear of being negatively evaluated by others reported in this study echoes the observations of people living with other appearance-altering conditions, (Kent & Keohane, 2001; Schmid-Ott, Schallmayer, & Calliess, 2007; Stock & Feragen, 2016). Participants also attributed their feelings of discomfort in social situations to FP not being widely understood by the public, including health care professionals. Concerns about being judged unfavourably due to their appearance led participants to question whether they should disclose their FP during social interactions. This dilemma has also been reported in studies of people with other appearance-altering conditions (Hamlet & Harcourt, 2020; Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2018).

Our appearance plays a crucial role in our self-concept (Moss & Carr, 2004). The loss of facial animation associated with FP not only affected how both male and female participants related to others, but how they related to themselves. Participants reported a discrepancy between how they felt on the inside and their outward appearance. Consistent with the findings of research about the experiences of other people living with an acquired facial disfigurement (see e.g. Martindale & Fisher, 2019), reflections in mirrors, photographs, and feedback from others in social situations were often an uncomfortable reminder of their 'lost' former selves. Participants also often referred to earlier identities in the third person, indicating they no longer felt able to identify with themselves before FP.

Perceptions of having self-control and autonomy have consistently been found to predict well-being in other health conditions (Benyamini, Nouman, & Alkalay, 2016; Will Crescioni et al., 2011), and in this study, resolving and managing the impact of FP and struggling to gain a semblance of control over the condition following diagnosis appeared to have consumed many of the participants' lives. They wanted to be active in the management of their FP but were frustrated at not knowing how to achieve this level of engagement. The uncertainty surrounding the likely trajectory of recovery and the unpredictability of FP symptoms combined to exacerbate the difficulties of adjusting to the condition.

The Common-Sense Model of Self-Regulation (CSM; Leventhal, Phillips, & Burns, 2016) could help explain the complexity of adjustment to FP (Pattinson et al., 2021), and patient reports of feeling 'in limbo' in this study. This model proposes that individuals are typically active problem solvers in relation to their health (Wearden & Peters, 2008).

People develop cognitive and emotional representations of their illness to interpret their experience and create action plans to manage symptoms and regulate negative emotions (Benyamini, Gozlan, & Kokia, 2004; Karekla, Karademas, & Gloster, 2019). The amount of control people perceive themselves to have over their condition is one attribute of illness representations, along with the identity attributed to the illness, beliefs about the cause of the condition, the length of time it will last, and the impact their condition has upon their lives (Cameron & Leventhal, 2003). The overall sense an individual is able to form of their illness is based on the interplay between all of these attributions (Vaughan, Morrison, & Miller, 2003). Acquiring FP may be particularly challenging because much of the information required to develop an understanding of FP cannot be accessed. For example, participants in this study did not know what caused their FP, leaving them to attribute their own cause (e.g. stress), and many described the uncertainty of the progression and duration of FP as emotionally challenging. In addition, despite desiring a sense of agency in relation to their condition, participants reported feeling they lacked control over their experience, exacerbated by the lack of knowledge amongst medical professionals about the most effective ways to manage and improve FP. One consistent attribution shared by participants was that the impacts of FP on many aspects of their lives were both detrimental and distressing.

Cross-sectional and prospective evidence suggests that the CSM can predict emotional well-being over a range of illnesses (Horne & Weinman, 2002; Law, Kelly, Huey, & Summerbell, 2002; Vaughan et al., 2003), including FP (Fu, Bundy & Sadiq, 2011). Pattinson et al., (2021) used CSM as a theoretical framework to explore patients' experiences of FP. Corroborating this study's findings, they found that patient distress could be accounted for by illness beliefs, and that patients experienced psychological distress, changes to their identity, frustration with healthcare services, and a lack of control over their FP and treatment. Future research should consider measuring the illness representations of FP and their relation to psychosocial outcomes. This could help identify targets for psychosocial support and intervention. This research should also consider the difference between individuals that have good chances of a physical recovery and those for whom FP is permanent. In the current study, those who knew their FP was permanent appeared to experience less distress and rumination than those who lived with uncertainty about the likely trajectory of the condition. This finding is supported by Bogart's (2019) study reporting those with acquired FP to be at greater risk of socioemotional problems (e.g. emotional clarity, anxiety, and depression) compared to those with congenital FP ( $n = 112$ ). Additionally, in a study with 1304 patients attending a specialist FP clinic in the USA, Tavares-Brito, van Veen, Dusseldorp, Bahmad, and Hadlock (2019) found that a longer duration of FP was associated with a higher quality of life. Taken together, these findings may suggest that time allows patients to incorporate FP into their self-concept, and adjust more successfully.

Overall, there was dissatisfaction with the provision of FP-related care within the NHS. Some participants were resentful at being left to manage the condition with little help and at not receiving adequate information about FP, its progression or treatment. Some reported being inappropriately referred for specialist treatment (e.g. to a generic not facial physiotherapist) and delays in receiving interventions in a timely manner (e.g. steroids within a 72 hour window to treat Bell's Palsy). These shortcomings resulted in some participants paying for interventions themselves (e.g. private Botox), or in them experimenting with interventions on their own. The lack of availability of treatment and care for the functional aspects of their FP resulted in significant levels of distress and rumination for many, over and above the impacts of their changed appearance. However,

participants did report positive interactions with health professionals, and those who were in receipt of specialist treatments (e.g. facial physiotherapy) reported this to be a source of reassurance and comfort, even if treatment was not 'successful'. Whilst FP presents many 'unknowns', including what the standard course of treatment should be for optimal functional and aesthetic outcomes, patients should have access to guidance and support from health professionals at a minimum. This is especially important if patients are seeking alternative treatment for their FP, as inappropriate treatment has the potential to cause further distress. Furthermore, future research should explore what influence access to treatment, care, and support has upon psychosocial outcomes in FP, also identified as a research priority amongst FP patients and health professionals in the UK (Hamlet et al., 2018).

### **Study limitations**

Whilst this research has provided valuable insights into living with acquired FP, some limitations should be acknowledged. Participants were recruited to the study via the charity Facial Palsy UK, and their attitudes, knowledge, and experience may therefore differ to those who are not on the charity's circulation list (e.g. in relation to their levels of distress and in the degree of medical support received). Additionally, all of the interviews were conducted over the phone, and whilst this appeared to be a positive experience for interviewees and the researcher, it limited access to some aspects of non-verbal cues and communication that may have embellished the interviews (Novick, 2008). Despite no gender differences in the incidence of Bell's Palsy in the UK (Rowlands et al., 2002), the sample of participants with Bell's Palsy in this study ( $n = 6$ , 60%) was predominantly female ( $n = 5$ , 83%). The male perspective was therefore underrepresented – a common limitation of visible difference research (Egan et al., 2011; Sharratt et al., 2018; Zucchelli et al., 2020). Further, access to and provision of FP care and treatment varies around the UK (Jing et al., 2014; Kilshaw et al., 2016), and half the sample lived in the South East of England. Additionally, there was often confusion amongst participants about the professional background and specific specialism of the health professionals they had met. Furthermore, the time since the participants' onset of FP ranged from 0 to 42 years, so although participants all had experience of FP, the availability of treatment and support may have changed over time, and time may also have affected the recall of experiences. Therefore, whilst there appears to be a need for clearer referral pathways to significantly improve access to care and treatment for those with FP across both primary and secondary care, in addition to psychosocial support and shared treatment decision-making, caution should be paid to generalising the negative experiences reported in this study to all services, medical professionals, and areas of the UK. Indeed, those services providing a high level of multidisciplinary support for those with FP should be encouraged to share their treatment models with others.

### **Clinical implications**

This study confirms that FP is a medically and psychosocially complex condition for both males and females and suggests that patients want and may benefit from increased access to psychosocial support, regardless of whether their FP is temporary or permanent. Indeed, along with previous research (Hotton et al., 2020; Pattinson et al., 2021) the findings of this study highlight the importance of routinely screening FP patients for psychological distress and a clear need for the availability of psychological support

amongst the services offered. Specific psychosocial interventions to tackle the challenges experienced by people with FP have yet to be developed. Cognitive behavioural therapy (CBT) appears to be the most widely adopted therapeutic model for those with other forms of visible difference (Bessell and Moss, 2007). Social interactions were a significant source of anxiety for participants; therefore, social skills and cognitive behavioural techniques could help people with FP to develop alternative ways of expressing themselves (e.g. via body language), together with strategies for explaining their condition and managing negative unwanted attention. However, given that one's appearance and the initial reactions of others are beyond the control of the affected person, there is increasing evidence to suggest Acceptance and Commitment Therapy (ACT), which aims to reduce the behavioural impact of difficult thoughts and feelings rather than challenge them, may be more appropriate for those with a visible difference (Zucchelli, Donnelly, Williamson, & Hooper, 2018). The goal of ACT is to develop psychological flexibility, which refers to the capacity to stay in contact with the present moment, regardless of unpleasant thoughts, feelings, and bodily sensations, and to direct behaviours in accordance with personally held values (Hayes, Luoma, Bond, Masudam, & Lillis, 2006). Whilst the preference would be for such interventions to be delivered by a Clinical Psychologist with specialist knowledge of FP, given the patchy nature of current service provision, the development of targeted self-guided interventions may be beneficial. Internet-administered CBT has been demonstrated as effective for managing distress for adults and young people with a visible difference (Bessell, Gozlan, & Kokia, 2012; Williamson et al., 2019), and in other health conditions such as cancer, chronic pain, and irritable bowel syndrome (Andersson et al., 2011; Beatty, Koczwara, & Wade, 2016; Cuijpers, Van Straten, & Andersson, 2008). However, such interventions will need to be tailored to the specific difficulties faced by those with FP. Additionally, as participants reported how valuable peer support was, clinicians should consider referring patients to peer support groups, such as those offered by Facial Palsy UK.

Corroborating other reports (Jing et al., 2014; Kilshaw et al., 2016; Pattinson et al., 2021), this study indicates that many UK FP patients have inadequate access to specialist services. As well as education and training for health professionals on the functional and psychosocial impacts of FP, there is pressing need to review how FP is managed at a national level. The National Institute for Health and Care Excellence has written guidance for Bell's Palsy (2019), but this focuses on the management of patients in primary care settings, and this study indicates that significant gaps in care remain. Guidance is clearly needed to improve care for people with unresolvable FP and FP due to causes other than Bell's Palsy. Clear treatment guidance, referral pathways, and holistic standards of care will enable health professionals to manage FP and could empower patients by clarifying what care and treatments might be helpful.

## **Conclusion**

Facial palsy is a condition associated with a myriad of functional and psychosocial challenges. This study demonstrates how disruptive FP can be to key aspects of the psychosocial well-being of those affected, including their sense of identity and several aspects of daily functioning, including inter-personal communication and social functioning. In addition, it has highlighted inequalities in the provision of specialist care and a lack of coordination in the care patients currently receive. The study lends further weight to calls to improve care for people with FP in future.

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## Conflict of interest

All authors declare no conflict of interest.

## Author contributions

Claire Hamlet, DHealthPsy (Conceptualization; Formal analysis; Funding acquisition; Project administration; Writing – original draft; Writing – review & editing) Heidi Williamson (Funding acquisition; Supervision; Validation; Writing – review & editing) Matthew Hotton (Validation; Writing – review & editing) Nichola Rumsey (Funding acquisition; Writing – review & editing).

## Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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### Supporting Information

The following supporting information may be found in the online edition of the article:

**Appendix S1** Interview schedule.