

## **Exploring Beliefs and Distress in Patients with Facial Palsies**

An Explorative Study into the Beliefs Held by Patients with Facial Palsies and How These Drive Levels of Distress.

Author list: R Pattinson MSc, H M Poole PhD. AFBPS. C Psychol, O Shorthouse BSc. MBChB. MRCPsych, S A Sadiq MBBS DO MRCOphth FRCS FRCOphth DM, C Bundy PhD. AFBPS. C Psychol

### **Corresponding author:**

Professor Christine Bundy PhD. AFBPS. C Psychol

School of Healthcare Sciences, College of Biomedical Sciences, Cardiff University, Cardiff, UK.

Address: 13.7 Eastgate House, 35-43 Newport Road, Cardiff. CF24 0AB.

Telephone: +44 (0)29 206 87842

Email: [bundyec@cardiff.ac.uk](mailto:bundyec@cardiff.ac.uk)

### **Other author details:**

Rachael Pattinson: School of Healthcare Sciences, College of Biomedical Sciences, Cardiff University, Cardiff, UK. **Address:** 13.18 Eastgate House, 35-43 Newport Road, Cardiff. CF24 0AB. **Telephone:** +44 (0)29 225 10732. **Email:** [pattinsonr@cardiff.ac.uk](mailto:pattinsonr@cardiff.ac.uk)

Dr Helen Poole: School of Psychology, Faculty of Health, Liverpool John Moores University, Liverpool, UK. **Address:** 3.21 Tom Reilly Building, Liverpool John Moores University, Byrom Street, Liverpool, L3 3AF. **Telephone:** +44 (0)151 904 6307. **Email:** [H.M.Poole@ljmu.ac.uk](mailto:H.M.Poole@ljmu.ac.uk)

Dr Oliver Shorthouse: Greater Manchester Mental Health Trust. **Address:** Greater Manchester Mental Health NHS Foundation Trust, Bury New Road, Prestwich, Manchester, M25 3BL. **Telephone:** +44 (0)161 773 9121. **Email:** [oliver.shorthouse@doctors.org.uk](mailto:oliver.shorthouse@doctors.org.uk)

Professor S Ahmed Sadiq: School of Psychology, Faculty of Health, Liverpool John Moores University, Liverpool, UK; Manchester Royal Eye Hospital, Manchester, UK. **Address:** Manchester Royal Eye Hospital, Manchester, M13 9WH, United Kingdom. **Telephone:** +44(0) 161 276 5561. **E-mail:** [a.sadiq@manchester.ac.uk](mailto:a.sadiq@manchester.ac.uk)

**Ethics Approval:** Ethics approval was provided by National Research Ethics Service Committee North West – Lancaster (11/NW/0103)

## **Abstract**

Facial palsy results in altered appearance which can have physical, psychological, and social consequences for patients. Clinicians typically focus on the physical and functional aspects of the condition. Evidence suggests that people with facial palsy may experience higher levels of distress, but the reasons for this distress are yet to be explored. The aim of this study was to explore people's illness beliefs, emotions, and behaviours in relation to their facial palsy and understand how distress is experienced in this patient group. Semi-structured individual interviews were conducted in the UK with adults with facial palsy. Interview questions were theoretically informed by the Common-Sense Self-Regulatory Model (CS-SRM). Thematic Analysis was conducted following a combined inductive and deductive approach to explore pre-determined CS-SRM components and identify additional emergent themes. Twenty people with facial palsy participated (70% female; aged 29-84). Patient distress was accounted for by illness beliefs (symptoms, cause, control and treatment, timeline and consequences), and four additional themes (coping behaviours, social support, identity and health service provision). Experiences of anxiety, depression, and anger were widespread, and some participants experienced suicidal ideation. The burden of managing a long-term condition, altered self-perception, and social anxiety and isolation were key drivers of distress. We believe there is a need for more integrated psychological support for patients with facial palsy. Within clinical consultations, patient's beliefs about facial palsy should be identified and systematically addressed plus service development should include appropriate referral to specialist psychological support via an established care pathway. A new patient-reported outcome measure of distress in this population could facilitate discussions about distress and screen for those needing psychological intervention.

## **Keywords**

Facial palsy; Common-Sense Self-Regulatory Model; illness beliefs; distress; coping; qualitative; thematic analysis; altered appearance.

## Introduction

Facial palsy arises from paralysis of the cranial nerve VII resulting from cerebrovascular disease, intracranial tumours, Lyme disease or facial nerve damage following surgical removal of an acoustic neuroma. It can be debilitating both physically and psychologically (Cross, Sheard, Garrud, Nikolopoulos, & O'Donoghue, 2000). Appearance is of fundamental significance to individuality (Bull & Rumsey, 1988) and any unplanned alteration can have profound implications for self-esteem, relationship building (Cole, 2001) and well-being (Partridge, 1998). There is now a body of research into altered facial appearance indicating distress in people across a range of conditions including: neck and head cancer (Hagedoorn & Molleman, 2006), Grave's ophthalmopathy (Farid et al., 2005), disfiguring eye conditions (Clarke, Rumsey, Collin, & Wyn-Williams, 2003), cleft lip or cleft palate (Cochrane & Slade, 1999), facial burns (Van Loey & Van Son, 2003), facial lacerations (Tebble, Adams, Thomas, & Price, 2006), vitiligo (Porter, Beuf, Lerner, & Nordlund, 1987), severe acne (Fried & Wechsler, 2006) and facial psoriasis (Fortune, Richards, Griffiths, & Main, 2002). Macgregor (1990) highlighted the impact of altered facial appearance on social interactions (i.e. unwanted staring, whispering, ridicule, pity, perceived hostility from other people, invasion of privacy and loss of anonymity), and the subsequent psychological impact, including depression (Valente, 2004), social withdrawal (Clarke, 1999), social phobia, and agoraphobic anxieties (Newell & Marks, 2000).

Less is known about the impact of facial palsy specifically, although some studies show notable psychological and social problems (Fu, Bundy, & Sadiq, 2012; Huang et al., 2012; Walker, Hallam, Ni Mhurchadha, McCabe, & Nduka, 2012). Jørgensen and Pedersen (1994) contend that total facial paresis causes psycho-social problems for almost all patients and Byrne (2004) estimates depression symptoms could be as high as 65%. Fu et al. (2012) found higher levels of anxiety (17.9%) and depression (23.1%) in patients with facial palsy compared to the general population, with significant associations between participants' beliefs about illness and their level of distress.

The higher levels of distress experienced by patients with facial palsy may be partly explained by functional and social consequences. This includes difficulty eating and drinking which may lead to self-consciousness (E. T. Bradbury, Simons, & Sanders, 2006); a dry eye with an inability to blink possibly resulting in corneal damage and subsequent inability to

express emotion such as tearing with emotion (E. T. Bradbury et al., 2006; Neary, Stephens, Ramsden, & Evans, 2006; Rahman & Sadiq, 2007) and diminished or altered facial expression which can affect communication and lead to embarrassment and feelings of isolation (E. T. Bradbury et al., 2006; Keillor, Barrett, Crucian, Kortenkamp, & Heilman, 2002; Stuart & Byrne, 2004). The embarrassment caused by these issues can result in lowered self-confidence, social anxiety and avoidance behaviours (Andersson, 1999; Coulson, O'Dwyer, Adams, & Croxson, 2004; Neary et al., 2006; Neely & Neufeld, 1996).

Despite this growing literature, most clinicians focus mainly on the physical and functional aspects of facial palsy with little consideration of the psychological and social issues arising. Smith, Mountain, and Murray (1994) assert that psychological and social problems are underestimated by clinicians. Patients can still experience significantly high levels of psychosocial distress despite a good technical facial nerve result (E. T. Bradbury et al., 2006). Moreover, Mei, Gao, and Chen (2010) argue that an individual's psychosocial adjustment to the facial impairment is a key indicator of overall recovery (E. T. Bradbury et al., 2006; VanSwearingen, Cohn, Turnbull, Mrzai, & Johnson, 1998).

Much of the previous research has been primarily concerned with measuring distress in facial palsy but has not considered in detail the drivers of distress. Fu et al. (2012) found significant associations between patients' illness perceptions and their levels of distress using the Illness Perception Questionnaire Revised (IPQ-R)(Hill, 2010) which has been developed to test the Common-Sense Self-Regulatory model (CR-SRM)(Leventhal & Steele, 1984). This model is used to explore important patient beliefs across a range of illnesses, and to develop psychological interventions (Fortune, Richards, Griffiths, & Main, 2004; Fortune et al., 2002). Key beliefs about a health threat regarding the cause, identity, timeline, curability/controllability, and consequences of health threats (i.e. facial palsy), generate affective responses and inform behaviours to counter that threat (Leventhal & Steele, 1984).

This paper is the first to attempt to understand the significance of individuals' beliefs about facial palsy and how they impact on their psychological health. The main research question is: What psychological factors are associated with distress in patients with facial palsy? The main aim is to identify key beliefs about illness and how distress is experienced in this patient group.

## **Materials and methods**

### ***Design***

This qualitative study used semi-structured interviews to capture data and its subsequent thematic analysis (Braun & Clarke, 2006).

### ***Participants***

Following ethical approval (NRES North West Reference 11/NW/0103), patients were recruited from a specialist tertiary facial function clinic if they met the following criteria: 1) a diagnosis of facial palsy; 2) an adequate level of English to participate in interview fully; and 3) a diagnosis of facial palsy for longer than six months. Patients below 18, those who had a previously diagnosed psychiatric illness, or currently receiving treatment for a psychiatric or psychological problem were excluded. Purposive sampling guided recruitment to ensure that demographically diverse participants were included to capture a range of views and experiences (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998). Recruitment continued until thematic saturation of the data was achieved. Twenty people (14 female and 6 male), mean age 55 ( $SD = 15.7$ , 29 – 84) with diverse ethnic origins, ages and religious beliefs, with non-remitting Bell's palsy and facial palsy following surgical removal of acoustic neuroma were included.

### ***Data collection & analysis***

Individual interviews used a topic guide comprising open questions and directive prompts informed by, but not confined to, the CS-SRM. The topic guide (Appendix A) was flexible enough to allow for conversation regarding issues that may have indirect effects (e.g. comorbidity) upon participants' facial palsy-related distress. Interviews were audio-recorded at private consulting rooms at the specialist tertiary facial function clinic and lasted between 20-52 minutes. Audio recordings were transcribed verbatim and anonymised.

Data were analysed using Thematic Analysis (Braun & Clarke, 2006) with a combined inductive and deductive approach in sequential stages enabling exploration of both predetermined and emergent issues (Gale et al., 2013). Stage one involved coding the data

according to the predetermined CR-SRM components (i.e. belief about the cause, identity, timeline, consequences, controllability/curability, emotional responses). Data that did not fit into the predetermined categories were noted as additional ideas. Three team members compared their analysis of a sample (n=3) of the transcripts to assess the level of agreement before analysing the data separately. Stage two consisted of inductive identification of overarching themes and sub-ordinate categories to illustrate patterns across the dataset. This analytic process resulted in a thematic framework incorporating key concepts and themes.

## **Results**

### ***Key Themes***

Seven themes are presented: six of the predetermined components from the CS-SRM (cause, identity, timeline, consequences, controllability/curability, and emotional responses) and ‘other’ themes which emerged outwith the model.

#### ***Key Theme 1: Symptoms***

Participants’ understanding of their facial palsy symptoms was consistent with a unidimensional biomedical model of the condition. Participants primarily reported their physical symptoms - facial paralysis, tinnitus, loss of balance, eye ulcers, loss of hearing, loss of sensation and weakened facial muscles - and the subsequent impact on function. Reported separately and secondary were pain and sleep disturbance. Some symptoms had a bidirectional link with emotions.

[Table 1 near here]

#### ***Key Theme 2: Cause***

Causal representations were also mostly consistent with a unidimensional biomedical model of the conditions possibly complicated by limited understanding of the condition. Some participants viewed facial palsy as a symptom of another condition, notably acoustic neuroma, rather than a condition itself. Participants varied in their certainty of the cause.

Those certain of the cause cited medical or psychological causes, including surgery, tumours, cysts and swollen glands, and were typically explicitly identified by a clinician. Patients who had not undergone surgery reported stress as a cause due to its proximity to onset. Those who were less certain of the cause attributed it to a virus (due to proximity to onset of facial palsy), chance or destiny.

[Table 2 near here]

### ***Key Theme 3: Control & Treatment***

Many participants held passive beliefs about control of the condition and treatment choices. Except for two participants who actively researched their condition and treatment options, others felt they lacked the medical knowledge to control their treatment choices and passively accepted clinicians' advice. Participants reported good adherence to their many treatments which they describe as often being time-consuming, uncomfortable, painful, inconvenient and ongoing. Some reported that treatments gave a sense of control over their condition and were psychologically helpful as they provided focus.

Participants felt the healthcare system had failed to provide adequate information on facial palsy, its treatment options and treatment outcomes. Not all information provided was helpful (see Key Theme 4: Timelines). Universally, patients reported a discrepancy between expected and actual cosmetic outcomes, leading to disappointment with results.

Some participants expressed anger and resentment towards the healthcare system reporting they had had to 'fight' for treatment and the funding that they believed they deserved. Some positive experiences in healthcare settings were reported, in particular one clinic and ophthalmologist provided physical, psychological and social support. For patients who had undergone surgery some time ago, some expressed anger and resentment that they had missed out on advances in surgery and the resultant improved outcomes. Others felt frustrated that they had exhausted treatment options.

[Table 3 near here]



#### ***Key Theme 4: Timeline***

In this sample, no participants fully recovered functioning from facial palsy. Up to 2 years following onset, many participants viewed or hoped their facial palsy would be acute, particularly if they had been given a specific timeframe for full recovery (e.g. many were told full recovery will not occur if not achieved within two years). Some patients were told timelines for typical symptom/appearance improvement (e.g. ‘if it is going to improve, it will within six months’) by clinicians. They viewed this as a rigid deadline and expected no further improvements if they did not make the expected improvements within this time. Consistent with an acute timeline, participants expected their condition to improve and were subsequently passive towards self-management. Many describe surprise at the actual recovery time with frequent symptom monitoring, uncertainty and psychological distress. When participants did not make a full recovery in the time they expected, their timeline representation changed and they viewed it as a chronic condition with little or no possibility of full recovery, though some believed improvement may still be possible. Some participants had experienced gradual improvement in symptoms over a relatively long period of time, which were often so small they had gone unnoticed and were often identified through comparisons with past self.

[Table 4 near here]

#### ***Key Theme 5: Consequences***

Participants varied in the degree to which facial palsy affected them. Some reported a positive effect by changing their perspective, fostering a greater appreciation for life; increasing understanding of and sympathy for others; improved relationships with family and friends; and found ‘overcoming’ the challenges of living with facial palsy increased their confidence. Interestingly, for some participants there was a discrepancy between *perceived* and *actual* impact on life, with some participants identifying experiences that facial palsy had impacted while claiming it had no impact.

More typically patients reported a decline in quality of life, across domains, including work, family and social life with challenges that had far-reaching consequences. The visible nature and physical limitations of the condition were key sources of distress, incorporating

slurred speech, loss of control and poor sleep, and impaired daily functioning, including the ability to eat and drink, drive, and perform tasks such as answering the telephone. The visible nature of the condition also affected participants' identity and confidence and was a source of social anxiety.

Palsy created an employment barrier, sometimes resulting in financial consequences. The nature and number of surgeries needed and symptom incompatibility with job roles (e.g. public speaking, customer service) and requirements (e.g. health and safety) resulted in lost potential and income. Many described having given up existing careers or taking early retirement. Participants reported on-going pain, fatigue, difficulty concentrating and embarrassment at work. It was common for spouses to become caregivers following surgery, compounding the financial ramifications. Successful return to work was a source of confidence, highlighting the weighted significance of employment following facial palsy.

Socialising posed physical and psychological challenges. Participants described problems communicating and expressing emotions, brought about by needing to avoid difficult to pronounce words, slurring, hearing loss, and needing time to prepare to speak; and avoiding some noisy social spaces (e.g. bars) which aggravated symptoms. Participants found actual and anticipated reactions to their appearance from others was a source of worry and rumination, resulting in social avoidance and increased isolation for some. Social support helped facilitate socialisation and avoid isolation, but also facilitated dependency on others.

Many participants reported a general loss of confidence in their self-image following onset. Some participants developed an unhealthy relationship with mirrors, avoiding them completely or obsessively checking for improvements in appearance. Universally, participants reported avoiding having their photographs taken other than for medical purposes. Photographs were viewed as an unwanted 'record' or 'documentation' of their disfigurement and the inability to smile emphasised their facial abnormalities. Women found applying makeup challenging, which reduced the ability to perform a previously enjoyable task and heightened feelings of unattractiveness.

[Table 5 near here]

### ***Theme 6: Emotions***

Anxiety and, to a lesser extent, anger and depression were reported in relation to their facial palsy. Heightened emotional responses exacerbated symptoms and those symptoms caused more emotional reactions. While some participants had not experienced depression, others reported feelings of low mood, depression and even suicidal ideation, particularly in the first few years following onset. Not meeting recovery timelines was a notable source of depression. Anxiety was experienced across the sample to varying degrees and was highest in the first years following onset. Embarrassment was a key source of anxiety, particularly in relation to eating, drinking, speaking and being 'stared at' in public. Participants report worry and rumination about reactions from others, disease progression, surgery, treatment choices and maintenance, and finances. Some developed anxiety in seemingly unrelated areas, for example, a fear of the dark. A proportion of the sample felt anger in relation to their facial palsy. Specifically, unresolved anger arising from developing the condition, frustration with physical effects such as pain and an inability to express oneself, and reactions from others, which typically manifested in outbursts and arguments. Resentment at not being diagnosed/treated quicker and needing to 'fight' for help was common. Also reported was resentment at missing advances in surgery, being misled about recovery and treatments being time-consuming.

[Table 6 near here]

### ***Key Theme 7: 'Other'***

There were significant themes that did not fit within the framework of the CS-SRM:

#### ***Social Support***

Social support from friends and family was reported as critical to alleviating social anxiety and isolation. Organised support in the form of patient support groups was viewed as helpful as they provided advice, information and a place to speak to people with similar experiences. One specialist clinic was praised by many as a good source of support ranging from information on treatment options to practical, teaching makeup application techniques. Some

participants felt meeting a patient with more experience of facial palsy would have helped them gain insight and reduce distress.

### *Coping*

The use of humour was reported to manage psychological distress, usually in a self-depreciating manner, e.g. ‘like Quasimodo’s sister’ (5), about oneself. Social comparisons with others considered more disabled or having more severe disfigurements was common. Some reported turning to new or existing religion or ‘faith’ to cope with facial palsy. Others reported engaging in positive experiences, continuing to engage in behaviours present before facial palsy onset and ignoring or ‘putting up’ with the condition were also perceived as helpful.

### *Healthcare System*

There was a general feeling of frustration with their care. Some participants felt they missed opportunities for better outcomes as they had to wait for treatment and often remarked that they had to ‘fight’ for specialist support because of funding. Many believed there was inadequate communication with patients which had practical and psychological consequences such as lengthy waiting times and unrealistic expectations for recovery. Some claimed they were not viewed as a whole person but an anatomical region and the challenges of living with facial palsy were not often acknowledged.

### *Identity*

Participants reported a discrepancy between their appearance and how they felt ‘on the inside’. They felt they were the same person as they were before they developed facial palsy, frequently describing ‘before’ and ‘now’ in relation to their palsy, indicating a change in their identity.

[Table 7 near here]

## Discussion

This is the first theoretically informed study to explore specific drivers of distress in people with facial palsy. Consistent with previous research using the CS-SRM (Fu et al., 2012), we found links between patients' illness representations and associated emotional processes to living with facial palsy. These factors are amenable to change, can reduce patients' distress and improve quality of life. Experiences of anxiety, depression and anger were widespread, and some participants experienced suicidal ideation. Thus, in addition to measuring distress, clinicians should also address the underlying beliefs, emotions and behaviours. The next step in this research will be to develop a Patient-Reported Impact Measure (PRIM), incorporating the results of this study, to screen for those showing early signs of distress and in most need of psychological intervention.

Representations of illness are shown to be important determinants of psychological adjustment and inaccurate or unhelpful representations can lead to delays in seeking medical attention, non-adherence to treatment and undue distress (Groarke et al., 2005; Turrisi, 2016; Walsh, et al., 2004). Some patients in this study described receiving no information regarding facial palsy from their clinician. Clinicians routinely provide information on palsy and treatment, typically shortly after diagnosis, indicating that patients do not process information well at this point. This may partially explain the passivity observed in the sample.

Furthermore, not all information was deemed helpful; prescriptive timelines for recovery were a source of distress when not met. As opposed to information-giving, increasing understanding and adjusting beliefs may play a part in reducing distress and increasing adherence to treatment. This would require extended clinical skills training for clinicians. A structured education programme at the time of diagnosis covering treatment options, alternative sources of support, understanding facial palsy and the patient's role in self-management may also be beneficial.

Rumsey and Harcourt (2004) have documented the issues faced by people with a range of visible differences, many of which are described in the present study. Altered self-perceptions, feeling unattractive and fear of negative appraisal led to difficulties with social interactions and social anxiety and isolation. The burden of managing a long-term condition - pain and discomfort, burdensome treatment regimes, frustration with health service provision and limited treatment options - also drove distress. Family support, faith, humour, sense of

self, social skills, determination and networking promoted resilience. An intervention to support patients to better self-manage their condition and develop adaptive coping skills may reduce distress.

The main focus of current assessment and management of facial palsy is on treating the underlying cause and reducing associated morbidity (Masterson, Vallis, Quinlivan, & Prinsley, 2015); no integrated psychological support is provided. Adherence to strict surgical protocols may exert undue pressure on patients to undergo surgical intervention and make shared decision-making difficult (Rumsey & Harcourt, 2004). Moreover, while medical and surgical interventions to reduce visible differences may be of benefit to some patients, this current model of care implicitly subscribes to the unsupported notion that severity of disfigurement is positively correlated with psychological distress (Clarke, 1999; Rumsey & Harcourt, 2004). Clinicians may be aware of patient distress but may not feel that they have the time, training or skills to deal with the issues in an evidence-based way. This study highlights the need for service development to include psychological assessment and appropriate referral for those who need it via an established care pathway.

Clinician and patient understanding of, expectations for and satisfaction with treatment may differ fundamentally. Previous research found that surgeons may aspire to an ideal aesthetic result, while many patients with disfigurements aspire to be unremarkable rather than perfect (E. Bradbury & Middleton, 1997; Pruzinsky, 2002). Interestingly, we found the converse true with patients in this sample tending to have higher treatment outcome expectations than clinicians. This finding may be idiosyncratic of this sample - all of whom were recruited from one clinic and seeking treatment – and may not generalise to non-treatment seeking patients or other clinics. Since discrepancies in treatment outcome expectations and satisfaction were a key driver of distress in this sample, future research should investigate the reasons underlying this discrepancy.

### ***Conclusion***

Facial palsy services typically fall short of managing the whole person by addressing the psychological and social consequences. We recommend more integrated psychological support for patients with facial palsy. Early psychological intervention may reduce the long-term costs of follow-up and reduce both clinical service and patient burden. Within clinical consultations, patient's beliefs about facial palsy should be identified and addressed. A new

PRIM to measure distress in this population would facilitate this and also screen for those needing psychological intervention. In addition, there is a need for service development to include appropriate referral to specialist psychological support via an established care pathway. A structured educational programme that addresses drivers of distress and self-management should also be considered.

### **Acknowledgements**

We would like to thank the participants who gave their time to take part in this research.

### **Conflicts of Interest and Source of Funding**

None declared for each author.

### **References**

- Andersson, G. (1999). Anxiety, optimism and symptom reporting following surgery for acoustic neuroma. *J Psychosom Res*, 46(3), 257-260
- Bradbury, E., & Middleton, J. (1997). Patient involvement in decision making about treatment. In R. Lansdown, N. Rumsey, E. Bradbury, A. Carr & J. Partridge (Eds.), *Visibly different: Coping with disfigurement* (pp. 172-179). Oxford: Butterworth-Heinemann.
- Bradbury, E. T., Simons, W., & Sanders, R. (2006). Psychological and social factors in reconstructive surgery for hemi-facial palsy. *Journal of Plastic, Reconstructive & Aesthetic Surgery: JPRAS*, 59(3), 272-278
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Bull, R., & Rumsey, N. (1988). *The social psychology of facial appearance*. New York, NY: Springer-Verlag Publishing; US.
- Byrne, P. J. (2004). Importance of facial expression in facial nerve rehabilitation. *Curr Opin Otolaryngol Head Neck Surg*, 12(4), 332-335
- Clarke, A. (1999). Psychosocial aspects of facial disfigurement: Problems, management and the role of a lay-led organization. *Psychology, Health & Medicine*, 4(2), 127-142. doi: <http://dx.doi.org/10.1080/135485099106270>

- Clarke, A., Rumsey, N., Collin, J. R. O., & Wyn-Williams, M. (2003). Psychosocial distress associated with disfiguring eye conditions. *Eye*, 17(1), 35-40. doi: 10.1038/sj.eye.6700234
- Cochrane, V. M., & Slade, P. (1999). Appraisal and coping in adults with cleft lip: associations with well-being and social anxiety. *Br J Med Psychol*, 72 ( Pt 4), 485-503. doi: 10.1348/000711299160194
- Cole, J. (2001). Empathy needs a face. *Journal of Consciousness Studies*, 8(5-7), 51-68
- Coulson, S. E., O'Dwyer, N. J., Adams, R. D., & Croxson, G. R. (2004). Expression of emotion and quality of life after facial nerve paralysis. *Otology & Neurotology*, 25(6), 1014-1019
- Cross, T., Sheard, C. E., Garrud, P., Nikolopoulos, T. P., & O'Donoghue, G. M. (2000). Impact of facial paralysis on patients with acoustic neuroma. *Laryngoscope*, 110(9), 1539-1542
- Farid, M., Roch-Levecq, A. C., Levi, L., Brody, B. L., Granet, D. B., & Kikkawa, D. O. (2005). Psychological disturbance in graves ophthalmopathy. *Arch Ophthalmol*, 123(4), 491-496. doi: 10.1001/archophth.123.4.491
- Fortune, D. G., Richards, H. L., Griffiths, C. E., & Main, C. J. (2004). Targeting cognitive-behaviour therapy to patients' implicit model of psoriasis: results from a patient preference controlled trial. *Br J Clin Psychol*, 43(Pt 1), 65-82. doi: 10.1348/014466504772812977
- Fortune, D. G., Richards, H. L., Griffiths, C. E. M., & Main, C. J. (2002). Psychological stress, distress and disability in patients with psoriasis: consensus and variation in the contribution of illness perceptions, coping and alexithymia. *British Journal of Clinical Psychology*, 41(Pt 2), 157-174
- Fried, R. G., & Wechsler, A. (2006). Psychological problems in the acne patient. *Dermatologic Therapy*, 19(4), 237-240. doi: <http://dx.doi.org/10.1111/j.1529-8019.2006.00079.x>
- Fu, L., Bundy, C., & Sadiq, S. A. (2012). Psychological distress in people with disfigurement from facial palsy. *Journal of Neurological Surgery, Part B: Skull Base*, 73
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*, 13(117), <https://doi.org/10.1186/1471-2288-13-117>



- Groarke, A., Curtis, R., Coughlan, R., & Gsel, A. (2005). The impact of illness representations and disease activity on adjustment in women with rheumatoid arthritis: A longitudinal study. *Psychology & Health, 20*(5), 597-613. doi: 10.1080/14768320500094177
- Hagedoorn, M., & Molleman, E. (2006). Facial disfigurement in patients with head and neck cancer: the role of social self-efficacy. *Health Psychol, 25*(5), 643-647. doi: 10.1037/0278-6133.25.5.643
- Hill, S. (2010). The Illness Perceptions Questionnaire-Revised (IPQ-R). *Journal of physiotherapy, 56*, 280. doi: 10.1016/S1836-9553(10)70062-X
- Huang, B., Xu, S., Xiong, J., Huang, G., Zhang, M., & Wang, W. (2012). Psychological factors are closely associated with the Bell's Palsy: A case-control study. *Journal of Huazhong University of Science and Technology - Medical Science, 32*(2), 272-279
- Jørgensen, B. G., & Pedersen, C. B. (1994). Acoustic neuroma. Follow-up of 78 patients. *Clinical Otolaryngology & Allied Sciences, 19*(6), 478-484. doi: 10.1111/j.1365-2273.1994.tb01273.x
- Keillor, J. M., Barrett, A. M., Crucian, G. P., Kortenkamp, S., & Heilman, K. M. (2002). Emotional experience and perception in the absence of facial feedback. *J Int Neuropsychol Soc, 8*(1), 130-135
- Leventhal, H., & Steele, D. (1984). Illness Representations and Coping with Health Threats. *Handbook of psychology and health volume IV social psychology aspects of health, 4*
- Macgregor, F. C. (1990). Facial disfigurement: problems and management of social interaction and implications for mental health. *Aesthetic Plastic Surgery, 14*(4), 249-257
- Masterson, L., Vallis, M., Quinlivan, R., & Prinsley, P. (2015). Assessment and management of facial nerve palsy. *BMJ : British Medical Journal, 351*, h3725. doi: 10.1136/bmj.h3725
- Mei, J. H., Gao, S., & Chen, G. H. (2010). [Relationship between neuro-psychological factors and effect of acupuncture in treating Bell's palsy]. [Chinese]. *Zhongguo Zhong xi yi jie he za zhi Zhongguo Zhongxiyi jiehe zazhi = Chinese journal of integrated traditional and Western medicine / Zhongguo Zhong xi yi jie he xue hui, Zhongguo Zhong yi yan jiu yuan zhu ban, 30*(10), 1026-1029
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative research methods in health technology assessment: A review of the literature. *Health Technology Assessment, 2*(16), vii-260

- Neary, W. J., Stephens, D., Ramsden, R. T., & Evans, G. (2006). Psychosocial effects of neurofibromatosis type 2 (Part 2): Effects on specific systems. *Audiological Medicine*, 4(4), 211-219. doi: 10.1080/16513860601113825
- Neely, J. G., & Neufeld, P. S. (1996). Defining functional limitation, disability, and societal limitations in patients with facial paresis: initial pilot questionnaire. *American Journal of Otology*, 17(2), 340-342
- Newell, R., & Marks, I. (2000). Phobic nature of social difficulty in facially disfigured people. *British Journal of Psychiatry*, 176(2), 177-181. doi: 10.1192/bjp.176.2.177
- Partridge, J. (1998). Changing Faces: Taking up Macgregor's challenge. *J Burn Care Rehabil*, 19(2), 174-180; discussion 169
- Porter, J., Beuf, A. H., Lerner, A., & Nordlund, J. (1987). Response to cosmetic disfigurement: patients with vitiligo. *Cutis*, 39(6), 493-494
- Pruzinsky, T. (2002). Body image adaptation to reconstructive surgery for acquired disfigurement. In T. F. Cash & T. Pruzinsky (Eds.), *Body image: A handbook of theory, research, and clinical practice* (pp. 102-111). New York: Guilford.
- Rahman, I., & Sadiq, S. A. (2007). Ophthalmic management of facial nerve palsy: a review. *Surv Ophthalmol*, 52(2), 121-144. doi: 10.1016/j.survophthal.2006.12.009
- Rumsey, N., & Harcourt, D. (2004). Body image and disfigurement: issues and interventions. *Body Image*, 1(1), 83-97. doi: 10.1016/s1740-1445(03)00005-6
- Smith, I. M., Mountain, R. E., & Murray, J. A. (1994). An out-patient review of facial palsy in the community. *Clinical Otolaryngology & Allied Sciences*, 19(3), 198-200
- Stuart, R. M., & Byrne, P. J. (2004). The importance of facial expression and the management of facial nerve injury. *Neurosurgery Quarterly*, 14(4), 239-248. doi: <http://dx.doi.org/10.1097/00013414-200412000-00009>
- Tebble, N. J., Adams, R., Thomas, D. W., & Price, P. (2006). Anxiety and self-consciousness in patients with facial lacerations one week and six months later. *British Journal of Oral & Maxillofacial Surgery*, 44(6), 520-525
- Turrisi, S. (2016). Illness Representations, Treatment Beliefs, Medication Adherence, and 30-Day Hospital Readmission in Adults With Chronic Heart Failure: A Prospective Correlational Study. *The Journal of Cardiovascular Nursing*, 31(3), 245-254. doi: 10.1097/JCN.0000000000000249
- Valente, S. M. (2004). Visual disfigurement and depression. *Plast Surg Nurs*, 24(4), 140-146; quiz 147-148. doi: 10.1097/00006527-200410000-00003

- Van Loey, N. E. E., & Van Son, M. J. M. (2003). Psychopathology and Psychological Problems in Patients with Burn Scars. *American Journal of Clinical Dermatology*, 4(4), 245-272. doi: 10.2165/00128071-200304040-00004
- VanSwearingen, J. M., Cohn, J. F., Turnbull, J., Mrzai, T., & Johnson, P. (1998). Psychological distress: linking impairment with disability in facial neuromotor disorders. *Otolaryngology - Head & Neck Surgery*, 118(6), 790-796
- Walker, D. T., Hallam, M. J., Ni Mhurchadha, S., McCabe, P., & Nduka, C. (2012). The psychosocial impact of facial palsy: Our experience in one hundred and twenty six patients. *Clinical Otolaryngology*, 37(6), 474-477
- Walsh, J. C., Lynch, M., Murphy, A. W., & Daly, K. (2004). Factors influencing the decision to seek treatment for symptoms of acute myocardial infarction: An evaluation of the Self-Regulatory Model of illness behaviour. *Journal of Psychosomatic Research*, 56(1), 67-73

## **Appendices**

### **Appendix A: Interview topic guide**

1. What do you understand by facial palsy?
2. What do you think has caused your facial palsy?
3. How this condition has impacted upon your:
  - a. Social life
  - b. Personal relationships
  - c. Life at home
  - d. Work
4. To what extent do you think you can control your condition?
5. What do you think about your treatment?
6. How do you cope with your condition on a day-to-day basis?
7. How do you cope with any problems that arise?
8. How do you see your palsy in:
  - a. 3 months' time? Better or worse or staying the same?
  - b. 1 years' time? Better or worse or staying the same?

## Tables

Table 1: Symptoms (Key Theme 1)

Subtheme	Data Extract
Physical symptoms & function	<p>You know how sometimes I feel like it's all like little pins and needles in me cheek. (14)</p> <p>It just felt like my face was pulling to one side, my eye and my mouth was tight. I just found difficulty drinking. I couldn't suck through a straw, I didn't have the sucking power because my lips wouldn't purse. (18)</p>
Sensory and psychological symptoms	<p>Depending on the painkillers, if I take them late enough in the night, they do see me through the night. If, for some reason I go to bed a lot earlier, the pain wakes me in the night. (1)</p> <p>When I'm tired it twitches, my face twitches a lot. (7)</p>
Bidirectional link with emotion	<p>I think looking back now, when I was very stressed having this operation, I think most of the illness, although I was very ill at the time and ... and everything, I think the worst part - the worst instance are caused by stress rather than the actual illness. They're exacerbated by stress. (18)</p>

Note: Numbers in brackets indicate the participant identifier

Table 2: Cause (Key Theme 5)

Subtheme	Data Extracts
Fixed view	<p>Well, it was an immediate result of the removal of the acoustic neuroma in 2008. (17)</p> <p>I blame it on stress. I really do blame it on stress. (4)</p>
No fixed view	<p>Nobody has ever told me, ever, why it actually happened. They've given me lots of possibilities, and the one I sort of jump on is that it was some sort of viral infection, because I can't see any other reason for it happening. (15)</p> <p>Felt I had no control at all over it happening. It happened suddenly, it wasn't something that was planned, it wasn't something that I could have...I'm well aware that I couldn't have stopped it. (15)</p>

Note: Numbers in brackets indicate the participant identifier

Table 3: Control & Treatment (Key Theme 3)

Subtheme	Data Extract
Passive/Trust in healthcare professional	<p>I haven't the medical knowledge to know what can be done. (2)</p> <p>You have got to do what they tell you. (4)</p>
Treatments	<p>But I had quite a lot done to me at the hospital. I had a lumbar puncture, a scan on the head, and stuff going in my arm, three times a day. It was on continually. It was alright. It got me better anyway, that was the main thing. (9)</p> <p>I'm actually having the Tens machine, you know, the electrodes, the four...what's it called, Neuro four? I've been doing that for three years now and it has actually improved, but they told me that in order to keep this tone in my face, I am actually going to have to use it, you know, say like three or four times a week for like the rest of my life, if I want...unless I wanted something permanent doing. (5)</p>
Drawbacks of treatments	<p>I wear a machine for two hours a day which is a bit time consuming. (1)</p> <p>It's not very nice anyway, every day getting this plaster correct. It's just got to be a certain way so that I've got sight, and it's very hard to do when you've only got one eye. And yesterday I didn't get it right. I had to go for the blood. And Lord, it was so painful! (9)</p>
Personal control	<p>Again, you know, using this machine every day at the moment, and then possibly like three or four days a week, that's how I'm going to control it. (5)</p> <p>One, learning it for myself; two, find the answers for myself; three, doing it myself, I suppose, being determined to do the physiotherapy and stick with it. (15)</p> <p>Not a lot, no. No, I don't have any control over it. (19)</p>
Resentment	<p>Slight amount of resentment ... unjustified ... advances in technique ...</p>

	If they had the techniques 20 years ago ... I wouldn't have this (3)
Inadequate information	I think it was a bit of a shock to us because we basically felt as though we'd been led to believe that this [facial palsy] would only last about six weeks. (14)

Note: Numbers in brackets indicate the participant identifier

Table 4: Timeline (Key Theme 4)

Subtheme	Data Extract
Acute representations	<p>I mean it's only...it is only six months and I think this kind of operation, you know, it could be twelve months before, you know, you feel right. (14)</p> <p>And then, you know, six weeks came and went and now we're six months. It has improved, it's improved no end (14)</p>
Chronic representations	<p>But when you realise that it's not going to be ever like it was before it's quite...I don't know, I don't know how to explain it really. Kind of you're told that; well, yes, it will improve, and you can hope that it will but you just don't know. But now I know this is going to be as good as it's ever going to be. (17)</p> <p>83% is the figure I've been given that I've just latched on to, I don't think that's the end. No, I think I'll probably try and do some more exercises, have a healthy lifestyle, to improve at least some extent. But I've been told that it's never going to be...I'm never going to be 100% the same facially that I was before I had Bells. (15)</p> <p>If it's any better that'll be great, but I'm using the word comfortable a lot but that's because with the people that I've been telling you and the people in my surroundings that I'm with, that's how they make me feel. So if I have that feeling all the way through I'd be happy with that but, like I say, there's...I've got room for some improvement, I don't mind if anything can be done to help in the meantime. If it's like this for the rest of my life it's, like I say...I'd say; well, you know what, like I said, it's something I'll have to live with, which I have done up to now and I'm pretty sure I can do as well. (10)</p>

Note: Numbers in brackets indicate the participant identifier



Table 5: Consequences (Key Theme 5)

Subtheme	Data Extracts
Employment burden	<p>I did try, because I'm on sickness benefit...I did try this 'Back to Work' but I just couldn't do it. Because I'm a nursery nurse and it's with children, and I can't even pick things up because I'm having a lot of headaches. So not at the moment, no. (1)</p> <p>Cyst caused lack of concentration.. before that I had no problem.. couldn't physically and mentally do the job I used to do.. operations affected balance.. people don't want to be served by somebody who cant smile.. and cant talk properly to them.. couldn't physically take the information in. (7)</p> <p>I think because my confidence has got better and better, now that I'm in work again, yeah, I think I cope okay with it, yeah. (5)</p>
Socialising	<p>When I'm going to...yeah, you could say I'm slightly uncomfortable meeting new people, if you know what I mean, it's the whole process of what I was saying before, it's like what they're thinking and maybe I have to explain, and it's just being really comfortable with people who I'm around with basically. (10)</p> <p>Like I said about going out on a Saturday night to clubs and things...that's not really the facial palsy, that's all the other symptoms, that I can't do it. (1)</p>
Dining out	<p>I lose a lot of food.. I dribble a lot.. if I have a hot drink.. I have to have it with a straw.. I try not to eat in public.. quite embarrassing.. get them to sit opposite me so they can see if Im losing food.. people can be quite rude.. really nasty.. look at you in strange ways. (7)</p> <p>Yeah, because when I used to eat something it was like, I don't know, I used to make a lot of noise because of my mouth, and I just felt like I was sort of lopsided and I probably looked a bit disgusting eating, really; and I just wouldn't go out and wouldn't eat in front of people. I mean I was a bit funny about eating in front of my husband at the beginning and he just says, 'Well, you're just eating the same.' And</p>

	<p>then I watched myself eating something, in a mirror, to see what I looked like, and it was silly really. (20)</p>
Self-image	<p>It's being out socially, not being able to put makeup on like I used to, get dressed up like I used to do, and because obviously you have a drink and you get merry and you're laughing; so I don't like people to see me laughing, I sort of hide my face, I put my hand up sort of or turn away, I don't like people to see when I do that. So if I was in a pub and there was a load of people there, well, obviously there's people are going to look at you so, I don't know, I just think people would stare. (15)</p> <p>I've not really been sort of like a very confident person anyway, but it did take a hammering, I think. (5)</p> <p>We had to have an identity card taken at work, and it's absolutely awful. Because the guy was saying oh go on, smile. I thought well, I can't, can I, you know. And it's funny because, like I said, I can look in a mirror now and I can see...you know, well yeah you look okay, but photographs completely different. I don't know why it is that, but seeing a photograph of yourself is completely different to looking in mirror, and I don't like it. (9)</p> <p>I can remember when I came out of the hospital, this small mirror that I had, I had it on my bedside table, and in the morning I'd look to see if it were better. I did that for weeks. (1)</p> <p>I don't know, whether you put it down to vanity or what, but it's different when you're a woman because you want to put makeup on and you want to look nice, and I think I've always done that ever since I was a young teenager, and I can't do it, I've tried to do it, and I've put waterproof mascara on and then at the end of the day you end up with one eye with mascara on and one off. So I just don't see the point. (20)</p> <p>After the operation I didn't feel like me any more, I mean I feel more like me now but I know that I'm not the person that I used to be, but I sort of try to hide it. Like, I mean people who are close to me know</p>

	that it bothers me but to people on the outside I can sort of put a face on that I'm coping with it okay, and that's just the ... face, but then when I get home reality is there (20)
--	--

Note: Numbers in brackets indicate the participant identifier

Table 6: Emotions (Key Theme 6)

Subtheme	Data Extract
Reciprocal relationship between emotions and symptoms	<p>When I get excited I get...I come out with all this strange language like Swahili. It's odd. Yeah, that's really all that bothers me. (7)</p>
Depression	<p>The first year I felt quite suicidal and I'd 'phone you at work. I'd phone my daughter at work and I'd be crying all the time,, wouldn't I? ... I kept saying things 'why did I come out of the hospital?' ... 'Why me? Why am I still here and everybody else has died, you know?'. (2)</p> <p>There's eight to 12, 14 weeks, when you're told it will get better in 14 weeks and then it does, and then you know it's not going to get completely better. I did get quite depressed then. There are degrees of depression, aren't there, and I don't think I...I didn't hit a rock bottom or anything (15)</p> <p>About a fortnight after the operation.. had a fit of depression, absolute depression.. withdrawal from morphine. (3)</p>
Anxiety	<p>I think that was the surgery actually, but I did. I come out frightened of the dark, wasn't I? I said 'leave that light on'. Don't turn it off'. (2)</p> <p>So next day when the Registrar came on the round and he spoke to me I was absolutely numb and cold. It was just kind of sweat running down my spine, and I thought no. I can't live this way. Really, I'm just 37 years old. And two daughters ...with my husband. I thought, no. My God. I want to ... and I just fought back from that moment. (16)</p>
Anger	<p>I felt really...I should have another scan before then to see what was happening and I think it was....I don't know...it was left a little bit late before they actually opened me up. Perhaps if</p>

	they'd have done the surgery sooner it wouldn't have got as bad. I might not have got the bad facial...I don't know, just assuming all this (12)
--	--

Note: Numbers in brackets indicate the participant identifier

Table 7: Other (Key Theme 7)

Subtheme	Data Extracts
Social support	<p>You do need support, and there's no support out there unless your family support you. (4)</p> <p>I think if you haven't had any support I think you're just floundering about and not knowing which way to turn. I think you need the support of friends and family and at the XXXX. (2)</p>
Coping	<p>When the facial palsy... when they damaged the facial... no doubt I was feeling depressed but I was with my Bible. I was just reading it all the time, and just going to church after some time and the pastor was praying for me, so that spiritual life has made a difference a lot. (16)</p> <p>There's people a lot worse off than I am. I mean my facial palsy is nowhere near as bad as some people, a lot of people. I mean it's really quite mild towards a lot of people that I've seen. It could be worse. It could be a lot worse, and it's not that bad. It's just that when I get up and I see it I'm like oh my god, what a mess. But it could be worse. And then you just get dressed, have a shower, get dressed, get on with the day. What's the point in crying over it? No point. (5)</p>
Healthcare system	<p>They don't see you as having had, like me, 53 operations. They don't treat you as a whole person, they just want to know about their bit. (18)</p> <p>Nobody explained to me that there were two different, or two or three different sorts of Bells Palsy. I think there's one that's, is it viral, and when you get better, you get better after six weeks. And there's another sort, which I now know I have in retrospect, that is permanent damage. Nobody...well, I don't think anybody explained that to me for the first little while. (15)</p>

Identity	<p>Well, I think that people who know me, well, they know that I'm the same person underneath. I mean when I went back to work – this one instance – somebody had warned one of my calls that I wasn't the same. (20)</p> <p>It has really, yeah, because I think you get to accept, you know, what you look like and I'm still the same person, and you just get to accept that I do look different, but it is actually a lot better than it was. It has actually improved a lot. (5)</p>
----------	--

Note: Numbers in brackets indicate the participant identifier