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ARTICLE HEAD AND NECK

Exploring patient values and perceptions with facial nerve palsy to help guide management: a qualitative study

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Abstract

Background: Facial nerve palsy (FNP) leads to a combination of aesthetic and functional deficits with profound psychosocial consequences. Significant advances have been made in restoring dynamic function through a range of facial reanimation solutions. Patient-reported severity scales are predetermined metrics that provide limited insight into patient values and perceptions. A qualitative study was conducted to elicit the experiences of patients with FNP and explore their views and motivations for seeking therapy.

Methods: Participants were sourced from the Sydney Head and Neck Cancer Institute Database, Australia. Eligibility for the study included age over 18 years and a diagnosis of complete FNP. Semi-structured interviews were conducted and the transcripts were subjected to thematic text analysis.

Results: Nineteen patients consented to participate in the study. One was excluded due to an isolated marginal mandibular nerve palsy. Five main themes emerged: eye symptoms, fear of judgement and social withdrawal, aversion to further invasive surgeries, the need for multidisciplinary streamlined care and lack of public awareness.

Conclusion: Eye symptoms and the social consequences of FNP carry significant impact on both personal and professional lives. There is a paucity of services that can support patients across the complex spectrum of problems seen in FNP.

Introduction

Facial nerve palsy (FNP) leads to a combination of aesthetic and functional deficits with profound psychosocial consequences. The dysfunctional facial mimetic muscles create facial asymmetry, which is often more apparent during voluntary and spontaneous movement. Lack of movement also impairs non-verbal communication and expression of emotions.[1] This causes patients with FNP to be perceived as less attractive and

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trustworthy compared to people with normal facial nerve function.[2,3] Patients also experience difficulty with oral competence, nasal obstruction, corneal keratopathy from lack of blinking and impairment of speech.[4,5] In the absence of intervention, the symptoms may be progressive as tissue laxity increases over time and/or the patient develops synkinesis where abnormal co-contraction of muscles occurs during facial movement.[6]

Significant advances have been made in restoring dynamic function through a range of reanimation solutions.[7] Numerous clinician-based evaluation tools have been implemented to assess the severity of FNP and effectiveness of these interventions. The Facial Disability Index (FDI) and Facial Clinimetric Evaluation (FACE) scale are the two commonly used patient-reported outcome measures.[8,9] They provide a global measure of the psychosocial burden of disease but fail to guide clinicians regarding which regions of the face require intervention. Patients attach different values to specific impairments and therefore their motivation for having each of these addressed may not be the same. In oncological cases where reanimation may immediately follow facial nerve sacrifice, the patient's ability to choose treatment depends on the clinician describing the anticipated deficit without fully realising patient values and motivations. Finally, both scales provide assessment of the patient's social and emotional wellbeing limited to a brief period in time without capturing the evolution of patient experience. Past experiences can inform future choices and skew attitudes towards therapy and hence its uptake.

The benefits of new therapeutic interventions aimed at improving patient quality of life must ultimately be measured against patient values. Therapy success is dependent on patients' willingness to receive it. This becomes particularly important in the context of implantable bionics where realising the value proposition for a therapeutic device is critical to its uptake by the patient and stakeholders in the provision of the service.[10,11] Studies already exist that attempt to evaluate patient perception of their illness with FNP and its treatment; however, this is done with tools used outside the clinical practice of, and not validated for, FNP.[12] While other studies have explored patient views and values outside the use of any clinical tool, they are limited to the impairments caused by FNP and its psychosocial consequences.[13,14] The aim of this study was to elicit the experiences of patients with FNP and explore their views and motivations for seeking therapy.

Methods

Participants

This study was approved by the Sydney Local Health District Human Research Ethics Committee (X19-0288 and 2019/ETH00637). Eligibility for the study included age over 18 years and a diagnosis of complete FNP. Participants were selected to ensure a range of FNP aetiology, duration, sex and ages were represented. Participants were sourced from the Sydney Head and Neck Cancer Institute Database, which includes participants referred to the Sydney Facial Nerve Service, Sydney, NSW, Australia. Participants provided informed consent and agreed for their contact details to be shared with a member of the research team, who then contacted them to schedule a 30-minute telephone interview.

Measures

Patient demographics were collected specific to the aims of this study, which included information on age, sex, occupation, type and aetiology of FNP, and the treatment received. This study draws on phenomenology as a theoretical orientation and research methodology. Phenomenology is concerned with the 'essence of consciousness as experienced from the first-person point of view' and, as such, aims to provide accounts that offer an insight into the subjective 'lived' experience of individuals.[15] A semi-structured interview was conducted, which broadly explored patient experience of FNP and their views on the treatment(s) received to date. For an inductive analysis, the interview was encoded after its collection rather than limiting it to specific hypotheses or predefined notions. A non-directive style of interview was thus adopted. In order to maintain the interview agenda, however, prompt questions were used (**Table 1**). These questions served as triggers for participants to talk. Interviews were conducted between October and December 2019 by SH. They were audio recorded and subsequently transcribed.

Table 1. Prompt questions

What has been your experience of facial paralysis?
What aspect(s) of the paralysis has been most difficult to deal with and why?
How have you managed to help the situation?
Are you satisfied with the help you have received so far?

Analysis

Transcripts of the interviews were subjected to thematic text analysis with an inductive data drive approach. The five phases of thematic analysis described by Braun and Clarke were adopted.[16] In the initial phase, the interview data was actively read for familiarity and searching patterns. Next, the data was organised by production of codes, which identified features in the data related to patients' main concerns about FNP and its treatment. In the following phase the codes were analysed to then combine under an overarching theme. Data within the candidate themes were then reviewed again to ensure they cohered together meaningfully and that there was clear and identifiable distinction between themes. Finally, the themes were defined and named so that the latter gave the reader a sense of what the theme is about. Prevalence of a theme was measured in terms of the number of different participants who articulated them. A theme was only selected for further discussion if it reached a prevalence beyond 25 per cent. Three investigators (SH, JC, HL) read the transcripts independently and collectively discussed the emerging themes. Differences were resolved by consensus.

Results

Participant demographics and clinical details are summarised in **Table 2**. Of the 29 participants approached, 19 consented to participate in the study and one was excluded because they had an isolated marginal mandibular nerve palsy. Of the remaining 18, five had Bell's palsy and the remaining 13 cancerous/non-cancerous tumours as their FNP aetiology. **Table 3** lists the prevalence of issues identified by the participants. Five main themes emerged: eye symptoms, fear of judgement and social withdrawal, aversion to further invasive surgeries, the need for multidisciplinary streamlined care and lack of public awareness. Representative data extracts under each theme are listed in **Tables 4–8**.

Eye symptoms

Number of participants: 16/18

Almost all the participants reported eye symptoms from incomplete closure of the affected eye (**Table 4**). They included 80 per cent (4/5) of participants with Bell's palsy and 92 per cent (12/13) of participants with tumour aetiology. Six reported

Table 2. Patient demographics

No.	Sex	Age	Occupation	FNP aetiology	Palsy duration (years)	Main concern
1	F	42	Marketing	Tumour	1.0	Smile
2	F	44	Unemployed	Tumour	3.0	Smile
3	F	45	Unemployed	Tumour	8.0	Smile
4	M	24	Student	Tumour	6.0	Eye
5	M	59	Teacher	Tumour	2.0	Smile
6	M	45	Disability nurse	Bell's palsy	5.0	Smile
7	F	49	Cancer care	Tumour	26.0	Smile
8	F	62	Retired	Tumour	4.0	Eye
9	F	34	Accountant	Tumour	5.0	Eye
10	M	24	Student	Tumour	2.0	Eye
11	F	48	Accountant	Bell's palsy	4.0	Smile
12	M	68	Retired	Tumour	3.0	Eye
13	F	53	Office work	Tumour	3.0	Non-specified
14	M	61	Unemployed	Tumour	10.0	Smile
15	F	74	Retired	Bell's palsy	1.5	Eye
16	F	24	Orthoptist	Tumour	8.0	Smile
17	F	58	Air hostess	Bell's palsy	1.5	Non-specified
18	F	45	Unemployed	Bell's palsy	16.0	Non-specified

Table 3. Themes identified

No.	Theme	No. of patients
1	Eye symptoms	16
2	Fear of judgement and social withdrawal	15
3	Aversion to further invasive surgeries	9
4	Need for multi-disciplinary streamlined care	7
5	Lack of awareness	5
6	Supportive company is empowering	4
7	Alternative medicine	4
8	Seeking new technology	3
9	Mental health problems	3 (PTSD 1, depression 2)
10	Problems with synkinesis	2
11	Problems with communication	1
12	Eating problem	1

MDT = multidisciplinary team; PTSD = post-traumatic stress disorder

this bothered them more than the social stigma they faced. Ocular problems were associated with a high maintenance care regimen. Executing simple daily activities became a challenge or were totally avoided as participants 'could not go out when windy' or would get a 'red eye with showering'. Senior participants described struggling with the care regimen or were dependent on a second person for its application, leading to 'eye drops all over their face'.

Table 4. Representative statements—eye symptoms

Percentage reporting: 89% (16/18)	
Participant 8	'My eye is irritated all the time and I have to use drops 4 or 5 times a day … I cannot swim anymore because my eye starts irritating. I cannot go out when its windy.'
Participant 16	'Initially I had to tape the eye regularly. I now use eyes drops 3 to 4 times a day maybe. But I have had to stop driving and playing sports. The air dries my eye very quickly.'

Fear of judgement and social withdrawal

Number of participants: 15/18

The majority of participants described significant disruption to their professional and personal lives, which included 80 per cent (4/5) of participants with Bell's palsy and 85 per cent (11/13) of participants with tumour aetiology. They felt a heightened awareness and fear of judgement from the people around them, leading to social isolation (**Table 5**). Of the 11 participants who were in the workforce or studying, all of them either resigned or took a prolonged break from their professional activities. Most identified 'difficulty meeting new people' because of the way they 'looked'. They avoided important social events as they 'panicked when someone took photos'. Parents described a sense of guilt for the resulting loss of family relationships.

Table 5. Representative statements—fear of judgement and social withdrawal

Percentage reporting: 83% (15/18)	
Participant 6	'Staff meetings were challenging. Instead of focussing on what I was saying I was focussed on what their reaction was to my face … I stopped working for some time.'
Participant 7	'I still get asked, did you have a stroke? People react curiously. I feel like it's too personal to be asking those kinds of questions from me. I get judged online if I put a photo up. I have been single for a long time now.'

Aversion to further invasive surgeries

Number of participants: 9/18

Despite the social consequences of facial disfigurement and a morbid eye, participants with an existing history of surgery were averse to further invasive surgeries (**Table 6**). Forty per cent (2/5) of participants with Bell's palsy and 54 per cent (7/13) of those with tumour aetiology fell into this group. Participants often expressed a strong desire to 'try anything to have their smile fixed' yet they would 'not want to try anything invasive'. Senior participants who had ablative surgery for a diagnosis of cancer were 'not wanting any more surgeries' to their face. However, they were open to the possibility of having a solution 'if it was

something simple' with nine out of 13 participants with cancer having received lid loading.

Table 6. Representative statements—aversion to further invasive surgeries

Percentage reporting: 50% (9/18)	
Participant 8	'I am 63 now and I don't want any more surgeries to my face.'
Participant 12	'I have had two surgeries in total and I am not keen on any more surgery. But if it was something simple then maybe yes, I would go for it.'

Need for multidisciplinary streamlined care

Number of participants: 7/18

Several participants identified lack of access to appropriate counselling and treatment as an added stressor (**Table** 7). While 80 per cent (4/5) of participants with Bell's palsy identified this problem, only 23 per cent (3/13) of those with tumour aetiology reported it. Participants did 'not know where to get help' and the 'uncertainty of what the cause of their problem (was) and what the outcome (would) be' became a problem itself. A range of healthcare professionals were involved in participant care but the participants poorly understood their roles. As a result, participants were 'searching on social media' and joining online support groups. One participant 'ended up having facial palsy for eight months before any surgery'. Participants appreciated a centralised and a standardised service to reduce the psychological impact of the disease. One described feeling 'confident when attending the Sydney Facial Nerve Clinic' as she felt the 'staff knew what they were doing and were the right people to help her'.

Table 7. Representative statements—need for multidisciplinary streamlined care

Percentage reporting: 39% (7/18)	
Participant 6	'The worst part of it all was that nobody knew the cause of my facial palsy and they couldn't offer me proper treatment.'
Participant 12	'The GP thought its Bell's palsy. My wife and I weren't convinced, so we did our own research. At the end I ended up having the facial palsy for eight months before having any surgery.'

Lack of awareness

Number of participants: 5/18

Several participants found themselves unprepared for the consequences of FNP and felt overwhelmed by the experience (**Table 8**). They included 20 per cent (1/5) of participants with Bell's palsy and 31 per cent (4/13) of those with tumour aetiology. Participants described a significant psychological impact as they 'did not appreciate how bad facial nerve palsy could be'. They were 'terrified' by their new appearance and the whole experience came as a 'shock', requiring a psychologist in one case. This was more common in FNP as a consequence of cancer surgery.

Table 8. Representative statements—lack of awareness

Percentage of participants reporting: 28% (5/18)	
Participant 5	'The worst part of the whole experience was not appreciating how bad facial nerve palsy could be.'
Participant 8	'I'm still terrified of looking into the mirror. I couldn't handle looking at myself at the beginning because I thought I looked hideous.'

Discussion

In the clinical setting there is no standardised method of evaluating patient expectations and motivation when selecting patients for treatment. Patient-reported severity scales based on predetermined metrics are useful because they provide insight into patient values and perceptions, albeit limited. This analysis of attitudes and experiences of patients with FNP corroborates the existing body of literature on the emotional and psychosocial impact of FNP.[13,14] It also however provides an insight into patients' perception of care and some gaps therein.

Participants described a disfiguring and a highly symptomatic illness that inflicted a heavy loss of social capital with disruption to both their personal and professional lives. Yet they generally declined further invasive surgeries to address their problems, coming from a position of experiencing delayed care and lack of information. The experience was largely common to participants in both Bell's palsy and tumour aetiology categories. Absence of a standardised care strategy for managing FNP sequalae furthered the psychological burden of disease and its associated disabilities. However, the perception of disability was reversible with restoration of self-image through the return of normal facial mimetic function. We feel that a collaborative effort of a multidisciplinary team and care coordination in conjunction with the benefits of novel reconstructive strategies may see the return of productivity and improve quality of life.

Facial disfigurement can create disability by leaving patients feeling disempowered in social spheres of life as they succumb to the fear of being viewed negatively by the people around them. Hamour and colleagues identified social anxiety and problems with self-confidence as the second most common outcome affecting patient quality of life.[14] There is growing evidence to show that patients with FNP are perceived as less attractive, less trustworthy and less intelligent.[3] In the present study, patients felt compelled to leave their professional duties (11 out of 11). In a group of 106 hemi-facial palsy patients interviewed by Bradbury and Sanders, nearly 90 per cent of the group reported intrusive questions by acquaintances and strangers, with more than half the group distressed by such questions.[17] The reduced self-esteem led patients to adjust their roles accordingly. This was quite telling in some cases where the participants changed professions to palliative care or work in disability centres to create some sense of belonging. It is known that people adjust their values to accommodate their disability, thereby limiting the negative effect on their quality of life.[18] Participants described great anxiety and fear of being seen or photographed that led them to avoid important social events. Bradbury and Sanders found that patients' primary motivation for corrective surgery was appearance rather than function.[17] Thus, social inhibition in patients with FNP is likely self-imposed and productivity can potentially be restored through aesthetic strategies, including reconstructive surgery.[17]

Lack of eyelid function was the most frequent complaint and identified as the second most concerning aspect of FNP, second to smile. Other authors have identified eye problems as the most frequent domain of concern for the patient.[14] The complaints mostly centred around symptoms, rather than cosmesis, which was associated with a high maintenance care regimen. Accordingly, ocular problems were not limited to social settings. Symptoms such as irritation or watery eye rendered daily activities challenging such as driving a car or showering. Relief practices, including patching the eye or using eye drops, which in themselves were seen as cumbersome and challenging, particularly for elderly patients with poor dexterity. One senior participant 'seriously considered taking (her) eyeball out' for unrelenting symptoms. Reduced field of vision and disfiguration from tarsorrhaphy were therefore seen as acceptable by some. Participants were also generally pleased by the relief offered by lid loading. Participants had procedures for eye problems more frequently than for any other area of FNP. The difference may be partly due to access to simple and immediate solutions, such as lid loading and tarsorrhaphy.

Participants in this study were generally reluctant to have surgery despite complaining of a very disabling condition. The elderly and those with a history of oncological resection were particularly resistant to further corrective surgeries. A 63-year-old female with acquired FNP from ablative surgery 'mourned' her normal look and suffered from an 'irritated eye all the time' yet she did 'not want any more surgeries to (her) face'. Patient motivation for corrective surgery may not correlate with disease severity. Wang and colleagues described this concept on a continuum where facial asymmetry is increasingly perceived until a threshold where perceptive discrimination is lost again for further asymmetry.[19] In a group of 348 observers who viewed FNP images, Su and colleagues demonstrated that willingness to pay to have their asymmetry corrected increased non-linearly with increasing severity of palsy.[20] These results indicate that ordinal grading tools do not necessarily inform patient value. Surgery is associated with pain, tissue damage and scaring, which naturally make many patients averse. A prior history of ablative surgery on the face is also associated with negative memories. The experience of FNP in some participants was overshadowed by the preoccupation with cancer. Minimising the number of reconstructive surgeries to a single-stage procedure may see patients more accepting.

Facial nerve palsy was most consequential at its onset. Patients face a rapid transition to their new appearance, particularly in Bell's palsy or traumatic cases. In addition to palsy, defects from ablative surgery add to the disfiguration, making it an even more difficult experience. In a group of 88 patients with FNP, Nellis and colleagues identified depression in 42 per cent.[21] In most cases, participants sought medical attention immediately and felt 'shocked' about 'how bad facial nerve palsy could be'. Being unprepared for the effects of FNP as it unfolded acutely led to the greatest disability and loss of productivity at onset when its psychological impact was most profound. Preparing patients is challenging when subjective experience forms the outcome. While immediate dynamic reanimation may avert some negative consequences, patients would have no prior experience to help them make such a decision. Accordingly, it was not surprising that more participants with tumour (versus idiopathic) aetiology were overwhelmed by FNP

despite the former being more prepared through preoperative counselling.

The paucity of coordinated care saw many participants follow a tortuous journey to receiving treatment. This experience was far less common in those with tumour aetiology compared to those with Bell's palsy, possibly because the former is more likely to be managed in a multidisciplinary setting. Participants suffered an added psychological burden as the lack of access creates feelings of a permanent and incurable disease. Significant association is found between participants' perception of consequences and the level of distress.[12] Absence of effective treatment led some participants to alternative solutions such as acupuncture, which may delay timely therapy. The diversity of aetiologies and spectrum of sequelae means that FNP cannot be effectively managed by a single physician. This challenge lends itself to a multidisciplinary team that can support patient needs in a single unit where patients can receive diagnostic workup, treatment of the underlying aetiology, reconstruction and rehabilitation in addition to allied health support. Hayler and colleagues highlighted the experience of managing FNP through a dedicated multidisciplinary clinic where just over a third of patients were recommended surgery, and a range of non-surgical options were offered to the rest including physiotherapy and Botox injection.[22] Provision of care can further be streamlined by increasing awareness about FNP management within the healthcare system and dissemination of guidelines. As new treatment paradigms evolve, such as novel reconstructive approaches and implantable bionics, understanding their appropriate role becomes more and more challenging. It is thus the authors' opinion that FNP is best governed by a team of dedicated clinicians with access to holistic alternatives to invasive surgery.

Limitations

This study has several limitations. The retrospective recollection of participants may differ with real-time experience.[13] Some biases may affect the validity of results, such as selecting participants from a single database and the small number of participants. However, only themes common among the study population were selected. Further, as Braun and Clarke point out, qualitative research tends to use far smaller sample sizes compared to, for example, questionnaire data, since the review process is quite time consuming.[16] The qualitative nature of the study inherently lends itself to reporting biases which were minimised by seeking the consensus of three different authors on result interpretation. Irrespective of the biases, however, studies of this nature are open-ended and difficult to replicate. Even with more representative and larger sample sizes, the findings may never be verified objectively. Unique to FNP is that the burden of disease is largely subject to patient experience of its sequelae and hence studies of this nature become necessary for a complete measure and to highlight the role of interventions which can then be investigated for causality in qualitative research.

Conclusion

Existing instruments do not capture patient perception or values with FNP, which is central to patient care. This qualitative study affirms the social penalty of facial disfigurement experienced by patients with FNP. In conjunction with eye symptoms, FNP carries significant impact on patients' personal and professional lives. There is a need for dedicated services that can support patients across the spectrum of problems seen in FNP and help empower them in seeking benefit from a range of rehabilitative and reconstructive solutions.

Patient consent

Patients/guardians have given informed consent to the publication of images and/or data.

Conflict of interest

The authors have no conflicts of interest to disclose.

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