The construction of 'self' in individuals with congenital facial palsy: A grounded theory exploration

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This is to certify that this research report is my own unaided work.

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Abstract

The construction of ‘self’ in individuals with congenital facial palsy: A grounded theory exploration

Background: Developmental and psychoanalytic research findings suggest that early face to face interactions with caregivers play a significant role in the construction of an individual’s sense of self and that disruptions to these interactions can have negative consequences for social and emotional development. However, there is currently a significant gap in the research literature regarding how the sense of self is constructed in individuals who have limited or no facial expression due to conditions such as congenital facial palsy. Consequently, little is known about how the sense of self develops in these individuals. The researcher had a diagnosis of congenital facial palsy and therefore had ‘insider experience’ which shaped the formation of the research question and aims of this study, which were twofold: to explore the construction of ‘self’ in individuals living with this condition and to construct a grounded theory of this process. It is hoped that these findings will add to the minimal psychological literature published in this area and encourage the development of specialist psychotherapeutic interventions for those living with this condition.

Method: A Constructivist Grounded Theory methodology was adopted, and a purposive sampling strategy used to recruit the initial sample. Semi structured interviews were conducted with 14 adults (8 male and 6 female) with a diagnosis of congenital facial palsy; eight interviews were conducted face to face with participants in the USA and six via Skype with participants in the UK. In the final stages of the analysis theoretical sampling was used to recruit two parents of children with congenital facial palsy. Participants were asked about their experiences across the lifespan of living with congenital facial palsy and their constructions of self were explored.

Findings: Participants’ retrospective accounts suggest that living with congenital facial palsy negatively influences communications with caregivers and others across the lifespan. Participants’ accounts suggest that two separate self-states were constructed through their interactions with others; a *“defective me”* and a “*validated me”.* Participants described how the *“defective me”* self-state was constructed through the following relational processes; ‘*struggling to make connections’, ‘experiencing invalidation,’* and *‘struggling with affect regulation*’. Conversely, several participants described how the construction of a *“validated me’’* self-state occurred through; ‘*making validating connections’*. Those participants who described the ability to move more fluidly between self-states described better psychosocial outcomes as they recovered more quickly from negative interactions with others.

Conclusion: The findings of this study highlight the central role that the face occupies in the construction of the ‘self’ and the unique challenges those with congenital facial palsy are likely to experience in constructing a validated self-state. It is suggested that psychotherapies which focus on healing the non-verbal sense of self may be one effective approach to working clinically with this population.

1.0 Introduction

1.1 Background and introduction to the study

The primary aim of this study was to explore the construction of ‘self’ in individuals with congenital facial palsy and the relational processes involved in this, and to construct a grounded theory of this process. My interest in this area arose through my personal experience of living with congenital facial palsy (Moebius Syndrome) and the difficulties I experienced constructing my ‘self’. I spent a significant amount of time in hospital during early childhood and underwent a series of surgeries to gain the ability to smile. Middle to late childhood involved regular hospital appointments to address the ongoing difficulties I experienced with my eyes and the special educational needs which resulted from this. I recall how some doctors treated me as a defective object which needed fixing.

I missed a significant amount of school during childhood and had to work hard to remain on par with my cohort. Consequently, childhood was an anxiety provoking time for me as I often felt that my teachers did not understand my condition or know how to address my additional educational needs. These difficult early interactions resulted in a strong sense of being different to others, as well as feelings of inferiority and shame which resulted in the construction of a defective sense of self.

Reflecting on my childhood, I am struck by the gaps in my memory of these early childhood years and the surgeries I underwent. It could be that these experiences were too traumatic for me to process at the time and so I repressed them. Nevertheless, the strong feelings of anxiety, frustration, shame and grief remain present and can easily be re-activated.

I have wondered how I might have constructed my sense of self had I had access to specialist psychotherapeutic support during my childhood and adolescent years. Unfortunately, such services were not available during my childhood or adolescence and while there is now specialist psychotherapeutic support for people experiencing visible differences, there remains limited specialist interventions for those living with facial palsy in the UK and worldwide. Informal conversations I have had with other individuals living with this condition suggest that difficulties accessing appropriate psychological intervention has had a negative impact upon their sense of self. This unmet need is one which I hope to begin addressing through undertaking this research.

As I have 'insider status' (Dwyer & Buckle, 2009) it was important for me to maintain high levels of personal and functional reflexivity throughout my research journey by continuously reflecting upon how my experience as well as my epistemology might influence my analysis of the data. I engaged in this process by maintaining a reflexive research journal and participating in reflexive discussions with my supervisory team and a psychology colleague with 'insider status' as well as other trainee Counselling Psychologists with 'outsider status'.

1.2 Definition and incidence of congenital facial palsy

Facial palsy can be either acquired or congenital and the causes for both are different (Müller, Cienki, Fricke, Ladewig, McNeil, & Teßendor, 2013). Acquired facial palsy can be the result of infection, accident or injury which results in damage to the facial nerve or it can be caused by a stroke or illnesses such as Parkinson's disease or head and neck cancers (Bogart, Tickle-Degnen, & Ambady, 2012). Müller et al. (2013) define congenital facial palsy as a condition which is present from birth and results in the weakening or complete paralysis of the muscles on one or both sides of the face. Medical researchers (see Hughes, Harley, Milmoe, Bala, & Martorella,1999) estimate the incidence rate for congenital facial palsy to be 2 to 8 cases per 1,000 births per year. Congenital facial palsy can be the result of birth trauma or the underdevelopment of facial nerves in the embryo in utero because of rare developmental syndromes (e.g. Moebius Syndrome or Hemifacial Microsomia), however, the exact causes of the congenital facial palsies have yet to be discovered (Müller et al., 2013).

1.3 The importance of the face in interpersonal relatedness

Findings from decades of psychological research illustrate the central role that the face plays in facilitating interpersonal relatedness across the lifespan including the mother-infant bonding process, emotion regulation and social communication (Fonagy, Gergely, Jurist, & Target., 2004; Stern, 2006; Schore, 2012; Beebe & Lachmann, 2013). The human face has been described as “the window to our inner selves; it represents the entire personality and is the focus of attention in every social interaction” (Coull, 2003, P.255). Furthermore, findings from Functional Magnetic Resonance Imaging studies of adult brains have confirmed that the degree of facial attractiveness which influences mating choice and other social judgements about a person is strongly associated with smiling and facial symmetry (Thornhill & Gangestad, 1999; O’Doherty, Winston, Critchley, Perrett, Burt, & Dolan, 2003).

Recent findings from developmental psychology and infancy research demonstrate how the nonverbal sense of self develops through face to face interaction and other forms of ‘embodied mentalising’ during social interaction with the primary caregiver (Beebe & Lachmann, 2013; Fonagy, Gergen, Jurist, & Target, 2004). ‘Embodied mentalising’ has been defined by Shai and Fonagy (2014) as the meeting of the minds of two individuals through their use of whole-body movements which occur during their interaction with each other. Although there is a body of research that highlights the central role of the face in the development of the sense of self, what has yet to be explored is how the sense of self develops in those who are not able to communicate and express themselves through facial expression.

1.4 Definition of the ‘self’

Storolow (1995) suggested that a new paradigm has emerged within the field of psychoanalysis, one which no longer conceptualizes the individual as a psychic structure governed by aggressive and sexual drives but one which constructs people as relational beings, governed by the drive to build relationships and connections with others. Within the field of relational psychoanalysis there is now a consensus that the infant's experience in relationship with the primary caregiver becomes the foundation upon which the sense of self and other is built (Mitchell, Aron, Harris, & Suchet, 1999; Magid & Shane, 2017). This relationship is stored within relational memory and guides future interactions with others and oneself (Mitchell et al., 1999). The relational conceptualisation of the 'self' will be expanded upon in the literature review section.

I share a similar view to that of contemporary relational psychoanalytic theorists in that I consider the 'self' to be a fluid relational process and the interface that connects cognitive, affective, sensory and physical experiences of being in the world. I believe that the experience of 'self' is continuously reconstructed as it is influenced by time, memory and social context.

1.5 Epistemological positioning

In terms of my epistemological positioning I consider myself to be a social constructionist (Gergen, 2011; Burr, 2015). Social constructionism is an approach which takes a critical stance towards knowledge construction viewing this as culturally and historically specific and constructed and maintained through social processes (Burr, 2015). My epistemological position will be discussed in further detail in the methodology section.

1.6 Psychosocial challenges of living with congenital facial palsy

Several studies have been conducted within the field of health psychology which have explored the psycho-social challenges experienced by those living with congenital facial palsy (see Bogart, Tickle-Degnen, & Joffe, 2012; Bogart, 2015; Bogart & Matsumato, 2010). The findings suggest that many of these individuals are likely to experience difficulties such as social anxiety and poor self-esteem and engage in self-protective behaviours such as avoidance of social situations (Bogart et al., 2012; Bogart et al., 2015). While these studies provide a good description of the social difficulties experienced, they do not provide an in depth understanding of the relational processes involved in the construction of ‘self’ or present a psychological theory illustrating this.

1.7 Aims of the study

Therefore, the primary aim of this study is to explore how individuals with congenital facial palsy construct their sense of self. I have focused on the subjective experiences and relational processes involved in this and I have aimed to construct a grounded theory of these processes. I have also attempted to ‘give voice’ to this minority group.

It is hoped that these findings will add a relational psychoanalytic perspective to the facial palsy literature which is currently dominated by a medical discourse. One of the central aims of Counselling Psychology is to develop psychological theory and psychotherapeutic models of practice which are grounded within the subjectivity of the population affected and generated through rigorous research methods (British Psychological Society, 2005).

Furthermore, the aims of this research align closely with the value that Counselling Psychology places upon recognising the importance of the relational and social context and working to empower those who might be marginalised within society or discriminated against (British Psychological Society, 2005; Motulsky, Saleem, & Trantham, 2014). It seems important to raise awareness of the intrapsychic and interpersonal challenges experienced by this population as currently it is very difficult for those living with congenital facial palsy to access specialist medical, surgical and psychological support from the NHS or other medical providers (Walker, Hallam, Ni Mhurchadha, McCabe, & Nduka, 2012). This is because facial palsy is often conceptualised as a cosmetic issue rather than one which has significant negative implications for mental health, social and occupational functioning (Walker et al., 2012).

Counselling Psychology has been criticised over recent years for paying too much attention to intrapsychic processes and neglecting to consider the relational and social factors that contribute to poor mental health and/or the social marginalisation of minority groups within society (Toporek, 2006). Therefore, this study aims to address this issue by utilizing a relational (intersubjective) framework. Furthermore, there appears to be a notable absence of research from the field of Counselling Psychology within areas such as visible difference and disability and this research aims to bridge that gap.

2.0 Literature Review

In the first section of this extended literature review, I will highlight the gaps that exist within the psychological literature in the area of congenital facial palsy, specifically in terms of understanding how those living with this condition construct a sense of self. In the second part of the review, I will explore conceptualisations of the ‘self’ focusing critically on relational theories of ‘self’ and how this develops. The exploration of the relational psychoanalytic literature has been informed by my personal experience of living with congenital facial palsy and my awareness that this condition can disrupt the implicit (the non-verbal, affective and embodied) sense of self as well as the explicit self (the verbal and conscious components of self). As relational psychoanalysis is concerned with healing the implicit sense of self (Schore, 2002), I will therefore be making the case throughout this literature review as for why it is important that a relational psychoanalytic understanding of how the ‘self’ is constructed in individuals with congenital facial palsy is developed.

I will suggest that although contemporary findings from attachment, infancy and developmental research have enhanced relational psychoanalytic understandings of how the ‘self’ develops, relational psychoanalysis has yet to consider how the ‘self’ might develop in those living with craniofacial conditions which alter appearance and can compromise facial expression. In order to gain insight into how congenital conditions which cause communication impairments (on a non-verbal level) can disrupt dyadic interpersonal communication and the implicit relationship with oneself, I will review relevant research from the congenital communication impairment literature. It is necessary to review findings from this field as this is something which has not yet been explored within the field of visible difference. In the final section I will make a case for why it is important that this current study is undertaken.

As the epistemological framework underpinning this qualitative study is social constructionist, I will be following the suggestion by Charmaz (2006 p.168) to critique the existing literature from a social constructionist perspective which involves; identifying the key themes, debates and gaps in knowledge and making a case for how this Constructivist Grounded Theory study can begin to address these gaps and make an original contribution to the field.

2.1 Congenital facial palsy

2.1.1 Defining congenital facial palsy

Müller et al., (2013) define congenital facial palsy as a condition which is present from birth and which results in the weakening or complete paralysis of the muscles on one or both sides of the face. Congenital facial palsy can be the result of birth trauma or can be caused by the underdevelopment of facial nerves in utero due to developmental syndromes (e.g. Moebius Syndrome). The exact causes of the congenital facial palsies have yet to be discovered (Müller et al., 2013). Symptoms vary from person to person but usually include some or all of the following: difficulties feeding and sucking during infancy and beyond, the inability to smile or close the eyes fully, difficulties controlling the movement of the mouth or speech, altered facial appearance, restricted eye movements, impaired vision and hearing and the inability to use the face to express emotion during social interaction (Sjogreen, Andersson-Norinder, & Jacobsson, 2001).

Most participants in the current study had a diagnosis of Moebius Syndrome, a rare neurological condition which typically results in bilateral facial paralysis and limits the abduction of the eyes (Moebius, 1888; Briegel, 2006). Typically, the individual affected is unable to smile or make any form of facial expression. Moebius Syndrome can often result in underdeveloped limbs (e.g. missing fingers or club feet) and can affect movement and balance (Briegel, 2006). The exact cause of Moebius Syndrome is unknown although medical researchers are currently investigating this; one of the main theories regarding etiology is that the condition might be caused by vascular disruption in utero (Briegel, 2006).

Speech and language delay occur in approximately 14% to 55% of children with Moebius Syndrome because of difficulties using the mouth and tongue to form words (Meyerson and Foushee, 1978). However, speech therapy appears to be highly effective for improving clarity of speech in this population (Meyerson and Foushee, 1978). It has also been reported that approximately 10% to 15% of people with Moebius Syndrome have a mild learning disability (Briegel, 2006), although some medical researchers have argued these generalisations are problematic as these studies had significant methodological flaws such as limited samples and selection biases (Verzijl, van Es, Berger, Padberg, van Spaendonck, 2005). Several studies have suggested that there is a higher incident rate of autistic spectrum disorders in people with Moebius Syndrome compared with the general population. However, Bogart (2010) argues that there is a significant problem with using the standard diagnostic criteria to diagnose autism in this population (e.g. lack of facial expression and gaze during social interaction and difficulties developing peer relationships) as facial paralysis will impact facial expression, gaze and speech, as well as cause language delays.

2.1.2 Psycho-social adjustment in individuals with craniofacial conditions

The visible difference literature provides some insight into the psychosocial difficulties experienced in infancy and childhood in individuals with craniofacial conditions, which is something which has not yet been researched in the area of congenital facial palsy. Given the view within the field of relational psychoanalysis that the foundations of the 'self' are constructed during the period of infancy and childhood (see Mitchell et al., 1999), it seems important that the research exploring the socio-emotional development of infants and children with a craniofacial condition is firstly considered. I will then review the psychological research which has been conducted with individuals with congenital facial palsy.

Several qualitative studies undertaken indicate that difficulties exist within the attachment and bonding process between infants with cleft lips and palates and their mothers. Owens (2008) used a blend of ethnographic and narrative methods to explore the feeding difficulties experienced by twenty mothers with new born infants who had a cleft lip and palate. Mothers were recruited through self-selection, a database and the Cleft Lip and Palate Association. Interviews were undertaken within their own homes, some of whom were accompanied by a trusted partner or relative. The findings suggested that the mothers in this sample struggled with feelings of frustration, loss, sadness, guilt and self-blame and delayed bond formation as a consequence of feeding difficulties caused by their infant's cleft lip and palate.

While the findings from the study conducted by Owens (2008) provide some novel insights into the impact disrupted feeding can have on the mother-infant bonding process, this study had several limitations. Firstly, some of the infants had additional syndromes and learning difficulties which may have also impacted the bonding process, however, the impact this may have had upon the feeding and bonding experience was not considered. Furthermore, although these findings provide evidence that some mothers experience difficulties attaching and bonding with their infant because of the feeding difficulties, the mother-infant dyad was not directly examined and therefore it is difficult to know if the 'actual relationship' between mother and infant was disrupted.

Lindberg and Berglund (2014) conducted a similar qualitative study whereby the experiences of twelve mothers of babies with cleft lip and palate were explored. Participants were strategically selected from attendance at a class run by a local hospital for parents of new born babies with a cleft lip and palate. A semi structured interview guide was used to guide the interviews with mothers and the data was analysed using a phenomenological approach. The findings suggested that the mothers required specialist information and support to aid them with difficulties within the feeding process and that their own personal resources, along with the support of the fathers and immediate family helped build resilience and the ability to cope with the challenges faced. Although these findings provide significant insights, this study only focused upon exploring the experiences of mothers who were in need of additional help/support. It is possible that not all mothers experience this and therefore, further samples need to be recruited and studied to gain a deeper understanding of the disruptions that might occur within the dyad and how to limit these. As above, further developmental research needs to be conducted to explore how these early feeding difficulties might influence the construction of 'self'.

Despars, Peter, Borghini, Pierrehumbert, Habersaat, Müller-Nix, and Hohlfeld, (2011) compared internal parent-child working models of 22 mothers of infants with cleft lips and palates with 36 mothers in a matched control group. Mothers were recruited from a local hospital situated in France. Mothers participated in a semi structured interview which explored their internal working model of their child and the Impact of Events Scale was administered to measure post-traumatic stress symptoms. Despars et al. (2011) found that mothers of children living with a cleft lip and palate experienced insecure parental internal working models of their child and higher levels of post-traumatic stress symptoms in comparison to mothers in the control group. The authors concluded that infants with a cleft lip and palate are therefore at greater risk of developing psychological problems.

It is important to note that the findings from Despars et al. (2011) are limited in several ways; firstly, the authors did not consider how the mothers' personal attachment style and previous psychiatric history might have influenced the parent-infant interaction and secondly, mothers who had psychiatric problems were excluded from participating in this study. Furthermore, this study did not directly examine the mother-infant interaction, and therefore, it is difficult to know if parents provided an accurate representation of their internal working models or how the parental working models impact the infant with the cleft lip and palate. The authors neglected to consider how the infant's relationships with other caregivers, relatives and their social environment might also influence their psychological development. Therefore, further research into these relational processes is needed in order to gain a deeper understanding around how these early relational experiences may shape the construction of self.

Montirosso, Fedeli, Murray, Morandi, Brusati, Perego, and Borgatti, (2012) assessed mother-infant interaction in 25 two-month-old infants with cleft lip and compared with 25 matched controls. The method of analysis involved video recording mother-infant interactions and maternal completion of questionnaires which gathered data relating to infant temperament, maternal depressive symptomology and socio demographic information. The findings suggested that infants with cleft lips were less engaged in social interaction with their mothers in comparison to the matched control group and mothers of infants with cleft lips displayed more negativity than matched controls. Montirosso et al. (2012) argued that the impaired facial expressiveness and vocal production in the infant with a cleft lip may make it difficult for the mother to accurately interpret the infant's signal and this will disrupt the dyadic interaction. However, these relational processes were not explored directly and it is not yet understood how these experiences impact the child's construction of 'self'.

Murray, Hentges, Hill, Karpf, Mistry, Kreutz, Woodall, Moss, and Goodacre, (2008) explored the interactions in 94 infants with cleft lips (with and without cleft palate) and 96 non affected infants (matched controls) at 18 months old. 48 infants had early lip repair for their cleft lip and 55 infants had late lip repair (aged three to four months old). Mother-infant interactions were assessed in both groups at two, six and twelve months old. The mother-infant interactions in both groups were video recorded and rated by trained psychologists at two, six and twelve months old. At 18 months old, trained psychologists who were blind to the timing of lip repair, assessed the cognitive development of infants, using the Bayley Scales of Infant Development (1993). Infant attachment to the mother was also assessed using the Strange Situation Procedure (Ainsworth, Blehar, Waters, & Wall, 1978). In addition, mothers completed a questionnaire exploring infant behavioural problems. The mothers were also interviewed by trained psychologists when their infant was two or six months old to explore if there had been any maternal depressive symptomology since the birth. The structured clinical interview for DSM diagnosis (Spitzer, Williams, & Gibbon, 1994) was used to assess depressive symptomology. Different researchers were used to rate the maternal and infant behaviours.

The findings from Murray et al. (2008) suggest that there were no differences in terms of attachment and behaviour problems between both groups. However, the infants who had a late lip repair performed significantly worse on the Bayley Scales of Infant Development, suggesting that these infants experienced poorer cognitive development at 18 months old. Murray et al. (2008) suggest that this was because more difficulties in mother-infant interactions occurred in the late repair dyads because the cleft lip disrupted mother-infant communication. Murray et al. (2008) concluded that interventions which facilitate the mother-infant interaction are necessary to enhance socio-emotional development in this population. However, as with the studies reviewed above, what is missing is an understanding of how these early relational experiences shape the infants' sense of self. A further limitation of these studies as a whole is that the samples consist of infants with a cleft lip and/or palate and neglect to consider how other craniofacial conditions such as congenital facial palsy impact the mother-infant bonding process.

In terms of later psychosocial development, there is a body of research findings which suggest that children and adolescents living with various congenital conditions which alter facial appearance are likely to have a poorer self-concept and lower levels of self confidence in comparison to their non affected counterparts (for review see Murray, Arteche, Bingley, Hentges, Bishop, Dalton, Goodacra, & Hill, 2010). However, this research has mainly focused on children and young people with a cleft lip and/or palate and neglected to consider other craniofacial conditions. Furthermore, in these studies the self-concept has been conceptualised as a cognitive construct, measured using cognitive tools and analysed using a quantitative approach. Consequently, these studies neglect to explore the impact upon the nonverbal (affective and embodied) sense of self and therefore do not provide a full picture of how the sense of self might be impacted.

Griffiths, Williamson, and Rumsey, (2012) conducted a mixed methods study exploring the romantic experiences of 40 adolescents (22 males and 18 females) living with a visible difference. An online qualitative survey was used to collect data from participants with a variety of visible differences, in which 26 participants had a cleft lip and the remaining visible differences consisted of skin conditions, eye conditions and a birthmark. The survey consisted of closed and open-ended questions, in which the frequency of responses was calculated using quantitative techniques and participant experiences were understood through the use of inductive thematic analysis (Braun & Clarke, 2006). Although the quantitative analysis revealed that the majority of adolescents had some experience of developing romantic relationships, the qualitative analysis illustrated how several participants felt that their appearance prevented the development of romantic relationships and impacted their overall enjoyment of romantic relationships.

Although this study was effective in terms of identifying the key themes, the qualitative data provided was descriptive and did not provide an analytic understanding of the psychological and relational processes underpinning these themes. It is important that these relational processes are understood, so that effective specialist psychotherapeutic interventions can be developed to support adolescents with a craniofacial condition who experience difficulties in this area.

Sharratt, Jenkinson, Moss, Clarke, and Rumsey, (2018), conducted qualitative research exploring the experiences of romantic relationships in individuals living with visible differences. Participants included 16 women and 6 men who were 18 years old or over and the sample was mixed in terms of congenital and acquired visible differences. Semi structured interviews were conducted and analysed using an inductive thematic analysis (Braun & Clarke, 2006). The findings suggested that visible differences negatively impacted participants' romantic experiences, including difficulties developing intimate romantic/sexual relationships due to feeling unattractive or non-sexually appealing to others, as well as concerns about sexual performance and heritability. However, while the study makes a novel contribution to the field in terms of identifying the key issues which negatively impact the experience of romantic relationships, what is now required is an in depth understanding of the relational processes involved in the construction of the 'self' as 'unattractive.'

Conversely some research findings have indicated that many individuals living with congenital conditions which alter facial appearance report positive psychological adjustment across the lifespan (Stock & Feragen, 2018). Persson, Aniansson, Becker, and Svensson, (2002) compared the self-concept and degree of introversion in 55 adolescents living with a cleft lip and/or palate with a control group of 31 adolescents. The Tennessee Self Concept Scale was used to measure self-concept and the Eysenck Personality Questionnaire inventory was used to measure introversion. The findings suggested that those with a cleft lip and/or palate did not experience a poorer self-concept or more introversion in comparison to the control group. However, as above, this study is limited in that it measures the cognitive aspects of self only and neglects to consider the nonverbal sense of self. It is possible that the additional use of qualitative methods may have resulted in the generation of richer data and resulted in the provision of a more comprehensive understanding of how the self develops in this population.

Egan, Harcourt, Rumsey, and McBain, (2011) conducted qualitative research exploring the experiences of 12 participants living with a visible difference who identified as adjusting positively. The visible differences reported included; psoriasis, a port wine stain, scarring, amputations, burn injuries, eye disease, mastectomy, and alopecia. A mixture of focus group and individual interviews were conducted. The findings suggested that individuals who can develop; inner strength and positivity, good coping techniques, downward social comparisons, humour and spirituality, are likely to adjust positively to living with a visible difference.

Egan et al. (2011) findings echoed findings from an earlier qualitative study conducted by Thompson and Broom (2009) who used semi structured interviews to explore how six women and two men with acquired and congenital visible differences positively managed intrusive reactions around their appearance. The data was analysed using interpretive phenomenological analysis (Reid, Flowers, & Larkin, 2005). The findings suggested that social inclusion and acceptance were important for facilitating the positive adjustment process.

However, one main limitation with the findings from Egan et al., (2011) and Thompson and Broom (2009) is that both studies recruited participants who identified as adjusting positively, therefore, the findings might not be representative of the experiences of the wider population. A second limitation for both studies was that the samples consisted of a mixture of congenital and acquired conditions. Although Egan et al. (2011) suggest that the themes of positive adjustment may be the same for those living with any type of condition which alters appearance, this hypothesis needs to be explored further. It could be argued that individuals with acquired visible differences are likely to have known a different embodied sense of self pre-injury/illness, whereas, those with congenital conditions will not have had this experience and therefore, a deeper understanding of the pathways involved in the adjustment to congenital and acquired conditions is needed before any conclusions can be made about the differences and similarities.

2.1.3 Psychosocial adjustment in individuals with congenital facial palsy

As congenital facial palsy does not only alter appearance but typically impairs facial expression, vision, hearing and speech (Müller et al. (2013), it is important to review the findings from the psychological research which has been conducted with individuals with this condition so that a deeper understanding can be gained around how the 'self' might be constructed in this specific population. As discussed above, there is currently an absence of findings for the period of infancy and childhood and hence the findings considered here will be those from studies undertaken with adolescents and adults with congenital facial palsy.

Bogart, Tickle-Degnen, and Joffe, (2012) and Bogart (2015) explored the experiences of social interaction with twelve adults and ten adolescents living with Moebius Syndrome using focus groups. The data was analysed using content analysis in which the findings from these qualitative studies suggest that participants had difficulties engaging in social interactions with strangers or groups because of their limited facial expression, fear of negative judgement by others, lack of self-confidence and low self-esteem and experience of prejudice and social stigma. These findings supported those from an earlier quantitative study conducted by Bogart and Matsumoto (2010) which found that those living with Moebius Syndrome scored significantly lower on Satisfaction with Life Scales than the control group. Whilst these findings provide some preliminary insight into the psychosocial experiences of those with congenital facial palsy, they do not provide insights into the relational processes that contribute to these negative social experiences and the impact this has upon participants' self constructions.

Cole (2001; 2009) collected single narratives from men and women with Moebius Syndrome and argued that these narratives are suggestive that those living with this condition are likely to experience an impoverished sense of self. Cole (2009) suggests that not only was the individual unable to express their personality and affectivity to others through facial expression but their ability to comprehend their affective states through the channel of proprioceptive feedback was likely to be compromised because of the facial paralysis. Cole (2009) surmised from the narratives gathered that significant disruptions in the interaction between self and other occur on both an implicit and explicit level. Although Cole's (2009) analysis provides a deeper insight into the psychosocial experiences of those living with Moebius Syndrome and begins to explore the impact this has upon the self on an embodied level, further empirical qualitative work exploring how the sense of self is constructed within this population is needed.

A relational psychoanalytic framework could enhance the work of Cole (2001; 2009) as it would provide an empirical understanding of the unconscious relational processes that occur during interpersonal interactions and intrapersonal relationships (one's relationship with self). This theoretical understanding is currently missing within the field of visible difference, relational psychoanalysis, disability studies and Counselling Psychology.

More recently, several studies have been conducted within the field of health psychology which have explored the factors that enhance social communication and quality of life in those living with congenital facial palsy. Bogart, Tickle-Degen, and Ambady, (2014) recruited 27 people with acquired and congenital facial palsy from support groups and video recorded them responding to a range of stimuli which triggered happiness and sadness. Five perceivers were recruited (individuals who did not have facial palsy) and they were asked to rate their perceptions of the emotions expressed by the participants with facial palsy. Bogart et al. (2014) found that using compensatory expressions during social interaction (e.g. gesturing or tone of voice) significantly improved the impression the individual with facial palsy made upon the 'other' during social interaction, all of which is likely to improve their self-esteem.

However, one of the main limitations of this study is that it fails to explain how compensatory expressions improve the social interaction and how this enhances self-esteem in the individual with facial palsy. Furthermore, the authors provide a cognitive conceptualisation of self-esteem and neglect to consider the impact upon the nonverbal (affective and embodied) experiences of self. It is important to understand how compensatory expressions influence the individual's sense of self and relationship with others on an implicit as well as explicit level, as Cole (2009) suggest that facial palsy significantly disrupts non-verbal communication.

Michael, Bogart, Tylén, Krueger, Bech, Østergaard, and Fusaroli, (2015) explored how compensatory expressions could improve the social interactional experiences of those with congenital facial palsy. Michael et al. (2015) tested the efficacy of a social skills intervention which was designed to teach adolescents living with Moebius Syndrome how to express themselves more effectively during social interaction. Five female adolescent participants living with Moebius Syndrome were paired (pre-intervention) with a control (teenager who did not have Moebius Syndrome) and with a different teenage control post intervention. Rapport between the pairs were assessed using a self-report measure and behavioural coding of video interactions, in which findings revealed that observer coded rapport was significantly higher post intervention. Further objective signs that there had been an enhancement of rapport post intervention included higher levels of nonverbal expressivity and a more varied speech rate between partners and the control participants displayed a significant decrease in fidgeting behaviour (Michael et al., 2015). The authors concluded that compensatory expressive strategies can improve the rapport between an individual with Moebius Syndrome and their interactive partner.

Although this study had several strengths in that the use of a multidisciplinary research team allowed for the integration of research methods which meant that changes in implicit as well as explicit interactional processes could be measured, the study did not explore the longer-term outcome such interventions might have upon the individual's social interactions and sense of self. Therefore, it is difficult to know how effective this intervention might be in the longer term. Further research in this area is needed to develop an evidence base and gain a better understanding of this.

Stock and Feragen (2016a) and Stock, Hammond, Owen, Kiff, Shanly, and Rumsey, (2016b) state that at present, it is difficult to draw any firm conclusions about the impact of congenital craniofacial conditions on psychosocial development across the lifespan. This is because there exists a lack of longitudinal data in this area and the published studies differ in terms of sample sizes and other demographic factors, including research instruments and data collection methods, recruitment criteria and the methodologies used (Stock et al., 2016a; Stock et al., 2016b). Stock et al., (2016a; 2016b) advocate for a cross fertilization of ideas between disciplines and for multidisciplinary research to address these methodological challenges and to develop more effective specialist psychotherapeutic interventions.

2.1.4 Current psycho-social interventions for individuals with craniofacial conditions

Harcourt, Hamlet, Billaud Feragen, Garcia-Lopez, Masnari, Mendes, Nobile, Okkerse, Pittermann, Spillekom-VanKoulil, Stock, and Williamson, (2018) recently conducted an online survey exploring the availability of specialist psychosocial interventions across Europe for people living with a variety of visible differences. Findings revealed that specialists had a tendency to use Cognitive Behavioural Therapy over other therapeutic interventions and that access to specialist psychotherapeutic support varied across Europe. Harcourt et al. (2018) concluded that more needs to be done to improve access to specialist psychosocial support and to explore the effectiveness of other psychotherapeutic approaches so that those living with a visible difference can access a psychological intervention that is most appropriate for their individual needs.

Although the study conducted by Harcourt et al. (2018) is significant for highlighting the inequalities that are experienced across Europe in terms of access to specialist psychosocial interventions and the over reliance upon cognitive behavioural interventions, the study provides a general overview and does not focus on specific conditions. It seems important that condition specific research is also conducted as the literature reviewed above indicates that each condition will have unique physical challenges associated with it and therefore, it is possible that some conditions such as the congenital facial palsies may require the development of condition specific specialist psychosocial interventions. At present, specialist psychological interventions do not exist for those living with congenital or acquired facial palsy (Walker, Hallam, Ni Mhurchadha, McCabe, & Nduka, 2012).

A specialist online intervention which is grounded within cognitive behavioural principles has been developed for young people living with a visible difference (YP Face It) and a version for adults (Face It). This has been found to be effective in reducing appearance related distress (Bessell, Brough, Clarke, Harcourt, Moss, & Rumsey, 2012). However, it has been suggested that in general, cognitive behavioural interventions for this population continue to lack a strong evidence base overall and that more research in this area is needed (Bessell & Moss, 2007; Jenkinson, 2012; Hansen & Butler, 2013; Norman & Moss, 2014). Furthermore, Hansen and Butler (2013) suggest that cognitive behavioural interventions may not be appropriate for everyone who experiences psychosocial difficulties due to living with a visible difference, as these approaches focus on improving symptoms rather than on self-identity and longstanding relational/interpersonal issues.

More recently, there has been a suggestion within the field of visible difference that third wave cognitive behavioural therapies such as Acceptance and Commitment Therapy (Zucchelli, Donnelly, Williamson, & Hooper, 2018) and compassion focused approaches (Krasuska, Millings, Lavda, & Thompson, 2017) could be used to enhance psychological wellbeing in this population. These third wave approaches attempt to change an individual's relationship with unhelpful cognitions or maladaptive behaviours through utilising acceptance, value driven and mindfulness-based techniques. Within the third wave therapies, more of an emphasis is placed upon understanding self experience as a relational process (Gilbert, 2009) which is impacted by social context, and developing different ways to be or relate with one's distressing thoughts and feelings when they cannot necessarily be changed through using traditional cognitive behavioural techniques. However, presently, there exists a lack of empirical research which has been conducted into the efficacy of these third wave models within the field of visible difference. It could also be argued that a deeper understanding of the relational processes involved in the construction of the 'self' is needed for those living with congenital and acquired visible differences before effective interventions can be developed to work with the 'self' in these populations on a relational level.

The constructions of 'self' will now be discussed in the section below and a case will be made for how a relational psychoanalytic perspective could enhance psychological knowledge and inform clinical practice within the field of congenital facial palsy. The argument I will make in the section below will be informed by my personal experience of constructing my sense of self and how my experience of receiving relational psychoanalytic psychotherapy and training within the relational psychoanalytic model as part of my Counselling Psychology doctorate facilitated the validation of my sense of self. I believe that this was achieved through developing a deeper understanding of the unconscious relational dynamics which were impacting my relationship with myself and maintaining my low self-esteem. This is something that I had not been able to achieve through cognitive behavioural therapy and in my opinion, this was because the cognitive behavioural therapy focused upon restructuring my ‘cognitive self’, however, my relationship with myself on an affective and embodied (implicit) level had been neglected. As my relationship with myself had been disrupted on this implicit level as well as on a cognitive level, these implicit relational processes needed to be repaired in order for me to construct a more validating relationship with myself. It is on this basis that I believe that the construction of a relational developmental theory explaining how the ‘self’ might be constructed within this specific population is necessary and could be highly beneficial for individuals living with this condition, as well as for their caregivers and families and the health and educational professionals and specialist organisations supporting them.

2.2 Constructions of the ‘self’

2.2.1 Social constructions of the ‘self’

Many different constructions of the ‘self’ and theories around how it is formed exist (Callero, 2003). Foucault suggests that a ‘true self’ does not exist but rather the ‘self’ is something which is socially constructed and forced into existence by the dominant institutions within society, to maintain power, control and social order (Foucault, 1994). Similarly, sociologist Hall (1996) argues that there is no ‘true self’ which can be discovered through psychological analysis and that this is because self and identity are constructed within discourses rather than outside of them.

These ideas support the cultural and anthropological argument that the ‘self’ is purely a cultural construction; it is argued that the idea of the ‘self’ as a unified, bounded psychic structure embedded within the psyche of every human being is a westernised construction (Heine, 2001). Cultural psychologists and anthropologists argue that the sense of ‘self’ is constructed through the culture one grows up within and finds oneself living within and cannot be separated from this (Markus & Kitayama, 1991; Kitayama, Markus, Matsumoto, & Norasakkunkit 1997; Triandis, 1989). It has been suggested that this can be seen through the analysis and comparison of the western notion of the ‘individualistic self’ with the eastern ‘collectivist self’ in which the different value placed by each culture on individualism and collectivism results in the different cultural constructions of ‘self’ (Markus & Kitayama, 1991; Gergen, 2011).

Symbolic interactionists (Mead, 1934; Wiley, 1994) conceptualize the ‘self’ as a reflexive process, in which all human beings have the unique capacity during social interactions to be both a subject (an experiencer or the ‘me’) and to become an object to oneself (to observe and reflect upon self, the ‘I’). Mead (1934) believed that the ‘self’ is constructed through the interaction between the ‘I’ (the reflector/observer) and the ‘me’ (which is constructed through the appraisals and interactions with others).

Similarly, social constructionists argue that what is known about self and others is derived through the process of social interactions with others and self across history and culture (Gergen, 2011; Burr, 2015). This school of thought is at odds with traditional western ways of conceptualizing the individual as the rational knower and challenges the westernised ontology that there is only one true reality which can be known (Burr, 2015). Rather, social constructionists believe that the knowledge generated about self, other and the world is dependent upon relationships with others and the individual’s interpretations of these (Gergen, 2011).

Social constructionists are particularly interested in how language is used to form narratives and the central role that narratives play in the construction of ‘self’ (Gergen & Gergen, 1983; McAdams, 2006). Narratives can be defined as the stories individuals construct to make sense of their lived experiences. The way these stories are structured, how they are told, the positionality of self and others within the narratives and the socio-cultural frameworks in which they are told are believed to shape identity and behaviour (Macintyre, 1984). However, Gergen argues that while it is helpful to understand the construction of ‘self’ through a narrative and discursive lens, this has resulted in a shift of focus away from understanding the ‘psychological self’ (Gergen, 2011). Gergen (2009; 2011) states that the need to bridge the gap between understanding the intrapsychic and social processes that contribute to the construction of the ‘psychological self’ has led to the construction of what is now known as the ‘relational self’.

2.2.2 Relational psychoanalytic constructions of the ‘self’

Storolow (1995) suggested that a new paradigm has emerged within the field of psychoanalysis, one which no longer conceptualizes the individual as a psychic structure governed by aggressive and sexual drives but one which constructs people as relational beings, governed by the drive to build relationships and connections with others. Within the field of relational psychoanalysis there is now a consensus that the infant’s experience in relationship with the primary caregiver becomes the foundation upon which the sense of self is built (Fairbairn, 1952; Klein; 1959, Winnicott; 1960; Mahler; 1974; Fonagy, 2001; Stern, 2006).

Relational psychoanalytic theorists such as Winnicott (1958; 1965); Kohut (1971) and Sullivan (1972) postulate that the infant begins life in a state of fragmentation in which experiences of self and others are scattered rather than unified and cohesive. The mother, or primary caregiver becomes the infant’s first mirror; reflecting the infant’s scattered experiences so that the infant can make sense of and internalise these experiences. Winnicott (1958;1965); Kohut (1971) and Sullivan (1972) argued that the infant’s internalisation of the mother-infant relationship becomes the foundation upon which the sense of self and other is built and which guides interactions with others across the lifespan.

Sullivan emphasised the impact of social, cultural and environmental factors upon the individual’s developing sense of self, especially the impact of loneliness, misfortune and alienation by others (Sullivan, 1938). Sullivan also distinguished between the ‘self’ and personality, describing personality as the entire functioning of a person including their emotional experiences and behavioural patterns whereas; the ‘self’ is made up of images and ideas concerning the individual’s experience of himself and is constructed upon reflected appraisals from others (Sullivan, 1972).

2.2.3 Attachment, Mentalisation and the construction of ‘self’

Bowlby (1969; 1973; 1980) proposed attachment theory as an alternative perspective to psychoanalytical explanations of human development. Attachment theory has since been widely researched and now has a strong supporting evidence base (Ainsworth,1970). Bowlby (1973) defines attachment as a longstanding emotional bond which one individual forms to another person. Attachment theory postulates that infants are biologically programmed to seek proximity and interaction with adult caregivers to ensure their physical and psychological survival (Bowlby, 1969). During the first year of life infants actively direct their proximity seeking behaviours towards several primary attachment figures. The infant integrates into memory these early interactions with his or her primary caregivers and these experiences are constructed into an ‘internal working model’ that guides interaction with others and self across the lifespan (Bowlby, 1969; 1973; 1980).

Under optimal conditions, the attachment figures are physically and emotionally accessible and sensitive to the needs of the infant which enables the infant to experience a secure base from which to explore the world (Ainsworth & Marvin, 1995) and develop a sense of identity (Bretherton, 1991). If the infant is unable to have consistent access to a secure base, he/she is likely to develop problematic attachment styles which will make it difficult for the individual to feel safe in the world and experience and maintain healthy and secure interpersonal relationships with others and self across the lifespan (Ainsworth, 1970).

Psychoanalytic clinician-researchers Fonagy and Target (1997) have advanced attachment theory by highlighting the relationship between attachment and mentalisation and the role this plays in the organization of the self. Mentalising involves developing the ability to make inferences about the thoughts, feelings, intentions and beliefs which may underpin the behaviour of the other and the self (Allen, Fonagy, & Bateman, 2008). The development of reflective function capacities renders the behaviour of others predictable and enables the individual to activate an appropriate self-other representation (internal template) to respond effectively during interpersonal interactions (Fonagy & Target, 1997). It has been suggested that the development of reflective function capacity begins during infancy through consistent access to the reflective mind of a mature other (Fonagy et al., 2004).

Bateman and Fonagy (2016) have argued that an infant develops a sense of self through using non-verbal modes of expression to communicate their primary affect. A caregiver who possesses good reflective function abilities is able to sense this and respond with an accurate representation of the infant's mental state, enabling the infant to recognise the mirrored affect as his or her own mental state and therefore regulate it. Fonagy et al. (2004) argue that the ability to mentalise is essential for the metacognitive monitoring of experience, affect and behaviour across the lifespan and that these mirrored affects become the foundation upon which the sense of self is built (Bateman and Fonagy, 2016).

Receiving inaccurate mirroring results in the infant becoming overwhelmed by their mental states which are mirrored through the facial expression and body language of the other and prevents connection to their own mental states because they are experienced as too frightening or threatening (Fonagy et al. 2004). This results in the construction of an 'alien self.' The individual experiences their 'alien self' as bad or hated and defends against this intense emotional pain by relating to their self as an external object (a 'not me' experience). Consequently, this results in the experience of self-regulation and interpersonal difficulties which repeat across the lifespan unless the individual learns to mentalise their experiences (Bateman & Fonagy, 2016).

Whilst Mentalisation theory has furthered relational understanding of how the self develops, it has come under criticism in terms of the social ontological assumptions in which it originates from (Koester, 2017). It has been argued that mentalisation theory remains grounded within a cartesian ontology as it neglects to consider how mentalising occurs through the experience of embodiment, focusing more on the cognitive representations and does not pay sufficient attention to the sociocultural dimensions of social cognition (Koester, 2017).

2.2.4 Contemporary infant research and the construction of self

Contemporary infant research has further advanced mentalisation and attachment theory by providing an understanding of the mother-infant dyad. Contemporary infancy researchers focus on understanding the dyadic communication field involved in the construction of the relational self; that is understanding how each partner's nonverbal behaviour mutually influences the moment by moment interaction between self and other and the interpersonal relationship that develops from this (Beebe & Lachmann, 2013). Infancy and attachment researchers Beebe and Lachmann (2013) have built upon the concept of parent-infant synchrony to enhance theoretical understanding of the attachment process. Synchrony has been defined by developmental psychologists as the dynamic process whereby hormonal, physiological and behavioural cues are exchanged between parent and infant during social interaction, as each attachment partner learns to adjust to the biobehavioural cues of the other and synchronize with them in terms of biological and interactive rhythm and reciprocity, so the parent-infant bond is formed (Feldman, 2007). Beebe and Lachmann (2013) have extended knowledge of how parent-infant synchrony facilitates the bonding and attachment process by using video microanalysis to explore how the pre-symbolic mother-infant action dialogues influence the formation of the infant's sense of self and attachment style.

Beebe and Lachmann's (2013) findings have illustrated the significant role that face to face communication (especially smiling and gazing), along with body movement plays during infancy in terms of establishing patterns of interpersonal relatedness which continue across the lifespan. Beebe and Lachmann (2013) compared attachment styles in twelve sets of mother-infant dyads at four and twelve months old. Beebe and Lachmann (2013) report that infants who had an insecure or disorganised attachment style at twelve months old experienced a dyadic system at four months old whereby their maternal partner recognised their distress but became overwhelmed and did not know how to accurately mirror it. Instead these mothers engaged in unhelpful behaviours such as overriding the distress with positive emotions by smiling when the infant was crying or distracting the infant with toys. Consequently, these infants appeared to become confused by their emotions and were not able to use the mother to regulate their distress. Beebe and Lachmann (2013) state that it is likely that these infants did not feel sensed, recognised, seen or known by their mother during these moments of distress and they were not able to find and use her to re-regulate their affect.

Harris (1997) has stated that although the work of Beebe and Lachmann (2013) provides a detailed description of the non-verbal pattern of interaction between parent and infant, what is missing is an understanding of the meanings both partners construct in relation to these self-other exchanges and how this influences the construction of self across the lifespan. Harris (1997) argues that more needs to be done to integrate the findings from mother-infant regulation studies with psychoanalysis which is invested in understanding meanings, as this will close the gap between theory and clinical practice. Harris (1997) also states that a further limitation of Beebe and Lachmann's approach is that it is overly focused on face to face interaction and neglects to consider how other forms of embodied interaction influence the patterns of relating within the mother-infant dyad.

It could be further argued that the research undertaken by Beebe and Lachmann (2013) may be culturally biased as the dyads consisted of mothers and infants, and so these findings might be less relevant within eastern cultures whereby extended family members play more of an active role in primary caregiving (Bornstein, 2013). There are also primary caregiving differences between cultures with regards to the frequency of use of face to face contact and touch in terms of parenting practices (Bornstein, 2013). Beebe and Lachmann (2013) neglect to consider how these cultural differences might influence the process of developing a secure bond and attachment with primary caregivers and constructions of the sense of self. A further limitation of the work of Beebe and Lachmann (2013) is the lack of consideration given to how the presence of a physical disability which might impair communication impairment in the mother and/or the infant could influence the dyadic communication system and in turn, the infant's experience of self.

I will now review the relevant literature from the communication impairment field in order to develop some preliminary insight into how congenital communication impairments might impact the dyadic communication system between the communication impaired individual and the other with whom they are interacting. As I am concerned with how the 'self' develops across the lifespan, I will begin by reviewing the findings within the area of infancy and this will be followed by a review of the relevant findings across the remaining stages of the lifespan (e.g. childhood, adolescence and adulthood).

2.2.5 Communication impairments and the construction of 'self'

It has been hypothesised that infants who have any physical disability which significantly impairs communication are likely to be at risk of developing an insecure attachment style (Koester & Harper, 2010). This is said to be because they often struggle to develop an effective shared communication system with their caregiver as he or she does not know how to adapt to meet the infant's unique communication needs (Koester & Harper, 2010). Consequently, this can result in parents experiencing a sense of helplessness and incompetence and can lead to an over directive parenting approach or reduced social interaction with the 'disabled' child (Clements & Barnett, 2002). It has been suggested that this can result in a frustration of the infant's social and emotional needs and stunts the social and emotional development of the infant, all of which is likely to impact their psychological development across the lifespan (Malekpour, 2007).

Interestingly, research findings have shown that minimal disruptions occur when both the parent and the infant have the same communication impairment, as has been reported in studies exploring communication between hearing impaired parent-infant dyads (Spencer, 2000). It has been suggested that this is because the hearing-impaired parent already understands the infant's unique communication needs and can intuitively meet these by engaging in multimodal forms of communication such as prolonged visual attention, use of sign language and appropriate repetitive rhythms of touch and movement, as well as increased use of facial expression, all of which provide the infant with optimal stimulation (Koester, Brooks, & Traci, 2000; Mohay, 2000; Pizer, Walters, & Meier, 2007).

Bornstein (1995) describes this intuitive ability to sensitively meet the unique communication needs of the infant as 'intuitive parenting.' Malekpour (2007) states that 'intuitive parenting' is essential for developing the disabled infant's ability to mentalise (understand the intentions and emotions of self and others) which equips them with the necessary social and emotional skills needed to interact with peers when they attend school. Steingberg (2000) notes that children with communication impairments are at risk of developing poor mentalising abilities due to difficulties establishing a shared communication system in the pre-verbal period of life and the tendency for parents to disengage from the social interaction in this early developmental period. However, it is important to note that this is something which has not yet been directly researched.

It has been reported that infants who have visual impairments, especially those who are blind, are at heightened risk of developing insecure attachment patterns and poor psycho-social outcomes in childhood and later life (Lang, Hintermain, & Sarimski, 2017). This is because the visual system plays a fundamental role in the cognitive, social and emotional development of an infant (Lang et al., 2017). Consequently, these infants face specific developmental challenges in terms of developing motor development, pre-verbal communication and concept formation because they do not have good access to the visual information needed to develop these abilities (Brambring, 2005; 2007).

Loots, Devise, and Sermijn, (2003) have stated that a visual impairment or blindness in an infant impairs their ability to experience intersubjectivity (self-other relatedness) because of difficulties establishing eye contact, gazing and registering the facial expressions of others due to poor vision. Loots et al. (2003) suggest that the visual impairment means that the infant is less experienced than sighted infants in terms of making and responding to facial expressions from others, as well as using other non-verbal forms of communication. Consequently, the observer often misinterprets these interactional difficulties as signs of social disinterest, which results in less frequent social interaction with the visually impaired infant (Loots et al. 2003).

Odom (2005) argues that in general, the research findings conducted within the field of disability studies suggest that children with disabilities do perform less well socially in comparison to peers without disabilities. Moreover, Odom (2005) argues that children who have more profound impairments which severely impact their ability to communicate with others seem to experience more social rejection than those who have less severe communication impairments (Odom, Zercher, Shouming, Sandall, & Brown, 2006). It has been suggested that this is because children do not know how to adapt their communication style to meet the unique communication needs of another child who has a communication impairment (Odom et al., 2006). This is believed to result in the build-up of frustration in the individual with the communication impairment, which is often displayed through aggressive behaviour towards others and/or self, emotional dysregulation or social withdrawal (Odom et al., 2006).

Findings from a study conducted by Molden (2014) provide evidence that disruptions within the intersubjective (interpersonal) process continues across the lifespan for some who live with a visual impairment. Molden (2014) conducted a qualitative study exploring the experience of parenthood in nine visually impaired mothers living in the UK and analysed the data using Interpretive Phenomenological Analysis. Findings from this study suggested that other sighted mothers would either avoid making eye contact and avoid interacting with the visually impaired mother or the visually impaired mother would become the object of their gaze. During such interactions the visually impaired mother would introject (take into the self) the shame and stigma projected onto them by the sighted other as a consequence of misperceptions around their ability to be a ‘good enough parent’ due to their visual impairment. Consequently, these participants reported withdrawing from social interaction and public places as these interactions were invalidating their sense of personhood.

However, whilst the communication impairment studies provide some insight into the difficulties encountered on a dyadic level between the ‘disabled’ individual and the ‘non-disabled’ other, what is currently missing from the literature, is a relational model which illustrates how these intersubjective experiences shape the construction of ‘self’ across the lifespan. Furthermore, the research that has been conducted in the field of communication impairments and disability has differed in terms of samples and research methods used to collect the data. Therefore, it is difficult to integrate the findings and build an accurate picture of how the ‘self’ might develop in individuals born with physical conditions which impair communication. This provides further evidence for why it is imperative that this current study is undertaken.

2.3 Rationale for the study

The challenges I faced in terms of developing a positive sense of self on a cognitive, affective and embodied level as a consequence of living with congenital facial palsy, prompted my exploration of the visible difference literature. Through my review of the visible difference literature I came to realise that whilst there is a body of research which postulates that living with a visible difference can have a negative impact upon self-esteem (for review see Murray, Arteche, Bingley, Hentges, Bishop, Dalton, Goodacra, & Hill, 2010), the findings relate to the ‘cognitive self’ whereas, the ‘relational self’ has yet to be explored. I was aware through my relational psychoanalytic training that there was a body of research that existed within the field of contemporary relational psychoanalysis which highlighted the significant role that face to face interaction played in the construction of the 'relational self' in the pre-verbal years. However, a gap currently exists within the visible difference and relational psychoanalytic literature in terms of understanding how the sense of self is constructed when the main non-verbal and verbal communicative channels (e.g. facial expression, smile, gaze, hearing, vision and speech) that are used to build interpersonal relatedness are disrupted from birth, as is the case in individuals born with congenital facial palsy.

It seems important that this research question is explored so that a deeper psychological understanding can be gained in terms of understanding the implicit as well as explicit relational processes involved in the construction of the sense of self in this population. The construction of a relational developmental theory illustrating this process could encourage the development of specialist relational psychotherapeutic interventions for this population and inform knowledge and professional practice amongst the health and educational professionals as well as the specialist organisations supporting these individuals and their families. This is very much needed in this field which is dominated by medical research findings and where the psychosocial needs of the population appear to have been neglected.

2.3.1 Aims of the study

(1) To explore how the sense of self is constructed across the lifespan in individuals with congenital facial palsy.
(2) To construct a Grounded Theory of this process.
(3) To 'give voice' to a marginalised group whose psycho-social needs are often overlooked.
(4) To add a relational psychoanalytic perspective to the psychological literature available within the area of facial palsy and field of visible difference.

2.3.2 Objectives of the study

1. To conduct in depth semi structured qualitative interviews with individuals with congenital facial palsy.
2. To utilise a constructivist grounded theory methodology (Charmaz, 2014) to construct the grounded theory.

3.0 Methodology

3.1 Epistemology

In terms of my epistemological positioning I consider myself to be a social constructionist (Burr, 2015; Gergen 2009; 2011). There is not a universally agreed definition of social constructionism however, an approach might be considered social constructionist if it takes a critical stance towards the construction of knowledge, and views knowledge as culturally and historically specific as well as constructed and maintained through social processes (interactions) all of which influence social action (Burr, 2015). Whilst I accept that there is a 'real' physical world, I believe that the ways in which we come to know this physical world is always influenced by culture, language and history. I believe that this is especially the case when it comes to understanding the social world and personal identity.

My theoretical framework is influenced by relational (developmental) psychoanalysis which places the relational 'self' at the heart of all therapeutic work. Relational theorists postulate that the sense of self is constructed through experience of relationships with others across the lifespan and the meanings individuals co-construct through their social interactions with others. I conceptualise the 'self' as a relational process which consists of cognitive, affective and bodily experiences, which is continuously re-constructed across the lifespan, through our social interactions with others through sharing language, signs, symbols and other cultural tools. My framework is also influenced by the principles of Counselling Psychology as well as my personal experiences of Moebius Syndrome and the therapeutic experience I have gained throughout my doctoral training; I have worked in a range of clinical settings including primary and secondary care community mental health teams, a health psychology service and within a university student wellbeing team.

3.2 Rationale for a qualitative methodology

Qualitative methodologies are primarily concerned with understanding meanings, processes and the contexts in which meaning is constructed; they aim to generate ‘thick and rich’ data which are rooted within the subjective experiences of participants (Braun & Clarke, 2013). Therefore, a qualitative methodology is compatible with my epistemological positioning as a Social Constructionist and Counselling Psychologist as I am concerned with developing theoretical knowledge and psychotherapeutic interventions which are grounded in the subjectivities (lived experiences) of those who require them. A qualitative methodology is also appropriate for this study as there has been a call for within the field of visible difference for more qualitative research projects to be undertaken to give a stronger voice to those living with visible differences (Stock et al., 2016a; Stock et al., 2016b). This is needed specifically within the field of facial palsy which continues to be dominated by the medical model (Walker et al., 2012).

Furthermore, a quantitative methodology would have been an inappropriate choice for this study as this paradigm employs a cartesian conceptualisation of the ‘self’, in that it is separated into distinct measurable structures such as ‘self-efficacy’, ‘self-image’ and ‘self-esteem’ (Hermans & Dimaggio, 2004). The Cartesian ‘self’ appears to have dominated the field of visible difference research whereby most studies appear to have utilised positivist paradigms and quantitative methods to measure ‘self’. Therefore, the application of a constructivist grounded theory methodology would provide a novel approach within the field of visible difference which could result in the generation of new theory and understandings of ‘self’.

3.3 Epistemology of Grounded Theory

3.3.1 Historical overview of Grounded Theory

Grounded Theory is a systematic qualitative research methodology used for analysing social processes and constructing theory that is grounded in data (Charmaz, 2006; 2014). Grounded Theory was initially developed by US sociologists Barney Glaser and Anselm Strauss (1965; 1967) in response to mainstream sociological research which became overly focused upon quantitative research methods to test existent theories rather than developing new theories and adding to sociological knowledge (Charmaz, 2006; Charmaz, 2014).

Glaser & Strauss' (1965; 1967) original version of grounded theory was viewed by many as a bridge between positivist and constructionist assumptions through its emphasis on applying rigorous systematic procedures when analysing qualitative data, whilst simultaneously seeking to understand participants' actions, assumptions and meanings through the use of language and interpretation (Charmaz, 2006). Grounded Theory gained acceptance from quantitative researchers because of its rigour and systematic procedures for analysing data (Charmaz, 2014). However, since then various versions of Grounded Theory have been developed which do not rest on positivist assumptions.

Charmaz's (2006) constructivist grounded theory approach is rooted within the Symbolic Interactionist tradition. Symbolic Interactionism originated from the field of sociology which is interested in understanding how individuals and groups construct selves and identities, societies and reality through social interaction. Symbolic Interactionism pays attention to the use of language and sign mediation and how these are used and interpreted by individuals and groups to construct individual and/or shared meanings. Symbolic interactionists take the view that social life is composed of social and interactional processes (Charmaz, 2006). Charmaz (2006) rejects Glaser's (1965; 1967) view that theory is ‘discovered’ or that it ‘emerges’ through the analysis of data; she postulates instead that theory is co-constructed by the researcher and participant through their social interaction.

3.3.2 Constructivism and Social Constructionism

Constructivism is a theoretical approach within the field of the social sciences which explores how realities are constructed (Ponterotto, 2005). Traditionally within the field of psychology, constructivists held the view that meanings and realities were constructed within the individual through cognitive processes and were interested in understanding the psychological processes involved in the construction of meaning and reality (Raskin, 2002; Ponterotto, 2005). However, Berger and Luckmann (1966) coined the term social constructionism which emphasised how cognitive development and learning always takes place within a social context. Vygotsky (1978) argued that learning and cognitive development is always dependent upon culture and the access to the minds of others.

Whilst constructivism and social constructionism are similar in that both focus on understanding the social world and how individuals’ roles within it are constructed, Social Constructionism differs in that it places greater emphasis upon understanding how meaning is constructed through one’s positioning within socio-political, historical and cultural contexts. Social Constructionists explore how these social contexts and meanings are constructed and re-constructed across time through social interactions between and within groups (Burr, 2003). McNamee (2004) states that social constructionists view meaning making as a relational process and that it is through this that a sense of individuality is developed.

3.4 Rationale for Constructivist Grounded Theory

A range of qualitative methodologies were considered when designing this research project. A Constructivist Grounded Theory methodology was chosen due to my previous background in sociology and my interest in the intersection between social and psychological processes and how meaning is constructed. As Constructivist Grounded Theory originates from the field of sociology (the symbolic interactionist tradition), is rooted within Social Constructionism and ‘is a method for studying process’ (Charmaz, 2010), this methodology felt like an ideal fit with the aims of this project. Furthermore, a constructivist Grounded Theory approach seeks to go beyond the description of themes or patterns within data and moves towards an interpretive analysis and theory construction (Charmaz, 2012). This further aligned with the aims of the current research project. Finally, this methodology was chosen as Charmaz (2006) advocates using a grounded theory approach in an area which has been under researched which is the case for the area of congenital facial palsy.

Charmaz’s constructivist approach was chosen over earlier versions of grounded theory (Glaser & Strauss, 1965; 1967; Corbin & Strauss, 1990) due to my awareness that constructivist Grounded Theory places importance on subjectivity, recognising that both the researcher and the researched will be influenced by their individual values, beliefs and assumptions and that these will always influence the construction of data and theory (Charmaz, 2010). This matched my epistemological stance as a counselling psychologist whereby I place great importance upon reflexivity in my role as a practitioner and researcher. Researcher reflexivity is not considered at any depth in earlier versions of grounded theory which are rooted in post positivist assumptions, whereby the researcher is viewed as an objective scientist who remains separate from the data and discovers theory hidden within the data (Charmaz, 2010).

Interpretive Phenomenological Analysis (Smith, Flowers, & Larkin, 2009) was considered as a methodological approach but the epistemology underpinning IPA does not fit with my personal epistemology as outlined above. Secondly the focus of IPA is to understand how an individual experiences a phenomenon and makes meaning out of their experience (Smith et al. 2009). I was more concerned with understanding interactional processes and wanted to construct a theory grounded in the data. Furthermore, IPA requires a homogenous sample which would have been difficult to recruit for this study as congenital facial palsy is a heterogeneous condition and therefore no two palsies are the same (Müller et al., 2013).

3.5 Reflexivity

Wilkinson (1988) suggests that there are two types of reflexivity; personal and functional. Personal reflexivity involves examining how the researcher's personal assumptions, values, beliefs and actions may have influenced the knowledge constructed. Whereas, functional reflexivity involves critically examining the ways in which the research tools and methodology may have influenced the research process and data obtained.

3.5.1 Personal reflexivity

I am a thirty-one-year-old, female, Trainee Counselling Psychologist and I have 'insider status' (Dwyer & Bukle, 2009) as I was born with Moebius Syndrome. I did not receive a formal medical diagnosis until I was three years old and I underwent 'smile surgery' (a cross facial nerve graft) aged four. My personal experience of living with this condition, the lack of specialist psychological support and the struggles I have had in terms of accepting this condition as part of my 'self' is what initially sparked my interest in this research area, along with my awareness that minimal psychological research has been conducted to date.

I recognise now how all the medical interventions I received during childhood, along with the experience of difficult early interactions with medical professionals and teachers resulted in me growing up with a strong sense of being different to others. This resulted in me developing a sense of inferiority and shame and the construction of a defective sense of self. During my late adolescence I began to experience a grief around this 'normal appearance' that I could never have but I felt too ashamed to share this with anyone. Instead I concealed the grief and shame from others but over those years the grief became more emotionally intense, and I began to feel frustrated, angry and struggled to control these feelings. It was at this point that I entered weekly long-term psychoanalytic psychotherapy.

This was a life changing experience for me as for the first time I was in a position where I was unable to hide from my feelings or the parts of myself that I wanted to disown. Instead I was encouraged to look at these ‘shameful’ parts of me and to verbally share with another what I thought and felt about these parts of me. Through engaging in this relational therapeutic process, I was able to see how I had specific difficulties in the area of trusting and being emotionally intimate with others, which stemmed from my early childhood experiences. Learning to trust and feel safe in the presence of another became the focus/aim of the therapy. This was a difficult process for me as learning to trust and be emotionally intimate with another evoked strong feelings of fear, anxiety, confusion and shame within me.

I noticed that whilst conducting the data analysis, there were periods where the anxiety and frustration resurfaced. In the early stages of analysis when the method was new to me, I found myself worrying about doing the analysis wrong and feeling riddled with self-doubt. It was often hard to contain these feelings and I would often become frustrated and angry with myself and feel helpless. I found it hard to tolerate the messiness and lack of direction that qualitative data analysis brings with it in the early stages. Through reflection I was aware that this experience was activating an earlier affective sense of self (my childhood sense of self) which consisted of these feelings.

Fortunately, my supervisory team were able to recognise this and supported me to find ways of managing this. There was one supervisory meeting which felt like the pivotal turning point for me whereby I regained a sense of autonomy over the project. My supervisors facilitated this process by explaining that these experiences were a normal part of the research process and encouraged me to play to my strengths by writing memos rather than worrying about diagramming which I considered to be my weakness because it involved visual skills. Through having these experiences normalised by my supervisors and playing to my strengths I was soon constructing a tentative theory and diagramming this process.

Although this was a very difficult period for me on an emotional level, it was also a valuable learning opportunity as it put me in touch with lost (forgotten) childhood experiences in terms of struggling to build a sense of autonomy and provided me with a 'in vivo' experience of how it might feel to construct a sense of self in the early years. Interestingly, when analysing my data, I had overlooked these similar experiences that had occurred for participants. Reflective discussion with my supervisory team prompted me to re-read and further analyse my data. This was significant as I was able to identify codes around frustration and anger which I had previously overlooked, and these eventually became a core part of the grounded theory constructed.
Upon reflection from a psychoanalytic perspective, it seems likely that I overlooked these codes, as like some of the participants, I have learned to dissociate my experiences of frustration and anger as a way of coping. Therefore, it was difficult to recognise participant's experiences of frustration as doing so would bring me in touch with my own.

My personal subjectivity was explored and reflected upon throughout the research process by keeping a reflexive diary (which included my dreams) as well as keeping memos of thoughts and ideas and theoretical memos. I also had regular reflective discussions with my Director of Studies whereby we explored my personal subjectivity so that we could be aware of how this could influence the analytical process.

3.5.2 Functional reflexivity

I maintained a high degree of functional reflexivity by following Charmaz's (2006; 2014) guidelines closely. This involved receiving ongoing training in the method from my Director of Studies throughout the research process and organising regular supervisory meetings whereby we discussed and reflected upon how I conducted the research interviews and each stage of the data analysis.

Through these reflexive discussions with my supervisory team, I was able to acknowledge how my ‘insider status’ (Dwyer & Buckle, 2009) influenced my analysis of the data. I reflected on how I may have obtained in depth accounts from participants because my ‘insider experience’ equipped me with the knowledge needed to ask the right questions and probes during the interview to obtain the data required to answer the research question sufficiently. Furthermore, I reflected on how several participants had commented that it felt easy to open up to me because they knew I would understand their experiences on a deeper level because I had ‘insider experience’.

I reflected with my supervisory team upon how my ‘insider experience’ may have resulted in a deeper analytic reading of the data than if I had been an outsider researching this area as I was careful to pay attention to the implicit as well as explicit relational processes and to consider how these impacted the construction of the ‘self’. We agreed that it was possible that a researcher who did not have ‘insider experience’ might not have paid sufficient attention to the implicit relational processes as it was only through my personal experience of the condition that I was aware of how fundamental these processes are in the construction of ‘self’.

Whilst having ‘insider experience’ brings unique strengths to this project (as discussed above), I was aware that this could also be problematic. This is because there was potential for me to unconsciously impose my own subjectivity onto the design of the interview schedule and the reading and analysis of the data. I managed this effectively by engaging in a reflexive dialogue (throughout the research process) with another psychological researcher who has the same condition and research experience within this area. For the purposes of this study, this researcher colleague with ‘insider experience’ adopted a critical stance, exploring with me my underlying assumptions, supporting me to develop the interview schedule, and challenging my reading and analysis of the data.

It was through these discussions with this research colleague with ‘insider experience’ that I made the decision to design interview questions that were wide and open ended and to focus on each stage of the lifespan. We agreed that it would be better to keep the questions wide and open so that the participant could discuss the experiences that they felt were most significant in terms of constructing a sense of self. We decided to ask a separate question about each stage of the lifespan as we were aware from our lived experience that facial palsy presents challenges at each stage of the lifespan and this would ensure that I obtained sufficient data which covered the life course. This was necessary in order to answer the research question fully and to meet the aims of the project. I was mindful when designing the interview schedule that this schedule might not have worked effectively had I been conducting research in cultures whereby the lifespan is not conceptualised in terms of life stages/developmental periods (e.g. infancy, childhood, adolescence, adulthood) as it is in westernised cultures such as the United Kingdom and the United States of America.

As well as gaining input from a research psychologist with ‘insider experience’, I also showed the interview schedule and discussed my analysis of the data with trainee counselling psychologists who were members of my training cohort. These colleagues did not have ‘insider status’ (Dwyer & Buckle, 2009) and therefore, they were able to challenge my underlying assumptions and analysis of the data from an outsider perspective. This was highly beneficial as I was aware that my findings would be of interest not only to those living with the condition but to health and educational professionals and families and carers working with and supporting them. I made notes in my research journal of these reflexive conversations that I had with my psychology colleagues and referred back to them throughout the research process. This helped me refine my coding, categories and grounded theory.

Finally, I maintained functional reflexivity by ensuring that my Director of Studies reviewed excerpts from my data analysis at each stage of the process and provided me with feedback which helped me refine my analysis further and enhance my data analysis skills. The systematic process involved in constructivist grounded theory (Charmaz, 2006) which I followed closely also contributed to the high degree of functional reflexivity present within this study.

3.6 Method

3.6.1 Research design

This was a qualitative study which used semi structured interviews. Participants could choose to take part in either a face to face interview or Skype based ‘video’ interview. All interviews were conducted and analysed by the researcher. A constructivist grounded theory methodology (Charmaz, 2006) was utilised to explore how the sense of self was constructed in adults living with congenital facial palsy and to construct a grounded theory of this process.

Semi structured interviews were selected as the method for data collection as Charmaz (2006; 2014) recommends using this approach when researching topics of a sensitive nature. This is because such a method can facilitate the generation of thicker and richer data for the following reasons; the participant can feel safer opening up in the presence of a skilful other and the researcher can use prompts or reflective statements to facilitate deeper participant reflection or exploration and to explore multiple perspectives (Charmaz, 2006; 2014). Generally, the use of qualitative surveys does not provide the same depth of data (Braun & Clarke, 2013).

Furthermore, semi structured interviews are highly compatible with the social constructionist epistemology as they are an intersubjective process in which the responses of participants influence the researcher’s interpretations and the researcher’s interpretations influence the response of participants (Mishler, 1991). The use of an interview guide allows the researcher to maintain a focus and increases their chances of obtaining relevant data, however, the semi structured nature provides space for other ideas to be discussed and for the data to be co-constructed. Focus groups were considered as an alternative method of data collection. However, due to the sensitive nature of the topic I was concerned that participants might struggle to talk in depth about their experience in the presence of others (Braun & Clarke, 2013).

3.6.2 Participants

Participants' ages ranged from 25 to 60 years old. The initial sample consisted of 14 participants (8 male and 6 female). Twelve had a diagnosis of Moebius Syndrome (three of which received smile surgery) and two had a diagnosis of congenital facial palsy. Six participants identified as White British and eight participants identified as white American.

The theoretical sample consisted of two mothers, both of whom resided within the UK and identified as white and British.

3.7 Procedure

3.7.1 Sampling

An initial purposive sample of fourteen adult participants living with a diagnosis of congenital Facial Palsy were recruited. As the research progressed, further theoretical sampling was undertaken in accordance with the Grounded Theory methodology (Charmaz, 2006). This involves identifying the gaps within the data analysis and recruiting participants who will be able to provide relevant data needed to fill those gaps and develop the grounded theory (Birks & Mills, 2011). Once the categories had been constructed, it became noticeable that there was an absence of data for the period of infancy and early childhood as participants struggled to recall memories from this early period of life. Therefore, two mothers were recruited to participate in this study. Both mothers lived within the UK and had raised their children here. One parent had a son who was eleven years old and the second parent had a daughter who was eighteen years of age.

3.7.2 Recruitment

The initial purposive sample of participants were recruited via advertisements posted by moderators of Facial Palsy UK and the Moebius Syndrome Foundation websites and Facebook pages. The study was also advertised in the brochure for the Moebius Syndrome Foundation conference which was held in Los Angeles in July 2016. The brochure was distributed to registered attendees prior to the conference and participants were encouraged to contact me for further information if they were interested in participating in the study.

Due to the rareness of congenital facial palsy it can be difficult for researchers to recruit participants. I considered recruiting through the NHS however the ethical application can be a lengthy and time intensive procedure and as this was a doctoral research project, I was concerned that any delay might have resulted in me not meeting my submission deadline. I had successfully recruited through the Moebius Syndrome Foundation and Facial palsy UK Facebook pages when I conducted my pilot study in the second year of my doctoral training, and I had learnt that this was the easiest way of reaching participants that would otherwise be considered ‘hard to include.’ The participants recruited for the purpose of theoretical sampling were contacts that I had made at a previous Moebius Syndrome event that had taken place in the UK.

3.7.3 The Research Setting

All six of the UK participants who had congenital facial palsy were interviewed via Skype due to the financial and time constraints faced by both the researcher and participants which meant it was not viable to travel to undertake face to face interviews. Janghorban, Roudsari, and Taghipour, (2014) state that the use of Skype to conduct research interviews is a good data collection method for projects whereby there are financial constraints, geographical distance issues and/or physical mobility issues which make it difficult for participant and researcher to meet in a face to face setting. Furthermore, the use of video chat enables both participant and researcher 'to meet' in a face to face way which could not have been done in the pre-internet era (Hanna, 2012). Hence both the researcher and participant are able to observe and respond to each other's body language as would be done in a traditional face to face setting.

However, as noted by Hamilton (2014) some concerns have been raised around this data collection approach such as disruptions within the non-verbal/embodied interaction between participant and researcher. It has been argued that this could happen as Skype presents a split screen whereby the user is able to see the other but also their own reflection. As such, this could result in participants trying to control their facial expression or body language in a way that they would not do during traditional face to face encounters and could result in an incongruent interaction with the researcher. There are also potential confidentiality issues, as it is difficult to know if other people are sitting in the room or listening from outside of the room (Hamilton, 2014). In addition, there is the risk that the flow of conversation could be disrupted should the internet connection drop unexpectedly.

I gave careful consideration to the advantages and limitations of this approach and initially I was concerned that given the importance of the face for this population that participants might not have felt comfortable to undertake Skype based interviews. However, due to geographical and financial constraints, it was necessary to use this approach in order to recruit the number of participants needed for this study. Surprisingly, participants reported feeling comfortable undertaking the interview from their own home and the data provided was of high quality as they talked at depth and were very open about their experiences of living with facial palsy. Interestingly, I noticed that I felt more comfortable conducting interviews via Skype than in person. On reflection, I believe this was because I had not met many people with facial palsy at that point and being in a familiar environment (my office within my home) helped reduce my anxiety around these meetings and made it easier for me to focus on the interview process. Therefore, this study provides support for the use of skype based interviews.

I conducted the remaining eight face to face interviews at the Moebius Syndrome conference which was held in a hotel in Los Angeles in July 2016. These participants resided in the United States of America and had a diagnosis of Moebius Syndrome. The Moebius Syndrome Conference organisers arranged for me to interview participants in an interview room located within the hotel where the conference was held. This room was located within a quiet part of the hotel and this corridor had been designated for Moebius Researchers to conduct their studies. It had adequate sound proofing and volunteers from the Moebius Syndrome Foundation were located at the end of the research corridor to provide participants with general information and advice.

In terms of the theoretical sampling interviews, these were conducted via Skype based video chat at the request of participants who lived too far away to conduct the interview face to face.

With the Skype based and the face to face interviews, I spent time building rapport with the research participants by answering any questions they had before commencing the interview and explaining to them that I also lived with the same condition. I also used the relational skills I have developed through my therapeutic training to help put participants at ease and to maintain rapport throughout the interview.

3.7.4 The research interview

Individuals who expressed an interest in the study were invited to contact me directly, in which I provided them with an information sheet detailing the aims of the study, their role as a participant, the risks of taking part and contact details for organisations offering emotional support. Participants were asked to read the information sheet and having been given sufficient time (at least two weeks) to consider what participation would involve and then to sign a participant consent form. All participants were given an opportunity to ask questions pre-and post-interview and were informed of their right to withdraw from the study at any point.

A semi structured interview schedule consisting of several broad open-ended questions was devised to facilitate in depth exploration around participants' constructions of 'self'. The interview questions centred around exploring childhood, adolescent and adulthood experiences of living with congenital facial palsy and how this might or might not have influenced their constructions of their sense of self. I decided to ask participants to discuss their sense of self in relation to the three westernised developmental life stages as I wanted to ensure that we covered the lifespan so that I could obtain data needed to answer the research question. When designing the interview, I considered an unstructured approach however, I was concerned that this could result in the generation of large amounts of data which would not be useful in terms of answering the research question, so I decided on a semi structured interview format.

Interviews lasted 60-90 minutes and participants were encouraged to take a comfort break if needed. During the interviews, I took a constructivist approach, attempting to elicit participant's underlying assumptions, implicit meanings, processes and actions involved in the constructions of their sense of 'self'. I did this by exploring the wider cultural contexts in which these senses of self were constructed.

3.7.5 Ethical considerations

Full university based ethical approval was obtained before conducting this research. All participants recruited were eighteen years old or above and were fully briefed by me before participating. It was recognised that participants were likely to have a fragile sense of self and that participating in this study may have caused psychological distress as participants were being invited to reflect on potentially painful material. I was mindful of how overwhelmed I had been when first attending a conference and reflecting on my own material and I was concerned to ensure that I did not overwhelm participants in the interview. This risk was managed by excluding from participation those who disclosed severe mental health problems or did not have access to appropriate or sufficient social/emotional support. This was done through clearly stating on participant consent forms that these individuals would not be eligible to participate in this study due to the potential emotional impact that the interview could have. I also assessed this with participants before commencing the research interview.

In terms of preparing to manage any emotional distress that might arise during the interview, I felt able to rely upon my psychotherapy skills to manage participants' potential distress. I planned with my Director of Studies that should issues of risk occur in either the Skype based or face to face interviews, I would contact her at the earliest opportunity and seek her guidance. I had planned that should participants have become distressed during the Skype based interviews then I would stop the interview and guide them to seek the support they might have needed. This might have involved providing them with contact details for relevant support organisations or encouraging them to seek support from a trusted relative or GP if I was concerned about a deterioration in their mental health. In this instance, I would have agreed with the participant that I would contact them later that day to check in with them and ensure they had accessed the support needed.

The conference was a safe setting in which to conduct the research as there were other trained and experienced health professionals present should significant issues of risk have occurred, and participants had access to sufficient emotional support after the interview as all participants attended with family members or close friends. Skype based interviews were undertaken from the comfort of participants' own homes and at a time that was convenient for them. Participants were asked to conduct the interview in a separate room so that confidentiality could be maintained and so that they would feel able to talk openly about their lived experiences. Contact details of relevant organisations offering emotional support, information and advice were also provided on the participant information sheets. Participants were informed that they could stop the interview and withdraw from the study at any point during the research process. Likewise, I maintained confidentiality by undertaking the Skype based interviews in a separate room in my house whereby I would not be disturbed by others.

Should participants have disclosed unethical practice in terms of support/intervention they had received from health professionals then it is possible that after discussing my concerns with the participant that I might have needed to report my concerns to their professional body. In order to maintain transparency, a confidentiality clause was included in my information sheet drawing participants attention to the limits of confidentiality.

I recognised that this project had the potential to distress me. I had a social support network in place consisting of family, friends and fellow trainees as well as my supervisory team who I was able to debrief with and receive appropriate support from throughout the research process. I had also completed four years of personal therapy shortly before commencing the interview process and I therefore felt psychologically resilient and prepared to undertake the interviews and data analysis.

3.7.6 Data handling

Interview data was audio recorded and transcribed verbatim. Identifying information was anonymised at the point of transcription.

Demographic information and participant contact details were stored in a separate lockable cabinet to which only I had access. Participant anonymity was maintained in all dissemination of the work using pseudo-names when quoting participants within the data. Audio recordings were undertaken using a digital recorder and were transferred onto the researcher’s secure password protected computer immediately after each interview. After all interviews had been transcribed the original audio recordings were erased from the Dictaphone.

3.8 Method of Analysis

The data was analysed using the constructivist Grounded Theory method cited in Charmaz (2006; 2014).

3.8.1 Open Coding

The constructivist Grounded Theory method (Charmaz 2012; 2014) used in this study involved initial line by line analysis of each interview and the construction of open codes. Open coding can be defined as breaking the data down into distinct units of meaning (Charmaz, 2014); following Glaser's recommendations, actions are captured through use of the gerund (Glaser, 1978). This involves converting verbs into action nouns which enabled me to construct processes which were grounded in the data (Charmaz, 2014). During this phase of coding I was explicating implicit meanings, assumptions and actions from the data and taking a critical approach when interacting with the data by asking myself what processes were taking place and how they could be defined. This initial phase of coding is regarded by Charmaz (2006) to be the descriptive phase.

3.8.2 Focused Coding

The second phase of analysis involved undertaking focused coding which consisted of identifying the most frequent/significant open codes and making analytic sense of these (Charmaz, 2014). Hence this phase of coding aims to go beneath the surface in which the researcher becomes more analytical and interpretive when engaging with the data. Focused codes were constructed for each separate individual and then a comparison was made across participants. The most frequent, similar and different/unique codes were selected and grouped together. These became the focused codes for the sample. Focused codes were then used to construct potential categories.

3.8.3 Constant Comparison

As each interview was analysed, data and codes were constantly being compared between interviews as well as comparing codes with data within interviews and within and between categories. This constant comparative method which takes place throughout the data analysis phase, enables the researcher to collect focused and relevant data and allows for a theory to begin to be constructed (Charmaz, 2012; 2014).

3.8.4 Memos and field notes

Memo/note taking occurred throughout the entire research process, allowing potential hypothesis around a category or relationships between categories to develop (Charmaz, 2006; 2014). Memo taking is an essential part of the Grounded Theory process which enables the researcher to document their ideas and hypothesis about the data, connections between categories and facilitates theory development and the reflexivity process (Charmaz, 2014). I also made memos about my ‘insider experience’ and how this might have been influencing my analysis of the data and co-construction of the grounded theory.

3.8.5 Constructing categories

Categories were developed through following the process outlined by Charmaz (2006) which involved clustering focused codes and the grouping of memos together based upon their similarities and differences. I categorised the focused codes by printing them out and organising them spatially on the floor, grouping similar codes together. I used the relevant memos to name each group of codes and hence this became the name of the category. I transferred the tentative categories (which consisted of a group of focused codes) onto a Microsoft word document. Engaging in the process of constant comparison meant that these categories and their sub properties were continuously developed and refined throughout the research journey in keeping with the Grounded Theory method.

This process eventually resulted in the construction of two self-states; a '"defective me"' self-state and a "validated me" self-state. At this point, I had developed a tentative diagram and I was able to identify gaps within the data and ask further questions of it. The gaps in my analysis were addressed through theoretical sampling.

3.8.6 Diagramming

A diagram was constructed throughout the coding, categorising and memoing process, to develop a clear visual representation of the relationship between categories and codes. The diagram was continuously refined throughout the analytic process and helped me identify gaps in the data which could be addressed in subsequent interviews and through the process of theoretical sampling. The use of a diagram lead to the eventual ordering of categories and the construction of a psychological theory of the processes involved in the construction of 'self' in those living with congenital facial palsy.

3.8.7 Theoretical Sampling

This involved recruiting participants who were able to provide data which could share further light upon the emerging grounded theory (Simmons, 2009). Theoretical sampling continued until 'theoretical sufficiency' had been achieved (Dey, 1999). 'Theoretical sufficiency' can be defined as occurring when the data and analysis no longer generates any new meanings, insights, concepts or categories (Dey, 1999; Charmaz 2006). Once data had been collected, selective coding (Charmaz, 2006; 2014) was undertaken to identify and extract relevant codes which could be used to further refine categories and develop the grounded theory.

3.8.8 Literature reviewing

Glaser advises grounded theorists to avoid reviewing the literature within the field before commencing data collection (Glaser, 1978) as this could lead to preconceptions (McLeod, 2007). However, Charmaz (2006; 2014) suggests that it is important that the existing literature is briefly reviewed beforehand in order to ensure that the potential topic merits investigation. Charmaz (2006; 2014) argues that if the researcher adopts a critical stance then this review can be done without becoming immersed in the existing literature. In line with Charmaz' (2006) recommendations, I undertook a brief literature review before conducting the study but delayed a full literature review until I had constructed potential categories. I used these potential categories to guide my full literature review whereby I occupied a critical stance, exploring the similarities and differences between my categories and the existing literature and by examining how the existing literature could shed further light on the links between my categories and guide the process towards a grounded theory construction.

4.0 Findings

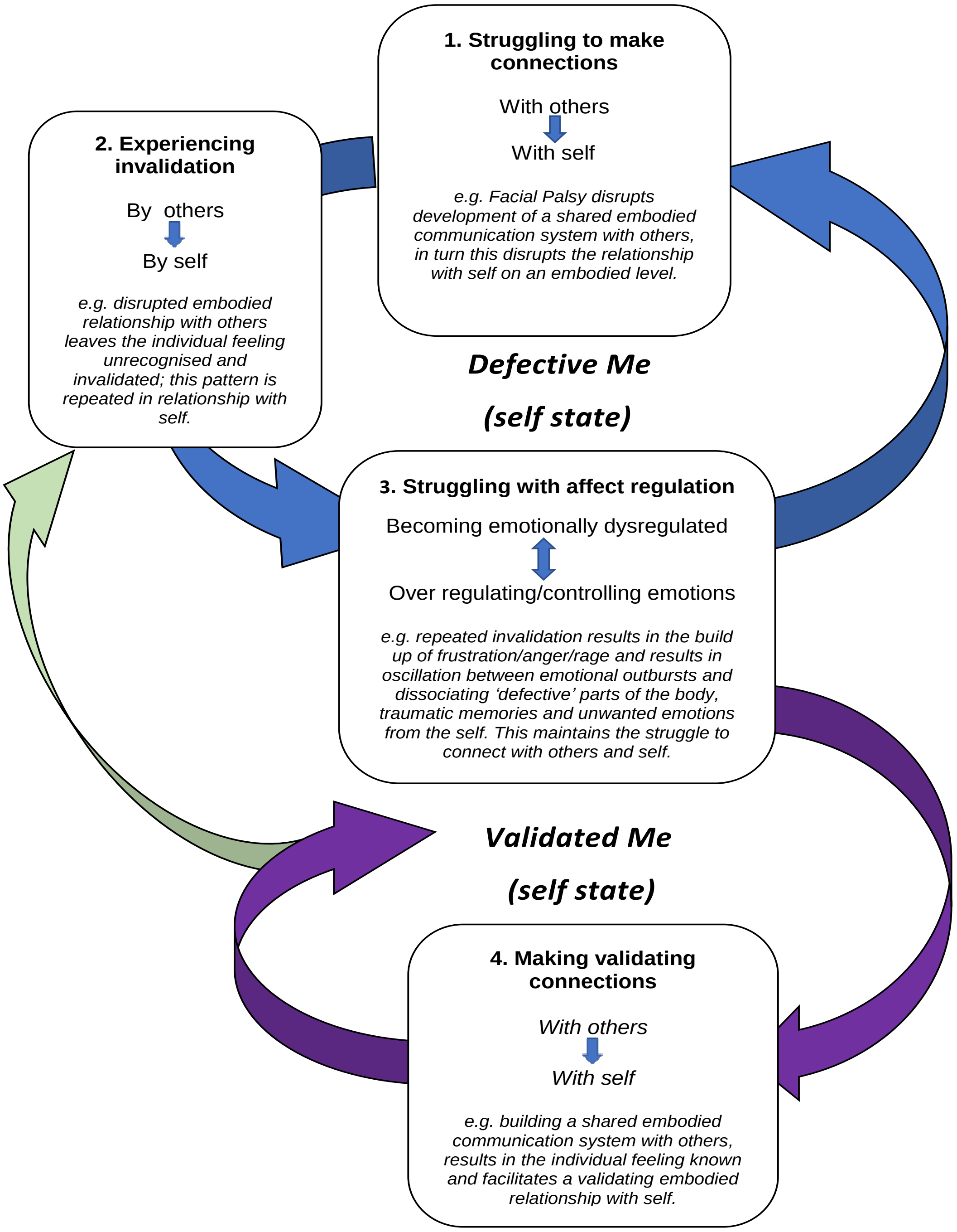
The grounded theory constructed from the data describes the processes involved in the construction of ‘self’ in those living with congenital facial palsy (see figure 1 below). The analysis suggests that the processes involved in the construction of ‘self’ were interconnected rather than linear, were repeated across the lifespan and became more entrenched as the individual progressed from childhood into adolescence and adulthood. Hence, the grounded theory outlined below depicts the ‘self’ as a fluid process which exists across time, rather than a single unitary structure which develops in sequential stages.

Self-states can be defined as different modes or experiences of self which come into being in different relational contexts. All participants described; *struggling to make connections, experiencing invalidation* and *struggling with affect regulation,* all of which became the categories involved in the process of *constructing a “defective me”* self-state. Those who became trapped within this process repeatedly experienced negative interpersonal encounters during childhood and adolescence and did not have consistent access to validating others and a validating environment which could meet their psychological and physical needs. Consequently, these participants seemed to experience a lack of self-worth and poor mental health.

Those who had consistent access to validating others and a validating environment during childhood and adolescence were able to construct a “*validated me”* self-state through; *making validating connections.* This resulted in the individual experiencing a strong sense of self-worth and good psychological wellbeing.

Any changes in the social environment which led to the disruption of connections between self and other and/or one’s relationship with oneself resulted in the re-activation of the *“defective me”* self-state. Movement between the *defective* and *validated* self-states continued throughout the lifespan; those who described the ability to move more fluidly between self-states described better psychological outcomes as they could recover more quickly from negative social encounters with others.

Figure 1: The construction of 'self' in individuals with congenital facial palsy: a grounded theory exploration



e.g. Facial Palsy disrupts development of a shared embodied communication system with others, in turn this disrupts the relationship with self on an embodied level.

e.g. disrupted embodied relationship with others leaves the individual feeling unrecognised and invalidated; this pattern is repeated in relationship with self.

e.g. repeated invalidation results in the build up of frustration/anger/rage and results in oscillation between emotional outbursts and dissociating 'defective' parts of the body, traumatic memories and unwanted emotions from the self. This maintains the struggle to connect with others and self.

e.g. building a shared embodied communication system with others, results in the individual feeling known and facilitates a validating embodied relationship with self.

Figure 1 illustrates the relational processes involved in the construction of self in individuals with congenital facial palsy. Participants constructed two self states; a 'defective me' and a 'validated me.' The relational processes in each self state were interrelated and could repeat across the lifespan. Participants could move between these self states and the movement was influenced by the social context (e.g. an invalidating or validating social environment).

4.1 CONSTRUCTING A “DEFECTIVE ME” (SELF-STATE)

Constructing a *“defective me”* self-state was a process which consisted of the following categories; *struggling to make connections, experiencing invalidation,* and *struggling with affect regulation.* The defective self-state consisted of cognitive and affective experiences of self, all of which lead to the conceptualisation of self as ugly, abnormal, alien, and to feelings of shame. All participants described experiencing negative social interactions during early childhood and beyond; these negative interpersonal interactions were often frequent and repetitive. Participants reported becoming conscious of their difference through the nonverbal and verbal behaviour of others towards them. Participants described how they internalised these negative interpersonal experiences and how they learned to relate to the ‘self’ in a similar manner - relating to their body as a defective object rather than a valued part of self. The *“defective me”* was described as a self-state which some people became stuck within. Moving out of this self-state depended upon consistent access to validating others and a validating environment, which facilitated a different way of relating with the ‘self’.

4.2 Struggling to make connections

Struggling to make connections was a category which formed part of the process of constructing a *“defective me”* (self-state). This category consisted of the following sub categories: *struggling to make connections with others* and *struggling to make connections with self*. *Struggling to make connections with others* and *self* seemed to be particularly difficult during infancy and childhood when children have a limited verbal capacity and therefore rely on nonverbal modes of communication and self-expression, especially facial expression. As participants were unable to remember these early developmental periods, parents of individuals with Moebius Syndrome were recruited to provide the missing data for the infancy period. Those individuals who did not have access to the support needed during infancy and childhood to develop alternative non-verbal forms of connection with others and self continued to experience difficulties in this domain across the lifespan. This resulted in the individual missing out on important relational and developmental experiences needed to grow as a person and resulted in the construction of a defective self-state.

4.2.1 Struggling to make connections with others

Accounts from parents shed light on the disruptions that occurred within the parent-infant bonding process during the pre-verbal years and the impact this had upon their son or daughters' sense of self. One parent described how she was separated from her infant immediately after birth when her daughter was taken away to be medically examined and then placed in a special care baby unit for five weeks. She described how the initial mother-infant bonding process was disrupted because of this separation and she told of the feelings of shock and grief that she experienced consequently. She explained how this took some 'working through' on an emotional level before she was able to fully connect with her infant and hence the formation of a bond was a slow process which gradually built up over time.

> *Samantha; "She was born just after nine in the morning and obviously they thought something was wrong, so they took her away and I was left on the surgical table and um they basically took me back to the ward and I had no communication from anybody until a really lovely nurse came down with the baby at 3pm in the afternoon with her in her incubator and introduced me to her. Cos literally they picked her up, showed me her face then took her away and I didn't even get to touch her."*
>
> *Researcher; "what was that like for you as the mother? You have just given birth and then they have taken her away?"*
>
> *Samantha; "It's a bit of an unreal situation….because you have just been through this traumatic process and then you feel like oh hang on a minute I've got nothing to show for that and you worry because everyone says oh you've got to hold the baby as soon as it's born or you won't have a bond otherwise…you've got to breastfeed or you won't have a bond and you have all these perfect stories fed to you throughout your pregnancy and you're in shock basically and you're just left there feeling completely numb and thinking right ok this story hasn't ended how I*

> *thought it was going to end…..and it takes a little while to get over that"……..*
>
> *(Samantha, aged 50, UK, parent of daughter with Moebius Syndrome)*

The theoretically sampled parents describe these early experiences as traumatic and therefore, it seems likely that their infants will have experienced the trauma and internalised this.

Theoretically sampled parent participants explained how their infants experienced feeding difficulties because of their facial paralysis which disrupted the bonding process during this period of life. Parent participants described how they needed to emotionally detach from their role as 'the mother' in order to feed their infant as parents described this process as invasive as the infant was fed via the nose or the stomach via a feeding peg. This emotional detachment was also reflected in parents' accounts of their child's early years:

> *" Ever since a young child, he preferred to play on his own, the other kids would say come and play pigs but he would wonder back and play on his own. He seemed to prefer that and he's the same way now. He says to me, mam don't worry about me, I'm not lonely."*
>
> *(Maria, aged 45, UK, parent of son with Moebius Syndrome)*

The struggle to make connections with others became a recurrent problem when participants attended school. Participants recalled memories of nursery and primary school whereby other children struggled to connect with them because of their absent facial expression. Some participants described how this pattern repeated across the lifespan and made it difficult for them to be fully present and enjoy social interaction with others because they became pre-occupied with ensuring that the other could understand them.

> *"when I meet new people- I'm very careful about my condition. And unfortunately, it means my mind is about 25% ahead of the mouth. So now, as I'm often trying to get sentences out, I spend more time formulating them into words that can be understood, and often lose the impact in my statements."*
>
> *(John, aged 48, USA, Moebius Syndrome)*

Participants stated how the repeated struggle to make connections with others on an affective level resulted in the construction of a lonely and isolated self, all of which fed into the sense of self as defective. The struggle to make connections with others was internalised (taken into the individual's psyche) and became the relational template which participants used to guide their relationship with their self.

4.2.2 Struggling to make connections with self

Overall, participants struggled to recollect memories (including context and emotion) from childhood in respect of growing up with facial palsy. It seems likely that participants struggled to connect with these memories as they were traumatic in nature and therefore may have been repressed within the unconscious.

Struggling to make connections with self became a relational pattern which repeated across the lifespan, in which several participants explained how they struggled to connect with their physical reflection in a mirror/photograph and/or on dvd as it did not match their internally constructed representation of their face. Participants described how their internally constructed image of their face had more movement and looked more like the faces of those without facial palsy and therefore, whenever they observed their face in the mirror/in photographs or on dvds they would relate to their reflection as an 'other' or an alien part of the self which they described as a 'not me' experience;

> *"I wasn't looking at it (dvd of wedding day) like wow this was my wedding day, great isn't it wonderful, which of course it was……but I was looking at it thinking….that's me with the facial palsy and wow that's how little movement I do actually have, I didn't actually realise how little movement I do actually have…..like now when I'm talking to you, I think I'm making more facial movement than I actually am"*
>
> *(James, 36, UK, Moebius Syndrome)*

Further 'not me' experiences occurred for some participants post facial re-animation (smile) surgery when participants observed their face in the mirror for the first time. Participants described how it was a new experience of self (on a proprioceptive and visual level) that felt unfamiliar and which they had not been psychologically prepared for. Therefore, the facial movement and change in aesthetic appearance was an ‘alien’ experience to the self;

> *Researcher; “what was it like when they took the bandages off, and you looked in the mirror post surgery?”*
>
> *Georgia; “At first I was kind of like "Ahhh, I don't really like it…. It kind of freaked me out….but then, I grew into it.”*
>
> *Researcher; “When you say, 'grew into it' what do you mean by that?”*
>
> *Georgia; “Just the way it looked, because I didn't have muscles in my face before that worked, so for me it was kind of big and awkward to begin with.”*
>
> *(Georgia, aged 25, USA, Moebius Syndrome)*

Other participants described struggling to connect with the ‘defective’ parts of their face and/or body because they did not receive a diagnosis until later life. These participants described how this meant that they grew up not knowing or understanding a significant part of their bodily ‘self’ and so again experienced these parts of the body as ‘not me’.

The struggles participants experienced in terms of fully connecting with their body and integrating it into their sense of self resulted in difficulties developing a sense of sexuality. This involved a difficulty connecting with one’s sexual feelings and urges/impulses on an emotional and bodily level as well as difficulties participating in sexual relationships with others. Some participants felt that the difficulty around developing a sense of sexuality originated from others not seeing them as a sexual being and therefore it became difficult to see themselves as sexual. This was further compounded for some by their medical experiences in earlier life whereby they became objects of fascination by medical professionals and bodies that were operated upon and invaded. Hence these participants learned to relate to their bodies in a similar manner and sexual intimacy represented an invasion of the embodied self rather than an embodied unity with another.

Conversely, other participants described experiencing sexual attraction but avoided participating in sexual relationships with others because of performance anxiety associated with their facial paralysis. Participants had specific concerns around kissing as they did not know how to adapt on a physical level so that they could become intimate in this way. Several participants described how sexual intimacy with another was not perceived to be a pleasurable experience but rather one which was perceived as threatening to the sense of self as they were concerned that the facial paralysis could significantly reduce sexual pleasure for the other, all of which could result in a shaming of the self.

> *"I was more worried about how the other person would react to the kiss and how it wouldn't work or it wouldn't be the normal way all that was running through my head and then I just didn't let myself get into that situation because I was so worried about how the other person would react so I avoided it in a way um yea there was a lot of avoidance…"*
>
> *(Sharon, aged 43, UK, Moebius Syndrome)*

Given the struggles experienced in early life in terms of establishing an embodied connection with others and the shame which accompanies such relational ruptures, it seems logical that participants were highly fearful of a re-enactment of these early relational experiences. This is because the foundations of participants' sense of self were built upon these shameful experiences which occurred during the presence of another and a re-enactment of this early relational trauma could threaten the collapse of the foundations upon which the defective sense of self is built upon. If this is the only sense of self that an individual knows then the collapse of this self-state could be catastrophic as it would leave the individual with no sense of self.

The struggle to make connections with others and self on an embodied level, resulted in participants feeling lonely and isolated and experiencing themselves as alien. The combination of these feelings comprises the foundations of the "defective me" self-state and triggered the next process in the construction of this self-state which involved 'experiencing invalidation.'

4.3 Experiencing invalidation

Experiencing invalidation was a category which consisted of two levels; by others and by self. Participants described how disruptions within the facial mirroring process with others during early childhood resulted in them feeling unknown, unsensed and misunderstood by others and how this pattern repeated across the lifespan and resulted in the experience of self as defective. Participants explained how disruptions within the facial mirroring process also occurred when observing one’s own image through a mirror or in a photograph.

4.3.1 By others

Several participants described how they experienced disruptions within the facial mirroring process during childhood when interacting with peers at school, who did not appear to be equipped with the relational skills needed to adapt to participants’ unique non-verbal communication needs. Participants had not developed compensatory non-verbal expressions and were unable to effectively express themselves using verbal communication as their verbal abilities were limited at this young age. Consequently, peers were not able to accurately recognise participants’ self-expressions during face to face interaction and this resulted in peers mirroring incongruent representations/reflections of participants’ affects. Consequently, participants internalised these incongruent images of self and constructed a sense of self which felt unknown, defective and alien.

> *“when I went to school, I noticed people didn't understand what I was saying. And then I wasn't...kids were kind of looking at me because I wasn’t smiling and stuff like this like the rest of them were…..some looks weren’t bad looks….some of them were just confused but I guess it just left me feeling different to others. “*
>
> *(Samuel, aged 28, UK, Moebius Syndrome)*

Participants explained how this lack of recognition by others persisted across the lifespan thereby strengthening the defective self-state . This was especially the case when meeting new people and might explain why many participants avoided novel environments or situations.

> *"I could be put in a room of strangers and talk quite happily….. um but you know how we communicate it's not just verbally …..it is how we communicate through facial expressions…..especially with new people or people you've just met and they will look for interaction through facial expression and when they don't get that they form an opinion uh understandably so but obviously it comes from a wrong opinion….."*
>
> (*James, Male, 36, UK, Moebius Syndrome*)

> *"some days, you occasionally get people that say "Cheer up mate", and that sort of thing. It's just an awareness thing, they don't know what the condition is that I've got, and they don't understand."*
>
> *(Luke, aged 30, UK, Moebius Syndrome)*

Several participants described the frustration they experienced when their emotional experiences of living with facial palsy were invalidated by health professionals and/or family relatives and friends. Participants described how these individuals would invalidate them through minimising the challenges they faced because of living with this condition, dismissing their painful feelings or telling them how to think and feel about their condition. This lack of understanding and empathy from others fed into the construction of a *"defective me"* self-state as participants felt lonely and isolated in their experience. The quote from the participant below illustrates how her experience of living with Moebius Syndrome was invalidated by her psychological therapist and how this left her feeling misunderstood and alone in her experience as well as frustrated. However, from her account it seems like she struggled to recognise the frustration and to address this directly with her therapist. Instead she appears to use passive aggressive strategies to communicate her frustration.

> *"They wouldn't really they'd just kind of sit there, and say to do this. One of them would say "I don't see anything wrong with the way you look". And it's like, I know you don't, but I do, you know. So she was kind of*

> *saying, there's nothing wrong with you. That type of thing. So in the end I would just go to the sessions and sit there in silence until it was over"*
>
> *(Georgia, aged 25, USA, Moebius Syndrome)*

A quote given by a different participant below illustrates how a medical doctor invalidated the emotional challenges the participant was experiencing because of living with a congenital facial palsy and the intense frustration she experienced because she had been emotionally invalidated by others throughout her lifespan;

Natalie; "I went to see plastic surgeons, and twice I was told "Don't worry, you're pretty enough".

Researcher: "Right, how did that feel?"

Natalie; "Pretty shitty."

Researcher: "In what way?"

Natalie; "Well, because I felt like; oh what because you think I'm pretty that's enough for me to live my life like this? Maybe pretty isn't what I'm going for here. Because I was actually going for my eye, because I can't close my eye, and you know going to the beach was a bitch, and swimming."

Researcher: "so you kind of felt like they weren't understanding it really?"

Natalie; "Yeah, not understanding it and just thinking; Oh if I tell her she's pretty that will just be enough like. That's not doing anything for the psychological bit of me that obviously I'm bothered enough about it to make an appointment with the plastic surgeon……… But not being heard then you know, not being heard that time, and not being heard the next time, kind of you know, it links too much into my personality of not being heard. And it took me a lot of courage to make that appointment, and to go and sit in front of someone I don't know and go "Listen, I am bothered about this". I just didn't think that was good enough from a medical professional to go "Oh well, you're pretty, don't worry about it", and send someone off like. You know, an extreme case, if I was extremely bothered about it I could have walked out of there and flung myself off a bridge you know what I mean, that I went to seek help and the person just said "No, don't worry about it".

(Natalie, 36, UK, Unilateral Facial Palsy)

The repeated emotional and relational invalidation resulted in participants internalising representations of self which did not match their internal experience of self. Nevertheless, this ‘self in relation to other’ template, guided their relationship with self and resulted in repeated self invalidation, all of which contributed to the construction of a “defective me” self-state.

4.3.2 By self

As well as internalising incongruent affective mirroring through their face to face interactions with others, several participants described how a similar process took place when observing their face in a mirror, photograph or on DVD. Participants described the incongruence they experienced between their internal affective state and their reflection in the mirror. Some participants described being disturbed by this mismatch between their internal affective state and the external image/mirror representation of themselves. This incongruent external image/representation of self was internalised, along with the feeling of ugliness and contributed to the construction of a “defective me” self-state.

> *Researcher; “ where do you think this feeling of ugliness comes from?”*
>
> *Sean; “It comes from within me, it comes from seeing my reflection in the mirror……every time I look in the mirror, I see my lip and then I just feel ugly….its’ self-generated and nothing anyone says can change that feeling……”*
>
> *(Sean, 60, UK, Unilateral Facial Palsy)*

Repeated failures in mirroring resulted in the experience of affect regulation difficulties as the individual became frustrated with the invalidating reactions of others towards them and frustrated with the mismatch between the internal fantasised image of self and the external mirror image/representation.

4.4 Struggling with affect regulation

Struggling with affect regulation was a category which consisted of the following sub processes; *becoming emotionally dysregulated* and *over regulating/controlling emotions*. Some participants described restricted emotional affect; finding it difficult to recognise and express their emotions, while others described feeling controlled by their emotions and several described oscillating between restricted affect and emotional outbursts. These struggles with affect regulation impaired participants' interpersonal relationships and resulted in an experience of the self as defective. These difficulties appeared to be the result of repeated experiences of communicative and emotional invalidation; those who had the greatest difficulties were those who experienced repeated invalidation during infancy and childhood and had not been able to access validating relationships in which to build an alternative validated self-state.

4.4.1 Becoming emotionally dysregulated

One parent gave an account of her son's difficulties regulating his frustration as an infant. She described her son as a 'distressed baby' due to his frequent episodes of distressed crying and screaming and difficulties with sleeping. Her account suggested that this distress may have originated from the traumatic birth he experienced and the invasive medical procedures he endured during early infancy. This parent participant described how the lack of specialist knowledge, advice and support given to her about how to address her baby's unique needs meant that it was difficult for her to care for him effectively and to help him regulate his distress:

> *"It wasn't a nice birth, he had forceps as well and he was very very unsettled when he came out…..he wasn't feeding and he lost all his baby weight and we went back to hospital and that's how we get his diagnosis at two weeks old. Um….for him as a baby he cried and just made this horrendous sqwawk…for the first three months…he cried during the*

> *night…he never slept…he still doesn't sleep now….he's a poor sleeper…he always has been…..he screamed and cried most nights…..he was a very distressed baby."*
>
> *(Maria, aged 45, UK, parent of son with Moebius Syndrome)*

This same parent described how the build-up of frustration throughout childhood resulted in her son transferring his frustration with his 'disabled body' onto his sibling and onto his mother due to his difficulties communicating effectively with others and consequently difficulties regulating the overwhelming affect which accompanied these experiences;

> *"He does get angry, he does…very angry…..obviously in the family unit I think he takes a lot of his frustrations out on his sister…and he has spoke to me about it…..you know she doesn't have what I have …..once he said he blamed me for his face …"*
>
> *(Maria, aged 45, UK, parent of son with Moebius Syndrome)*

Several participants described how they experienced frustration during childhood and adulthood when teachers or potential employers were unable to see past their facial paralysis or recognise their abilities. Participants described how experiencing repeated invalidation resulted in the build up and expression of anger and rage;

> *"my career advisor just went no you're not going to be able to do childcare and I remember you get your little letter or document from her saying what she feels you should do as a job and she'd actually put on there uh I can't remember how she worded it but I remember being in the classroom and everyone was sat down and I can remember she gave it to me and I looked at her and I was gobsmacked ….I was quiet at school but I think I might have actually sworn at her and stormed out of the classroom and to this day… I just stormed out of the room and proper slammed the door on the way out and completely shocked everyone because I shouted and I was like no no no you're wrong and I will show you kind of thing……"*
>
> *(Sharon, aged 46, UK, Moebius Syndrome)*

One wonders from a psychoanalytic perspective if this is a consequence of early pre-verbal communicative difficulties which meant that participants never learnt how to regulate difficult emotions. I noted how during the interviews how some participants struggled to control/regulate their emotions and would quickly express frustration when I mis attuned to them or would become defensive when I asked questions about their emotional experience.

4.4.2 Over regulating/controlling emotions

Participants resorted to engaging in a range of psychological defence mechanisms in order to defend a fragile sense of self from the overwhelming difficult emotions they were experiencing as a result of living with congenital facial palsy. However, participants described how utilising these protective measures activated and maintained the "*defective me"* (self-state) as their interpersonal need for intimacy, understanding and validation remained unmet, and it seemed as though this also led to a sense of fragmentation in the sense of self. These protective strategies were resistant to change in those who had engaged in them since early childhood. This could be because these participants did not know an alternative sense of self and therefore, removal of these protective strategies could result in a complete collapse/loss of self which would be catastrophic in terms of their psychological wellbeing.

Several participants described controlling negative affect experienced in relation to their appearance by splitting themselves into 'good me', 'bad me' and 'not me' representations. The parts of the face (and other parts of the body) that did not function as they should were often referred to as the 'bad' parts of self. Some participants seemed to keep a separateness from these 'bad' parts of self by referring to them as 'not me'. Participants were not aware that this was what they were doing however, it was noted how they frequently switched to the third person pronoun when discussing their facial palsy which they referred to as 'it' or 'the condition' rather than 'my' or 'me.' This appeared to feed into the construction of a "*defective me"* self-state as participants were unable to accept and fully integrate their face (or other affected parts of their body) and continued to treat it as something alien to the self.

> *"I think that's when I started to notice it and probably when I spoke to my mother about it and …and had to live with it and had to get on with it."*
>
> *(Sean, aged 60, UK, Unilateral Facial Palsy)*

Several participants questioned whether they had learned to manage the difficult affect associated with early difficult interpersonal relationships by blocking out (dissociating) experiences that were too emotionally distressing and threatening to their sense of self to call to conscious mind. This seemed to feed into the construction of a *"defective me"* self-state as participants were unable to process and integrate dissociated traumatic relational experiences and hence this disrupted their relationship with self on an affective and bodily level.

> *"I know it sounds dramatic, but honestly I've blocked out a lot of my childhood. I don't know if other people have said the same thing…..I really don't have a great long term memory."*
>
> *(Lucy, aged 34, USA, Moebius Syndrome)*

One parent described how her daughters' over regulation of emotion, resulted in a gradual build-up of negative affect and resulted in an 'emotional meltdown' during late adolescence.

> *" When she was 17 she just broke down one day, she'd been very tired and not her usual self, cos usually she's always been a happy person, within herself but obviously behind that there's been a lot going on….so when she was younger she'd always been singing around the house and just a happy kind of child that you thought oh doesn't she do well she's so sorted you know but actually in her older years there was a delayed reaction towards all that's gone on and she just said I'm depressed."*
>
> *(Samantha, aged 50, UK, parent of daughter with Moebius Syndrome)*

Two participants described resorting to misusing alcoholic substances as a way of regulating their emotions. It appears that these individuals used these external objects in the absence of access to self-regulating others such as a supportive parent, friend, partner or health professional.

> *" to be honest I started drinking at an early age and started going down the pub drinking out and around people's houses drinking when I was 14 and I think really that was my way of tryna…I was drinking to make me feel happy….it made me feel happier about things and when I wasn't drinking I started thinking about things more and getting down so then I'd start drinking more again."*
>
> *(Sharon, aged 46, UK, Moebius Syndrome)*

Whilst these strategies are functional in the sense that they prevent the self from becoming overwhelmed by negative affect and maintain self cohesion, they keep the individual trapped within the defective self-state as they prevent the individual from engaging in new relational-developmental experiences which could facilitate the construction of a "validated me" self-state. Liberation from the "defective me" self-state was dependent upon 'making validating connections with others and self'.

It is important to note that affect regulation is something which has not been well explored within the visible difference literature and therefore this is a novel and significant finding.

4.5 CONSTRUCTING A "VALIDATED ME" (SELF-STATE)

The "validated me" self-state, was a relational process which consisted of the individual feeling sensed, known and accepted by others and self.

4.6 Making validating connections

The process of *constructing a "validated me"* (self-state) consisted of the following category 'making validating connections' and sub categories; *'with others'* and '*with self*' . Participants who were able to internalise the experience of validating relationships with others described feeling known, sensed and understood, which in turn enabled them to build a deeper connection with self. Those who experienced validation through relationships with others in childhood constructed a stronger "validated me" self-state than those who did not experience these reparative relationships until adolescence or adulthood. These participants found it easier to return to this self-state after their *"defective me"* self-state had been activated and to self-regulate when experiencing negative interpersonal encounters.

4.6.1 With others

Making validating connections with others began in infancy for some in which the theoretically sampled parents described how in the absence of facial expression, an emotional connection was made with the infant through reading their eyes, hand movements, head movements and body movements. One parent described how she engaged in lots of face to face play with the infant and relied on the other non-verbal communicative modalities to mentalise her infant's feelings, wishes and behaviours. The second parent spoke about how she emotionally connected with and validated her infant through singing and playing music.

> *Maria; "The way I learnt to read him was always through his eyes, and still now, it's still the same it's through his eyes, not so much those first six months when he was in and out of hospital and crying and unsettled but I'm talking about when babies start to develop and they giggle and my son can do it vocally he just can't express it and his eyes have just always told the story."*
>
> *Researcher; How can you see it in his eyes? I'm interested in how you can read what he feels through his eyes?*
>
> *Maria; "His eyes go a little bit bigger and they just have a sheen of happiness…..it's the only way I can describe it……and then yesterday when he didn't have a good day they were smaller and looked more sunken back."*
>
> *(Maria, aged 45, UK, parent of son with Moebius Syndrome)*

Samantha; "I think because I did give up work and because we spent so much time together, she just learnt ways to communicate in terms of using her eyes, and then as she got a bit older her body and expression in her tone of voice….that was when she was verbal but before that I think we just did lots of playing and lots of face to face contact….so I just treated her like she was normal, like any other baby so exactly the same….."

Researcher; "So how did she use her eyes?"

Samantha; "She would open them wider and I think this is what people miss when they don't know her that well….they won't pick up on things like that but I think when you spend a lot of time with your child as a baby you can just tell from looking into their eyes how they are feeling somehow….it's just something you build up….and you have to do that because you don't have any other way of doing it"

Researcher; "was that easy to do at first or did it take a while?"

Samantha; "It took a while because as a parent it's upsetting that your child is giggling away but they can't smile at you but you just have to put that aside…so it does take a while because like I said before you're in that grieving process but I don't think I bonded any less with my daughter than I did with my son who doesn't have the condition"

(Samantha, aged 50, UK, parent of daughter with Moebius Syndrome)

The theoretically sampled parents explained how they validated their infant's emotions through using their own facial expression, tone of voice and body movement to communicate their understanding of the infant's mental and emotional states and their recognition of them as a separate person. The quote given below illustrates this;

"I think in terms of understanding your baby, you can't go wrong with just showering them with love and it's a two-way thing, it's a relationship but you just have to put that little bit more hard work in but your baby will find a way of telling you….obviously lots of patience is needed ….. big big voices, use your own expression…just because they can't it doesn't mean to say you can't…..let them see how happy you are….be big your movements and embrace it because these children need to know it….they'll survive ….so I would say go bigger and better."

(Maria, aged 45, UK, parent of son with Moebius Syndrome)

Some participants recalled how learning to communicate effectively on a non-verbal level during the pre-school years gave them the confidence and the communicative skills needed to communicate effectively with peers when they began school, which enabled them to feel known and understood by their peers. This pattern of relating became second nature and repeated across the lifespan. Consequently, these participants described finding it easier to develop friendships and experience a sense of self-worth in comparison to those who did not make these early validating connections with others.

Acquiring the ability to smile through undergoing smile surgery enhanced the experience of validation in relationships with others; as these participants were able to express emotion and connect with others through the universal language of facial expressions which was a new experience of self and participants described this as a humanising experience. This contributed to the construction of a "validated me" self-state. Participants were in agreement that the earlier this surgery could be undertaken then the better as it made it easier for others to connect to them which in turn reduced their sense of defectiveness;

> *"Well, I can smile at people. For people that aren't quite sure what to make of me, the smile usually makes them a little, maybe more accepting and less fearful. Or less confused. It puts people at ease. Sometimes, not all the time, but more….for someone without facial movement to have facial movement is a tremendous change………I only see it as a positive.*
>
> *(Barbara, aged 60, USA, Moebius Syndrome)*

Participants described how making nonverbal connections with others through a smile after undergoing smile surgery was not something which happened instantaneously. Connecting with others through a smile was described as an explicit process as it required conscious effort and practice. Learning to smile was also described as a relational process as this learning took place within the context of relationships with others. Participants described how repeated practice of smiling accompanied by receiving sufficient validation from others resulted in this becoming an implicit (unconscious) and spontaneous process.

In addition, several participants described how having their emotional struggles heard and empathised with by significant others (e.g. parents, teachers and health professionals) helped them feel understood and validated as a person. Furthermore, being heard and understood by others helped them process the difficult and sometimes traumatic interpersonal or medical experiences they had encountered. Emotional validation took place through the process of engaging in open conversations about their condition and their feelings about this.

> *"I think I was very secretive, but if I was bullied, I would go home and be upset, and my mum would pick up on it, and we'd have a chat about it, and work out a way to deal with it."*
>
> *(Luke, aged 30, UK, Moebius Syndrome)*

Participants also described how they experienced emotional validation by sharing their experiences with others who have the same condition, either through attending facial palsy conferences or through online groups. Participants described feeling emotionally validated when they heard others with the same condition describing similar experiences or struggles. This helped them feel understood, accepted and less alone in their experience, all of which contributed to the construction of a "validated me" self-state;

> *"It's absolutely phenomenal to meet people who for the first time in your life, you don't have to explain what you have. You don't have to apologise for what you can't do, people understand you clearly. They know what you've gone through, they've been there. And I think, words just don't do justice."*
>
> *(William, Male, aged 35, USA, Moebius Syndrome)*

Consequently, participants internalised these validating connections with others and in turn, they were able to make validating connections with parts of self that they had previously related to as ‘bad me’ or ‘not me’, this included making connections with self on a cognitive, affective and bodily level.

4.6.2 with self

Several participants described how they were able to validate self through internalising a primary caregiver, health professional and/or educator who was empathic, hopeful and skilful in their approach with them. Participants described how they were able to construct internal representations of these ‘validating others’ in their mind and connect with these internal representations whenever they were trying to experience a sense of physical or psychological agency across the lifespan. Participants described how bringing to conscious mind memories of the relationships with these internalised ‘validating others’ helped the participant experience the “validated me” self-state and deal effectively with any psychological or physical challenges they were facing.

Several participants described experiencing a range of physical problems during infancy and childhood which made it challenging for them to learn how to use their body to express themselves and communicate with others, feed themselves and to explore their physical surroundings. Participants’ accounts of these struggles consisted of personal memories and accounts received from their caregivers. Some gave accounts of how health professionals and educators would spend time containing their caregiver’s anxiety and teaching them how to support the participant to develop sensorimotor and speech and language skills. These individuals described how parents internalised this experience and then provided the same relational template when supporting and teaching them to develop these skills. Consequently, participants internalised these validating relational templates and built confidence in their ability to control their body and navigate their physical and social environment.

> *“I went to a special needs school when I was two and half… Because before that… At 2 ½ I wasn’t walking, I wasn’t crawling… I could just about sit up with support… And that school literally taught me everything because you had physiotherapy, speech therapy, every other therapy*

> *you could think of I had there… And they taught me and my mum everything… They taught me how to use things, the physiotherapy built my muscles up, the occupational therapy helped me to feed myself… Everything…and when I was learning to crawl, if I was struggling, my parents would sit there and encourage me and say go on, you can do it and they wouldn't come over and do it for me. I mean if I was really struggling to do something then they would step in, but they were always trying to encourage me to become as independent as possible. And now as an adult I am like that with myself, I always find ways around doing things, but I have learnt to ask for help if I really need it"*
>
> *(Sharon, 43, UK, Moebius Syndrome)*

In summary, the findings suggest that those born with congenital facial palsy experience interpersonal challenges from the beginning of life because of their difficulties expressing self and relating to others on a non-verbal level. As non-verbal communication is the only form of communication during infancy, this places this population at high risk of constructing a defective sense of self. The data suggests that this is because often these individuals do not receive the congruent mirroring and validation needed as others struggle to read them accurately on an affective level. Consequently, these individuals internalise inaccurate and negative representations of self during these early developmental periods and this becomes the foundation upon which the defective self-state is constructed. The findings suggest that non-verbal communication with others remains important across the lifespan in which those who do not learn how to communicate effectively on a non-verbal level during infancy and childhood are at risk of experiencing repetition of this invalidating relational pattern. Repeated invalidation strengthens the *"defective me"* self-state, reducing psychological flexibility which in turn makes it harder to construct a *"validated me"* self-state.

However, sufficient experience of validating relationships with others buffers against becoming trapped within the defective self-state. This is because these individuals are able to receive congruent mirroring and internalise an accurate positive representation of self. In turn, participants are able to relate with themselves in a validating manner, all of which facilitates the construction of a “validated me” self-state. The findings suggest that those who experience sufficient relational validation during childhood, find it easier to remain within the *“validated me”* self-state or to move back into this self-state after the “defective me” has been activated. This is because early experiences of validating relationships result in the development and internalisation of self-regulation skills which enhances emotional resilience within the individual. However, it is important to note that the grounded theory constructed illustrated how both self-states are relational processes rather than structures and therefore, activation of the self-state is dependent upon relational context (internal or external relationships) in which movement between the self-states is continuous across the lifespan.

5.0 Discussion

5.1 Summary of the Grounded Theory

The grounded theory outlined above describes the processes involved in the construction of ‘self’ in those living with congenital facial palsy. The analysis suggests that these processes were overlapping rather than linear, were repeated across the lifespan and became more complex as the individual progressed from childhood into adolescence and adulthood. Hence, the grounded theory outlined depicts the ‘self’ as a fluid relational process and flow of experience which exists across time, rather than as a single unitary structure which develops in sequential stages. The construction of the theory was influenced by my social constructionist epistemology and my relational psychoanalytic framework.

To summarise the grounded theory is as follows: the construction of ‘self’ was appeared to be a relational process in which two separate self-states were constructed, a *“defective me”* and a *“validated me”*. Self-states can be defined as different modes of being (experiences of self) which can be activated by different relational contexts. The construction of these self-states appeared to begin during infancy and continued across the lifespan. The *“defective me”* self-state consisted of the following categories; *struggling to make connections, experiencing invalidation* and *struggling with affect regulation*. The *“validated me”* self-state consisted of the following process; *making validating connections.* Participants appeared to move in and out of these self-states; those who described the ability to move fluidly between self-states described better psychosocial outcomes when faced with adverse situations. The analysis suggests that the earlier in life that the *“validated me”* self-state was constructed, the easier it was to move into this self-state after the “defective me” self-state had been activated.

5.2 Theoretical discussion

The grounded theory constructed highlighted how individuals with congenital facial palsy are at risk of experiencing significant disruptions within the attachment and bonding process during infancy due to difficulties developing a shared non-verbal communication system with the primary caregiver due to their limited ability to reciprocate facial expressions and disrupted gaze. The parents in this study described how facial paralysis made it difficult to know how to accurately read their infant's mind and how to attune and attend to their infant's emotional and physical needs. The early disruptions within the facial mirroring process for this population provide support for mentalisation theory (Fonagy et al., 2004).

According to mentalisation theory an infant needs to find themselves in 'the face of another' (usually their primary caregiver) in order to feel recognised and validated as a person. This occurs through 'the other' mirroring back an accurate representation of the infant's psychological and emotional state (Fonagy et al., 2004). However, parents' accounts indicate that there may have been a breakdown in 'embodied mentalisation' during infancy and childhood possibly leading to the construction of a "defective me" self-representation. It seems possible that participants with facial palsy were unable to form validating connections with the mirrored representations (reflections) of 'self' that they were presented with through interactions with others as these representations did not match their original internal experience of 'self'. Hence, participants may have come to understand these mirrored reflections as 'bad/defective me' or in some instances, 'not me' experiences. However, this can only be a tentative hypothesis at this stage as first-hand data is missing for the infancy period.

While it would be problematic to speculate about participants' preverbal experiences, this relational pattern did appear to be indicated in participants' later accounts of relationships across the lifespan and hence participants experienced repeated invalidation, all of which further invalidated the sense of self and strengthened the *"defective me"* self-state. Several participants described how these invalidating experiences were most frequent during childhood because they had not learned how to express themselves and communicate effectively with others on a non-verbal level. Furthermore, their school peers with whom they were spending most of their days with also had limited capacity to 'mentalise' in the absence of facial expression. Fonagy et al. (2004) suggest that children have limited verbal/linguistic abilities and so non-verbal communication remains an important channel for establishing interpersonal connections during this developmental period. These findings highlight how 'peer mentalisation' plays a significant role in the construction of self and how children with congenital facial palsy are at a significant socio-emotional disadvantage during this period of life.

The findings suggested that these repeated invalidating early relational patterns meant that interpersonal relationships became a source of pain rather than pleasure or comfort for participants. Many participants described engaging in a range of defensive strategies (e.g. hiding/withdrawing) in childhood in order to regulate the frustration, anger, shame and hurt that they experienced during these social interactions. Whilst these strategies were self-protective to a degree, they were repeated across the lifespan as the individual avoided social situations whereby there might have been opportunities to develop communication and other interpersonal skills and experience validating relationships with others.

These findings support Johnson's (1994) relational psychoanalytic theory which postulates that early experiences of invalidation, rejection and shame, can result in the development of a 'schizoid' character style. Those with schizoid character traits usually fear emotional and physical intimacy because they have learned during early life that interpersonal relationships are dangerous and threatening to their sense of self (Johnson, 1994; Guntrip, 1992). These individuals learn to protect their fragile sense of self by avoiding interpersonal relationships and dissociating traumatic experiences (including memories and associated emotions). Furthermore, Johnson's (1994) description of the 'schizoid issue' might explain why participants struggled to recall memories of childhood because they were too threatening to the sense of self.

The findings from this study make a novel contribution to the area of visible difference, relational psychoanalysis and disability studies as they highlight how the medical traumas and/or procedures, as well as repeated relational invalidation disrupt the individual's relationship with their body and in turn their ability to develop a sense of sexuality. Sexual intimacy with another becomes something that is feared and split off from self experience rather than something that is desired. Johnson (1994) stated that this is another core feature of the 'schizoid issue.' Participants described how often they avoided engaging in sexual relationships as they were concerned that they would not be able to sexually perform because their disability provided real physical challenges in terms of performing certain sexual acts such as kissing. These findings are novel as this specific issue has not been explored within the field of visible difference or within the field of relational psychoanalysis in terms of how this impacts the construction of self.

Another novel finding that emerged from this study was the struggle with affect regulation; participants described how they needed to have consistent access to self-regulating others (what Kohut termed 'self objects') in order to learn how to regulate their own affect and build a robust/resilient sense of self. This finding provided empirical support for Kohut's (1978) self psychological theory. Kohut (1978) postulated that if an individual does not learn to self-regulate during childhood through the internalisation of relationships with self-regulating others, the individual would find themselves continuously looking to others to regulate their affect and maintain their self-esteem and/or would experience emotional and behavioural disorders. This appeared to be the case for several participants in this study who did not have sufficient access to self-regulating others during childhood and adolescence.

The struggle with affect regulation in this population supports and further extends mentalisation theory (Fonagy et al., 2004). Participants described how during interpersonal situations they became overly pre-occupied with what the other was thinking and feeling about them and this resulted in becoming hypersensitive to the non-verbal body language of others, looking out for any signs which might indicate negative judgement or misunderstanding. Some participants described becoming over pre-occupied with their own lack of facial expression which made it difficult for them to be fully present within the social interaction; this made interpersonal interactions highly anxiety provoking, to the point that participants needed to engage in defensive behaviours (e.g. withdrawing/hiding) to regulate the intense affect. Bateman and Fonagy (2016) have referred to this behaviour as 'hyper-mentalising' and state that this mental process creates difficulties regulating affect (Bateman & Fonagy, 2016). It appears that 'hyper mentalising' might be a key interpersonal difficulty for this population and that this difficulty might be the result of earlier invalidating relational experiences in which participants ability to live through the body has been traumatically disrupted.

Another novel finding in this study was the qualitative reports provided by two parents who described the 'embodied mentalising' process and how this helped them create validating connections with their infant in the absence of facial expression. 'Embodied mentalisation' is a new sphere of mentalisation research and theory (Shai & Fonagy, 2014) and describes the process by which the caregiver uses whole body movements to mirror back an accurate understanding of their infant's needs and wishes. The findings from this study provide further empirical support for 'embodied mentalisation' by indicating that whilst facial mirroring plays a central role in facilitating interpersonal connectedness and the construction of a validated self, it can be compensated for through using other parts of the body and whole-body expressions and gestures to accurately mirror and mentalise the infant. Furthermore, these findings provide the first qualitative account which tentatively suggests how this process may work during infancy. The findings from this study indicate that congruent facial mirroring is needed throughout the lifespan in order to maintain a validated sense of self; lack of reciprocation from either side of the dyad can dysregulate the affective experience of the partner and disrupt the intersubjective/interpersonal process, which in turn activates the '"defective me"' self-state.

The grounded theory indicated that individuals could improve these invalidating relational dynamics by making validating connections. As previously suggested by Bogart et al. (2012; 2014; 2015) this involved developing nonverbal and verbal communication skills. The current study extends Bogart et al's findings as the grounded theory suggests that those who developed these skills during infancy and early childhood were more confident and skilled at developing interpersonal relationships across the lifespan. The findings further extend the work of Bogart et al. as they highlight how in addition to learning communicative skills, it is essential that children with facial palsy learn to talk about difficult experiences they might have in relation to the condition and to have these heard and validated by their caregivers. Participants who had this experience in earlier life found it easier to move between the self-states, whereas those who did not, reported becoming trapped within their "defective me" self-state more often.

Hence, the grounded theory constructed makes a novel contribution to the visible difference field as it highlights how the construction of a "validated me" self-state is dependent upon internalising validating relationships with others and explains the relational processes involved in this. This involves internalising validating signs and symbols which in turn, validates the 'self' and provides the individual with a validating relational template in which to relate with their self.

From an 'insider perspective' the grounded theory constructed resonated strongly with me, especially in terms of the construction of and movement between the *'defective me'* and *'validated me'* self states. I resonated with the difficulties participants experienced connecting on a non-verbal (embodied level) with others who were unfamiliar with them and their condition and the emotional invalidation they experienced as a consequence. I also resonated with the difficulties experienced in terms of oscillating between over-regulating emotions and becoming emotionally dysregulated. However, similar to some of the participants in this study, although I had some difficult early relational experiences, I was fortunate to experience validating relationships with my caregivers, friends and some teachers in childhood and adolescence and I believe that the internalisation of these relationships enhanced my social competence and facilitated the construction of my *'validated me'* self state. I particularly resonated with participant accounts around how acquiring a smile through undergoing successful smile surgery can facilitate the construction of a validated self state. I agreed with their view that acquiring a smile can facilitate the embodied connection between self and other as this was my experience too. However, as only three participants within this study had underwent smile surgery, it is difficult to draw any conclusions at this stage, and it seems that this is an area where more research might be needed.

To conclude the theoretical discussion, the findings from this study provide a preliminary relational psychoanalytic model/theory of self-development for those living with a congenital facial palsy and offer novel insights into the reparative relational processes needed to facilitate the construction of a “validated me” self-state in the individual with this condition. Furthermore, these findings highlight the need for the development of relational psychotherapies to support those with congenital facial palsy who might have complex psychosocial needs. This will be discussed further in the implications for practice and future research sections below.

5.3 Ensuring quality and rigour in the research

Constructivist Grounded Theory is concerned with ensuring quality and rigour throughout the research process. Charmaz (2006) advocates using the following criteria to implement and assess this; credibility, originality, resonance and usefulness. I will firstly consider the credibility of the findings from this study.

Credibility

The sample of participants was diverse in terms of age, geographical location, educational and social background, age upon which a diagnosis was given and severity of the condition. There was an equal balance in terms of gender. As all participants were adults, I was able to obtain in-depth retrospective accounts using in depth qualitative interviews regarding how their sense of self developed. The recruitment of parents during the theoretical sampling phase facilitated the data gathering for the infancy and early childhood period which otherwise would have remained missing from this theory as participants were unable to remember this early phase of life.

Constant comparison and data analysis guided each interview process and ensured that the codes and categories generated through previous interviews were further developed and refined with each subsequent interview. Hence the grounded theory constructed was grounded within the data provided by participants.

The method of constant comparison meant that categories were continuously compared with each other in terms of how they related to each other and areas of divergence. Memos were made about these comparisons, as well as of my observations throughout the research process.

The analysis of the data provided by participants was considered against the existing literature within the field and the analysis was built upon this. During this process I was continuously asking myself questions such as; how does this data compare or contrast with previous literature? How does the data address the gaps within the literature in terms of self-development within this population? How does this data provide a novel contribution to this area? I ensured that logical links were made between the data and analysis by engaging in regular reflective and reflexive discussions with my supervisory research team.

This was done sufficiently through providing transparency in terms of my personal interest in this area and my epistemological and theoretical framework. I provide evidence in the appendices of how I engaged in regular reflexive journaling and memoing and how my codes, categories and diagrams were used to construct my theory. I also provide evidence of how I engaged in reflective discussions throughout the research process with my supervisory team and psychologist colleagues with ‘insider status’ and ‘outsider status’, to ensure that my ‘insider experience’ could be used in a way which strengthened the quality of the research conducted. I also presented my rationale and preliminary data analysis at three international conferences. This provided me with an invaluable opportunity in which to engage with other researchers’ and clinicians’ views on the data analysis and helped me consider and refine my findings further.

Originality

Undertaking this research has resulted in the construction of a novel theory in an under researched area. A thorough literature review suggests that this is something which has not been done within the field of visible difference, relational psychoanalysis, developmental psychology or Counselling Psychology and therefore this renders these findings highly original and makes a significant contribution to all of these fields. Furthermore, it begins to bridge the theoretical gap between the fields.

My analysis provides a new ‘conceptual rendering of the data’ (Charmaz, 2006) as it highlights the centrality of the face in the construction of the sense of self and the unique relational developmental challenges that those living with congenital facial palsy are at risk of experiencing because of the disruption that occurs within interpersonal relationships on an implicit and often unconscious level. These findings are therefore highly relevant to health and educational professionals working in this field, family members and most importantly those living with congenital facial palsy. My ‘insider experience’ played a fundamental role in the development of a research project which produced novel findings. It was through my personal experience of living with congenital facial palsy and the difficulties I experienced around constructing my sense of self, along with my knowledge of relational psychoanalysis that I was able to recognise that there was a need to develop a relational model which explains how the sense of self might be constructed in individuals with this condition.

Resonance

Resonance was explored by presenting the findings at the Moebius Syndrome Conference in Florida in 2018. The room consisted of a range of health and educational professionals and some adults living with congenital facial palsy. During the question and answer section after I had given the presentation of the findings, several adults living with the condition commented on how the theory constructed resonated with their lived experience and helped them gain a deeper understanding as to why they have found themselves stuck within the “defective me”’ self-state. Furthermore, health professionals working in the field commented on how the theory helped them make better sense of the psychological struggles past clients had discussed with them and offered them new insights in terms of developing their clinical practice in order to enhance effectivity.

In addition, I presented the findings to several participants who participated in this study and all of these participants confirmed that the theory constructed resonated with their lived experience. The grounded theory constructed also resonated with my personal experience of living with congenital facial palsy and constructing a sense of self, especially the difficulties experienced around connecting with the face or body and affect regulation during early childhood.

Usefulness

It is hoped that these findings will be useful for individuals living with congenital facial palsy as it provides a process model of how they might become vulnerable to constructing and becoming trapped within a defective sense of self. It also provides an understanding of the relational processes they need to engage in in order to construct and move into the validated self-state. Furthermore, the theory is of use to family members and the range of professionals working with them as it provides insights into the ways in which they need to engage with the individual in order to support them to construct a validated self-state. In addition, this theory could be used to develop specialist relational psychotherapies which aim to support the individual to understand the difficulties they experience (through developing a relational based formulation) and repair the disrupted relational processes which feed into the *"defective me"* self-state. The theory also provides guidance around the future research that is needed within this area; this includes gaining a deeper understanding of the relational disruptions which might be occurring within the pre-verbal period of self construction, especially the parent-infant dyad and also during childhood. This is discussed further in the implications for research section.

5.4 A critique of constructivist Grounded Theory methodology

Whilst constructivist grounded theory has many strengths, it also has some limitations which must be acknowledged. Glaser (2002) has criticised the constructivist grounded theory idea of 'co-constructed meaning' by arguing that it is an attempt to conceal researcher bias and legitimise the 'forcing of data'. Whilst I agree that my relational psychoanalytic framework and my "insider experience" will have influenced to some extent my reading of the data and construction of codes and categories, I do not agree that this led to the production of biased data. Conversely, my constructionist stance and continuous engagement in reflexive dialogue with colleagues who had 'insider status' and 'outsider status' allowed me to acknowledge my own subjectivity and reflect upon how this might have influenced the co-construction of the theory, all of which enables the reader to reach their own conclusion about whether or not they agree with the theory generated. Furthermore, this can be evidenced in the breadth of data presented in this study and the clear logical links between the data and the analysis which are present.

One further limitation with the constructivist grounded theory method is that it is a lengthy and fairly complicated process for the novice qualitative researcher, which can result in becoming 'lost' in the data and overwhelmed by it (Allan, 2003; Myers, 2009). I frequently felt like this during the early phases of data analysis. However, Charmaz (2006; 2014) advocates obtaining guidance from an experienced grounded theory mentor with each stage of the research process and I was able to do this through regular contact with my Director of Studies. Therefore, I was able to maintain quality and rigour throughout my analysis.

Constructivist Grounded Theory has several key strengths. Charmaz (2006) states that the researcher is both a participant and an observer within the research process and researcher reflexivity is a central tenet of grounded theory construction. Charmaz advocates that researchers should keep memos and a reflexivity diary in order to monitor their personal and functional reflexivity (Charmaz, 2006; 2014). A further strength of the constructivist grounded theory method is the process of coding which involves firstly coding for the 'action' (using gerunds) and then coding analytically for implicit as well as explicit meanings. This method improved rigour as I was aware that I was bringing my own personal and professional experience to the data analysis and this method helped me remain grounded within the data whilst acknowledging my part in the co-construction of the data and analysis.

It is likely that had I not followed this coding method that I may have not captured the significant 'actions' and this would have had a negative impact on the construction of categories and overall theory construction. This coding method allowed for rigour without stifling my creativity. Engaging in the process of constant comparison throughout the research journey is a further strength of constructivist grounded theory. This is because it enhances researcher reflexivity as the researcher is continuously reflecting upon the data collected, how it contributes to the construction of theory and provides the researcher with the opportunity to address any gaps. The method of theoretical sampling is invaluable for addressing the gaps that emerge within the data analysis as was the case in this study with the absent first-hand accounts of the experience of infancy.

5.5 Limitations of the study

Although this study has many strengths, it also has several limitations. The first of which is the paucity of data from the infancy period. This is a struggle that all infancy researchers experience however, many now use video microanalytic and observational methods to collect some ‘in vivo’ data of this early developmental period. This was something which was not possible to do within this study and therefore it was necessary for me to rely upon the descriptive accounts from parents of those with congenital facial palsy.

Furthermore, several participants struggled to recall their later childhood in depth. As described in the findings section, this may have been due to early relational trauma and dissociation. In addition, retrospective accounts have the potential to be full of distortions/inaccuracies in memory as memory is a construction which is affected by time and context (Conway & Pleydell-Pearce, 2000).

In addition, it was noted that most of the participants recruited for this study had bilateral facial palsy (and a diagnosis of Moebius Syndrome) and hence the sample was lacking in terms of data from those living with unilateral facial palsy. This could be problematic as those living with unilateral facial palsy typically have some degree of facial expression and hence their lived experience could be quite different to those with Mobius Syndrome because of this difference. In hindsight, the quality of this research could have been enhanced further had I theoretically sampled those living with unilateral facial palsy and compared their lived experience with those who had a bilateral facial palsy.

It could be argued that one further possible limitation of this study was the use of Skype interviews. There are theorists who would argue that important aspects of relationality become lost when one is interviewed via online video chat rather than in person (McCoyd & Kerson, 2006). Such theorists argue that what can be lost is the embodied (non-verbal) aspects of relating and that this is something worth paying particular attention to given the nature of this study (Cater, 2011). Hence providing participants with the option of undertaking a Skype based interview might mean that the researcher does not obtain a real felt sense of what it is like to be in the same room interacting with someone who is not able to express themselves and communicate through facial expression and hence further meaningful observations (data) could be lost (Cater, 2011).

Some important ethical questions have been raised around using Skype based interviews in place of face to face interviews. It could be argued that with Skype the researcher has no way of knowing if there are other people sitting in the same room as the participant (or listening in from another room) and hence this could affect the level of confidentiality and how the participant answers questions, all of which could negatively impact the overall quality of the research. I tried to prevent this from occurring by checking with participants that they were in a separate room to others before commencing the interview and given the sensitive nature of this topic participants seemed to want to be interviewed away from others. Some participants ensured this by arranging an interview time when they knew that they would be the only one at home.

As a relational psychologist, I can understand the concerns raised about undertaking Skype based interviews and what can potentially be lost on a relational level. However, I am in agreement with Janghorban, Roudsari, and

Taghipour (2014) and Hanna (2012) that much can be gained from recruiting individuals who otherwise would be deemed unreachable. It was necessary to conduct skype based interviews with this study because of the difficulty recruiting participants due to the rarity of the condition and hence those affected are dispersed across the globe.

One main limitation with the face to face interviews that were undertaken at the conference was the busy conference schedule which meant that I did not have the flexibility to extend interviews to explore some topics further like I did with the Skype based interviews. However, as I interviewed 16 participants in total with diverse backgrounds and experiences, I obtained the rich and thick data needed to construct the grounded theory.

5.6 Implications of the research

5.6.1 Implications for individuals with congenital facial palsy/carers/family

The study gives voice to an under represented and marginalised population and is grounded within their lived experience. The findings provide an in-depth account of the challenging psychosocial experiences that these individuals often encounter across the lifespan and makes the case for the need for early psychosocial intervention and access to specialist intervention. This includes access to specialist psycho-social interventions for caregivers and their families as these agents play a significant role in the construction of ‘self’ in those with congenital facial palsy.

Furthermore, the findings suggest that medical interventions which restore facial function and/or expression enhance the overall psychological wellbeing of individuals living with this condition by improving their ability to make validating non-verbal connections with others. Hence, the findings make a significant psychosocial contribution to a field which is dominated by the medical model.

5.6.2 Implications for healthcare and educational professionals

The findings from this study have significant implications for the healthcare professionals and educational professionals working with individuals with a congenital facial palsy and their carers/family members. It is suggested that specialist psycho-social support could be highly beneficial for the individual with this condition as well as for their family due to the disruptions to the bonding and attachment process that can occur in early life.

In order to prevent the development of a defective sense of self, it is essential that health professionals and educational professionals working with these individuals provide integrated care which focuses on the development of the individual's sense of self. This includes specialist grief counselling for caregivers and specialist support/training to learn how best to support their child to develop physical autonomy, mastery of speech and alternative non-verbal communication strategies. It seems likely that caregivers might require specialist support from their medical team during infancy to teach them how to adapt to the infant's unique feeding needs in an attuned and sensitive manner. Supporting the family to build an alternative shared communication system when facial expression is limited or completely absent would facilitate the construction of a validated self-state.

Therefore, early intervention is crucial for this population and the findings indicate that what is needed is a multidisciplinary team-based approach. Biopsychosocial support needs to be provided in an integrated, relational and client centred way, all of which is necessary for facilitating the construction of a validated sense of self within the individual with congenital facial palsy. At present, only a handful of multidisciplinary facial palsy teams exist within the UK

(Walker et al., 2012) and this places those who live outside of these regions at a disadvantage in terms of access to specialist care.

These findings have significant implications for medical professionals who make decisions about the provision of facial re-animation surgery and other surgical interventions for facial palsy. These findings indicate that these surgeries are essential for the restoration or improvement of facial function which has a direct impact upon mental health/psychological outcomes in this population. Participants who experienced some restoration in facial function reported an improvement in psychological outcome as they found it easier to make interpersonal connections with others. Those who were denied access to these surgeries described how they missed out on an intervention which could have enhanced their psychological wellbeing and improved their social interactions with others.

Participants' accounts suggest that many medical/health professionals could benefit from undertaking training in relational skills to enhance their interactions with individuals with facial palsy and their caregivers. Findings revealed that the language used by medical professionals or teachers was often felt to be stigmatising and fed into the construction of the "*defective me"* self-state.

Finally, the grounded theory constructed illustrates how the educational context plays a significant role in the construction of the child's sense of self. Developing positive peer relationships and making appropriate adjustments to the learning environment to meet the child's individual needs are important tasks which needed to be achieved for the child to learn effectively and construct a positive sense of self. Recommendations for practice within an educational setting include; developing individual learning support plans, providing specialist equipment or learning materials to facilitate the learning experience in the classroom and access to a peer mentor and/or school-based counselling should the individual need space to process their experience of school and to develop strategies to overcome any psycho-social challenges they are experiencing.

5.6.3 Implications for the field of Counselling Psychology

The field of Counselling Psychology is underpinned by a relational philosophy and a social constructionist framework (Douglas & Woolfe, 2016). One of the central aims of the profession is to develop psychological theory and psychotherapeutic practice which is grounded within the lived experience of the clinical populations with whom counselling psychologists work (British Psychological Society, 2005). The current study fulfils these aims by giving voice to a minority population whose' psychosocial needs are often overlooked due to the dominance of the medical model within this area. Furthermore, the findings promote the profession's humanistic ethos by encouraging the health and educational professionals working with these individuals to work in a relational and holistic way

To date, the field of Counselling Psychology has made minimal contribution to the field of visible difference and wider disability, both in terms of research and practice. Therefore, the findings from this study are significant for the field of Counselling Psychology as they make a novel and significant contribution to this area. It is hoped that the findings from this study will encourage other Counselling Psychologists to undertake much needed research within the field of visible difference or disability to enhance the psychological wellbeing of those living with these conditions.

5.7 Recommendations for practice

5.7.1 Recommendations for therapeutic practice

The findings highlight the need for access to specialist psychotherapy for individuals with this condition and their caregivers throughout the lifespan. The grounded theory presented highlights the need for the provision of specialist relational psychotherapies which facilitate the simultaneous healing of the non-verbal self as well as the narrative self in order to develop a “validated me” self-state. Recommendations for how this can be facilitated at different stages of the lifespan are discussed below.

Provision of parent-infant psychotherapy

Parent-infant psychotherapy is a dyadic psychodynamic intervention, grounded within psychoanalytic theory, attachment theory and findings from infancy research, which aims to address difficulties that occur within the parent-infant relationship during the pre-verbal period (Baradon, Biseo, Broughton, James, & Joyce, 2016). Parent-infant psychotherapy aims to identify unconscious unhelpful relational patterns that occur within the dyadic system and to teach the parent new ways of relating with the infant which improves the parent-infant relationship (Baradon et al., 2016). The grounded theory constructed has indicated that infants with congenital facial palsy and their caregivers might benefit from this type of intervention as facial paralysis in the infant can heighten the risk of experiencing these relational difficulties. However, given the unique challenges faced by this parent-infant dyad, this psychotherapy model might require adaptation in order to meet the unique needs of these infants and their caregivers. Recommendations for research in this area are discussed below.

Provision of embodied mentalisation programmes

It is suggested that a specialist relational ‘embodied mentalisation’ skills training be offered to school age children as this would help children with facial palsy and their peers develop a range of non-verbal communication skills so that they could make validating connections on a non-verbal level. This could be very helpful for the child with facial palsy as they would develop these skills from a young age, enhancing their ability to communicate effectively with peers and the ability of peers to accurately read and connect to them. This might enhance social inclusion for children with congenital facial palsy and other communication difficulties and contribute to the construction of a validated self-state. This intervention is likely to be significantly less stigmatising than the traditional school assembly whereby other children are educated about the child with facial palsy which in itself constructs an ‘otherness’. The data revealed that whilst school assemblies of this kind were delivered with the best intentions, they were highly stigmatising for the individual and fed into the construction of a defective sense of self. Again, given the unique relational challenges faced by this population, further research would be needed to be undertaken in this area.

Provision of specialist relational based individual psychotherapies

Findings highlighted how the difficulties communicating effectively with others on a non-verbal and verbal level extended across the lifespan for those living with congenital facial palsy. It is therefore recommended that the provision of specialist relational based individual psychotherapies which focus upon simultaneously healing the non-verbal and narrative self are accessible for children, adolescents and adults with congenital facial palsy.

Mentalisation Based Therapy (see Bateman & Fonagy, 2016) could be one effective psychotherapeutic approach for working with this population. This approach is grounded within the principles of attachment theory and psychoanalysis and aims to facilitate a change in cognitive affective processes that occur on an interpersonal and intrapersonal level. This approach has a good evidence base in which it has been recommended in the NICE (2009) guidelines for individuals who experience complex interpersonal and affect regulation difficulties. Furthermore, it is a structured and time limited approach and has already been adapted to meet the needs of children, adolescents, adults and families and can be delivered as a group intervention as well as an individual based treatment (Bateman & Fonagy, 2016).

This particular therapy could be effective for individuals with congenital facial palsy who experience hyper mentalisation difficulties (due to becoming pre-occupied with how the other is experiencing them) and experiencing a high degree of interpersonal anxiety as a result. The approach could also be effective for those who become easily frustrated or angry due to difficulties with self-expression and a lack of validation from others. The mentalisation therapist supports the individual to use the therapeutic relationship as a secure base, one in which the individual's attachment system can become activated and interpersonal difficulties can play out. The therapist uses the therapeutic relationship to support the client to gain a deeper understanding of these interpersonal difficulties which activate the "defective me" self-state. This involves teaching the patient to notice where failures in mentalisation occur and how to use a range of techniques to slow their mental process down and to restore mentalisation when it has been lost. Restoring mentalisation enables the individual to regulate affect appropriately and de-activate the "defective me" self-state (Bateman & Fonagy, 2016).

As discussed above, whilst these relational psychotherapies could provide a good framework in which to support individuals with congenital facial palsy to address relational developmental challenges, it is possible that these models may need adapting to meet the idiosyncratic needs of this population. Therefore, further research is needed.

5.8 Recommendations for future research

The findings indicate that further psychoanalytical research into how the 'self' develops in the period of infancy and childhood in this population would be beneficial.

One line of inquiry could be to replicate the infancy studies conducted by Beebe and Lachmann (2013) whereby video microanalysis is used to explore the dyadic interaction between caregiver and infant with congenital facial palsy. Should this research be conducted then the findings could be used to understand how the parent-infant dyad develop a non-verbal shared communication system in the absence of facial expression and how this influences the infant’s attachment style and sense of self. These findings could support researcher-clinicians to develop parent-infant psychotherapies or programmes to help new parents who are struggling to bond and interact with their infants because of the absence of facial expression.

These findings could be used to develop embodied mentalisation programmes for children, adolescents and adults who may have experienced these relational disruptions during early life and may continue to struggle with self-expression due to a lack of these relational skills. As with the findings from the infancy studies conducted by Beebe and Lachmann (2013), the findings could be used to build upon the grounded theory constructed and to develop specialist relational psychotherapies for those living with congenital facial palsy.

There may also be scope for researchers to conduct longitudinal research to explore how such early life interventions with parent-infant with facial palsy dyad influences the development of the self and psychological outcomes across the lifespan.

One final recommendation for future research could be to replicate this current study with adults who have acquired facial palsy (e.g. through accident or illness) as the research suggests that those who acquire facial palsy in childhood or in later life report experiencing disruptions within their sense of self (Callahan, 2005). A replication of this study with those who acquire facial palsy could lead to a deeper understanding of the processes involved in reconstructing the sense of self in this population and any similarities or differences that occur between congenital and acquired facial palsy in terms of psychosocial adjustment.

5.9 Conclusion

This study makes a novel contribution to the field of Counselling Psychology, visible difference, relational psychoanalysis, developmental psychology, and disability studies as it begins to bridge the gap between these fields by offering a developmental psychoanalytic theory explaining how the ‘self’ is constructed in individuals with congenital facial palsy. The findings provide some preliminary insight into how this population are at risk of experiencing significant injury to their non-verbal sense of self during infancy and early childhood as their ability to express themselves and communicate via facial expression is compromised. This results in the initial construction of the “defective me” self-state.

Without appropriate early psychosocial intervention, these relational patterns are likely to persist across the lifespan and strengthen this self-state. Participants in the current study learned to cope with repeated invalidation by engaging in a range of self-protective mechanisms. However, the longer these self-protective behaviours are left unchallenged, the more robust they become, and this reduces the individual’s psychological flexibility. Consequently, it becomes more of a challenge to internalise validating relationships with others and to construct a “validated me” self-state. Even when this is achieved, it appears to be harder for these individuals to re-activate their “validated me” self-state after they have experienced invalidation within their environment. In contrast, the findings indicate that those who construct a validated self-state during childhood and adolescence, find it easier to move back into this self-state after experiencing invalidation. The findings suggest that this is because these individuals had greater psychological flexibility as their self-protective mechanisms were less robust and hence, they could be more open to new experiences.

The grounded theory constructed introduces new theoretical knowledge to the field of facial palsy which in turn could be used to encourage the development of specialist relational psychotherapies which focus on working at relational depth in order to address the complex interpersonal and intrapersonal dynamics which can negatively impact the sense of self in individuals with congenital facial palsy. However, it is important to remain mindful that this was a small-scale study and therefore provides a preliminary exploration into how the ‘self’ is constructed in this population. Further research is needed in order to deepen knowledge in this area, especially for the period of infancy and childhood.

The findings from this study illustrate that there may be a need for a re-conceptualisation of the ‘self’ within the field of visible difference so that it is recognised as a fluid relational process, consisting of self-states which are comprised of unconscious as well as conscious processes. Hence the findings suggest that there might also be a need for a shift in terms of how the ‘self’ is measured within this field. It is suggested that the use of qualitative research methods and other developmental psychoanalytic research methods (e.g. video microanalysis) can be helpful in this area.

To conclude, it seems essential that the fields of visible difference, relational psychoanalysis, and developmental psychology begin to work more closely together so that multidisciplinary research can be conducted, and effective relational psychotherapeutic interventions can be developed for those who experience self-identity and self-development issues as a consequence of living with a craniofacial condition. These relational based interventions need to be developed on an individual and systemic level as the findings suggest that the ‘self’ is something which is constructed through a combination of dyadic relationships, group relationships and relationships with wider social systems.

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APPENDIX A – PARTICIPANT DEMOGRAPHICS

Participants recruited through purposive sampling

Participant identifier	**Participant age**	**Gender**	**Country of residence**	**Diagnosis**	**Received smile surgery**
Sean	60	Male	UK	Congenital (unilateral) Facial Palsy	No
James	36	Male	UK	Mobius Syndrome	No
Luke	30	Male	UK	Mobius Syndrome	No
Samuel	28	Male	UK	Mobius Syndrome	Yes
Barbara	60	Female	USA	Mobius Syndrome	Yes
Natalie	36	Female	UK	Congenital (unilateral) Facial Palsy	No
Sharon	43	Female	UK	Mobius syndrome	No
Susan	45	Female	USA	Mobius Syndrome	No
Lucy	34	Female	USA	Mobius Syndrome	No
Simon	32	Male	USA	Mobius Syndrome	No
Carl	58	Male	USA	Mobius Syndrome	No
John	48	Male	USA	Mobius Syndrome	No
William	35	Male	USA	Mobius Syndrome	No
Georgia	25	Female	USA	Mobius Syndrome	Yes

Theoretical sampling participants

Participant identifier	**Participant age**	**Gender**	**Country of residence**	**Sex of child with facial palsy**	**Age of child with facial palsy**
Samantha	50	Female	UK	Daughter	18
Maria	45	Female	UK	Son	12

APPENDIX B – STUDY INFORMATION SHEET FOR PARTICIPANTS

University of the
West of England
BRISTOL

1. Study title

‘The construction of ‘self’ in individuals with congenital Facial Palsy; A Grounded Theory Exploration’

You are being invited to take part in a research study. This study has received ethical approval from the UWE Research Ethics Committee. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

2. Who is carrying out this research?

My name is Laura Davies and I am a Trainee Counselling Psychologist in my final year of training on the Doctorate in Counselling Psychology at UWE. I am also an adult living with Facial Palsy (Moebius Syndrome). This study is being supervised by Andrea Halewood, and Dr Liz Jenkinson who are Senior Lecturers in Psychology at the University of the West of England.

3. What is the purpose of the study?

The purpose of this study is to better understand how people living with congenital Facial Palsy develop a sense of identity as they grow from infancy into adulthood. In order to explore this, you will be required to participate in a 60 - 90 minute audio recorded face to face interview with me.

4. Why have I been chosen?

You have been selected as you are either living with Facial Palsy or you are a relative of someone who lives with this condition and I would be interested in asking you about your experience of this. You and approximately 15 other adults with the same *condition have been recruited to participate in the initial stage of this study. Further interviews may be conducted as the study progresses.*

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any point and you will not be required to state your reasons for withdrawing.

6. What will happen to me if I take part and what do I have to do?

You will be asked a series of questions which will focus on exploring how the sense of identity ('self') develops in people living with congenital facial palsy. I would encourage you to be as open and as honest as you feel able to be during the interview and to remind you that you are not obliged to answer any questions which you do not feel comfortable answering.

7. What are the possible disadvantages and risks of taking part?

It is possible that reflecting upon your personal experiences during the interview might evoke some uncomfortable emotions within you e.g. feeling sad or upset. For this reason I would caution you against participating if you are currently feeling vulnerable or experiencing ongoing mental health problems. Should you choose to participate in the interview, it is important that you are aware that you have the right to stop the interview at any time and to withdraw from the study if you wish.

8. What are the possible benefits of taking part?

While there are no immediate gains for you in participating in this study other than the opportunity to reflect on your experiences, it is hoped that the findings from this study will inform the development of future psychological resources available for people living with Facial Palsy.

9. What if something goes wrong?

Should you wish to make a complaint about the conduct of this study then please feel free to contact me or you may prefer to contact my Project Supervisor Andrea Halewood at andrea.halewood@uwe.ac.uk

10. Will my taking part in this study be kept confidential?

Your participation in this study and what you say during the interview will remain confidential. The only time confidentiality could be broken would be if you disclose something which indicates that either you, or someone else, is at risk of serious harm. In such instances, I would discuss this with you first, unless doing so would put you or others at further risk of serious harm.

11. What will happen to the results of the research study?

Interview data will be analysed and the findings will be written-up and submitted as part of my Doctoral research. Papers for publication in academic journals may also be written based upon the findings however please be assured that all identifying features will be removed in order to maintain your anonymity.

12. Contact for Further Information

Should you have any further questions in relation to this study then please do not hesitate to contact me or my Project Supervisor. If you decide you would like to take part in this Study, please sign and return the consent form to the Researcher (Laura Davies) .

Researcher's contact details: Laura16.Davies@live.uwe.ac.uk

Project Supervisor's contact details: Andrea Halewood; tel; (0)117 32 83889; email - andrea.halewood@uwe.ac.uk

I would like to take this opportunity to thank you for your interest in this study. You will be given a copy of this participant information sheet and your signed consent form to keep for your records.

APPENDIX C – CONSENT FORM FOR PARTICIPANTS

Project Title: **‘A Grounded Theory exploration of the development of the ‘self’ in adults living with Congenital Facial Palsy.’**

Principal Investigator: Laura Davies

CONSENT FORM

1. Are you Male or Female? **Male/female/transgender**
2. Do you have a medical diagnosis of Facial Palsy (present from birth)? **YES/NO**
3. Are you currently receiving psychological or medical treatment for a Mental Health condition? (if yes, it will not be appropriate for you to participate in this study) **YES/NO**
4. Are you aged 18 or above? **YES/NO** (please state age) _____________
5. Have you read the information sheet explaining the nature of the study? **YES/NO**
6. Do you have a clear idea about what is expected of you? **YES/NO**
7. Do you understand that you can ask questions about the study after you have completed the study? **YES/NO**
8. Do you consent to the interviews being audio recorded? **YES/NO**

DO YOU UNDERSTAND:

That you are free to withdraw from the study:

9. At any time? **YES/NO**
10. Without having to give a reason for withdrawing? **YES/NO**

11. That you are free to withdraw your data from any future analysis and/or publication, without giving a reason? **YES/NO**

I fully and freely consent to participate in a study entitled:

A Grounded Theory exploration of the development of the self in adults living with Congenital Facial Palsy

I understand the nature and purpose of the procedures involved communicated to me on a separate information sheet and in discussion with the principal investigator (the researcher).

I understand and acknowledge that the investigation is designed to promote scientific knowledge and that the University will use my data for no purpose other than research.

I understand that a numerical code will replace my name so that my data can remain confidential and that I will not be identified in any way when the research is published.

I agree to the researcher recording and processing the data I provide during the course of this study unless I state otherwise. I understand that this information will be used only for the purpose set out in the information sheet, and my consent is conditional upon the University complying with its duties and obligations under the Data Protection Act.

Signature Participant: ______________________________ Date:_______________

Name in BLOCK letters: ____

APPENDIX D – DEBRIEF FORM

Debrief

University of the West of England
BRISTOL

Title of study: 'A Grounded Theory exploration of the development of the self in adults living with Congenital Facial Palsy.'

Thank you for taking part in this study; if you have any questions about the study or would like to say anything about your experience of participating then please feel free to discuss this with me.

Please remember that you have the right to withdraw the information collected about you at any time during or after the study. All you have to do is email me giving your ID number (which can be found at the top of your Participant Information Sheet) and your data will be removed from the study.

It is possible that you may have experienced some distress as a result of talking about your experiences of living with Facial Palsy. If this is the case, then you may wish to contact the following support services:

Facial Palsy UK

A specialist charity offering information, support and advice to individuals of all ages (and their families) living in the UK with Facial Palsy.

Telephone (enquiries); 0300 030 9333

Email; info@facialpalsy.org.uk

Website; http://www.facialpalsy.org.uk/

Moebius Research Trust

UK charity offering specialist information for individuals living with Moebius Syndrome and their family/carers.

Telephone (enquiries); 01875 819822

Email; info@moebiusresearchtrust.org

Website; http://www.moebiusresearchtrust.org/

Changing Faces

A charity for people and families who are living with conditions, marks or scars that affect or alter their appearance.

Telephone: 0300 012 0275

Website: https://www.changingfaces.org.uk/Home

Email; support@changingfaces.org.uk

Samaritans

Confidential listening and emotional support helpline for anyone living in the UK who may want/need to talk about how they are feeling or any personal difficulties they are experiencing in life.

Telephone; 08457 90 90 90

Email: jo@samaritans.org

Website; http://www.samaritans.org/

USA Participants

Please call the National Suicide and Crisis Prevention Lifeline, which is available 24 hours a day, 7 days a week, at 1-800-273-8255.

f you have any comments or concerns about the study, please email me at:

Laura16.Davies@live.uwe.ac.uk or my supervisor on andrea.halewood@uwe.ac.uk

APPENDIX E – INITIAL SAMPLING INTERVIEW SCHEDULE

Interview Schedule

1. Can you tell me a bit about yourself?

   E.g. who you live with, where you were born and grew up, employment status/education, Hobbies/interests.

2. When and how did you first become aware of your facial palsy?

   - Explore when he/she received a medical diagnosis of this.

3. What was it like to be a child living with Facial Palsy?

   - *Explore Parental attitudes towards Facial Palsy*
   - *Relationship with parents/siblings/family*
   - *Explore body image*
   - *Explore Relationships with other children in and out of school*
   - *Explore Relationships with Teachers*
   - *Explore Engagement with academic work*

4. What was it like to be a teenager who had Facial Palsy?

   - *Explore friendships/relationships with peers*
   - *Romantic/sexual experiences*
   - *Body image*
   - *Engagement with Academic aspects of school and career goals*

5. What is it like to be an adult living with Facial Palsy?
   - *Explore friendships/relationships with peers*
   - *Romantic/sexual experiences*
   - *Body image & work*

6. What factors do you think influenced your sense of identity growing up?

7a. Have you received any medical or surgical interventions for your Facial Palsy?

(b) If you have, has this influenced your sense of self/identity in any way?

- *Explore Experience of surgery (e.g. pain, trauma, physical recovery)*
- *Explore Experience of interactions with Medical Staff*

(c) If you have never received any medical or surgical intervention(s) for your Facial Palsy, please could you describe what it has been like for you to live without this?

8. What do you think about yourself when you look at your physical reflection in a mirror or photograph?

- Explore thoughts
- Explore feelings
- Explore what parts of the body they focus their attention on

9. a. Could you tell me your reasons for attending the MSF conference?

   b. What does it feel like to be here at the conference with other people who also have Moebius Syndrome?

10. Is there anything else that you would like to tell me about your experience of living with facial palsy?

APPENDIX F – THEORETICAL SAMPLING INTERVIEW QUESTIONS

Theoretical sampling interview questions

1) Can you say something about your son/daughter's experience of congenital facial palsy? (Prompt questions - ask about experiences as a baby? As a child?)

2) Can you say something about their early relationships, including their relationship with you? How did they relate to others? Can you say something about their sense of themselves?

3) Can you tell me about your experience of parenting/raising a son or daughter with congenital facial palsy?(Prompt questions - ask about experiences as a baby? As a child?)

4) Can you think of any positive or negative experiences your child had which may have related to their experience of living with CFP?

5) Is there anything you would like to add?

APPENDIX G – SAMPLE CODING OF TRANSCRIPT FOR PARTICIPANT 1

Commentary	Open Coding (more descriptive – level of analysis = gerund) First part of code = action, 2^{nd} part descriptive	Focused Coding: higher level of abstraction /analysis
Researcher: Can you tell me a bit about yourself and when you first became aware of your Facial palsy? (three second pause)		
Participant: Uh.....well....It's a strange thing really because ....I only…I only found out exactly what my condition is uh a few years ago…because my mother who died in 2001	Finding it strange that he only found out about his condition fairly recently	
always.....um.....she said, she said that my lip was distended because I sucked my fingers when I was a child….and I grew up believing that……	Receiving an incorrect explanation as a child Believing mother's account of cause of Facial Palsy	Growing up accepting mother's narrative that he caused condition
Researcher: Hmmm		
Participant: um.....So I didn't really, I didn't begin to investigate what my condition was until probably about 4 years ago …. Um I, I, I became semi-retired in 2004 so I had a little bit	Investigating condition due to becoming retired	Focusing more on self, following retirement (mother's death?) Questioning/ making own enquiries about 'condition'
more time to do these things and I suppose because you're not	Thinking about condition more when semi-retired	
engrossed in a full time job…. you think about these things more and um I started to make some enquiries and I was ultimately referred through	Making enquiries into condition when semi retired Being referred by GP to facial palsy unit.	Making enquiries into condition when semi retired and only then being referred to facial palsy unit

my GP to the Facial Palsy unit at Oxford in John Radcliff….	Getting Botox treatment	
Researcher: Oh yea yea		
Participant: Um….and um it went on from there really and I started getting Botox treatment about……uh I think it's probably about 18 months ago um and it's only relatively recently that they've given me you know a proper diagnosis so that I'd known what the condition is which is Congenital….I've got the letter here (holds it up to show me)…..Congenital Facial Palsy affecting the right sided marginal menibula nerve……	Receiving proper diagnosis only recently/during retirement Referring to consultant's letter to describe diagnosis Taking 62 years to have a name put to condition	Receiving formal diagnosis in retirement/later life Stressing the congenital nature of his 'condition' (Holding up letter as proof?) Waiting a lifetime to have label for condition Distancing self from 'it' (Disowning? Dissociation?)
Researcher: ah ok……..		
Participant: You know I'm, I'm 62 and it's taken all this time to….to have a name put to it ……	Knowing that something wasn't right with lip	Always Knowing something not quite right with lip/wrong with appearance
Researcher: Yea yea…. wow……	Feeling sad about length of time taken to get diagnosed	Grieving time taken to gain understand what was wrong with lip/regretting believing mother's account/ not trusting own 'knowing'
Participant: So…..you know…I've always known that there hasn't been something quite right but um um it's taken all this time to (slightly laughs) to get a diagnosis for it which is a bit sad but…there we are you know ………because I just believed what my mother said, maybe my mother believed that herself …. I, I don't know …..	Believing mother's account Wondering if mother believed it too Not knowing what was true.	
Researcher: Sure		

Participant: I …..yea ……. Researcher: How old….how old do you think you were when you first noticed uh you know that difference with your lip? Participant: (pause) …..ummmm…….I suppose it would probably have been as I approached adolescence and ….. but that that's probably when I started to notice it although when I look at pictures of me I was adopted when I was nearly, I was adopted when I was 2 and a half……….and I've got a picture of me downstairs on our cabinet of when I was…..shortly after I was adopted and it's very very noticeable there …….because obviously you don't, you don't….hide it when you're a young child….it's ….you don't think about it do you ……and it just went on from there but I suppose it started to bother me when….when I was in my adolescence and has ever since…you know…… Researcher: sure, sure ….. so it sounds like you are saying that you noticed it as a child but it didn't bother you as a child ……	Noticing lip difference when approaching adolescence Being adopted at two and a half. Describing how noticeable the difference was in a childhood Becoming aware during adolescence Not hiding facial palsy during early childhood Not thinking about Facial palsy when he was a young child 'it' (Facial palsy) starting to bother him during adolescence Children not bothering too much about their appearance Appearance becoming important when approaching adolescence	Becoming aware of visible difference during adolescence Recalling past experiences with uncertainty/struggling to access childhood memories Describing how noticeable the difference was in a childhood photograph but remembering becoming aware during adolescence Expressing uncertainty when recalling childhood – surmising and generalising about how children feel without being able to access own feelings Not hiding/concealing visible difference during childhood Becoming bothered about visible difference during adolescence Referring to Facial Palsy as 'it' (objectifying or distancing the condition from 'self'?) Appearance only becoming important when approaching adolescence Speaking to mother about FP during adolescence

Participant: No not, not particularly…I suppose you know children don't bother too much about their appearance do they….it's when they begin to get older and they approach adolescence and appearance becomes more important to you…um…I mean I guess I just…I guess that's….I suppose that's when I spoke to my mother about it, you know I can't remember exactly when I discussed it…..I don't think I discussed it regularly with her , I don't recall doing that…um…and it's just something that I…that I just ….you know grew up with and had to deal with…….	Speaking to mother about 'it' when approaching adolescence Being Unable to remember exactly when 'it' was discussed Not discussing 'it' regularly Growing up with 'it' (Facial palsy) Having to deal with 'it'	Referring to Facial Palsy as 'it' (objectifying/distancing from 'self'?) Not discussing concerns about appearance/lip during adolescence even though he was bothered by it Growing up with 'it' Having no choice but to deal with/live with 'it'.
Researcher: Yea sure Participant: But didn't get any ….any medical….support because I wasn't aware then that I had Facial Palsy you know….it was many….many years later before I found that out for myself …….	Absence of medical support Being unaware that he had facial Palsy during childhood/teenage years Finding out he had a congenital condition many years later Finding out for himself	Absence of medical support/information resulting in difficulties relating to/dealing with 'it' Not knowing/understanding visible difference during childhood Having to do the work of a medical physician in order to find out what was wrong with lip
Researcher: Yea…sure, sure……do you know what your Mother was told about it, if anything at all? Participant: No……I….I……you know I just remember discussing it with her and she said you used to	Remembering sucking fingers as a child Mother saying cause of facial difference was because of sucking fingers as a child believing mother's account of cause of condition Growing up with 'it' 'it' bothering him hugely	Sucking fingers during childhood Mother indirectly blaming /holding him accountable for facial palsy? Passively believing mother's account/narrative during childhood Growing up with an unknown part of self that can't be changed

suck your fingers when you were a child and I can remember doing that and she said that's, that's the cause of it and I guess I just believed it…..I just believed what she said …….and um but I didn't discuss it with her at any other degree and I just grew up with it and that was it really um…..it bothered me hugely …….	'it' still bothering him hugely as an adult	Facial Palsy bothering him massively as an adult Investigating background history during semi-retirement in search of deeper self-understanding
Researcher: Hmmmm sure		
Participant: It still does	Not knowing if mother believed her own account Investigating his background during semi retirement	Constructing a narrative of rejection by birth mother because of Facial Palsy
Researcher: Yea sure ….. do you think that's what your mother believed up until that point?	Believing his mother gave him away because of his Facial palsy Wife challenging his lifelong belief Not sure whether or not to believe wife's alternative perspective	Narrative of rejection resistant to change through challenge by another
Participant: Yea….I I don't know…..I really don't know Laura ….. I really don't know…um…..well I've done a little bit of investigating, you see I was adopted when I was nearly, I was 2 and a half when I was adopted um …..and…..you know I've always believed that my mother gave me away because of my Facial Palsy but my wife says no way would that have happened but I'm not so sure….I don't know ……..I don't know the answer to that …..um …..so but what my mother knew that she didn't tell me I don't know …….		Internalising mother's narrative/account of cause of Facial Palsy and making it his own
Researcher: hmmmm		

Participant: But for me, she died in 2001 and that's that you know….so I don't know (laughs) Researcher: yea …… so it just sounds like that's the explanation that she gave you um and that's (Participant interjects)…… Participant: yea and I accepted it and I just believed what she said……. Researcher: hmmmm hmmmm Participant: And I can remember going to bed at night and sucking my fingers from the other side and hoping that it would pull my lip down but I soon got tired of that (laughs)….. Researcher: (laughs too) Researcher: How old were you when you did that when you used to go to bed and suck the other side? Participant: Um (laughs) oh dear I don't know probably maybe early teens when it started to bother me I suppose….you know when I began to be conscious of it…… Researcher: Hmmm…..so it was kind of like an attempt to change it? Participant: rectify it…yea…..but I soon gave up…..I didn't, I didn't do	Accepting mother's explanation of cause of Facial Palsy Believing mother's account Sucking fingers at night in the hope it would correct lip Quickly getting tired of attempts to correct lip himself 'It' starting to bother him during early teens Beginning to become conscious of 'it' during early teens Rectifying lip through self-attempts Giving up attempts to rectify lip himself	attempting to correct facial palsy during childhood and Losing hope/belief in ability to correct lip himself Lack of personal autonomy/control over correction of facial palsy visible difference beginning to bother him during early adolescence Becoming consciously aware of visible difference during adolescence Giving up hope/belief in personal ability to rectify facial palsy Sucking fingers during infancy to cope with feeling lonely in the care home Comfort sucking as an infant to cope with absence of mother figure

that for very long …..I can remember doing it….I can definitely remember doing it…..because that was my logic if my lip…sucking…I used to suck those two fingers (shows me) ……	Sucking fingers a lot before he was adopted Feeling lonely in the care home as an infant	Trying to correct lip (‘it’) during adolescence due to believing he had caused it (fixing physical self)
Researcher: Hmmm Hmmmm	comfort sucking in the care home Not having a Mother for first 2.5 years of life	
Participant: And I think I sucked my fingers a lot before I was adopted because when I was in the home I was very lonely I guess …….	Trying to put ‘it’ (lip) right due to believing he had caused ‘it’	
Researcher: Hmmmm hmmmm		Inconsistency in narrative about when condition began to bother him
Participant: and it was comfort sucking so I didn’t have a ….I didin’t have a mum around me for 2 and a half nearly three years so my logic was if that had caused it right I’ll try and put it right…….	Experiencing discomfort trying to put ‘it’ right	Distancing self from condition/objectifying ‘it’ Feeling self-conscious about condition in absence of negative remarks from others Blaming condition for feeling ugly
Research: Yea sure makes perfect sense ………	‘it’ (Facial Palsy) bothering him hugely as a child growing up	Questioning/uncertainty around where self-consciousness originates from
Participant: It was pretty uncomfortable so I didn’t bother to, I didn’t keep doing it for very long.	Other people not making comments on ‘it’ Never bullied at school Feeling self conscious of ‘it’ despite absence of comments from others	Inconsistency in narrative around absence of negative remarks from others about appearance
Researcher: Yea sure ….. and what was it like to be a child growing up with Facial Palsy?	‘it’ making him feel incredibly ugly	Constructing the self as ugly
Participant: Uh…..(sighs) well it bothered me hugely um and it was one of those things that other people didn’t seem to make any	Lived with a feeling of incredible ugliness Still living with a feeling of incredible ugliness Feeling of ugliness not quite as bad now	Being highly sensitive towards other people’s evaluations of his appearance

comment on it you know I was never bullied at school, no-one ever said anything, um but I was desperately conscious of it myself and it made me feel incredibly ugly…..(pause) which is something I lived with and still live with ummm it's not quite as bad now but I did grow up, I had this incredible complex that I was ugly and that people thought I was ugly and I was incredibly sensitive to what people said about my looks and if they said anything that um that seemed to suggest that I was ugly I found it desperately upsetting and I would perhaps try and try and find or put a positive gloss on it so that I could sort of live with it and accept it……. Researcher: Hmmm Hmmm Participant: I remember my PE teacher at school called me gorgeous …….now why he did that I don't know but I remember he did and I remember that it used to be a comfort to me um but I was incredibly self-conscious of it um and it affected how I saw myself, I felt that I was really ugly and I think I feared that I would never get a girlfriend and um It was, it was, it wasn't easy at all ………um and I didn't like to buy clothes, I'd find buying new clothes was an effort, my	Growing up with incredible complex that he was ugly Believing people thought he was ugly Feeling incredibly sensitive to people's comments about his looks Feeling desperately upset if others made comments that suggested he was ugly Putting positive gloss on upsetting comments to live with them Being comforted by positive appraisal of appearance Feeling incredibly self-conscious of 'it' (Facial palsy) 'it' (facial palsy) affecting how he saw himself Feeling really ugly growing up Fearing he would never get a girlfriend because of his 'ugliness' Growing up with facial difference wasn't easy for him disliking buying new clothes during teenage years disliking buying clothes during adulthood Believing new clothes won't hide his 'ugliness' Feeling of ugliness was huge/profound from early teens to present day	Putting a positive gloss on to protect the self against distress. Feeling incredibly self conscious of facial palsy during teenage years which intensified his perception of self as ugly Feeling really ugly growing up Fearing ugliness would prevent him getting a girlfriend Facial Palsy as an obstacle for dating Believing his ugliness can't be concealed from others feeling of ugliness having profound impact upon sense of self throughout lifespan Botox treatment in adulthood reducing intensity of feeling of ugliness

mother had to virtually buy them for me and my wife still does now my wife has to take me to buy clothes and if I buy clothes it's because she's dragged me to the shops to buy something…..because I feel what's the point of looking smart when I 'm ugly…… and that had a profound, that was massive, huge, right through from probably in my early teens right through to the present day….you know it's not quite as bad now, now I've got the botox treatment which does seem to have helped a bit….um but massive and even now you know I …….my wife has to drag me to the shops to buy clothes and shirts because I'm just not interested and I think it's, I think that's the reason because I still feel I'm ugly and I've always felt that so what's the point you know…..it was huge…it just had a tremendous impact throughout my life ….. huge. Researcher: Sure I can hear that yea ……where do you think that feeling of ugliness has come from? Participant: I suppose just looking in the mirror every day….seeing myself….seeing my lip….um I guess that's where it's come from…..um …..it's just me….it's just how I see myself literally see myself and how I um visualise myself……..	Feeling of ugliness not quite as bad in adulthood due to botox treatment Feeling of ugliness persisting in adulthood Feeling of ugliness having tremendous impact throughout lifespan Looking In mirror Seeing self Feeling ugly Feeling ugly	Feeling of ugliness persisting across lifespan and having significant impact on life Constructing self as ugly through seeing self in mirror reflection Feeling ugly Sense of self as ugly resistant to change through verbal challenge from an 'other'

Researcher: Sure……so you mean your actual visual uh image of yourself when you look at your physical reflection in the mirror. Participant: Hmm …..yea ….yea…. Researcher: Do you mind if I ask you if you could explain a little bit about what you see when you look at your physical image in the mirror? Participant: I just feel……I just feel that I'm ugly you know I've always felt that and my wife is constantly telling me that I'm not cos obviously she's the only one I ever share that with….I think I did mention it once to someone I can't remember but she's constantly saying you know she's re-assuring me, you know she says well you had quite a few girlfriends before I came along so you can't be ugly and I sort of think well you know I joke about it and say they should have gone to spec savers and this kind of stuff but um it's not going to shift it I don't think, anyone telling me otherwise because that's how I see myself and I think my lip has had a massive impact there because you know you only see yourself in the mirror don't you……… Researcher: Yea, yea, yea sure…….what happens when you look in the	Wife constantly challenging his view that he is ugly Sharing negative self-views with wife only Wife constantly re-assuring him he isn't ugly Joking about appearance Saying his ex girlfriends should have gone to spec savers Wife's constant re-assurance not shifting how he sees himself Lip having a massive impact on how he sees himself Only seeing himself in the mirror Focusing on lip (facial palsy) when looking at self in the mirror Not liking what he sees Having to accept he can't change his appearance Not being able to do anything to change it Botox treatment not improving appearance as much as hoped Feeling disappointed with outcome of Botox treatment	Using jokes to communicate his disbelief that women would find him physically attractive Sense of self as ugly not able to be re-constructed through re-assurance from others that he isn't ugly Mirror reflection of lip maintaining his sense/perception of self as ugly Focusing on defective part of self when looking in mirror Not liking physical self but having no ability to change it change Having to accept appearance but not wanting to Botox treatment not meeting expectations of constructed internal image of face post intervention Grieving/moruning the failure of botox treatment to meet expectations of face/appearance post intervention Contradicting later account around his difficulties agreeing with the Psychologist's challenges around his perception of his appearance

mirror? What do you tend to look at? Participant: Oh I tend to look at my lip I guess and see how it is and um and just don’t like what I see but I have to accept that’s how it is and there’s nothing I can do about it and the Botox treatment has helped a bit….not as much as I would have liked….I found it a little bit disappointing …um in some ways…….um and uh I saw a Psychologist at John Radcliff hospital…I saw her quite a few times…it suddenly stopped in April that’s another story nothing to do with this um so I haven’t seen her now for about 6 months but I found that helpful um she was able to give me some things to think about and made me realise that it’s not as bad as I make it out to be and all the rest of it and we talked that through so that was helpful………… Researcher: Sure……what was helpful about that in terms of like what she did and how that helped you? Participant: Well I think um she helped me to….because I you know I tend to when you put the Television on it’s full of pretty faces and good looking guys and we talked that through and she sort of explained that they are not representative of the general public….they get the job because they are pretty or they are good	Finding it helpful seeing Psychologist at Facial Palsy unit Psychologist helping him realise it’s not as bad as he makes out Helpful talking through feelings with Psychologist Psychologist helping him realise good looking celebrities are not representative of the general public Making comparisons between his appearance and those of good looking celebrities Psychologist trying to teach him to stop labelling self - helpful intervention Psychologist trying to help him understand that his Label of ugliness was taking	Psychologist facilitating the processing of feelings about Facial Palsy and self through dialogue with him Psychologist challenging unrealistic expectations and negative evaluations of self/appearance Making comparisons between his appearance and those of good looking celebrities Psychologist trying to re-organise different labelling of self Psychologist trying to facilitate re-organisation of self-labels and the space that these theories occupy within the self Feeling objectified by others during social interaction

looking and obviously you make those comparisons don’t you……	more prominence than it should have done	Finding people’s stares upsetting and disrespectful
Researcher: Of course yea		
Participant: She tried to teach me to stop labelling myself…..I was putting the wrong label on my luggage as she put it and I found that helpful um yea ………..	Sensing people look at his lip when speaking to him Finding people’s stares upsetting	Feeling angry when sensing that other people were staring at lip Psychologist minimising/invalidating his social experience through challenging his interpretations
Researcher: Say a little bit more about that, about the luggage and labelling yourself…….	Feeling angry when sensing people were looking at his lip	
Participant: Yea I think she tried to help me to understand that um I think she sort of likened it to a piece of luggage with all sorts of different labels on it and the one with ugliness on it in my view was taking more prominence than it should have done um and she …. I think she ….. one of the issues that….one of the things I do find quite upsetting when I talk to people is that quite often you sense that they are looking at your lip…..you know when you address someone you should look in their eyes…….um I was told that with my job and yet you’d think they were just looking at my lip and that would make me feel angry because I’d feel what’s it to you and I’d sometimes get quite angry about that ym and she tried to re-assure me that that’s not necessarily the case when	Getting angry about his sense that people were looking at his lip when interacting Not totally agreeing with Psychologist’s alternative view Seeing people look at his lip all the time Sometimes finding it difficult to live with people looking at his lip Psychologist encouraging him to write things down Stopped writing things down when sessions finished Thinking about going to see the Psychologist again Thinking it’s a bit of a trek	Finding it difficult to tolerate the feeling that others might be staring at lip/facial palsy during social encounters (feeling persecuted?) Stating he found it helpful seeing the Psychologist but yet not continuing to use the techniques he learnt during therapy once it finished Feeling ambivalent about going to see the Psychologist in the Facial Palsy unit again

when people do talk to you they tend to look at your whole face and all your features….well I'm not sure I totally agree with that but you know and people still do it….I see it all the time, their eye goes down and I find that difficult to live with sometimes…..you know um….no I found that, I found her helpful, she encouraged me to write things down and make notes and do this sort of stuff which I did. I haven't done it now for some time because I stopped seeing her um and I may go and see her again but she's over in Oxford so that's a bit of a trek…… Researcher: Ah yea sure….so it kind of sounds like you're saying from your side or your perspective you feel that when you are interacting with people that they are focusing on your lip whereas the Psychologist was giving you a different perspective that you know that actually people take in the whole face but it was quite difficult for you to kind of believe that perspective ….. is that what you were saying? Participant: Yea….. cos I see what I see you know um…..but you know…..but generally it was helpful , generally the time I spent with her was helpful and it might be worth going to see her again….we'll have to see……	Seeing what only he sees Finding it generally helpful to see the psychologist	Only being able to see his physical appearance through his eyes and not finding psychologists' challenges particularly helpful in terms of shifting his perspective or re-constructing his sense of self

Researcher: Sure …. You know you were talking about the labels and you said that she got you to realise that the big piece of luggage with ugliness on it was the one that was taking up most of the room for you, what other pieces of luggage did you discuss with her? Participant: oh dear…I can't remember now…um…..I don't know really um I suppose other family issues and things like that um …….. Researcher: Ah ok so am I right in thinking that by luggage that your definition of luggage was like things that were I guess weighing you down…….. Participant: yea Researcher: Ahhh ok and that feeling of ugliness for you was the heaviest piece of luggage or the biggest piece of luggage? Participant: Yea, yea, yea Researcher: Ah I get what you mean Participant: yea um yea I think, I don't know life brings lots of different pressures um I'm not saying that …..I think she was trying to point out that my lip was having far too much an impact on my life than it needed to and than it should have done um I think	Psychologist trying to point out lip was having more impact on his life than it needed to/should have done Lip is a constant issue weighing heavily on him. Accepting Psychologist's interventions/challenges to his viewpoint. Accepting Psychologist's challenges/interventions as she was from the Facial Palsy unit. Psychologist being understanding Finding it helpful to talk things through Unwrapping condition in his sixties Trying to do something to help himself live with 'it'	Psychologist invalidating his experience through telling him it was having more impact than it needed to Psychologist not attuning to/accepting the depth of distress he experiences around his lip Being brought down through constant awareness of Lip/Facial Palsy Feeling able to accept alternative perspectives provided by Psychologist but unable to internalise them (professional) Accepting Psychologist's challenges because he trusted that she would be knowledgable as she was from the Facial Palsy unit Finding it helpful to share his problems/experiences of living with facial palsy with another professional Sadness/frustration/ regret that opportunity to explore/understand condition only arising in late adulthood Botox treatment not fully meeting his expectations Experiencing the facial palsy unit as supportive and understanding

that’s probably what she was trying to say cos you know I do have other issues in my life that weight heavily upon me that are totally unrelated to that um but my lip is a constant you know it’s just always there you know um (laughs slightly) Research: Yea sure that makes sense ….. what did it feel like to have this professional who I guess didn’t have Facial palsy to sit there and reflect that back to you? Participant: Yea yea I think I accepted it….I think I accepted what she said um she knew what she was talking about, she was from the Facial Palsy unit , you know she was very understanding, she was very supportive…..I found it very helpful to talk these issues through but um afterall you know I’ve had this condition now for nearly 62.5 years um and it’s only the last 3 or 4 years that I’ve unwrapped it ….you know in terms of finding out exactly what it is, what the condition is and trying to do something to help me to live with it you know um…..it’s been good to have the Botox treatment but as I say it hasn’t done all that I would have liked it to have done um but it’s certainly a step in the right direction….but I found the Facial palsy unit very supportive, very understanding ……..	Botox treatment not doing all he would have liked it to have done Stepping in the right direction by receiving Botox treatment Finding facial palsy unit to be very supportive and understanding Liberating to unwrap condition in his sixties/late adulthood Growing up with ‘it’ Family never mentioning ‘it’ to him. Wife feeling ‘it’ is not an issue Mentioning ‘it’ to one of his sons previously Family never thinking of labelling him as a condition Absence of experience of being bullied at school One person making comment and finding this incredibly hurtful Hurtful comment going against what he had been told by others	Feeling liberated to be able to have a space where he can talk about his experience of living with facial palsy which he has not had the opportunity to do in relationships with family and friends Growing up with facial palsy but not being permitted to talk about it in depth with family and friends due to them not seeing it as an issue Struggling to make sense of feelings of ugliness in the absence of bullying/negative comments by others Feeling wounded by insensitive questioning from another person Hurtful comment confusing experience of self which had been constructed/built upon feedback from those who didn’t see his facial palsy as an issue Being painfully wounded by insensitive questioning

Researcher: hmm…..what was it like to unwrap it at this point in your life at 62 years old…what was that like for you? Participant: Um…..liberating…I guess….um that's probably the best word to describe it because you see that's the other strange thing ……. That I've grown up with it um….I don't know how can I express it really….um…..you know my family have never mentioned it to me, my wife feels that you know it's not an issue um…..I've only mentioned it to one of my sons and he said well it's just you Dad, we've never thought of labelling you as a condition….I was never bullied at school um uh I think only one person ever made a comment about it which I found incredibly hurtful because it went against what other people were telling me……..	Woman asking what was wrong with lip feeling like someone sticking a knife into him Hurtful question making him realise there is something that's not right with his lip	Realising through the questioning by another that there is something wrong with his lip and it's noticeable
Researcher: right yea Participant: I remember she said oh what's wrong with your lip…and it was like someone sticking a knife in me …..	Experiencing question about lip as awful Parents in law never asking about his lip	Struggling to take the perspective of another/see that his facial palsy might be less of an issue for others than himself

Researcher: Yea yea ….sure Participant: Um because it made me realise that there is something that’s not right even though everyone else tells me that I’m ok or doesn’t make any comment about it ………. Researcher: hmmm hmmm Participant: Um so I, I,….that was hard …..sorry the trouble with talking is that I can’t always remember what the question was…..what was the question again? Researcher: No it’s all good we are following it great …..um it sounds like that was quite a powerful experience to you know as you say it sounds like a lot of people throughout your lifespan have told you that you’re fine, you’re you, they see it as part of you but then to have one person that kind of picks up on it sounds like and tell me if I’m wrong here but it sounds like you were saying that it was more power or as powerful…….. Participant: oh it was awful….it was awful….it was awful……because most people don’t say anything, you know my parents in law they’re dead now but they never said anything because I asked my wife about it the other day…I said didn’t your parents ever say anything	Finding it extraordinary that his parents in law didn’t comment on his lip FP affecting whole personality Talking about ‘it’, finding out about ‘it’ having a name for ‘it’ Talking to people who understand the condition Finding that there is support available Not following up on support Considering following up on support Not talking about it because wife doesn’t see ‘it’ as an issue Living with ‘it’ up until late adulthood Liberating to talk about ‘it ‘with Researcher and Psychologist	Facial palsy affecting development of entire personality Feeling liberated through dialoguing with others who understand the condition Considering following up on accessing support through facial palsy charity but not making a definitive decision around this Not talking about condition with family due to their denial/minimisation of condition Liberating experience talking about it with Researcher as opposed to living with it

about me and she said no they didn’t …and I find that extraordinary um and I think going to the Facial palsy unit has confirmed that I do have this condition and now I’ve got a name for it um but so I duno it’s been a difficult one really….but it’s been huge to me….massive …..it’s affected my whole, it’s affected my whole personality aswell you know you might want me to unwrap that later on but massive massive ……….. Researcher: yea sure…… what was liberating about finally being able to unwrap this at 62 years old? Participant: I think I guess just being able to talk about it um finding out more about it, having a name for it and talking to people who obviously understood what they were talking about and finding that there is support available although I haven’t followed that through with the Facial Palsy charity, I may do that um but it’s just been great to just talk about it because in some ways my wife bless her um she’s always said it’s not an issue and therefore because of that I haven’t really talked about it anymore, I’ve just sort of lived with it and you know whereas it’s just been liberating to be able to talk about it with you and being able to talk about it with the Psychologist at the hospital …….	Health Professionals helping him understand what ‘it’ is Health professionals being able to re-assure him condition isn’t as bad as he thinks Health professionals recognising he has a condition has been helpful for him Talking about ‘it’ immensely liberating Talking about ‘it’ helped him deal and cope with ‘it’ Botox treatment helping and being disappointing Hoping Botox treatment would have done more than it has Feeling determined not to allow facial palsy to take over his life Feeling very conscious of ‘it’ when standing up in front of others Getting on with job despite feeling self conscious No-one commenting on appearance Not letting ‘it’ beat him	Conversations with Psychologist facilitating understanding of condition and lived experience Talking about facial palsy with health professionals has enhanced coping ability Feeling determined to prevent Facial Palsy dominating more of his life than it already has Feeling self-conscious of lip when standing in front of others but not allowing it to stop him doing his job Fighting/battling against condition Daily struggle/battle to live with the condition

Researcher: What’s been helpful about talking about it with various professionals recently? Participant; Um …… well you know they’ve been able to help me to understand what it is ……um they’ve been able to I think re-assure me that it’s not as bad as I make it out to be whilst also recognising that I do have a condition um but just being able to talk about it I think has been immensely liberating and helpful um and helped me to deal with it and cope with it and you know the botox treatment has certainly helped but as I say it’s been a bit of a disappointment in some ways…it hasn’t done as much as I had hoped it would have done um I find it…I’m an invigilator at the local academy um I’ve been doing that for ten years because I’m determined not to allow this to you know stamp more of my life than it’s already stamped um and I find that quite hard because I have to stand up sometimes in front of 160 kids and I’m very conscious of it then …very conscious of it but I do it and I get on with my job and no-one says anything and um I’m not going to let it beat me I guess…….. Researcher: that’s a good attitude……..but it sounds like it takes a lot of energy and effort to try and get on	Not finding it easy to get on with daily life Wondering for a long time about tracing birth mother Lip pulling him back from searching for his half brother Not knowing if he could cope meeting his birth mother with his lip as it is ‘It’ (lip) pulling him back ‘It’ (lip) stopping him from tracing his birth mother Filling up with the feeling of dread around being paraded Facial palsy holding him back from finding his roots (birth parents) Worrying birth family would label him as ugly Worrying birth family would not want him because he was ugly Questioning if birth mother gave him up because of his facial palsy ‘It’ holding him back hugely	Wanting to trace birth mother/trace roots but Facial palsy holding/pulling him back due to dread around being paraded in front of birth family Fearing he would be rejected by his birth mother due to her labelling him as ugly Constructing a narrative of his birth mother rejecting him due to facial palsy Feeling sadness/regret that Facial Palsy has held him back from tracing his family of origin (identity)

with life and function as well (participant interjects) Participant: Yea it does….I don’t find it easy, I don’t find it easy……I think um as I say I was adopted when I was nearly 3 and my dad died in 79 and my mother died in 01 and I’ve long wondered about um trying to trace my birth mother…I know I’ve got a half brother but my lip pulls me back because I don’t want, I don’t know if I could cope with being reunited with my birth mother with this …. And it pulls me back…it stops me from doing it…I may do it one day I don’t know but the thought of being paraded in front of another family that I’ve never met with my lip like that it fills me with dread and I don’t think I could go through with it….which is holding me back really from finding my roots and my birth parents but there we are……. Researcher: what are you concerned might happen if you were to find them? Participant: I suppose they’d label me as ugly and they’d not want me and if my birth mother gave me up for adoption because of this then…..well if that was the case I suppose she wouldn’t want to see me again anyway …..that’s assuming she’s alive, I have no idea, um she’s probably in her late 70s um….but it has held	It would be really upsetting for him to find out he was given up because of his facial palsy Not feeling convinced by wife’s alternative view ‘It’ pulling him back from searching/tracing birth family Long lost family programme cutting him deeply Having the same conversation with wife about tracing family Wife encouraging him to trace birth family	Narrative of rejection at birth due to facial palsy resistant to reconstruction/change through challenge by another Wanting to take steps forward to trace birth family but behing held back by fear of rejection due to facial palsy Feeling deep emotional pain/being wounded when watching long lost family Having the same conversation with his wife about tracing birth family but not moving forward with this Needing to work through decision to trace birth family for himself

me back…hugely…and that’s a shame because you know it’s a pretty big issue when you could trace and find your birth mother and my wider family because I’m an only child I’ve got no adopted siblings um you know hmmm………	Needing to work through decision to trace birth family for himself	
Researcher: Sure…it sounds like that would be a scary thing to happen to find them and for them to talk about that or tell you that was part of the reason you were given up for adoption….I mean what do you think would happen to you if that was the case?		Becoming stuck within the process of making a decision about wether or not to trace his birth family
Participant: I don’t know really, I guess it would really upset me um but I would have thought if that was the case and they had traced my birth mother then she wouldn’t want to see me so that would be the end of it anyway. I mean my wife says there’s no way that would happen but I’m not so convinced.	Not knowing wether he will trace birth family or not	Struggling to take the perspective of another/acknowledge that his facial palsy might not be an issue to others Acknowledging that his narrative of why he was adopted might be inaccurate
Researcher: hmmmm hmmmm	Thinking other people should think his facial palsy is huge as he does	
Participant: but it pulls me back….it pulls me back from doing that otherwise I think I would forge ahead and try and discover my birth parents….I see that family programme long lost family and it cuts me to the quip when I see that programme and when it finishes I sort of think and I always have the same conversation with my	Acknowledging it might not be the case that he was given up for adoption because of his FP	

wife when it finishes you know what do you think, do you think I should try and pursue this and she says yea I think you should and you know she's always encouraged me and she said the other day, we watched one last week and she said for the very first time she said if I was in your shoes I would want to know whether my mother was still alive and whether my half brother was still alive and where he was……but that's something I've still gota work through for myself I think…… Researcher: Yea sure….it sounds like you're saying that you want to do it but you so sort of scared of people talking about this or you finding out that this may have been the reason you were given up for adoption that you're worried about the impact that that would have on you as a result……. Participant: yea …..yea, yea…..I don't know…I don't know whether I will or not ….I just don't know….I don't know …… Researcher: No it sounds like really difficult decision…..I mean why do you think you've come to this kind of conclusion or um you know that your mum might have given you up because of your Facial Palsy?	Suspecting he will make some enquiries into his birth family Wanting to push the door open Will continue to feel it was a strong possibility he was given up because of his FP unless proven otherwise	Anticipating he will make some enquiries into tracing his birth family but not sure when he will fel ready to do this Needing concrete proof/evidence in order for him to reconstruct his narrative around why he was given up for adoption

Participant: I guess it’s part and parcel of the fact that to me it’s just big, it’s massive and um and because I think it’s huge I suppose I think other people should think it’s huge and huge enough to give me up for adoption…..it’s possibly not the case….I was born in 1953 out of wedlock and it was a taboo in those days and I think a lot of children that were born out of wedlock were taken away from their mothers forcibly and had no say in the matter and I could fall into that category…..I don’t know wether you saw that series call the Midwife? Researcher: Yea yea I did yea ……. Participant: Well when that started it was in that era of these Nuns taking adopted, taking children away from their Mothers against their will whereas nowadays it’s completely gone the other way…..you know…. You know I just don’t know but I suspect I will make some enquiries just to push a door open and to see what happens …….. Researcher: Sure…….As you say though it sounds like you can see that there’s a plausible alternative explanation as to why she gave you up because of the times and the cultural stigma around having a child out of wedlock but for		

you it sounds like you're saying that you still feel more drawn to the explanation that it was because of your Facial palsy ……. Participant: (pause)…yea I think unless I'm told otherwise….unless it's proved otherwise I shall still feel that that was a strong possibility…		

APPENDIX G – SAMPLE CODING OF TRANSCRIPT FOR PARTICIPANT 2

Transcript	Open coding	Focused coding
Researcher: Can you tell me a little bit about yourself? Participant: Yea an introduction is fine…….I'm a 33 year old male..…um I have Moebius Syndrome which is a rare Facial Palsy and erm yea that's me in a nutshell…..so…..um yea……… Researcher: hmmm…..what is it that you work as again? Participant: Yea I'm a fraud analyst so I work for an [redacted]	Recently married wife [redacted]	

[redacted] Researcher: Oh cool……that sounds really interesting….. Participant: (laughs) yea after a while it’s like any job (laughs) job titles can sometimes be misleading but no no I uh yea it’s a yea it is interesting yea ……… Researcher: (laughs) thanks for that introduction, that’s great……so you mentioned that you had		

Moebius Syndrome….how would you describe how that affects you because Moebius Syndrome as you know kind of affects people in different ways doesn't it …….. Participant: Yea it's uh mean I went to a….uh a get together, conference you could say, just over a year ago and you were at that too Laura weren't you and uh there were a couple of specialists that talked about Moebius and I thought they….they um …….articulated the condition quite well in the sense that the word Moebius is this all encompassing…it's a word that is all encompassing you know cos there's people with Moebius who like you said you could turn people up against the wall and each person would be different to the other in terms of severity um so I mean the bare….the basics	Attended Moebius conference in UK 1 year ago Recognising Researcher from previous conference Thinking the condition was explained well by specialists at the conference Moebius as an all encompassing word Each person with Moebius different to another	Attending Moebius conference during adulthood Acknowledging researcher as peer and specialist Experiencing Moebius as all encompassing Highlighting the uniqueness of each person's Moebius symptoms and severity Positioning himself into expert role

of the condition are two really…..one being the um facial paralysis which is the 6th and 7th cranial nerve I think and also the lateral eye movement so….that's what I would have however, you will find I'd say, the majority of people with those two things will have additional issues such as um limb uh limb deformities or other sensory issues such as uh I've heard people are hard of hearing or blind for example or and they also say autisim can occur with Moebius and learning difficulties and I could reel of another few	Informing/educating researcher about the diversity of symptoms within Moebius Syndrome	Positioning himself in relation to Researcher as another individual with Moebius
complications that are associated with it….you see because it's so rare no-one can really ….i'm sure with Moebius you could subsection people into smaller	Questioning whether people with Moebius could be sub sectioned into smaller diagnostic categories	Doctors constructing a condition through labelling a group symptoms
categories….that conference we went to you know ……we might all have this condition that	Doctors labelling/naming condition	Characterizing his Moebius Syndrome as a mild form through

Doctors have given a name for Moebius but it was very hard for me to connect to quite a few of the other people at the conference…..not because they weren't nice people but to have a connection there because of the condition was very hard because I would characterise my example as something that was a very mild form of Moebius and you'd have people with quite severe issues and I found it hard to relate to them and vica versa……. Researcher: yea sure sure sure…..I mean how would you say…..how would you say it's um impacted on you physically? Participant: In regards to myself the….well the lack of facial movement is the biggest issue I mean like I say to everyone I come across when I talk about	Characterizing his Moebius Syndrome as a mild form Finding it hard to relate and connect with people who had more severe forms of moebius at the conference Lack of facial movement as biggest issue Moebius not affecting/disabling in	comparing self with others Experiencing a sense of mutual disconnection in contact with others with the same condition due to differences in severity Feeling impaired by Moebius in social rather than physical functioning

Moebius it doesn’t affect me daily in terms of functioning in the world um it doesn’t cause me any pain and it’s not disabling in terms of like I said functioning….my especially now at the age of 33 being able to look back at my life I suppose up to now I think the biggest issue for me is the lack of facial movement erm and the social interaction, not because I’m timid or shy cos I come across as quite confident in terms of talking to people but my wife would often say you know that I could be put in a room of strangers and talk quite happily….. um but you know how we communicate it’s not just verbally …..it is how we communicate through facial expressions…..especially with new people or people you’ve just met and they will look for interaction through facial expression and when they don’t get	terms of physical functioning Looking back at life and realising biggest issue has been lack of facial movement and impact on social interaction Social interaction difficult for him due to recognising that people communicate through facial expressions as well as verbally New people/strangers looking for interaction through facial expression and forming wrong opinions of him in the absence of this	Identifying lack of facial movement rather than character traits as inhibitor of Social interaction Highlighting contrast between verbal competence and non verbal impairment due to lack of facial movement and impact on social interaction Being misunderstood/misread by strangers Finding it hard to make and keep genuine friends

that they form an opinion uh understandably so but obviously it comes from a wrong opinion…..uh and I’ve found it uh quite hard to make uh and keep you could say what I’d say genuine friends….you know I have lots of acquaintances but I have found it hard to like I say make uh you know close friends or people you know I wouldn’t have any people I could call up and say do you fancy going for a pint or to the cinema or and um I’ve never been one of those people who would use Moebius as an excuse cos I can be quite an opinionated person (laughs) so they might not get on with me because of my personality but you know it’s hard to look past the fact that having a lack of facial expression would have played a major part like I said in me having difficulties uh having	Finding it hard to make and keep genuine friends Not having friends he can socialise with as an adult Not being one of those people who uses Moebius as an excuse Describing self as opinionated Lack of facial expression playing a major part in his absence of friendships/social circle	Questioning if he doesn’t have friends because of moebius or because of an unrelated personality trait. Trying to make sense of his lack of friends during adulthood Wondering what role his facial expression plays in his absence of friends Interjecting when beginning to discuss his personality traits and potential links to absence of friendships

uh…..a circle of friends or whatever………. Researcher: Sure…..so you are kind of saying that physically uh although you don't have the lateral eye movement um that's not really been an issue for you physically but…….(Client interjects) Participant: ah yes sorry I forgot to mention the lateral eye movement…..so the lateral eye movement and also I'm unable to close my eye fully so when I attempt to close my eyes the eyeball will roll….roll inside out so to speak so to the back of my head so the whites of my eyes show…..so for example I am quite sensitive to the sun so would have to wear sun glasses and would have to wear sun glasses in fact I find it difficult sometimes to find sunglasses that would wrap around because I	Being unable to move eyes laterally or close them fully Needing to wear sunglasses due to sensitivity to sunlight Finding it difficult to find appropriate sunglasses that meet his visual needs Wearing goggles in the shower as a child to protect eyes	Describing/explaining his physical deficits/impairments Finding it difficult to get his visual needs met due to them being different to the average person Adapting more easily to physical symptoms of Moebius Syndrome compared with the social consequences of the condition

have a prescription I'm short sighted um I need sunglasses that will wrap around so that sun doesn't get in between….that would be the only and when I was younger I used to wear goggles in the shower to protect my eyes and little things like that but that's quite minor compared to the facial palsy itself……. Researcher: Sure ……so you're kind of saying that for you the difficulties have been around the social interaction really rather than the physical functioning……. Participant: Yes….yes……I mean there's you know there's little things that might crop up so for example eating sometimes cos I can't close my mouth while I'm eating I'd hold my hand over my mouth as I eat so you know it would be quite off putting to	Wearing goggles in shower to protect eyes as a minor inconvenience compared to facial paralysis itself Holding hand over mouth whilst eating	Adjusting behaviour to compensate for facial impairments and adhere to social etiquette Fearing he would be off putting to others if he doesn't use compensatory behaviour when eating Needing to monitor/censor self when around other people due to physical deficits Downplaying the impact of needing to censor self Minimising the adjustments he has to make to be acceptable to others

people looking at me eating like that otherwise but again in the grand scheme of things I don’t really find that an issue so it doesn’t really have an inconvenience for me you know…..it’s like for example wearing glasses,	Likening adapting his social behaviour to wearing glasses	Adapting to physical symptoms of Moebius Syndrome as natural lifelong process
I’ll always wear glasses and I’m sure for someone who has never worn glasses if they were told	Adapting to medical condition as second nature	
today well you have to wear glasses for the rest of their life I’m sure they’d find it an inconvenience but	Not perceiving adjusting behaviour for others as an inconenience	
when you you know putting glasses on when I need to see something it’s second nature and I guess it’s like that with a medical condition you know you adapt to it cos you’ve	Interjecting	Needing to rely on facial expression rather than verbal language to participate in social interaction in a noisey environment
always adapted to it, it’s second nature so you don’t really perceive it as an inconvenience you know……	Wanting to go out socially in the evenings	Not being able to use compensatory behaviour to participate in social interactions in noisey environments
Researcher: Yea sure and as you were saying earlier		Feeling excluded due to environment getting in

the interactional side or the social side of it is the bit that has been more difficult (client interjects)…..	Being relient on facial expression in noisey environemnts	the way of him being able to use compensatory behaviours effectively
Participant: Yes it is…so to elaborate on that erm…….I'd quite like to go out in the evening time perhaps to the pub but when you'd uh especially the evening times the atmosphere can be quite loud and you've got music and general chit chat at quite a loud level you would interact by facial expressions like laughing, smiling you know because you know yourself if you go to a pub or a club you know I find it's too loud but you know what I mean ……	Having no choice but to interact with others through facial expression Seeking confirmation of experience Finding it too loud	Being judged and misunderstood by others in noisy social events through inability to express self through facial expression
Researcher: Yea ….yea……	Being judged for not using appropriate facial expression	
Participant: You can't have a conversation with someone….you interact through your facial expressions you	Not being able to convey emotions	

know…….and um it's a you know…yea if someone's telling a joke and you can't convey your amusement by laughing you know and because you can't convey your amusement through facial expressions they perceive that as your ……..you've took offence cos I get it quite a lot when they say oh you know I'm only joking don't you? If I had a pound for every time someone said that I'd be a millionaire by now	through facial expression	Seeing self through the eyes of another Being objectified by self
Researcher: Sure sure		Feeling shocked not to see his emotions reflected in his facial expression
Participant: So I think….and quite recently actually I was….I recently got married and we had a dvd um produced and I was watching it the other week and obviously we don't watch ourselves on TV unless we're famous and I was just watching myself on the tv and I was quite….I duno if shocked is the right word but I became	watching video image of self and becoming aware of how he looks to someone else Feeling shocked Looking at self on video camera and being struck by the little/limited facial	Being confronted with his own visible difference memon

quite aware of how I look to someone else cos I’m now looking at how….so you know and obviously it’s my wedding day and I’m having happy emotions and all that but I was quite struck looking at me at how ….how little or no movement I do actually have you know…..it’s like talking to you now you know I think I’m making more of an expression than I actually am and seeing that on a dvd that you know I literally don’t have any expressions on my face, I found that quite uh duno….I don’t know the word to….I found it quite uh ……I don’t know if interesting is the right word but you know but it sort of spooked me a little bit as like I said you know this is how people view me you know well not view me but that is how I look to other people and now I’m seeing how I look to someone in an environment where	movement he possesses Thinking he is making more facial expression than he actually is when talking to others Feeling spooked when seeing his absent/limited facial expression on video camera and thinking this is how he looks to other people Seeing through video camera image how he looks to someone in an environment where emotions are quite high Observing absent facial expression on video camera giving	Feeling spooked when seeing his lack of facial expression in a highly emotive situation Observing self through video camera enabling him to see self through the eyes of another Downplaying emotional reaction/shock of seeing his face not moving Blaming face for other people’s negative reactions towards him Putting up with other people’s negative reactions towards him Believing other people are justified to have negative reactions towards him because of his FP Constructing self as not normal due to not being able to give others the

emotions are quite high and I just found that quite interesting and it gave me quite a different perspective uh of how I should tolerate people’s um you know people’s perceptions of me….you know new people you come across you sort of think well if that’s what they see of course they’re perhaps going to be a bit stand offish or a bit you know cool because they don’t really or	him more tolerance for strangers perceptions of him Not being able to give strangers the facial expressions they would get off normal people	facial expression they would get from ‘normal people’ Not being able to conceal visible difference/lack of facial movement from self when watching self on a video camera Being able to hide visible difference from self in the crowd and briefness of the news video clip
they’re not going to get um things that they get off to use that awful word of normal people you know	Seeing self in photos as a different experience to video image because it’s not in real time or	Not being able to hide visible difference from self when centre of

…so….and I think um yea……. Researcher: Was that the first time that you'd ever seen yourself from….(participant interjects)….. Participant: ummmm obviously you know photos are different because it's not real time and you're not seeing yourself you know for a few seconds and so I may have seen myself in a news clip you know watching a football club and I may have seen myself in the crowd uh….I think I saw myself once in the crowd, Wrexham had just scored a goal and you know everyone was happy and uh smiling as you would but I had a blank expression so again but that would be the first time that I've sat down and watched myself for a good few minutes ……	lasting longer than a few seconds Seeing self in crowd and noticing others smiling as they should be and his blank expression Watching wedding video as first time sitting down and watching self for a few minutes	attention on wedding day Downplaying emotional reaction to seeing self on video Finding it unnerving watching self on dvd because of lack of facial expression Being distracted by his lack of facial expression

Researcher: in motion Participant: yea ….it was just interesting shall we say……	Feeling surprised at how little movement he had in face when watching self on video camera	when seeing his face on video
Researcher: Yea sure….were you aware of any sorts of um sorts of thoughts that you had as you were watching yourself? Participant: Well um the initial let me think uh the thoughts around how I looked or?...like like I said to you I felt um….uh I felt quite uh….I was just surprised at how little movement I ….I….I did have so I think it's um it's quite unnerving you know like (laughs) most people would find you know watching themselves Im sure lots of people wouldn't like to watch themselves like that but I found it quite unnerving and the lack of facial expression…..I think I	Finding it unnerving watching self on dvd because of lack of facial expression Focusing on his face and lack of facial expression rather than on others when watching his wedding dvd Not looking at video reflecting on how wonderful wedding day was but focusing on and realising how	Needing to tell self that the man on video with facial palsy is him (disconnecting from physical self?) Not being able to hide from self when watching self on video

focused on that more than like on the other people in the uh in the uh congregation area and things you know I sort of focused on me and my face and the lack of facial movement…….	little facial movement he has Looking at video thinking that's me with the facial palsy Not realising how little facial movement he had until watching self in wedding video	Seeing a less defective physical self in a photograph or mirror compared to self he sees on a dvd/video
Researcher: hmmm hmmm		
Participant: And I sort of took an interest in that um….you know I wasn't looking at yea I suppose quite interesting….I wasn't looking at it like wow this was my wedding day, great isn't it wonderful, which of course it was……but I was looking at it thinking….that's me with the facial palsy and wow that's how little movement I do actually have I didn't actually realise how little movement I do actually have so that's that was my thoughts…….	Seeing self in wedding dvd very different to what he sees when looking in a photograph and mirror	Watching self on wedding video making him more consciously aware of his visible difference and how that looks to others
Researcher: Right yea sure…..so is that different		

to when you have looked in the mirror or looked at photographs previously?		
Participant: Yes yea it is different to previously…I can’t explain why but it is yea how I looked in that dvd video very much different to how I look at myself in the mirror or in a picture so yes very much so….don’t ask me why but it is……..	Watching self on wedding video making him more consciously aware of how he looks to others.	
Researcher: Hmmm…..I mean would you say since watching that that it’s sort of changed the image that you have of yourself in your head in terms of how you look or not?		Not remembering a sense of self where he was not aware of his facial palsy
Participant: ummm………no I’m not less confident or more negative in terms of how I look…perhaps it’s made me even I mean I’d like to think I was quite aware already but made me even more aware of how I		Facial Palsy is a part self engrained in him from birth Never being labelled by parents with the term facial palsy

actually look to other people um ….yea so I think that would actually be …yea how I look to other people would be perhaps more conscious…… Researcher: Ahhh sure sure …….yea that's very interesting I'm glad you've shared that actually you know it's quite an interesting thing that's happened by the sounds of it for you …… Participant: yea yea Researcher: And actually it leads…it kind of um leads really nicely on to my next question which was um I was wondering when and how you first became aware of your facial palsy? Participant: oooo that's a very good question …… I suppose ….I can't really give you a specific time I think most people would….I think give a	Can't give a specific time of when he became aware of his facial palsy Facial palsy is something you have from birth Parents never using the term facial palsy to single him out Never using term facial palsy to feel sorry for self Growing up in family where he was treated like anyone else	Not allowing self to feel sadness/sorrow around having facial palsy Growing up in a family where he was treated the same as others Becoming aware of his being different through giggles and sniggers from other children when joining a new primary school

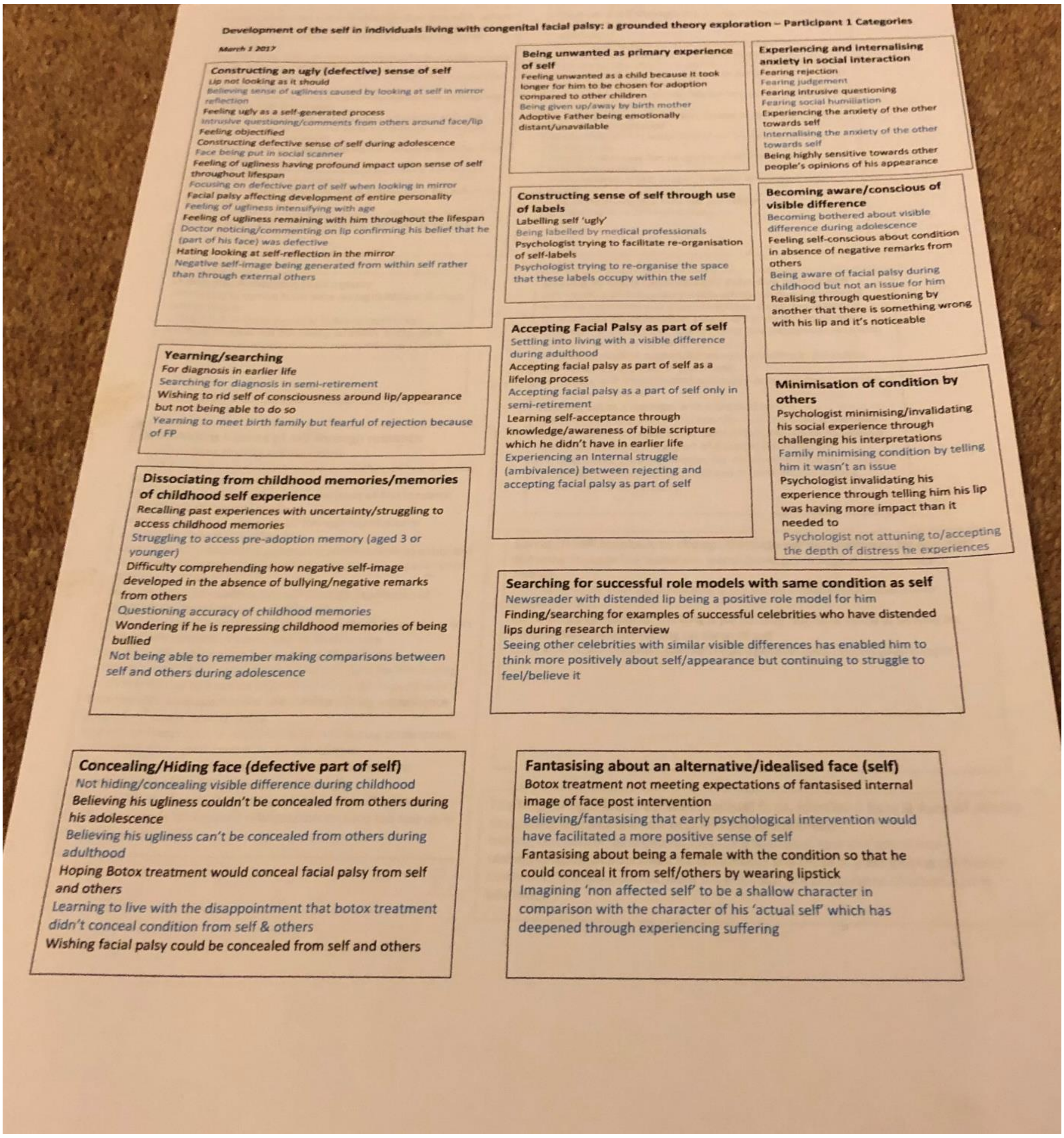
similar answer in the sense that you know it is something you have from birth and you I think you sort of …..you….you know it's sort of engrained in you that you have….well for a start I mean my parents didn't use the term you know…..… it was never used as a…as a…..as aaaa….as a means to feel sorry for myself or to use it to ….uhhhh to single me out from anyone else……you know I…..it's I uh…… I grew up in a family where they want to treat you just like anyone else…… like I said I couldn't really give you a definitive time period ahhh but what I could say is I suppose you know looking back now there would be times in primary school where I joined a new school perhaps and you might recollect people Ident…singling you out uhhh I can't remember exactly but there would	Earliest recollection of being different through giggles or sniggers from other children when joining a new primary school	Becoming conscious of facial palsy from an early age through being told by other children Not consciously recollecting parents speaking to him about facial palsy but having a sense/feeling that they did

have been giggles or sniggers you know look at him that type of thing so uh I suppose that would be it if I joined a new school or new environment where there were new kids of children that probably would have been my earliest recollection of being uh …..Different…. Researcher: Ahhh ok sure so you're kind of saying that it was through other people or children potentially pointing it out to you that you became more aware of it…… Participant: exactly yea you know I can never remember my parents putting me down or saying no you are this that or the other….I can never remember that…..yea definitely I think I was conscious of it from that early age from people ….you know telling me you've got a or making fun	Becoming conscious of facial palsy from an early age through children telling him, making fun and pointing it out. Children pointing it out and making fun making him think he had something different from the rest (others) Not recollecting parents talking to him about facial palsy but feeling sure they did	Experiencing apprehension joining a new school Noticing bullies sniggering at him when joining new schools Dealing with the bullies by distancing self from them

off or pointing something out that made me think well I have got something different from ….the rest……..		Hiding from bullies and removing self from situation
Researcher: Hmmm….sure….sure…..so it sounds like you're saying that your parents just treated you as you really and didn't really bring it up……..	Feeling apprehensive Joining new school	
Participant: Yea ….I'm sure they did talk to me about it but I've certainly got no recollection of it……..	Noticing bullies sniggering at him when joining new schools	Remembering children commenting on his facial palsy from the age of seven onwards
Researcher: yea sure……sure…..what was that like at school in those situations when children pointed it out to you?	Giving bullies a wide birth	Hearing others comment on his appearance when joining a new school
Participant: Uh it's uh…..it's a difficult one I mean I have to say I wasn't really bullied to any great extent you know…..we uh…..you	Shying away or avoiding bullies	Being ridiculed by another child when joining a new school

know if people would have said unkind things it was nipped in the bud straight away but the initial……joining…..I think I joined 2 or 3 new schools uh growing up and I think it's um….you know children have that apprehension joining a new school anyway so if I did uh notice a couple of bullies or whoever looking at me and sniggering at me I wouldn't have gone up to them and said Hi I'm so and so…..uh I probably would have given them a wide birth or you know I mean what can you do you know I mean if you walk away…I certainly wouldn't have gone up to them and said look what's your problem or gone up and said hi I'm so and so you know I wouldn't have done that I would have shied away or gone somewhere else…….	Remembering being 7 or 8 years old when people first started commenting on his moebius Remembering joining a new school aged 12 and comments being made about his appearance Noticing comments over the first few days of joining a new school Children sniggering and looking at him Someone making fun of him at dinner table	Being objectified by other children Being protected from the bullying through the teachers dealing with it Being separated by teachers from class Imagining teachers telling off the children who were bullying him

APPENDIX H – SAMPLE GROUPING OF CODES – PARTICIPANT 1



Development of the self in individuals living with congenital facial palsy: a grounded theory exploration – Participant 1 Categories

March 1 2017

Constructing an ugly (defective) sense of self
Lip not looking as it should
Believing sense of ugliness caused by looking at self in mirror reflection
Feeling ugly as a self-generated process
Intrusive questioning/comments from others around face/lip
Feeling objectified
Constructing defective sense of self during adolescence
Face being put in social scanner
Feeling of ugliness having profound impact upon sense of self throughout lifespan
Focusing on defective part of self when looking in mirror
Facial palsy affecting development of entire personality
Feeling of ugliness intensifying with age
Feeling of ugliness remaining with him throughout the lifespan
Doctor noticing/commenting on lip confirming his belief that he (part of his face) was defective
Hating looking at self-reflection in the mirror
Negative self-image being generated from within self rather than through external others

Yearning/searching
For diagnosis in earlier life
Searching for diagnosis in semi-retirement
Wishing to rid self of consciousness around lip/appearance but not being able to do so
Yearning to meet birth family but fearful of rejection because of FP

Dissociating from childhood memories/memories of childhood self experience
Recalling past experiences with uncertainty/struggling to access childhood memories
Struggling to access pre-adoption memory (aged 3 or younger)
Difficulty comprehending how negative self-image developed in the absence of bullying/negative remarks from others
Questioning accuracy of childhood memories
Wondering if he is repressing childhood memories of being bullied
Not being able to remember making comparisons between self and others during adolescence

Being unwanted as primary experience of self
Feeling unwanted as a child because it took longer for him to be chosen for adoption compared to other children
Being given up/away by birth mother
Adoptive Father being emotionally distant/unavailable

Constructing sense of self through use of labels
Labelling self 'ugly'
Being labelled by medical professionals
Psychologist trying to facilitate re-organisation of self-labels
Psychologist trying to re-organise the space that these labels occupy within the self

Accepting Facial Palsy as part of self
Settling into living with a visible difference during adulthood
Accepting facial palsy as part of self as a lifelong process
Accepting facial palsy as a part of self only in semi-retirement
Learning self-acceptance through knowledge/awareness of bible scripture which he didn't have in earlier life
Experiencing an internal struggle (ambivalence) between rejecting and accepting facial palsy as part of self

Experiencing and internalising anxiety in social interaction
Fearing rejection
Fearing judgement
Fearing intrusive questioning
Fearing social humiliation
Experiencing the anxiety of the other towards self
Internalising the anxiety of the other towards self
Being highly sensitive towards other people's opinions of his appearance

Becoming aware/conscious of visible difference
Becoming bothered about visible difference during adolescence
Feeling self-conscious about condition in absence of negative remarks from others
Being aware of facial palsy during childhood but not an issue for him
Realising through questioning by another that there is something wrong with his lip and it's noticeable

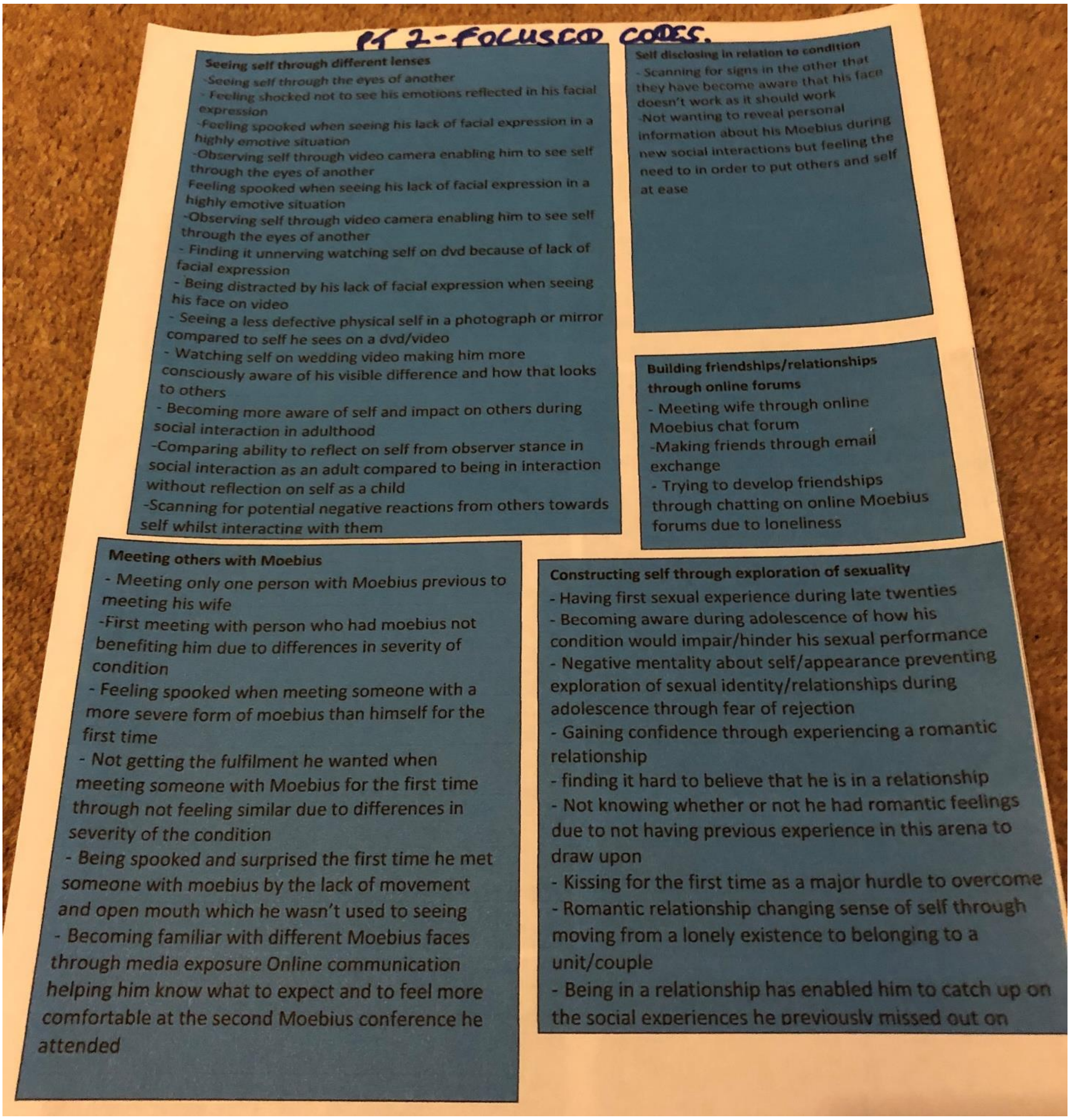
Minimisation of condition by others
Psychologist minimising/invalidating his social experience through challenging his interpretations
Family minimising condition by telling him it wasn't an issue
Psychologist invalidating his experience through telling him his lip was having more impact than it needed to
Psychologist not attuning to/accepting the depth of distress he experiences

Searching for successful role models with same condition as self
Newsreader with distended lip being a positive role model for him
Finding/searching for examples of successful celebrities who have distended lips during research interview
Seeing other celebrities with similar visible differences has enabled him to think more positively about self/appearance but continuing to struggle to feel/believe it

Concealing/Hiding face (defective part of self)
Not hiding/concealing visible difference during childhood
Believing his ugliness couldn't be concealed from others during his adolescence
Believing his ugliness can't be concealed from others during adulthood
Hoping Botox treatment would conceal facial palsy from self and others
Learning to live with the disappointment that botox treatment didn't conceal condition from self & others
Wishing facial palsy could be concealed from self and others

Fantasising about an alternative/idealised face (self)
Botox treatment not meeting expectations of fantasised internal image of face post intervention
Believing/fantasising that early psychological intervention would have facilitated a more positive sense of self
Fantasising about being a female with the condition so that he could conceal it from self/others by wearing lipstick
Imagining 'non affected self' to be a shallow character in comparison with the character of his 'actual self' which has deepened through experiencing suffering

APPENDIX H – SAMPLE GROUPING OF CODES – PARTICIPANT 2



PT 2 - FOCUSED CODES.

Seeing self through different lenses

-Seeing self through the eyes of another
- Feeling shocked not to see his emotions reflected in his facial expression
-Feeling spooked when seeing his lack of facial expression in a highly emotive situation
-Observing self through video camera enabling him to see self through the eyes of another
Feeling spooked when seeing his lack of facial expression in a highly emotive situation
-Observing self through video camera enabling him to see self through the eyes of another
- Finding it unnerving watching self on dvd because of lack of facial expression
- Being distracted by his lack of facial expression when seeing his face on video
- Seeing a less defective physical self in a photograph or mirror compared to self he sees on a dvd/video
- Watching self on wedding video making him more consciously aware of his visible difference and how that looks to others
- Becoming more aware of self and impact on others during social interaction in adulthood
-Comparing ability to reflect on self from observer stance in social interaction as an adult compared to being in interaction without reflection on self as a child
-Scanning for potential negative reactions from others towards self whilst interacting with them

Self disclosing in relation to condition

- Scanning for signs in the other that they have become aware that his face doesn't work as it should work
-Not wanting to reveal personal information about his Moebius during new social interactions but feeling the need to in order to put others and self at ease

Building friendships/relationships through online forums

- Meeting wife through online Moebius chat forum
-Making friends through email exchange
- Trying to develop friendships through chatting on online Moebius forums due to loneliness

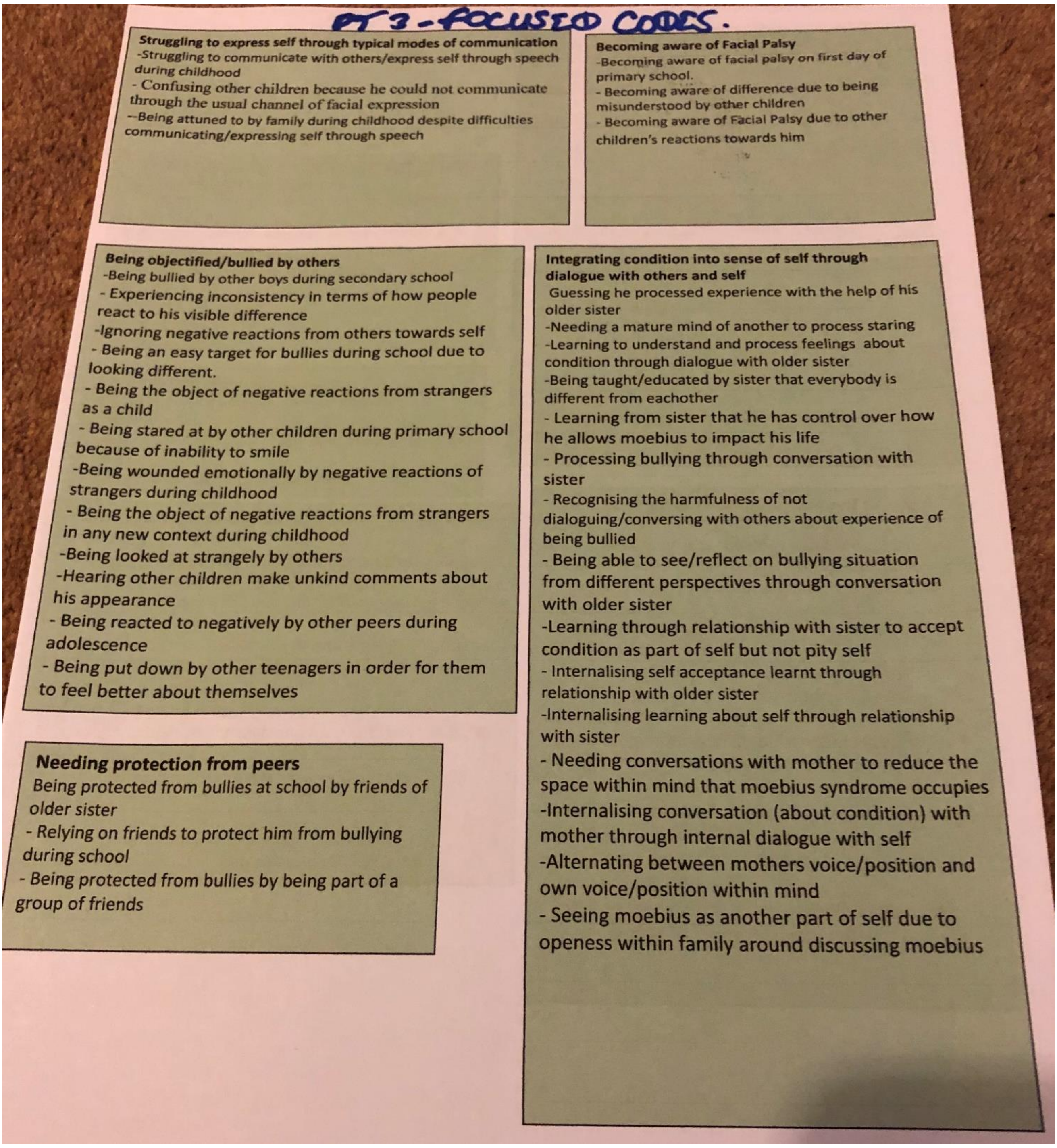
Meeting others with Moebius

- Meeting only one person with Moebius previous to meeting his wife
-First meeting with person who had moebius not benefiting him due to differences in severity of condition
- Feeling spooked when meeting someone with a more severe form of moebius than himself for the first time
- Not getting the fulfilment he wanted when meeting someone with Moebius for the first time through not feeling similar due to differences in severity of the condition
- Being spooked and surprised the first time he met someone with moebius by the lack of movement and open mouth which he wasn't used to seeing
- Becoming familiar with different Moebius faces through media exposure Online communication helping him know what to expect and to feel more comfortable at the second Moebius conference he attended

Constructing self through exploration of sexuality

- Having first sexual experience during late twenties
- Becoming aware during adolescence of how his condition would impair/hinder his sexual performance
- Negative mentality about self/appearance preventing exploration of sexual identity/relationships during adolescence through fear of rejection
- Gaining confidence through experiencing a romantic relationship
- finding it hard to believe that he is in a relationship
- Not knowing whether or not he had romantic feelings due to not having previous experience in this arena to draw upon
- Kissing for the first time as a major hurdle to overcome
- Romantic relationship changing sense of self through moving from a lonely existence to belonging to a unit/couple
- Being in a relationship has enabled him to catch up on the social experiences he previously missed out on

APPENDIX H – SAMPLE GROUPING OF CODES – PARTICIPANT 3



PT 3 - FOCUSED CODES.

Struggling to express self through typical modes of communication
-Struggling to communicate with others/express self through speech during childhood
- Confusing other children because he could not communicate through the usual channel of facial expression
--Being attuned to by family during childhood despite difficulties communicating/expressing self through speech

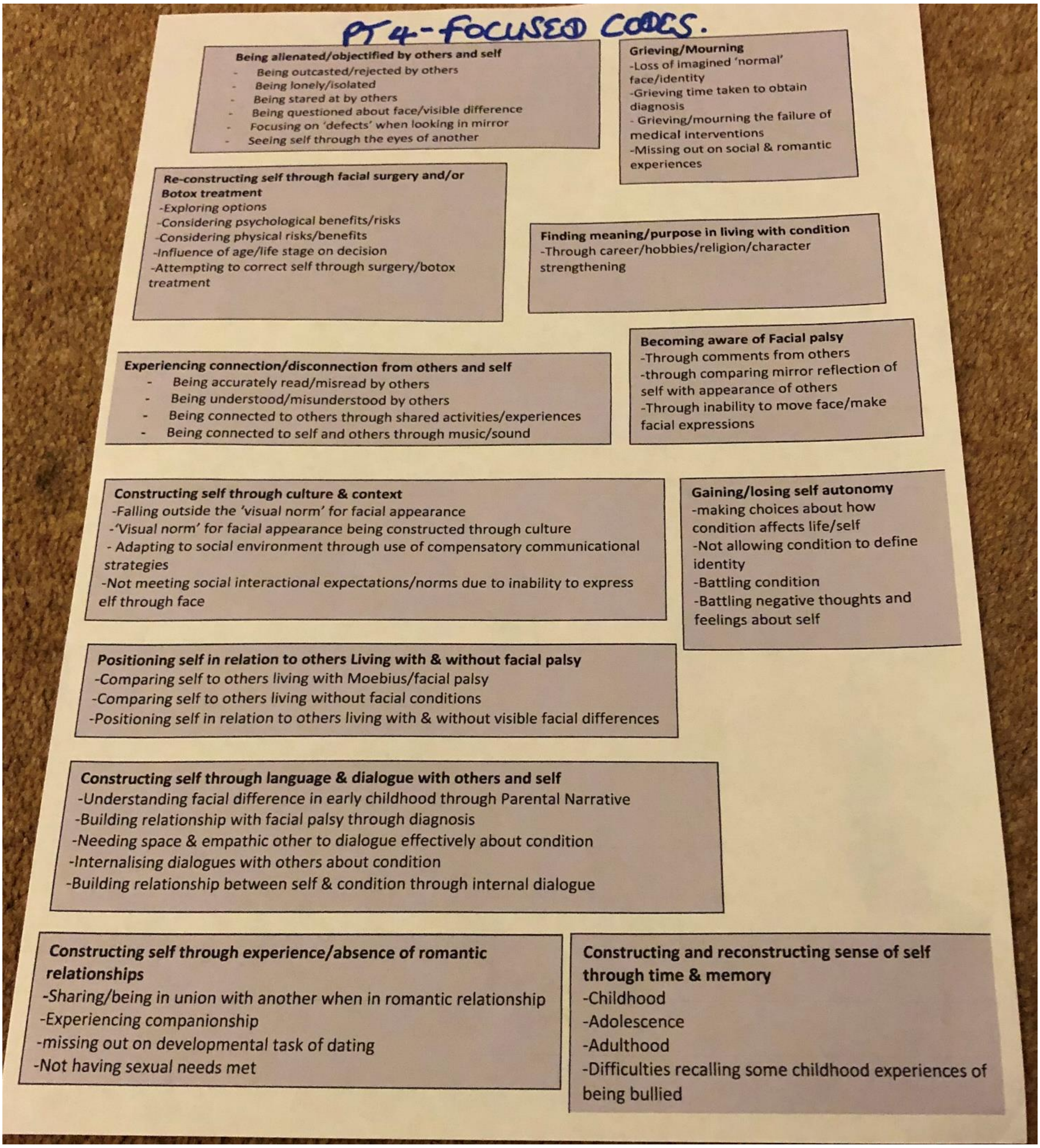
Becoming aware of Facial Palsy
-Becoming aware of facial palsy on first day of primary school.
- Becoming aware of difference due to being misunderstood by other children
- Becoming aware of Facial Palsy due to other children's reactions towards him

Being objectified/bullied by others
-Being bullied by other boys during secondary school
- Experiencing inconsistency in terms of how people react to his visible difference
-Ignoring negative reactions from others towards self
- Being an easy target for bullies during school due to looking different.
- Being the object of negative reactions from strangers as a child
- Being stared at by other children during primary school because of inability to smile
-Being wounded emotionally by negative reactions of strangers during childhood
- Being the object of negative reactions from strangers in any new context during childhood
-Being looked at strangely by others
-Hearing other children make unkind comments about his appearance
- Being reacted to negatively by other peers during adolescence
- Being put down by other teenagers in order for them to feel better about themselves

Needing protection from peers
Being protected from bullies at school by friends of older sister
- Relying on friends to protect him from bullying during school
- Being protected from bullies by being part of a group of friends

Integrating condition into sense of self through dialogue with others and self
Guessing he processed experience with the help of his older sister
-Needing a mature mind of another to process staring
-Learning to understand and process feelings about condition through dialogue with older sister
-Being taught/educated by sister that everybody is different from eachother
- Learning from sister that he has control over how he allows moebius to impact his life
- Processing bullying through conversation with sister
- Recognising the harmfulness of not dialoguing/conversing with others about experience of being bullied
- Being able to see/reflect on bullying situation from different perspectives through conversation with older sister
-Learning through relationship with sister to accept condition as part of self but not pity self
- Internalising self acceptance learnt through relationship with older sister
-Internalising learning about self through relationship with sister
- Needing conversations with mother to reduce the space within mind that moebius syndrome occupies
-Internalising conversation (about condition) with mother through internal dialogue with self
-Alternating between mothers voice/position and own voice/position within mind
- Seeing moebius as another part of self due to openess within family around discussing moebius

APPENDIX H – SAMPLE GROUPING OF CODES – PARTICIPANT 4



PT 4- FOCUSED CODES.

Being alienated/objectified by others and self
- Being outcasted/rejected by others
- Being lonely/isolated
- Being stared at by others
- Being questioned about face/visible difference
- Focusing on 'defects' when looking in mirror
- Seeing self through the eyes of another

Grieving/Mourning
-Loss of imagined 'normal' face/identity
-Grieving time taken to obtain diagnosis
- Grieving/mourning the failure of medical interventions
-Missing out on social & romantic experiences

Re-constructing self through facial surgery and/or Botox treatment
-Exploring options
-Considering psychological benefits/risks
-Considering physical risks/benefits
-Influence of age/life stage on decision
-Attempting to correct self through surgery/botox treatment

Finding meaning/purpose in living with condition
-Through career/hobbies/religion/character strengthening

Becoming aware of Facial palsy
-Through comments from others
-through comparing mirror reflection of self with appearance of others
-Through inability to move face/make facial expressions

Experiencing connection/disconnection from others and self
- Being accurately read/misread by others
- Being understood/misunderstood by others
- Being connected to others through shared activities/experiences
- Being connected to self and others through music/sound

Constructing self through culture & context
-Falling outside the 'visual norm' for facial appearance
-'Visual norm' for facial appearance being constructed through culture
- Adapting to social environment through use of compensatory communicational strategies
-Not meeting social interactional expectations/norms due to inability to express elf through face

Gaining/losing self autonomy
-making choices about how condition affects life/self
-Not allowing condition to define identity
-Battling condition
-Battling negative thoughts and feelings about self

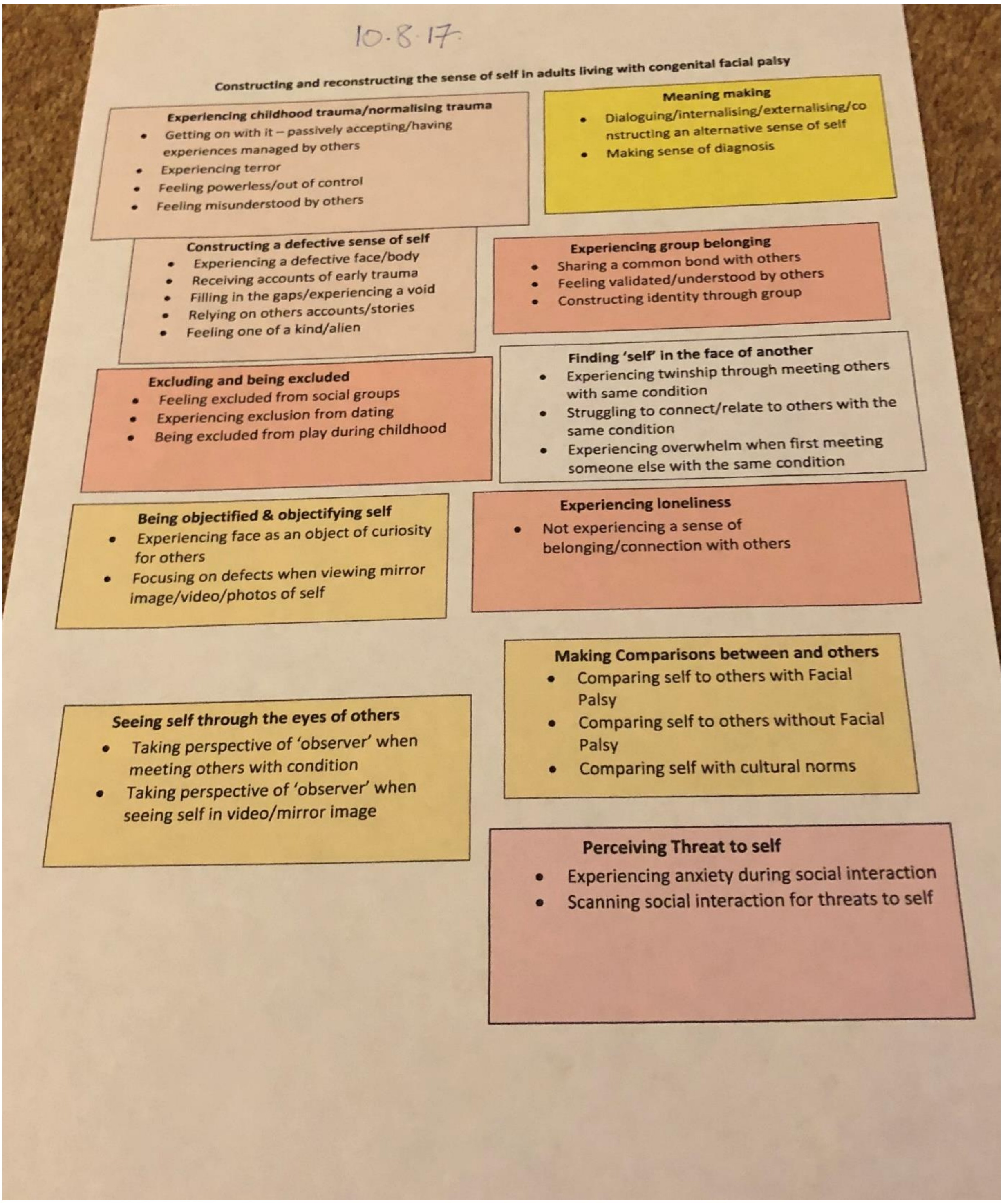
Positioning self in relation to others Living with & without facial palsy
-Comparing self to others living with Moebius/facial palsy
-Comparing self to others living without facial conditions
-Positioning self in relation to others living with & without visible facial differences

Constructing self through language & dialogue with others and self
-Understanding facial difference in early childhood through Parental Narrative
-Building relationship with facial palsy through diagnosis
-Needing space & empathic other to dialogue effectively about condition
-Internalising dialogues with others about condition
-Building relationship between self & condition through internal dialogue

Constructing self through experience/absence of romantic relationships
-Sharing/being in union with another when in romantic relationship
-Experiencing companionship
-missing out on developmental task of dating
-Not having sexual needs met

Constructing and reconstructing sense of self through time & memory
-Childhood
-Adolescence
-Adulthood
-Difficulties recalling some childhood experiences of being bullied

APPENDIX I – SAMPLE GROUP CATEGORIES AND SUB CATEGORIES



10.8.17

Constructing and reconstructing the sense of self in adults living with congenital facial palsy

Experiencing childhood trauma/normalising trauma
- Getting on with it – passively accepting/having experiences managed by others
- Experiencing terror
- Feeling powerless/out of control
- Feeling misunderstood by others

Meaning making
- Dialoguing/internalising/externalising/constructing an alternative sense of self
- Making sense of diagnosis

Constructing a defective sense of self
- Experiencing a defective face/body
- Receiving accounts of early trauma
- Filling in the gaps/experiencing a void
- Relying on others accounts/stories
- Feeling one of a kind/alien

Experiencing group belonging
- Sharing a common bond with others
- Feeling validated/understood by others
- Constructing identity through group

Excluding and being excluded
- Feeling excluded from social groups
- Experiencing exclusion from dating
- Being excluded from play during childhood

Finding 'self' in the face of another
- Experiencing twinship through meeting others with same condition
- Struggling to connect/relate to others with the same condition
- Experiencing overwhelm when first meeting someone else with the same condition

Being objectified & objectifying self
- Experiencing face as an object of curiosity for others
- Focusing on defects when viewing mirror image/video/photos of self

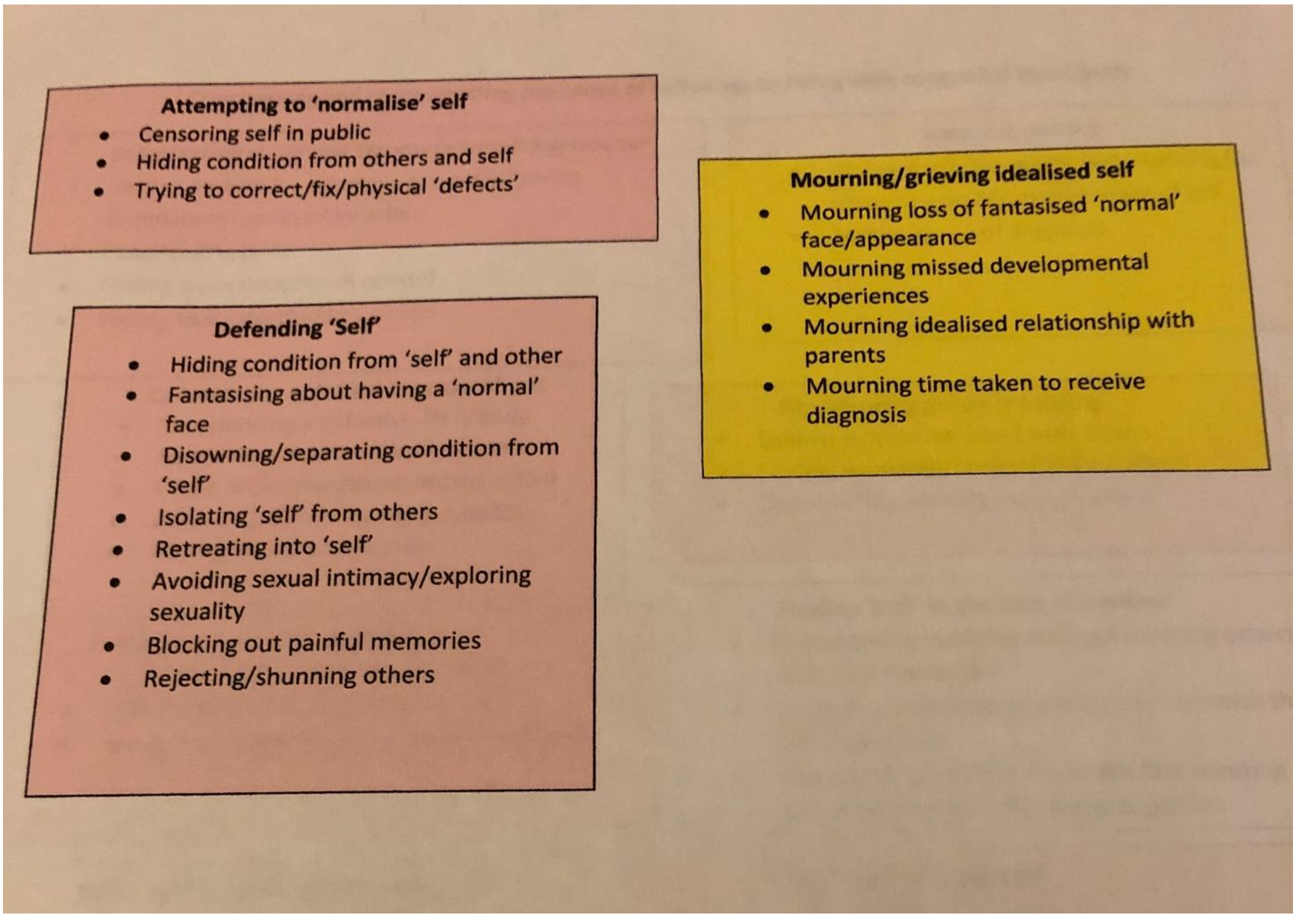
Experiencing loneliness
- Not experiencing a sense of belonging/connection with others

Making Comparisons between and others
- Comparing self to others with Facial Palsy
- Comparing self to others without Facial Palsy
- Comparing self with cultural norms

Seeing self through the eyes of others
- Taking perspective of 'observer' when meeting others with condition
- Taking perspective of 'observer' when seeing self in video/mirror image

Perceiving Threat to self
- Experiencing anxiety during social interaction
- Scanning social interaction for threats to self

APPENDIX I – SAMPLE GROUP CATEGORIES AND SUB CATEGORIES



Attempting to 'normalise' self

- Censoring self in public
- Hiding condition from others and self
- Trying to correct/fix/physical 'defects'

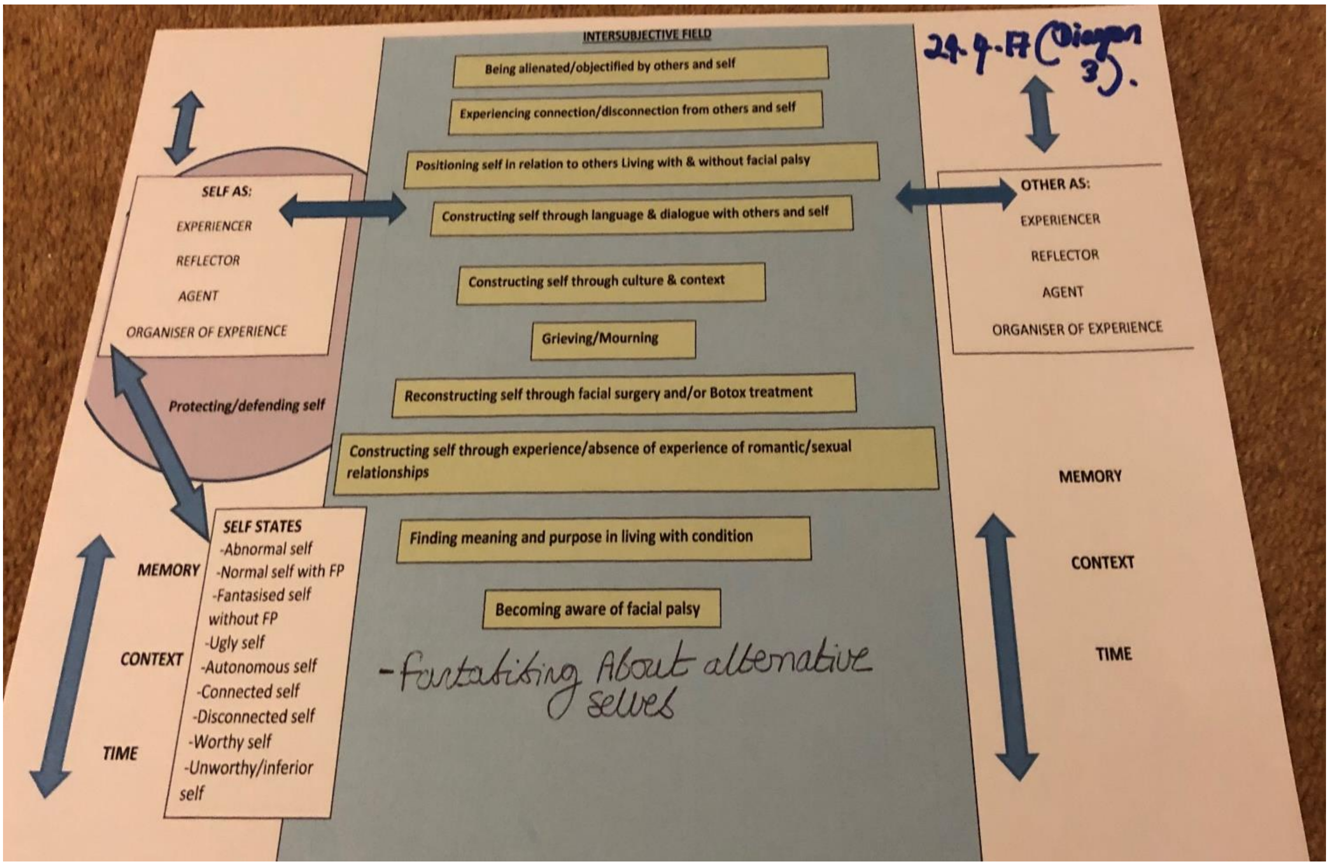
Defending 'Self'

- Hiding condition from 'self' and other
- Fantasising about having a 'normal' face
- Disowning/separating condition from 'self'
- Isolating 'self' from others
- Retreating into 'self'
- Avoiding sexual intimacy/exploring sexuality
- Blocking out painful memories
- Rejecting/shunning others

Mourning/grieving idealised self

- Mourning loss of fantasised 'normal' face/appearance
- Mourning missed developmental experiences
- Mourning idealised relationship with parents
- Mourning time taken to receive diagnosis

APPENDIX J - DIAGRAMMING – EVIDENCING THEORY CONSTRUCTION


24-4-17 (Diagram 3).

INTERSUBJECTIVE FIELD

Being alienated/objectified by others and self

Experiencing connection/disconnection from others and self

Positioning self in relation to others Living with & without facial palsy

Constructing self through language & dialogue with others and self

Constructing self through culture & context

Grieving/Mourning

Reconstructing self through facial surgery and/or Botox treatment

Constructing self through experience/absence of experience of romantic/sexual relationships

Finding meaning and purpose in living with condition

Becoming aware of facial palsy

-Fantasising About alternative selves

SELF AS:
EXPERIENCER
REFLECTOR
AGENT
ORGANISER OF EXPERIENCE

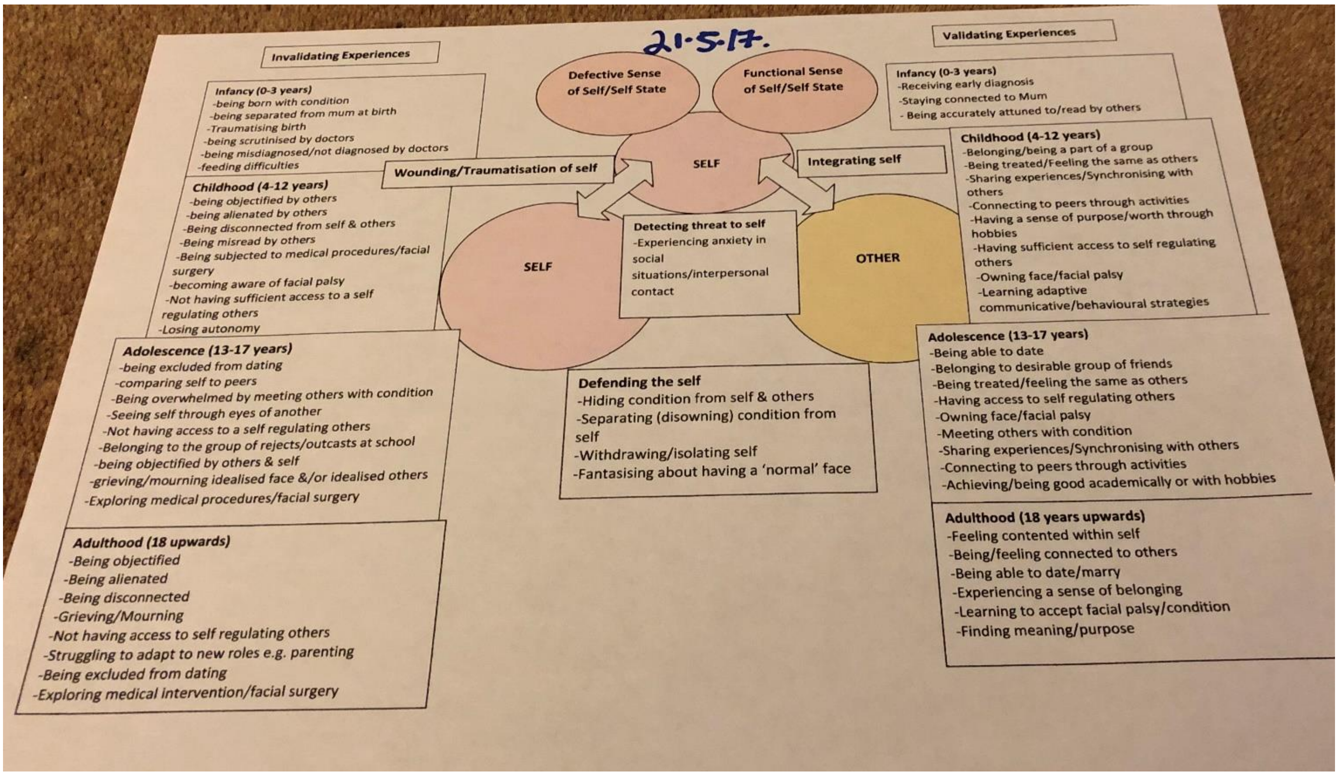
Protecting/defending self

SELF STATES
-Abnormal self
-Normal self with FP
-Fantasised self without FP
-Ugly self
-Autonomous self
-Connected self
-Disconnected self
-Worthy self
-Unworthy/inferior self

MEMORY
CONTEXT
TIME

OTHER AS:
EXPERIENCER
REFLECTOR
AGENT
ORGANISER OF EXPERIENCE

MEMORY
CONTEXT
TIME


21-5-17.

Invalidating Experiences

Infancy (0-3 years)
-being born with condition
-being separated from mum at birth
-Traumatising birth
-being scrutinised by doctors
-being misdiagnosed/not diagnosed by doctors
-feeding difficulties

Childhood (4-12 years)
-being objectified by others
-being alienated by others
-Being disconnected from self & others
-Being misread by others
-Being subjected to medical procedures/facial surgery
-becoming aware of facial palsy
-Not having sufficient access to a self regulating others
-Losing autonomy

Adolescence (13-17 years)
-being excluded from dating
-comparing self to peers
-Being overwhelmed by meeting others with condition
-Seeing self through eyes of another
-Not having access to a self regulating others
-Belonging to the group of rejects/outcasts at school
-being objectified by others & self
-grieving/mourning idealised face &/or idealised others
-Exploring medical procedures/facial surgery

Adulthood (18 upwards)
-Being objectified
-Being alienated
-Being disconnected
-Grieving/Mourning
-Not having access to self regulating others
-Struggling to adapt to new roles e.g. parenting
-Being excluded from dating
-Exploring medical intervention/facial surgery

Defective Sense of Self/Self State

Functional Sense of Self/Self State

SELF

Wounding/Traumatisation of self

Integrating self

SELF

OTHER

Detecting threat to self
-Experiencing anxiety in social situations/interpersonal contact

Defending the self
-Hiding condition from self & others
-Separating (disowning) condition from self
-Withdrawing/isolating self
-Fantasising about having a 'normal' face

Validating Experiences

Infancy (0-3 years)
-Receiving early diagnosis
-Staying connected to Mum
- Being accurately attuned to/read by others

Childhood (4-12 years)
-Belonging/being a part of a group
-Being treated/Feeling the same as others
-Sharing experiences/Synchronising with others
-Connecting to peers through activities
-Having a sense of purpose/worth through hobbies
-Having sufficient access to self regulating others
-Owning face/facial palsy
-Learning adaptive communicative/behavioural strategies

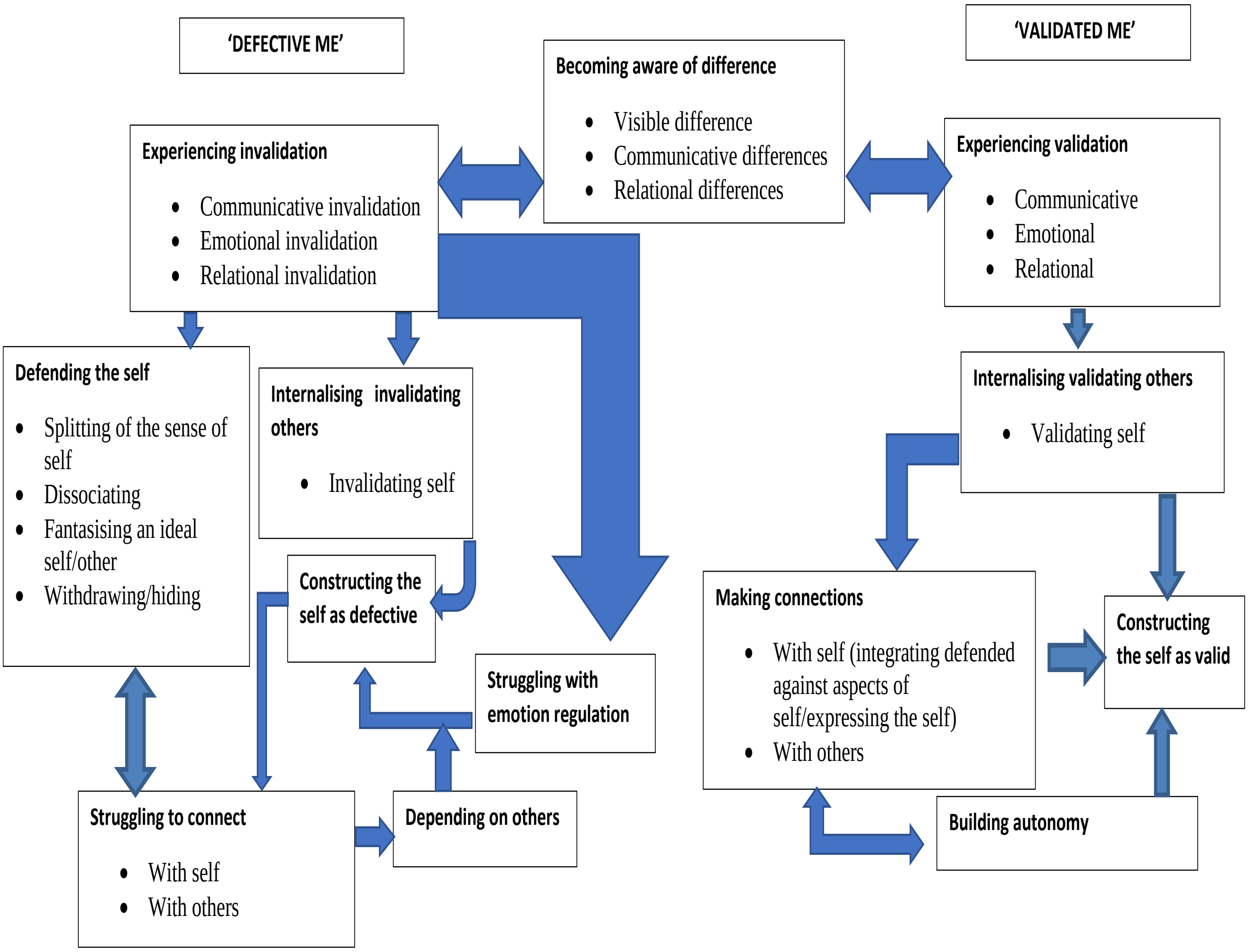
Adolescence (13-17 years)
-Being able to date
-Belonging to desirable group of friends
-Being treated/feeling the same as others
-Having access to self regulating others
-Owning face/facial palsy
-Meeting others with condition
-Sharing experiences/Synchronising with others
-Connecting to peers through activities
-Achieving/being good academically or with hobbies

Adulthood (18 years upwards)
-Feeling contented within self
-Being/feeling connected to others
-Being able to date/marry
-Experiencing a sense of belonging
-Learning to accept facial palsy/condition
-Finding meaning/purpose

APPENDIX J - DIAGRAMMING – EVIDENCING THEORY CONSTRUCTION

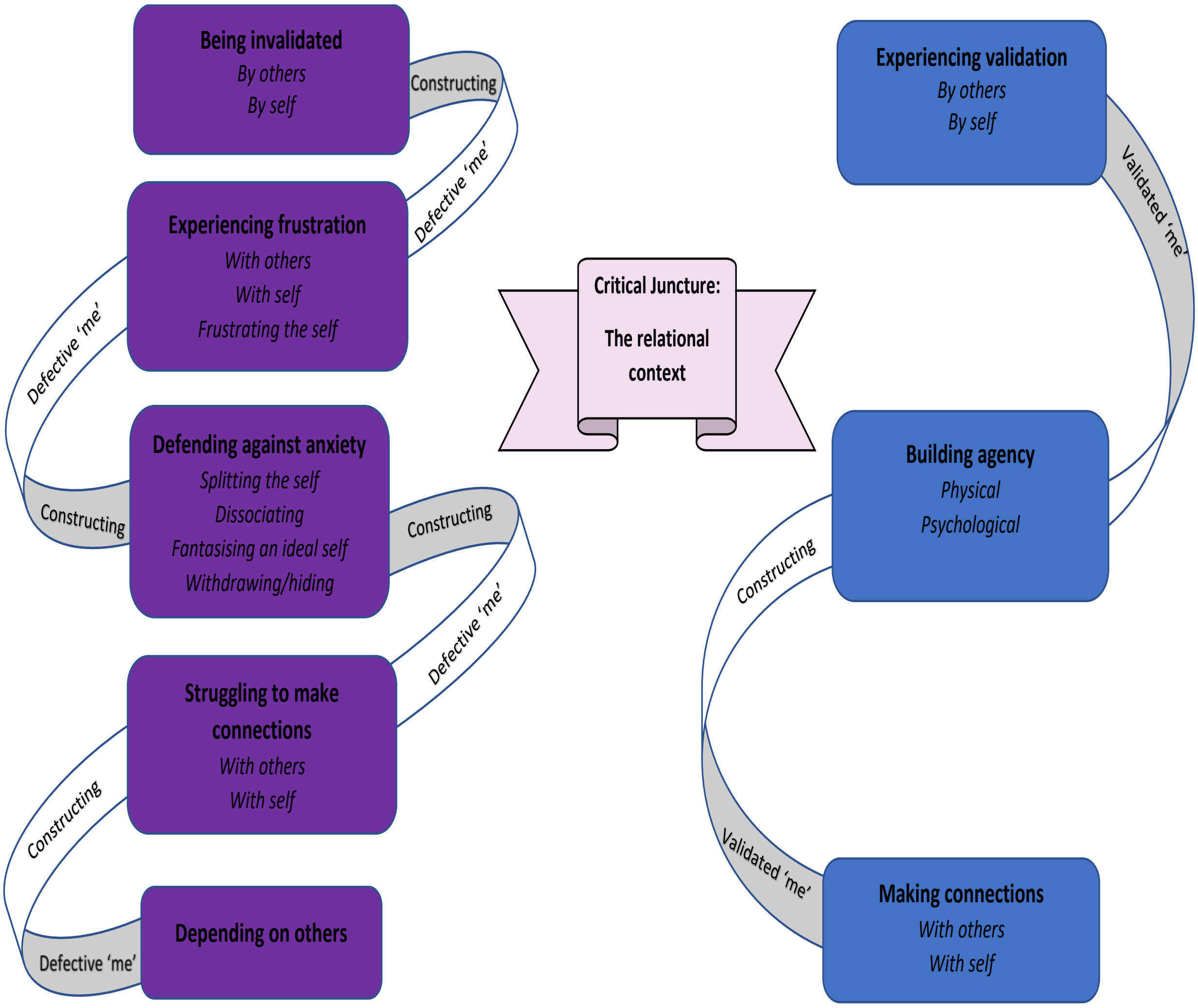
January 2019 diagram

Figure 1: The construction of 'self' in individuals with congenital facial palsy: a grounded theory exploration



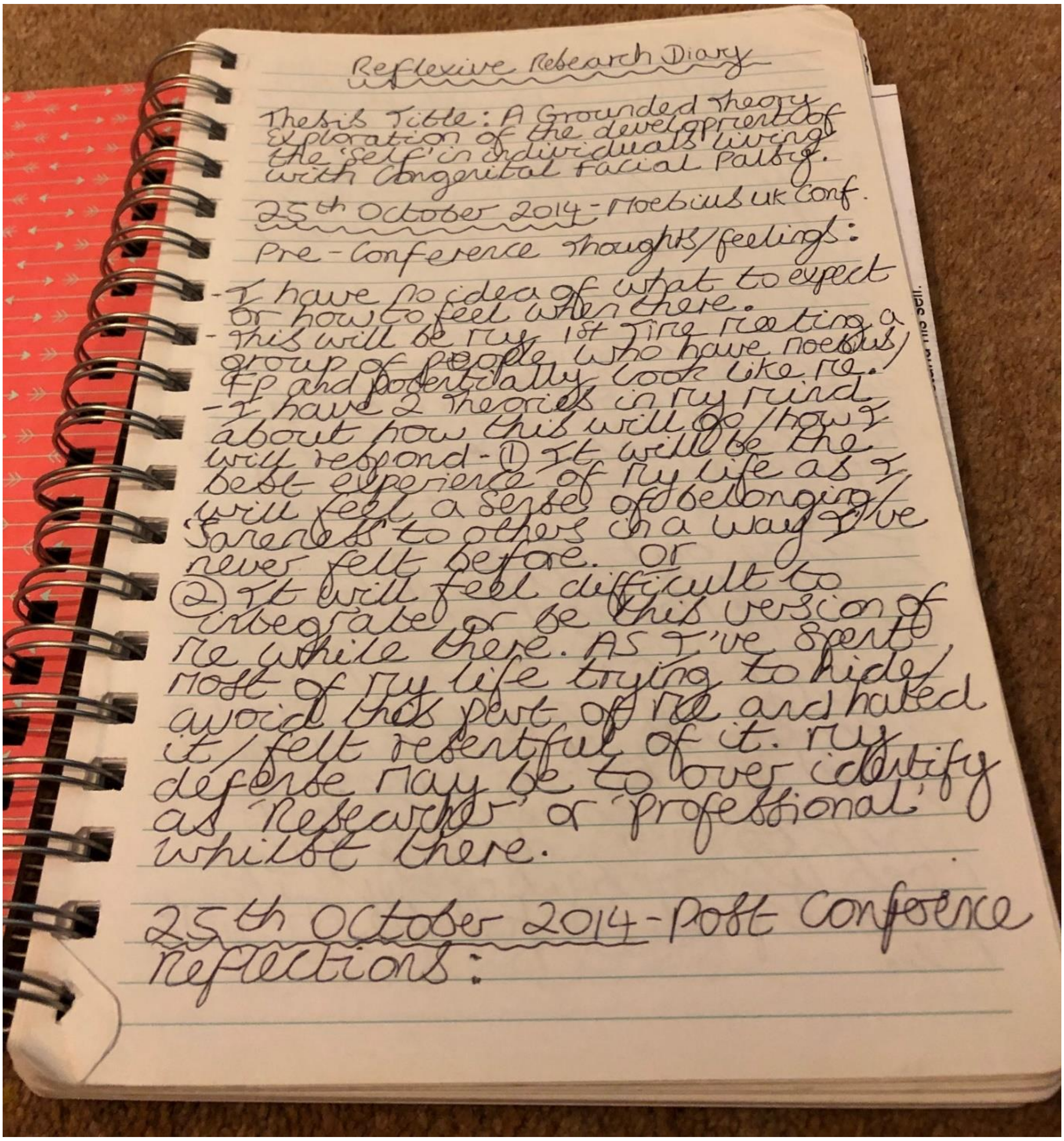
APPENDIX J - DIAGRAMMING – EVIDENCING THEORY CONSTRUCTION

February 2019 diagram



APPENDIX K – EXTRACTS FROM REFLEXIVE JOURNAL

(My reflections on the Moebius Syndrome conference in the United Kingdom 2014)



Reflexive Research Diary

Thesis Title: A Grounded Theory Exploration of the development of the 'self' in individuals living with Congenital Facial Palsy.

25th October 2014 - Moebius UK Conf.

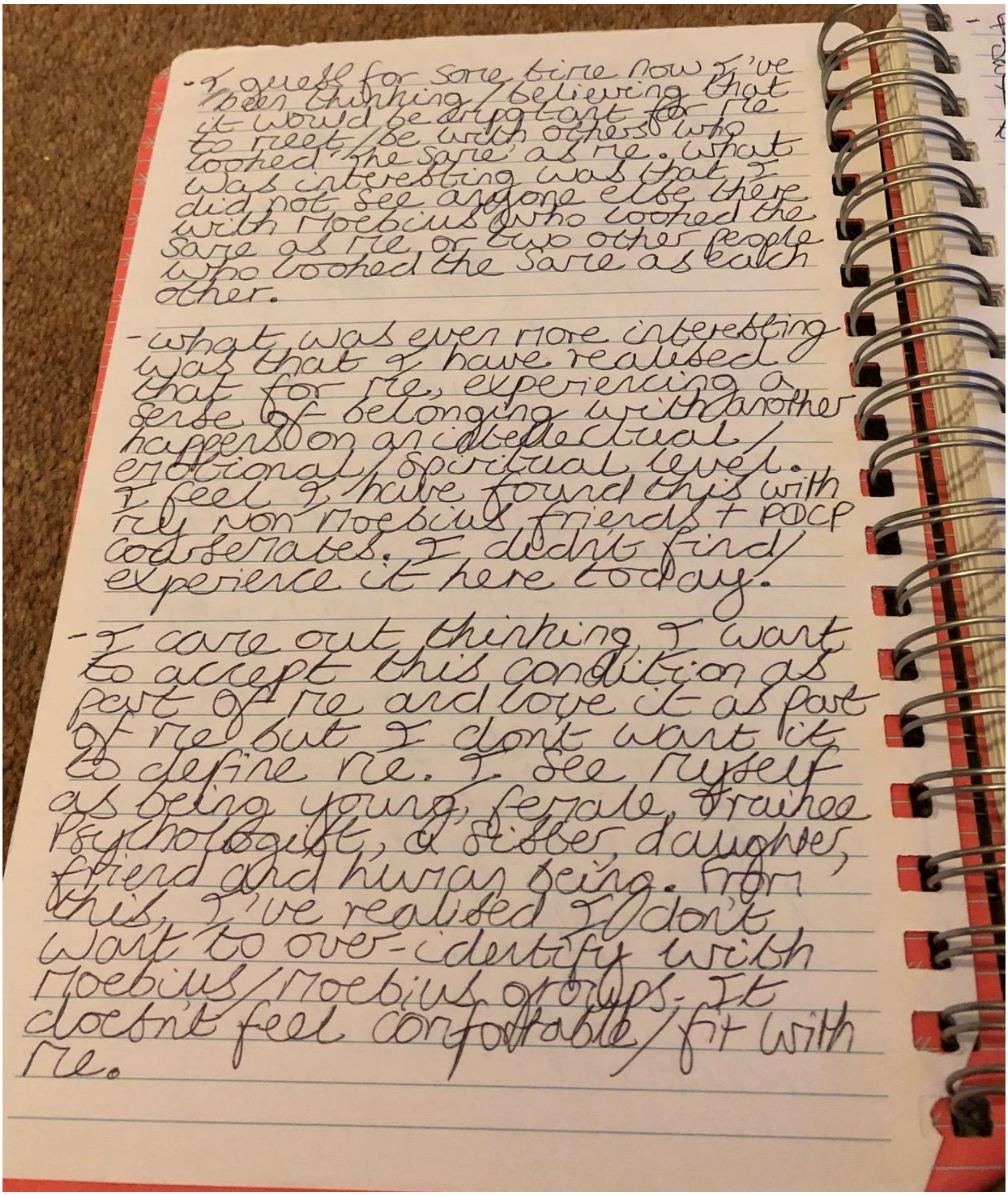
Pre-Conference thoughts/feelings:

- I have no idea of what to expect or how to feel when there.
- This will be my 1st time meeting a group of people who have moebius/FP and potentially look like me.
- I have 2 theories in my mind about how this will go/how I will respond - ① It will be the best experience of my life as I will feel a sense of belonging/'Sameness' to others in a way I've never felt before. or ② It will feel difficult to integrate or be this version of me while there. As I've spent most of my life trying to hide/avoid this part of me and hated it/felt resentful of it. My defense may be to over identify as 'Researcher' or 'Professional' whilst there.

25th October 2014 - Post Conference reflections:

APPENDIX K – EXTRACTS FROM REFLEXIVE JOURNAL

(My reflections on the Moebius Syndrome conference in the United Kingdom 2014)



- I guess for some time now I've been thinking/believing that it would be important for me to meet/be with others who looked 'the same' as me. What was interesting was that I did not see anyone else there with Moebius who looked the same as me, or two other people who looked the same as each other.

- what was even more interesting was that I have realised that for me, experiencing a sense of belonging with another happens on an intellectual/emotional/spiritual level. I feel I have found this with my non Moebius friends + POCP coursemates. I didn't find/experience it here today.

- I came out thinking I want to accept this condition as part of me and love it as part of me but I don't want it to define me. I see myself as being young, female, trainee Psychologist, a sister, daughter, friend and human being. From this, I've realised I don't want to over-identify with Moebius/Moebius groups. It doesn't feel comfortable/fit with me.

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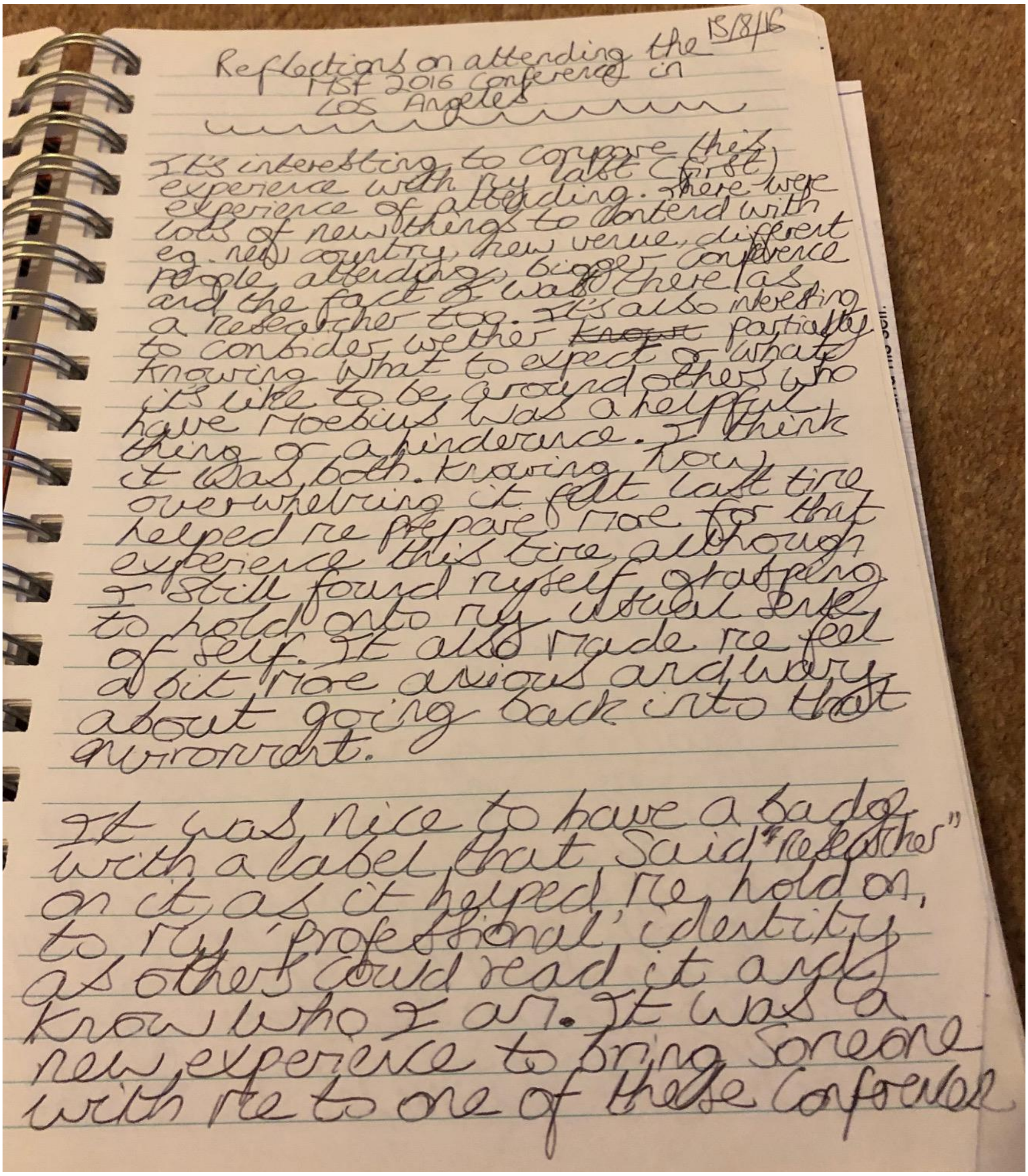
(My reflections on the Moebius Syndrome conference in Los Angeles 2016)



15/8/16

Reflections on attending the
MSF 2016 Conference in
Los Angeles

It's interesting to compare this experience with my last (first) experience of attending. There were lots of new things to contend with eg. new country, new venue, different people attending, bigger conference and the fact I was there as a Researcher too. It's also interesting to consider wether ~~know~~ partially knowing what to expect & what it's like to be around others who have Moebius was a helpful thing or a hinderance. I think it was both. Knowing how overwhelming it felt last time helped me prepare more for that experience this time, although I still found myself grasping to hold onto my usual sense of self. It also made me feel a bit more anxious and wary about going back into that environment.

It was nice to have a badge with a label that said "Researcher" on it, as it helped me hold on to my 'professional' identity as others could read it and know who I am. It was a new experience to bring someone with me to one of these conferences

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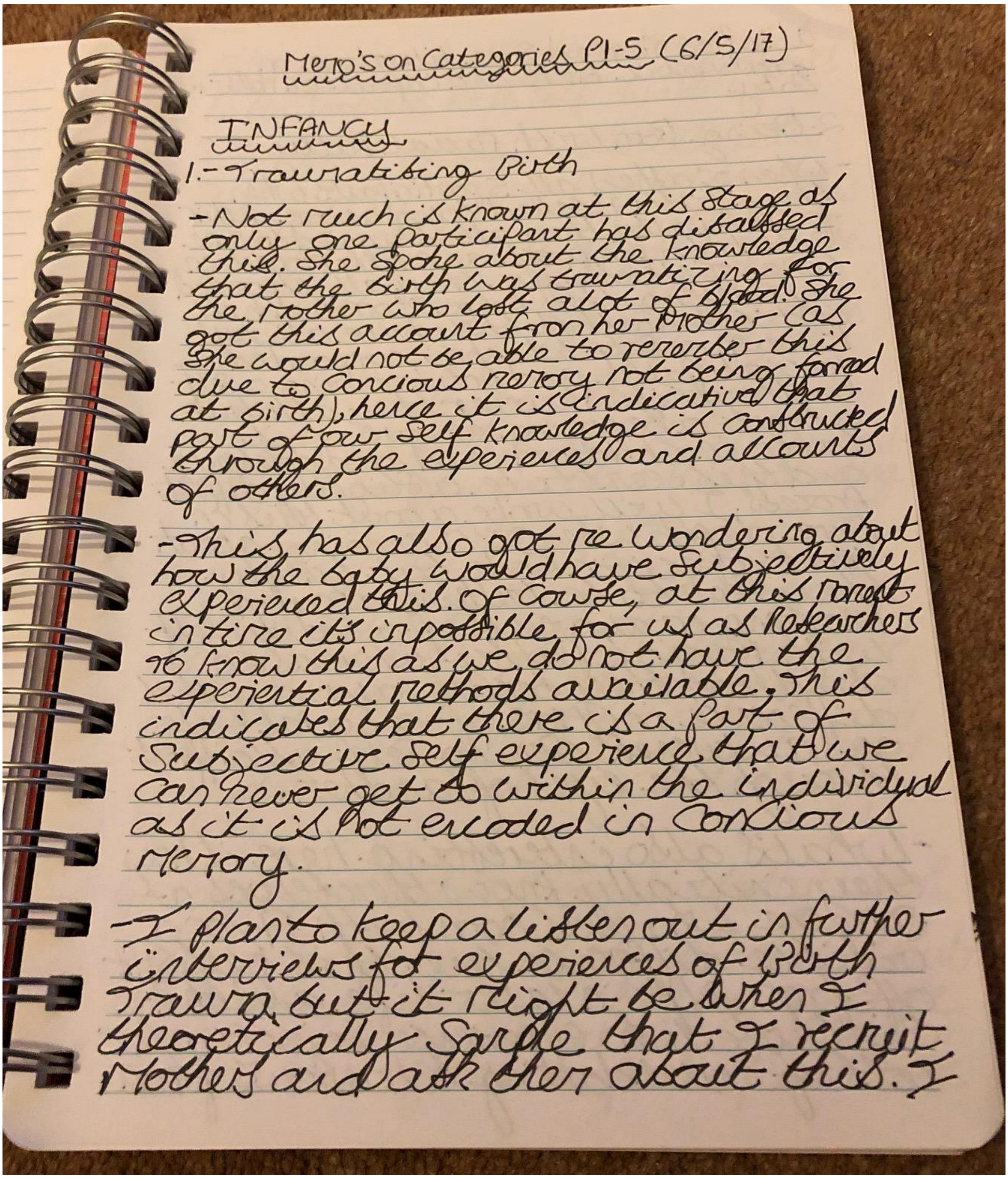
(Memos)



Memo's on Categories P1-5 (6/5/17)

INFANCY

1.- Traumatising Birth

- Not much is known at this stage as only one participant has discussed this. She spoke about the knowledge that the birth was traumatizing for the mother who lost alot of blood. She got this account from her mother (as she would not be able to remember this due to concious memory not being formed at birth), hence it is indicative that part of our self knowledge is constructed through the experiences and accounts of others.

- This has also got me wondering about how the baby would have subjectively experienced this. Of course, at this moment in time it's impossible for us as Researchers to know this as we do not have the experiential methods available. This indicates that there is a part of subjective self experience that we can never get to within the individual as it is not encoded in concious memory.

- I plan to keep a listen out in further interviews for experiences of birth trauma but it might be when I theoretically sample that I recruit mothers and ask them about this. I

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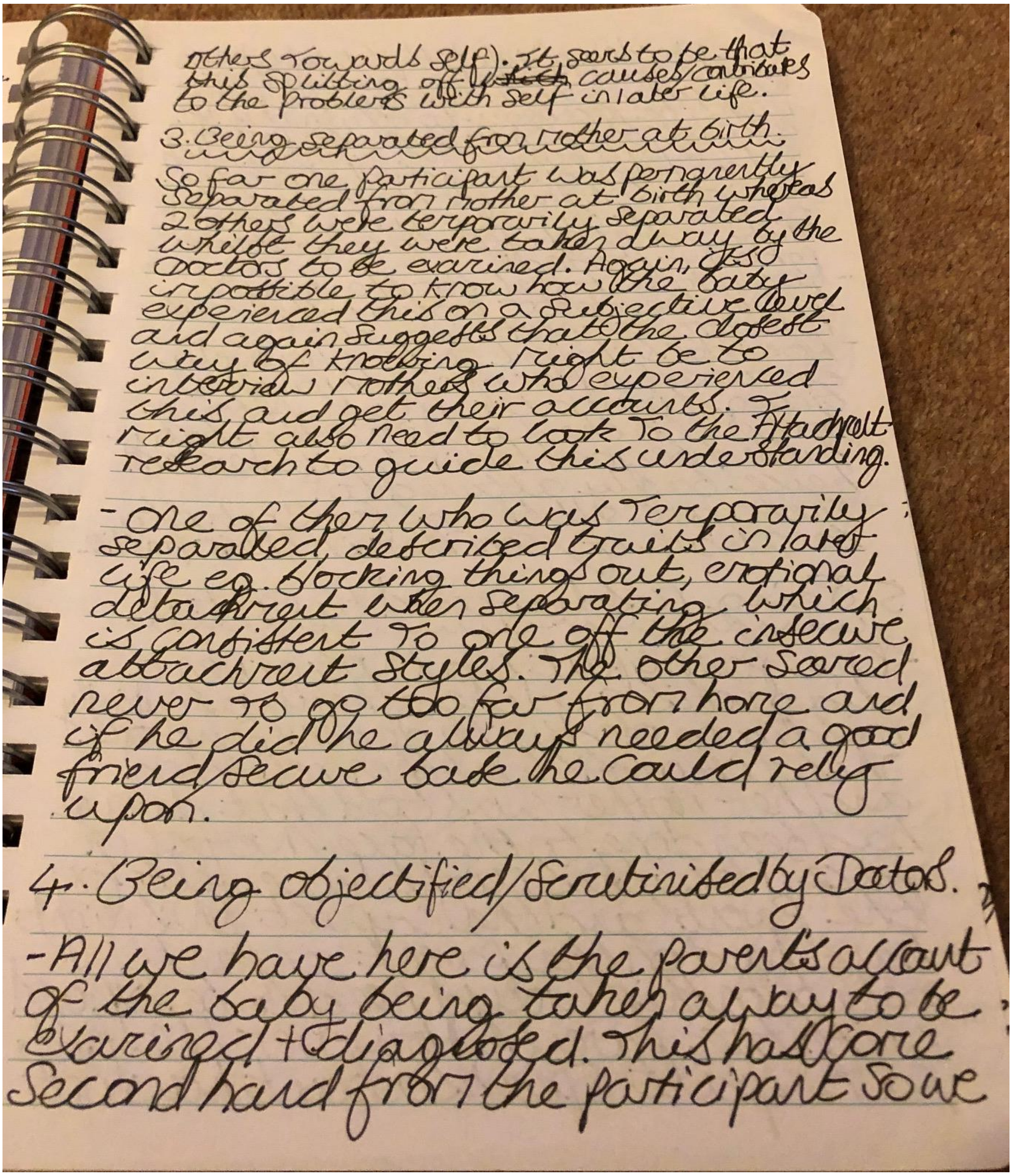
(Memos)



others towards self). It seems to be that this splitting off ~~which~~ causes/contributes to the problems with self in later life.

3. Being separated from mother at birth.

So far one participant was permanently separated from mother at birth whereas 2 others were temporarily separated whilst they were taken away by the doctors to be examined. Again, it's impossible to know how the baby experienced this on a subjective level and again suggests that the closest way of knowing might be to interview mothers who experienced this and get their accounts. I might also need to look to the Attachment research to guide this understanding.

- One of them who was temporarily separated, described traits in later life eg. blocking things out, emotional detachment when separating, which is consistent to one off the insecure attachment styles. The other seemed never to go too far from home and if he did he always needed a good friend secure base he could rely upon.

4. Being objectified/Scrutinised by Doctors.

- All we have here is the parent's account of the baby being taken away to be examined + diagnosed. This has come second hand from the participant so we

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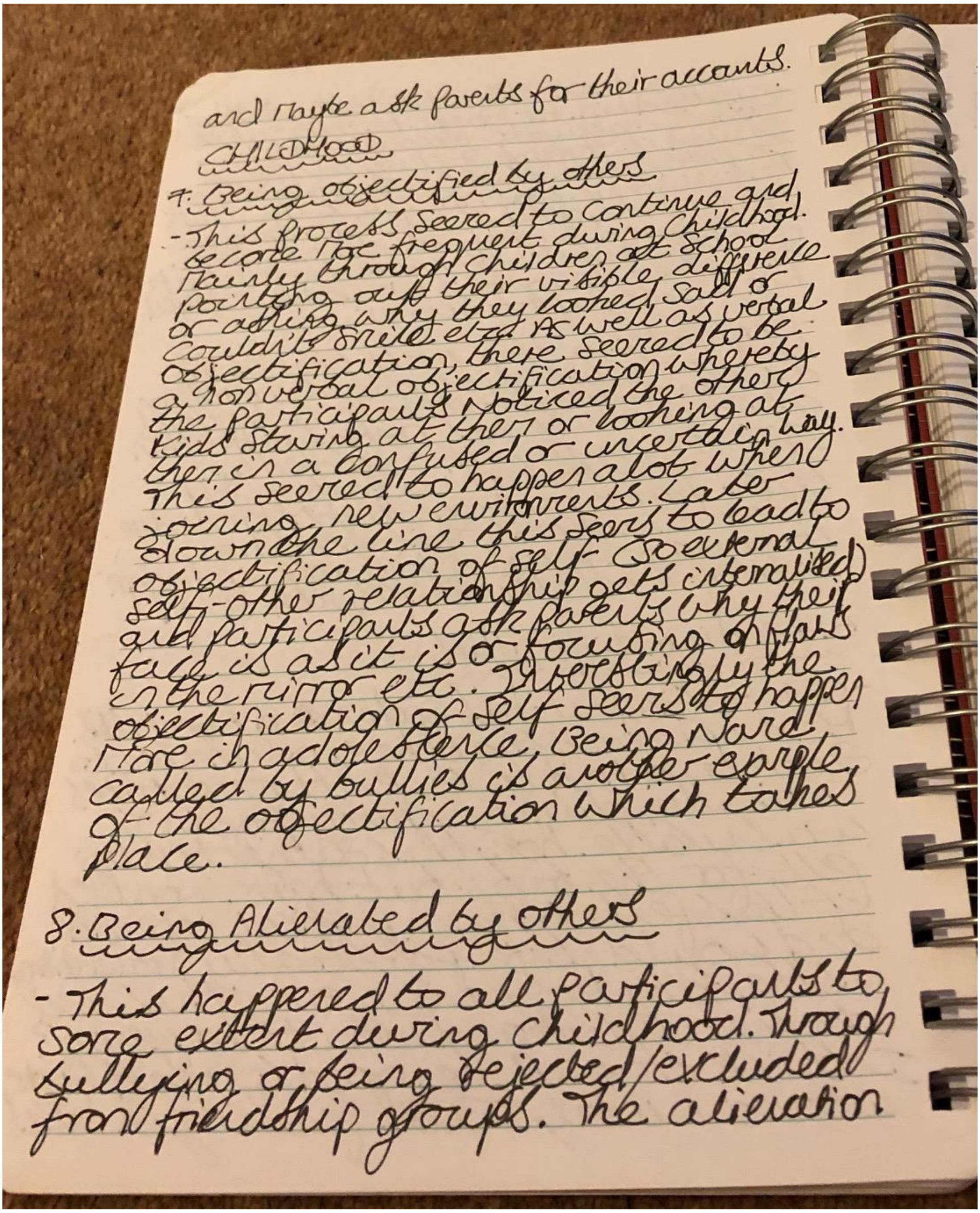
(Memos)



and maybe ask parents for their accounts.

CHILDHOOD

7. Being objectified by others

- This process seemed to continue and become more frequent during childhood. Mainly through children at school pointing out their visible difference or asking why they looked sad or couldn't smile etc. As well as verbal objectification, there seemed to be a non verbal objectification whereby the participants noticed the other kids staring at them or looking at them in a confused or uncertain way. This seemed to happen alot when joining new environments. Later down the line this seems to lead to objectification of self (so external self-other relationship gets internalised) and participants ask parents why their face is as it is or focusing on flaws in the mirror etc. Interestingly the objectification of self seems to happen more in adolescence. Being name called by bullies is another example of the objectification which takes place.

8. Being Alienated by others

- This happened to all participants to some extent during childhood. Through bullying or being rejected/excluded from friendship groups. The alienation

APPENDIX L – RATIONALE RESEARCH ARTICLE

I am intending to submit the research article to a journal which specialises in Counselling Psychology. This journal has been selected as it welcomes qualitative studies which are relevant to counselling/psychotherapy and Counselling Psychology practice, and especially those which are undertaken with minority groups. It is hoped that by submitting this research to a Counselling Psychology journal that it will raise the awareness of congenital facial palsy and hopefully encourage further research and clinical interest from practitioners working within the Counselling Psychology and Psychotherapy field.

In terms of the submission guidelines, the main body of the article and reference section must be double spaced and should not be longer than 45 pages in total. The abstract should be no longer than 250 words and should have 5 keywords for indexing underneath. The authors names and institutional affiliations should be written at the top of the page under the title. The title should be no more than 12-14 words.

In line with the guidelines in the programme handbook, I have ensured that I have not named the intended journal in this thesis as this could be a breach of copyright should my research article be accepted for publication in the future.