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Exploring the Experiences of Women who were born with Cleft Lip and Palate: An IPA Study

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Portfolio submitted in fulfilment of the requirements for the Professional Doctorate in Psychology (DPsych)

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THE FOLLOWING PART OF THIS THESIS HAS BEEN REDACTED FOR COPYRIGHT AND DATA PROTECTION REASONS:

Pages 13, 59, 64, 161, 162, 165, 166, 176, 181-184
Section B: client study/process report .....pages 198-226
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Abstract

Introduction: Cleft lip and palate (CL/P) is characterised as a birth defect or congenital anomaly which occurs in one in every 500-700 births globally. This research study explores the subjective, phenomenological experiences of eight women with CL/P using Interpretative Phenomenological Analysis (IPA) to determine how women experience and manage living with CL/P and to consider implications for counselling psychology. Quantitative and qualitative studies indicate the overall low psychological impact of being born with CL/P, but also show disparities and contradictions. This author was born with CL/P.

Method: Ethical approval was obtained. Semi-structured interviews and open-ended questions were used. Eight women born with CL/P were recruited using purposive sampling. Participant accounts of their lived experiences were recorded and transcribed verbatim. Interviews took 73 to 120 minutes, (mean 90 minutes).

Analysis Four themes were identified: 'The threatened self' explores the complexity inherent in the development of identity; '*being different to others'* explores interpersonal experiences of participants; *'facing challenges'* explores challenges and *'wishing things had been better'* explores experiences which participants share as a means of acting as advocates for others.

Discussion: My research supports existing CL/P literature. 'Wishing things had been better' has not been explored previously. I found that meaning-making is important for individuals with CL/P.

I consider that it would be beneficial for CL/P to be conceptualised as a long-term condition requiring psychological support, and if adult CL/P should have improved access to support, including psychological, for key life events. I designed a check-list of issues to consider when working with a client with CL/P.

This research has demonstrated that women's experiences of living with CL/P are multi-faceted and demonstrates a duality of experience in which being born with and living with CL/P throughout life may be thought of as both 'not a problem' and 'a problem' at different stages of life.

Preface

"Life can only be understood backwards. But it must be lived forwards." –
Soren Kierkegaard

The preface will introduce and provide an overview of the components in this portfolio: the doctoral thesis, the client study and the publishable paper. These pieces of work are combined under an overarching theme of embodiment. The preface consists of four main sections as well as initial reflections. Section A explores the relevance of the concept of embodiment. Section B, the doctoral thesis, explores the subjective phenomenological experiences of women with cleft lip and palate (CL/P). Section C provides an overview of the combined client study which used transdiagnostic CBT for eating disorder. Lastly, Section D gives an overview of the publishable paper which is a phenomenological account of my experience of the research process.

Personal Journey

I found the focus for my research topic gradually over the first year of my doctoral training. Knowing I would be working on my project for a lengthy period, I was interested in discovering something which would be a valuable learning experience and allow me to examine subjective stories in-depth and learn from them. I previously chose a quantitative method in my master's research and wanted to experience a different methodological perspective to broaden my experience. I hoped to be able to draw on a range of theoretical models, from psychodynamic to humanistic to systemic to behavioural and cognitive approaches to produce a holistic understanding of a phenomenon and its context within counselling psychology. In part, this may be due to having worked at the time for five years as a qualified CBT Therapist in pressured, target-led services where little time for reflection was possible. As a trainee Counselling Psychologist, I was drawn to an opportunity to slow down and reflect on meanings. During the research process, I have come to value personal reflexivity as an essential and ongoing skill and I greatly value the opportunity that my research project offered in that I could choose a focus that fit with my professional and personal development.

For some time, I struggled to identify a research topic, feeling somewhat hesitant to look inwards to my own life for inspiration but not feeling connected enough with other ideas I had. Eventually I realised was missing something I could see in the mirror each day. I was born with a cleft lip and palate, having had nine corrective operations to date. While I was growing up, outside of medical and dental appointments there was no education or psychological support on navigating difficulties, but I was aware of certain experiences I felt were different for me than for my peers or siblings. I had never talked at length with anyone about what it means to live with a cleft lip and palate and yet these experiences are woven into the story of my own life along with many others. I struggled with my realisation that I could conduct research on experiences of cleft lip and palate because it felt uncomfortably self-exposing, and while my own experiences are not new, they have always been private. My journey presented layers of complexity to work with, experiencing my own reactions to my data while I worked to set aside my own personal interpretations to make phenomenological interpretations of it. It has been a fascinating, challenging and rewarding process. During the research process I was powerfully surprised by my own responses to the analytic work and so I decided to use my own personal reflexivity throughout.

Section A: Embodiment

I have been fascinated by the link between the mind and the body since I undertook my undergraduate training in Psychology with Health Studies. Embodiment is the assumption that thoughts, feelings, and behaviours are grounded in sensory experiences and bodily states (Barsalou, 2008; Spellman & Schnall, 2009). Embodiment is the connecting theme of this portfolio. It considers the relationship with the body; in the context of a congenital condition in the research thesis and the publishable piece, and in the context of an eating disorder in the combined client study. Both living with cleft lip and palate (CL/P) and suffering an eating disorder involves a complex journey which includes the mind and body, and which has to be navigated towards some conclusion. I believe Counselling Psychology is uniquely placed to play a crucial role in facilitating or supporting the journey process because of its pluralistic strengths. These include its ability to pay attention to the mind and body. In contrast, the medical profession is arguably less able to offer embodied support, as reported by Loja et al (2013), “the medical gaze plays a crucial role in invalidating bodies that do not conform to the norm”.

Section B: Doctoral Research

This is an original piece of research, constituting the main component of this portfolio. The research explores the in-depth, subjective experiences of women who were born with cleft lip and palate (CLP). The research used material generated from semi-structured interviews of eight participants selected from the general population using purposive sampling. Participant accounts were analysed using the qualitative methodology Interpretative Phenomenological Analysis (IPA). Themes were identified and explored, and findings were discussed in light of the existing literature. The research is concerned with and reports on all aspects of experience, including embodied experiences of participants which are presented in the analysis section.

Section C: Client Study / Process Report

The combined client study and process report explores [redacted] treatment for eating disorder, using a transdiagnostic CBT model (Fairburn et al, 2003) and drawing pluralistically on a range of perspectives such as attachment theory, DBT and mindfulness amongst others. It speaks to the theme of embodiment by addressing the difficulties experienced by [redacted] in coming to terms with her body image and her relationship with her physical self; seeking to 'perfect' her body as a means of coping with her internal distress. I found this to be an invigorating and thought-provoking piece of work. I enjoyed the flexibility of drawing on pluralistic principles to meet [redacted] individual needs and I also felt I greatly developed my skills as a practitioner in using transdiagnostic CBT. Above all, I felt the work stayed true to my person-centred values of unconditional positive regard, congruence and empathy. I consider person-centred values to be an integral part of my work as a Counselling Psychologist and feel my understanding of working within these values has developed and consolidated throughout the doctoral training program.

Section D: Publishable Paper

In this final section of the portfolio, I discuss the phenomenological experience of being a 'knowing researcher', reflecting on my personal journey throughout the research process. Here my own embodied experiences are reflected upon. This piece was personally challenging to write due to feelings of self-consciousness around my own

self-disclosure. It was also immensely rewarding and freeing to share my experiences. I have found self-reflection to be a hugely important skill and feel I have developed my skills in this over the duration of developing the portfolio. My confidence and my perception of myself have changed and improved during this time. I feel I have emerged from the research process with something of a new identity and a new relationship to the field of psychology. In future, I hope to take opportunities to use self-disclosure in an appropriate, thoughtful, meaningful and professional way within clinical practice and supervision to enhance understanding, learning and practice for myself and others.

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Section A: Doctoral Research

1. Introduction

"Ordinary life is pretty complex stuff" *– Harvey Pekar (2003)*

Cleft lip and palate (CL/P) is characterised as a birth defect or congenital anomaly which occurs in one in every 500-700 births globally (World Health Organisation, 2012). A cleft lip is characterised by the upper lip not joining together prior to birth and a cleft palate is characterised by a hole in the roof of the mouth which does not join prior to birth. The development of the face and the palate takes place between the 5th and 11th week of gestation in embryos (Watson, 2002). Individuals can be born with either a cleft lip or a cleft palate and most frequently, both. In addition, the cleft lip may be unilateral (left or right-sided) or bilateral (both sides) (Rumsey & Harcourt, 2012). While there is no known single cause, it is shown to develop through a complex interplay of genetic and environmental factors (Murray, 2002). Individuals born with CL/P usually have a number of operations and procedures throughout childhood to repair the lip and palate, sometimes continuing into adulthood. CL/P is commonly associated with other difficulties including speech and hearing problems. In the UK, cleft lip repairs begin from birth to 6 weeks with cleft palate repairs following at 6-12 months (NHS, 2016). Great Ormond Street Hospital (GOSH, 2016) describe that "all children diagnosed with CL/P in the UK follow a similar treatment pathway, with the aim of improving outcomes for all children. The long-term NHS treatment pathway outlines that care providers must provide a comprehensive CL/P pathway that comprises of 21 elements of care. The management of CL/P requires the multidisciplinary involvement of many specialties throughout growth and development to the age of at least 20 years, as well as treatment of adults of any age (see Appendix 12 for detailed diagram).

The Cleft Lip and Palate Association (CLAPA) is a parent and patient group within the charity sector which plays a complementary role in support provision. It offers a range of support services; including online and local support groups to help people affected by CL/P, it provides specialist feeding equipment for babies and supplies welcome packs

for new families, it trains parent and patient volunteers who offer one-on-one support and it offers an information service which is community-led as well as participating in research opportunities (CLAPA, 2018).

I was born with CL/P and I refer to myself at times throughout the study as being a "knowing researcher" where relevant.

1.1 Aim of the Study

I am interested in exploring the subjective, phenomenological experiences of women born with CL/P. Adults are the primary interest for this study. In part this was because I felt adults would have more experiences to draw from and I also assumed that, given that centralised cleft teams, which include psychology and therapy professionals, were only formed in 2001, I anticipated that adults were less likely to have been offered psychological support as part of their medical care while growing up with CL/P. I was interested in sense and meaning making of participants. Women were selected to meet the requirements of homogeneity necessary for IPA study (Smith et al, 2009) and constructs of female beauty ideals will be explored and reflected on.

To the best of my knowledge the experiences of women with CL/P are under-represented and have not been explicitly researched to date. It is hoped that the pluralistic nature of the research will provide a significant contribution to the field of Counselling Psychology by informing clinical theory and practice about the ways in which living with CL/P is experienced by women.

1.2 Why is CL/P research important?

CL/P is conceptualised theoretically as a visible difference. 'Visible difference' refers to physical appearance which differs from the norm, whether present at birth of acquired later in life. The charity Changing Faces estimates that 400,000 people in the UK have some kind of visible difference (Changing Faces, 2001). A visible difference "can have a profoundly psychological impact upon the individual concerned" (Rumsey & Harcourt, 2004, p. 83). Rumsey & Harcourt (2012) describe that "individuals with a

congenital condition resulting in a difference of the face or body have to cope with a social visibility that most people do not experience on a daily basis", (p. 2). Difficulties arising from visible difference include adverse effects on body image, quality of life and self-esteem (Rumsey & Harcourt, 2004). Visible difference can also impact on an individual's social experiences although Rumsey and Harcourt (2004) acknowledge "the extent to which a visible difference results in social disability involves a complex interplay of social and individual factors", (p. 84). CL/P research is also important because CL/P has long-term, complex treatment implications (see Appendix 12 for treatment pathway) which are made more complicated by the ability of some of these interventions to permanently alter appearance. The breadth of potential psychological concerns associated with visible difference makes CL/P an important area for psychological research.

Further, CL/P research is important within the psychology field because traditionally it has been a surgically-dominated field with little attention paid to patient experience, the impact on the whole family and the impact on partners and children in the future.

Two literature reviews on CL/P have been conducted within the field to date. Hunt et al. (2005) and Stock and Feragen (2016) both found that while the overall impact of being born with CL/P is low, a deeper exploration of the literature identifies complex and conflicting findings and numerous methodological challenges, all of which will be discussed within this literature review. The fact that findings have been shown to be contradictory is a very important reason why further research is needed in the field.

In conducting this research, I am a "knowing researcher" because I was also born with cleft lip and palate, the phenomenon I am researching. My own personal experiences have inevitably shaped my understanding, expectations and perceptions of living with CL/P. To the best of my knowledge, no qualitative, "knowing research" has been conducted within this field to date before and it is hoped my research may therefore provide a valuable contribution.

During the process of conducting this research I have learned more than I ever knew about CL/P and have thought and talked about it more deeply as a result. Exploring the breadth of associated issues and challenges has been at times grounding and confirming, and at times threatening and challenging. I have used supervision, personal therapy and

reflective journals to process these complicated and mixed feelings. I believe my own experience supports a need for a deeper exploration of associated issues pertaining to CL/P.

1.3 Relevance to Counselling Psychology

"Counselling Psychology exists in relation to, and is situated within, the wider contexts with which it interacts." (Douglas et al., 2016, p. 3). Counselling Psychology is situated within the helping professions and in order to 'help' it is necessary to understand what helping *is*, how it is we determine *what* people need and *how* to go about helping them best. During this process we draw on the subjective experiences of the individual, the values, processes and meanings they bring. There is an inherent dialectical nature of the duality of these processes and the process of therapy is constantly evolving and changing as new understandings and meanings are developed. As a Counselling Psychologist practitioner my role involves being both a reflective and scientist practitioner, moving between worlds of scientific psychological knowledge and philosophical theories, practicing integration through drawing on a range of theoretical models and applying integrated practice in a reasoned way while simultaneously holding space for connectedness and experiences outside of or round the edges of theoretical models.

Throughout my doctoral training I have developed a sense of myself as thinking more dialectically about emotional difficulties, able to hold multiple realities, which, although feelings and thoughts and beliefs can contradict each other, all can be accurate portrayals of experience located within the same individual.

Within this study, the aim is to provide in-depth insight into the ways in which living with visible difference is experienced for women, allowing experiences to be represented as they are. I believe that the breadth of psychological concerns which have been researched in relation to CL/P, and which will be discussed within the literature review, demonstrate the need for a greater understanding of any and all social and psychological concerns.

1.4 Critical Literature Review

1.4.1 Introduction

In conducting this literature review I used the City, University of London Moodle library to gain access to a wide range of research literature. A literature search using the search term “cleft lip and palate” brought interesting results in terms of the different fields in which research has been conducted. The largest disciplines in terms of research located within journal articles are medicine (16,642 results) and dentistry (6,280). When the search terms were filtered to include only psychology research, 482 papers were available. Many of these are researching children and families. Other search terms, for example, “visible difference” and “congenital defects” also yielded relevant papers and it took time to explore and extract relevant papers for the purposes of this research.

1.4.2 Overview

A review of the literature on the psychological aspects of CL/P highlights an association with a number of potential psychological and psychosocial concerns but it also highlights numerous gaps in research, contradictory findings and methodological challenges.

Roberts, Neate and Gierasch (2016) conducted a study on external and internal perceptions of visible difference. Previous findings within this field suggest that while explicit (overt) attitudes towards those with a visible difference are positive, implicit (internal, personal) attitudes are likely to be negative. They found in contrast that no negative implicit attitudes were identified in a sample of 129 adult respondents. They concluded by suggesting that implicit attitudes and behaviours towards visible difference may in fact be a result of uncertainty about how to behave. If this is so, then information and education would play a vital role in increasing certainty and influencing implicit attitudes, meaning that a greater understanding may allow something positive to come from the research. These negative implicit findings further justify the rationale for this research.

In a systematic review of 64 articles, Hunt et al. (2005) concluded that the majority of individuals with CL/P do not experience major psychosocial problems; however, they identified a number of specific problems found in children and adults with CL/P. They

state that “for every study reporting psychosocial problems among those with CL/P, there are others which refute this finding” (p.282) and “further research is needed in all areas of psychosocial functioning” (p. 282).

Psychological concerns that Hunt et al (2005) reviewed include *social problems* (Peter & Chinsky, 1974; Turner, Rumsey & Sandy, 1998), *facial satisfaction* (Marcusson, List, Paulin & Akerlind, 2001), *behavioural problems* (Richman & Millard, 1997), *anxiety and depression* (Ramstad, Otten & Shaw, 1995), *family dynamics, education and vocation* (Turner, Rumsey & Sandy (1998), *attachment, self-concept and interpersonal problems* (Hunt, Burden, Hepper & Johnston, 2005). CL/P has also been indicated in a single study to be a risk factor for suicide (Christensen, Juel, Herskind & Murray, 2004).

In 2016, Stock & Feragen conducted a narrative review of literature from 2004 – 2015 and concluded that, in line with Hunt et al. (2005), that the overall the impact of cleft lip and palate on psychological adjustment appears to be low. However, when the research is examined in more detail, again it is found that there are numerous contradictory findings as well as methodological challenges which make it very challenging to draw conclusions and they note that findings remain largely inconclusive, requiring further investigation. These findings are discussed in section 1.4.7.

The research literature has been fascinating to explore. During the process of conducting the literature review I contacted my childhood hospital and was able to order old paper copies of my medical history from birth which was an emotive experience. I decided to do this because the literature awakened a curiosity in me to consider my own CL/P and my experiences. It felt like the first time I had thought about CL/P in a broader sense, outside of myself and I felt a desire to retrace my own life story so that I could assess it against the literature. It felt helpful to order my medical records in case they contained details I did not know. The records contain brief, factual accounts and do not hold the richness and broadness of the many experiences I connect together in my own narrative. Nonetheless, they helped me to construct parts of my early medical history and gave me a timeline that helped me to interact with the literature from both a researcher and a knowing researcher perspective.

1.4.3 Research findings on psychological problems in children and adults with CL/P

While my research is interested in developing more understanding of adult experiences, I have elected where relevant to include children in the literature review because participants will be reflecting on their experiences across their lifetimes and childhood is of critical importance within this subject area since individuals are born with cleft lip and palate. I feel it is important to note that memories are subjective so accuracy of memory of earlier life events cannot be assumed, however in terms of exploring the meanings of experiences for individuals; memories may offer rich sources of material.

Noar (1991) conducted a postal questionnaire survey on 32 patients aged 16-25 and their parents to explore attitudes and concerns about their treatment. The research used closed questions to determine satisfaction on 4 variables; treatment aspects, facial appearance and speech, social and emotional aspects and the perceived success of the specialists. Noar found that patients themselves did not report significant emotional maladjustment but individuals' parents believed that their child had in fact been socially and emotionally affected. A commentary from Professor Clifford (Cleft Palate-Craniofacial Journal, July 1991) notes that the results of the study are largely pleasing, but he cautioned on the effects of closed question formation on shaping responses and the desire to give positive responses. He noted that research in this field has rarely explored patient dissatisfaction and tends to measure satisfaction in a simplistic rather than multidimensional way which could contribute to responses that are difficult to interpret.

Turner, Rumsey & Sandy (1998) discuss associated psychological difficulties with CL/P. They pointed out that, at the time of writing, only 20 per cent of cleft teams world-wide carry out psychological assessments on patients and suggest that the prevalence of psychological problems is likely to be higher than the literature suggests due to this disparity. They also describe the challenge of psychometric testing in making subjective experiences of CL/P objective because of their subjective nature. I have included this older finding here because this challenge is a theme I became familiar with throughout my review of the literature. I was unable to find more recent data on the percentages of psychological assessments carried out by cleft teams, but as cleft teams

only emerged in the UK in the mid 1990's I cannot assume the figure quoted here remains accurate.

It is helpful to note here the history of the introduction of psychologists to cleft teams in the UK. Following a report from the Clinical Standards Advisory Group (CSAG) in 1998, cleft care was significantly reorganised (Sandy et al., 1998). The paper recommended centralisation of cleft services and the introduction of psychologists to such services. Prior to this there were no standardized treatment protocols across teams and no psychological input was routinely offered. Service changes recommended in CSAG were implemented in the early 2000's, although some teams were not fully centralised until 2007 and 2-3 teams are still without regular psychology input today (Scott et al., 2014). This suggests that adult individuals' experiences of CL/P treatment may vary widely depending on the age of the individual.

Recently, Stock & Anwar (2018) conducted thematic analysis on qualitative data extracted from two previous larger studies (n = 16 participants) to explore the views of adult 'returners' who have experienced both pre and post centralisation treatment. Involvement in treatment decisions, integration of psychological support, opportunities to engage in peer support and improved standards of care were all shown to have improved patient coping abilities. These findings indicate that centralisation of cleft services has greatly enhanced patient experience across multiple domains. It will be interesting to reflect on the breadth of experiences reported by participants based on their CL/P treatment in this research.

1.4.4 First Review of the Literature – Hunt, Burden, Hepper & Johnston (2005)

Hunt, Burden, Hepper & Johnston (2005) conducted a systematic review of 64 studies (selected from 652 abstracts from data searches) using keywords to identify studies which examined the psychosocial impact of CL/P on children and adults with CL/P. The studies were cross-sectional, longitudinal or retrospective. Most involved the use of questionnaires by means of data-collection. Hunt et al. explained they elected to use a narrative approach to report the findings because the original study methodologies lacked homogeneity therefore it was not possible to apply a traditional systematic review. Neither was it possible to conduct a meta-analysis due to the lack of similarity

in the populations studied or the measurements used. They describe their significant findings to date:

Psychological functioning, personality and psychosocial adjustment – children with CL/P were found to have a more external locus of control; in other words, beliefs that life is determined by external factors such as other people, luck, fate etc. (Brantley and Clifford, 1979b). An external locus of control is associated with poorer levels of mental health. Tyl et al., (1990) found that children with CL/P are significantly more sensitive to social environments, experience higher levels of hostility, more negative self-worth, more negative outlook and a greater dependence on others. Children with CL/P experience that their parents have more negative feelings and worry more (Kasuya, Sawaki, Ohno & Ueda, 2000) and adolescents with CL/P report a lower degree of perceived parental acceptance (Brantley and Clifford, 1979b). The literature does not refer to research on adults with CL/P in this domain.

Self-concept (including self-esteem and self-confidence) – findings on self-concept appear mixed. Although some studies report good levels of self-concept amongst children with CL/P, other studies report children may have lower personal and social self-concept scores than control groups (Broder & Strauss, 1989). As with other findings in the literature, it may be that specific concerns need to be identified, in this case to do with an individuals' opinion of their facial appearance. Starr (1978) found that children who are more accepting of their cleft tended to have higher levels of self-esteem. Across the age ranges Noar (1991) and Turner et al. (1997) have found that children, adolescents and adults have all reported their self-confidence has been affected by having CL/P.

Body image and satisfaction with facial appearance – these findings indicate that while children and adults appear to report not having concerns to do with overall body image, specific features, in particular the nose and teeth are reported to be considered less than satisfactory (Tyl et al., 1990). A visible scar is reported overall to be the most concerning aspect of body image; Bernstein and Kapp (1981) report that this is the case even if speech and hearing problems are also present. Additionally, as with Turner, Thomas, Dowell, Rumsey & Sandy's (1997) findings on the disparity between child and parent reports, other studies have found little agreement about satisfaction with facial

appearance between children with CL/P and parents (Thomas et al, 1997; Slifer et al. (2003).

Satisfaction with speech – Noar *(1991)* reports few self-perceived problems with speech in adolescents and young adults. None of the literature records perceptions of children on their speech, in spite of young childhood being the most likely time for speech interventions associated with CL/P (NHS, 2016). Chapman, Graham, Gooch & Visconti (1998) found that children with CL/P have poorer conversational skills compared with controls. Richman (1997), in a longitudinal study, found that children who have fewer speech problems also showed increased levels of internalising behaviours (negative behaviours including fearfulness, social withdrawal, and somatic complaints) which could suggest a vulnerability to internalising behaviours generated by another aspect of CL/P.

Social functioning. Noar (1992) records the views of professionals who are involved in the care of patients with CL/P and reports feeling that many individuals are affected socially as a result of CL/P. Adults with CL/P similarly self-report a number of social problems. Peter & Chinsky (1975) found that individuals with CL/P are more likely to drop out of school and are less likely to be members of clubs and societies. There is also evidence to indicate individuals with CL/P are less likely to get married (McWilliams & Paradise, 1973; Broder, Smith & Strauss, 1994) and when individuals do it tends to be later in life. There is also a higher incidence of childless marriages for individuals with CL/P than without. Additionally, Noar (1991), Ramstad, Otten & Shaw (199b); Bressman, Sader, Ravens-Sieberer, Zeilhofer & Horch (1999) all found that children and young adults have fewer friends than controls without CL/P. No studies have investigated friendship rates of adults with CL/P in comparison to normal controls.

Anxiety and depression. Individuals with CL/P have been shown to suffer from anxiety and depression at twice the incidence rate when compared with individuals without CL/P (Ramstad et al., 1995b). Berk et al. (2001) found significantly more social anxiety and avoidance among individuals with CL/P than amongst their siblings and controls. When individuals with CL/P are dissatisfied with their facial appearance this is shown to increase vulnerability to depression (Marcusson, Paulin & Ostrup, 2002).

Attachment, development and learning – although several studies find few differences between children with CL/P and controls with regards to mother-child attachments, Maris, Endriga, Speltz & Jones (2000) found lower attachment security with infants at 12 months although this difference was no longer observed at 24 months.

In terms of cognitive development, a number of studies have observed differences between infants with CL/P and controls, for example delays in development were observed in babies with CL/P at 5 months (Neiman & Savage, 1997). They reported that these differences had dissipated by 36 months, apart from the area of expressive language. Other studies reported on specific learning problems at school for children with CL/P (Millard & Richman, 2001). Broder, Richman & Matheson (1998) found that one in four children with CL/P repeated a year in school.

Hunt et at. (2005) have reported on a number of specific findings. They go on to discuss some of the difficulties involved in assessing the data. They describe how, due to the large variation in study design and outcome measures it was impossible to assimilate the data using statistical techniques. The review found conflicting evidence throughout the literature making it more difficult to draw conclusions. Overall, they determined that "while the majority of children and adults with CL/P do not appear to experience major psychosocial problems, some specific problems may arise." They caution that studies to date "lack the uniformity and consistency required to adequately summarize the psychosocial problems resulting from CL/P". They additionally note a dearth of literature on the lived experiences of individuals with CL/P, stating that "the vast majority of studies do not include an interview with the affected individual" (p. 283) as well as a lack of longitudinal studies and they draw attention to the lack of non-cleft control studies available. Finally, they suggest that some individuals with CL/P and their families may do better than others due to the concept of resilience (Strauss, 2001). These conclusions strengthen the rationale for this research because this research uses in-depth interviews with participants with CL/P and invites them to report on a broad range of lived experiences across the lifespan.

I found that the theoretical concepts Hunt et al. (2005) used to group their findings together were interesting. While I found them relevant, accurate and across a necessary broad spectrum of life experiences, I felt unsure whether I was relating to these concepts because they were accurate or whether putting words and language to experiences was

reshaping my personal experiences in some way. As I worked through the literature this sense lessened in me, but I felt initially a slight sense of *loss*, as if I were being advised these areas may be relevant to me, rather than recognition of my own voice and my own perceptions. Hunt et al. do critique research findings to say that participant voices were not representative enough which I agreed with, but I generally found the organisation of experiences into categories somewhat thought provoking and I felt some resistance when processing these. Reflecting on this further, perhaps what I felt was an overall *newness* in exploring the literature, as this research was not available while I was growing up. I had been familiar with drawing on my own experiences as evidence, because other evidence had not been available to me. In particular, *social functioning* and *attachment, development and learning* were new concepts for me in relation to CL/P and I felt the research literature invited me to consider my own relationship to these domains.

1.4.5 Qualitative research

Within the research literature there is a comparatively small amount of qualitative research, which is reviewed further in section 1.4.7. Two studies have explored the lived experiences of individuals with CL/P in a way which feels especially relevant and meaningful to the rationale for this research and are explored further here.

Stock, Feragen & Rumsey (2015) carried out qualitative research into the psychological adjustment and support needs of adults born with CL/P. Stock et al (2015) conducted telephone interviews with 52 participants, eliciting qualitative data. Five themes emerged from the research. They describe the effects of additional surgery as an adult, social and romantic relationships, higher education, vocational achievement and access to psychological support. They also draw attention to the heritability of CL/P, describing that 1 in 3 participants with children also had a child with CL/P, but that most had been unprepared for this possibility having not previously been informed of heritability. They conclude that adults with CL/P may require psychological support, information about the heritability of cleft, advice on signposting and further treatment and the opportunity to take part in research and activities. They also identify that further research is needed to identify factors that contribute to emotional distress and factors that contribute to resilience and to be mindful of the timing of key risk points e.g. having children as well as opportunities for personal growth. I found this research

especially helpful because it was able to define a number of practical ideas for support, perhaps by focusing on adult's present concerns this enabled the focus to remain contained.

Additionally, Stock, Feragen & Rumsey (2016) conducted a thematic analysis on the experiences of 52 adults growing up with CL/P. Factors and processes relating to psychological adjustment were explored. They identified three main themes: background factors, external factors and internal psychological factors, each of which contained a broad range of sub-factors within. They concluded that psychological input in the field of CL/P is hugely important given the breadth and number of factors identified. In particular, they recommend that appearance-related concerns, designing educational materials, supporting decision-making, improving social interaction and providing specialist support are all areas where psychology interventions are needed. They note that "the question of why some individuals struggle with the challenges of CL/P while others cope well sits at the core of psychological research in this field", p. 222-223.

These studies highlight the need for further psychological research to draw on the breadth of potential psychological concerns for individuals with CL/P and better understand the mechanisms for coping which contribute to contradictory findings within the literature to date.

1.4.6 Reflections on appearance concerns

One consideration I have had is about access to information for people with CL/P. Through my experience of conducting this literature review I became aware of potential issues which could be medically relevant and meaningful for me, but which I would otherwise not have been aware of. I must acknowledge that I have not tried to gain access to cleft services for many years but nonetheless, advances in treatments available have been made that are relevant and helpful to me but were only discovered after conducting this research. I have wondered whether, in the history of cleft care services, if there has been an oversight in thinking about associated concerns and difficulties as they may still relate to adults with CL/P. I have wondered why those who may be affected have not been made aware of these changes. Speaking only of my experience, I was able to access adult care support once I was made aware it existed and even then, I

needed to make three visits to my GP to request a referral into a cleft team, finally taking printed notes on what cleft teams are on my third visit, before being referred to the right service.

An individual cannot access support if they are unaware it exists. These thoughts made me reflect on which professions conduct research and who it is commissioned by. I thought about the roles of the NHS and the government within research. As mentioned earlier, a City, University of London online library literature search on 'cleft lip and palate' showed the majority of articles were within the medical and dental fields with comparatively few within psychology. Psychological concerns associated with cleft lip and palate therefore seem somewhat overlooked. I considered other forms of visible difference and explored literature pertaining to birthmarks, clubfoot, wearing glasses or braces in childhood but could not find any literature to indicate that the challenges of other visible differences have been overcome. Masnari et al (2013) in a study on children and adolescents with visible difference found that experiences of stigmatization act as predictors for psychological adjustment and quality of life with poorer outcomes reported as a result of greater experiences of stigmatisation, indicating there is still some way to go in tackling stigma and associated difficulties around visible difference.

Accessing information has become easier as a result of charities such as CLAPA, The Centre for Appearance Research and Changing Faces; a UK-based charity which supports children and adults with visible difference to the face, hands or body. Changing Faces were featured in the media on the Telegraph website (Telegraph, 2014) with personal stories shared by individuals with visible differences including facial birthmarks and facial palsy. A number of themes are discussed, including the theme of stigma which is linked to societal ideals of physical appearances. The concept of "lookism" (Etcoff, 1999) is explored; a cultural setting-up of ideals, suggesting that appropriate physical ideals are given which people are then expected to live up to, with negative consequences for those who cannot meet them and, as with other isms such as sexism and racism, it "is hugely damaging and pervasive" to individuals who do not live up to ideals. The article also discusses analysis conducted by Wardle & Boyce (2009) in which 9000 hours of television was analysed to identify how visible difference is portrayed. It was found that "disfigurement is repeatedly linked to evil, reclusiveness and bitterness" when portrayed on television.

Stock (2016) discusses societal focuses on appearance, happiness and success in her paper on the impact of trying to measure up to unrealistic beauty ideals. She notes that, as a consequence of more extreme preoccupations with appearance, dissatisfaction about appearance has become normalised across the general population with at least 61-82% of adult men and women having significant concerns about their appearance (Liossi, 2003). Stock also discussed the role of the media in fuelling unhelpful and unrealistic beliefs about appearance, including the suggested belief that 'what is beautiful is good'. Stock reports that the determinant of negative affect such as low self-esteem is more closely linked with a preoccupation about appearance rather than the presence of a visible difference itself. She concludes that progressively high standards are rapidly becoming unattainable for all in society and attempts to meet these high standards carry risks of heightened emotional distress, for example, surgical interventions to 'fix' appearance. Such a disproportionate focus on external appearances may also detract from considerations about what makes humans most happy and connected.

CL/P is discussed briefly in literature on body dysmorphic disorder (BDD) in discussions around the similarities between the cognitive processes of individuals with BDD and with individuals with disfigurements regarding the visibility of the problem area. Phillips (2005) notes that people with severe BDD experience similar feelings, fears, behaviours and isolation as observed in severely disfigured individuals because of their strong beliefs about how others react to them. This led me to reflect on the role of the brain and on phantom limb research (first described by Weir Mitchell over a century ago) and what implications it might have post-surgery for individuals with CL/P and how they perceive differences to their appearance. I have not been able to ascertain whether this is explored within medical literature, but it was interesting to me to consider whether individuals with CL/P perceive their appearance differently and negatively to observers and if so, whether this might be explained by BDD or by the brain not having caught up with physical changes from operations which means that the individual can't see those changes in themselves.

Harcourt et al (2018) surveyed 116 psychosocial specialists from 15 European countries to learn about interventions available for individuals negatively affected by CL/P. They found specialists were most likely to prioritise Cognitive-Behavioural approaches although a wide range of approaches and interventions were also offered. Variations in

the availability of support and a need for improved access to psychological interventions were observed, as well as additional training needs, including a greater awareness of psychosocial issues around visible differences.

I wondered whether an assessment tool could be developed which includes questions across all domains where psychological issues relating to CL/P have been identified even when findings are not conclusive. Such a tool may then serve to act as a guide in helping therapists to pay attention to a broad spectrum.

1.4.7 Reflections on experiences of marginalization

Although literature in the field discusses 'marginalized groups' I think it is helpful to consider that this does not mean that individuals have been part of a 'group experience' of living with CL/P. The charity Cleft Lip and Palate Association (CLAPA) has a feature that allows affected children and their families to contact other affected individuals. CLAPA became a national charity in 1995, beginning as a small volunteer-based partnership in 1979 so adults with CL/P may be less aware of its existence. I first became aware of CLAPA by chance as an adult, when I spotted a London marathon runner with the logo on their shirt and looked up CLAPA out of curiosity. Given the prevalence of CL/P, unless interventions are in place to allow individuals to meet and physically be part of a group, it may be reasonable to assume that individuals with CL/P do not have a strong experience of being part of a 'group' within wider society.

It is helpful to consider the role of stigma when reflecting on marginalised groups. The dictionary definition of stigma is that of a strong feeling of disapproval that most people have about an occurrence. People are influenced by social norms, which are informal understandings that govern behaviour within society. Social attitudes have been shown to have changed in relation to CL/P through artwork depicting CL/P throughout the ages (Saman et al, 2010). This suggests that changes in instances of stigma and discrimination regarding CL/P have also occurred. Saman et al. (2010) give a fascinating account of depictions of CL/P in the middle-ages across English, Korean and Indonesian artworks including paintings and pottery, which depict unflattering and stigmatising images of people with CL/P. In today's society, physical representations of what is 'good' and "attractive" are depicted and reinforced in forms of art media e.g. films, and advertising. Social media also has a large role to play in defining societal

norms. Thus, barriers in media representations can act to marginalise those perceived as different. Saman et al. (2010) state, "in order to more equally include individuals born with CL/P in society, it is important to represent them equally in […] media".

Pausch et al. (2016) conducted a study to analyse reactions of a panel of adults without CL/P when observing images of individuals with CL/P to discover whether attitudes towards CL/P have changed. Using polarity profiles which have been used since 1973 to measure social distance in regard to people with CL/P, they found that although rehabilitation of CL/P is much better than it was 40 years ago, social distance remains a problem in society. Specifically, they found that life situations which require greater emotional proximity e.g. marriage continue to cause concerns.

I found that a review of popular culture, as depicted in film, TV and books, tends on the whole to offer little by way of drawing helpful attention to the condition. A recent example is Disney's (2013) film "The Lone Ranger" in which the villain is depicted with a cleft lip because, according to promotional material," [the villain] is a ruthless outlaw whose terribly scarred face is a perfect reflection of the bottomless pit that passes for his soul." This depiction feels instantaneously exposing, threatening and shaming to me. I feel 'othered' and stigmatised. Stigma around cleft lip and palate is explored in the literature. Bull (1990) describes that unfavourable social responses e.g. overt teasing, bullying, unwanted questioning or subtle changes in normal patterns of interaction including facial expression, e.g. closed, negative or hostile, can all be the result of stigma. As well as conclusions that can be drawn about stigma and reduced feelings of self-worth in an individual, Bull observes that individuals with CL/P do predict and notice social rejection from others. Turner et al. (1997) state that "stigma is a problem for cleft affected individuals. For example, fewer social activities are undertaken by CL/P affected individuals and they are judged to be less intelligent and less social than other people." (p. 1).

Individuals with a facial deformity tend to be stigmatised due to negative stereotypes held about them (Edwards & Watson, 1980). Crocker & Major (1989) discuss self-esteem and the self-protective properties of stigma for individuals deemed to be part of marginalised groups. They propose that members of stigmatized groups may attribute negative feedback to prejudice against their group rather than themselves as individuals; compare their outcomes with those within their group rather than with an outside, more

advantaged group and they may also choose to devalue dimensions on which their group is perceived poorly and value dimensions on which their group excels.

In contrast, social media can offer a supportive space for individuals with CL/P. Stock, Martindale & Cunniffe (2018) carried out a content analysis and online survey of two CL/P groups on the social networking site Facebook. They found that key areas of discussion for adults with CL/P were expectations, experiences and outcomes of further treatment. Advantages of online groups included connecting with others, learning about local events and being able to give and receive emotional support. There were associated disadvantages which included access to opinions rather than facts and frequent use of inappropriate terminology however these are health-related information concerns. Peer support appears to be a valuable positive benefit of such online groups.

Crocker & Major (1989) explain that while theories have predicted a correlation between stigmatised groups and low self-esteem this has not been supported in empirical research. They propose a number of theories to explain their findings: they summarised that stigmatised groups may attribute stigma to the group rather than themselves individually; that peer comparison may be used within a stigmatised group rather than in comparison to the wider group; that any dimension the stigmatised group is judged negatively on is devalued by the stigmatised group and therefore not valued while other dimensions the group do better on are held in higher value.

The literature presented here indicates that individuals with CL/P can be exposed to stigmatising experiences which increases the risk of a psychological impact on individuals, which further demonstrates why understanding lived experiences of CL/P is an important area for research.

1.4.8 Second Review of the Literature – Stock and Feragen (2016)

A comprehensive narrative review of literature pertaining to cleft lip and / or palate was carried out by Stock & Feragen (2016), published only months after my decision to embark on my research project. The review was of 128 quantitative studies and 20 qualitative studies between 2004 and 2015. This review was an extremely interesting and helpful follow-on from Hunt et al.'s (2005) review, which I had read in preparation for an earlier draft of my literature review and I felt that the two papers together told a

detailed and comprehensive 'story' of the history of research into CL/P over the past few decades, containing the associated challenges with gaining knowledge and understanding about the phenomena being researched. This review, together with Hunt et al.'s review, mean that literature on concerns relating to CL/P cover published research over a time frame ranging from 1966 to 2015.

Stock & Feragen organised their findings into five key domains and further data pertaining to general wellbeing was also discussed. They ultimately concluded that, in line with Hunt et al.'s findings, "overall impact of CL/P on psychological adjustment appears to be low" (p. 777) but that research findings point to complexity within and across domains and that methodological challenges reoccur throughout the literature. They suggested that large samples which are comparable across studies and including greater participant perspective are needed to generate conclusive results.

To better understand the complexity of research findings, it is helpful to describe Stock & Feragens' work under their chosen domains of adjustment which they explained were guided by recent literature (e.g. Feragen et al, 2015). Findings of each article are thus categorized according to Developmental Trajectory; Behaviour, Emotional Well-being, Social Experiences and Satisfaction with Appearance and Treatment. It is not possible to present all findings here in detail due to the volume of material included within the review and word restrictions for this project, so I have presented sub-categories which demonstrate a rationale for the need for further research into the subject areas.

Developmental trajectory explores research within the following sub-categories (p. 780-784); general health, associated conditions, neurological aspects, cognitive development and language, educational experiences and employment.

I will explore *educational experiences* findings here. Studies found conflicting results. While two studies (Knight et al., 2015 and Wehby, Collett et al., 2014) found individuals with CL/P have lower educational achievements than individuals without CL/P and increased academic difficulties (Persson, Becker & Svensson, 2012), incongruously, three other studies found no significant differences in educational achievement between individuals with or without CL/P (Cheung, Loh & Ho, 2007; Collett et al., 2014; van der Plas et al., 2012).

Five studies showed young people with CL/P were more likely to access special education (Collett et al., 2010; Damiano et al., 2006, Hentges et al., 2011; Wehby, Collett et al., 2014) and this was especially the case with cleft palate (Collett et al., 2010, 2014; Damanio et al., 20016) and hearing difficulties (Tierney et al., 2015).

Two qualitative studies showed that hearing difficulties and ear infections impacted on development at school (Stock et al., 2016; Tierney et al., 2015). It was also identified that children with CL/P miss school more frequently than their counterparts without CL/P in three studies (Chimruang et al., 2011; Knight et al., 2015; Lorot-Marchand et al., 2015). Another qualitative study found a lack of support and understanding from teachers (Stock, Feragen et al., 2016).

Finally, while studies found no difference in self-reports of competence at school across individuals with or without a CL/P (Gkantidis, Papamanou, Karamolegkou & Dorotheou, 2016; Gussy & Kilpatrick, 2006; Oosterkamp et al., 2007; Stock, Feragen & Rumsey, 2015) another showed that young people with CL/P's perceptions of school were less favourable than their peers (Aravena, Gonzalez, Oyarzun & Coronado, 2016) and another found that individuals with CL/P reported having to work harder to demonstrate their abilities than their peer group (Stock, Feragen et al., 2015).

These findings demonstrate mixed, inconsistent findings in which it not possible to ascertain what the most pertinent areas of concern might be while simultaneously suggesting that concerns across a broad spectrum may be present.

Emotional wellbeing explores research in sub-categories (p.785-787) of psychiatric conditions, emotional functioning, self-concept and self-esteem. I have chosen to focus on *self-concept* here but think it is useful to note that similarities are apparent across the sub-themes of emotional functioning and self-esteem and the previous sub-theme of internalising behaviours in girls. Self-concept research shows interesting variations. While one study found no significant differences between individuals with and without CL/P (Boes et al., 2007), three studies found that individuals with CL/P scored better than controls in relation to self-image (Aravena et al., 2016; Gussy & Kilpatrick, 2006 and Pisula, Lukowska & Fudalej, 2014) while another study found individuals with CL/P to scored worse on self-concept than controls (Tiemens, Nicholas & Forrest, 2013). It is difficult to decipher what these conflicting results mean. I wondered whether

individuals in the three studies who scored better on self-image may have come into contact with research through being in contact with cleft teams and support services or whether individuals may have scored better to deflect attention or whether these findings point to a form of coping or resilience by identifying positive attributes to CL/P and / or from strong family support.

Social experiences explores research under sub-categories (p.787-792) of parent-child relationships, social functioning, communication difficulties, social reactions to CL/P, reports of teasing, social acceptance and romantic relationships. A broad range of literature is reviewed here which, again, offers conflicting and inconclusive findings.

Research on *social acceptance* highlighted that individuals with CL/P reported no concept of themselves as different until late childhood (Chetpakdeechit et al., 2009). It was commonly reported by individuals and parents that unwanted attention such as staring, comments and questions and perceived stigma were common (Alansari, Bedos & Allison, 2014; Chetpakdeechit et al., 2009; Tiemens et al., 2013). Tiemens et al. (2013) and Havstam, Laakso & Ringsberg, (2011) found in qualitative studies that there was a tension between individuals wanting to feel good about their difference while also wanting to feel normal and accepted. Stock, Feragen et al., (2016) also found a spectrum of responses to individuals' perceptions of being different, with some individuals with CL/P not feeling different, to seeing themselves as different either in a positive or negative way. They also found varied responses in terms of the perceived visibility of CL/P, with some individuals reporting they did not feel their cleft was very noticeable to others and others reporting they felt their CL/P was noticeable and made them stand out, and again this was seen in both a positive and a negative way. Another tension was observed by Hamlet & Harcourt (2015) in a study with older adults who reported that while they did not want to be noticed for their CL/P, neither did they want to be ignored because of their age.

Slifer et al., (2004) found that when social acceptance was perceived to be lower, this was associated with greater avoidance of gaze and more unassertive patterns of social behaviour, however, interestingly, Slifer et al.'s (2006) later study found no differences in perceived social acceptance scores between individuals with and without CL/P. This appears to suggest that such behaviours are common across people when perceiving they are socially excluded.

Finally, Hamlet & Harcourt (2015) found that feelings of social isolation were common. While I find it interesting to consider the different ways in which difficulties have been identified within social acceptance, it is difficult to draw conclusions because findings are again, conflicting. Methodologies vary, with some studies using qualitative and others using quantitative methods which makes it difficult to compare studies.

I have reflected at length on the concept of social acceptance and feel it is intrinsically linked to self-concept, although both can impact, whether positively or negatively, on each other. For instance, an individual with a positive self-concept may interpret social experiences in a different way to an individual with a negative self-concept and at the same time, positive or negative social experiences could confirm or challenge self-concept over time. These, along with multiple other variables which characterise lived experiences over time, make the experience of understanding concerns relating to CL/P difficult to pinpoint and draw conclusions about.

Finally, *Satisfaction with appearance and treatment* explores research within sub-categories (p.792-797) of patient and parent satisfaction with appearance, perceptions of appearance among professionals and laypersons, objective assessment of aesthetics, satisfaction with function, motivations for surgical intervention, experiences of treatment and satisfaction following medical interventions and timing of surgery. Again, there is an overlap across sub-categories between perceptions of appearance and the previous sub-category social acceptance.

Studies on *experiences of treatment* produced fewer conflicting results. Individuals reported feeling nervous, intimidated and sometimes frightened of treatment in eight studies (Bos & Prahl, 2011; Dogan, Serin, Uzel & Seydaoglu, 2013; Hall et al., 2012; Krikken et al., 2015; Luoto, Lahti, Nevanpera, Tolvanen & Locker, 2008; Noor & Musa, 2006; Tierney et al., 2015; Vogels, Aartman & Veerkamp, 2011). Anxiety was found to be highest in younger children aged four to six years (Vogels et al., 2011).

There were some variations when discussing liaison and treatment with consultants, with some individuals reporting feeling more confident (Hall et al., 2012; Noor & Musa, 2006) while others found the experience difficult (Hall et al., 2012) and there

were some reported challenges in understanding clinical information (Noor & Musa, 2006).

Experiences of treatment were likened to a "process" (Alansari et al., 2014; Gkantidis et al., 2013; Hall et al., 2013) within which improvements from the point of referral onwards were recommended (Augsornwan et al., 2011; Hamlet & Harcourt, 2015; Stock & Rumsey, 2015; Stock et al., 2015). It was also found that individuals who experienced fear reported that they used more coping skills (Vogels et al., 2011).

Conflicting information was found with regards to the number of surgeries, with one study indicating that more surgeries were associated with higher symptoms of anxiety, depression and somatic symptoms (Wehby et al., 2012) while in contrast a further two studies indicated that a higher number of surgeries were linked to more positive psychological outcomes (Demir et al., 2011; Luoto et al., 2008). It would be interesting to learn whether coping skills were developed based on experiences of surgeries and whether these may account for differences here. Another explanation might be that positive effects are due to habituation; which is also somewhat suggestive of coping or overcoming a challenge.

Stock & Feragen (2015) also present a separate section on general psychological wellbeing (p. 797-798), providing findings on individuals' quality of life and health-related quality of life, general adjustment and the decision to have children. The effect of CL/P on total quality of life was found to be low according to five studies (Aravena et al., 2016; Augsornwan et al., 2011; Kramer et al., 2008; Smith et al., 2014; Stock et al., 2015). Similarly, there were no significant differences found between individuals with and without CL/P in terms of overall psychological adjustment (Berger & Dalton, 2009; Smith et al., 2014).

Differences between groups were more apparent with regards to the decision about whether or not to have children. Here, one study (Yttri, Christensen, Knudson & Bille, 2011) found that childlessness was higher amongst women with CL/P compared to women without CL/P and they also found that women with CL/P who had children did so at a later age compared with women without CL/P. This finding is thought-provoking because although it is shown that quality of life and general adjustment with CL/P are not significantly different to that of the population without CL/P, women with CL/P

may nonetheless have reasons to choose not to have children. This research finding is somewhat saddening, and my thoughts are that research may be missing aspects of experience that might help to make greater sense of this finding and what it might be that women with CL/P experience that may make them less likely to go on to have children themselves. While it is the right of every woman to choose whether or not to have children, the fact that women with CL/P are less likely to have children than those without CL/P makes it important to better understand what factors make up this choice.

In reading Stock & Feragen's research I felt a little like I was also reading mental chapters in my life and comparing the two; I found myself considering each domain as it relates to myself past and present. This focused my attention from the macro to micro and back again repeatedly. I am encouraged by their report in the discussion that there has been an increase in research which includes the voice of the individual with CL/P since the time of Hunt et al.'s (2005) review, specifically as I felt I could relate to familiar voices throughout.

Of the 148 articles suitable for inclusion in Stock & Feragen's review, very few had used qualitative methods. Most studies had used quantitative validated or unvalidated measures, including questionnaires, cognitive assessments and observations. Only 16 studies had used qualitative methods, with all but two of these published in 2011 or later. I wondered whether perhaps part of what makes it difficult to draw conclusions is that there has not been enough qualitative research conducted which seeks to *understand* before looking to measure the phenomenon being researched. I also wondered about the impact of changing norms within society; one example is the fast availability of information on the internet and these ways in which modern life may make existing research 'out of date' more quickly. Part of my interest in carrying out this research is because I can access my earlier experiences (through the lens of memory) and reconceptualise them or update my thinking on them in a new way because the world has changed and is becoming less stigmatising and more open and vocal about a wide range of issues, and additionally information is more accessible.

1.4.9 Positive adjustment and resilience

A theme of positive adjustment and resilience was identified in both Hunt et al. (2005) and Stock & Feragen's (2016) reviews as an area which needs more attention within research.

Searle, Neville & Waylen (2017) conducted face to face interviews in a recent qualitative study of 15 individuals aged 17-62 born with CL/P. They challenge the theoretical concept of resilience in reference to CL/P and propose that self-determination theory instead of resilience is a better way of conceptualising how to maximise psychological growth and wellbeing in individuals with CL/P.

Searle et al. (2017) draw attention to the epistemological underpinnings of the theoretical concept of resilience and state that it does not fit because of three key factors: that resilience literature focuses on 'at risk' children; it suggests that environmental factors play an important role in the development of resilience and also that it does not pay attention to intrinsic factors, such as personality, and the role they play in adapting to challenges.

Searle et al. (2017) suggest that for individuals with CL/P, interpreting life experiences through self-determination theory, 'a broad theory of human motivation' (Silva, Marques & Texeira, 2014) which encapsulates *autonomy, competence* and *relatedness* offers a better psychological resource against damaging effects of stigmatisation. Searle at al. (2017) assert this is because it captures how the interplay between these intrinsic factors and extrinsic factors within different contexts play out. In a supportive environment, positive psychological growth and wellbeing is anticipated but in a thwarting environment, a negative impact on psychological growth and well-being may occur. By providing a more realistic and holistic world view, Searle et al. (2017) assert that research carries less risk of inadvertently condoning stigmatising experiences.

It was somewhat unsettling to discover this critique of resilience as a concept as it challenged the way I had conceptualised it. While Searle et al.'s research contains valuable and interesting accounts from participants, I found myself wondering about the duality of experience e.g. the ability of an individual to both cope and struggle at the same time. Searle et al. (2017) note that "the framing of CL/P as a 'blessing' is rarely

found in the literature", (p. 461) but I found myself questioning whether a previous lack of focus on positive experiences within literature could encourage a future focus towards the positives but potentially losing experiences which are in fact negative. I feel an acknowledging and balancing of both positive and negatives is essential. They conclude with a point I very much agree with; that "the gaze is on the response of the affected individual rather than how society responds to visible or audible differences" (p. 477). I found the idea of holding a mirror up to society in its responses to visible difference very refreshing.

The protective role of resilience in CL/P is also referenced in 1.4.5 by Stock & Feragen & Rumsey (2016); it links in with literature on stigma in 1.4.7 in demonstrating a need to better understand how society responds to visible difference and it is referenced in 1.4.8 in Stock & Feragen's (2016) review under *emotional wellbeing*. The arguments presented and inconsistent findings further highlight the need for greater clarity of understanding through further research.

1.5 Summary and revisiting the gap in the literature

As shown in the literature review, research into the psychosocial adjustment of adults with CL/P is limited and there is disparity in all areas, reinforcing the rationale for further research in this area. Many existing research findings have been shown to be contradictory and methodological limitations make it difficult to draw definitive conclusions. Research has been reviewed across quantitative and qualitative methods by both Hunt et al (2005) and Stock & Feragen (2016) across a timeframe stretching from the late 1960's to 2016 and findings have concluded that, on the one hand there is no conclusive research that living with cleft lip and palate is causing significant psychological distress or is characterised as a traumatising agent but at the same time, the literature has identified that it is a challenge and that there are issues emotionally and in other ways that can be present.

Research also tends to focus on problems with little or less attention given to explore positive attributes which may develop as a consequence of living with difference. There is a particular lack of research exploring individuals' self-perceptions and a significant lack of qualitative research, although qualitative research within the field has increased

in the last decade. Voices of participants with CL/P have been under-represented in research. Further qualitative research may be imperative in helping to draw out the complex issues that individuals with CL/P are most affected and concerned by and therefore help to inform future study.

Qualitative research is the only means to help us to understand how it is that a phenomenon can be both 'not a big deal' and 'a big deal' at the same time so it is necessary to explore this qualitatively to try to understand the meanings behind what seems to be contradictory information.

This research is seeking to respond to these challenges by exploring the meanings attributed to the experiences of participants in relation to their lived experiences of CL/P. I feel my research differs from that of other work conducted in the field in that it allows meanings given to experiences to be explored more explicitly. It is greatly hoped that the findings of this research will allow a less-heard voice to tell us "what has it been like for you, living with cleft lip and palate?" Using my own "knowing researcher" perspective will, I sincerely hope, help to shed light on these apparent contradictions and contribute further to the field. It is also hoped that the study will help inform clinical theory and practice within Counselling Psychology.

2. Methodology and Procedures

"All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless." Merleau-Ponty (1962)

2.1 Research Question and Aims

2.1.1 Research Question

How do women experience and manage living with cleft lip and palate? An IPA Study.

2.1.2 Rationale for a broader research question

IPA is interested in the detailed, flexible examination of a particular lived experience. As such, research questions are usually framed openly and broadly, although Smith et al (2009) recommend not to "expect one's research question to be on too grand a scale or too ambitious in its reach".

I talked at length with my supervisor about my research question and we considered whether or not it may be considered 'too broad', especially given that it does not specify a particular time in a participant's life and also that it implies the use of retrospective accounts because reported experiences can be from anytime in a participant's life e.g. accounts of being born and of early years or school experiences.

I felt it was difficult to narrow the research question without losing the overall aims of the research. Participants with CL/P have always had CL/P and I wanted to represent what participants reported of their experiences without directing them to a particular time frame or life event. Salmon (2002) identified that with very open research questions it can be a challenge to know whether they have been answered. Stroud (2015) conducted his doctoral thesis at City, University of London on the experiences of circumcised men and his research was one of the early inspirations for my research in my first year. In a similar way to this study, circumcision pre-dated conscious

participant experience in some cases. He was nonetheless able to use IPA to answer his research question by identifying common themes and exploring the meanings of these.

2.1.3 Research Aims

This research study is interested in exploring the subjective, phenomenological experiences of women with cleft lip and palate (CL/P). The research aims to explore subjective experiences of adult participants with CL/P selected from the general population.

During the research process, I was so struck by my own responses to the analytic work I decided to share my own personal reflexivity and therefore I weave my own personal insights throughout.

2.2 My methodological stance

2.2.1 Rationale for a Qualitative Research Approach

The primary aim of this research is to capture in-depth subjective experience, making a quantitative method inappropriate for the purposes of the research. Additionally, given the inconclusive nature of quantitative research to date in the field of CL/P, I thought that another quantitative design with a small sample size would do little to further develop understanding and a larger sample size is beyond the scope of this research.

My research is interested in an in-depth exploration of women's experience of CL/P from a phenomenological, interpretative perspective. As shown in the literature review, qualitative research into adult experiences of CL/P is limited and there was found to be disparity in all areas of quantitative research. I outlined that much of the existing literature is outdated and focusses primarily on children or parents of a child with CL/P. Additionally, research findings were shown to be contradictory and methodological limitations make it difficult to draw definitive conclusions. There is a lack of research that explores adults' self-perceptions and a significant lack of qualitative research. Existing research tends to focus on problem areas, for example psychological problems or ongoing surgery needs. Consequently, I was struck by how little attention has been

given in existing research to exploring positive attributes which may develop as a natural consequence of living with difference.

My research question is exploratory in nature making a qualitative design appropriate. Qualitative researchers are concerned with meaning. “They aim to understand ‘what it is like’ to experience particular conditions and how people manage certain situations” (Willig, 2013, p. 8). A qualitative research method fits with my role as a trainee Counselling Psychologist working in-depth in clinical practice. It also fits with a personal preference for person-centred approaches in seeking to develop knowledge and understanding of an individual’s experience. For example, I am interested in learning about individuals’ experience in a way that is non-pathologizing and is not goal focussed (Rogers, 1961). In the past, my interests lay more with quantitative methodologies. I now feel that my personal and clinical experiences have shaped my perspectives. In terms of personal ontology, I sit somewhere between realist and relativist positions.

My rationale for adopting a qualitative research paradigm is further supported by my status as a Counselling Psychology trainee. Qualitative research fits with many of the characteristics of Counselling Psychology. Cooper & McLeod (2007, p. 136) define pluralism as “an ethical and political commitment to respecting, valuing and being inclusive towards otherness.” McAteer (2010) identifies that pluralistic epistemology is ‘at the core of Counselling Psychology’. Kasket (2013) describes that the profession of Counselling Psychology regards all individuals as “inevitably subjective” (p. 7) and Orlans & van Scoyoc (2008) identify that an awareness of subjectivity lies at the heart of Counselling Psychology practice. Kasket (2013) notes that researchers can aim to translate subjectivity into an awareness of the research process and the relationship with participants through the process of ongoing reflexivity. Henton (2016) identifies other characteristics of Counselling Psychology, including an exploration of depth and a “between-ness”, conceptualised as an openness to possibility and uncertainty. Rafalin (2010, p. 41) stated of the Counselling Psychology profession that “in homage to its humanistic roots, Counselling Psychology values a search for understanding, rather than demanding universal truths.”

A further rationale for adopting a qualitative research method is that it fits with my epistemological position which is enhanced by my therapeutic practice experience of

relating to clients at interpersonal depth and supports my personal valuing of in-depth reflection and understanding of experiences.

Kaskett (2012, p. 65) further describes counselling psychology research as "a particularly honest, realistic, pluralistically orientated member of the family of applied psychologies, in that it is willing to expand its horizons to accommodate a plurality of view-points, a multitude of possibilities, and an infinite variety of potential 'truths'… our experience is full of paradoxes, and our selves are multifaceted. Much depends on the contexts in which we are always inescapably, relationally embedded. Much is unknown and never will be known. Very little can be reduced to bare fact or absolute certainty." Kaskett's description encapsulates what my research is hoping to achieve. Given that research findings into the psychological impact of cleft lip and palate explored in the literature review highlight complex and contradictory evidence, I felt that qualitative research is the best option for exploring participant's multiple truths. I feel this offers the highest chance of developing a greater understanding of how participants make sense of their experiences. It also allows and reflexivity to be utilised throughout the process. Additionally, I see qualitative research as an opportunity to develop and strengthen both my own self-awareness and my interpretative skills, which I regard as valuable assets going forwards as a Counselling Psychologist practitioner.

2.2.2 Epistemology and epistemological position

Ontology asks, "what exists?" The researcher must decide where to position themselves on the nature of reality, between beliefs regarding objective and subjective reality; or realism or relativism (Ponterotto, 2005). Willig (2013) illustrates that the researcher must decide what perspective on 'reality' best fits with the research question. A realist approach (ranging from naive to critical realism) seeks to produce knowledge "that captures and reflects as truthfully as possible something that is happening in the real world" (Willig, 2013, p. 15). A phenomenological approach aims to produce knowledge about subjective experiences of participants. Characteristics from the participant's world are important, for example, their thoughts and feelings, yet no links are made to possible causes. Instead, value is placed on "what it is like" to have the experience (Willig, 2013, p. 16). A social constructionist approach focusses on the ways in which participants talk about the world and their experiences without being concerned about

the true nature of events or about the quality of experiences. The focus is on "the process of how knowledge is constructed" (Willig, 2013, p. 17).

Epistemology asks, "how can I (as a researcher) know and how are things known?" I believe that what I can claim to know is an interpretative analysis of the subjective accounts of a homogeneous group of participants, producing themes that can be used to help others. I can reflect on my lived experiences both of professional life experiences as a Cognitive Behavioural Therapist and an Interpersonal Therapist prior to embarking on Counselling Psychology training and of having been born with CL/P. I am a student, a practitioner and due to my own experience of CL/P, I have 'insider knowledge' which I consider to be both my own subjective experiences related to CL/P and some knowledge of medical procedures and other related information pertaining to CL/P. My professional background in treating a wide range of emotional difficulties means I may experience and think about accounts in which difficulties relating to depressive and anxiety disorders are raised, differently to an individual without this background training. My professional background gives me access to theoretical frameworks with which to consider and conceptualise participant material and to consider material in light of existing literature. Since I am not seeking to fit participant experiences into theoretical frameworks, I am mindful that I will need to be aware of both my own assumptions and my capacity to formulate and these will need to be bracketed so that participant accounts remain central to the research.

What is most useful to me as a researcher and as a practitioner is what is useful to psychological practice within ethical and legal frameworks. I hope to use themes generated from the analysis to bring an increased awareness of the experience of CL/P and discuss how these may inform Counselling Psychology as a profession and how themes may be worked with therapeutically in practice.

The epistemological position of this research adopts an interpretivist paradigm which recognises that reality is a construct that occurs in the mind of an individual, therefore multiple and equally valid realities exist. In line with this position, the research recognises that research findings are co-constructed through interactions between individual participants and me. While the research is seeking to get close to experience, by analysing data carefully and closely, it is doing so to extract meaning from the data

which participants may not otherwise be able or willing to attribute to it (Willig, 2012, p. 13).

The research overall assumes there are truths about the lived experiences of women who were born with CL/P that can be understood (Cohen, Manion & Morrison, 2000), and places the epistemology of the research within a critical realist perspective. “The type of knowledge sought in [realist knowledge] aspires to capture and reflect as truthfully as possible something that is happening in the real world and that exists independently of the researcher’s, and indeed the research participants’, views or knowledge about it” Willig (2012, p. 4). Critical realist perspectives are situated between positivist perspectives, which assert that it is possible to accurately describe a phenomenon in order to form a ‘correct view’, and extreme relativist perspectives, which altogether reject conceptualisations of ‘truth’ or ‘knowledge’ Willig (2012, p. 4). with therapeutically in practice.

Intricacies exist around the realist – relativist continuum concerning the epistemological status of the data collected for the research. I have taken a realist perspective of participants’ accounts by taking participant descriptions of thoughts, beliefs, feelings, events and memories of events that took place in the lives of participants as true. My methods of data collection, discussed later in this chapter, seek to capture the efforts made to ensure accuracy and truthfulness of data by creating favourable, optimal conditions under which participants were interviewed.

At the same time, I am interested in the meanings that participants have constructed about the reality of having been born with CL/P over a descriptive account of the events that have occurred in their lives. I am interpreting subjective participant accounts, all of which hold meaningful similarities and differences and all of which are influenced by subjective memories across the lifespan. Additionally, an interpretative method is subjective by nature making multiple truths valid. On balance, I feel this makes the analysis more relativist in nature because I am most interested in the meanings given to individual experiences.

The epistemology of the data collection is separate to the data analysis (Willig, 2012). The analysis of the data aspires to produce valid knowledge about the lived experiences of women with CL/P and the meanings they constructed which can then be used to help

others. In this respect, the analysis adopts a realist perspective on relativist data. In the analysis, I am "holding up a mirror to accurately reflect what is going on inside the mind of the research participant" (Willig, 2012, p. 13).

2.2.3 Methodological reflexivity

While I believe that we live within a wide range of structures that are real and organised, for example, material, physical, social, economic, political and psychological, and that we can 'know' things about them; within data analysis I do not believe a single version of objective truth exists. Within clinical practice, I have often observed that what helps one person with depression may not help the next person in the same way. As a practitioner, I recognise that human experience can be complex and multi-faceted and so I value complexity as a means of deepening understanding, while respecting that it can be a challenge to accept multiple, and sometimes conflicting, accounts. Therefore, a relativist approach to my data analysis, which recognises that knowledge is a social reality which is value-laden and can only come to light through interpretation fits well with my overall stance. There appears to me to be no single reality; illustrated by the different ways that people can experience what appears to be the same, measurable, event e.g. divorce, buying a house, CL/P fits well with the critical realist epistemological position of this research. In other words, I see that reality is understood and experienced in different ways and that knowledge is regarded as relative, for example, to time, to place, to society, to culture, to gender and to the individual. In line with this position, it is recognised that research findings are co-constructed through interactions between researcher and participant (Smith et al, 2009).

In clinical work the epistemological question "how, and what, can we know? (Willig, 2013, p.4) is being inadvertently considered from the moment the clinician is aware of the client. In reflecting on my personal worldview, I recognise that my own professional experiences have shaped my perspectives. I think my relativist beliefs have developed in part as a consequence of observing a clinical culture, which has become increasingly concerned with evidence-based policy and practice (Biesta, 2007). Much research that informs clinical services adopts an empirical, quantitative viewpoint (Mullen & Streiner, 2004). While research-informed practice is vital for the profession (Health Professions Council, 2009), I believe that more political shifts towards empirical evidence-based practice may have implications for the profession of Counselling

Psychology in terms of placing less emphasis on valuing of subjective experience and meaning for individuals. Current political trends towards distinct therapies practiced in 'pure' form rather than integratively e.g. CBT Therapy, CAT Therapy, DIT Therapy all within IAPT services (NHS, 2008), may result in clinicians having less broad theoretical knowledge to draw on, which may then affect reflective capacity. Nomothetic research, e.g. in CBT, has been said to be currently dominating in the field of psychology (Gaudiano, 2008). The 'breaking down' of psychological approaches and the potential for subsequent, unintended losses particularly around clinical reflective capacity and practice sit less comfortably with my own worldview. My valuing of the subjective and of reflexivity strengthens my belief in the unique value of qualitative research experiences.

2.3 Interpretative Phenomenological Analysis

2.3.1 Choosing IPA as a research method

I am using Interpretative Phenomenological Analysis (IPA) (Smith et al, 2009) as the methodology for this research. IPA is a phenomenological method that adopts an interpretative perspective. It accepts "the impossibility of gaining direct access to research participants' life worlds" (Willig, 2013, p. 87). The theoretical underpinnings of IPA are phenomenology, hermeneutics (the study of interpretation) and idiography, a conceptualisation that is interested in 'the particular', meaning that attention is focussed on detail and a subsequent depth in analysis (Smith et. al, 2009). IPA asserts that we do not find knowledge, but rather we *construct* it. IPA is "especially interested in what happens when the everyday flow of lived experience takes on a particular significance for people" (Smith et al, 2009, p.1).

I chose IPA as a research method for several reasons. Firstly, IPA allows for richer, in-depth analysis of lived experiences of CL/P which are lacking in the present literature on CL/P. Qualitative, semi-structured interviews record participant accounts reflecting their lived experience. Secondly, IPA recognises that the researchers' own view of the world and the interaction between researcher and participant mean that participants' experience can never be entirely known. IPA is phenomenological because it "is concerned with the detailed examination of human lived experience. It aims to conduct

this examination in a way which, as far as possible, enables that experience to be expressed in its own terms, rather than according to predefined category systems." (Smith et. al, 2009, p. 32). IPA elicits an interpretation of the participant's experience; the recognition of the impact of the researcher on research is particularly important given that I was born with CL/P and IPA allows for reflections on the ways this may impact on my research findings.

Mason (1996) states of qualitative research that "the researcher should constantly take stock of their actions and their role in the research process, and subject these to the same critical scrutiny as the rest of their data" (p. 6). Reflexivity is embedded within the methodology of IPA through its commitment to interpretation.

In IPA, the researcher interprets the participants' accounts making IPA hermeneutic. Recognition of double-hermeneutics, the process by which the researcher tries to make sense of the participant trying to make sense of the phenomenon is particularly important given my personal experience of the phenomenon being studied. IPA's attention to the double-hermeneutic has allowed me the opportunity to reflect on the ways this dynamic may have impacted on the ways in which I made sense of the research findings.

2.3.2 Critiquing IPA

It seems prudent to consider ways in which my choice of IPA as a methodology may impact on the data collected and how I intend to rectify any tensions or omissions. One recognised limitation of IPA is that it can pay insufficient attention to how language can *construct* experience rather than *express* it (Willig, 2013). Since the same event can be described in a number of different ways, language can add meaning, but this does not allow 'direct access' to experience. It will be important therefore that the role that language plays in the construction of meaning is given sufficient attention and will be explicitly explored in the discussion of research findings.

A second limitation is that IPA has been criticised for not explicitly paying attention to body sensations which may also be relevant to experience. Allen-Collinson (2008) in a paper on sports and qualitative research calls for IPA to "Bring the Body Back" to IPA research. In understanding women's experiences of CL/P, I believe that body sensations

(for example possible recollections of physical pain from surgery or sensations of anxiety in social contexts) might be an important or noteworthy focus. I will reflect fully on body sensations in the construction of experience in the discussion of research findings.

Briefly, my reflections are that transparency and reflexivity are essential aspects of the research process and the limitation of IPA's attention to language and body sensations will be fully acknowledged and explored alongside discussion of what this may mean for research findings.

2.4 Consideration of alternative Research Methods

2.4.1 Thematic analysis

Initially I considered using thematic analysis, 'a method for recognising and organising patterns in content and meaning in qualitative data' (Willig, 2013, p. 57). Thematic analysis involves 'a search for themes that emerge as being important to the description of the phenomenon under investigation', Fereday & Muir-Cochrance (2006, p. 82) which was very relevant to the kinds of knowledge I hoped to produce. Nonetheless, thematic analysis is only meaningful if the researcher is clear about what identified themes represent (Willig, 2013). Given the lack of clarity in CL/P literature, at the time I was unsure whether it would be possible to gain this precision. I also considered using grounded theory, a methodology underpinned by thematic analysis which involves the construction of meaning, or new theories, through the analysis of data (Willig, 2013) but I questioned its suitability due to its systematic categorisation technique as opposed to allowing for the unfolding of social processes. After consideration I felt less concerned with producing theory and more committed to holding true to a phenomenological focus.

2.4.2 Narrative analysis

I also considered whether narrative analysis, a method which is interested in how individuals organise and therefore bring order to experience, (Willig, 2013). However, Herndl (2006) describes, the narrative connectedness can result in the painting of an

unproblematic picture. I felt this might inhibit my getting closer to participant experience and gathering the fullest description of experience.

2.5 Reflexivity

2.5.1 Personal reflexivity relating to the studied phenomenon

"A counselling psychologist who has fully engaged in reflexive activity should have a reasonably good idea of what her presuppositions are and how they may affect her research process; she might even decide that she is 'too close' to the topic" (Kasket, 2013, p. 7).

Coffey (2002) stated that "the [qualitative] researcher is simultaneously involved in autobiographical work of their own". I recognise that my role as researcher involves being continually reflexive and that participants have their own unique feelings and experiences and I need to separate these out from my own. I feel there are clear strengths to having personal experience of the topic of research, especially with in-depth research, because of a personal recognition of the depth of experience, a personal experience of a lack of knowledge and awareness within society and a strong desire to capture authentic experiences and to listen to voices that may previously not have been heard. I considered that my interactions with participants may have had a unique dynamic, in that they were talking about their experiences of CL/P with a researcher who was also born with CL/P. I am interested to reflect on whether this experience helped to facilitate authentic sharing of lived experiences or whether it was possible this may have inhibited sharing in some way and how it may have shaped the way in which experience is shared.

It is important that I acknowledge my own subjective role within the research, having been born with CL/P, and to consider ways in which my experiences and beliefs initially informed my understanding of the research.

This research is semi-autobiographical in that I am a 'knowing researcher'. The language most familiar to me from an early age about CL/P *felt* negative but there were

few negative experiences I attributed to my CL/P. I have explored my feelings in depth in personal therapy and talked with my supervisor and felt I had processed earlier feelings from my childhood. Oguntokun's (1998) paper conceptualises a "seduction of sameness", whereby despite identification with a homogenous group, individuals within the group can hold greater differences than similarities. I found this to be very thought-provoking and helpful in working through some of my earlier assumptions. I asked myself "what assumptions am I making about my participants and their experiences?" "How will I recognise if I am comparing their experiences to mine?" "How might it impact on the research if I understand their experiences as having been significantly better or worse than mine?" "What if I don't find what I think I will find?" "What if the research leads me to reappraise myself?" "What if my research question is a question for me?" Allowing myself space to reflect on these questions and to understand and process them in discussions with my supervisor and personal therapist and adapting my understanding of the research methodology gave me a sense of freedom to move beyond them while holding in mind the need for continual reflection throughout the research process. I have been in personal therapy as part of Trainee Counselling Psychology course requirements and would seek further support should any adverse effect of carrying out the research become apparent.

Doctoral research is necessitated by a "gap" in the literature and my challenge was to seek out new knowledge and understanding (Rugg & Petre, 2004). Early in the research process I recognised an analogy in the language of a "gap" with the focus of this research; which explores a phenomenon which essentially begins as "a gap" in the upper lip and in the roof of the palate in the mouth of an unborn baby. From the early stages of the research project I found searching for a gap in the literature and finding one in the 'gap' left by a cleft a powerful analogy, one which seemed to develop further later in the research process where seeking meaning and understanding of the phenomenon seemed to hold parallels with the conscious and the unconscious, what is known and meanings which are not yet apparent. From a psychoanalytic perspective, reactions to physical disability and difference can be viewed with disgust due to fear of mortality, a reaction which is not necessarily recognised consciously by the individual experiencing it (Wright, 2012). Davis (1995, p. 130) suggests "the divisions whole / incomplete, able / disabled neatly cover up the frightening writing on the wall that reminds the hallucinated whole being that its wholeness is in fact a hallucination." This

is the final observed analogy; that my interpretation seeks to discover the 'hallucination' from the 'hallucinated whole'.

2.5.2 Personal reflexivity as a 'knowing researcher'

I am 'a knowing researcher' because I was born with CL/P. I am very aware of the risk of imposing my own meaning, so I have had to be especially cautious and careful not to think I know how others with CL/P feel. Keeping a research journal has been a useful way of identifying my own predictions and reflections on transcriptions and slowing down the analysis process to ensure as best I can that I have recognised my own voice and reflected on this and extracted it. In the analysis chapter I identify and reflect on exceptions, where there are instances where what I thought was being said was challenged, which I looked for systematically and made a note of when I recognised this occurred.

2.6 Quality Markers and Evaluation

I hope that the findings of this research will enhance understanding of lived experiences of CL/P within Counselling Psychology and will positively inform both theory and clinical practice.

Quality markers for qualitative research are necessary to ensure that qualitative research is of a high standard. Yardley (2008) outlines four principles to guide quality control in qualitative research. These principles are represented in the methodology of this research in the following ways:

Sensitivity to context. I have aimed to achieve sensitivity to context through reading extensively within the relevant literature. I have joined the Cleft Lip and Palate Association (CLAPA) as a volunteer to further develop my knowledge and experience. I believe I am engaged in ongoing reflexivity about my role as a researcher and as a woman with CL/P.

Commitment and rigour. I have engaged in discussions with my research supervisor and with colleagues and attended IPA lectures and workshops. I have also engaged in a

pilot interview to practice, obtain feedback and further reflect on my interview questions and style.

Transparency and coherence. Having described my epistemological and methodological positions, below I describe my research procedures to outline the steps involved in this research.

Impact and importance. I have elected to study an area where there is little previous psychological focus; an in-depth understanding of women's experiences. The impact and importance of my research findings will be explored in the discussion section and will reflect on the relevance of findings for the field of Counselling Psychology.

2.7 Ethical Considerations

My main ethical concern was around not causing harm to participants. I was also concerned with obtaining informed consent, maintaining anonymity and emphasising the right to withdraw from the research. I carefully considered my role as researcher, which was to be neither detached nor leading, and I continually reflected on my own processes throughout the interviews.

2.7.1 Ethics Approval

The City University London Psychology Department Research Ethics Committee approved my light-touch project application on 9th Feb 2017 - ethics code PSYETH (P/L) 16/17 110. Alongside my ethics form, I submitted my risk assessment, my research flyer; a comprehensive participant information sheet; a participant consent form and a participant debrief information sheet including a list of relevant organisations and resources felt to be most pertinent to participants and a demographics sheet tailored for the purposes of my research.

2.7.2 Informed consent

Participants were invited to take part in the research once permissions were granted via the City University ethics board. No other permissions were required. There were no

known risks to participants and no disadvantages in not taking part. If participants had been unable to provide informed written consent they were to be excluded from the research.

2.7.3 Interview briefing and dissemination of research findings

Participants were briefed and given a comprehensive participant information sheet (Appendix 2) and consent form (Appendix 3) before interviews took place. The information sheet explained the reasons for the research; what would be asked of participants; what happens to information; the potential benefits of taking part; that no potential disadvantages have been identified, that they could withdraw at any time up until data analysis without penalty and how research findings are disseminated. Permissions were sought in advance from participants with regards to the dissemination of this work, for example in the form of research papers or journal articles.

Participants were made aware that a copy of my completed thesis will be available at the City, University of London library before interviews took place and they were made aware of their right to withdraw their information from the research for any reason up until the point of data analysis.

It is anticipated the research study will be published, possibly as a psychology journal article or research paper. All participant anonymity would be maintained should this be the case.

2.7.4 Confidentiality and privacy

I requested a pseudonym of participants' own choosing prior to interviews taking place for the storage of all interview data so that no data would exist which linked interview material to its author. For transparency, participants were informed prior to interviews that confidentiality could not be met should a risk of danger to a participant or others be disclosed and in the unlikely event of such information being shared with me, I would have had a duty of care to notify an appropriate professional e.g. GP. For such risk management purposes, I requested GP details from participants prior to interviews and securely disposed of this information after interviews. This was asked following the

optional demographic questionnaire however, this question was not optional, and interviews could not have gone ahead without it due to my own duty of care towards participants. In fact, all eight participants were happy to share this information, with some commenting they found it reassuring and helpful that I had considered participant welfare in this level of detail.

2.7.5 Managing distress

As the research explored experiences in-depth there was a small risk that interviews could be emotionally distressing because they involved recalling memories or exploring current difficulties, although it was anticipated this would not be to an excessive degree. A thorough post interview debrief was available after each interview and I followed up with appropriate signposting to services alongside a comprehensive written debrief information sheet with further sources of support, for example; psychological support; national charities and organisations pertinent to the area of research (see Appendix 4). The research was not perceived to be any more potentially harmful than day-to-day life experiences because the nature of the research was transparent, and no deception was involved and because participants had choice in what they shared.

2.7.6 Data storage

All information pertaining to the research has been securely locked away at my home, accessible only to me. This data has been archived in accordance with BPS and HCPC guidelines. After a timeframe of ten years (as directed by City, University of London, BPS and HCPC on storage of research data), all materials will be securely destroyed.

2.8 Methods: Data Collection

2.8.1 Sampling; inclusion and exclusion criteria

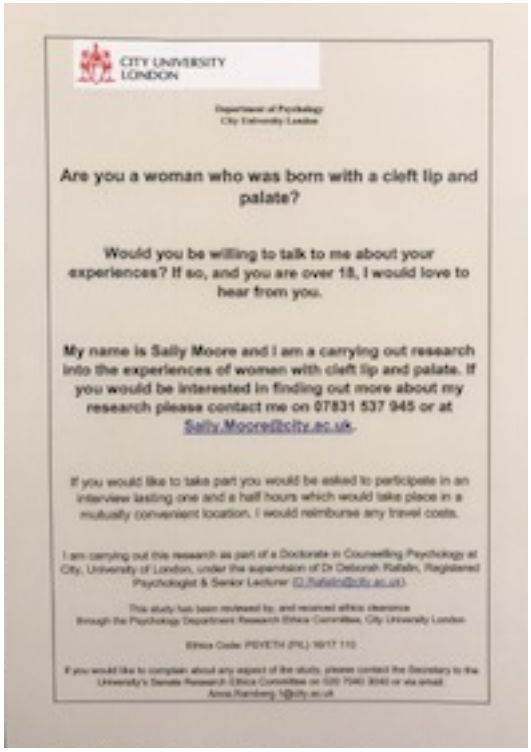
I used purposive sampling, consistent with IPA's orientation, to recruit eight women born with CL/P who wished to take part. I initially considered interviewing both men and women but anticipated that gendered constructs of beauty ideals (Forbes, Collinsworth, Jobe, Braun & Wise, 2007) might have meant that men and women have

had different experiences, and this would have impacted on the homogenous sample necessary for IPA analysis. I also considered that female beauty ideals may be a recurrent theme in research findings. While I believe that male experiences of CL/P would be a fascinating area for further research I believed it to be beyond the scope of this piece of research to have explored gendered themes in adequate depth. I excluded children under Age 18 because the research is interested in the reflective experiences of adults. I also excluded family members and friends of individuals with CL/P because the research is focused on an in-depth exploration of the direct experience of living with CL/P.

2.8.2 Recruitment

Eight adult women born with CL/P were recruited from a range of places:

- I produced a recruitment flyer (see Figure 1) which I handed out randomly to adult women in the streets at the Southbank, London and in Richmond, Surrey and at West London supermarkets and gyms to gain access to a wide range of participants from a broad population group.


CITY UNIVERSITY LONDON

Are you a woman who was born with a cleft lip and palate?

Would you be willing to talk to me about your experiences? If so, and you are over 18, I would love to hear from you.

My name is Sally Moore and I am a carrying out research into the experiences of women with cleft lip and palate. If you would be interested in finding out more about my research please contact me on 07831 537 945 or at Sally.Moore@city.ac.uk.

If you would like to take part you would be asked to participate in an interview lasting one and a half hours which would take place in a mutually convenient location. I would reimburse any travel costs.

Figure 1: Research Flyer

- I posted on a Facebook social media page named 'CLAPA Adult Voices (Cleft Lip and Palate Association – Adults)' (See Figure 2). I attached my research

flyer which included my City, University of London email address. When individuals replied requesting further information, I asked that individuals email me to avoid any group discussion to take place on Facebook. I then forwarded on my Participant Information Sheet (see Appendix 2). I felt this allowed space for individuals to learn more about my research before opting in. When individuals emailed me agreeing to take part, I held screening calls both to ensure participants met my research criteria and to risk assess. I clarified that participants were adult women who were born with cleft lip and palate. I did not receive any interest from individuals who indicated they may be vulnerable adults or experiencing mental health problems and I did not request any documentation or medical records; all of which would have had ethical implications which would have needed to be addressed. I carried out an informal risk assessment by hearing participant's motivations to take part and satisfying myself these were genuine. I then established the location of the interview and ensured I was aware of transport links. On the day of interviews, I ensured my mobile phone was fully charged and I used a 'buddy' system where I notified a colleague of my whereabouts and contacted them before and after interviews. I asked my colleague to raise the alarm in the event I were not to make contact following interviews.

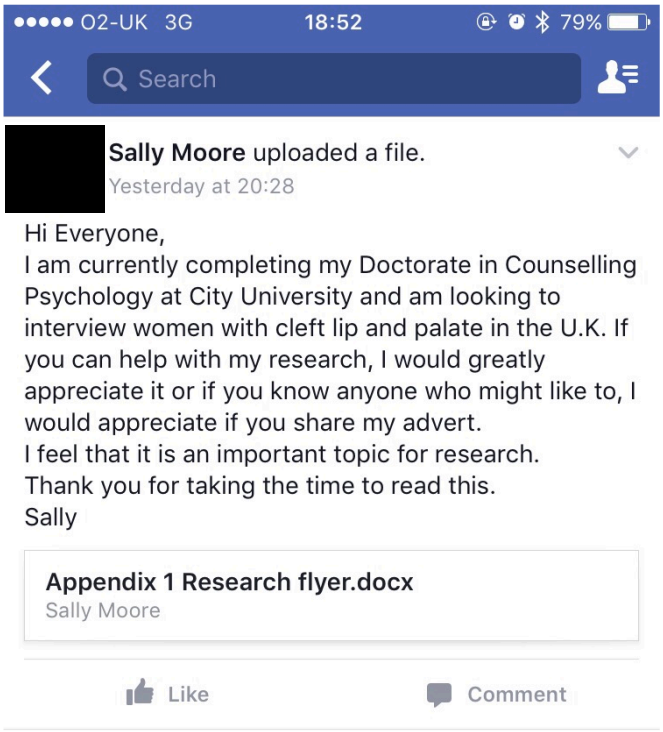


Figure 2: Advert on CLAPA Facebook page

- I approached CLAPA (Cleft Lip and Palate Association) which is the only UK-based charity for cleft-affected individuals as a volunteer, before deciding not to proceed as a volunteer at this stage due to time constraints. I attended a single training day for CLAPA volunteers and shared information on my research project, sharing my City, University of London email address

While I felt that contributions from individuals at CLAPA would be very valuable, I also felt that recruiting solely from CLAPA could potentially limit the scope for investigating broader experiences within the CL/P population. This is because assumptions might be made that CLAPA volunteers identify more openly as having CL/P suggesting they might have a greater acceptance of CL/P and any related issues than individuals with CL/P who are not affiliated with CLAPA. I was mindful of the need to recruit a homogenous sample necessary for conducting IPA research but felt confident homogeneity would be met even if experiences were broad and diverse due to the specificity of the population group being selected.

2.8.3 Pilot interviews and revised interview schedule

I carried out two pilot interviews with colleagues. The first was an opportunity for me to practice and revise asking my interview questions (see Appendix 7) as an interviewer, reflecting on my words, meanings, understanding and responsiveness. This was a positive experience although it was not possible to interview an individual with CL/P, so we picked another theme (a broken arm in childhood) and the participant asked helpful questions about the meaning of some questions which I then reflected on in supervision and changed. One initial question had been "given the choice would you have been born with or without CL/P?" which I reflected on and recognised this does not fit within an IPA study because it is a leading, closed question. I found it more difficult than anticipated to adopt a neutral interviewer stance which was a valuable learning point for me to reflect on and develop my interviewer style.

The second pilot was an opportunity for me to experience my own questions as a participant, answering my interview questions about my own experiences of CL/P. This provided a hugely valuable learning experience for me for several reasons. One reason was that it helped to develop my reflexivity and to better understand the role of the

double hermeneutic within IPA. Additionally, I was struck by how emotionally affected and exposed I felt in sharing my personal experiences of CL/P with someone. It was much more emotional and exposing than I anticipated. It highlighted to me that I have seldom spoken at length about having CL/P and had only spoken to one other person with CL/P in my lifetime up until embarking on my research project. I found myself sharing more than I had thought I would, while I was also aware of holding some things back, for self-protection. I also found the experience cathartic and I enjoyed 'telling my story'. I had been unaware of the CLAPA community and of the medical advances and support structures that have taken place and changed over the past twenty years before embarking on this research and the pilot was helpful in consolidating my new learning. One of the things the pilot helped me to address were feelings of an 'outsider looking in' as I learned of CLAPA community groups which I had been unaware of and of medical procedures I had not known were available, such as genetic testing. My pilot interviewee was very empathic during debrief and expressed surprise I had never met anyone else with CL/P prior to this research. I felt this pilot interview allowed me to become more conscious of the subjective nature of my own experiences and to develop a way of bracketing these off by utilising my reflexive diary which was especially helpful during analysis.

2.8.4 Interview schedule

It was important to me that the interview space was in a place of the participants' choosing e.g. their home or office or an agreed neutral venue and that it be confidential and convenient so that participants would be as comfortable as possible as I anticipated that this would support in-depth interviewing. Six interviews took place at participant's homes and two were held at participant's place of work.

Face-to-face interviews offered the opportunity to observe body language and facial expression. It also allowed participants to see me and be interviewed by a researcher they may have been able to notice also has CL/P. Participants were not explicitly informed I was born with CL/P until debrief after interviews. I chose not to inform participants in advance as I did not want to be leading and assume that this would be a factor, but I hoped it might lead to an increase in depth exploration of responses. I recognise that I was assuming a positive reaction to any potential impact of my CL/P. It is possible that other impacts might have been made for example how participants spoke

about my CL/P, comparisons, assumptions they may have made about me or my experiences and it is possible therefore that my CL/P might have inhibited rather than enhanced what was said. Ultimately, there was a dilemma; if I decided to disclose it might appear that this was an issue and if I did not, I was potentially exposing participants to surprise and a situation they might not have known how to handle. It was thought about carefully, and I decided on balance it was better to take a more natural approach than make assumptions about what it might mean to participants.

There was a small potential risk to me in entering the home or office of people who were not known to me. I carried out a risk assessment and from this; precautions were in place in the form of a 'buddy' system whereby I notified a colleague before and after interviews with a procedure to follow if I did not make follow-up contact. I also had a fully charged mobile phone with me.

2.8.5 Demographic data collection questionnaire

Prior to interviews I completed a demographic questionnaire (see Appendix 5) which collected demographic data on age, occupation, academic attainment, relationship status and parental status and geographic area. I chose to collect demographic details because I thought it would be helpful for the reader in order to contextualize the sample. I explained this was optional and would not impact on the interview in any way. My rationale was that I did not know the participant and would not have any other way of alerting an appropriate person should any participants disclose they were having significant emotional or mental health difficulties. All eight participants shared this information with two commenting it felt a helpful consideration to make.

2.8.6 Interview questions

A semi-structured interview agenda was used, guided by Smith et al. (2009). A series of open-ended questions were asked which were recorded securely on a Dictaphone. Questions were designed not to be leading but to be exploratory, enquiring and focussing on the experiences shared by participants.

Devising interview questions was a process that took several drafts and I sought guidance from my supervisor. I struggled initially because in asking the questions I

wanted answered, my own subjective experiences were accidentally coming into play and I received feedback from my supervisor that my initial questions were somewhat leading. One piece of feedback received was that it appeared I wanted positive aspects to come out, but I was assuming that there would be positives. In line with my supervisor's guidance and also Smith, Flowers & Larkin (2009, p. 59), I revised my questions to be "open and expansive" so that the participant would then "be encouraged to talk at length". This shortened my interview schedule to three key questions, which were descriptive and evaluative, with continual use of prompts and probes (see Appendix 7).

2.8.7 Participants

Homogeneity amongst participants is recommended in IPA (Smith et al, 2009) to illuminate the experience of the phenomenon being studied. I felt that a broader age range was an important factor as an influence on experience given that national changes in the structure of care services for babies and children with CL/P (cleft teams) were introduced in 1995 in the UK. I found I did not need to selectively request participants from any particular age range except to request Age 18 and over because interest in my research was broad in terms of age ranges. The youngest participant was Age 23 and the oldest participant was Age 57 at the time of interviews. Selection was partially based on factors such as geographical location and the availability of a confidential space and mutually convenient time to conduct interviews; for example, I received two expressions of interest from people living outside of the UK and four from different parts of the UK, but it was not possible to agree a mutually convenient time and space to conduct interviews. Geographically, participants who took part lived or worked within a radius of 8 to 86 miles from my home base. Seven participants were White British, and one was Greek Cypriot. Six participants had a unilateral CL/P and two had bilateral CL/P. Two participants reported waiting for further surgery and a third reported having recently turned further surgery down. In terms of relationship status, five participants were married, one was in a civil partnership, one was co-habiting and one was single. Two participants had children and six did not. See Figure 3 for further demographic information. Most participants responded to my advert on the Facebook "Adult Voices' page, with only one individual contacting me in response to my flyer.

Financial costs were minimal. I absorbed travel and refreshment. Participants were advised they had the opportunity to have their story heard in a sensitive, empathic and non-judgemental way. To avoid any risk of negatively influencing the reasons for interest in taking part in the research, no financial incentives were offered.

2.9 Methods: Data Analysis

2.9.1 Interviews

Interviews ranged from being 73 minutes to 120 minutes in length with the mean interview lasting 90 minutes.

2.9.2 Transcription

A series of open-ended questions and responses were recorded securely on an encrypted Olympus Dictaphone meeting confidentially requirements and with participant's signed consent which was obtained face-to-face prior to interviews commencing (see Appendix 3). An Olympus foot pedal was used to type out full transcriptions of each interview.

2.9.3 Analysis stages

The steps in IPA data analysis were as follows, guided by Smith et al. (2009):

- I typed the transcription of my first interview; this included non-linguistic features such as laughing, clearing the throat and on one occasion, a cat walking into the room. When volume changed, I noted this in brackets following the quieter segments. Following this, I read the transcription several times while listening again to the interview. Initial notes of first impressions and thoughts were made in the margin.
- I transcribed the next interview. My notes began to reflect on descriptive, linguistic and conceptual observations. I made two columns in the margins: exploratory comments and sub-themes which I found helpful and I used this system across all transcripts, including going back to the first interview.
- I selected the next participant for analysis when each set of notes were made for the previous participant.
- Further development of themes was facilitated with *abstraction* (identifying patterns between sub-themes); *subsumption* (a sub-theme which achieves a super-ordinate status because it brings related themes together); *polarisation* (examining oppositional relationships between sub-themes); *contextualisation* (exploration of the narrative elements of themes); *numeration* (the frequency with which a theme is supported) and *function* (examination of the specific function of sub-themes).
- I developed a table of super-ordinate themes and themes which was used to inform the analysis write-up.

For clarity, I use the following terminology throughout to describe different levels of themes, guided by Smith, Flowers & Larkin (2009) from lowest to highest:

- Exploratory comments
- Sub-themes
- Themes
- Super-ordinate themes

I opted not to use the term ‘master themes’ because I wanted to be gender neutral in my terminology. I felt this was especially reasonable given that I am a female interviewing all-female participants.

2.9.4 Detailed Process of Analysis

2.9.4.1 Early reading and organising material

Following each IPA interview, I wrote reflections in my journal. I listened to interviews several times before transcribing into a Word document.

After transcribing, I trialled different methods of organisation; initially printing interview transcripts and writing notes by hand then using colour coded post-it notes to note emerging themes that I felt were relevant while holding in mind my research question which was stuck to the wall in front of me as a prompt. I read each transcript before beginning notes, while listening to recordings of the interview and reading my own post-interview notes written soon after I left the interview. I reflected on the material within the interview and noticed my own reactions to it, considering a range of feelings which at times brought me in touch with feelings from my own life narrative. I reflected on each experience and gave myself sufficient time to process the emotional impact of the interview before moving on. I began to take notes of descriptive and linguistic aspects of the interview. It was helpful to listen back to interviews in this regard as I was better able to identify changes in tone and pitch and at more emotional parts of interviews. I reflected on meaning and moved gradually towards conceptual, interpretative notes, finding a space where reflecting on meaning is possible without moving too far towards the direction of theory and explanation.

I then created an Excel spreadsheet and copied the transcript into one column which cascaded down the spreadsheet in rows, adding additional columns along the top bar of the spreadsheet named “exploratory comments - descriptive; linguistic & conceptual”; “emerging themes - what's of most interest in answering the research question”; “subthemes - how participant feels at ground level”; “themes - what is participant doing or being?” and “superordinate themes – abstract summary”. I worked through each column systematically, later adding a further column “my reflections on the material”. The tentative development of subthemes was guided by how well I felt the material answered the research question. I paid attention to emotional aspects of accounts, or material where emotional affect may be guessed at, for example, when hearing changes in vocal tone and pitch, pauses and silences and in recalling my own felt sense in the

room. I was also guided by Smith's (2011) value of shining, suggestive and secret 'gems', a "relatively rare utterance that is especially resonant and offers potent analytic leverage" (p. 6) and when I was unsure if an identified piece of material would be replicated enough across interviews to develop into a theme I opted for caution and included accounts with a view to collapsing later.

I found that the column 'my reflections on the material' was helpful for my own reflexive process. In some interviews, details were shared which had a more personal significance for my own medical care; for example, two women older than me shared that further cleft repairs are common in later life as muscles become looser which I had not known. I wondered whether I might need further surgery or other interventions in the future. Not being linked in with any cleft services myself, I decided to request a referral to a cleft-team from my GP, a process which has taken 17 months from GP request to initial consultant appointment, and which seems to have echoed some of the concerns shared within interviews around GP lack of awareness of cleft issues and services (I had to make three GP requests before showing details of cleft-services on my phone to make the GP aware of the correct referral pathway). While I feel I have separated out the experiences of my participants from my own, I have unexpectedly learned things which could lead to specific interventions for me, possibly even further surgery for me. I feel a sense of gratitude, but it also feels slightly surreal. When I designed my research, I was keen to explore the past and present experiences of women with CL/P and less consideration had gone into thoughts about the future. Additionally, my initial assumption at the beginning of my research was perhaps of being in a position of being 'okay' in talking to people who may be struggling. During the process of participants sharing details of helpful things I did not know about, I felt somewhat unsettled and panicked that participants knew more than I did about the phenomenon. I had a sense of foreboding that perhaps I was going to discover that I was struggling in comparison with my participants. Later I was able to reflect that this process may have unsettled the assumed power relation existing between interviewer and interviewee. I had not known there was a group at CLAPA, a community. Not only had I never heard of it; I'd never had a concept of CL/P being anything other than just my own personal experience. Even though I was aware others were also born with it, I assumed they were also managing on their own. Identifying and challenging this assumption felt overwhelming. I felt some sadness at the loss of something I never had, even while recognising it may not have even been something I wanted. Recognising these

unanticipated consequences of my research for me leads me to think more deeply about the future care and support for adults with CL/P and I endeavour to fully explore options in my discussion.

2.9.4.2 Development of Themes

When I completed analysis of a transcript, I copied it into a second spreadsheet tab and deleted all rows not identified as a potential superordinate theme. Using this shorter list, I began collapsing the data, examining it for repetitions and using my judgment to decide 'which one says it best'. I continued to consolidate until I could not collapse further, then I would begin the next transcript and repeat the process.

When beginning analysis on the next transcript, I found myself resisting a desire to read the data as fitting into previously identified subthemes and themes from previous transcripts so that I could treat each transcript as a unique, discrete piece of work. I wanted to avoid making assumptions that participants felt the same way about the same things e.g. early operation experiences, as nuances could have been different. I became aware of idiosyncrasies within each transcript which added richness to the research process, and I kept a record of these even as I began to recognise these may not be eventually grouped into common themes, suspending ideas rather than rejecting them immediately. Idiosyncrasies were eventually excluded when it was evident to me they could not be grouped together. Subsumption was then used to raise sub-themes to the level of super-ordinate themes.

When I had analysed all eight transcripts and produced eight separate tables of themes and sub-themes, I used abstraction to create labels to describe higher level meanings. I printed the themes and sub-themes out, cut each row into strips so that each one represented a single participant and arranged these on the floor. By reflecting again on my interpretation of the meanings of each, I slowly began to group similar themes together into four super-ordinate themes which felt distinct enough from each other to create super-ordinate themes. Here I was most aware of common themes across participants. I developed a superordinate themes and themes table across all participants (Appendix 9). When this was completed, I created a separate superordinate theme, theme and sub-theme table for each of the eight participants, so I could read each participant's material separately. I felt this might be a helpful way of checking the data

for errors or accidental omissions by comparing it with my initial notes and reflections on the participant, to see how the data had developed and to see whether material I had initially felt was meaningful had been reflected (see Appendix 8 for an example). I found this a helpful exercise because it allowed me to feel satisfied, I had achieved what I set out to do in representing faithful interpretative phenomenological accounts of all interviews that captured the essence of participant's experience of living with cleft lip and palate.

Direct quotes from the interviews were used. To preserve anonymity, participants chose pseudonyms and any identifiable data was omitted. When quoting from the transcript, the pseudonym and the location within the text are given. Omitted text is indicated by: […] and potentially identifiable text is replaced with [___]. Pauses and silences are indicated by … The text was left un-edited to stay as close as possible to participant narrative. Occasionally in cases where it was necessary, a word was added {in brackets} to make a point clearer or, on occasion, to describe an emotional affect present in the interview.

The analysis process took several months to complete. I struggled initially with the tension between description and interpretation, gradually developing an awareness of my own assumptions and consciously bracketing these. I developed an understanding of empathic interpretation (i.e. knowledge gained through understanding accounts without digging below the surface for deeper meaning), and suspicious interpretation (i.e. explanations which can go too far and lead to misrepresentation and which a participant may not be aware of or agree with) (Willig, 2012). For some time, I found myself moving backwards and forwards between the two. Material which had an emotional impact on me was frequent throughout each interview and the analysis process, and I needed to unpick the meanings of each for myself before I could return to the data to analyse. I found myself questioning whether, if I had a different experience of a particular event e.g. school life, might that make me more suspicious of hearing differing accounts? Might I recall emotive episodes from my own life and search for these in the lives of participants? Equally I was challenged by the task of not searching for theoretical meaning. As a Counselling Psychologist in Training my therapist skills are quick to respond to material by seeking to formulate and in the earlier stages of analysis this was something I constantly had to challenge. For example, hearing participant accounts of feeling anxious and uncomfortable in social situations in which

the individual would avoid talking to others to cope led me to wonder about social anxiety disorder. I began to conceptualise the task as about finding a 'space in the middle' between content and theory, where meaning was the only objective. Over the course of the analysis process I found it became easier to detach from emotional content and return to the data with a more objective perspective. As the material generated has challenged me to question my own assumptions and beliefs, I have been extremely careful around the dangers of aligning myself too closely with either empathic or suspicious interpretation. Re-reading of the material, especially after short breaks from it, has been helpful in refreshing my perspective and allowing me to view it in different ways. When I felt particularly stuck, I sometimes tried to imagine the phenomenon as a different kind of facial difference, for example, a birth mark, or glasses or braces. I also found it useful to decontextualize on occasion (reading text backwards) until I felt I had regained sufficient emotional distance from it.

Throughout the process, I reflected on what participants might make of my interpretations. I hoped they would feel well-represented but what if they were to feel misunderstood, misrepresented, unheard, judged? I was concerned that my meanings might unconsciously overshadow theirs, discrediting their voices in placing my own there instead. I wondered how my findings might impact on others, for example, others with cleft lip and palate or their family and friends, or in wider settings. One observation I have noted is that experiences seem to have been greatly influenced by the era in which a person was born, seemingly due to the medical treatments available and societal norms of the time. I wondered how might it feel for a younger person with cleft lip and palate to read accounts of an older women's experiences of bullying and abuse? Or vice versa. As I have been explicit about the in-depth nature of the research, I considered that it may be more expected that accounts may be emotional to read and, I hope, of value and interest to participants.

Equally, as I produced my table of super-ordinate themes, I became struck by how much of the material felt negative, and I considered that this was how language around cleft lip and palate felt to me while I was growing up. I reflected on whether this suggests this is what I have listened out most for. Upon reflection, I considered that given the qualitative nature of the research it may be more likely that I would access a broader range of experiences and perhaps because of a willingness to go towards

difficult parts of experience I may have encouraged the expression of more painful experiences simply by allowing space for them to be shared.

Throughout the research process I have found it invaluable to journal my reflections and to discuss analysis methods in research supervision. In the earlier stages of the analysis I found my own reflections to be 'loudly distracting' and this seemed to slow down my progress as I grappled with developing an understanding of what to do with my own thoughts and memories. I found that in reading a single sentence I could be transported back to earlier times in my own life and I digested the material in terms of how familiar it felt to me and how my own 'story' had been experienced. During supervision, I had a breakthrough when we identified that my own experiences are also a valuable part of the research process and I could include these within the analysis of the data. We agreed that I would include my own personal reflexivity throughout where pertinent and I have therefore sought to be reflexive throughout in response to the analysis presented, especially at parts which provoke an emotional reaction due to parallel experiences in my own lived experience of cleft lip and palate.

2.10 Summary

It is hoped that the findings of this qualitative study will enhance understanding of lived experiences of CL/P within Counselling Psychology and will positively inform both theory and clinical practice. Results will be published in journals.

3. Analysis

"Nothing in life is to be feared, it is only to be understood. Now is the time to understand more, so that we may fear less." *– Marie Curie (1973)*

3.1 Overview

In this analysis chapter I am presenting themes developed from eight IPA interviews which were conducted to explore and better understand lived experiences of women born with cleft lip and palate.[1] I explore each super-ordinate theme and related themes within subheadings, which are represented in Figure 3.1. A super-ordinate themes and themes table with selected quotes is represented in Appendix 9. The super-ordinate themes provide an organisation or framework for the analysis while themes are discussed in detail throughout this chapter. Finally, I reflect on my own position, experiences and process throughout the analysis.

[1] Throughout this chapter I refer to cleft lip and plate and do not use an abbreviation. This was a meaningful decision as I feel using the full name slows the reader down and facilitates more reflective thinking.

Figure 3 Representation of super-ordinate themes and themes

3.1.1 How to read the super-ordinate table of themes (Appendix 9)

The analysis is organised into four super-ordinate themes. "The threatened self" explores ways in which cleft lip and palate can have implications for participants' overall sense of self. "Being different to others" explores the inter-relational experiences of participants, ranging from feelings of acceptance to feelings of difference. "Facing challenges" describes participants' responses to challenges and the methods drawn upon in overcoming challenges. The final theme, "wishing things had been different'", while connected to the particularities of the other themes, comprises of insights and suggestions offered by participants to others who were born with cleft lip and palate, family and friends or professionals working within services offering specialist cleft lip and palate care.

The super-ordinate themes table separates themes to highlight they are different from each other however themes do relate to each other. For instance, in the theme "Being different to others; the super-ordinate themes are all part of the repertoire of feeling safe in the world. They are not opposites but different parts available to a person.

I am now going to provide a narrative account of how I put super-ordinate themes together to draw conclusions about the experiential phenomenon.

3.2 Super-ordinate Theme A: The Threatened Self

Heidegger (1962/1927) asserted that we have no access to experience of ourselves except through the lifeworld:

"[The individual] never finds itself otherwise than in the things themselves, and in fact in those things that daily surround it. It finds itself primarily and constantly in things because, tending them, distressed by them, it always somehow rests in things. Each of us is what he pursues and cares for. In everyday terms, we understand ourselves and our existence by way of the activities we pursue and the things we take care of." (Heidegger 1988/1975, p. 159).

I have chosen this quote because I think it illustrates the complexity of how we come to know ourselves and the relationship we have with ourselves which is important in terms

of developing an understanding of what 'sense of self' is. I have reflected on 'sense of self' at length before conceiving it to be an embodied felt sense of how we believe ourselves to be which is consciously accessible to us in part, but also unconsciously driven. Our actions are in accordance with how we see ourselves and others. The parts of us which we are aware of and therefore accessible to us, are subject to the ways we make sense of them and how we experience them both in an emotional and in a physiological embodied sense. They become part of us through our subjective conscious experience. Our history inevitably plays a role in shaping our present. For individuals born with cleft lip and palate, this has always been part of experience, there is nothing else it can be compared to and it was present prior to verbal abilities or conscious thought. It can be a challenge to identify ways in which it might have influenced sense of self.

In capturing participant's subjective threatened sense of self, I explore the following super-ordinate themes, *identification with cleft lip and palate* and *self as not good enough*.

3.2.1 Identification with cleft lip and palate

IPA is "committed to the examination of how people make sense of their major life experiences" (Smith, Flowers & Larkin, 2009, p. 1). The analysis begins by exploring how participants make sense of their identity in terms of cleft lip and palate. I selected the descriptive *identification* to locate this experience as central to how participants experience themselves and to explore how significant the experience of cleft lip and palate is within sense of self. The terms *sense of self* and *identity* are understood to hold the same meanings, and both are used interchangeably because identity is more frequently used in everyday language whereas sense of self is more conceptual.

As I began to think that age is an important factor to reflect upon in terms of what this may have meant regarding medical support and societal norms, I have included participant ages after quotes. Participants are reflecting on memories and questions around the construction of memory will be addressed explicitly in the discussion.

The interview begins with participants responding to the question "can you tell me how it's been for you, having cleft lip and palate?'

"I deal with it better now than I did when I was younger… yeah, I feel… well… not unique but you know, sort of, within you know, special in a way I suppose, […] I mean obviously, I think the bottom line is… I suppose I still do feel I would rather not have it but in the same way I also recognise [tone becomes emotional, almost tearful] I don't think I'd be the person I am today and in a lot of positive ways if it hadn't been for that…. its emotional this isn't it (laughs)."
(Traveller: 51, 22-31)

As traveller discusses what having cleft lip and palate means to her, she becomes more emotional as she describes something positive arising from her experience of cleft lip and palate. I understand this to be describing a sort of overcoming, looking back and recognising that challenges have been met and resolved and feeling proud but perhaps also somewhat vulnerable when recalling challenges. Oscarbertie and Puddle give their experiences of cleft lip and palate similar positives:

"I've got a positive outlook even though I do get anxious and I do get stressed but […] it's not about this [points to mouth]. Cos this is me, this is what makes me [voice increases in volume and tone becomes emotional]. I can take the mick out of myself, I can laugh at myself and I think, once you can do that… but it's taken me fifty odd years to get there."
(Oscarbertie: 54, 184-193)

"So, from… teenage years it definitely, definitely did affect me, […] you know, going to get boyfriends and things, but interestingly erm I've lived with it […] and I wouldn't change it now, you know, I notice you have a cleft as well and I... I wouldn't change it, it's part of who I am. I'd like to see what I [might have] looked like [without it, though] … [laughs] you know?"
(Puddle: 55, 129-136)

Traveller, Oscarbertie and Puddle describe a sense of cleft lip and palate being a lifelong part of identity which holds value. I believe this points towards a relationship between cleft lip and palate and learning to cope from having overcome obstacles subjectively attributed to cleft lip and palate. It seems to represent cleft lip and palate as a long-lasting characteristic of identity rather than a temporary 'state', which can be

experienced as emotionally painful but can be accepted and integrated into sense of self following struggle. It may be that there are times when emotional pain 'flares up' while at other times it lies dormant.

Anna describes a different experience:

"In this context, I'll be honest and the answer I give you will be different from what I would say to other people… because in this context I would say, it's bloody awful. I don't like it. […] it's been I think probably the thing that has probably most shaped my whole life and that's partly because of my age and the time that I was born and what was going on in society at the time…erm, so how I feel about it is… sad actually, the feeling is sad"
(Anna: 51, 3-13)

Here, cleft lip and palate has been experienced as difficult and unwanted and Anna says it has been fundamental in influencing life, but this does not hold positive characteristics for her. She links her experiences directly to age and to society while growing up. Geographical and socio-economic differences may also be important considerations to reflect on which challenges my earlier assumptions of homogeneity amongst the participant group.

Flower and Stormy make a direct link between learning more about cleft lip and palate and developing greater self-acceptance. This tells us something interesting about the experience of having cleft lip and palate, that a person with cleft lip and palate does not necessarily have access to sufficient knowledge and understanding to make sense of it:

"I think as I've gotten older I know more about it. And so, I understand a bit more. Erm… yeah, I think I'm more accepting of it now."
(Stormy: 29, 202-204)

"It probably took me until I was about fifty to come to terms with it. But still, having… giving me the choice not to have it I would not have it but now I'm at my most comfortable with it, and I think it's because I had my daughter, so I understood more about it, I informed myself."
(Flower: 57, 84-89)

Flower is referring to the fact that her daughter was also born with cleft lip and palate, so Flower has dual experiences of being born with cleft lip and palate and being a mother of a child born with cleft lip and palate. She is describing how having her daughter was a catalyst for learning more about it.

Stav shares a different perspective:

"I'm not going to be sitting back and crying about it cos it's not going to do anything, at the end of the day it is what it is and basically I've got through it and I kind of see it as, people have way worse things that are going on in their life […] so, yeah, it's a minor thing to me, very minor."
(Stav: 23, 717-726)

I selected this quote because of the line "*at the end of the day it is what it is and basically I've got through it"* which I might interpret as alluding to something without saying what it is. 'Getting through' something implies a challenge of some sort, while 'at the end of the day' could be describing a definitive conclusion to something but it also might be interpreted as a kind of weariness, as if the subject matter is a tiring one to contemplate and a summary of where things are now is emotionally easier to give.

Smith (2011) describes finding 'gems' within text that offer strong insight into lived experience. 'Suggestive gems' are where a phenomenon is partially within the participants' awareness, but further interpretation is needed, and I think the above quotes contain suggestive gems. Traveller and Flower acknowledge they'd rather not have been born with cleft lip and palate; Flower, Stormy and Oscarbertie describe it's taken time to come to accept it; Puddle wonders what she might have looked like without it; Stav has 'gotten through it' and Anna has felt lifelong sadness. I feel it a reasonable interpretation that cleft lip and palate poses something of a threat to self which leads to tension between acceptance and non-acceptance.

These insights allow me to question these tensions to consider how we come to know and construct ourselves. What does it mean for an individual to accept themselves? Is self-acceptance intrinsically tied with our relationships with others, who act as mirrors to ourselves? Could an individual feel non-acceptance of the self without the 'other'

with which to compare oneself? Is our identity most closely tied to feelings of sameness or difference to others? Further analysis will allow me to address these questions.

3.2.2 Self as not good enough

Self as not good enough is inexorably linked to sense of self. Here I feel it valuable to reflect on painful sense of self accounts, which may contrast to differing accounts in 3.3.1 but do not contradict them, rather they illuminate the complexity of identity and, I feel, shed light on multi-faceted elements of being. Accounts from the same participant can differ, yet both are part of whole experience.

Traveller reflects on her experience of judgement.

"So, it's not just been other people judging me it's been me judging me"
(Traveller: 51, 50-51)

Traveller's use of the word *just* at the beginning suggests that perhaps it is worse for her to have judged herself than for others to have done so. If we come to know ourselves through the ways in which we are treated by others, does this suggest that negative experiences by others become internalised and form part of identity, thus becoming part of our own internal voice? Which external voices were most available and what did they have to say? In trying to understand I feel that historical context is important to bear in mind. While the focus of the analysis was on participant's subjective experience, naturally participants were located within individual family structures, within different geographical regions and grew up in different eras, all of which could objectively be considered to impact on available social constructs such as stigma and on support and knowledge available.

"I think it is so people like me, that's what it is Sally, it's about people liking me, I'm gonna cry [voice tearful]."
(Puddle: 55, 1430-1432)

Puddle explored an acknowledged desire to put others at ease by looking after them. Here, she uncovers her own meaning behind this, which is so that she will be accepted by others. Suspicious interpretation might suggest that Puddle does not believe she will

be accepted without going above and beyond while empathic interpretation may understand that it is a human need to feel accepted; I feel both have merit here.

Fred, Stav and Stormy also describe themselves in relation to others:

"When I was young… because of my cleft lip and palate I thought I was ugly and then you therefore think 'well no-one's going to like you or want to go out with you because you're ugly' so it's that whole association that then eats… corrodes your self-esteem."
(Fred123: 41, 323-328)

"I think, obviously as a kid it would be a lot harder cos you're the odd one out."
(Stav: 23, 20-21)

"And growing up I didn't know any different really until I had, I think, at eleven until I had the major operation… that was only time I sort of, I really realised I was different to everyone else."
(Stormy: 29, 73-76)

There is an implicit assumption in all three accounts that having a cleft lip and palate means difference and this has negative connotations. Stormy says '*I realised' and* Stav's use of '*obviously*' suggest the assumption was experienced as fact. Fred123 appears to have developed a distance from this earlier memory; she recalls her thoughts and feelings, clearly linking cleft with being unwanted and this leading to low self-esteem.

I find it helpful to reflect on Traveller's earlier comment here. Would an individual who never had contact with others learn to see themselves as not good enough? Or is our concept of how we measure up tightly bound to the feedback others in the world give us? I believe we are most vulnerable when painful feedback is experienced as a global negative 'truth' about the self, then this sense of difference becomes part of conscious awareness.

I was powerfully moved, and disturbed, by an account by Gregg et al (1981) who reported a dearth in archaeological evidence of cleft lip and palate across the globe which was explained by primitive groups most likely excluding people with cleft lip

and palate (and other defects) from community burial areas. Wright (2011, p. 14) asks "why are there so few examples [throughout history], especially when it is known that oral clefts are the second most common birth defects amongst new-borns?" Historical accounts of cultural beliefs that birth anomalies were affiliated with evil actions and sin were common; and marginalising depictions of artistic representations until the late nineteenth century illustrate such widespread past beliefs (Wright, 2011). Medical advancements and societies have changed, and these past worlds appear almost unrecognisable now. Today, stigma remains a powerful, destructive force, less around those old beliefs but stigma is commonly found wherever there is a perception of difference (Turner et al., 1997, Crocker & Major, 1989, Masnari et al., 2013, Alansari et al., 2014 & Tiemens et al., 2013).

My perception is that all forms of difference, particularly during late childhood and adolescence, can be experienced negatively and can invoke stigmatising reactions from others. What drives individuals and communities to stigmatise and how, if cleft lip and palate is stigmatised by others, would an individual protect their own sense of self from its effects? Here, I question whether the concept of difference is in fact introduced into an individual's life by others, simply because difference has a conceptual meaning within society, and this then becomes a painful challenge for the individual to seek resolution to.

Feedback from others can be realised in several ways, not all feedback is verbal. Flower and Oscarbertie gave accounts of how they experienced their own parental reactions. Flower describes the sense she made of cleft lip and palate not being talked about.

"No-one talked to you as a child, they talked to your Mum…or your Dad, erm, so the fact that you weren't part of it, although it was part of you made me feel that there was something wrong having it [coughs]"
(Flower: 57, 34-38)

"So basically, she [Mum] turned round and said, […] "even though she was imperfect", this is her words, "we still loved her". And that… I think that's the worst thing that's ever… that hit me like a hammer."
(Oscarbertie: 54, 633-635 & 639-640)

In both accounts, a sense of something being wrong is communicated. Flower experienced an exclusion from something which was hers, her own experience. Flower's cough at the end of her comment seemed timely. I guessed that it may have felt worse than '*something wrong'*, perhaps shameful. Oscarbertie had read the words she describes on paper, her description "she turned around" is her way of bringing the story to life but she was reading words written in a diary. Both accounts highlight that non-verbal communication can have a powerful and painful impact. I felt huge empathy towards Oscarbertie. Her pauses hinted at what she didn't say. I felt it had been devastating; her whole being described in this one word 'imperfect'. It felt desperately unfair to me on hearing it. Later, I considered that I rarely hear this word spoken in day to day language, and I wondered (or hoped) if perhaps the speaker had used terminology which was understood in a slightly different way to how we might understand it today, or if it is possible to really understand the meaning of an account produced in a different time.

Finally, Anna reflects vividly on her inner experience of her awareness of cleft lip and palate and all the meanings associated for her. She describes a daily consciousness of awareness from almost as soon as she wakes:

"I know what that feeling is and then it lives within my body as like a… and I can only describe it… it's like a gritty erm depression, sort of an inward feeling that sits here (points to chest) erm there are some days when it's less there, but pretty much every day that is there, in it comes […] it's almost a pre-verbal thing."
(Anna: 51, 62-77)

I think this account is so vivid that descriptive analysis is sufficient to understand its meaning. I find Anna's 'pre-verbal' language particularly interesting, as it speaks to a deep or lifelong awareness of emotional pain which she associated with her experience of cleft lip and palate.

Willig (2015) challenges the idea that shared themes provide full access to the meaning and significance of experience. In identifying common themes in IPA, I have had to choose to exclude rich data which I do not feel fully comfortable with. I am including one account here as an additional observation within this theme which I think illuminates understanding of cleft lip and palate hospital experience. All other

participants' reflections indicate a certain level of self-reflection whereas this account is a rawer description of a memory of experience where identity is only implicit.

"That whole operation didn't go that well […] and they sent me home, unbeknown to us, but when they checked, the drugs that they used made me sick. So, I got home with my jaws wired together and I was wanting to be sick and […], you don't know whether you can be sick, […] well they rang the hospital and they said, "well you can either drive her back to [___], or you can take a pair of wire cutters to her". So, we did neither (laughs).
(Fred123: 41, 80-91)

I have chosen to include this account because it is powerful; the description is brutal and holds a sense of uncertainty or fear and of being overlooked and treated with indifference. There is an urgency for help which cannot be accessed. Fred123 seems to construct herself as an object in her account. It is helpful to note that I understood this account to have been a deeply upsetting experience at the time based on my felt sense in the room and in her delivery of the account, which was given almost in a rush, with no pauses or space for questions from me, in a tone of voice which conveyed a mixture of tension and gave me a sense of weariness, hurt and disappointment. Other accounts within the interview were not delivered in the same way so it stood out to me as striking. Her descriptive account and its delivery may be the closest way of accessing her emotional memories of the experience. This anecdote answers my research question "how women experience and manage living with cleft lip and palate?" by suggesting her experience has been harrowing at times and her emotional self at that time may be noticeable by its absence.

It is helpful to draw a distinction between different times in a person's life and how memories are experienced, and these topics will be expanded on further in my Discussion chapter. Fred123 may have chosen not to share her feelings about this experience verbally or she may no longer have access to her past emotions. Experiences add layers of complexity to identity over time and since it is only possible to interview participants in the present, Fred123 may not have reported on how she felt at the time, but this is not the same as it not having impacted on her sense of herself.

3.3 Super-ordinate Theme B: Being Different to Others

Anecdotes regarding social and interpersonal experience were present repeatedly throughout interviews. I regard this theme as a natural follow on, in which interpersonal influences have been interwoven with sense of self. I chose to represent these as a separate theme to engage with richer data. 'Being Different to Others' pays attention to the social and relational experiences of participants in relation to others and whether participants regard cleft lip and palate having had an impact on these experiences.

I chose to separate 'safety and acceptance' and 'interpersonal unpredictability' within this section to illustrate that experiences of both were common across participants so there was a duality to reported experience. Being Different to Others is not confined to any specific social group so I did not ask participants to tell me specifically about their families, partners, friendship groups, work colleagues, peers at school or the general public; rather I suggested these as possible groups to talk about and asked participants to share the relational experiences which were most meaningful for them.

This has been a challenging theme to write about. In part this has been due to the frequency with which relevant accounts have been given, so selecting the quotes that 'say it best' was necessary. It has also been difficult because of the broad nature of social and relational experience, across each participant's lifespan, for example, in establishing that a past family experience for one participant links with the current experience of another participant in their workplace. It has also felt, frequently, like a minefield to walk through because of my own personal experiences. I hoped to be an advocate for others but, in carrying out this piece of research, many feelings have been evoked in me. I had not known there were support groups available for people with cleft lip and palate; when I learned this, I felt a sense of loss. To some extent I have felt myself reframing my own past experiences to make room for additional knowledge gained. I have found it important and necessary, but painful, to reflect on the impact of my early care on my family. I have wrestled with how I relate to concepts of difference and of not fitting in, and I have found myself pulled in two directions. I don't wish it had been different for me, but perhaps part of me does. I had always identified with a positive sense that having cleft lip and palate had *made* me something and I valued that something. I believed it had made me more empathic and understanding, stronger and more resilient. In carrying out this research I have needed to question and sometimes

challenge my long-standing beliefs and that has been difficult. I have regularly needed to take time away from the research material to reflect, and to explore my thoughts, before bracketing these off to return to the participant's material. Keeping a reflective journal has been invaluable in this regard. I think this theme provoked stronger emotional reactions in me because it made me confront the reality that others may have perspectives which challenge my own perceptions, and this has felt somewhat threatening and unnerving. In particular, it has put me back in touch with a sense of others being unpredictable, of not knowing whether external perspectives will be accepting or critical of me, which generates a sense of anxiety.

3.3.1 Safety and Acceptance

The accounts given here are not the complete accounts of all participants in relation to sources of support. I decided to select a range of comments to represent powerful accounts across an interpersonal spectrum rather than select accounts based on similar reports e.g. all participants found friendships supportive, because I wanted to represent both what felt meaningful for each participant and demonstrate a broad spectrum of social and relational areas of interest. It was outside of the scope of this research to include accounts of parenting a child with cleft lip and palate and in this limited space I have sought to focus on participants' experience of their parents.

"I can remember my Mum telling me stories that I cried for the first year of my life and it was because they couldn't work out you had to make a bigger hole in the bottle in the teat because I was hungry all the time… because I cried all of the first year my Mum had post-natal depression."
(Flower: 57, 1004 -1010)

A lot of details are contained within this account. We learn there is an understanding that a baby with cleft lip and palate cannot feed properly and needs an adapted teat or they will not feed. We learn that this information was not known and that this impacted on Flower as a baby because she did not feed and therefore was in distress, and she also names the experience her mother was having with post-natal depression. The account does not say how either were resolved. It also seems as if Flower places responsibility for her mother's depression on herself.

"The consultant told my parents not to treat me any differently so it was never discussed […] I lived with my [extended family] for a few months [as a baby] so the bonding side didn't happen as well you know, obviously cup and spoon in those days… […] and my poor Mum had [surgery] in the middle of all this erm, then my [___] had really, really awful [___] as well and nearly died so my Mum had a lot to cope with."
(Puddle: 55, 536-543 & 655-669)

Puddle says '*obviously'* she was fed with a cup and spoon then. I wonder how families gained access to relevant information.

"My Mum used to tell me that I was, this is how I was born, it was no-one's fault, erm, […] I think my Mum, my parents, especially my mother were like "you I've know what, I can't deal with [___] going to hospital again, I can't deal with worrying about her" … because Mum had mental health issues."
(Oscarbertie: 54: 29-31 & 394-396)

In all three quotes here, I observe participants taking great care to protect their parents from criticism; they are talking in a very understanding and protective way. As a Counselling Psychologist I can speculate on this. There is a descriptive of the unavailability of the maternal presence which is not being acknowledged. A perceived or felt lack of maternal love is extremely threatening and painful. Perhaps a reconciling of situations which can't be changed in reality is a safer way of coping, e.g. there's no point blaming anyone. This made me wonder about wider support services and who was responsible for ensuring a child received the care they needed. I interpret Oscarbertie as meaning that she remembers not being able to access hospital support as much as she required which is something she confirmed in the interview. This feels very painful and provokes a sense of injustice in me.

"My Mum and Dad have actually been my bedrock; they've always been there for me… […] I think they probably told her [Mum] I needed some operations but that was about it erm, so she was sent home and was given nothing to help feed me. So, I couldn't suck because obviously, I had no palate, so she just spent almost 24 hours a day just literally spoon-feeding me, so it was obviously a pretty tough time… […] and they [nurses] were horrified that I'd even survived, really, given how my Mum had been left."
(Traveller: 51, 671-672 & 920-932)

Traveller's linguistic use of the word '*horrified'* intrigued me here. Was she saying the nurses were pleased, or horrified at the lack of support? While I cannot gain further access, there is a matter of fact tone here:

"People would look in the pram and go "oh" and not know because they couldn't say "lovely baby" like you usually do."
(Traveller, 51, 949-952)

What is this hinting at, this sense, from others, that something horrifying is there?

'They were not supportive parents… very supportive grandparents, not supportive parents so my grandparent's houses were the safe spaces […] My parents separately and together from as long as I could remember told me that people would not like me and people would not accept me so I had to be clever and get away […] and I think they were just completely unsupported, not able to cope with me, the hospital and everything."
(Anna: 51, 334-337 & 360-363 & 390-393)

Throughout these accounts there are second-hand accounts of parental experiences with what I think is a background story revealing a lack of societal support for parents in previous generations and stigmatising attitudes amongst society which became part of participant's stories because these experiences happened to them. From a phenomenological point of view, what is important about this is that participants present their parents as being free of blame. They are excused, and great care is taken to avoid presenting them in a negative light. They are presented as victims, too, and this is important in understanding participants' experiences of their parents.

"But my Dad fought, and I'm using a funny word here, fought for me to be seen at [___] …And my parents didn't treat me any differently cos my cleft lip and palate."
(Fred123: 41, 70-72 & 280-282)

A parent who fights on your behalf is likely to be experienced as supportive. Does Fred123's account add anything new? I wondered whether, a decade or so later; fighting for access to care was more common across society. Being treated the same is not

necessarily being treated equally in the eyes of the law as it stands today. I began to reflect on 'worlds within a world'; considering the past and conceptualising how medical professionals advised parents based on knowledge of the era.

These accounts inform us somewhat about support available to participants' parents. Flower, Puddle, Oscarbertie and Traveller, all born in the 1960's, were given accounts of being fed with spoons because it was not known that a cleft palate affected the suck reflex, so babies could not suck without specialised bottles. While it is not my purpose here to draw any generalisations about any challenges around early bonding experiences, I feel a 'background history' is useful in reflecting on the ways in which cleft lip and palate care may have challenged families to better understand how these challenges shaped participants' experiences. Accounts here seem to vary depending on when participants were born, as Stormy and Stav give different accounts here:

"[I've] got really supportive family and friends. […] my family, my friends they've never treated me any different really. I'm lucky really, I've never been bullied, or do you know what I mean… or had a hard time from it."
(Stormy: 29, 46 & 93-97)

I found it interesting here that not being treated as different can be experienced as both helpful and unhelpful, depending on context.

"It's helped, having a big family I think, and it's been really nice, not a lot of people have that… I've noticed […] so I think I'm very lucky in that sense."
(Stav: 23, 191-193 & 196)

Both accounts here from participants born in the 1980's and 1990's respectively express a sense of *luck* and were spoken as summaries, giving no indication of any associated challenges.

3.3.2 Felt sense of visible difference

Some themes have been repeated throughout the interview. The selected quotes have been selected because they have made the point in the best way. When a theme has been repeated throughout the interview it is difficult to replicate this here without relaying

large quantities of transcript which means that I am explaining the meaning through my double-hermeneutic lens.

All participants gave accounts of occasions which proved challenging because of their perceptions of their own appearance and how it might be experienced by others:

"My relationship broke down so then I was on the market so to speak, to meet someone else so then it rears its ugly head again, so you have to explain to people again or be conscious of it."
(Flower: 57, 69-72)

"No, it's not something I really talk about. I don't openly tell people, with internet dating that was quite difficult."
(Stormy: 29, 264-266)

In these accounts, the question of cleft lip and palate visibility became an issue around the prospect of dating, at a time when many people could reasonably be assumed to consider their own attractiveness and acceptability to potential others.

"You know you look at yourself in the mirror and you don't see what other people see, you just see a scar, or you see a nose that's not how you want your nose to be or when you hear yourself you think" oh, no wonder people can't understand me"."
(Oscarbertie: 54, 121-126)

This may mean additional challenges relating to appearance are experienced by women with cleft lip and palate. Oscarbertie's account shines a light on the difference between her own perception of her appearance and the feedback she gets from other people about her appearance. She is describing how selective attention leads her to notice what she thinks is not right, but she is aware that other people might not do the same. Others may look at her and see the whole picture; which is why she describes two physical impressions of herself. Her last statement is also revealing, her thought processes lead her to interpret cognitively what she thinks others are thinking in a way which, objectively, could impact on her mood and lead her to feel bad about herself.

I think when you're younger it does [affect you] because you wanna fit in and that's the big thing."
(Fred123: 41, 889-890)

Fred123 is making a link between the visibility of her cleft lip and palate and fitting in with others. This overlaps with the theme of self as not good enough but I chose to place it here because visibility is perceived as a barrier to fitting in.

"If someone is just staring then I'll smile but if it's two people making comments and pointing which still happens, I'm amazed to say, even when I'm with other people… then I feel a bit more hurt."
(Anna: 51, 187-191)

"I could just be serving a customer and they will just straight out be like 'oh so you were born with a cleft lip and palate?' and I'm like, taken aback, you know."
(Stav: 23, 511-514)

Anna and Stav's accounts lead me to question my own experiences. Since embarking on this research, I have talked about my cleft lip and palate more to strangers than I ever had previously. I have been astonished to discover that many people I see regularly told me they did not know. I have lived my life under the assumption it is visible, and everyone can see it. Yet I have also had experiences like these highlighted above, so I think there is perhaps an uncertainty or unpredictability in determining how visible cleft lip and palate is to others. Additionally, there is variability of cleft lip and palate appearance and so it is not possible to generalise either. An example comes to mind when I conducted Fred123's interview. When I arrived at the location, I gave her name to the concierge, an older gentleman, who instantly looked puzzled and surprised. He kept looking at me and asked me if I was family, exclaiming "you look just like her!" As I spoke further, he exclaimed "and you sound just like her". Having not met Fred123 in person I was unaware of how alike we may in fact be, but I could sense his confusion which was still apparent as I left. I felt inclined to leave before 'the penny dropped' because I anticipated he would recognise my cleft lip and palate and for self-protection, I did not wish to see his reaction. My perception later was that Fred123 and I do not particularly look or sound alike, any further than we are both white British women, but I saw in the man's face an instant recognition of *something* he was not aware of, and I

also sensed a less than respectful response might have been due, had he become aware. My own language here betrays a certain shame, of being discovered, of somebody realising there is something wrong, with me. This is not a conscious thought I have when I think about myself, but it reveals itself in an unpredictable interpersonal arena.

Scrutiny from strangers is rarely welcome and there are differences in the two accounts because Anna is describing what could reasonably be called harassment while I think Stav is describing perhaps a more benign (thoughtless) expression from a stranger which was not wanted. Puddle further demonstrates here this was not uncommon across participants:

"We were just having a conversation and […] he said to me oh, where did you have your cleft lip and palate repaired? […] I didn't think anything of it and he said… well there's a chap who came to the hospital […] would you like me to refer you for it? He said they can do wonderful things, erm, and I was so gobsmacked."
(Puddle: 55, 146-159)

Puddle was describing an encounter with a friend who, unexpectedly suggested she have further surgery which was hurtful to experience. I wondered whether a facial difference along with constructs of gender there are even more dynamics at play. An early episode of Mad Men makes this claim; "a boy with a scar is nothing, but on a girl, it's so much worse" (Betty Draper, Mad Men, 2007).

I selected this last account because Traveller had been searching for a way to capture the experience of being evaluated by others based on looks and was able to give this phenomenon a name:

"It's all to do with image isn't it, really, so. Yeah. Imagism [laughs]."
(Traveller: 51, 775-776)

Something else is showing itself in the last two quotes which is to do with experiencing oneself as the object of the other's gaze and evaluations. Participants experience how the presence of cleft lip and palate seems to legitimise intrusive behaviour from others. This can occur in other contexts, for example in pregnancy, where complete strangers can comment on the size of the bump or even reach out and touch the woman's stomach

or in relation to having an accent, where complete strangers ask me where I'm from and make evaluative statements based on regional stereotypes.

3.3.3 Interpersonal unpredictability

Continuing within the Being Different to Others theme, interpersonal experiences which require some form of managing were repeated across interviews. I came to think of these accounts as an unpredictability around the reactions of others. All participants belonged to multiple support networks and described positive relationships in their lives, but all had experienced negative or unwanted experiences which were understood to be due to the reaction of others to their cleft lip and palate. I wondered how it is possible to know and understand the intentions and meanings of others, particularly strangers. It seemed to me a logical assumption that the less visible a facial difference is, the less noticeable it is and therefore easier to live with, but I began to wonder whether this is in fact true. People overall tend to prefer a degree of certainty, of predictability. When your world is unexpectedly intruded upon by another does this impact on how you learn to interpret and interact with the world?

"Other people's reactions aren't just cos they're horrible, it's mostly due to their lack of understanding, their lack of knowledge and it's kind of like, innate fear you know."
(Traveller: 51, 586-589)

Traveller's statement is powerful. She locates within the other an innate fear, of her, which leads to negative reactions. Such a statement invokes a powerful empathy in me, for an individual to experience herself as to be feared, not because of anything she has done but simply for having a difference, which is reacted to by some and not others. Anna adds to this:

"So, it's like there's two things always going on, there's the me that is living exactly the life I probably would have had without a cleft and then there is the me that is in the world dealing with people's reactions. And that's the thing, it's the people's reactions that are the problem, not the cleft itself."
(Anna: 51, 157-163)

Here, Anna names the problem as the reaction of others to her cleft. I find the description of two worlds here intriguing. Anna seems to be describing that having cleft lip and palate has brought a duality to her life, something extra that needs to be dealt with.

"The good thing is that they [my children] see if you're born with a cleft you still have a good life, you still have a good career, you still have a partner, you still have children […] ... do people treat you differently because of it? I think initially maybe but then they soon forget that you have it."
(Flower: 57, 984-990)

Flower is referring to the genetic possibility of her adult children having children who could be born with cleft lip and palate. I find this interesting to reflect on. She is describing the positives about her life, summarising how her life has been. I wonder if Flower is presenting a 'best version' of herself, to manage the lack of control she has over their circumstances. Her statement summarises the things in her life she values most then she pauses. Her comment regarding other people 'they soon forget you have it' is also interesting. Why not 'it makes no difference to them". Why do they need to 'forget' to make things okay? Flower's tone altered in her last sentence, she sounded less certain.

"I think I do hold back quite a lot. I can come across quite shy because I am quite reserved --I don't know if reserved is the right word, but it takes me a while to get to know people and trust people and be comfortable with people. I think that's probably the main impact really… […] I don't want to be friends with people who aren't genuine, or I don't want to allow people to hurt me."
(Stormy: 29, 917-923)

This is very revealing. Stormy tells us she holds back until she feels trust, which allows her to feel comfortable. If we do not feel trust for others and we feel neutral, do we hold back? Or is it more likely to hold back due to a feeling of threat, or unpredictability? Stormy refers to others potentially hurting her which suggests that strangers and acquaintances feel threatening and she needs to guard against this.

"People who don't know me, I have to work twice as hard to get them to understand me."
(Oscarbertie: 54, 24-25)

This sounds tiring. Oscarbertie is describing that her speech, which is affected by her cleft lip and palate, impacts on communication when she meets new people because she does not know if they will be able to understand her speech or not and if they don't, she will need to increase her effort to be understood.

"*I have got female friends but it's similar people in that they've had a bit of a battle in their life… we don't talk war stories, but it is a bit like that."*
(Fred123: 41, 875-878)

Fred123 expresses how she finds support amongst friends. Without saying what for, her comment allows us to understand that there have been battles, war stories, to process. I wonder whether Fred123 feels most affinity with people whom she perceives to have had challenges in their life. If so, does this mean she feels less affinity with people whom she perceives to have had an easier life? I feel this suggests Fred123 experiences herself as a member of an 'embattled group'.

"I feel safer with that with you than I probably would have, I think if you hadn't, I would have been a bit more like 'why?' [are you doing this research]."
(Puddle: 55, 1612-1614)

Puddle has acknowledged here that if I had not had cleft lip and palate, she wouldn't have felt as safe with me. When I arrived at her home, Puddle was extremely gracious towards me, offering beverages and food and checking my comfort levels several times. I hear her question (why do you want to know) would have been a polite way of being wary, checking for threat, in case it was not safe to share her thoughts and feelings in the interview. Her assertion that she felt safer with me implies that I 'understand'. While the whole focus of this research is to do that very thing, I have found it harder than anticipated to specify what understanding actually is. Each account here speaks to an unpredictability of the reactions of others, with something of a need to protect the self. Is this as close as we can get to understanding this experience? Cleft lip and palate takes on a meaning here of something that makes an individual more vulnerable to

potential threat. Potentially the threat may have been to be 'othered', to be made to stand out and apart from the group, to be positioned as 'different', as 'other than' what's expected and seen as the norm. To have to account for oneself and therefore to be classified as 'not one of us', like a stranger.

3.3.4 Bullying and abuse

Bullying during childhood and adolescence is unfortunately so commonplace that I reflected at length at how to conceptualise bullying and how meaningful it might be for the purposes of this research. I decided to think of 'cleft-themed bullying' and be curious about the sense participants had made of experiences of bullying.

I found it very helpful, if somewhat emotive, to reflect on Wright's (2011) account of able-bodied fear of dis-abled bodied individuals. Wright explains that face to face encounters with any form of disability or deformity frightens people due to their sudden conscious awareness of their own vulnerability to disability or deformity. Such fears, usually lurking out of awareness, are experienced. Davis (2002, p. 39) asserts that in facing these fears one must "shift from the ideology of normalcy […] to a vision of the body as changeable, unperfectable, unruly and untidy."

Perhaps I have sought to understand bullying and abuse here as an antidote for myself, a possible way of understanding and identifying who the problem is really located within. The last time I experienced unwanted attention was five years ago, when a stranger asked me "what was wrong [with my lip]" then when I explained, immediately replied "oh God, you're the reason I'm scared to have kids." To me this was indicative of the 'out of awareness' fear present in some individuals in society. It was deeply unacceptable but sadly not too uncommon. It remains a difficult experience to adequately describe in words; a sense of powerlessness against the reactions of others while having a defining mark on the face which is both visible and invisible, depending on the gaze of the observer. To me there is an invisibility and insidiousness around cleft lip and palate bullying; the depth of emotion it inflicts on the stigmatised individual is felt but not necessarily seen by others and perhaps because there was never a beginning to the story, it was always just 'there', it can be complicated and difficult to explain to another, the judgement and emotional assault that has occurred. It adds to a repertoire of a story that has always been there and is interwoven into the interpersonal experience of

others in general. The accounts presented here are across the lifespan, although most are located within childhood.

Anna speaks of abuse by adults when she was a child, that was done deliberately out of earshot of anyone who might stop it, while Fred123, refers to spoken words about cleft lip and palate only coming either from playground bullies or by the clinical language used at hospital appointments.

"Every time somebody would say something […] And it would be an adult. And it would be a different adult and then, when they saw me with my Mum or my sister they would say nothing."
(Anna: 51, 292-296)

"I look back now, and I think, well, they could have been bullying you about anything but at the time it was also centred around my face… so it was all… so yeah…
(Fred123: 41, 185-189)

Fred123 is speaking of her school days and of being bullied in the playground. She links bullying and facial appearance.

Its [talking at hospital] all very clinical… you don't talk about it at home because… to them you are not different… and the only time […] it is negatively done."
(Fred123: 41, 1066-1069)

Here Fred123 illuminates another point which I found very revealing. Fred123 is describing an absence of positive language used about cleft lip and palate. As she says, it was not talked about at home because it had no relevance, however cleft lip and palate was talked about in a detached, clinical sense at hospital, and previously she describes it being a focus for playground bullies. I wonder about the impact of hearing others talk about cleft lip and palate in only either negative or neutral terms. If language influences how we make sense of things, then what is the impact of not hearing positive language too which could help somewhat to challenge or counteract negative language? Further accounts of school ground bullying are given by Stormy and Traveller:

"When I was quite young someone said that my voice was like a helium balloon and I was just like … oh you know, it's really hurtful."
(Stormy: 29, 193-195)

"The first time I remember being teased because of my, erm, my face and my cleft and... that issue, erm, was when I went into secondary school […] It's part of growing up really but at the time, it hurt lot. […] somebody squished their nose because erm this is before I'd had an operation on my nose and my nose was more, you know, wide and flat than it is now and erm, they squished their nose like that {presses nose} and erm, I can't remember exactly what they said but they obviously made a face at me and erm, and then said something about, erm, 'chinky.'"
(Traveller: 51, 87-90 & 97-107)

Language here has included name calling by others which is specifically related to cleft lip and palate and which has been experienced as painful by both Stormy and Traveller. Traveller's account is very detailed and evocative; she has not forgotten the emotional experience of it. She appears hesitant to recall the term "chinky', which is preceded by several 'erm's' and she states she can't remember what they said before sharing it. It feels significant to reflect on the experience of a phenomenon that is described by others solely in negative language, or not given words at all, as Flower describes:

"When you go somewhere new you have to deal with the issues of explaining what's different about you […] sometimes people can be awkward and difficult so when I went to another school, erm, I remember not quite feeling like I fitted in, erm, sort of being on the periphery, would I say I was bullied…I think I was bullied in that isolation way of bullying so kind of left out... I remember I would stay home quite a lot."
(Flower: 57, 184-193)

Flower is referring to bullying in the form of exclusion, whereas previous accounts have demonstrated more overt forms of bullying e.g. teasing. Her account identifies herself as different and indicates she expected to have to explain this to others at school. Flower links her experience of exclusion to being different and not fitting in. It is interesting she does not say she is different because she has a cleft lip and palate; I understood this was implicit in her account. While no language is specifically referred to here, I wonder

whether the lack of positive language about cleft lip and palate overall in accounts emphasises a sense that others will react negatively, based on past experiences.

Experiences were not confined to school environments. Puddle recounts an experience in hospital with a nurse after she had vomited and been cleaned up following cleft lip and palate surgery, and had vomited again:

"I was about ten, she said you're the oldest child on the ward and you're the most trouble, and you know, I'm not going to bother to change you."
(Puddle: 55, 65-68)

This account brought back a vivid memory for me aged 7 of waking in hospital following surgery and experiencing what I thought was vomiting blood but was normal bleeding from the surgery. I can recall how frightening and disorientating it felt to be in a strange bed, drifting in and out of consciousness, and seeing bright red blood spreading across white sheets and I recall nurses rushing over to change them. This memory gave way to other memories, and, as has frequently been the case throughout this research, I have needed time to process and bracket my own experience to return to focus on those of participants. Having cleft lip and palate means being exposed to hospital experiences to navigate. Puddle said her incident strongly affected her and was directly linked to her career choices in later life because she chose to enter into a caring profession working with children in the hope that other children would not have to experience what she did.

In adult life, Oscarbertie describes a work-based experience. I chose to include this to highlight that bullying experiences were not confined to childhood.

"You could see the guy up on the [___] looking at you going, 'what can I do to her today?" It was a bully environment and you had to be strong to stand up to that and in the end I couldn't… […] they don't understand how you're feeling and basically… you're easy pickings."
(Oscarbertie: 54, 503-504 & 558-560)

Oscarbertie's description 'easy pickings' is suggestive of her feeling vulnerable and exposed. She describes a 'bully environment' which sounds like a hostile space. Her

tone lowered when she said, “in the end I couldn’t” which felt painful and sad because she was describing her bravery in the face of a hostile environment in which it perhaps wasn’t possible or worth persisting in.

Stav holds a philosophical perspective:

“*I think secondary school is the hardest in life for everyone, it doesn’t matter in life if you’ve got a cleft or not.”*
(Stav: 23, 104-107)

I reflected on whether Stav’s experience, as the youngest participant in the study, might hold hope that within a changing society, negative experiences of cleft-themed bullying are becoming less common or whether there are greater support resources available. Or it could be that awareness of bullying in general has been raised in society which means that Stav is able to contextualise her experience by understanding it as just one manifestation of the phenomenon of bullying which many young people are subjected to. The next theme explores in more detail how participants managed their experiences.

Smith & Osborn (2003, p.51) describe IPA involving a ‘double hermeneutic’, referring to a recognition of researcher and participant as making sense of the phenomenon. My role as researcher is also influenced by my personal experience of the phenomenon. I relate to Traveller’s description of feeling ‘special’, having attributed overcoming difficulties to my earlier experiences of needing to overcome painful operations, treatments and experiences. When I was Stav’s age, I also felt it was very minor and all ‘in the past’. I have explored whether I would choose not to have it if I could and I have always felt I would not change it. Until embarking on this research, I have never had a reason to question *why* I feel this way. There are no objective advantages to having been born with it, but my assumptions have always been that it has made me more resilient, that it has given me insight into my own capacity and I assumed it taught me how to overcome obstacles. Now I ask what if it wasn’t the cleft lip and palate? It’s only skin, flesh and (lack of) bone after all. This question has left me pondering my own experience at length and at times has felt quite uncomfortable. I have frequently paused my analysis to reflect and write about my own experiences. My journal dated 17 November 2017 reads:

I feel extremely inhibited writing about this [cleft lip and palate]. I can't explain why it's so hard. It feels incredibly threatening, I feel exposed. A freak. An embarrassment. I've always kept it so private, but I've also always felt like it's written all over me. Everyone keeps telling me they can't even see it. Why didn't I ask anyone sooner? And how come the last time a stranger asked me about it they insulted me and said I'm the reason they're scared to have kids? How come I get such a horrible comment from one person but others say they have no idea I have it? How am I meant to explain how others experience it when I can't even say what it is for me?

Doing this research has ultimately made me reappraise what it means for me to be living with cleft lip and palate. I believed I was simply supposed to stay out of the way, not create too much fuss, that I was a burden, unwanted. It has been a felt sense all my life, brought to life at various times and often simply lurking in the background but nonetheless always there.

3.4 Super-ordinate Theme C: Facing Challenges

A repetition of participants sharing coping styles were described throughout interviews. As has been the case with previous themes, these themes capture different aspects of experiences related to coping with specific cleft lip and palate related concerns.

3.4.1 Overcoming Obstacles

I considered at length whether overcoming obstacles was the most accurate name for this theme. At times participants describe ways of 'getting on with things' and a form of 'acceptance and becoming the person they are' rather than overcoming obstacles but I felt it could be argued that overcoming obstacles is in fact the product of 'getting on with it' and 'acceptance and becoming the person they are'.

Accounts of overcoming obstacles were given multiple times across interviews. These were frequently linked to life and career aspirations. Participants frequently shared ways in which they found strength in themselves to meet challenges. In selecting quotes to represent this I opted to attempt to demonstrate a range of ways in which this occurred.

"I've been treated pretty badly sometimes but I just put it down to experience and move on cos there's nothing else you can do, […] you can't change everybody's perceptions of everything but what you can do is you can get on with your life, […], they might be nasty but erm, you're not nasty, you're a nice person."
(Oscarbertie: 54, 455-462)

This is an explanation which sounds like a motto for life, how Oscarbertie strives to live. Her voice drops in pitch when she began to speak, dropping her eyes briefly but then she connects with the meaning of her words and she sounds more determined and confident. She is describing how she finds ways of getting on with things.

"I became a bit more open about it because there was another girl in sixth form […] so she had a sort of slight scar on her lip, so I just talked to her and […] it was then I realised that …. how I thought other people thought I looked was actually very different you know, to the reality, erm…. and that in actual fact most people were far less aware of it than I was. […] it was kind of a turning point, because she actually thought of me as being quite confident"
(Traveller: 51, 239-245)

Previous themes have demonstrated that visibility of cleft lip and palate may be experienced as threatening. Here Traveller demonstrated that by speaking up and talking about visible difference she could obtain feedback which challenged or reframed her perceptions about the visibility of her scar. As Traveller spoke, I could hear hesitation and surprise in her voice, almost as if she were reliving the experience in recounting it.

"*I think I can honestly say I don't think my cleft has affected me at all in my career, erm, I chose to go into [___] and I'm pretty sure that's because I spent so much time in hospital, so I felt very sort of… comfortable in that environment… actually, I've got to switch back a bit. I do remember having operations as a young child and being very scared."*
(Flower: 57, 214-223)

"it would have been interesting to… have gone through life or my formative years not having that, to be fair, quite honest talking to you now it would be good but I… then you

never have that same experience and then maybe I wouldn't have been a [___]… I hope I've changed people's lives."
(Puddle: 55, 1223-1230)

"*I was reading it going 'mmm, I am in the risk category', my life, just seeing it like that, […] and I got my pen, I was ticking off, oh, hang on a minute, […] I would have been the child that my program was aimed at, and oh well, now I know why I'm doing this job you know… I'm going to save the world for all these other vulnerable children."*
(Anna: 51, 755-764)

Anna is talking about a work role in which she designed a program for use in supporting vulnerable children. She had described that if she had done a risk assessment on herself based on her own childhood experiences she would have met indicators for a child at risk. She had not recognised the parallels between the program she was designing in her job and risk indicators from her own childhood experiences until she had completed it and then sat down and read it. She experienced this as confirmation that she was in the right role for her, working to protect other children from harm.

Here we have three accounts of how cleft lip and palate experiences have been linked with later career choices. Flower questions her own perception after stating she felt comfortable in hospitals when she recalled her earlier memories of fear. She is saying that at some point, she overcame her fear and became comfortable. Puddle is describing something slightly different, almost like finding her way because of her experiences into a career she values. She considers whether her life might have been better if she hadn't been born with cleft lip and palate and seems to reconcile herself; if she has made a significant difference then it has been worth it. Anna also describes having found herself in a role, only then realising its meaning and relevance to her based on her childhood experiences which she has previously described as being negatively impacted on due to her cleft.

"I'm quite a strong person. Just try to be strong and, you know, look on the bright side really."
(Stormy: 29, 178-180)

"I'm very empathetic towards people, that's all, kind of, shaped me, to put me there."

(Fred123: 41, 251-253)

Stormy and Fred123 both share evaluative statements to summarise the qualities they value about themselves the most; strength and empathy respectively. Finally, Stav gives insight into recovery from an operation and how she has coped:

"You kind of do what you have to do really, to get through it, […] I always used to say that to myself at the end of the day once it's over it's done, and you just have to focus on sitting there and getting well really and that's your body kind of doing it yourself for you."
(Stav: 23, 942-949)

3.4.2 Making Use of Defence Mechanisms

Several accounts have given insight into painful life experiences and insights were explored into ways participants found themselves defending against emotional injury. All accounts may be read as containing a degree of bracketing off, or avoidance of own feelings, to manage whatever context the participant was in.

"[You] kind of just have to sometimes ignore certain people and not let it get to you really."
(Stormy: 29, 188-189)

"I used to walk down the road with my halo on and… go swimming with it on, I didn't, I was brought up to be tough and say, 'well actually I'm, not going to care' when inside you do care."
(Fred123: 41, 205-209)

Fred123 identifies here with being *'tough',* a characteristic which enabled her to go out publicly wearing a halo as a teenager (metal head frame worn after surgery for some weeks). I felt admiration in hearing this and sad that she described not sharing her feelings as a means of coping.

"I understand that was just a natural part of going up, it's how we operate as a society and I've you know, learned to depersonalise it and that's a lot of how I deal with it, even though it is a personal thing."
(Traveller: 51, 575-579)

Traveller recognises she depersonalises personal things, thereby distancing herself from emotional distress. There is a tension here when she notes that it is nonetheless 'a personal thing'. I wonder whether there is a degree of acceptance over things that are not within Traveller's control, such as another individual's behaviour, which may protect her somewhat from feeling distressing effects from it.

"I feel more comfortable, with people I know. Erm I would reckon the biggest one is avoidance really, erm, not sure if there's any other way… maybe a bit of humour, I might have used humour."
(Flower: 57, 497-500)

I asked Flower about ways she managed things that have been difficult, the 'biggest one' referred to here is a coping style of avoidance. She also refers to humour, which is further commented on here.

"I can take the mick out of myself, I can laugh at myself and I think, once you can do that, but it's taken me fifty odd years to get there…"
(Oscarbertie: 54, 190-193)

Oscarbertie describes 'taking the mick' out of herself, suggesting she can laugh at herself. Perhaps it also might mean she can be self-depreciating. She references that it has taken her a long time to reach a point where she seemingly feels more comfortable. I wonder about the function of humour here, is it for Oscarbertie or is it for others, a way of stopping people teasing her because she does so first? If it is the latter, it may be protecting her from more immediate effects of the potential behaviour of others, but it does not say if it allows her to also experience herself in other, more vulnerable ways.

"You know it was stupid, erm, that sort of thing, trying to get a laugh erm but I became form captain, I was very popular… […] I definitely did things like that and I became the class clown."

(Puddle: 55, 372-374 & 410-411)

The last three accounts here are of using humour as a way of coping. Puddle also refers to making herself 'the class clown' as a way to get others to laugh. She shares that she was very popular. I understand the two to be linked, that Puddle wants to be liked and therefore accepted by others, so she adopts a persona of a clown to make others laugh. It is reminiscent of 'putting on a costume, or an act'. Additionally, clowns are recognisable by the fact they cover their face. What is not said is whether Puddle might have felt it was possible to be liked and accepted if she didn't make others laugh.

"*I was quite creative like trying to do piano classes and recorder classes and get myself into doing something creative to again, probably take my mind off things or just put my energy into something other than just feeling the outsider [laughs] you know."*
(Stav: 23, 394-399)

Stav's account sounds upbeat, until she uses the word 'outsider'. She laughs, perhaps as a way of identifying with her creative self rather than the part of her which may have more painful feelings around the sense of being an outsider.

"*Inside I would have an adrenalin response and I would feel frightened, but I learnt very early on to control my face and so erm, I learnt very early on to just set my face and keep walking."*
(Anna: 51, 305-308)

Anna is describing something based in fear; she recalled feeling frightened and not showing her feelings. She recognises changing her expression in a way which sounds like the embodied experience of putting on a mask. This feels like a conscious threat response, in which Anna feels unsafe so she takes steps to cover up her vulnerability. While the contexts are different, both Puddle and Anna use descriptives which allude to them changing the appearance of their faces.

3.5 Super-ordinate Theme D: Wishing things had been better

This final super-ordinate theme focuses on an interest held by participants, which was to share their less favourable experiences. I understood this to be a way of processing more difficult or less resolved experiences and also, perhaps, to provide information or advocacy for others based on each participant's own lived experience. These accounts within interviews were hugely affirming and moving to hear.

3.5.1 Not knowing what to expect

The first theme centres around information not being available to participants at times when they might have found it valuable to know, with repeated suggestions that better access to education, information and support might benefit others with cleft lip and palate.

"My Mum said, "it's a lovely little tip top nose" and all the rest of it, I mean I wasn't aware, but it was an improvement."
(Traveller: 51, 1005-1007)

Traveller's tone dropped when she recounted '*I wasn't aware'*. She is recalling not being able to see a visible improvement following an operation and I understood this to have been disappointing to her. I found it interesting that she described she could not see a difference, but others could, which suggests to me a kind of disconnectedness to the experience of being operated on and not being able to notice afterwards.

"As a child […] they didn't really tell you much, I went in for an operation and I was convinced I was coming out perfect, so you go in, have an op and you go out without a cleft, that was my opinion in those days, and I'd come out, look in the mirror a week later and it was still me and I couldn't actually see any difference [laughs]."
(Flower: 57, 829-836)

Flower laughs at the end of what feels a very painful experience to have had. Although Flower does not name disappointment, I imagine this would have been part of the experience. Hearing these accounts brought back memories of my last operation, when others told me they could see a difference but, at least initially, I could not. I had not

known that others having cleft lip and palate surgery might have looked in the mirror and experienced a similar thing. While wishing it was different, it is somehow comforting to know that this can happen to others too.

"You thought, being positive, that those things [bullying] could come to an end by having an operation then, bearing in mind you were a child, so you were thinking like a child and […] the end never comes, so therefore you feel disappointed and you feel… angry, and you feel upset and you feel like… no-one cares, yeah. […] I suppose nowadays, you'd say I had depression."
(Oscarbertie: 54, 271-286)

A very similar account is given by Oscarbertie. She names disappointment as well as other painful feelings, such as anger and upset, which she now recognises as depression. She describes her positivity, or hope, that an operation could end bullying at school. It is crushingly painful to imagine her, as a child, hoping desperately for her operation to remove visible signs of cleft lip and palate so that it will end bullying and other problems, not knowing what to expect from the operation and having to find out the hard way that this was not the case. Her conclusion that 'no-one cares' feels very lonely. Her account seems to indicate that no intervention came in her childhood as this is where the story ends.

I remember operations as a child feeling quite traumatic, it is a big event for a child and I cannot recall doctors telling me what to expect either. I do recall the feeling of being back at school as a teenager with a bright red scar and having to endure stares and sniggers while still in pain. There was a disconnect between each environment I found myself in, from hospital to home to school and I do not recall there being guidance as to how to navigate each one.

"You never as a child ask questions about it and no-one ever sits down and explains it properly either, and then when you go to have it done it's just a mechanical… treadmill that you're put on… that you go down, have an operation, come out and go home and there's no… concept… of what comes with that."
(Fred123: 41, 1028-1035)

Fred123 makes a very familiar point to me. I find the use of her words 'mechanical treadmill' very striking because it sounds so detached and depersonalised. She sounds like an object in her own experience. When she says there is no concept of what comes with it, I assume she is referring to medical staff, but I wonder what concept Fred123 might have had herself? Without specific information to draw on, her emotional experience may have been confusing and hard to verbalise.

"I know that they have therapy sessions for children in hospitals and things like we didn't have when I was younger… it was just 'go to your appointments' you know… 'and then we'll just take you home'… it wasn't very much 'how are you feeling?' you know, as a kid you just didn't get that… […] I think it probably would have helped."
(Stav: 23, 282-289)

Stav's account does not use Fred123's term "mechanical treadmill" but I understood it in a similar way. She considers that talking would have helped but it wasn't available. Her account made me feel sad because I was quite surprised to hear she had not been offered any psychological support. I had thought that was part of the new service under cleft teams and, given Stav's age, I had assumed this would have happened.

"I think now with social media there is more of that isn't there […] you can talk to people now and it's a lot easier whereas growing up you didn't really have that."
(Stormy: 29, 255-259)

Stormy affirms too that she did not have people to talk to about her cleft lip and palate care while she was growing up. She links the ability to talk with making things easier and highlights that social media may help facilitate this, which is described in a positive way.

None of the participants were offered any psychological support throughout their childhood. I feel it is helpful here to report briefly on specific findings from the participant group regarding adult cleft care. I did not ask each participant specifically about the number of operations they had had but, in some interviews, it came up. Three participants reported ten, eleven and fifteen operations apiece. I considered this to be characteristic as I'd had nine but when I shared my own medical history with peers, I found people were surprised to hear how many operations can be involved. I also

learned that of five participants aged over age 50 at the time of interviews, four of them had been offered further surgery for cleft lip and palate.

Finally, Puddle's account gives rich insight into several life factors in amongst her lived experience of cleft treatments:

"You didn't have that psychological support with what happens now with kids or even meeting other kids... you know I didn't have… I didn't go to a clinic with cleft lip, I went to a clinic with, at [___] and it was the guinea pig club from the war, so all I remember going to clinic were these men with {medical implements} and being really frightened of them… And, because it was plastics, but I didn't meet anybody else and it was very much stiff upper lip […] but interestingly […] because of that my father didn't really ever mention it much, I mean he did a couple of times but when he passed away […] erm, it'll make me cry, erm he, all donations went to CLAPA, so it was never really mentioned but [tearful] so that was lovely."
(Puddle: 55, 691-673)

We are able to learn here that Puddle's father, who she reported been advised not to discuss cleft lip and palate by consultants, communicated support for cleft lip and palate care after his death. It is showing a sense of him speaking from the 'other side' saying 'I always cared about you and about your cleft lip and palate; these are my true feelings expressed in this way.' Puddle's experience of her father's action was that she felt loved. Although done in an unconventional way, not how we usually think empathy works, through the will Puddle experienced an empathic parent and although it was never spoken of, it was nonetheless communicated.

3.5.2 Sharing what I've learned

This is the final theme and one in which I have understood to contain motivations for taking part in this research. It allows participants a platform to share their voices directly about what they have struggled with. Sharing these accounts may have a dual function; to move on from such struggles and to share with others as a way of helping others, and so to make meaning from these challenges:

"I think that's why I volunteered. I think it's because it's important that somebody's looking at that […] and talking was something that's never been available actually, for me… and although I've found my way […] and over the years I've found ways of dealing with it… maybe if that had been something that had been built into what's offered to people in this situation from a young age then maybe so many of these things that have been such a battle for me to come to terms with myself, might have been addressed far earlier and it might not have been so difficult, so it might [be] valuable for other people."
(Traveller: 51, 876-892)

Traveller is explaining that her motivation for taking part was because she believes talking is helpful. She acknowledges that talking therapies were not available to her and she reflects on whether, if they had been when she was younger, if this might have made her life easier. This is suggestive that at one time, this may have been an unmet need. She suggests that talking may be valuable for others with cleft lip and palate.

"I will always say to the Mum's you know […] I'll say, 'oh what a beautiful baby' and you know […] if you've got a, you know, a baby that wasn't so perfect or you know, a baby that's slightly different, people do look and stare and I do get angry about that and so I always, always in my little world make sure that they do get recognition that their child is beautiful."
(Puddle: 55, 1512-1525)

Puddle gives an account of complimenting mothers if she notices their baby has been born with a disability or congenital condition. She shares her anger at the prospect of people staring at a baby who has a visible difference and her reaction is one of reassurance to the Mum. I wonder whether this is also a form of reconciliation for Puddle, that she was also born with a visible difference and, while she won't have memories of herself as a baby, she may have an impression of herself as a baby. Perhaps this is a way for her to treat others as she would have liked to be treated herself.

"I don't have a problem talking about it now […] In fact, I think I might be on a bit of a crusade [laughs] and see it as my duty to inform people."
(Flower: 57, 726-732)

"I sat there, and I said, 'you know what I can advocate for these people, but I can't advocate for myself' and that was my reflection on it all… actually I was standing up for these people because I feel they are in a minority."
(Oscarbertie: 54, 172-176)

Flower and Oscarbertie describe seeing themselves in roles now as educators, or advocates. Flowers assertion that she doesn't have a problem talking about it *now* tells us it has been something of a journey to reach this point where she now feels on a crusade, ready to act. Oscarbertie describes her professional role where she advocates on behalf of vulnerable people. In taking part in this research, she is perhaps also advocating for others, but it could be reasoned, also for herself.

"No-one sees that actually the mind could've been traumatised through it… so it's something about having checkpoints around the big operations I think when you're little and you have your lip done and the palate and things, that's less of, I don't really remember any of those it is really the big traumatic operations, the two, and then it's about the bullying and I dunno, maybe educating parents a bit better, teachers…"
(Fred123: 41, 1454-1462)

Fred123 states that no-one considers the potential for cleft lip and palate to be traumatic. I wonder whether trauma was part of her experience. She refers to 'big traumatic operations' and bullying as potential traumatising agents. The fact that she remembers little of other operations but two stand out are indicative of them having had a greater impact. She suggests that educating parents and teachers may systemically benefit children with cleft lip and palate.

"It kind of shapes what I want to do with my future… and I want to help other people with it you know, and I want to raise more awareness."
(Stav: 23, 1066-1068)

Stav expresses a wish to help others with cleft lip and palate in the future, based on her experiences. She describes it as shaping her future in a sense, which is powerful.

"It would be good if there was more medical knowledge out there. I think they are working on it, but yeah… my GP hasn't got a clue."

(Stormy: 29, 1160-1162)

Stormy also recognises a need for access to information and her tone sounds hopeful when she says she thinks this is being worked on but then she acknowledges she currently cannot access this support through her GP. I find it helpful to include this here because it represents her lived experience. Stormy's tone was stoical rather than distressed when recounting this.

"I think there is a huge denial that actually people with clefts live with their cleft throughout their life, it is a long-term condition and that's the medical language […] if we're going to label it that way."
(Anna: 51, 1414-1418)

Anna is talking about a different stage in the life span. She uses the word *denial* to describe responses to the life-long impact of cleft; although it is not named here, she is referring to medical, statutory and charitable services. I find it helpful that she is labelling it as a long-term condition, because this is clear, and it tells us that this is a label Anna can identify with.

3.6 Summary

In this analysis chapter I have discussed my super-ordinate themes and themes table (see Appendix 9); I have systematically worked through four super-ordinate themes with a combined total of ten associated themes, presenting my analysis alongside personal insights gained. Taken together, the super-ordinate themes 'the threatened self', 'being different to others', 'facing challenges' and 'wishing things had been better' demonstrate a broad spectrum of experiences which allow us insight into the lived experiences of women with cleft lip and palate. This has given insight into the duality of experiences, demonstrating that having cleft lip and palate can be both an issue which impacts on life and not an issue, depending on context and other factors.

'The threatened self' tells us about how participants experience themselves and conceptualise their cleft lip and palate; 'being different to others' tells us how participants interact with, experience and feel in relation to others; 'facing challenges'

tells us how participants have managed challenges and finally, a ‘wishing things had been better’ tells us about the motivations participants had in improving things for others by taking part in this research.

I would like to say a special thankyou to participants for giving their time and for sharing their personal stories for the purposes of this research.

4. Discussion

"A people without the knowledge of their past history, origin and culture is like a tree without roots." *Charles Seifert (1938)*

The content of this discussion chapter is structured in the following way: it starts with an overview of the analysis, presenting a 'bird's eye view' of participant experiences presented in the analysis. It explores transferability issues; quality markers are revisited and reflexivity on methodological, epistemological and personal issues are discussed which are relevant for the reader in considering the significance of the research. It goes on to discuss the contributions this research makes to counselling psychology in terms of theory, research and practice and areas for future research and practice are considered. Finally, reflexive conclusions are made.

4.1 Overview of the Analysis

My endeavours to understand the ways in which CL/P has impacted on the lives of participants led to the development of four super-ordinate themes and ten themes; see Appendix 9 for a diagrammatic representation. As a recap, I will present a brief description of each super-ordinate theme analysis here.

'*The Threatened Self'* explores the complexity inherent in the development of *identity* through coming to know oneself. It explores how participants experience themselves and how meaningful the experience of CL/P is to them. CL/P was identified for some as being a lifelong part of identity which holds value. This points towards a relationship between CL/P and learning to cope from having overcome obstacles subjectively attributed to CL/P. CL/P was also interpreted to pose something of a threat to self-identity which leads to a tension between acceptance and non-acceptance. Conceptualising and experiencing the self as not good enough may be the assumption drawn from experiences of *difference.* The concept of difference may be introduced into an individual's life by others, becoming a painful challenge for the individual to seek resolution to.

'*Being Different to Others'*, in which interpersonal influences have been interwoven with sense of self, explores the social and relational experiences of participants in relation to others and how participants regard CL/P having had an impact on these experiences. Participants were shown to take great care to protect their parents from criticism; talking about them in a very understanding and protective way. Generational differences were apparent between participants in their reported early experiences of cleft care for infants and stigma within society, with those born in the 1960's reporting experiences differently and less positively to those born in the 1980's onwards. CL/P visibility was seen to be an issue within the arena of dating, with heightened visibility perceived as a barrier to fitting in or being accepted. Participants' experiences of how the presence of CL/P seems to legitimise intrusive behaviour from others was demonstrated. The unpredictability of the reactions of others was also identified. Additionally, CL/P seems to take on a meaning of making an individual more vulnerable to potential threats such as being 'othered', being positioned as 'different', to have to account for oneself and bullying in the forms of exclusion and more overt forms of bullying e.g. teasing.

'Facing Challenges' explores accounts of overcoming obstacles which were given multiple times across interviews. Obstacles were frequently linked to life and career aspirations. Several accounts have given insight into painful life experiences and insights were explored into ways participants found themselves defending against emotional injury. This may be read as containing a degree of bracketing off, or avoidance of own feelings, to manage whatever context the participant was in. Humour was frequently employed as a way of coping and covering up as if in costume or mask was also identified.

'*Wishing things had been better'* explores experiences which participants share as a means of acting as advocates for others based on each participant's own lived experience. It allows participants a platform to share their motivations for taking part in this research, sharing what they see as helpful insights to share with and inform others, possibly as a way of making meaning out of their own experiences. It is also reflective of wanting something good or constructive to come from having struggled. Perhaps it suggests that suffering and/or struggles become meaningful if something positive (e.g. learning, growth and/or helping others) can come out of it.

Critically, I would argue that my themes as a whole are able to bring together themes that are not presented as opposites but different things that make up the whole of experiences reported. I have been able to identify experiences, reactions and emotions that could appear to be separate and contradictory but have been brought together by my understanding of the experience as involving a dynamic between having problems and not having problems.

4.2 Theory and literature

4.2.1 What does my research support?

My research supports existing literature within the field of CL/P. Stock & Feragen (2016) organised the findings of their comprehensive literature review of 148 quantitative and qualitative studies into five domains and sub-domains, some of which closely correspond with the super-ordinate themes identified in this research. Stock & Feragen's *emotional wellbeing* closely corresponds with the super-ordinate theme 'sense of self'; *social experiences* correspond with 'Being Different to Others' and the sub-domain of *internalising and externalising behaviours* within *behaviour* corresponds with 'Facing Challenges'. In particular, my analysis represented CL/P as a long-lasting characteristic of identity which is shown to be experienced as emotionally painful but can be accepted and integrated into sense of self following struggle. It appeared that there are times across the life trajectory when emotional pain 'flares up' while at other times it lies dormant. I think this finding shed light on contradictory findings explored in the literature review because identification with CL/P is conceptualised as an evolving and changing process. Perhaps rather than existing studies not being accurate because they are contradictory, perhaps they are all accumulating important information which characterises different parts of an evolving process.

4.2.2 What does my research add to the literature?

I believe my research has contributed to the literature in a number of ways. Firstly, I used an IPA approach which is a different approach to other studies in the field which largely use quantitative methods (Stock & Feragen, 2016) or other qualitative methods

e.g. thematic analysis (Egan et al., 2011, Stock et al., 2016, Stock & Anwar, 2018). My research has also developed a better understanding of adult women's experiences which is a valuable contribution given the overall lack of clarity in the literature on lived experiences. I also incorporated coping strategies and resilience which is little referenced in the literature. Searle et al (2017) argue that a greater focus on psychological growth and resilience is needed in the field.

Additionally, I reflect throughout on my personal reflections of being born with CL/P throughout the research process which I have not come across in other literature in the field. I believe this adds texture and meaning because it adds another perspective to the research. I am also contributing a perspective from Counselling Psychology and bringing in related theory.

Finally, the fourth super-ordinate theme 'wishing things had been better' does not appear to previously have been addressed in the literature to date although these are some similarities between accounts given within this super-ordinate theme and Stock and Feragen's (2016) *experiences of treatment* within the domain of *satisfaction with appearance and treatment*. I suggest that further significance has been established here in terms of recognising that meaning-making is shown to be important for individuals with CL/P.

4.2.3 Does my research contradict others?

The third super-ordinate theme 'Facing Challenges' includes the theme 'overcoming obstacles'. The concept of resilience in understanding individuals with CL/P has been recently challenged in a paper by Searle et al (2017). They argue that the concept of resilience has been uncritically accepted and is problematic because it was conceptualised for use with a different discipline and is closely aligned to psychopathology. They propose *self-determination theory*, which encapsulates autonomy, competence and relatedness in the attainment of good psychological health, to be a robust theory for exploring the psychological impact of CL/P. While I felt self-determination theory was interesting, especially in its identification of social environments to be either 'needs supporting' or 'needs thwarting', I also felt there seemed to be an overall emphasis on finding positives which I struggled somewhat to share. One example is in a discussion about stigma; they make the point "the framing of

CL/P as a 'blessing' is rarely found in the literature." (p. 461). While this is true, I was less clear on how thinking of CL/P as a blessing would mitigate public stigmatising experiences; as it seems to place responsibility on an individual with CL/P to respond in a more positive light, rather than being critical of elements within society that behave poorly in response to difference.

4.2.4 Similarities with Ashworth's 'Lifeworlds'

Ashworth (2016) proposes that participant phenomenological experiences are inevitably shaped and layered by the individual's 'lifeworlds'; aspects of being human which influence subjective experience. Ashworth discusses eight lifeworlds which incorporate the way phenomena appear to us; selfhood, sociality, embodiment, temporality, spatiality, project, discourse and moodedness. I was not aware of Ashworth's lifeworlds until after I completed my analysis, but I find lifeworlds an extremely helpful concept with which to explore meaning. I feel that Ashworth's 'lifeworlds' support my findings due to the way that his descriptives of the organisation of human experience correspond with some of my research findings. My own super-ordinate themes, although I have used different descriptives, capture and mirror some of the lifeworld's Ashworth proposes; these are 'The Threatened Self' (or self-hood) and 'Being Different to Others' (or sociality).

4.2.5 Identity Process Theory (IPT)

As meanings of identity are reflected on at length in the analysis, it is useful to consider models of identity construction to further illuminate the findings of this research. This theory feels especially relevant to include because participants in my research gave their own subjective accounts of their experiences of themselves, e.g. in super-ordinate theme 'the threatened self' and this theory proposes a framework for better understanding how identity is experienced. Breakwell (1986, 2001) developed Identity Process Theory which suggests that self-identity is a structure organised by universal processes of *assimilation–accommodation (*the immersion of new information into the identity structure) and *evaluation* (places meaning and value on the contents of identity). Breakwell (1986) originally identified four principles of identity; continuity across time and situation (*continuity*), uniqueness or distinctiveness from others (*distinctiveness*),

feeling in control of one's life (*self-efficacy*) and feelings of personal worth (*self-esteem*).

A central prediction of Identity Process Theory is that if identity is threatened, an individual will need to employ coping strategies to deal with the threat. Coping strategies can function at three levels: intrapsychic (e.g. denial), interpersonal (e.g. avoidance), or intergroup (e.g. social mobilization). Some forms of threat may induce coping at multiple levels in order to optimize identity processes. Breakwell (2010) asserts that in order to understand the processes that drive identity construction, it is necessary to examine how individuals react when their identity is threatened. Interpersonal threats which were managed by the use of defence mechanisms were identified in this analysis in sub-section 3.4.2 (Facing Challenges).

Breakwell (2014, p. 4-5) summarised, "Identity process theory is a theory of identity; it is concerned with the holistic analysis of the *total identity* of the person. It proposes that this identity will encompass elements that are dynamically derived from every aspect of the person's experience – social category memberships, interpersonal relationships, social representational exposure, individual activity and observation and so on. Identity Process Theory struggles to find a way of articulating the complex dynamic process of personhood that incorporates the personal and the social – the active, subjective conscious self and the objectified, known self. At the core of Identity Process Theory is the assertion that the person seeks to construct and maintain an identity – and that this process is orderly. It is clearly argued that this identity comprises many elements (some derived from social category membership; some derived from other aspects of experience within the social world). Identity is a multifaceted, complex phenomenon. It is both a dynamic process and a dynamic state of being." Breakwell here links identity to the sum of dynamic experiences an individual has. She acknowledges that it is difficult to express the complexity of both the individual and social influences on identity. I resonate with this description because I have held a sense of duality throughout the analysis process, instinctively sensing congruence in participant accounts that were suggestive of both individual tenacity and resilience and social anxiousness and threat. It has been difficult to express the complexity of identity. One key example is in exploring participants' accounts about whether they wish they had not been born with CL/P or whether they wouldn't change it if they could (see analysis

subsection 3.2.); participants sometimes reported both, that they wish it had been different and nonetheless they wouldn't change it.

Narrative identity is another model of identity which describes how an individual's internalised and evolving life story provides unity and purpose (McAdams & McLean, 2013). It posits that an individuals' life story "synthesizes episodic memories with envisioned goals, creating a coherent identity in time. Through narrative identity, people convey to themselves and to others who they are now, how they came to be, and where they think their lives may be going in the future". (p. 233). McAdams & McLean describe ways that humans may narrate suffering in their lives. They identify that a two-step process (Pals, 2006) is often engaged in for adults who become enhanced and strengthened as a result of challenging or negative life experiences. The first step involves detailed reflection of the experience, for example, how it happened, what the outcomes may be and what impact it may have on an individual's life. The second step is where an individual articulates and commits to positive resolution of the experience. There is a natural progression described here, from identity to Facing Challenges with adversity caused by life experiences which is also demonstrated in the structure and order of the super-ordinate themes in this research. Redemptive meanings drawn from suffering and adversity appear to be highly protective and are linked to personal growth and happiness. Perhaps this helps to explain something of participant accounts of not wishing to change their CL/P if they could; that positive meanings have been infused into the presence of CL/P. Existentially, I can feel quite moved and unsettled by knowing things could have been different while at the same time not wanting them to have been, for example, in considering whether I would choose not to have been born with CL/P if I could.

4.2.6 Difference, Stigma and Beauty Ideals

Theory relating to difference, stigma and beauty ideals are important to explore because these are concepts which are reported on and interwoven throughout the analysis chapter in the super-ordinate theme 'being different to others'.

I begin here with literature which I found especially helpful in reflecting on my role as a 'knowing researcher'. Oguntokun (1998) wrote about her experience of being a black African woman interviewing black African women as part of her doctoral thesis. Her

study explored the psychological and social effects of war, refugee and immigrant experiences of her interviewees. Through the research process, she discovered a 'seduction of sameness', a term she coined to explain the process by which she discovered that the similarities between hers and her interviewees' experiences had been far less important than the differences that existed between them. She owned an assumption that she and her interviewees would be 'us' rather than 'other' in relation to each other. She describes how she had always felt 'othered' as a black African woman living and studying in the UK and had strongly identified with African women as a result. She writes "I realise now that any attempt to equate this [interviewee feelings of displacement and homesickness] with my own feelings of displacement and homesickness is not only patronizing: it is contemptuous." (p. 526). Interviewees shared brutal and shocking accounts of their suffering and victimisation which were far removed from the lived experiences of the author. She describes a "powerful moment as I realised, I was an outsider looking in… not only were they 'other' to me but I may also have been 'other' to them." She argues that otherness and insider status "cannot be assumed in a simplistic way." (p. 528). In her closing summary she also questions whether "sameness" exists, in a similar reflection I made on whether "human homogeneity" is possible earlier in this chapter.

Oguntokun's paper led me to consider the extent to which I had assumed "sameness" with participants in this study. My reflections led me to realise that my sameness to participants lies in the shared experiences of similar multiple surgical interventions (e.g. cleft lip repair, cleft palate repair, bone graft, dental problems) and physical challenges at relatively similar times in earlier life (e.g. speech and hearing difficulties), living, at least for some of their childhood, in the UK. All participants and I are white women and all of us hold at least one University degree. I experienced a challenging process of recognition that shared experiences do not necessarily mean all experiences were shared, or that experiences most meaningful to me would be most meaningful for participants and that shared perceptions of those experiences would be the same, or that Facing Challenges would be the same. This also led me to recognise that participants themselves could not be assumed to be 'the same', that each had their own experiences which were at times similar, and at other times were different to each other. My current perspective is that I am more closely similar to the participants in my study than Oguntokun found herself to be in hers, nonetheless there are differences between all of us.

Following on from considerations of difference, individual and group experiences of difference can become problematic and detrimental due to the effects of stigmatisation of individuals or groups. Public stigmatisation can lead to stereotyping, prejudice and discrimination within society (Corrigan, 2004). Lebel et al. (2011) report that stigma occurs when "society labels a person as tainted, less desirable than others, or handicapped" (p.140). They note that stigma can be both 'felt' and/or 'enacted'. Felt stigma refers to an internalized sense of shame about having a condition and a fear of discrimination due to imputed inferiority or social unacceptability. Enacted stigma refers to discrimination of this kind when it actually occurs. Either or both forms of stigma can lead to a sense of a 'spoiled identity', meaning a sense that an individual is inferior, 'defective', and socially undesirable. Over recent years, 'ideals' of physical appearance have become more extreme and demanding (Stock, 2017). Large scale studies in the early 2000's (Harris & Carr, 2001 & Liossi, 2003) estimated that 61-82% of men and women had significant concerns about appearance and Stock (2017) notes that these figures are believed now to be even higher. Stock (2017, p. 28) reports on Partridge and Julian's (2008) findings that there are more than one million people in the UK with "significant disfigurement to the face and / or body, occurring due to a congenital or acquired condition, e.g. birth mark or burns scar". This population may be affected by appearance concerns that differ from both the ideal and the norm. As described in the literature review, film and TV continue to depict physical flaws and imperfections as indicative of mental illness, a lack of intelligence, social isolation and immorality while beauty is repeatedly associated with positive characteristics (Goode et al., 2008).

In spite of these pervasive representations of physical appearance, Stock (2017) notes that outward appearance is not a determinant of subjective wellbeing, rather, psychological and social factors such as investment in core values and key relationships have a much greater influence on wellbeing. Stock also notes that high levels of psychological adjustment can be faced by those with appearances differing from the norm because of the inherent challenges in living within a highly image-conscious society. A range of unhealthy behaviours have been observed in individuals who have an over-investment in their appearance e.g. disordered eating, disproportionate use of cosmetics, engagement in painful surgical procedures (Grogan, 2007).

One participant shared her understanding which had been explained to her by a health professional that the brain does not necessarily catch up with physical changes made by surgery and this may explain why she did not see a difference in her appearance until several years later. While I have unfortunately not been able to identify a medical source for this, I was fascinated by this concept. If there is indeed a brain mechanism that can prevent immediate recognition of alterations to physical appearance this feels very important for individuals with CL/P to be aware of prior to surgery.

4.2.7 Interpersonal Threats

Interpersonal threats are reported on in three of the superordinate themes; 'the threatened self, 'being different to others' and in 'facing challenges'. Literature on interpersonal threats allows us to consider the broad ways in which individuals with CL/P may be exposed to threats due to visible difference in the eyes of others, leading to complex challenges.

Evolutionary theories (Gilbert, 2010) offer explanations which help to understand the powerful need for humans to be part of a group for survival. Social threat is experienced as a powerful deterrent for inviting the ire of the group which in evolutionary terms, could lead to severe and fatal consequences. As well as this, humans have evolved to be social beings who derive satisfaction and wellbeing through connection with others. There is a tension for all people in terms of being accepted and being safe with others which is a strong and protective place to be or being devalued and excluded by others which is deeply threatening. This tension is inevitably shaped by an individual's experience; it is sad but not surprising that an individual who has experienced stigma at the hands of others may feel wary in social encounters.

Ryan et al. (2011) conducted an empirical study of 98 participants on societal reactions to facial disfigurement and reported that people have an evolved predisposition to avoid individuals who exhibit signs of disease; for self-protection, disgust responses are provoked, and avoidance is employed. Sadly, this response was shown to occur regardless of the fact that it is explicitly clear that signs of disfigurement (e.g. CL/P, birthmarks) are not contagious. Similar findings were observed by Shanmugarajah et al. (2012) who linked disgust emotions to observer responses to facial disfigurement and found the more visible the disfigurement, the higher the levels of observer disgust were

displayed. Similar patterns of reluctance to engage with individuals with facial disfigurement were also reported and Macgregor (1990) reported intrusive behaviours from others towards individuals with facial disfigurement especially during first encounters, including stares, startle reactions, whispering remarks, curiosity, personal questions, pity, aversion and ridicule. These studies do not describe whether an initial disgust response is then mediated by knowledge of the disfigurement and its non-threat to others, but Ryan et al. note people may have an implicit inclination to avoid people who appear sick and this may indicate that "educational programs designed to eradicate avoidance towards individuals with facial or other lesions may have little effect unless people are able to consciously (and effectively) suppress their implicitly driven motivation to avoid (p. 645)."

These studies describe an evolutionary response to facial disfigurement which involves avoiding such individuals due to powerful feelings of disgust. Elzen et al. (2012) compared adults with and without facial disfigurement exploring whether the impact of appearance impacts on social functioning. They found significant differences in social functioning between participants with and without facial disfigurement. They also found that stress levels, social anxiety and distress evoked by interpersonal behaviour were not significantly different and concluded that subjective perceptions of appearance were the only predictor of social functioning. They concluded that adults with facial disfigurements are less likely to engage in frequent interpersonal behaviour due to stress caused by stigmatisation and uncertainty about the reactions of others. Although I have described feeling uncertain myself about the reactions of others, it is something of a challenge to have it confirmed in literature. However, one hopeful finding is that subjective appearance is a significant determinant on social functioning. Springer et al. (2012) found similar responses in a study of 141 subjects on self-perceptions of facial beauty versus judgements by others found strong proof that individuals' self-perceptions of their appearance are far more significant than perceptions from others. These results indicate there are psychological mechanisms that locate self-confidence and resilience internally within an individual.

4.2.8 Making Meaning and Positive Adjustment

In this final theory, I feel my research supports Egan et al's (2011) findings and I find it helpful to draw attention to the ways in which similar findings can be constructed or presented differently.

Egan et al (2011) conducted a thematic analysis on 12 participants with a visible difference who identified as having adjusted positively to a visible difference. Four central themes emerged, categorised as *importance of appearance, personal growth, relationships with others* and *coping*. As with other literature (Stock & Feragen, 2016 & Ashworth, 2016), these themes bear similarities with superordinate themes and themes identified in this research e.g. Being Different to Others & Facing Challenges. Coping styles were seen as central to positive adjustment, which is defined as positive mental health (Seaton, 2009). Factors within coping included inner strength and positivity, active coping techniques, downward social comparisons, taking things day by day, spirituality and humour. This research also identified humour as a way of coping (see analysis sub-section 3.4.2). While this finding on humour in Egan et al.'s research and this one is the same, they are being presented slightly differently. In Egan et al.'s paper, the focus is on positive adjustment whereas in this research I have attempted to stay close to the meaning of the behaviour for participants. As I have discussed previously, I have repeatedly found a duality to experiences reported on throughout the analysis. I analysed humour to be used as a defence mechanism, rather than as a form of positive adjustment but I believe both can be true and humour can be employed for different reasons at different times, so humour may not itself just be one thing.

4.3 Methodological reflexivity

4.3.1 Limitations of the study

Selecting IPA as a methodology is not without its challenges. Firstly, IPA's assumption of homogeneity raises questions. Homogeneity was a concern at the start of the research when I selected female participants to take part. The idea of meeting homogeneity by selecting only participants of the same gender was a concept I held in the earlier stages of the research but in practice I found that the concept of homogeneity dissolved quite quickly. For example, none of the participants reported experiences that were exactly

the same. I became aware of biographical, geographical and historical differences and each participant had their own distinctive voice with their own interpretations of phenomena. There were variations based on age, of different medical interventions and societal reactions, which also may have had geographical or community differences. There were differences in descriptions of families' participants were born into and accounts of how families coped, there were also differences in the support and education available. From an assumption of homogeneity, I developed a perception of contextual issues being more meaningful than having the same phenomenon in common. This issue around homogeneity is a challenge of IPA and not my research specifically. The research has led me to consider whether any human group can be identified as truly homogenous and I have not been able to justify to myself that it can. Other social categories such as age, ethnicity, sexual orientation or status hierarchies may also have been relevant in shaping participant experience.

Another challenge inherent in IPA is its dependence on language, with less emphasis placed on other forms of expression, for example body language and tone of voice. IPA requires articulate participants who are able to communicate the sense they have made of their experiences (Willig, 2001). The use of objects or artefacts within research was an interesting idea to me initially, for example, inviting participants to select items which had resonance for them regarding the subject matter and bringing them to interview, but this was not explicitly encouraged within IPA and I did not explore it further. To address IPA's over-reliance on words, I took care to note and reflect on tone of voice and body language in the analysis to gain access to richer material.

Finally, it felt slightly limiting that rich data was not always included because it did not form part of a common theme which is central to IPA analysis. I was guided by Smith's (2011) value of 'gems' in experiential qualitative psychology and I reflect here on a couple of idiosyncrasies from interviews that were not included in the analysis chapter. 'Gems' are parts of accounts which are seen to hold great meaning. One participant alluded to a sense she had that anything might have been possible in life if she had not been born with CL/P. In this way, CL/P was being given the status of an explanation for things in life that the individual wished had been different. I considered this to demonstrate how, when one looks for an explanation for something that has gone 'wrong', it can be easier to find an explanation in something already conceptualised as wrong, similar to hindsight bias as described above. I also found that almost all

participants shared that they disliked having their photo taken. Accounts of being in photos or having a photo seen by others provoked strong reactions in some participants and I was struck by the felt sense and expression of this dislike. This nearly became a theme, but I had to opt not to include it because I had run out of room. Part of my thinking around deciding not to include it is because individuals across the population commonly report disliking having their photos taken. I conceptualised it as being part of participant's overall feelings about their appearance and the threat inherent in others viewing and potentially judging their photos. In a similar area, three participants told me they recognise immediately if another individual has CL/P which I reasoned was possibly to do with hypervigilance around appearance. Interestingly, two other participants had not recognised I had a CL/P and we had sat in relatively close proximity face to face for interviews. I would have liked to analyse the contrast here, particularly as it was the youngest two participants who had not noticed my CL/P. Finally, all participants had strong academic achievements; with at least one University degree each. Two participants spoke about pursuing academic achievements as a teenager because of a lack of confidence regarding appearance. Four participants described being influenced by early experiences relating to their CL/P and strove to attain respective careers which involve helping vulnerable people.

4.3.2 Justifying the contribution

Despite challenges, this research demonstrates that it is robust and transparent. It's worth reflecting on all of these points because it makes the research salient for those who share similar characteristics. The gap in the literature was the complexity of findings, the contradictory findings and the lack of direct conclusions about experiences of living with CL/P. The research supports and illuminates the complexity and duality of experience represented in the literature, while shedding further light on the numerous factors at play e.g. geographic, historic, culture, class, access to education, support, family and school, community and society, and it also pays attention to meaning-making for the individual with CL/P; therefore, it makes a significant contribution to the field.

4.3.3 Transferability & Quality

It is helpful to revisit quality markers as guided by Yardley's (2008) four guidelines in evaluating the validity of qualitative research, which were first explored in Methodology sub-section 2.5. It is also helpful to reflect on methodological, epistemological and personal issues.

4.3.3.1 Sensitivity to context

Participant interviews allowed insight into how the era in which participants were born played an important part of defining experience because of specific sociocultural contexts which were not within the control of participants, such as routine medical interventions available and attitudes towards difference within society.

I have attempted to demonstrate context explicitly by grounding the analysis within its context and I have provided contextual information where relevant, for example, in outlining feeding information for a baby with CL/P in the analysis in sub-section 3.3.1.

4.3.3.2 Commitment and rigour

I engaged in a lengthy and thorough process of analysis, regularly accessing supervision and attending lectures and IPA workshops. I was rigorous in my approach to recruitment, in my approach to interviews and making notes after interviews and in my data analysis. Throughout the analysis it was necessary to challenge myself and my assumptions throughout, re-visiting material repeatedly. I was also rigorous in my own reflexivity, exploring my own responses to the material presented. I will leave it up to the reader to determine whether sufficient depth of meaning and insight has been established.

4.3.3.3 Transparency and coherence

My reflective research journal has been a valuable aid throughout the research process (see Appendix 8). In reviewing my journal, I can see the development of my understanding of the research process and of my feelings and responses towards participant experiences and the literature. I kept a paper trail of every stage of the

analysis and made every effort to make ensure the analysis is coherent, thinking in detail about the relationships between the themes.

I initially found literature on first person phenomenological accounts to be illuminating and fascinating but also slightly intimidating because I felt somewhat exposed at the prospect of giving my own phenomenological account. Gradually throughout the process my feelings have evolved, and I have found it easier to share my contributions and feel less intimidated.

4.3.3.4 Impact and importance

My impression of the impact and importance of this research has developed progressively. When I was engaged in recruitment, I was approached by more participants than it was possible for me to interview. I received approximately twenty expressions of interest within a week from locations across the UK and one from an individual in Europe who offered to put me up in order to conduct the interview. This quickly led me to believe that there may be a large number of women who feel their CL/P has impacted on their life who have not been approached before to 'tell their story'. As my own experience has been similar in that I had never taken part in research on CL/P until I began this research, and as I would likely have responded to my own advert had somebody else been conducting the research, I found that my subjective impression that this would be an area of interest for women with CL/P, was confirmed. The impact of CL/P could potentially be an issue for women that arises in therapy or remain unspoken. In Appendix 13 I suggest a check-list for clinicians who see clients with CL/P to hold related issues in mind and I will speak about this further later in this chapter when exploring theories.

Given the significant changes made to cleft services in the NHS which have been implemented since the 1990's due to centralisation, it is important to consider what can be learned from my findings about improving service provision. One finding was that none of my participants were offered psychological support during childhood and adolescence. While this may have been more predictable for older participants it was something of a surprise for me to learn that the younger participants had not had access to psychological support either. Psychological support is an area for services to consider when it comes to making improvements. Another point to consider is that adults of all

ages may have psychological support needs which are not being met and these needs may be present for the duration of life given that CL/P is a lifelong condition.

Finally, my research findings may be of interest for research into other conditions e.g. other congenital / chronic conditions and other visible differences. Publishing my research may allow others to recognise similar experiences or develop research into other conditions to explore outcomes.

4.3.4 Reflecting on the breadth of the research question

I used a broad, inclusive question which is possible to do in IPA, e.g. Smith's (2007) research on chronic pain. IPA questions can take different forms, some are more specific, and some are broader. Usually when there is little research into a particular field, questions tend to take a broader approach. Once research findings have established an understanding of a phenomena, this is when questions may become more specific to better understand aspects of the phenomenon (Smith et al., 2009). There are benefits and downsides to my choice of question which will be explored here.

The main benefit of using my research question was that I did not confine myself to focusing on a particular aspect of being born with CL/P before a more solid understanding in the literature has been established. Equally, given the lack of clarity in the literature I would have found it difficult to justify why I was interested in a particular area over another. My own experience of CL/P has been a holistic one and perhaps that also influenced my thinking, not having had an experience of separating out one experience from another.

One downside may be that it is more difficult to ascertain whether the research was able to include all information generated in a meaningful way. I considered whether saturation, a theoretical concept used in grounded theory, had been reached. It is helpful here to borrow this concept given the breadth of my research question in order to consider whether I gained all I could from the data.

Saturation is defined by Howitt (2010) as follows; "when additional participants or data no longer bring new information which encourages the refinement of the analysis. That is, nothing new is being learnt by doing more data collection. It can serve as a means of

deciding when no further participants will be recruited but, equally, it can be indicative of when a particular stage of the analysis is complete."

On balance I feel I did reach saturation because I mined the data for meaning until there was nothing else I could find but at the same time, as described above in 4.3.1, I acknowledge there are limitations to my study in not being able to use all rich data gained from participants.

4.3.5 Use of memory in IPA

The role of memory in analysis also deserves consideration here. IPA is focused on experience as it presents itself in the here-and now but there is little guidance about how to interpret memories. It is necessary therefore to consider what options there are in deciding what status to give to a memory and I discussed this with my supervisor. I could have adopted a naïve perspective and assumed the individual was telling me exactly what an experience was like, as if it were in the present but coded in memory, however, this would have been more of a construct than an experience. It was therefore safer to assume that an individual relates now to how they feel about a memory, so we gain access to how they feel about the memory now rather than assuming we are gaining access to how they felt about it at an earlier date. This second perspective describes the position this research has taken. I took accounts of early experience and anecdotal accounts to be a reflection of how participants feel about these events now.

As I learned about psychological support within cleft teams available for individuals today, I felt contemplative and I wondered about the impact of appraising memories against today's social norms. I considered that it might be possible to feel a sense of having missed out on something. While I felt it natural to look back and think that support may have been helpful at key times, I wondered if such thinking might contain a degree of misrepresentation. Society changes and will continue to change. In another generation it is entirely possible that things will come along in the future not currently available, which could be conceptualised as having been 'missing' even though what's *missing* would not be recognisable in life today. I understood this to be hindsight bias (Roese & Vohs, 2012) which is "where an individual believes an event is more predictable after it becomes known than it was before it became known" (p. 411).

4.4 Epistemological reflexivity

As a 'knowing researcher' I held assumptions and expectations about participants and the subject material which were continually brought to the surface and challenged throughout the research process. I initially had a model of the participant as an ally, a peer, like myself. I assumed that having been born with CL/P would have had some kind of challenging impact and that participants would have found a way to manage this. Early on I assumed that participants would have likely experienced difficulties in similar areas to me. I probably held an assumption that I could help, that I could speak for participants on their behalf. I learned to recognise and bracket off my assumptions during the research process and I found it easier to do this as I went on. Through discussions with my supervisor I elected to own my own assumptions and reflections throughout the analysis.

Following my analysis, my findings seemed negative to me, illustrating painful experiences and challenges across the life span, compared to what I had been anticipating. I considered whether my own bias from my subjective experiences might have caused a blind spot where I had not recognised positives, or if I had misread and misunderstood material. I wondered if ethically I was honouring participant voices and representing these accurately. From the beginning of the research, I had aimed to achieve a balance, to explore all aspects of experience and not shy away from whatever I found, negative or positive. I had wanted to be prepared to reflect whatever I found, not to cover anything up because it felt uncomfortable to talk about or to portray individuals with CL/P as they would wish to be seen, rather I aimed to provide a deeper exploration of lived experiences which, while these experiences can be painful and challenging, all have been parts which form the whole of experience as described. After careful reflection I considered that the analysis had achieved what I had aimed to do, and it was a learning point for me that reported experiences had been more negative overall.

4.5 Personal reflexivity

I came to the project thinking I might be able to give others guidance or advice and be an advocate, but during the research process I found it became more about participants

telling me about what I didn't know. My initial assumption had been of being in a position of being 'okay' talking to people who may be struggling, and I was not expecting to then find that participants were telling me about helpful things I did not know about. For a time, this unsettled the assumed power relation between interviewer and interviewee and made the prospect of transcribing interviews and analysing them, somewhat intimidating. As I continued to analyse and reflect I able to resolve my own tensions through a process of self-honesty about my own personal feelings and this helped me to feel more grounded and surer of myself.

I found a great deal to reflect on during the course of conducting interviews. Six of the interviews took place at participant's homes, and two at participants' places of work. In one interview at a place of work, the participant took care to show me round the premises and tell me about her role. My interpretation was that I was very aware of her professional identity which was because I interviewed her in her work setting after she had taken me on a tour of her work premises and told me about the work she did and who she was professionally. In another interview, I was struck by the participant's account of her younger years which felt very different from how she talked about her later years. I was struck by the contrast and it made me wonder whether her earlier experiences had been processed. After another interview, in which I had learned about children's group activities through the CLAPA charity, I found myself experiencing a powerful sense of loss and sadness for things that 'hadn't been' in my own childhood and adolescence. I felt a vivid concept of the prospect of *belonging* to a group of people with CL/P that I had never experienced in my own life. This felt overwhelming and I found myself tearfully making my way home, aware for the first time that other lived experiences of CL/P are possible, other than managing it alone. Later, I reflected that the sadness I felt did not mean I wished my own life history had been different, rather that I gained an existential insight into how it might have been different. This perception itself is loaded with assumptions and I cannot know what the outcomes would have been if things had been different and I had belonged to a group with others with CL/P when I was growing up.

I found it thought-provoking that five of my participants had elected to work in the caring and helping professions. Interviews yielded insight into the reasons, including being in a familiar, safe environment e.g. in a hospital setting, relating to 'being different' or wanting to make a positive difference to others. As I have gravitated

towards the caring professions myself, I can relate to these reasons on a personal level, they feel familiar to me. I wonder about whether such professions feel safer and more inclusive environments to be in, which may be an important factor for individuals who have experienced exclusion from social groups.

I found myself feeling more exposed by talking about CL/P to peers, and by reading the literature in the field. I was told growing up that my scar was not very visible and medical professionals tended to speak of it to me in glowing terms. Several consultants have told me they would have been proud if they had conducted my surgeries and obtained the outcome. Nonetheless, visibility has remained a puzzle to me throughout my life because while I do not draw attention to it, responses in all forms have come my way at various times. Responses are external, coming from other people, making others unpredictable to a degree in their responses to me. Lansdown et al (1991) suggest that social unpredictability is more likely to lead to greater struggle. Although Lansdown et al. were talking about transitions of school age children to another school, I wondered if it might also be true that the unpredictability of the visibility of a scar might also be a challenge. To put it another way, it's not necessarily the case that the less visible a scar is the easier it is, because people can be unpredictable. While I have been met with surprise and ease when telling a number of people of my personal connection to the subject matter, I have had other experiences which lead me to know that a broad range of social responses to the presence of CL/P can and do exist. I once held a social conversation with an individual who sat, giving the impression of politely listening to me, before pressing their finger on their upper lip and shoving it up to distort the appearance of their upper lip, where they then remained, sitting in this way, continuing to give the impression of listening, while I continued to talk. Such an act is almost impossible to react to appropriately in the moment as embarrassment, shock, and intimidation are so prevalent. The felt risks of sharing such encounters are that others might discredit or minimise what occurred, or even join in, so they tend to go unchallenged, at least with me. However, they do remain a puzzle and a challenge, and at worst, a threat.

I also found myself thinking more about memory and wondering what happens to experiences that pre-date verbal memory. An anecdotal story I had been told about myself at nine months old was that I had been in considerable pain after my cleft palate operation and had "crawled around and around in my cot, like a dog in a basket that

can't get comfortable" until the doctors sedated me to relieve the pain. One participant told me she experienced pain in her foot in the same place as she was told she had injections as a baby. While studies on memory indicate that it is not possible to recall early memories (Howe, 2011), I wondered what impact (if any) early operations might have on the central nervous system, on brain development and neural pathways. I wondered whether such early experiences might provide insight into a later sense of safety with others. Babies and toddlers with CL/P are operated upon, handled by strangers, and undergo painful surgeries. I wondered about what the body can remember of such experiences. It is outside the scope of this piece of research to report on related literature, if it exists, but I would be interested to learn about early memory formation and whether an association between strangers and pain and fear might be linked in some way. I think the development of memory is fascinating and raises many other questions, for example, what happens to memory when a child with CL/P grows, and words are put to experiences? When a child brings thought into it? Those thoughts in themselves would be influenced by everything else a child has been told and experienced, so this is complex and subjective, but I wonder if common themes would emerge if this area was researched.

A final point to make is that throughout the research process I have been a clinician engaged in conducting research and carrying out interviews which has added another dynamic to the roles I have undertaken. The experience of conducting research interviews is different to clinical work for a number of reasons, however I found that there are transferable skills that can be utilised, for example, listening skills, being able to manage silences, being able to cope with emotional distress in others. One of the most challenging aspects for me as a researcher was an inclination to understand material by formulating in my mind when emotional difficulties were described. I also found it difficult not to identify and label potential problems e.g. social anxiety or low self-esteem in my mind. As time went by and my confidence in interviewing gained, I felt more able to manage and disregard these thoughts as not being relevant to the research process and this resolved much of the initial disorientation for me. I also felt that frequent supervision, peer supervision, lectures and research reading materials were all invaluable in working through these challenges.

4.6 Implications for clinical practice and research

Throughout the analysis process, I was mindful of the need not to draw on psychological theories in order to focus on the meanings of participant accounts and their interpretation. At the same time, a number of theoretical models felt relevant to me during this process, which I bracketed off during analysis. Psychological issues have been identified in individuals with visible difference, e.g. low mood, feelings of shame or inadequacy, depression, anxiety, dissatisfaction with appearance (Rumsey & Harcourt, 2005 and Appearance Research Collaboration, 2009). I describe different therapeutic approaches here which I believe could be particularly beneficial for individuals with CL/P who were seeking psychological support.

I think that existing literature on body dysmorphia (Veale & Neziroglu, 2010), a problem whereby an individual's idea of some part of their body is so flawed that it leads to exceptional measures to hide or fix it, is relevant because women with Cl/P report an increased awareness of the appearance of CL/P. Even if no extreme measures are taken, I wonder whether there is a potential vulnerability for individuals with CL/P to regard their appearance negatively on a long-term basis and for this to go unnoticed by professionals.

I also felt that evolutionary theories underpinning compassion-focused therapy (Gilbert, 2010), are relevant because they allow insight into neurobiological threat responses by showing how, in survival terms, when threat is present, it may be safer not to show fear or to avoid threatening situations. One relevant example is Anna in section 3.4.2, describing how she learnt very early on to 'control' and 'just set' her face in response to threats from bullying as a way of coping. Compassion-focused therapy was developed to help individuals who were experiencing strong levels of shame which were not relieved by engaging in traditional cognitive behavioural therapy. The super-ordinate theme 'Being Different to Others' is particularly pertinent here because feeling safe (or not) with others leads individual to move between *threat mode* and *safe mode* accordingly, impacting on thoughts, feelings and behaviour in ways that may not always be helpful.

Other therapeutic models which may offer useful frameworks include acceptance and commitment therapy (Harris, 2009), where individuals are supported to identify and live

life according to their own values; models of social anxiety (e.g. Wells, 1997) which help to understand how self-focused attention in social situations increases anxiety and leads to unhelpful behaviours which interfere with social interactions; models of low self-esteem (Fennell, 2006) which recognise that unhelpful unconsciously felt core beliefs and rules for living are the driving force behind day to day difficulties with mood and anxiety; models of depression such as Moorey's (2010) 'sad flower' formulation which includes the physiological impact of depression on the body and theories on trauma (van der Kolk, 2014) might all be useful for individuals with CL/P who were seeking psychological support. Additionally, systemic and family theories (Burnham, 1986) and literature on long-term conditions may also potentially be valuable in clinical practice within the field. In Appendix 12 I propose a check-list of potentially relevant issues for practitioners to be aware of when assessing clients with CL/P who are seeking psychological support.

In terms of future research, I feel that my research findings point towards some interesting areas to explore. One idea, based on the breadth of my research question, would be to go from a broad question to a specific question – e.g. researching a particular demographic or age group to learn more about the specific issues that affect that group. Perhaps a study on older adults with CL/P may help to better understand the difficulties faced by adults with ongoing surgery needs and associated psychological support needs. Another idea would be to carry out similar research into men's experiences, to see whether issues are similar or whether additional or different experiences are described. It would be particularly interesting to learn more about how men with CL/P experience visible difference through the lens of idealised standards of appearance.

4.7 Summary and conclusions

In this discussion chapter I have given an overview of the analysis, I have explored transferability and I have discussed the contributions this research makes to counselling psychology in terms of theory, research and practice.

In considering areas for future research and practice, there are three suggestions I believe are worthy of further consideration. Firstly, I wonder whether it would be

beneficial for CL/P to be conceptualised as a long-term condition. Prior to conducting this research, I would not have identified as having a long-term condition, however, difficulties across the lifespan have been shown to be common for individuals with CL/P and access to adult services has been reported to be difficult to access due to lengthy waiting times. Although not everyone may wish to identify with a long-term condition because CL/P is not experienced in the same way for everyone, I wonder whether if it were an option to identify in this way, that access to services and services themselves might be improved. For example, Improving Access to Psychological Therapies services (IAPT) are increasingly offering treatment and support for long-term conditions (IAPT-LTC) as part of an NHS England drive to improve access to support. Counselling Psychologists would be well placed to deliver treatment, training and consultancy to offer CL/P support as part of this drive and offer more specialist support to individuals with CL/P.

Secondly, I think that psychological support around key events should be more widely available, for example, key surgeries in childhood or around planning to have children, and better support to access adult CL/P support including psychological support. In addition to the suggestion above, there are a range of services that would be well placed to provide education and support, e.g. CAMHS services who can liaise closely with schools and primary or secondary care psychological services who can liaise closely with GP's. If individuals with CL/P who seek psychological support are seen by professionals who have little or no knowledge of the issues associated with CL/P, and the individual themselves does not know that issues have been identified in individuals with visible difference, there is potential for aspects of difficulties to be missed and not addressed.

Finally, I have designed a check-list of potentially relevant issues that a practitioner might want to think about when working with a client with CL/P. Care has been taken to consider the possible impact of being asked the questions on the list on a client who does not him/ herself link the issues/distress they are bringing to therapy with their CL/P so as not to undermine trust and make such a client feel misrepresented or misunderstood. I conceptualised that a check-list may be helpful for clinicians working in IAPT services where a wide range of Axis 1 presentations are treated, as well as offering psychological therapies for long-term conditions. There are already specialist psychologists working in cleft teams and I do not propose that IAPT services would be

an alternative; rather that for short-term Axis 1 difficulties, IAPT are in a good position to support specialist cleft teams by both offering local psychological support and promoting education and signposting to cleft services where appropriate. See Appendix 13 for further details.

In a final return to reflexive conclusions, I feel that more than anything, this research has demonstrated that women's experiences of living with CL/P are multi-faceted and demonstrate a duality of experience in which being born with and living with CL/P throughout life may be thought of as both 'not a problem' and 'a problem' at various different times. The research supports Stock & Feragen's (2016) conclusions that evidence in the field is inconclusive. I believe this is symptomatic of the fact that experience cannot be defined as one particular thing at one point in time, but rather the experience of living with CL/P and the challenges it can pose are variable according to individual differences, the kinds of support available to the individual and attitudes represented in wider society.

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Appendices

Appendix 1 Ethics approval letter

Psychology Research Ethics Committee
School of Arts and Social Sciences
City University London
London EC1R 0JD

9th February 2017

Dear Sally Moore and Deborah Rafalin

Reference: PSYETH (P/L) 16/17 110
Project title: Exploring the experiences of women with cleft lip and palate

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

(a) Recruit a new category of participants
(b) Change, or add to, the research method employed
(c) Collect additional types of data
(d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee [redacted], in the event of any of the following:

(a) Adverse events

(b) Breaches of confidentiality

(c) Safeguarding issues relating to children and vulnerable adults

(d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Hayley Glasford	Richard Cook
Course Officer	Chair

[redacted]

Appendix 2 **Research Flyer**

Department of Psychology

City University London

Are you a woman who was born with a cleft lip and palate?

Would you be willing to talk to me about your experiences? If so, and you are over 18, I would love to hear from you.

My name is Sally Moore and I am a carrying out research into the experiences of women with cleft lip and palate. If you would be interested in finding out more about my research, please contact me on [redacted] or at [redacted]

If you would like to take part, you would be asked to participate in an interview lasting one and a half hours which would take place in a mutually convenient location. I would reimburse any travel costs.

I am carrying out this research as part of a Doctorate in Counselling Psychology at City, University of London, under the supervision of Dr Deborah Rafalin, Registered Psychologist & Senior Lecturer [redacted]

This study has been reviewed by, and received ethics clearance through the Psychology Department Research Ethics Committee, City University London

Ethics Code: PSYETH (P/L) 16/17 110

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on [redacted] or via email: [redacted]

Appendix 3 **Participant Information Sheet**

Pre-interview information sheet

My name is Sally Moore and I am carrying out this research project as part of my Doctorate in Counselling Psychology at City, University of London. Thank you for your interest in this research, titled "Exploring the experiences of women with cleft lip and palate." The research is being supervised by Dr Deborah Rafalin, Registered Psychologist & Senior Lecturer.

Before you decide whether you would like to take part it is important that you understand why the research is being done and what participation would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information.

The research is an exploration of women's experiences of cleft lip and palate and what it means to them in the ways they feel about themselves, how they feel in their relationships with others and how they have coped with any challenges that may have arisen. The research is most interested in exploring experiences that are most meaningful to you and the sense you have made of them. Hopefully it will be a valuable opportunity to talk about your experiences in a safe, non-judgmental space. It is very much hoped that the proposed study will have benefits to future patients, to wider services and to contribute to knowledge within the cleft research networks. If you would like a copy of the study when it is completed I would be happy to provide this.

If you would like to take part, you will be asked to take part in a single face-to-face interview with me for an hour and a half and this interview will be recorded on a secure recording Dictaphone. You will be asked to sign a consent form and complete a short questionnaire before the interview.

The interview will be semi-structured. This means you will be asked some questions about your sense of yourself, your relationships with others and how you have managed any difficulties. There will be time to explore topics in-depth and you will have space to talk about your experiences.

As the study explores experiences in-depth there is potential for this to stir up emotions although it is anticipated this would not be to an excessive degree. A full debrief will take place after the interview and I will follow up with any appropriate signposting to services. For transparency, confidentiality where there is a risk of danger to yourself or others cannot be met and in the unlikely event of such information being shared with me, I would have a duty of care to notify an appropriate professional e.g. your GP.

Following interviews, I will be analysing data from interviews using a qualitative research method which means I will be looking for shared themes and experiences of difference across all interviews. All data will be anonymised directly after your interview and a 'nickname' of your choosing will be used to save all written information. All information pertaining to the study will be securely locked away at my home and will only be accessible to me. This data will be archived in accordance with BPS and HCPC guidelines. After a timeframe of seven years (as directed by BPS and HCPC on storage of research data), all materials will be securely destroyed.

Key Points

- Your participation is voluntary
- If you decide to take part, you are still free to withdraw at any time up until the point of my data analysis and without giving a reason.
- Interviews will take place at a mutually convenient location. This can include your office or home if you wish.
- I will meet the costs or reimburse any travel expenses and refreshments.
- You will have the opportunity to have your experiences heard in a sensitive, emphatic and non-judgmental way.
- No financial incentives are involved in the study.

- It is not yet known whether the research study will be published but it is possible it may be published in future psychology journals. All participant anonymity would be maintained should this be the case.

Thankyou in advance for your interest in this research.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone [redacted] You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: "Women's Experiences of Cleft Lip and palate. An Interpretative Phenomenological Approach."

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: [redacted]

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study, you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City University London Psychology Department Research Ethics Committee. Ethics Code: PSYETH (P/L) 16/17 110.

Further information and contact details

Research supervisor: Dr. Deborah Rafalin. Please email [redacted]

Thank you for taking the time to read this information sheet.

Appendix 4 **Consent Form**

Title of Study: **"How do women experience and manage living with cleft lip and palate? An IPA Study."**

Ethics approval code: PSYETH (P/L) 16/17 110

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • being interviewed by the researcher • allowing the interview to be audiotaped	
2.	This information will be held and processed for the following purpose(s): to answer the interviewer's research question I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw my data up until the point of data analysis without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement	

	and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

Name of Participant	Signature	Date
Name of Researcher	Signature	Date

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix 5 **Debrief Information**

Department of Psychology
City University of London
Post-Interview Debrief Information

Thank you for taking part in this study. Now that it's finished I'd like to tell you a bit more about it. The aims of my research are to explore how cleft lip and palate may have affected women's experiences in relation to how women see themselves, how they feel in relationships with others and ways in which any challenges along the way have been managed. I will have asked you about the experiences that have had most meaning for you and the sense you made of them and we will have explored these in some detail. The purpose of the research is to develop insight and understanding into these experiences in order to allow psychologists to better understand common themes which are important for women born with cleft lip and palate. The contribution you have made has been valuable; little in-depth research has been done in this area and I thank you for taking the time to share your experiences. If you have already let me know you would like a copy of the final report, then I will send you one in due course. If you have not and later decide you would like a copy, please feel free to contact me to request this.

Thank you for your participation. I hope it has been a rewarding, enjoyable and respectful experience for you.

Getting Help and Advice

As I mentioned at debrief following our interview, if taking part in the research has raised any concerns for you, I have put together a list of resources here which I hope you find helpful.

- **For Urgent Health Problems:**
  - Your GP Practice

- Local Hospital Urgent Care Centre
- NHS Direct 24-hour medical advice and information service. Tel: 0845 4647. Web: www.nhsdirect.nhs.uk
- If you or someone else is in immediate danger, call the Police on 999.
- If you require urgent mental health help in an emergency: Go to your nearest Accident & Emergency Department and ask to speak to the duty Psychiatrist or call 999 for the Ambulance service.

❖ **Cleft Lip and Palate Association (CLAPA):**

UK wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate.

Tel: 0207 833 4883

Website: https://www.clapa.com/ **Website:** https://www.clapa.com/support/local-groups

Address: 332 Goswell Road, London, EC1V 7LQ

❖ **Samaritans 24-hour helpline:**

Provides confidential non-judgemental emotional support 24 hours a day to people who are experiencing feelings of distress or despair, including those which could lead to suicide.

Tel: 08457 90 90 90. Helpline: 116 123

Email: jo@samaritans.org

Website: https://www.samaritans.org/

❖ **Saneline:**

Out of hours mental health helpline offering specialist emotional support.

Tel: 0300 604 7000. Open 6pm – 11pm.

Email: info@sane.org.uk

Website: https://www.sane.org.uk

❖ **Victim Support:**

Information on types of crime and their effects and information about how court cases work.

Tel: 0808 1689 111

Website: https://www.victimsupport.org.uk/

- **Women's Aid**

National charity working to end domestic abuse against women and children. Provide 300
local services across the country. Run campaigns to achieve change in policy, practice and
awareness

Tel (enquiries): 0117 944 4411 **Helpline:** 0808 2000 247

Email: helpline@womensaid.org.uk

Website: https://www.womensaid.org.uk/

Address: Women's Aid Federation of England, PO BOX 3245 Bristol, BS2 2EH

- **National Domestic Violence Helpline**

Freephone 24-hour National Domestic Violence Helpline for women experiencing domestic
violence. Can give support, help and information over the phone.

Tel: 0808 2000 247

Website: http://www.nationaldomesticviolencehelpline.org.uk/

- **National Association for Children of Alcoholics (NACOA)**

Run freephone national telephone helpline for children/adults who have/had an alcoholic
parent/carer. Offer telephone advice/support

Tel: 0800 358 3456

Email: helpline@nacoa.org.uk

Website: www.nacoa.org.uk

- **RELATE**

Offers relationship counselling, family counselling, mediation, children and young people's
counselling, sex therapy and workshops.

Fees: £45.00-£50.00

Tel: 0300 100 1234.

Email: counselling@relatelondonsw.org

Website: www.relate.org.uk

- **National Childbirth Trust (NCT)**

Offer information, reassurance and mutual support through pregnancy, birth and early childhood. Run antenatal/postnatal classes e.g. preparing for labour/birth, breastfeeding, signature and essentials course, postnatal 'early days' course, introducing solids courses and
first aid courses.
Tel: 0300 330 0700.
Website: www.nct.org.uk

- **The British Pregnancy Advisory Service**

Unplanned pregnancy advice and counselling options. Advocating for women who decide to
end pregnancy. Provide contraception and abortion service
Tel: 03457 30 40 30
Email: info@bpas.org
Website: https://www.bpas.org/
Address: BPAS Southwark, 45 Columbo Street, Southwark, London, SE1 8EE

- **Anxiety UK**

Relieve and support those living with anxiety and anxiety-based depression by providing
information, support and understanding. Offer support for: agoraphobia, BDD, GAD, OCD,
PTSD, panic attacks, social phobia. Offer CBT, EMDR, counselling, massages, reflexology,
Reiki healing, acupuncture
Tel: 08444 775 774
Email: support@anxietyuk.org.uk
Website: https://www.anxietyuk.org.uk/

- **B-eat**

Supporting anyone affected by eating disorders e.g. anorexia, bulimia, ENDOS. Has a HelpFinder on website which lists directory of local eating disorder services
Tel: 0345 634 1414

Email: help@b-eat.co.uk
Website: http://www.b-eat.co.uk/

- **Central London Self Help and Support Group for Sufferers**

Support group for adults (18+) who suffer from eating disorders e.g. anorexia, bulimia, binge
eating etc. Must call/email before attending the group
Tel: Sue - 07957 641 449 (Between 9:00pm and 10:30pm on Sunday evenings only)
Email: beatlondon@outlook.com
Website: http://helpfinder.b-eat.co.uk/view-profile-and-listings/central-london-self-help-and-support
-group-for-sufferers/
Address: All Souls Clubhouse, 141 Cleveland Street, London, W1T 6Q

- **Campaign to End Loneliness**

The Campaign to End Loneliness is a network of national, regional and local organisations and people working together through community action, good practice, research and policy to ensure that loneliness is acted upon as a public health priority.
Tel: 020 7012 1409
Website: http://www.campaigntoendloneliness.org/

- **MIND Befriending Service**

Practical suggestions and how to get support for loneliness
Tel: 0300 123 3393
Website: http://www.mind.org.uk/information-support/tips-for-everyday-living/loneliness/

- **Improving Access to Psychological Therapies** (IAPT) services:

NHS Mental health services available locally throughout the UK. Ask your GP or look online for your local service information. IAPT services are able to provide psychological support with a wide range of problems, including: depression, anxiety, low self-esteem, panic attacks, agoraphobia, obsessive-compulsive disorder, shyness and social anxiety, post-traumatic stress disorder, health anxiety, specific phobias, sleep

problems, anger problems, relationship problems, perfectionism, procrastination, body image problems.

Website: www.england.nhs.uk/mentalhealth/adults/iapt/

London NHS IAPT Services:

● Barking & Dagenham IAPT Tel: 0300 300 1554 Email: bdtalkingtherapies@nhs.net

● Barnet Psychological Therapy Service Website: http://www.lets-talk-iapt.nhs.uk/

● Being Well in Bexley Tel: 020 8303 5816 Email: info@beingwellinbexley.org.uk

● Brent Psychological Service Tel: 0208 438 1777 Address: Willesden Centre for Health &
Care, Robson Avenue, London, NW10 3RY

● Bromley Working for Wellbeing Website: http://bromleyworkingforwellbeing.org.uk

● Camden & Islington Psychological Therapies Service Website: www.icope.nhs.uk

● City and Hackney Psychological Therapies Service Website: http://www.cityandhackneytalkingtherapy.nhs.uk

● Croydon Psychological Therapies and Wellbeing Service Website: https://slam-iapt.nhs.uk/

● Ealing Mental Health and Wellbeing Service Website: http://www.ealingiapt.nhs.uk/

● Enfield Psychological Therapy Service Website: www.lets-talk-iapt.nhs.uk

● Greenwich Time to Talk Website: http://oxleas.nhs.uk/services/service/greenwich-time-to-talk/

● Hammersmith & Fulham Back on Track Website: http://www.backontrack.nhs.uk/

● Haringey IAPT Team Website: http://www.lets-talk-iapt.nhs.uk/

● Harrow Psychology Services http://www.cnwl.nhs.uk/service/harrow-talking-therapies/

● Havering Psychological Therapies Service Website: http://www.nelft.nhs.uk/

● Hillingdon Wellbeing Service Website: http://www.cnwl.nhs.uk/service/hillingdon-talking-therapies/

● Hounslow IAPT Website: http://www.hounslowiapt.nhs.uk/

● Kensington and Chelsea Psychological Service Website: https://www.take-time-to-talk.com/

● Kingston Right Steps Psychological Therapies Tel: 020 3513 3000 Address: 204 Acre Road, Kingston Upon Thames, KT2 6EX

● Lambeth Psychological Therapies Website: https://slam-iapt.nhs.uk

● Lewisham Psychological Therapies Service Website: https://slam-iapt.nhs.uk/

● Newham Psychological Services Website:
https://www.newhamtalkingtherapies.nhs.uk/
● Redbridge Psychological Therapies Website: http://www.nelft.nhs.uk
● Redbridge Sanibel Psychological Therapies Website: www.sanibel.org.uk
● Richmond Wellbeing Service Website:
https://www.richmondwellbeingservice.nhs.uk/
● Southwark Psychological Therapies Service Website: https://slam-iapt.nhs.uk
● Sutton and Merton Psychological Therapies Website:
http://www.letsfindawayforward.nhs.uk/
● Waltham Forest IAPT Solutions Website: http://wftalkingtherapies.co.uk/
● Wandsworth Psychological Therapies and Wellbeing Website:
http://fis.wandsworth.gov.uk
● Westminster Centre for Psychological Wellbeing Website: http://cnwl-iapt.uk/

- **British Psychological Society (BPS):**

Use the find a psychologist tool to find Psychologists working privately near you and find out more about the Psychologist representative body in the UK.
Tel: 0116 254 9568
Website: http://www.bps.org.uk/

- **British Association for Counselling and Psychotherapy (BACP):**

Check the register for accredited Counsellors and Psychotherapists
Tel: 01455 883 300
Website: www.bacp.co.uk

- **British Association for Behavioural and Cognitive Psychotherapies (BABCP):**

Check the register for accredited Cognitive Behavioural Therapists
Tel: 0161 705 4304
Website: http://www.cbtregisteruk.com

- **Health and Care Professions Council (HCPC):**

Check the national UK register for accredited Practitioner Psychologists. All qualified, accredited Psychologists must be registered with HCPC in order to practice.
Tel: 0300 500 4472

Website: www.hcpc-uk.co.uk

- **College of Sexual and Relationship Therapists (COSRT):**

Practical suggestions and advice on personal relationships. Find an accredited Therapist.

Tel: 0208 543 2707

Website: http://www.cosrt.org.uk/

Thanks again for your participation. If you have any questions, please do not hesitate to contact me at:

Sally Moore [redacted]

If you would prefer, you can contact my supervisor Dr Deborah Rafalin at [redacted]

Ethics approval code: PSYETH (P/L) 16/17 110

Appendix 6 Demographic Information

Please highlight in bold or write your answer.

1. **How old are you?**

   ……

2. **What is your marital status?**

   Single

   Living together

   Married / Civil Partnership

   Divorced

   Separated

   Widowed

3. **What is your sexual orientation?**

   Heterosexual

   Gay / Lesbian

   Bisexual

   Other: please specify

4. **Do you have children?**

   Yes

   No

   If yes, how many?

   ……

5. **What is your highest level of formal education?**

   None

   GCSE's

   A Levels

   Certificate of Higher Education

   Higher National Diploma

   University degree BA / BSc

   Postgraduate Certificate, Diploma, Master's

Postgraduate PhD, Doctorate

6. **Are you currently employed?**

Yes

No

If yes, what is your current occupation?

……

If no, have you had an occupation in the past? If so, what was it?

……

7. **What is your nationality?**

……

8. **How would you describe your ethnic origin?**

White

- British
- Irish
- Other White background

Black or Black British

- Caribbean
- African
- Other Black background

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Other Asian background

Chinese

- Other Chinese

Gypsy and Traveller

Irish Traveller

Gypsy

Roma

Other

Mixed

White and Black Caribbean

White and Black African

White and Asian

Other Mixed background

Other Ethnic background (please specify)

9. First two letters of your postcode

……

10. GP Surgery name

……

11. 'Nickname' for data storage

…….

Thank you.

Appendix 7 Interview schedule

Interview questions

"Thank-you for coming. Before we begin I need to check some things with you [consent form and demographic questionnaire]. Would that be okay?" (Complete this together)

1. Tell me how you feel about having CL/P
    - Are there any particular moments or experiences that you want to share?
    - How has having CL/P made you feel about yourself?
    - Has the way you feel about having CL/P changed over time?
    - Has the way you have coped changed over time?
    - Can you elaborate? Can you tell me more?

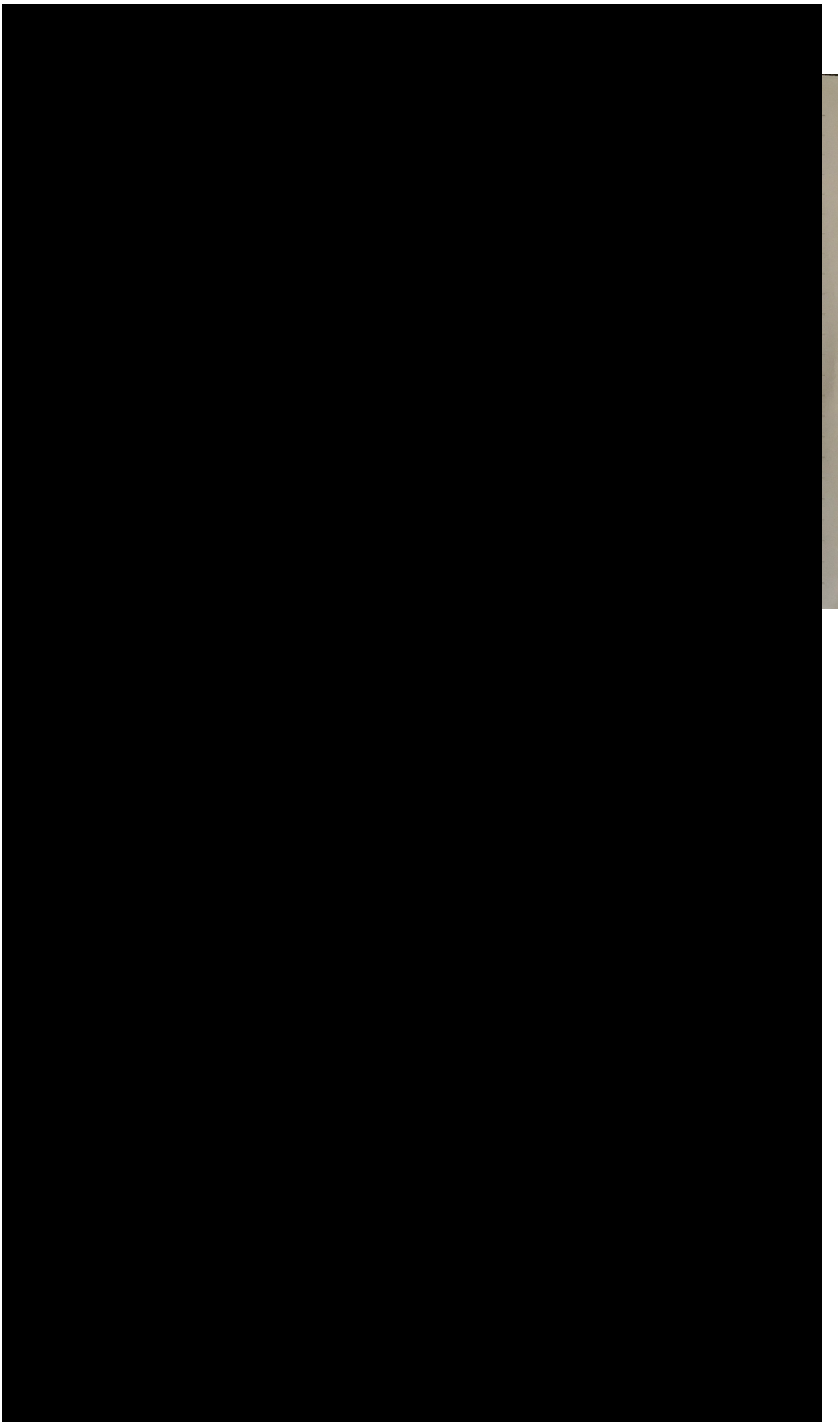
2. How has having a cleft impacted on relationships with others?
    - E.g. think about your family, romantic relationships, sexual relationships, friendships, work, school, college or university, with anyone else e.g. in the wider community
    - How has this experience made you feel about yourself?
    - How have you managed this?
    - Can you elaborate? Can you tell me more?

3. Earlier you told me about a number of ways you've managed having CL/P, can you tell me a bit more?
    - How have you managed this?
    - What would you say it's been like for you, having CL/P?
    - Can you elaborate? Can you tell me more?

4. We've come to the end, is there anything else you'd like to tell me about your CL/P?

5. I wonder if we can take a few minutes to reflect on how this [the interview] has been for you?

Appendix 8 Photos of analysis process



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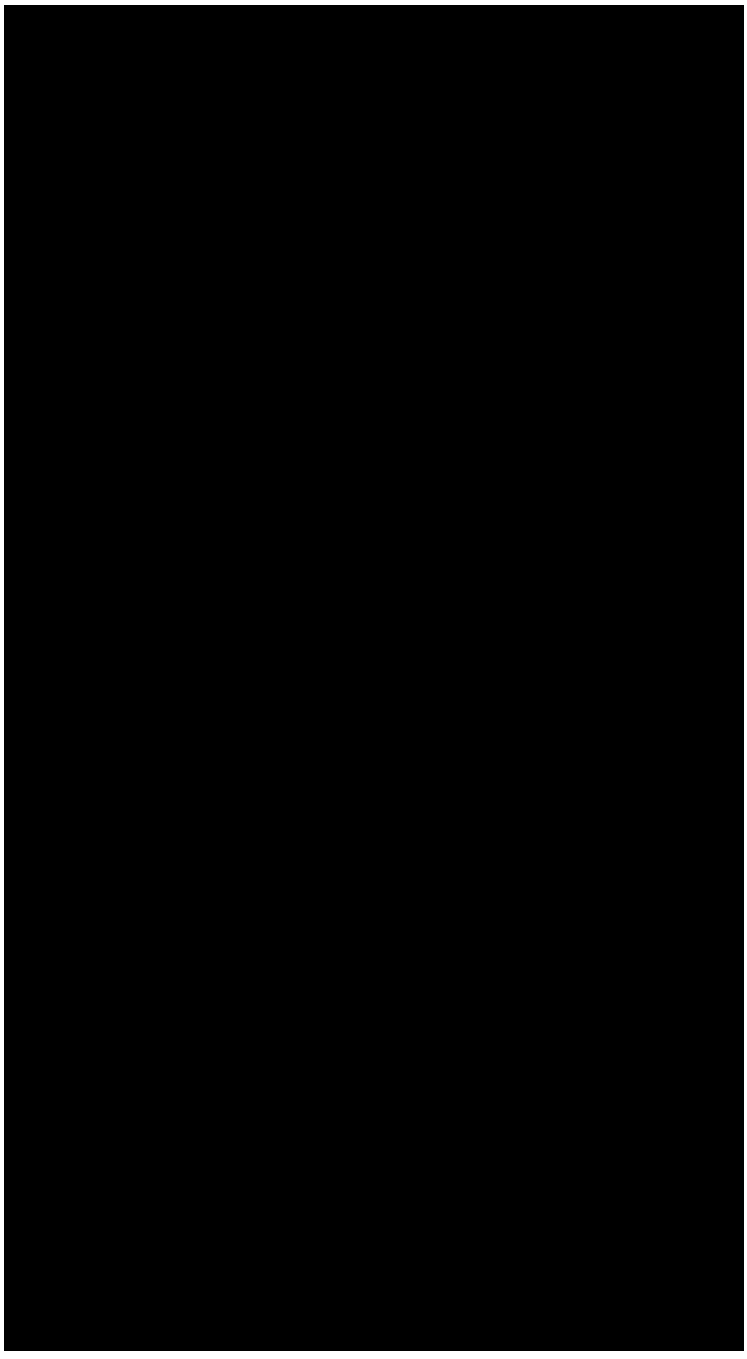

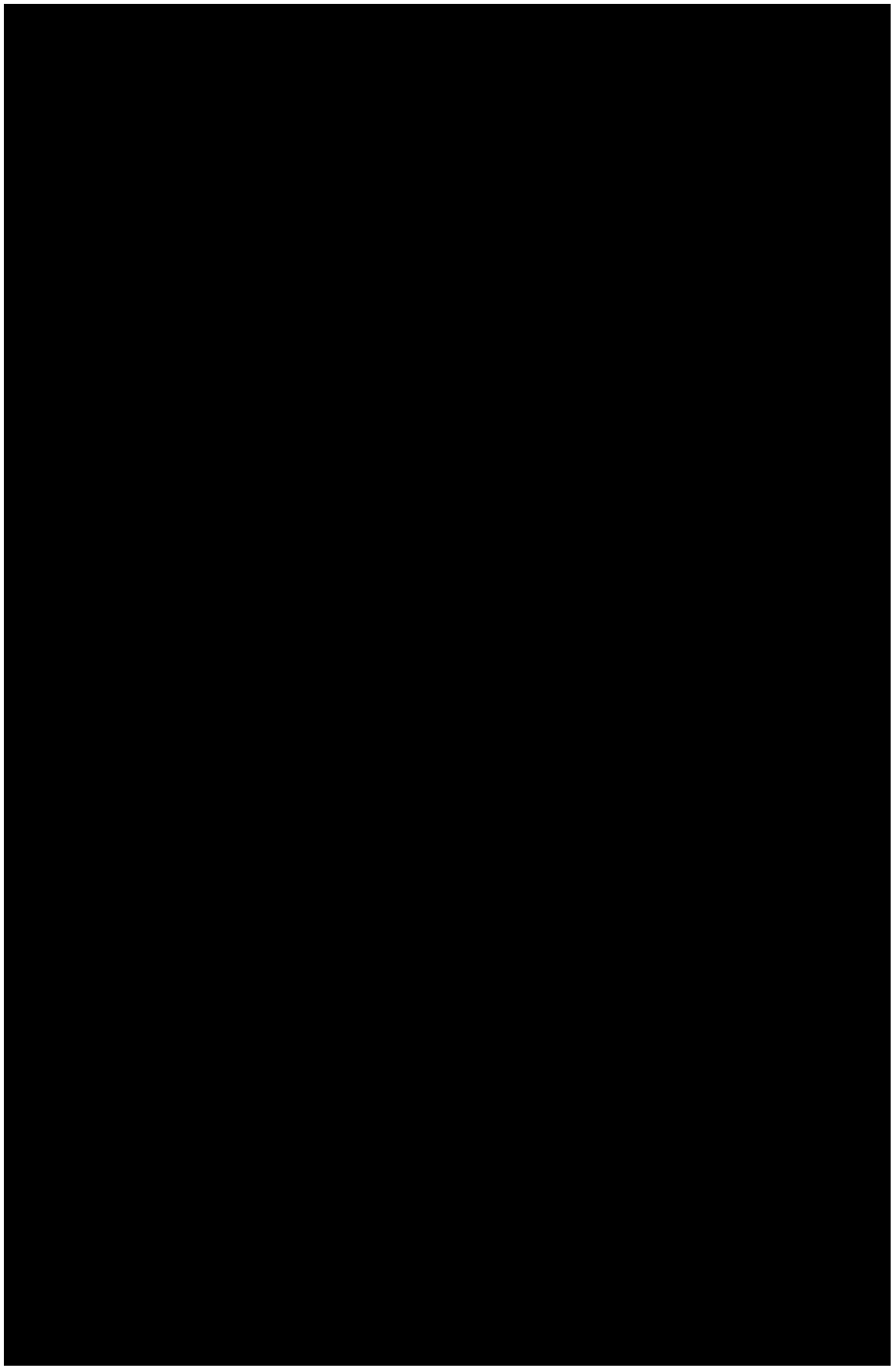

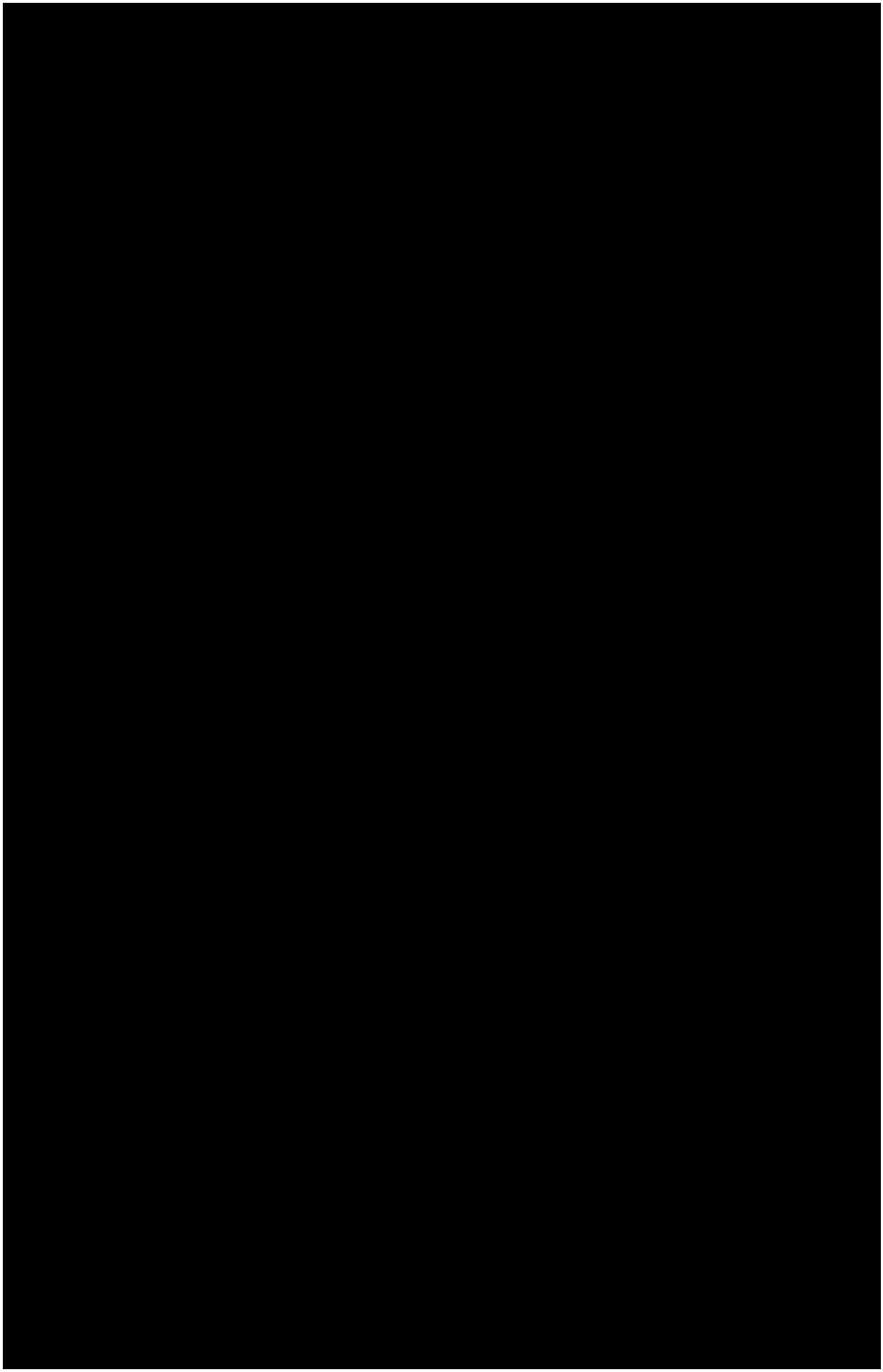

Appendix 9 Super-ordinate Table Themes

A. The Threatened Self	
Identification with CL/P	
Traveller: Part of me feels special	22-31
Flower: I wouldn't wish to be born with CL/P but I'm at my most comfortable now	84-89
Oscarbertie: This is me, this is what makes me 'me'	184-193
Fred123: You think everyone else is normal	1052-1053
Anna: Having CL/P has shaped who I am more than anything else	3-13
Stav: Having CL/P is a very minor thing to me now	717-726
Stormy: The more I've learned about it the more I've accepted it	202-204
Puddle: I wouldn't change my CL/P because it's part of who I am	129-136
Self as not good enough	
Traveller: It's been me judging me too	50-51
Flower: Nobody talked to me about it, so I learned to associate shame with having CL/P	34-38
Oscarbertie: My most painful memory was of my Mum calling me 'imperfect' because of my CL/P	633-635 & 639-640
Fred123: They said to take a pair of wire cutters to me	80-91
Anna: Almost a pre-verbal feeling	62-77
Stav: When you're younger you feel like the odd one out	20-21
Stormy: I wasn't aware of being different until I had my major operation	73-76
Puddle: I go to great efforts with people because I want them to like me and I am afraid they won't	1430-1432
B. Being Different to Others	
Safety and Acceptance	
Traveller: I always felt accepted by my parents	671-672 &
I couldn't feed as a baby	920-932 &
People couldn't say 'lovely baby' about me	949-952

Flower: I was told I cried for the first year of my life	1004-1010
Oscarbertie: My Mum used to tell me that it was no-one's fault	29-31 &
My Mum couldn't cope with all my hospital appointments	394-396
Fred123: My Dad used to fight for me	70-72 &
My parents didn't treat me any differently	280-282
Anna: They were not supportive parents	334-337 &
I had very supportive grandparents	360-363
My parents told me no-one would like me	390-393
Stav: Having a big supportive family has been a huge positive for me	191-193 & 196
Stormy: I have really supportive family and friends	46, 93-97
Puddle: The consultant told my parents not to treat me any differently	536-543 &
My parents had a lot to cope with	655-669
Felt sense of visible difference	
Traveller: "Imagism"; a name for the problem of being judged based on appearance	775-776
Flower: Dating feels exposing due to negative feelings about self with CL/P	69-72
Oscarbertie: I see my physical appearance differently to how friends see it	121-126
Fred123: When you're younger you want to fit in, so appearance matters more	889-890
Anna: Negative reactions include staring, comments and pointing whether I'm alone or with others	187-191
Stav: I've had people ask me about it when I was serving them at work which feels a bit rude and contradicts feedback that people don't notice	511-514
Stormy: Internet dating was difficult due to fearing being judged on appearance	264-266
Puddle: It's upsetting for others to mention it out of the blue because it makes me question how visible it is	146-159
Social unpredictability	
Traveller: I overcompensate socially because I think people fear difference	586-589

Flower: Others appear unpredictable which feeds into anxiety	984-990
Oscarbertie: It's harder to communicate with strangers due to speech but I persevere	24-25
Fred123: My friends now are mostly women who have also had battles in life	875-878
Anna: Its people's reactions that are the problem, not the cleft itself	157-163
Stormy: I can come across as shy until I know people to protect myself from being hurt	917-923
Puddle: I feel safer talking to you knowing you have CL/P too, otherwise I'd have wondered why you wanted to know	1612-1614
Bullying and abuse	
Traveller: I was teased because of my face	87-90 & 97-107
Flower: I was bullied in that isolation way of being left out	184-193
Oscarbertie: I was targeted in a bullying environment; I was easy pickings	503-504 & 558-560
Fred123: The only times I recall CL/P spoken of in childhood were at clinical appointments or by playground bullies	185-189& 1066-1069
Anna: As a child when I walked down the street adults I passed would say cruel things about my appearance	292-296
Stav: I was bullied a bit in secondary school, but I think school is the hardest time for everyone	104-107
Stormy: Someone said my voice sounded like a helium balloon and I felt really hurt	193-195
Puddle: As a child, I remember a nurse at hospital shouting and leaving me in my own vomit all night after because she said I was sick too much	65-68
C. Facing Challenges	
Overcoming obstacles	
Traveller: I've learned that asking for feedback from others is valuable	239-245
Flower: Early familiarity with hospitals shaped my career choices	214-223
Oscarbertie: I put bad treatment by others down to experience and	455-462

move on	
Fred123: My experiences have made me more empathic towards people	251-253
Anna: I designed a support program for children that I realised was tailor-made for my childhood	755-764
Stav: I use positive self-talk to pace myself through the operation process	942-949
Stormy: I see myself as strong and I look on the bright side	178-180
Puddle: I chose to be a [….] and maybe I wouldn't have	1223-1230
Making Use of Defence Mechanisms	
Traveller: I rationalised and depersonalised bullying	575-579
Flower: I use humour as a safety strategy in social situations	497-500
Oscarbertie: I developed a self-depreciating coping style	190-193
Fred123: Acting tough meant I had the confidence to walk down the street with my halo on	205-209
Anna: I coped with bullies by keeping my face 'set' while underneath I could feel the fear and adrenalin	305-308
Stav: I coped with feeling like an outsider by putting my energy into creative things, like piano and drama	394-399
Stormy: There's a need to ignore certain people and not let it get to you	188-189
Puddle: I became popular at school by becoming the 'class clown'	372-374 & 410-411
D. 'Wishing things had been better'	
Wanting to make things better for others	
Traveller: I hoped I'd look normal after my operation, but I didn't	1005-1007
Flower: I have memories of strong hopes that childhood operations would look 'perfect', followed by disappointment	829-836
Oscarbertie: After operations I remember feeling angry, upset and like no-one cared, nowadays you'd call it depression	271-286
Fred123: Teenage operations were like a mechanical treadmill with no-one being curious about the emotional impact	1028-1035
Stav: I wasn't asked how I was feeling emotionally at hospital but I	282-289

think it would have helped to talk	
Stormy: I didn't have any contact with others with CL/P until social media took off	255-259
Puddle: Nobody ever talked to me about what it was like having CL/P as a child	691-673
Making meaning by helping others	
Traveller: I've found my way, but it might not have been such a battle if I'd had someone to talk to	876-892
Flower: I'm on a crusade to educate people now	726-732
Oscarbertie: I pursued a career where I advocate for others who are marginalised	172-176
Fred123: Educating parents and teachers might help	1454-1462
Anna: I think there's a huge denial within support services because people with CL/P live with it throughout life, like diabetes	1414-1418
Stav: It's shaped my future because I want to help other people	1066-1068
Stormy: GP's don't know about specialist cleft services and I have to educate them	1160-1162
Puddle: I make a point of complimenting Mum's and babies	1512-1525

Appendix 10 **Example Table of super-ordinate themes for individual participant**

Traveller

1. The Threatened Self
    - 1.1 Making Sense of Who I Am
        - 1.1.1 I don't Feel Good Enough
        - 1.1.2 I'd be More Confident if I Didn't have a Cleft
        - 1.1.3 I'm Naturally Sociable and Creative
    - 1.2 Myself as Different
        - 1.2.1 My face is Different
        - 1.2.2 Having a Difference does not Make Me Different
        - 1.2.3 Shamed Sense of Self
        - 1.2.4 I'd call it a Disfigurement
        - 1.2.5 Feeling Allied around Others With Difference
    - 1.3 Mixed and Changing Feelings
        - 1.3.1 My Feelings Have Changed and Evolved
        - 1.3.2 I would Rather Not have it
        - 1.3.3 It's Been Me Judging Me Too
        - 1.3.4 It's Still An Emotional Subject
    - 1.4 Positivity and Growth
        - 1.4.1 CL/P made me Stronger
        - 1.4.2 CL/P made me More Understanding
        - 1.4.3 Part of me Feels Special and Proud
        - 1.4.4 Self-esteem developed by Confronting Fears
2. Perception of Appearance
    - 2.1 Image-Conscious Society
        - 2.1.1 I Believed I Couldn't be Pretty
        - 2.1.2 Imagism: A Name for the Problem of being Judged on Appearance
        - 2.1.3 I hoped I'd look Normal (after my Operation) but I Didn't
    - 2.2 Memories of My Infancy
        - 2.2.1 There are No Baby Photos of Me
        - 2.2.2 I'm Sad for What my Parents Must Have Gone Through

3. Being Different to Others
    - 3.1 I Learnt to Feel Different
        - 3.1.1 No Concept of Difference as a Young Child
        - 3.1.2 Always Felt Supported by my Parents
        - 3.1.3 Avoided Romantic Relationships as a Teenager
    - 3.2 People Are Unpredictable
        - 3.2.1 Meeting New People Worries Me
        - 3.2.2 I Overcompensate Socially
        - 3.2.3 People have an Innate Fear of my Difference
4. Coping and Not Coping
    - 4.1 Avoidance as Coping
        - 4.1.1 I've Gone into my Shell
        - 4.1.2 Academic Work Became a Compensation
    - 4.2 Finding Ways to Overcome
        - 4.2.1 Using Public Speaking to Confront My Fears
        - 4.2.2 Feedback from Others is Valuable
        - 4.2.3 I Depersonalised Being Bullied
5. Medical Care
    - 5.1 Educating on CL/P
        - 5.1.1 Overcame Early Speech Issues
        - 5.1.2 Overcame Dental Problems
        - 5.1.3 It Might Not Have Been such a Battle if I'd had Someone to Talk To
    - 5.2 Surgery as an Adult
        - 5.2.1 I Deserve the Chance to Feel Good About Myself

Appendix 11 Check-list of potentially relevant issues for practitioners

Function: a check-list of potentially relevant issues to support Applied Psychologists in assessing people with CL/P for psychological support.

"Research has found that some people born with CL/P have reported they have had difficulties in particular areas. This is not the case for everyone with CL/P, so these questions may not be relevant to you. Can I ask a few brief questions to check whether any of these issues may be a concern for you?"

Potential Questions to ask at assessment:

CL/P background history

- *How many surgeries did you have and how old were you? How did you manage when you had key surgeries e.g. bone graft? Were you offered support?*
- *Are you anticipating having further surgery in future?*
- *Do you have support from adult services or know how to refer yourself if you needed to in future?*
- *Do you or have you had associated problems e.g. hearing, speech, dental? Do you need ongoing support with any of these? Are you getting support, if you need it?*
- *Do you feel you have been affected by your experiences?*

Body dysmorphia

Phillips, K. A. (1996. *The Broken Mirror. Understanding and Treating Body Dysmorphic Disorder*. Oxford University Press. Oxford.

- *Do you feel worried or distressed about your appearance?*
- *Do your feelings about your appearance affect your day to day life?*

Low self-esteem

Melanie Fennell (2009). *Overcoming Low Self-Esteem*. Robinson, London.

- *Do you feel good about yourself in general?*
- *Do you accept yourself as you are?*
- *Have experiences in life helped you to appreciate and value yourself?*
- *Do you feel it's okay to accept help from other people?*
- *Do you look after yourself properly and treat yourself kindly?*

Depression

Gilbert, P. (1997). *Overcoming Depression*. Robinson, London.

- *How would you describe your mood over the past week?*

Social Phobia

Butler, G. (1999). *Overcoming Social Anxiety and Shyness*. Robinson. London.

- *Do you feel nervous or anxious in social situations because you worry about what others may think of you?*
- *If yes, how long has this been a problem?*
- *What is the worst that you thought could happen? (what did you fear people would notice/think?)*
- *What are the main social situations you find anxiety provoking?*
- *How much time do you spend thinking about the situations that you fear entering beforehand?*
- *Do you feel self-conscious when in social situations?*
- *Is there anything that you do to ensure that you come across well?*
- *How much time do you spend thinking about these situations afterwards?*

Post-traumatic Stress Disorder

Herbert, C. & Wetmore, A. (1999). *Overcoming Traumatic Stress*. Robinson. London.

- *Have you ever experienced a very traumatic event? Check for recurrent memories/ thoughts/ dreams/ distress when reminded? Do you avoid places/ people?*

- *Are you bothered by such things as recurrent memories, thoughts or dreams about the event or distress when you see or hear things that remind you of it? Are there any places or situations that you avoid because they may remind you of this event?*

Appendix 12 – NHS Care pathway for cleft lip and palate, NHS Commissioning Board, 2013
Banding as 0-2 years, 3-7 years, 8-14 years, 15-21+ years

	Ante-natal	Birth to 8 wks	9 wks - 2 yrs	3 - 7 years	8 years – 14 years	15 – 21+ years	> 21 yrs returning
Local Obstetric Units	Ultrasound scan diagnosis, confirmed if necessary by foetal medicine specialist Local obstetric unit to contact Cleft Team within 24 hours of diagnosis	Local maternity unit to contact Cleft Team within 24 hours of birth					
Main 'Hub' Cleft Centres (including MDT clinics organised by the Hub at Spokes)	Contact by Cleft Clinical Nurse Specialist (CNS) within 24 hours of referral. Provide printed	CNS visit within 24 hrs of referral Specialist feeding assessment and management, printed information, offer	Lip repair at 3-6 months Palate repair 6- 12 months Refer for local ENT assessment and mgmt	Psychological support prior to school entry Surgery to revise lip and speech (velo-pharyngeal) surgery if necessary, these to be available if	Assessment between 7 years of age and before 9 years by Cleft team Orthodontist, Paediatric Dentist and Surgeon	Definitive orthodontic care Full MDT clinic and records at 15 and 20 years Offer Genetic referral	Continuation of/or return to care from previous period Adult patients returning for care may require Speech and

Ante-natal	Birth to 8 wks	9 wks - 2 yrs	3 - 7 years	8 years – 14 years	15 – 21+ years	> 21 yrs returning
information Negotiate face to face meeting offer contact with CLAPA	Cleft Lip And Palate Association (CLAPA) referral Meet Cleft team and/or Multi-disciplinary Team (MDT) Baby clinic before any cleft surgery Ensure appropriate Paediatric surveillance for co-morbidity & syndromes Clinical Psychology support offered at all team clinics and available throughout all the time points in the care pathway	if cleft palate Speech and language assessment usually at 18 months, and management Paediatric dentist for dental health education/ advice by 6 months of age and direction / liaison with appropriate general dental care Later investigation (e.g. nasendoscopy and videofluoroscopy) for speech problems if necessary and this may be required at any stage in the care pathway	needed throughout the care pathway Full MDT and records at 5 years Paediatric Dentistry advice and/or intervention if necessary	responsible for ABG, if an alveolar defect is present Paediatric Dentistry and Orthodontic treatment If required, pre- ABG orthodontic care followed by Alveolar Bone Grafting completed before 12 years – follow-up at 6 months post-op Full MDT and records at 10 years Speech and Hearing checked and managed if palatal involvement Definitive	Team assessment for Orthognathic surgery if indicated Planning and pre-treatment for skeletal surgery Orthognathic surgery and associated Orthodontics if indicated Revisional surgery if indicated (nose, lip) Paediatric to Restorative Dentistry as indicated Completion of Post-Orthognathic surgery records and Speech assessment Speech revision	Language assessment and therapy Lip / Nose revisional surgery Speech revision surgery Palatal fistula repair Orthodontics ABG if not done previously Orthognathic surgery Clinical Psychology Hearing assessment and treatment Restorative

	Ante-natal	Birth to 8 wks	9 wks - 2 yrs	3 - 7 years	8 years – 14 years	15 – 21+ years	> 21 yrs returning
		Genetics referral if indicated			Orthodontic care Paediatric Dentistry if necessary	surgery if indicated	dentistry
Local Care		Paediatric surveillance for co-morbidity & syndromes Neo-Natal Hearing Test within first few days after birth for ALL babies Genetic counselling to parents if indicated	10 months hearing test if cleft palate and treatment as necessary Annual hearing assessments up to 3 years of age if cleft palate Speech and language therapy assessment	Later Speech and language therapy ENT and audiology assessment if cleft palate at 3 years of age, pre-school entry and 5 years of age (5 years of age assessment may be local or at Cleft Team 5 year MDT)	Speech and hearing problems managed Local Orthodontics	Continuing orthodontic treatment- paediatric and restorative dental care in close liaison with 'centre'	
Primary Care		Dental health education in liaison with main centre	Dental health education in liaison with main centre Routine child health surveillance	Routine preventative dental advice and treatment	Routine preventative dental advice and treatment	Regular dental care	Regular dental care

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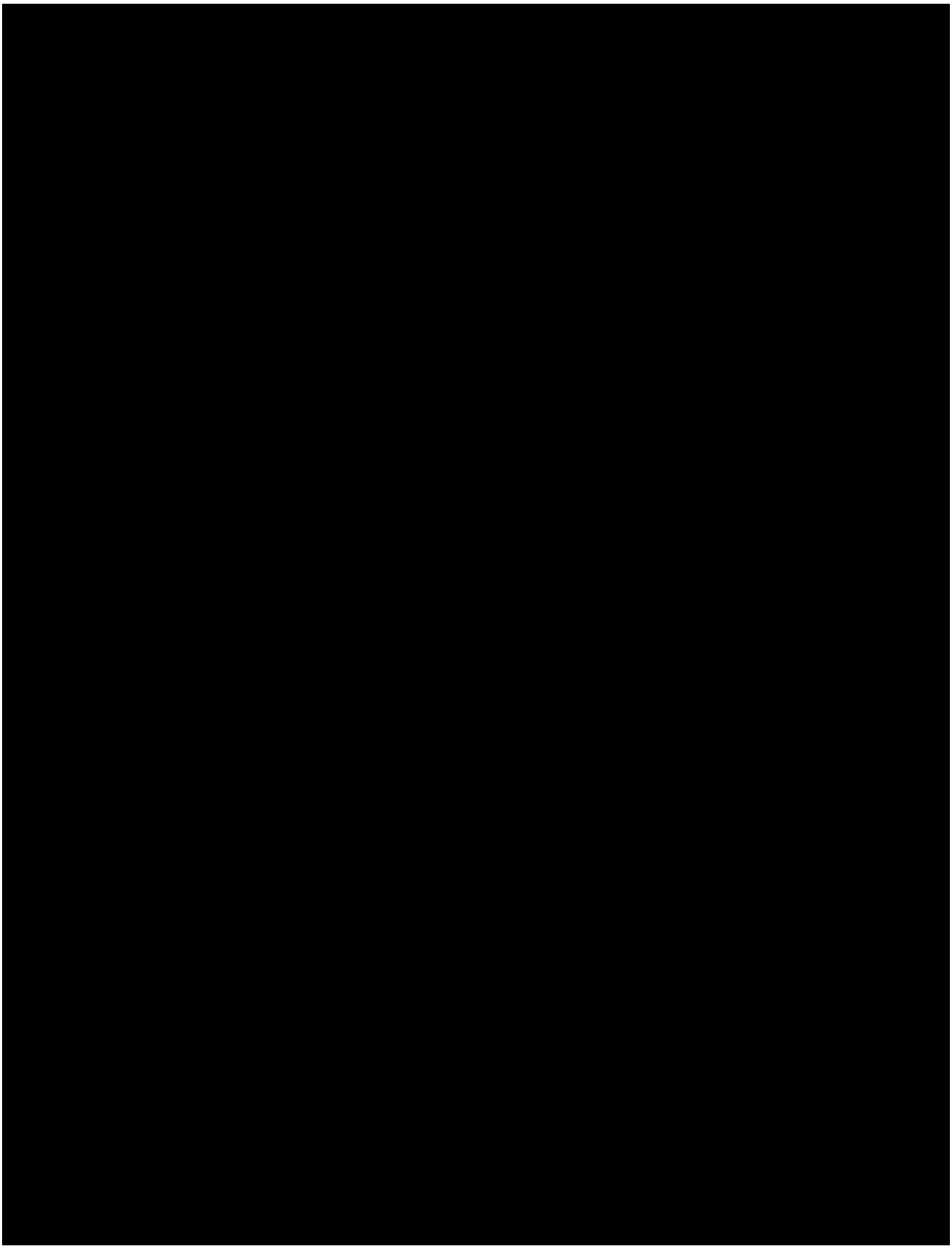
Section B: client study/process report pages 198-226

Section B: client study / process report



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Section C: publishable article pages 227-255

Section C: Publishable Paper