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Relationships, Personal Communities and Visible Facial Difference

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Abstract

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Keywords: Visible facial difference; disfigurement; personal community; relationships; social networks; social support; stigma; belonging; resilience; social self.

People with visible facial difference often experience other people reacting negatively to their appearance. For many, this is part of everyday life. Research has identified social support as critical in adaptation processes. This is the case both for those whose facial difference was apparent at birth, and those who experienced injury or illness. There is a lack of a comprehensive theoretical construct for exploring how personal communities provide resources needed by adults to live well with visible facial difference.

The combination of semi-structured interviews and creation of personal community maps provided opportunities to explore the interplay between respondent accounts and patterns of relationships people are embedded within. Seventeen adults with visible facial difference and two unaffected ‘significant others’ were interviewed.

The findings provide evidence that personal communities are important social spaces for negotiation of resources that enable adults to feel connected, valued and safer within wider communities. Social support was not described as a property of the individual, but as experienced with combinations of people that change according to situation, place, or time. A diversity of personal community patterns were found, largely consistent with findings from Spencer and Pahl (2006), with one variation which increased intimate support. Some personal communities were less supportive and consequently people were at risk of isolation. Processes within personal communities were helpful both in dealing with negative social environments and in helping establish different versions of ‘normal’ life. The importance of focussing on social contexts, when seeking to understand how people live with visible facial differences, is highlighted.

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Dedications

This work is dedicated to Brendan, Matthew and Jon. It is also dedicated to my late parents Beryl and Matthew who were keen that I got an education!

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Glossary of terms

Brachytherapy*	A type of internal radiotherapy
Burn*	Damage to skin caused by hot liquid, object, flame, electric current or corrosive substances.
Cerebral palsy*	Affects muscle control and movement, usually caused by injury to the brain before, during or after birth. It can affect body movement; muscle control, coordination, or tone; reflexes, posture and balance.
Cleft lip and/or palate*	A cleft is a gap in the upper lip, the roof of the mouth (palate), or sometimes both. It occurs when separate areas of the babies face do not fuse during pregnancy. The type, severity and effect on speech vary from person to person.
Commando procedure	Surgery for cancer in oral cavity and/or oropharynx. Consists of radical surgical procedure which includes resection of primary site, mandibular surgery, neck resection, reconstruction of bone and soft tissue defect and temporary tracheotomy (de Boer et al., 1995)
Crouzon syndrome*	A genetic disorder characterized by the premature fusion of certain skull bones, which affects shape of head and face. Affected children have a range of problems from mild facial appearance symptoms to those affecting breathing, feeling and vision.
Epidermolysis Bullosa (EB)*	A group of genetic disorders that result in fragility of the skin and, in some cases, other internal membranes and organs. Blisters, open wounds and sores form as a result of the slightest touch, rub or trauma.
Eczema*	A group of dry skin conditions and is highly individual. Patches of skin become rough and inflamed with blisters which cause itching and bleeding.
Head and neck cancer*	Cancer which occurs in any of the tissue or organs of the head and neck. Cancer varies by stage, effects on facial functions and appearance depending on treatment required.
Haemangioma**	The most common type of birthmark. It is a collection of small blood vessels that have formed a lump in or under the skin. Haemangiomas can be superficial or deep.
Moebius syndrome*	A rare neurological disorder present at birth. It primarily leaves those with the condition unable to move their faces or their eyes laterally. There may be hand/feet anomalies, respiratory problems, speech and swallowing disorders, visual impairments, sensory integration dysfunction, sleep disorders, and weak upper body strength.

Neuro-fibromatosis 1 (NF1)**	A genetic condition; some symptoms develop over many years. In most cases the skin is affected, causing symptoms such as: pale, coffee-coloured patches with smooth outlines; soft, non-cancerous bumps on or under the skin.
Neuro-fibromatosis 2 (NF2)**	A genetic syndrome characterised by development of nervous system tumours, eye abnormalities and skin tumours. Symptoms include hearing loss, balance problems and facial palsy.
Orthognathic surgery***	Jaw surgery
Retinoblastoma (RB)*	RB is an uncommon eye cancer in children
Skin cancer*	There are three main types of skin cancer: basal cell carcinoma, squamous cell carcinoma and malignant melanoma. Cancer varies by stage, effects on facial functions and appearance depending on treatment required.
T1 larynx	Referred to by de Boer et al. (1995) indicates a full course of radiotherapy for a small carcinoma limited to the vocal cords
Treacher Collins syndrome****	Affects development of bones and tissues of the face. Effects range from almost unnoticeable to severe. Most affected individuals have underdeveloped facial bones, particularly the cheek bones, and a very small jaw and chin.
Vitiligo*	Long-term skin condition which makes the skin, and sometimes the hair, turn white in patches. White patches to develop on the skin due to lack of melanin.

List of abbreviations

BLESMA	British Limbless Ex-Service Men's Association
CLAPA	Cleft Lip and Palate Association
DEBRA	Dystrophic Epidermolysis Bullosa Research Association
DSQOL	Disease Specific Quality of Life
EORTC QCL-C30 H&N35***	European Organisation of Research & Treatment of Cancer Quality of Life Core Questionnaire with Head and Neck specific modules.
HADS	Hospital Anxiety and Depression Scale
HRQOL	Health Related Quality of Life
NHS	National Health Service
TBSA	Total Body Surface Area burned, expressed as a percentage

Sources: *relevant charity website; **NHS website; *** professional association website; ****National Library of Medicine website.

Chapter 1: Introduction to the thesis

1.1 Introduction

Our eyes are drawn to faces of other people; the face is a key part of our communicating body. When another face is different from what we expect, our attention can intensify. The result of this intensification is referred to as 'social visibility' or noticeability (Feragen , 2012). People with visible facial difference often have a history of other people reacting negatively to their appearance. This can be accompanied by feelings of unease which, for many, is a continuing part of everyday life. These experiences foreground the continuing presence of stigmatising attitudes and discrimination (Goffman, 1963) in relation to visible facial difference within social contexts and cultural worlds. However, valued relationships with other people, with families and friends, may act as resources and enable the development of zones where one is valued and feels safe (Kittay, 2006). They may act as a bridge to other social connections within wider communities of which the person with visible facial difference is already a part. Furthermore they may also contribute to the development and sustenance of resilience in a context of living with facial difference within a potentially stigmatising social world (Ungar, 2010 and 2013). Personal communities are a route to exploring a range of relationships with family members and friends who are important to the individual. The emphasis is on exploring the value of personal communities in contributing to living well with visible facial difference and the variety of forms these communities can take. In-depth explorations of personal relationships are presented.

1.2 Context and justification for the research

In the UK research in the field of visible facial difference is largely situated within the domain of psychology (Rumsey and Harcourt, 2012). This has sought to understand links between the marked body, appearance cognitions, and psychological adjustment and adaptation. The cognitive psychosocial approach has made important contributions with findings indicating that severity of visible facial difference does not necessarily predict psychosocial distress.

However, this is not to say that living with visible facial difference is the same as living with no disfigurement or ‘difference’ to the face (Newell, 2000). While much of the literature has focussed on deficit and negative functioning there is work which looks at the development of coping skills and resilience within adaptation (Thompson, 2012). The role of social support has been recognised as providing important resources for adjustment, adaptation and coping. These studies provide useful quantitative and descriptive data, and have been reviewed in Chapter 3. Social support is seen as coming from family and friends, and some studies have differentiated between types of support as well as why they act as support.

However, there are many questions still to address about ‘social support’ (Finch and Mason, 1993). Social support is not a commodity that an individual just ‘has’. Rather through processes of negotiation, within networks of family, friends and other important relationships, it develops through reciprocity and a sense of duty (Wellman and Wortley, 1989; Phillipson et al., 2004; Spencer and Pahl, 2006). These processes change over time, influenced by many factors including life events, history of a relationship or groups of relationships, geographical moves, age, ethnicity, gender, class, and life stage needs. These networks can also be affected by health issues (Vassilev et al., 2010), and attitudes to stigmatised difference (Yang et al., 2006). This study has explored what is important to people living with visible facial difference and whether valued relationships in patterns of personal communities act as resources in helping them achieve these things.

Resources and selves are viewed as emerging through interactional processes. Personal micro-social worlds are viewed as nested within wider meso and macro social worlds (Bronfenbrenner, 2005). In order to capture relationships from both family and friends, this study has utilised the concept of personal community, as described by Spencer and Pahl (2006). Their work can be situated within the field of the sociology of personal life (Smart, 2007; Morgan, 2011). Spencer and Pahl’s (2006) primary interest was in the role of friendship and they focus on identifying patterns of connection within personal relationships. This proposed exploring friend and family relationships together, suggesting that in some situations for some people relationships and roles of family and friends overlap, or are suffused.

Spencer and Pahl (2006) suggest the increased emphasis on the significance of friendship arises as a feature of contemporary life, and this development, rather than being a sign of fragmentation or isolation, can be a source of ‘hidden solidarity’. The personal communities they identified were grounded within relationships with family of origin, family of one’s own, and partnerships rather than solely being displays of friendship patterns. The study presented in this thesis is the first time this approach has been applied within the field of visible facial difference.

Visible facial difference is experienced as a limitation largely due to intolerance, and affected persons may experience social disruptions and encounter stigmatisation or marginalisation (Asch, 2006). This is a social issue which can affect identities and a sense of self-worth. Kleinman and Hall-Clifford (2009) suggest that stigmatising social contexts affect ‘that which matters most’ to people within their social and moral local worlds. ‘That which matters most’ can include wealth, education, relationships and life chances. This has led some researchers in the field to suggest that greater attention needs to be paid to supportive, loving environments which encourage social comfort to develop (Lawrence et al., 2004). To this end, this study has focussed on exploring these aspects of people’s personal micro-social worlds, utilising the method of personal communities.

Another issue considered in this thesis is whether visible facial difference can be viewed as separate from other aspects of a person’s embodiment. It is entangled with other functional aspects of the face and of the body. For example, if a person eats in a way considered different, this may have aesthetic as well as functional implications, and this may also trigger reactions from other people about what this difference might mean or symbolise. The face is part of the body. One’s social life and social self is influenced by one’s embodiment (Waskul and Vannini, 2006). The visible facial difference literature has identified that subjective experience seems to be a better predictor of psychological adjustment than either subjective or objective measures taken by an observer (Moss, 2005; Brown et al., 2010). The perspective adopted in this study places social actors in a relational context which both enable and constrain, and also serves as the basis for an embodied reflexivity (Burkitt, 1999).

Interactions with others shape us and are sources of approval, recognition and love (Smart, 2007). Strong emotions and self-feelings come into play, whilst the desire to be perceived or recognised in ways that we wish, goes alongside the prospect of rejecting unfavourable judgements. Bodies and faces are negotiated in the context of social worlds and much of a person's awareness of their body derives from those around them (Crossley, 2006). In this study, visible facial difference has not been viewed as a separate body part which determines social or personal outcomes, but part of negotiation with other people in relational worlds.

Many people living with visible facial difference do not have continuing illness conditions, disability, or necessarily have conditions that affect activities of everyday life. This study has focussed on living with visible facial difference over the longer term rather than at the stages of diagnosis, treatment or recovery. Longer term processes for some might not continue to feature ongoing illness or disability, and might be viewed as continuous rather than disruptive biographically (Williams, 2000). However, there is evidence which suggests that people's lives are shaped by their visible facial appearance long after hospital has been left behind (Knudson-Cooper 1981; Ablon, 1996; Bonanno et al., 2011, Bonanno and Esmaeli, 2011; Stock et al., 2014).

A gap in the literature concerns how psychological adaptation translates into fulfilling lives within potentially stigmatising social contexts. Pre-existing circumstances such as social support aid adaptation, possibly through buffering against stress. However, there has been little research looking at the particularities of relational patterns in which selves are embedded, and how these might contribute support and belonging. There is also comparatively little research looking at how support and connection with family and friend relationships interact with and shape resilient voices in adulthood. The presence of stigmatising attitudes continues despite advances in reconstructive and cosmetic surgery which seek to normalise appearance. Indeed there is a connected debate about whether ableist social pressures to hide the non-normal body may socio-culturally reproduce stigma (Kendrick, 2008).

Yet the desire for normality or a return to near normality is not unreasonable on the part of an individual, possibly because of an inherent sense of safety within conceptions of the ‘normal’. As Kittay (2006) argues, the desire to be normal may be the desire to be included within functionally relevant and socially valued areas of life. Increasing knowledge of relational aspects of individuals’ social networks is important, because these play a part in social connection, integration, and emotional health and can be conceived of as a doorway to resources in wider worlds of work, education, and other facets of life. This study explores whether personal communities contribute to a sense of safety, of being valued, and connected to a wider community of which one is a part. There is a significant value in learning more about how relationships protect against stigmatising actions and contribute to promotion of resilience.

The study used a combination of qualitative methods and involved two interviews with each respondent. These were a visual mapping exercise which the respondent used to construct their personal community, combined with semi-structured interviews to talk about the significance of the mapped personal community. This combination of semi-structured interviews and creation of maps of personal communities provided the opportunity to explore the interplay between respondent accounts and the pattern of relationships in which people are embedded. These methods were considered to be an effective way of extending the work of Spencer and Pahl (2006) to the field of visible facial difference and to answer the research questions detailed below.

1.3 Research questions

Spencer and Pahl’s (2006) work is important because it identified diversity in how individuals feel they receive companionship, intimacy and support from a wide range of close relationships seen through a lens of personal communities. Spencer and Pahl did not, however, include people with visible facial difference or explore whether personal communities are shaped by a need for protection from negative interactional experiences.

The questions asked in this thesis are whether Spencer and Pahl's (2006) concept of personal community has currency in understanding the personal communities of relationships of people living with facial difference:

- What are the characteristics and value of these personal communities of people with visible facial differences?
- Do personal communities contribute to resilient adaptation and protection against stigma for people with visible facial difference?
- What roles do people with visible facial difference play within their personal communities?

1.4 Structure of the thesis

Following this introductory chapter, Chapter 2 introduces the concept of visible facial difference, looking at definitions, terminology and estimations of rates of occurrence. The chapter introduces the sensitising theoretical context for the exploration of personal communities of people viewed as embodied social selves. The interactional context of looking and staring is explored and the notions of resilience are introduced. The concept of personal community is then examined in detail (Spencer and Pahl, 2006).

Chapter 3 reviews visible facial difference literature to identify knowledge about the roles of personal relationships, networks and social support in relation to adaptation over time to visible facial difference. It locates the field within psychology and maps the main areas explored. It finds there is a lack of exploration of the social context despite perceptions of social support having been found to have significant influence on subjective well-being.

Chapter 4 presents the methodological and philosophical approach used. The framework developed used five overlapping concepts to explore personal communities and relationships with people with visible facial difference. These are embodiment, embeddedness, moral dimensions, relationality, and biography.

Chapter 5 describes the methods selected and discusses their suitability. Recruitment of respondents, ethical issues and methods of data collection and analysis are presented and discussed.

Chapters 6, 7, and 8 present analyses of the findings of this study. Chapter 6 explores what is important to respondents and the roles they play in their personal social worlds.

Chapter 7 looks at perceptions of the responses of others to visible facial difference and explores respondent voices in relation to the complications that can ensue. Three voices of resilience are introduced. Chapter 8 examines in detail the patterns of personal communities constructed and respondents' perspectives about how these contribute to living with visible facial difference.

Chapter 9 discusses the main findings in relation to the associated literature. It identifies the contributions and limitations of the study. A diversity of personal community patterns were found and were generally seen to be sources of significant resources. The richness of personal communities challenges harmful and inaccurate stereotypes of people with visible facial difference as 'damaged and isolated loners'. Some personal communities were less supportive than others and consequently some people were at risk of isolation. These findings are discussed and suggestions made for future research taking a social and relational approach to visible facial difference.

Chapter 2: Social context of visible facial difference

The face is not the property of an individual; it is part of our communicating body (Goffman, 1982). It is seen in social interaction and seen and responded to within historicised and gendered ideals of the normal, the able, and of beauty (Peacock et al., in press). This chapter explores the concept of visible facial difference and how interactional contexts and cultural representations shape an individual's experience of living with visible facial difference. The way facial difference illuminates debates on bodily representation is explored and how people living with visible facial difference invoke discursive formations of disfigurement (Garland-Thomson, 2009). The chapter contextualises the relevance of the face for communication. It asks how we encounter and respond to facial difference and examines how close personal relationships can be sources of support important for well-being and health. The chapter concludes by examining the potential role of personal communities in creating social spaces where people can feel safer, accepted and valued.

2.1 What is visible facial difference?

There is no shared category of visible facial difference, or, for that matter, of 'normal' facial appearance. There are, though, medical categories which seek to describe the phenomena of disfigurement and other ways in which a face can be atypical. *Changing Faces*, a charity prominent in championing the rights of people with visible facial differences describes facial disfigurement as:

> "the aesthetic effects on facial appearance of a scar, mark, rash, or a skin graft on a person's facial skin or an asymmetry or paralysis to their face" (Changing Faces, 2009, p.1).

Causes include those arising from appearance-altering medical conditions, from injuries and from the treatment responding to them; differences can be manifest at birth or occur at any time of life.

There is a long standing association, made by some, between facial appearance and cognitive ability. There are also assumptions made about the psychological effects of trauma resulting from this. These associations have an imagined reality which pervades both medical and cultural conceptions of the meaning of facial appearance and facial difference.

Appearance cannot be measured objectively and there is no specified range for normal appearance (Harris, 1997). The perspective of a person with visible facial difference may differ from that of an observer, and both these viewpoints will be affected by social and relational contexts, life experiences, and norms within wider cultural contexts. Expectations of how one ‘should’ look affect how individuals see themselves and others. There is no single point where appearance can be said to be different from what is commonly regarded as ‘normal’. Difference may take the form of a continuum; however, this is unlikely to be linear as there are complex and entangled dimensions of aesthetics and functions of the face. Visible facial difference simultaneously has medical, social and emotional aspects, and an embodied social reality. In response, people with visible facial difference may require, or decide to take up, various forms of repair offered by surgery or by psychosocial interventions (Rumsey and Harcourt, 2004; Talley, 2014).

2.2 Terminology

The term ‘visible facial difference’ denotes non-chosen, atypical facial appearance or disfigurement. There are ongoing debates among people living with atypical facial appearance about the most appropriate terminology to use. One point of view is that the terms ‘disfigurement’ and ‘disfiguring’ are too negative; they are seen as ‘medicalising’ the person rather than critiquing the social situation. In addition, they are terms that some people with visible facial difference do not use to self-identify. This has led to use of the terms ‘visible facial difference’ or ‘altered facial appearance’ in an attempt to side step the negativity of ‘disfigurement’ while still indicating where differences are more atypical than those expected within usual human variation. These terms have the value of appearing more inclusive. However, they can also be seen as diluting the supposed or actual experiences of disfigurement because visible differences could refer to many physical differences between individuals such as hair colour, skin colour, gender, or effects of ageing. In this thesis the term ‘disfigurement’ is used where it has been specifically used by a respondent, a cited author or in reference to equality legislation. The term ‘visible facial difference’ is used where a more generic or inclusive term is more appropriate. This clarification of terms used, leads onto questions about what visible facial difference actually is.

Disfigurement is recognised within UK equality legislation as potentially leading to disabling experiences. The Equality Act, Schedule 1, Part 1, Section 3 (2010) has established legal protection for people with severe disfigurement. This applies when an impairment which consists of a severe disfigurement has a substantial negative effect on the ability of the person to carry out normal day-to-day activities and these effects have existed for over one year. Disfigurement under the Act could be anywhere on the body, and could also be co-morbid with other impairments. Living with visible facial difference may not in itself trigger protection under UK law, as it may not be assessed as sufficiently detrimental to activities of daily life. However, given the importance of the face for personal and social identities and the accompanying potential to affect interaction with others, differences that are judged less than severe may still have profound psychological or social effects. The notion of visibility to others is important as it indicates that difference has the potential to affect interactions with other people, as well as feelings about the self (Rumsey and Harcourt, 2005). Subjective judgement of the person with visible facial difference is a useful starting point for determining the severity of impact on interactions. Some of the reported experiences of people with visible facial difference share commonalities with those experienced by people with other impairments or long-term conditions and for this reason relevant scholarship from disability studies and medical sociology is examined alongside literature from the psychology of appearance.

2.3 Occurrence of visible facial difference

There are few figures which capture the extent of visible facial difference within the UK population. The Office of Population Censuses and Surveys’ (OPCS) Disability Survey estimated there were at least 400,000 people in the UK with a disfigurement to their face and/or body defined as a scar, blemish or deformity which severely affected their ability to lead a normal life (Martin et al., 1988). In relation to the impairment of disfigurement the survey conceptualises the disadvantage that might follow to be that of a limitation on ‘social integration’. The survey is thought to underestimate of the number of people living with disfigurement because it only counts those who might also be defined, within the terms of the study, as disabled.

Furthermore, it provides little information about the occurrence of visible *facial* difference because it does not distinguish location of disfigurement on the body. The survey has also been criticised as it does not include perspectives of disabled people about other aspects of their world which are disabling, beyond activities of daily living (Abberley, 1992). Not only is the survey thought to underestimate gross numbers, it also fails to identify those whose lives are affected by the social or psychological consequences of difference (Newell and Marks, 2000; Changing Faces, 2007). *Changing Faces* have estimated that 542,250 people in the UK have a significant disfigurement to the face (Changing Faces, 2007), it uses a broader definition of disfigurement than the Disability Survey (Martin et al., 1988) and differentiates by location and extent, focusing on the face and head only. The *Changing Faces* estimate includes congenital conditions, accidental causes, such as burns, scarring, facial fractures, cancer treatment and disease process, eye conditions, such as loss of eye, facial paralysis and skin conditions such as psoriasis, vitiligo and acne. However, this estimate is unverifiable for a number of reasons to do with the methodology used and also the lack of epidemiological data published about the incidence or prevalence of enduring facial differences. ‘Visible facial difference’ is not an epidemiological category. Facial scarring, for example, might be seen as a by-product of surgical interventions it is not routinely recorded across medical systems. The complexities of categorisation within medical conditions, when disfigurement might be said to be present and the subjective nature of visible facial difference can complicate estimations of when an altered or atypical appearance can be said to be ‘different’. Furthermore, visible facial difference does not just affect ‘visual aesthetics’; other facial functions such as facial movement and sensation, vision, speech, eating and hearing, can also be implicated, and, if they are, these also affect facial appearance through effects on for example smiling and saliva control. The numerical extent of visible facial difference remains largely unknown and is likely to be underestimated.

2.4 Bodily representation

There are a number of books written by people living with acquired facial difference in the UK: prominent amongst them are Christine Piff (1986), Simon Weston (1989, 2003), James Partridge (1990) and Katie Piper (2011).

Some are autobiography and some self-help, some exploring a journey through life, providing narratives with different outcomes. These accounts seek to communicate the challenge of **resisting** negative perceptions, **adjusting**, **achieving** in the face of visible facial difference. The autobiographies of people with visible facial difference provide journeys of reconstruction of bodies and selves embedded in personal and social worlds. The more ordinary story, of visible facial difference experienced since birth, has been told by fewer writers - those who have, have done so outside the narrative of tragedy (Zitzelsberger, 2005).

Images of the face have currency in consumer society alongside idealised notions of self-transformation with the aid of surgery, style and make-over advice and through learning presentation of selves that communicates confidence (Featherstone, 2010). Conceptions of beauty[1] can be historicised and ‘relativised’ to their cultural context. It has been theorised that contemporary constructions position beauty as something that can be bought, modified or fixed (Synnott, 1988). This can be linked to the growing mass market in cosmetic surgery.

People with visible facial difference have long lived alongside the promise of plastic surgery and its close relation, cosmetic surgery. Plastic and reconstructive surgeries seek to improve function through changing or restoring faces closer to facial normality. They also claim to enable people to live more confidently with their appearance (Kittay, 2006). Cosmetic surgery, on the other hand, offers the promise to provide interventions in ‘smoothing’ the processes of ageing. The celebrity focussed, visual culture we find ourselves in has been implicated in producing rising levels of body dissatisfaction among ‘normal’ people (Rumsey and Harcourt, 2012).

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[1]. Eco (2007) theorises that the traditional view has ugly/beauty as an opposition, in which ugliness is obvious and speaks for itself. Eco (2007) traces the changing aesthetics of ugliness in Art historically and detects that ugliness and beauty are defined by reference to a standard relevant to that time period. Eco argues that there has always been some sort of standard against which things are aesthetically judged and there has also been a shadow side to what is considered beautiful. Ugliness is used to represent that which is bad in the world e.g. war, genocide. Another study would be required to explore aesthetics of beauty and ugliness in relation to visible facial difference.

It might be that this heightened interest in understanding the dynamics of altered appearance or modifications of the body (Featherstone, 2010) could create opportunities for other voices to be heard.

Images of characters and people with visible facial difference are commonly found in a range of visual and cultural media, such as fairy tales, novels, films and make-over television shows, communicating different meanings about facial difference. Physiognomic linkages are made between visible facial difference and moral character, positioning scarred or damaged faces with bad or damaged character (Partridge, 2012; Twine, 2002). Although the 'science' of physiognomy has had its day, it lives on culturally through these representations which act as heuristic devices that misrepresent experience within lived, everyday worlds. The visual senses are an important aspect of embodiment, providing connection with others and contributing to the constitution of our embodied selves. As Twine puts it:

> '…my particular critique of physiognomy is not about excluding the body from our self-constitution, but about resisting the body's entrapment within physiognomic discourse that tends to define our bodies for us' (Twine, 2002, p.83).

Twine (2002) historicises discourses of physiognomy, finding indications that meanings of appearance are not timeless and absolute. He argues that relying on the physiognomic marking of the body is 'sloppy' and risks making generalised and unwarranted claims about the subjectivity of another human being, which can affect processes of interaction. Twine (2002) questions the value of popular faith in a direct relationship between visual appearance and generalised, stereotyped meaning. The perceptual aspects of noticing difference are hard to tackle and Twine (2002) suggests that in the interests of humanity a more mindful approach is cultivated within interactions where judgements about appearance occur.

This line of argument has been taken up by others such as Langer (1989), Partridge (1990) and Garland-Thomson (2009 and 2011). Garland-Thomson (2011) theorises that shared human experience of embodiment is influenced by a cultural ability/disability system of significance.

This affects how we see and live the limits of our bodies, and their aesthetics. Garland-Thomson defines the ability/disability system as:

> '…a pervasive cultural system that stigmatises certain kinds of bodily variation' (Garland-Thomson, 2011, p.17)

This perspective challenges ideas that differences associated with disability need to be about inferiority or tragedy. Instead, the comparison of bodies is seen as embedded in culture and is used to interpret an unequal distribution of resources, status, and power within a biased social environment. Garland-Thomson (2011) outlines four aspects of this system: interpretations of bodily variations; government of relationships between bodies and their environments; a set of practices that produce able-bodied and disabled bodies; and a way of describing the instability of the embodied self. Taken together, these are theorised as contributing to marginalisation of those who have certain attributes and bodily forms. This approach enables a broader view of disability and includes ideological categories such as 'ugly', 'maimed' and 'mad'. Garland-Thomson's argument is that this ability/disability system serves to privilege categories such as 'beautiful', 'healthy', and 'normal' and it is in the interaction between bodies and the world that disability becomes material above and beyond usual human variation.

Appearance norms have a long history within western culture (Synnott, 1988) and the perspective offered by Garland-Thomson adds that health norms provide similar cultural functions. She theorises that these cultural ideas, alongside market mechanisms, push bodies towards a set of standards called 'normal' and 'beautiful'. From this perspective, the idea of beauty has become suffused with the idea of normal, producing a tendency at an individual level to avoid looking 'disabled', 'ugly', 'fat' or 'raced'. The possibilities provided by advances in medical surgical techniques have also become entangled with appearance norms (Synnott, 1988; Garland-Thomson, 2011; Talley, 2014). Adopting this perspective is not about negating the value of modern medicine to improve body function, but rather to emphasise that availability of these techniques has a role in reinforcing the idea that certain bodily differences are intolerable to live with and can be made to go away!

2.5 Looking and staring

The discriminating eye of perception cannot be ignored. Garland-Thomson seeks to explore aspects of visual culture and how they impact on the lives of people with physical difference in ‘Staring: How We Look’ (2009). She draws on the work of Langer, who hypothesised that people stare at ‘novel stimuli’ as a form of ‘exploratory behaviour’ (Langer et al., 1976, p.461) and as a means of reducing unease and uncertainty in an uncertain world. Using a psychological approach as her baseline, Garland-Thomson discusses the automaticity in staring:

> ‘Stareable sights seduce us into an attention crisis in which random visual intrusions, not a disciplined will, assert control’ (Garland-Thomson, 2009, p.21)

She recognises the problematic nature of staring, locating its useful as well as destructive powers, identifying its role as a response to the unexpected and unusual; as a form of communication; an expression of dominance and as stigma assignment. What is needed, she seems to be saying, is a wedge between acts of staring and the negative judgements that can flow from staring interactions, a separation in understanding of these processes. Garland-Thomson suggests that, in part, one’s dislike of being found staring arises from being found in an act of social rudeness and the attendant unmasking enhances the negativity of the action. However, staring does not have to be regarded as purely negative. It can provide useful information about the world. She proposes a new ethic of looking and of being looked at, and suggests that the ethical questions to consider are more about how we should stare, rather than whether we should stare and *how* will we be stared at, rather than *whether* we will be stared at:

> ‘We become ethical starers by being conscious in the presence of something that compels our intense attention. What gives such attractions power in these formulations is their capacity to vivify human empathy through bearing actual witness…the impulse to stare at novel sights, whether we understand them as conventionally beautiful or repulsive, can move us toward recognising a “newness” that can be transformative. These stareable sights disturb not just the visual status quo but the ethical status quo as well’ (Garland-Thomson, 2009, p.188).

This stance places some weight of responsibility on the person who knows they are likely to be stared at, such as using learnable techniques for dealing with starers ethically, teaching others how to look, and being seen, rather than avoiding being seen, in public (Partridge,1990). This constellation of activities Garland-Thomson calls ‘visual activism’ (2009, p.194), taking a position in the public eye. This provides part of the context for this study and for understanding the experience of stories of **resisting, adjusting and achieving** in the worlds of people living with visible facial difference**.**

2.6 The significance of the face

Turner (2000) claims representations of the body have become central in a consumer society. Analyses of lived experiences have been used as a means of articulating oppressions based on race, disability, class and gender from the 1960s onwards. A body is not just a body, it is also symbolic. The perceiver and the perceived are intertwined and connected to our corporeality. The process of becoming a particular body is tied up with the making of selves.

The face can be seen as focal in human interaction and communication. It can be seen in many ways at the same time, with multiple streams of information and signals which co-exist and can be read simultaneously. Black (2011) uses the metaphor of a ‘multiplex’ to understand the fluidity, complexity and lack of fixity of the face. Multiple accounts of the face arise from social, psychological, medical and cultural investigative perspectives and none of these are able to fully capture what a face is and what a face does. Seeing the face only in terms of ‘subjectivisation’ underplays the anatomical and cognitive uniqueness of the face as a living organ of communication, and indicates difficulties in seeing communication as detachable from the body (Black, 2011). The face has a central role in communication and to generate meaning for the observer.

Black (2011) identifies ties between emotion and facial movements; the face exudes emotions through a process which is largely out of conscious control. Communication need not depend on language or conscious cognitive activity. The face results from physical evolution and the redeployment of physical features of the head to the tasks of communication, producing facial features and muscles which are capable of complex mobility and have the ability to perform many functions (Cole, 2001).

All faces can be seen as performing these functions, although not necessarily with the same levels of functional ability. However, when communication functions are disrupted by paralysis, stasis or scarring, communication may also be disrupted. The meanings of these disruptions in lived experience and the roles they play in the interactional contexts are only partially known and understood. Qualitative studies investigating how people living with Moebius syndrome develop their communicative abilities indicate facets in the learning of emotion which go beyond the face. People can gain abilities to utilise embodied non-facial expression and contexts of empathic interactions with interested others as part of the basis in the development of understanding emotion (Meyerson, 2001; Cole and Spalding, 2009; Bogart et al., 2010 and 2012). It is the observer who may miss subtly different facial signs or misinterpret compensating actions involving other parts of the body, rather than the lack of an emotional life on the part of the bearer (Cole and Spalding, 2009, Bogart et al., 2010 and 2012).

Turning to how the face is used, Black (2011) highlights the cultural specificity of the ways that social interaction occurs. Learning to recognise other faces seems more reliant on the mind of the observer than on the physical characteristics of the face being observed. Emotional involvement and cognitive processes of generalisation over and above perceptual systems are required in order to fix the face into a pattern that we recognise. The mapping of identities and categories onto the face comes from socially formulated categories, and it is the mutability of the face and adaptability of brain structures that allow for a huge range of cultural and social categorical and identity possibilities. Basically, the face becomes an important identifier and is used to categorise us. As Black writes:

> ‘…the face as a material component of the body, which is never fully fixed, grasped or possessed by the viewer of the face’ (Black, 2011, p.21)

Socially constituted structures of significance are used to stabilise and fix faces into categories such as ‘beautiful’, ‘ugly’, ‘acceptable’. The face is presented as significant in the processes of recognition, communication, and in creating relationships between bodies.

A lack of ‘fix’ in these biological and cultural processes leaves room for possible variation in lived experience (Black, 2011). Visible facial difference can be seen as having the potential to affect one or a combination of the multiple processes and functions of the face. The possible combinations and the effects on the person with facial difference, as well as those with whom they have contact, are complex.

Featherstone goes further, by not placing sole emphasis on the visual and bringing into the debate the idea of the moving body and its effects (Featherstone, 2010). He uses the term ‘body without image’ to describe an affective body which moves, uses proprioception and other senses to communicate. The notion of body image is a visual and mental construction which can obscure the involvement of the body’s other sensory motor capacities such as smell, taste, hearing, touch and movement in achieving a sense of bodily integrity and communication. It is, however, a moving body which enters interactions, with differing possibilities (consequences) for the development of relationships. In visible facial difference, while movements of the face may be disrupted, other aspects of embodiment might not be.

2.7 Social significance of visible facial difference

The sociology of visible facial difference came into being through the accounts of Macgregor et al. (1953 and 1974) and Goffman (1963, 1982 and 1990). Macgregor et al. (1953 and 1974) began exploring facial disfigurement in plastic and reconstructive surgery clinics at the end of the Second World War. She identified that having an atypical face was potentially a significant social problem for the person affected, as the face was central to the person and their social relations and interactions. She identified the main difficulty associated with facial disfigurement as a psycho-social threat to mental health. She found that some people living with disfigurement found establishing relationships problematic and were hampered by beliefs that they could not be loved because of their appearance. Interviewees spoke of experiences of rejection, feeling unsuitable for marriage or having difficulties gaining desired employment. Her studies explored the problems of families with children who were disfigured from time of birth or during childhood, the impact on the family and maternal attachment. Adult family relationships were not explored in depth, although ‘successes’ in achieving friendships and marriage were recorded.

In respect of the idea of the family serving as a haven, Macgregor et al. (1953, 1974) were not naively venerating the way all families treated their members. Interviews were interpreted as indicating that some people had perceptions of having married beneath their class and having constrained relationship choices, because of their facial disfigurement. Macgregor et al. (1953) proposed the problems encountered went beyond physicality. These studies identified that the physical severity did not directly relate to an individual's psychological adjustment. Adjustment was better understood in relation to interaction with others and views of the self. They reasoned that visible facial difference was more usefully seen as a social disability as it was 'rarely physically disabling' (Macgregor et al., 1953, p.4). Their work made linkages between socio-cultural meanings of disfigurement and physical and psychological aspects (Macgregor et al., 1974). While the dominant language in Macgregor et al.'s work was of suffering, it challenged readers' assumptions about the nature of suffering and whether this was necessarily linked to the physicality of visible facial difference. Macgregor et al.'s work (1953 and 1974) argued that social and cultural judgements about facial aesthetics were causal in social or personal suffering of facially different people. In so doing they brought to the field the idea that a person's concerns about their appearance are not simply pathological or minor. This body of work by Macgregor et al. can be seen as establishing a psychosocial discourse which has had significant influence on the development of psychological studies in this area.

Goffman's (1963) work on stigma included illustrations from Macgregor et al. (1953) of the significance of socially and culturally situated interaction. He described how, through the use of what he called 'face-work', (Goffman, 1982) and interactional strategies (Goffman, 1990), all people maintain their social self and social identity. These are viewed as part of social reality rather than as individualised strategies for action. His work on stigma concentrated on how people manage social encounters in a specific context, rather than exploring how ever-present difference affects relationships in everyday life. Goffman (1963, 1982 and 1990) described techniques of self-presentation which are used in processes of encounter and interaction. Encounters take place within an 'interaction order', to which everyone belongs. He described the notion of 'face-work' as a metaphor for a version of the self which is projected socially.

Face-work has ritualised forms which are recognised by others and if people get the rules of an encounter wrong it can be mutually embarrassing. Garland-Thomson (2009), in her work on staring, reasons that atypical faces can throw simple recognition rituals into chaos, the loss of ability to read the social situation heightens the risk of uninvited face-work, such as staring.

Goffman (1963) has been a major influence in understanding how a face can become a marker for stigma and associated losses of social status or ‘face’. He conceived of stigma as a psychological and social process, as a condition of the interaction order rather than an objective of it. He suggested that no-one can meet the mythical ‘normal’ and defined ‘discredited’ persons as those whose social status is stigmatised and which is apparent in the response of others to it. The term ‘discreditable’ described those whose stigmatised social status is not apparent, but who are responded to as if it were. In social interaction people who are ‘discredited’ or ‘discreditable’ have a more difficult time than others, on more occasions.

Goffman’s interest did not lie in subjective effects or causes of stigma, but in describing how the social knowledge of stigma affects interactions between people. For Goffman, the face he described is not the property of an individual but something performed or acted in social interaction: it is symbolic. Coupled with his conceptions of stigma, face-work produces ways of interacting that seek to maintain ‘face’ in encounters and social interaction. Social situations are maintained by strategic cooperation between people using reciprocal face-work to maintain their own face as well as others’.

The concept of stigma has been critiqued and developed considerably. Kleinman and Hall-Clifford (2009) emphasise moral dimensions and suggest that stigma affects ‘that which matters most’ to people within their local worlds, and ‘that which matters most’ includes wealth, education, relationships and life chances. It can be argued that what is at stake in the processes of face-work is the integrity of a person’s social self. One would be hard pressed to say that visible facial difference is not a potential source of stigmatisation or that interactions are not scattered with ambiguities, embarrassments and unwanted behaviours.

Effects of visible facial or bodily difference are not set aside in processes of interaction. This area has been extensively debated within disability studies where focus has been placed on the role of social barriers and discrimination in lived lives, with social barriers theorised as creating disability (Shakespeare, 2006 and 2014; Thomas, 2007). Some visible facial differences may be seen as having direct effects, as well as effects that can be tagged with significance; they may affect bodily function, and may set into effect different trajectories of socialisation (Cole and Spalding, 2009). An understanding of visible facial difference can be linked with thinking around impairment effects because while visible facial difference may not (using a narrow definition of disability) disable, a loss of confidence connected to appearance can prevent people doing what others take for granted in the routines, relations and movements of everyday life. People may need to negotiate difference in everyday life in public and private spheres; living with visible facial difference is an important issue for both self-identity and inclusion. It is not helpful to think of facial appearance as a shallow personal concern, as it is seen as conferring supposed status and is associated with successes in life through the so called ‘beauty premium’ (Feingold, 1988; Eagly et al., 1991). Benzeval et al. (2013) investigated this claim using longitudinal data following up a general population cohort 20 years after their first point of research. They reported associations between assessments of physical attractiveness at age 15 with higher socio-economic positions at age 36 in terms of their employment status, housing tenure, income and likelihood of being married, even after adjusting for the socioeconomic background of their parents, their intelligence, education attainment and other adult socio-economic outcomes. Gender differences were only found in relation to educational outcomes; for women, educational achievement trumped attractiveness in relation to their socio-economic outcomes. Their findings were not explained by associations at age 15 between greater attractiveness and parental higher socio-economic status. Further examination is needed on the role of those who act of gatekeepers to resources and opportunities that might enhance greater achievement in later life (Benzeval et al., 2013).

2.8 Face inequality

An active charitable sector has developed around facial difference and bodily disfigurement. For example, *Changing Faces* campaigns to achieve greater ‘facial equality’ (Partridge, 2012). Their campaign challenges cultural ‘face values’, which are regarded as responsible for unwanted sympathy, discrimination, prejudice or avoidance. ‘Face equality’ promotes the idea that people should be treated equally and fairly irrespective of their appearance (Partridge, 2012). Beliefs, such as ‘good looks’ equating with happiness, or ‘not looking so good’ with a life of despair or second rate prospects, act as personal and social barriers and are challenged. Moral judgements that link disfigurement with a poor or dangerous character, which pervade the media particularly within the crime genre, are questioned, to increase public understanding of power and unfairness of such generalisations, and also of the limits of what can be achieved through plastic and reconstructive surgery.

Partridge (1990 and 2012) developed the idea of active and positive ways in which facially different people can use techniques in social interaction. He describes how the facially atypical person can take more control of one to one encounters and deal with staring and comments. These skills involve distraction, disarming or open acknowledgement of difference so the encounter moves forward more effectively. His account is striking in identifying the amount of effort or work a person with visible facial difference has to put into encounters, particularly with strangers, and this has to be seen as worth it:

> ‘…when a person with facial disfigurement meets someone for the first time (and indeed sometimes for quite a few occasions afterwards), s/he is likely to have to make up to 95% of the effort in the interaction because face-to-face signalling can be confused and the person with the disfigurements has to do and say things to get attention – or rather, to distract attention away and ensure meaningful communication. In a world in which face equality operated, there would be 50:50 division of effort’ (Partridge, 2012, p.476-477).

His analysis is based on the view that although staring might *come* from hostility it *can* be converted into something more benign in some situations.

Observations of this nature have informed the development of interactional skills training for people living with visible facial difference. As less effort is required in interactions with friends and relatives (Lansdown et al., 1997), these close relationships are potentially a valuable respite for people with visible facial difference.

2.9 Living with visible facial difference: social selves

Lived experiences of visible facial difference are structured by the reactions of others, by anxiety about appearance and how others will react. Relationships are central to these processes, from an early point in life and in everyday life. As well as social connection, relationship with others also can be seen as constituting the self as a social entity (Burkitt, 2008; Ketokivi, 2012). The theoretical perspective of the social self, as based on the symbolic interactionist work of Mead (1967) and Cooley (1965) and developed by Burkitt (2008), is particularly relevant for a study exploring personal relationships. Selves can be seen as being constituted through relationships. This self is relational and is entangled and shaped by ties with significant others, whether the individuals concerned are present physically or symbolically (Burkitt, 2008). The reflexive and emotional self as theorised by Burkitt (2012) emphasises the importance of others in processes of understanding ourselves, the meaning of our actions and our feelings about the world. Emotions are at the heart of reflexivity and, with knowledge, influence an individual’s reflexive choices. Reflexivity is typified as having a hermeneutic or self-interpreting role. This implies internal conversations between the subjective-stance of ‘I’ and the objective-stance of ‘me’ and being able to reflect on self as if it were an object. Cooley’s (1965) metaphor of the ‘looking glass self’ identifies that the way we feel about ourselves cannot be separated from the way others express feelings about us. However, this does not mean that we are a simple reflection of those around us; instead it is how we *imagine* the other is looking at us and our interpretation of their judgement, that is, more important. One’s interpretations, memories and imaginings may, in their turn, depend on past social experiences and processes of socialisation.

As Burkitt (2012) puts it:

> '…imagination itself will be coloured by self-feeling we have developed from the past, so that, for example, someone who has developed a positive self-feeling about themselves may tend to imagine that others see them in a more positive light, while those who feel they have been rejected or unwanted may look for that response from others, feeling in general that others judge them more negatively. So, while all of us are likely to feel pride or mortification if we think others judge us either positively or negatively, we are still inclined to imagine certain judgments in the minds of others depending on self-feelings we have developed throughout our life experiences in social interaction' (Burkitt, 2012, p.466).

This emotional and reflexive self is influenced by its value judgements and the responses of others and these, in combination, create the individual's style of reflexivity. This self is intersubjective, individuals understand the views of those with whom they are emotionally engaged because their views matter to them and they put more energy in to understanding them. The source of people's emotional distress or anxiety can be seen as emerging from particular disordered social interactions and relations rather than directly from concerns produced by social structures - the processes are interactive, emotional and cognitive. This way of theorising does not place 'disordered' reflexivity or decision making processes as the property of dysfunctional individuals, but rather holds that emotions are experienced by everyone and particular sets of circumstances can trigger minor or major distortions in processes of reflexivity (Burkitt, 2012).

Constructing a sense of self is both an individual and a social endeavour: we may choose who we wish to associate with and others do as well. Bourdieu (1989) described two concepts which prove useful: social field and *habitus*. An individual's social field is made up of various situations and contexts through which they move. Depending on the individual's social position within a particular social field, they develop habitual ways of doing and seeing the world which forms *habitus*. In a field where we feel at home, we know how to behave, we have interpretations for what's going on and may feel more at ease.

Bourdieu (1989) theorises that *habitus* allows categorisation of both the self and others according to taste and these are shared affinities with people from similar fields. For Bourdieu (1989), *habitus* is deeply engrained and operates on a largely unconscious level, as with the making of choices come limitations on one’s awareness of different possibilities outside of the range of our cultural experience. Burkitt (2012) highlights the relationship between reflexivity and *habitus* and the unconscious, which makes changing habits hard because they are part of ourselves and have become engrained over the life course. *Habitus* can be seen as contributing to a sense of being valued and being safe (Kittay, 2006). The fields explored in this thesis are subjectively important personal social worlds to which people feel they belong. These may be patterned by class, gender, age, life course stage and race and within this or, and alongside this, the experience of living with facial difference has been explored for its contribution.

The need for a comforting or safe social environment for selves to develop is indicated. Experiences which are personal have social significance; they speak of acceptance, love, reciprocity, and living across difference. Shakespeare (2006) observes that the isolation and loneliness that figures at particular points in the life course for people with disabilities can be experienced differently by social location and gender; it is not a fixed or universal phenomenon. However, these realities cannot easily be overcome by removal of barriers or explained by oppression alone. Positive social relationships between people with and without difference or disability are necessary to optimise flourishing, while recognising the well documented difficulties of interaction, reciprocity and respect between non-disabled and disabled people (Shakespeare, 2006 and 2012; Turner, 2006).

2.10 Living with visible facial difference: disruption, continuity and resilience

This thesis is concerned with the perspectives of people with visible facial difference from a diverse range of causes. The presence of facial difference cannot *per se* be assumed to be connected with biographical disruption.

A disruptive life event is conceptualised as one which breaks the ordinary flow of life and biographical expectations in an acute way and which may require a re-working of relations with close or significant others, as well as of self-identity (Bury, 1982). People, who have lived with difference since birth, are more than likely to have integrated this in their self-identity from an early life point (Williams, 2000; Bronfenbrenner, 2005). An individual life may be disrupted or different, but identity cannot be said to have ‘shifted’ in relation to visible facial difference acquisition. Williams (2000) argues that the idea of biographical continuity might be more useful. Acquiring visible facial difference later in life may originate with a disruptive life event, such as an illness or trauma which may require significant processes of recovery and adjustment. A blanket conception of disruption is therefore inappropriate as self-identities are both physically and emotionally defined, generated reflexively through a cyclical process of revision across the life course (Williams, 2000). This more fluid approach can allow for more positive interpretations of living with visible facial difference, accommodate the diverse nature of the phenomenon, and allow room for accounts that feature notions of resistance or resilience (Goodley, 2011).

Some researchers have sought to shift focus from the immediate aftermath of acquiring difference to longer term perspectives. Lau and van Nierkerk (2011) applied a strength-based framework to understanding resilience of burn survivors. They highlighted that strength and development occurs alongside extreme distress which they describe as ‘struggling well’. Using a post-structural lens they argue that positive aspects co-exist alongside negative and deficit aspects of disability and injury. Rejecting an individualised notion of resilience as an internal psychological state of well-being, Ungar (2004) defines it as

> ‘…the outcome from negotiations between individuals and their environments for the resources to define themselves as healthy amidst conditions collectively viewed as adverse’ (Ungar, 2004, p.242).

Ungar (2010) theorises the concept of resilience from an ecological perspective. His empirical work does not identify a single adaptive behaviour pattern but rather *tensions,* common to accounts of lives.

These are: access to material resources, access to supportive relationships, development of a desirable personal identity, experiences of power and control, adherence to cultural traditions, experiences of social justice, and experiences of a sense of cohesion with others' (Ungar, 2008). He claims that resolution of these tensions is associated with self-descriptions of resilience. This reconciliation of tensions occurs over and over again, in a continuous process, rather than as one with a fixed end point:

> 'The successful individual or family is the one that functions to a standard he, or she, or it, sets, in concert with others whose opinions are valued. In such a negotiated realm, individual families (and family members) will be looking to elicit from complex environments meaningful resources. The most resilient will have the most responsive physical and social ecologies' (Ungar, 2010, p.13).

Ungar (2010) advocates that helping professionals are most likely to be effective when they share with their clients the skills to help cope with change and complexity and consider how well-being will continue after treatment ends. This work represents a conceptual shift from a focus on outcomes to processes, about long term processes of adaptation that may come and go and come again over time. This thesis is particularly interested in the dimension of relationships in this adaptation process.

2.11 Relationships and resources

There is a wide literature demonstrating associations between social support and well-being, including literature that has applied a network concept to examine mediating and moderating effects of social support on health (Berkman et al., 2000). Berkman et al. (2000) conceptualised a 'psychosocial level' which comprises of four main pathways: the provision of social support; social influence; engagement and attachment and, finally; access to material goods and resources. Benefits are found from social support and participation in social networks in areas of health (Gallant, 2003), ageing (Allen et al., 2000) wellbeing and living with chronic health problems (Vassilev et al., 2010) and linkages with mental health (Kawachi and Berkman, 2001). Berkman et al. (2000) have described three main types of support: emotional, instrumental and informational.

Emotional support is defined as sharing life experiences and involves empathy, love, trust and caring. Instrumental support involves the provision of practical help and services that directly aid a person in need, and is often provided by partners, close friends, colleagues and neighbours. Informational support involves the provision of advice, suggestions, and information to help a person address particular problems. It is recognised that different types of support are often difficult to disentangle (Berkman et al., 2000). Social support can be given, received and developed (Kahn and Antonucci, 1981). No single relationship type has been found to provide social support, but rather it is a generalised set of resources available from network members (Wellman and Wortley, 1989). Many resources run through social networks and most network members can provide some form of specialised care. Wellman and Wortley (1989) describe four types of specialised supportive care: emotional aid, material aid, information and companionship, and individuals are seen as searching through their network to access specialised assistance. Family members have been suggested as a primary source of support and friends as important sources of support, but with differing levels of availability and degrees to which it would be considered appropriate to ask for help. The physical location of those providing support is also considered important. For example, emotional support might be available from those further away via telephone, Facebook, or other means of social correspondence, however practical, instrumental support needs to be closer to hand (Wellman, 2007). Social network analysis approaches have been based on a structuralist approach, as well as on a large scale quantitative network surveys. Macro-social forces are described as ‘upstream’ with micro-level and individual processes considered as ‘downstream’ (Berkman, 2000).

A relational approach is gaining currency (Crossley, 2011) and there is also a developing interest in the use of mixed methods to explore the complexity of networks (Bellotti, 2015). Social relationships provide more than support and are a basis for intimacy and attachment as well as providing opportunities for social engagement, participation and a sense of belonging (May, 2013). The process and strength of bonding is thought to be significant for the different types of support available (Bjornberg and Ekbrand, 2008).

Widmer et al. (2008) theorise a configurational approach which sees families as configurations:

> '…sets of directly or indirectly interdependent persons sharing feelings of family belonging and connectedness' (Widmer, et al., 2008, p.3)

These are patterned and embedded in social structures. Identifying a relational aspect to support and aid, Finch and Mason (1993) investigated family obligations to each other. They found that a sense of responsibility for helping someone else develops over time through interaction between the individuals involved. Commitment to others was conceptualised as developing through processes of negotiation over time. They observed interdependencies to have developed in which responsibilities were created and which sought to maintain balances between receiving assistance and maintaining independence. Family relationships were identified as a source of support and, at a minimum level, were those who would be called on in a time of crisis. The study did not promote the idea, or find, that all family relations are positive or only beneficial, but that they were significant, complex, dynamic and created (Finch and Mason, 1993; Smart, 2007). The resources that can be accessed are unequally distributed as is the durability of the network in which people are enmeshed (Spencer and Pahl, 2006).

Early work in the field of visible facial difference has conceptualised the family as a 'haven' from a hostile world (Macgregor et al., 1953). It posited facial disfigurement as a social disability, which placed stress on mental health and could cause difficulties in social integration. The social world has changed since Macgregor started her work in the 1940's, not least through the impact of civil rights, feminist and disabilities movements and also in family structures and practices as well as benefit systems. Critiques from feminist scholarship have challenged the idea of family as simply supportive by revealing gendered inequalities and the role of the family in perpetuating these (Gillies, 2003; Jamieson, 1998). Trends in changes within family structure indicate increases in diversity of living arrangements, higher levels of divorce and lower levels of marriage, more single parents and greater numbers of step-families (Jamieson, 1998). These changes have been used to illustrate significant transformations in personal relationships, as developed under the various forms of the so-called 'individualisation' hypothesis (Giddens, 1992; Bauman, 2003).

These characterised society as becoming more atomised and individualised, with increasing lack of commitment to others and increased isolation for some. These trends in family change have also been used to argue for the enduring nature of the family and for traditional ties (Jamieson, 1998). Shakespeare (2006) has, however, expressed concerns that people living with disability may be disproportionately affected by social changes that increase isolation and disconnection.

The way the family is theorised has also changed. The conceptual foundation has shifted from emphasising the family as an institution, as a source of duty and obligation, to the study of family practices and displays (Jamieson, 1998; Smart, 2007; Finch, 2007; Morgan, 2011; McCarthy, 2012). Pahl and Spencer’s (2010) work contributes to this field by identifying the presence of different types and levels of commitment from families and friends. They argue that rather than necessarily representing a privatisation of experiences, these commitments are part of the bedrock of connection. Pahl and Spencer’s (2010) emphasis on solidarities seeks to challenge claims that personal relationships are increasingly superficial and transitory. While practices of personal relationships seem to be changing, a range of forms seem to provide solidarity, care or support. Their account claims that the nature of care and support cannot be directly read off from the individual’s personal, economic or social characteristics. They found no single ‘normal’ personal community pattern and the patterns they did find were seen as having a diverse range of personal, social and connecting functions. They suggest these relationships to be an important part of the social fabric, a kind of ‘hidden solidarity’ connecting people in changing times.

2.12 Personal communities

This study has adopted the approach developed by Spencer and Pahl (2006) to explore meanings present within personal networks. Their approach builds on Wellman’s (1990) conception of personal communities and can be connected to family practice research and the sociology of personal lives (Smart, 2007; Morgan, 2011).It was chosen because it did not limit investigation of personal worlds to either family or friends but conceived of a way of combining different types of relationships.

The typologies devised arose from an empirical base and even though a wide ranging sample was involved, this did not include people with visible facial difference who might be thought of as potentially at some risk of difficulties in social integration. This has left open an opportunity for an exploration of personal communities with visible facial difference and as a way of adding to their findings.

Other typologies of networks were considered, particularly from social gerontology, with older populations looking at social support, and from the work of Wellman (Phillipson, 2004). Spencer and Pahl's (2006) approach was selected for a number of reasons. First, its qualitative design was considered appropriate for an exploratory study design. Second, the degree of detail it gave to friendships as well as family relationship was felt likely to be important when considering living with visible facial difference. Third, its relative simplicity, for example, Wellman and Potter's (1999) typology contained sixteen different kinds of personal community. Fourth, its design had been based on empirical work from a diverse population rather than a particular population, such as the elderly.

The approach of Spencer and Pahl (2006) contributes to the study of personal lives and has affinity with affective social network approaches (Phillipson, 2004; Smart, 2007; Morgan, 2011). Networks deliver more than support, having relational and affective dimensions of love, friendship, companionship, intimacy and generation of purpose (Ell, 1996; Mason, 2004; Smart, 2007; Gabb, 2008; McCann and Roberto, 2012). A number of studies in health and well-being have adopted affective social network approaches to explore subjective perspectives of personal social networks, for example, in self-care and management of long term conditions (Vassilev et al., 2011; Morris, 2011; Brooks et al., 2012), identity (Ketokivi, 2008 and 2012) and ageing (Kahn and Antonucci, 1980; Antonucci and Akiyama, 1987; Wenger, 1990 and 1997). Wellman and Wortley (1989) found that no single type of relationship provides support, rather it flows through the informal network and people find different types of support from different people. Morris (2011) found that social support is not just a matter of perception or role, but is a quality that emerges from personal networks.

She found, in chronic health condition management, that networks fluctuated over time in size and were not patterned by age or medical condition. There was a selectivity, flexibility and negotiation in navigating support from a small, functional network within a social network.

These relationships shaped the normalisation of self-management practices. Ketokivi (2008 and 2012) investigated social selves and found both individuality and social bonds to emerge from relational networks. She argues that the selves she and her respondents identified were at odds with the societal conceptions of an autonomous individuality. She found that this becomes most apparent when people are facing disruptions or changes in their lives.

Spencer and Pahl (2006) adopted the term ‘personal communities’ from Wellman (1990) rather than using the term ‘network’. They developed their approach to personal communities, in order to explore meanings, rather than focus on quantitative aspects of network ties. The conception used by Spencer and Pahl (2006) sought to uncover ‘hidden solidarities’ in personal network relationships. Instead of positioning the direction of network effects as causative from social to personal (Berkman et al, 2000), the effects were seen as emergent from the patterns of relationships within the personal community. Their approach provided a different and complementary view of a social phenomenon. Spencer and Pahl (2006) focussed on exploring meanings of relationship networks and what connections ‘do’ in individual lives. They took a non-categorical approach to defining relationships and explored the open question of who is important to individuals. The purpose of this was to allow individuals to work from their own definitions of close personal relationships, rather than exploring a specific relationship category. Friend and family relationships categorised as friend-like played an interesting part in providing a range of social connections and bonds. Spencer and Pahl (2006) argue that these informal connections have been under recognised in studies of ‘social capital’. They contest the claim that social change has resulted in weaker social bonds at an individual level and argue that ‘personal communities’ can capture patterns and functions associated with active and intimate ties and their roles in current times.

They introduced the notion of ‘communities in the mind’, representations of people’s sense of connection across different types of relationships, places and times, rather than focussing solely on place-based or family-based groupings (Pahl and Spencer, 2004). Through the process of describing ties, affective relations were seen as emergent and led to a sense of identity and belonging to produce an understanding of the dynamics involved in constructions of personal communities.

Spencer and Pahl (2006) developed a typology of personal communities which combined friend and family relationships (Appendix 2). They constructed seven types: ‘family-like’, ‘family-enveloped’, ‘friend-like’, ‘friend-enveloped’, ‘neighbour-based’, ‘partner-based’ and ‘professional-based’ personal communities. These personal communities had several dimensions and were built based on the following concepts: balance between number of ‘given’ and ‘chosen’ relationships and between different kinds of kin; friendship repertoires, friendship modes and patterns of suffusion or specialisation.

2.12.1 Given and chosen

Pahl and Spencer (2004) problematise the dichotomy of ‘given’ and ‘chosen’ ties, whereby ‘given’ is seen as family and ‘chosen’ as friends. In their analysis they identified that the concepts of ‘choice’ and ‘commitment’, which can vary in degrees and can exist within the categories of both ‘given’ and ‘chosen’ (Appendix 3). They analytically identify new possibilities of ‘given-as-chosen’ and ‘chosen-as-given’, which can be used to describe relationships which may have started as a particular category but come to be regarded in a different way. There may be an exercise of choice for individuals in working out which members of the family are close, depending on the degree of commitment in the relationship.

2.12.2 Friendship types and repertoires

Spencer and Pahl (2006) developed a typology of relationships based on their data around the idea of friendship (Appendix 3). This identified eight friendship types ranging from ‘simple’ to ‘complex’. For example, ‘fun’ friendships were described as ‘simple’ friendships based on enjoying each other’s company and socialising. Examples of a more ‘complex’ type is ‘soul mates’ who are very close, intimate, supportive, socialise together and are often described as ‘best friends’.

They characterised friendships as having four different types of patterns developed over a life course: ‘narrow’, ‘intense’, ‘focal’, and ‘broad’. These repertoires contained different combinations of friendship types. For example, ‘narrow’ repertoires comprised of only ‘simple’ type friendships and ‘intense’, only ‘complex’ types.

2.12.3 Friendship modes

This concept was an attempt to capture the dynamics of friend making over time and life-course transitions. They identified four patterns of friend making in their data: ‘evolving’, ‘ruptured’, ‘bounded’ and ‘serial’ (Appendix 3). Each of these modes differs in the way friends are made, kept or lost over life time and events. For example, the ‘ruptured’ friendship mode was one in which there was an almost complete replacement of the friendship repertoire after a significant change in circumstance. The ‘serial’ mode portrayed those who replaced friends at new life-course stages or events with new friends relevant to their new stage. ‘Bounded’ friendship modes were where people had made most of their important friends in a particular context or stage in life and these were people who very often had remained in the same area for a long time. The ‘evolving’ mode included both ‘bounded’ and ‘serial’ patterns, with new friends added at new points in life but with some friendships retained from earlier stages. These descriptions of modes are imprecise and require interpretation to identify.

2.12.4 Suffusion and specialisation

The final element Spencer and Pahl (2006) included in their typology was whether family and friend relationships overlapped in terms of their role and degree of commitment in a personal community. They called this overlap ‘suffusion’. Situations where families and friends played different roles or were interacted with differently, they called specialisation. These distinctions rest on the idea that there is not a clear cut division between friend and family roles and relationships. It is not suggesting that friends are replacing family relationships, but rather that the difference between these relationships is complex, culturally, contextually and relationally diverse. The ‘given-as-chosen’ and ‘chosen-as-given’ relationships are examples of ‘suffused’ relationships. Partners are examples of relationships which are ‘chosen’ but come be seen as family ‘given’.

They argue that the presence of suffused relationships indicates that ‘people engage in relationships based on distinctive mixes of choice and commitment’ (Spencer and Pahl, 2006, p.126) and the presence of diverse patterns of such mixes cannot be read as a sign of either destructive or transformative social change. They analysed the patterns in terms of the degree to which people might be considered ‘vulnerable’ to poorer mental health. They found poorer scores on the General Health Questionnaire among some people with personal communities too small to fit into their typology and those which had some elements of ‘partner-based’ or ‘professional-based’ types. In other personal community patterns isolated cases of vulnerability were found in other patterns, but these seemed more connected to specific circumstances. They argue that their evidence indicates that the robustness of a personal community relates to its degree of suffusion and redundancy. These features are connected to the degree of flexibility in a personal community. Suffusion can provide flexibility because members can play multiple, overlapping non-specialised roles and redundancy because there are a number of people who can provide intimacy, aid and sociability. They conclude that in these terms the most robust patterns in their study were ‘family-like’, ‘friend-like’ and ‘friend-enveloped’. ‘Family-enveloped’ personal communities were potentially less robust because of their lesser flexibility, and ‘partner-based’ and ‘professional-based’ personal communities lacked diverse sources of social support (Spencer and Pahl, 2006).

2.13 Summary

This chapter has introduced the sensitising theoretical context for the exploration of personal communities of people living with visible facial difference. It has provided a theoretical background through which the research questions for this study have developed. The social context of visible facial difference can be stigmatising. Resisting, adjusting, achieving are important challenges for adults in living with visible facial difference. The micro-social worlds of personal communities would be a valuable means of studying the interplay between social selves and their relational and social context. The next chapter explores the visible facial difference literature and identifies what is known about the roles of personal relationships and social support.

Chapter 3: Relationships and visible facial difference

3.1 Introduction

Within the field of visible facial difference psychological approaches have a considerable presence, and there is an informative literature. The purpose of this chapter is twofold: it discusses the broader context of developments within this field and against this backdrop presents the findings of a systematic, integrative review. This review aimed to identify what is known about the impacts of visible facial difference on relationships and social networks, and the contributions of personal relationships and social support to living with visible facial difference. The chapter identifies the main lines of arguments developed as well as gaps in knowledge.

3.2 Review methods

A systematic, integrative review method was chosen in order to include qualitative and quantitative studies to map out the main lines of arguments (Whittemore and Knafl, 2005; Booth et al., 2012). The PRISMA statement and guidelines (Moher et al., 2009) for review processes were followed (Appendix 4 for review flowchart). Medline, PsychInfo and Cinahl databases were searched for papers about visible facial difference, personal relationships and adaptation among adults and results were systematically combined (Appendix 5 for search terms). Papers were also identified from other sources such as reference lists from key books, hand searching of journals, and through examining grey literature including project reports (Appendix 6).

The title and abstracts, where available, were screened using inclusion and exclusion criteria (Appendix 7 for inclusion/exclusion criteria). The papers so identified were examined to ensure relevance and quality. Information on study aims, sample characteristics, methods, measures used, types of relationships considered, conceptualisation of social support used and key findings were extracted from each paper and a quality assessment of the papers was carried out (Appendix 8 quality appraisal tools).

Included studies were compared in a matrix format and similar data was grouped together into categories. These categories were then further compared and organised into themes. This stage was influenced by the critical interpretative approach of Dixon-Woods et al. (2006). Each paper was examined and sub-themes identified. Patterns, themes and relationships found were checked against the primary data source, which is the original work.

3.3 Results of the integrative review

133 papers were identified by systematic database searches and a further 158 papers from other sources. After removing duplicates and screening title and abstracts, 139 full-text papers were assessed for eligibility (Appendix 9 excluded papers). This resulted in 57 studies being included, of which 32 used qualitative methods (Appendix 10) and 25 quantitative (Appendix 11). The majority of qualitative studies used purposive or self-selecting samples and were focussed on living with relatively uncommon conditions. In the quantitative studies, recruitment was often limited to single clinics. In larger studies, self-selection processes were characteristically used.

From the selected papers, one before and after evaluation study was identified which included an outcome measure of perceived social support, but no randomised control trials were retrieved. The majority of the studies were cross-sectional studies but three had prospective designs and two were retrospective in design. Complex regression analyses with small numbers are likely to produce results which are underpowered. However, this practice is typical in the field as analysis is carried out on relatively small populations. As a consequence, it would not be secure to endorse the predictive power from such studies. Because of these characteristics, exclusions have not been made on the basis of the robustness of the analysis. Had exclusions been made on this basis, a great number of studies would have been excluded which meet the inclusion criteria in other areas. There is a high degree of heterogeneity in the research questions, designs, samples and ways in which visible facial difference is identified, as well as in the outcome measures used. As a result, thematic analysis was carried out and results presented as a narrative (Appendix 12 thematic chart on visibility, contribution from relationships and social support; Appendix 13 summarises main themes by paper).

Many of the studies in the field focus on the presence of psychological distress or adjustment problems, rather than identifying the variables that influence psychological adjustment (Klinge et al., 2009. Studies examined a range of visible facial difference categorised by cause, 17 related to the effects of cancer treatments, 14 to burn injury, 13 to craniofacial conditions (Appendix 14). None of the included quantitative studies were about skin conditions. This is very likely because of the search design which excluded studies that did not specifically include an interest in facial location, rather than because of a lack of recognition in the field of the importance of appearance and visibility (Schofield et al., 2009; Lavda et al., 2012). The review found that personal relationships have been studied in several overlapping topic areas: social integration, social support, protection from stigma, and resources for resilience and coping. The contribution of social support to adjustment or well-being has been focussed on within the fields of head and neck cancer and burn injury, and social integration has been a central concern for congenital conditions.

3.4 Overview of the field

One of the achievements of this literature has been to question assumptions about simple, linear relationships between physical severity and severity of psychosocial need within conditions associated with visible facial difference (Clarke, 1999). As well as presenting evidence challenging the notion of severity of facial difference as a single, sufficient predictor, the literature presents a discourse seeking to shape health professionals’ responses to visible facial difference, specifically by attacking assumptions that low medical severity means low need. This has important implications for providers of health care as low severity cannot be equated with no or low need. This understanding can be seen as the start of a journey to understand better how multi-dimensional conceptions of visible facial difference affect lives, families, communities, delivery of health care services and what social and individual steps can be taken to improve experiences. Questions have mainly been addressed through the discipline of psychology, which has sought to understand the individual capacities that may predict why some people can take the same experience and minimise it, whilst for others it is overwhelming and affects life chances and choices.

Clarke (1999) identifies a need to investigate visible facial difference as a phenomenon independent of its cause. She argues that even though visible facial difference is dispersed across a diverse range of medical conditions, the presence of significant commonalities have been established, particularly problems in communication, social interaction, and discriminating experiences (Partridge, 1990; Clarke, 1999; Newell, 2000; Thompson and Kent, 2001; Rumsey and Harcourt, 2005). Clarke (1999) suggests exploring how social communication processes are interrupted, with severity as one factor to be considered in this process.

The dangers in this approach are of over-generalising commonalities in interactional experiences which may not be present or which have different manifestations across visible facial difference conditions, individuals or situations. A number of different lines of enquiry are required. Detailed studies of how these particularities work are called for both between conditions and within conditions. Newell (2000) points out that one of the barriers to situating enquiry within medical conditions is that the illness is associated with bodily and functional changes. In head and neck research a psychosocial approach has been well established; however, disentangling the effects of appearance change from other functional effects of the disease is fraught with measurement and ethical issues. The influence of appearance on cancer care still needs more specific work in order to develop measures and interventions (Williamson and Wallace, 2012). Flexen et al. (2012), for example, identified the need for two questionnaires, in combination, to ensure identification of those who had appearance related concerns following treatment for oral and oropharyngeal cancer.

In their recent book, Rumsey and Harcourt (2012) identify a diverse range of clinical and research interests under the overarching theme of appearance.

They extend the range of concerns about appearance and have established appearance psychology as a field. In the introduction, their aim was summarised:

> ‘to include the full spectrum of appearance-related issues rather than focussing solely on ‘body image’ and its concomitant emphasis on issues relating to weight and shape, and to include disfigurement in this spectrum, rather than treating research and practice on visible difference as a sphere of activity entirely separate from the more ‘mainstream’ area of body image’ (Rumsey and Harcourt, 2012, p.2).

Rumsey and Harcourt (2012) aim to give a voice to those personally affected, as well as practitioners from medical, psychological and charitable settings. Appearance psychology focusses on ‘body image’ but there is a considerable way to go in building evidence that understands its role or predictive ability in relation to embodied visible difference (Newell, 2000; Thompson, 2012). Furthermore, this is unlikely to be the only concern of people living with visible facial difference and, for some, body image may not be their greatest challenge. Rumsey and Harcourt (2004) questioned the idea that visible facial difference results in ‘social disability’ for all individuals and argued that many of the difficulties experienced are similar to:

> ‘…those experienced by persons who are dissatisfied with aspects of their ostensibly “normal” looks’ (Rumsey and Harcourt, 2004, p.84).

Emphasis is placed on individual concerns using ideas of normalisation. By taking this line of argument, connections have been made between those living with visible facial difference, and those who do not, on the basis of hypothesised commonalities in some aspects of appearance related distress, such as concerns about weight and shape (Thompson, 2012). Thus, people with visible facial difference might be ‘one among many’ rather than a distinct minority. The psychological focus on normalisation, however, does not preclude a social reality of stigmatisation. A danger in the use of strategies of normalisation lies in unintended consequences of how the ideas are interpreted and used.

For example, in programmes to normalise appearance after cancer treatment the approach adopted may reinforce generated attitudes to appearance and sexuality, creating a new kind of ‘normal’ which may then be oppressive for a different section of the population living with cancer (Kendrick, 2008). Furthermore, for some with facially distinctive appearances, normalisation may still be an unlikely possibility.

The idea that appearance concerns affect a wider population of people with health conditions has been discussed by Bessell et al. (2012b). They reason that acquisition of appearance difference from many long-term health conditions, for example, diabetes can “exacerbate pre-existing body-image distress” (Bessell et al., 2012b, p.1139). They argue that needs arising from these exacerbations should be addressed within health care environments and research, with clinical applications tackling appearance aspects of chronic illness. Clarke (1999) identifies that although there is a consistent body of work describing problems in interaction for people with visible facial difference, less is known about how to manage this clinically or how everyday life is affected. The importance of psychosocial issues, such as findings of increased risk of more negative body images, lower self-esteem and self-confidence has been highlighted. Rumsey et al. (2004b) reports that across disfiguring conditions, levels of depression, anxiety, social anxiety, social avoidance and quality of life compared unfavourably to published population norms from the general population. Newell (2000) reviews evidence for the application of a cognitive-behavioural model of body image and its disturbance:

> ‘with a particular emphasis on fear and avoidance as mediating factors in determining the extent of adaptation following a threat to body image such as disfigurement’ (Newell, 2000, p.120).

In an investigation of levels of anxiety and avoidance among respondents with visible facial difference, Newell (1998), found the majority reported low body image disturbance. However, in relation to facial attitudes and avoidance, the majority of respondents (77.86%) felt their facial appearance was a barrier sometimes and 42.48% said it was a barrier ‘often’, ‘usually’ or ‘always’.

Avoidance in personal and social realms was found: 29.06% reported avoiding walking in the street because of facial appearance sometimes, 53.19% avoided social situations, 40.34% avoided sexual intercourse, 36.91% avoided certain types of clothing sometimes, and 30.80% avoided looking at their own face often. Limiting patterns of behaviour were found without reported psychological disturbance. Newell (1998) suggests this could be because people are required to adapt to an adverse social and cultural climate, however, they manage to find ways of living lives within limits.

Newell (2000) and Rumsey and Harcourt (2004) put forward ideas about how noticeability and visibility, set within a social context, have potential as predictors of adjustment:

> ‘…a person’s subjective perception of how noticeable their difference is to others is a better predictor of psychological and body image disturbances than is the assessment of a dispassionate observer or clinician’ (Rumsey and Harcourt, 2004, p.86).

A large survey by the Appearance Research Collaboration (2010) reports visibility of a disfigurement as a main concern for 65% of the respondents. However, other appearance-related cognitions seemed to have greater impact on the outcome measures used than visibility. Perceptions of fear of negative evaluation from others, social acceptance and satisfaction with social support also significantly correlated with outcome measures. The complex and multi-variant nature of adjustment is a key finding.

An overarching framework has been developed to situate enquiry about appearance concerns (Appearance Research Collaboration, 2010; Thompson, 2012). The biopsychosociocultural framework adopted was felt able to accommodate a number of theories. Individual experiences of visible facial difference are recognised as variable and multi-faceted, involving individual, interactional, social and cultural factors, which are experienced subjectively (Thompson, 2012). This framework’s foundation is in cognitive behavioural theory; a close relationship is theorised between body image and self-concept.

The degree to which an individual has invested in their appearance and to which appearance is central to the self is seen as key to understanding disturbances in body image. These individual understandings are shaped by cultural meanings related to appearance. One of the stated intentions of the Appearance Research Collaboration framework is to shape health research agendas to encourage research design that is not based solely on demographic, physical or biological characteristics (Thompson, 2012).

Some aspects of difficulty cannot be seen by an ‘objective clinician or researcher’; the points of view of those who experience the difficulty often provide a better assessment of the problems involved (Moss, 2005; Brown et al., 2010). It has been identified that there is a need for self-report multi-dimensional psychometric tests to capture outcomes and quality of life. There have been developments in the fields of burn injury and head and neck cancer. However, the complexity of experiences of living with visible facial difference also calls for more focussed qualitative studies which capture nuance and detail of changes in lives (Semple et al., 2008; Konradsen et al., 2012).

A turn to considering the phenomenon of resilience is evident in the literature (Rumsey and Harcourt, 2004). Studies with a ‘resilience’ orientation tend to explore ‘identities’ and buffers from distress. This development is based on findings that a majority of people make a successful adjustment to living with visible facial difference evidenced through high levels of perceived quality of life. Turning away from a deficiency focus has taken some studies into looking at how people manage or thrive and how they deal with negative aspects of social contexts (Eiserman, 2001; Meyerson, 2001).

Although many studies have been carried out, the area is considered to be in its infancy when judged from a scientific perspective. Bessell et al. (2007) undertook a systematic review of the efficacy of psychosocial interventions for adults with visible facial differences and found none of the 12 papers they identified demonstrated adequately intervention effectiveness, although fruitful ideas for further work were indicated. There have been few randomised control trials, epidemiological studies across conditions are almost non-existent and are patchy within conditions, and few interventions have been evaluated. In addition to the need for better subjective psychometric measures, detailed qualitative research is also required.

Demographic variables have not been found to be primary predictors of psychosocial distress and there is an under-exploration of how gender, age, ethnicity, socio-economic status or social capital intersects with difference. Under-exploration may be linked to the dominance of psychology. A sociological focus would hold that complex social phenomena need to be considered in relation to demographic variables, yet, at the level of variables there are gaps in the knowledge base. In relation to gender, Newell (2000), Thompson and Kent (2001) and Rumsey and Harcourt (2004), point out that assumptions that women will have greater appearance related adjustment problems have not been confirmed. Williamson and Wallace (2012) reported there are many studies in which women express greater dissatisfaction with appearance post-surgery than men; however both men *and* women have difficulties with visible facial difference. Thomson and Kent (2001) suggest, meanings and inequalities of visible facial difference are gendered and these remain largely unexplored.

Empirical work on age has investigated problems faced by children, adolescents and their families, with visible facial difference positioned as a potentially disruptive element in socialisation processes (Thompson and Kent, 2001). Visible facial difference is characterised as an underlying stressor through the lifespan which increases pressures associated with each life stage (Thompson and Kent, 2001; Rumsey and Harcourt, 2004, 2005 and 2012).

This review focusses on the experiences of adults where there has been less attention, particularly on the life stages of middle and later adulthood (Rumsey and Harcourt, 2004). In relation to adulthood, Rumsey and Harcourt (2004 and 2005) noted that personal accounts suggest difficulties in finding desired types of employment and difficulties in intimate relationships. Appearance evaluations are thought to be more central to the selves of adult ‘poor adjusters’ (Rumsey and Harcourt, 2005). There has been little attention on whether, with greater age, people cope differently, or whether appearance has different meanings for younger or older people (Thompson and Kent, 2001; Rumsey and Harcourt, 2004 and 2005). Cross-cultural responses to visible facial difference have been largely under investigated, as have experiences of people from diverse ethnic backgrounds (Thompson and Kent, 2001; Rumsey and Harcourt, 2004 and 2005). Studies looking at demographic factors such as ethnicity, socio-economic status, or social capital are more notable by their absence.

3.5 Social aspects

Beyond severity, appearance effects and individual capacity to adjust, other lines of enquiry are worthy of exploration to inform a better understanding of living with visible facial difference. Since this is the focus of the present study, this review now moves on to examining social aspects such as friendship, social engagement and support. The literature indicates that social-cognitive approaches are also influential in this field. Clarke (1999) summarised that perceptions of social support are important in predicting psychosocial outcomes. She identifies that more needs to be known about the value of different types of support at different stages of conditions, points in the life course, or as a result of individual preferences. Re-entry into school settings after an appearance changing event has been a focus of interest (Jenkinson, 2012). Rumsey and Harcourt (2004) regarded social support as a buffer to the consequences of stress but noted:

> '…unfortunately the social avoidance and withdrawal that are common reactions to disfigurement can result in a smaller network of support for those affected' (Rumsey and Harcourt, 2004, p.88).

There has been little empirical work exploring this claim. Rumsey and Harcourt (2004) identified a paradox for 'close others'; they are in a position 'to see the 'real' person behind the difference', (Rumsey and Harcourt, 2004, p.88) but have to deal with their own reactions to ideas and feelings about difference. Perceptions of social support do not occur in a social vacuum: there is a context of informal social network members, family and friends, health care providers, and the social and physical environment, and these contexts are worthy of further investigation. Rumsey and Harcourt (2004) advocate a 'normalising' rather than a 'pathologising' approach to care which includes psychosocial support and family involvement. Clarke (1999) recognised the need for wider social change:

> '…the role of the non-disfigured majority in changing their behaviour to accommodate those who do not necessarily fit a standard or norm…' (Clarke, 1999, p.132).

However, ultimately the field sees its contribution as assisting individuals to find ways of dealing with what they are confronted with in social worlds.

Medical sociology and disability studies research have not had a strong presence in recent studies of adults with visible facial difference. For disability studies this may be due to the sustained focus on social models of disability, which do not theorise a causal role for impairment (Shakespeare, 2006; Thomas, 2007; Shakespeare, 2014). Cultural disability studies have focussed on cultural representations of disabled people and social theory, rather than dealing with lived, everyday experience. However, this is a changing area and more writers are emphasising the importance of embracing psychological responses from a critical perspective (Goodley, 2013; Thomas, 2007; Watermeyer, 2012). Others have proposed an interactional approach which distinguishes multiple factors involved in bodies, contexts and environments in producing difference (Shakespeare, 2006 and 2014; Rhodes et al., 2008). These approaches allow questions of social justice, investigation of inequalities and an informed focus on the complexities of rehabilitation experienced by different people with varying conditions in different times, contexts and places.

In sociology, the body is a mainstream area of interest, and there is a substantial literature about chronic illness and disability; for example, Charmaz (1983 and1995), Williams (1999 and 2000), and Turner (2001). Elsewhere in body studies, scholars of body aesthetics have explored matters of social identity or agency in situations where people have created appearance change. This might be through body art, or cosmetic surgery, with an interest in what this says about society (Featherstone, 2001). The phenomenon of visible facial difference has not recently been widely researched; however, there are important exceptions. The work of Garland-Thomson (2009) on staring combined cultural analysis and studies of human behaviour. Garland-Thomson writes about the need for a new ethic to govern behaviour of both starers and starees. Other works of note are accounts and autobiographies of Piff (1986), Weston (1989 and 2003) and Partridge (1990) who insightfully explore areas that academic research has found difficult, for example, disentangling social, psychological, material and political matters. Citing Coleridge’s (1993) research on disability activists, Watermeyer notes:

> ‘…for the overwhelming majority of his respondents, social change was first and foremost contingent upon disabled people achieving some form of emancipatory internal transformation’ (Watermeyer, 2012, p.169).

In summary, this work indicates a need for exploration of how social contexts, such as personal communities, are utilised by people living with facial difference.

3.6 Themes

This section presents five main themes: social interaction and stigma; contribution of social support; importance of personal relationships; coping, recovery, time and resilience; and finally social support and demographic factors. Visibility and its perceived relative importance are discussed within each of these themes (Appendix 12 and13 summarise how main themes relate to each paper).

3.6.1 Social interaction and stigma

Studies looking at relationships of people with visible facial difference report incidents and perceptions of negative behaviour from others, across all the associated conditions. For example, in Knudson-Cooper's (1981) sample of young adults with severe burns, 97% felt they were treated differently by other people, when they were injured. At the time of the study, which was between 4-23 years later, this had only dropped to 52%. Different treatment came mostly, but not entirely, from strangers. Acquaintances have been identified as a potential source of feelings of stigmatisation among people who have had facial surgery for cancer (Bonanno and Choi, 2010; Bonanno and Esmaeli, 2011). Intrusive reactions to disfigurement such as being stared at, being ignored and acts of discrimination are present within many of the studies and some studies have specifically focussed on the processes involved (Kent, 2000; Hawkesworth, 2001; Thompson et al., 2002; Rossi et al., 2009; Thompson and Broom, 2009; Thompson et al., 2010; Dures et al., 2011). Visibility of perceived difference is seen as central to reactions from other people, and with both visible and non-visible aspects implicated in effects on intimacy and personal relationships.

The concept of stigma has been used to explain experiences of people with visible facial difference, whilst close relationships have been identified as providing 'safety' for the individual (Hawkesworth, 2001; Thompson et al., 2002; Rossi et al, 2009; Thompson and Broom, 2009; Thompson et al., 2010; Bonanno and Choi, 2010; Bonanno and Esmaeli, 2011).

Some studies have identified situations in which the family is a source of negative responses and behaviours, particularly in the context of studies looking at cultural factors (Rozario, 2007; Thompson et al., 2010). However, implicit in many studies is that negative reactions and practices can come from family members and friends, as evidenced in Murray and Rhodes (2005). The social nature of stigmatising experiences is found a useful source of explanation for negative experiences of people with burn injury (Rossi et al., 2009). Unwanted attention to burn marks is seen as a source of discrimination and prejudice. Rossi et al. (2009) theorised that a burned appearance was stigmatising, because it broke cultural conventions of what was acceptable in terms of appearance. This study reports that burns invoked other cultural categories such as ‘ugly’, ‘feared’, ‘alien’ or ‘inhuman’. Sensitivity to, and vigilance about, whether respondents felt they were perceived as achieving normal performance of roles legitimised by society, were seen as increasing feelings of vulnerability or anxiety on the part of the person with burn scars.

A psychosocial dimension of perceptions of stigmatisation has been explored by Lawrence et al. (2004, 2006b and 2010) in a series of studies validating two new scales which aim to measure perceived social stigmatisation and perceived social comfort. Lawrence et al. (2004) look at the role of burn scarring on perceptions of body esteem. The relationship between both burn severity, and burn scar visibility, with body esteem ranged from low to moderate, depending on how burn severity or visibility were measured. Subjective respondent-assessed measures of visibility produced the strongest associations. Lawrence et al. (2004) found the relationship between burn characteristics and perceptions of body esteem was mediated by perceived social stigmatisation. Perceived social stigmatisation and perceived social comfort accounted for the majority of the variance in body esteem and depression. The social origins of the some of the problems faced by people with burn scarring are highlighted. In addition the study makes a case for rejecting the notion of direct association between severity of burn and adjustment, and using measures based on medical characteristics or observer only based assessments. The literature underlines a need to explore perceptions of personal social environment which promote greater comfort while living with difference.

3.6.1.1 Staring, noticing and managing social interaction

Other people, it seems, voluntarily or involuntarily, notice visible facial difference, and others may take this further by asking intrusive questions or staring. The notion of curiosity has been deployed as a part of a social skills approach within interventions that are part of a normalising strategy (Clarke, 1999). Social skills approaches to managing social interactions have sought to reframe interpretations of other people's reactions, breaking down the interpretation from one of hostility into more benign possibilities (Kleve et al, 2002). The literature indicates that the feeling of being scrutinised by the curious, however, has emotional consequences for the recipient (Kent, 2000; Thompson et al., 2002; Murray and Rhodes, 2005). Learning to deal with the emotions aroused takes resources (Konradsen et al., 2012) and practise at an interactional level (Bonanno and Choi, 2010; Bonanno and Esmaeli, 2011). Rossi et al. (2009) found curiosity was sometimes noticed as empathic, but other times it had a hostile edge; they reported the experience of a respondent who described feeling like a 'tourist attraction' because of their visible burn scars.

Kent (2000) identified types of event which triggered appearance related concerns for people living with vitiligo. Socially or interpersonally threatening events led to protective strategies or impression management. The most used impression management strategy was concealment and avoidance, for example, arranging one's hair to hide different skin colourations, or avoiding using swimming pools. Similarly Rossi et al (2009) reported those with facial burns spoke of curtailing leisure activities. Kent (2000) identifies that these strategies could have unintended consequences, such as continuing the experience of anxiety rather than reducing it. Bogart et al. (2012) noted the exhausting nature of the process of making one's self understood observing that the pressures and tensions in social interaction never really went away, although participants became accustomed to them. Patel et al. (2011) highlights experiences of social isolation as an impact of living with neuro-fibromatosis 2 (NF2). Avoidance is a much identified theme, particularly of activities or situations where embarrassment, shame or self-consciousness may be experienced, often related to difficulties in communication because of hearing loss, or to facial impairment and appearance.

Furness et al. (2006) distinguish between short term avoidance and longer term passivity, suggesting short term avoidance is not necessarily detrimental. They found avoidance to be used as a deliberate response to overwhelming stress, used by otherwise ‘active copers’ to provide temporary relief in the early stages of recovery from facial surgery. Lau and van Nierkerk’s (2011) study identified the life-long psychological work of living with burns. Respondents reported feeling vulnerable to the judgements of others. An experience of feeling ‘invisible as a person’ could arise when respondents felt misunderstood because the other person only seemed to be responding to their scars. The authors’ interpretation was that this represented a symbolic, rather than a physical struggle, in which feelings of transformation and despair, survival and suffering co-existed.

3.6.1.2 Visible and hidden signs of difference

A protective identity of cancer is identified by Semple et al. (2008). In situations where appearance change was visible after facial surgery, adaptation was facilitated by reasoning that these changes were necessary to remove the cancer. Konradsen et al. (2009 and 2012) and Röing et al. (2009) noted that respondents were aware of diversity of reactions to facial cancer from other people. A common judgement was that the respondents themselves had contributed to their disease through life-style choices such as smoking, and drinking alcohol. It seems that some types of cancer may induce a more protective identity than others. Attempts to evade blame were noted by Rossi et al. (2009) who found, when respondents were asked about their burn injury, that they emphasised the cause was outside their control.

Bogart et al.’s (2012) respondents reported that facial immobility could be taken as a sign of intellectual impairment. Stavropoulos (2011) and Patel et al. (2011) link visible facial difference with feeling less attractive. Hawkesworth (2001) found some of her respondents were able to present themselves in a way that gave an appearance of self-acceptance of their visible facial difference. However, even these apparently confident respondents went to great lengths to conceal mental health consequences and the extent to which these could at times, and in certain situations, be felt to control their actions.

The recognition that visible differences can be accompanied by psychological difficulties, does not ‘let one off the hook’ of societal expectations of normalcy. Hawkesworth concludes that feelings of shame connected to mental health problems were more inhibiting than facial difference (in this study, acne) itself.

Several studies identified genetic fears - particularly the risk of passing on a hereditary condition to children - compounded experiences of difference (Ablon, 1996; Rozario, 2007; Dures, 2011; O’Hanlon et al., 2012; Roberts and Mathias, 2012). O’Hanlon et al.’s (2012) study explored, in-depth, how diagnosis of cleft lip and/or palate could affect parental needs. It’s presence in the literature underlines a need to look beyond how people deal with perceptions of appearance and into ways in which living with difference may enhance or complicate life roles.

3.6.1.3 Safety and shielding

Hawkesworth (2001) included a spatial dimension in her study examining how social responses, institutional conditions, and public policies as well as public attitudes, incorporated standards about appearance which acted as obstacles to people who felt not able to meet these because of their visible facial acne. She calls this the 'disabling spatialities of disfigurement', through which marginalisation results because of not ‘fitting in’ and feeling shame and embarrassment. Three narratives of people affected by mental health problems associated with their acne were used to illustrate how processes of avoidance appear to reduce the respondent’s social world to a limited number of safe places and safe relationships. Safe people or relationships are those who accept the individual as they are and do not make hostile reference to their appearance.

Two studies identify how close family members shield their relatives from negative responses from strangers and acquaintances (Bonanno and Choi, 2010; Bonanno and Esmaeli, 2011). These studies explored interaction patterns with strangers and acquaintances of people who had had head and neck cancer surgery at least six months prior to the study. They looked at whether the size of the group in which the interaction takes place made any difference. They identified three interaction patterns which they called intrusion, sympathy and benign neglect.

Their respondents reported both ‘enacted’ and ‘felt’ stigmatisation when experiencing intrusive reaction from others, no matter what the group size. Sympathy was experienced as enacted in small groups and both felt and enacted in large groups. Benign neglect was described as the most desired response. Respondents often limited their social activities and this also limited their family members’ social activities. Family members found themselves with conflicting social roles of shielding their relative whilst also seeking to facilitate their inclusion in social activity.

3.6.1.4 Life course stage

The literature identifies pressures faced by respondents in their childhood years. There are reports of teasing and/or bullying at school (Bogart et al., 2012; Lawrence et al., 2006b; Rozario, 2007) and adolescence is remembered as a testing time. Studies indicate that these experiences continue into adult years, with varying degrees of difficulty experienced. Bogart et al. (2012) reported that adults living with Moebius syndrome still noticed others avoiding them. Furness et al. (2006) found some respondents noticed avoidance by others up to three years after facial surgery. Uttjek et al. (2007) reported that respondents feeling marked as a ‘social misfit’ were more commonly in the under 45 age group, whilst older respondents living with psoriasis reported, contrary to their earlier fears, they had been able to successfully find suitable jobs and partners. Hawkesworth (2001) and Murray and Rhodes (2005) found respondents who reported that because they were outside the age range when acne might be considered normal, in other words the teenage years, they felt judged and stigmatised. Lawrence et al. (2010) compared perceived stigmatisation and social comfort of paediatric burn survivors. They compared the perceptions of survivors who were adult with those under 18 years of age. The two groups did not differ on measures of perceived stigmatisation the adult group, however, scored lower on perceptions of social comfort. These findings are not supportive to an account that assumes that greater difficulties are experienced by children and adolescents and indicate that difficulties with social comfort continue into the adult years.

3.6.2 Contribution of social support

An association between perceived social support and improved psychosocial adjustment has been established in the literature studying acquired visible facial difference. As well as dealing with others' responses, those living with visible facial difference also need to deal with their own feelings and adjustment to appearance change. These factors have been identified as part of recovery and rehabilitation processes (Gamba et al., 1992; Lawrence et al., 2004; Lawrence et al., 2006b; Semple et al., 2008; Konradsen et al. 2009; Röing et al., 2009; Bonanno and Choi, 2010; Bonanno and Esmaeli, 2011; Konradsen et al., 2012).

Efforts have been made to explore how social support works, by looking at whether perceived social support buffers against stresses experienced during diagnosis, treatment and longer term living with visible facial difference. As the field has developed, social support has been conceptualised as a multi-dimensional construct. Distinctions have been made between received and perceived support; social support is recognised as being of different types, such as practical, emotional, and informational; and to come from different sources, such as family members, friends or healthcare professionals. A temporal understanding of individual rehabilitation trajectories has been identified, with both negative and positive effects for social support. People appear to use social support differently and subjective engagement with each patient and their particular circumstances is indicated to be an important factor (Howren et al., 2013).

The effects of perceived social support have mainly been explored in quantitative studies, most of which have a cross-sectional design (Appendix 11). The findings indicate that measures of perceived social support seem to have a greater influence on post-treatment or injury psychosocial adjustment, than measures of severity of facial disfigurement.

3.6.2.1 Visible difference studies

One evaluation of a cognitive-behavioural intervention, for people with a range of disfigurements, used a measure of perceived social support as part of the assessment of effectiveness (Kleve et al, 2002). They found that perceptions of social support were greater at six months after the cognitive-behavioural intervention.

They were able to identify a sub-group of respondents whose improvement was not as great and these were people who had more complex life and family situations. From the qualitative component of a mixed method study, Rumsey et al. (2004) found an association between social support and reduced impact of appearance concerns in respondents’ lifestyles. Their study identified perceptions among outpatients, receiving treatment for a range of disfiguring conditions, that the appearance aspects of their concerns were not being fully addressed.

3.6.2.2 Burn studies

An early study by Bowden et al. (1980) found that visibility and severity of burn, as measured by physical characteristics, did not affect perceptions of self-esteem. Perceived social support was reported as indicating improved mental health quality of life scores of burn patients with massive injury, including facial burn (Anzarut et al., 2005). Wallis et al. (2006) compared the emotional distress and resources of a group of patients with burn injuries, with norms from the general population. In the burn sample, they found significantly greater values of anxiety, depression and post-traumatic symptoms and psychosocial resources. They found perceived social support and optimistic self-beliefs were significantly correlated; however, these resources were not predictive of levels of distress.

Strong effects of perceived social support from friends were found on levels of self-esteem, depression and body image in Orr et al.’s (1989) study of young adult burn survivors who had suffered severe injury within the previous ten years. They argued their findings supported a buffering hypothesis: acceptance by others is linked to the social construct of self-esteem and helps blunt emotional distress. While support from both family and friends had positive effects, the stronger effect came from perceived social support from friends.

Two studies by Lawrence et al. (2004 and 2006b) from the field of burn injury are of significance for this review. The first study set out to clarify relationships between location of scarring and perceptions of body esteem and the mechanisms by which disfigurement is translated into body image dissatisfaction. Lawrence et al. (2004) found a subjective measure of burn severity had a low/moderate correlation with social and emotional outcome variables.

Severity had a small but significant relationship with more frequently perceived stigmatising behaviours by others. These subjective burn severity scores also related to a lack of social comfort, but were unrelated to depression or worry about appearance. The subjective burn severity scores were consistently related to an aspect of body esteem, attitudes of others, and significantly correlated with social support. Similar results were found for burn visibility. The relationship between burn characteristics and body esteem were mediated by perceptions of social stigmatisation. Lawrence et al. (2004) concluded that self-acceptance and perceptions of social comfort were more important than burn severity or scar location in predicting body-esteem, and they suggested social comfort might be a potential area on which to base interventions.

The second study (Lawrence, 2006b) started from the premise that vulnerability is social in nature. The study examined correlates and predictors of depression in burn survivors three years after injury. Significant levels of depression, 20-30% were found in their sample, higher than their population comparison sample. Gender did not explain the difference and, of the burn characteristic variables used, only self-rated change in appearance was correlated with depression. The study posited that the lack of consistent findings in the burn literature about the effects of burns, emanated from the persistence in using ‘objective’ observer-assessed gross measures. The importance of scarring emerges in reciprocal interactions between the scarred person and their social environment and through functional limitation. Taken together, body esteem, perceived social support and social comfort explained 60% of the variance of depressive symptoms. The researchers concluded that strengthening people’s ability to deal with social situations, questioning the belief that one’s worth is linked to one’s appearance and encouraging people to create systems which enhance social comfort, would all be valuable steps forward in working with people recovering from visibly scarring burns.

3.6.2.3 Head and neck cancer studies

In a study of head and neck cancer patients six months after treatment, Baker (1992) found perceived social support was associated with better rehabilitation outcomes. She found severity of facial disfigurement significantly correlated only with the category of ‘eating’.

Vickery et al. (2003) also concluded that facial disfigurement *per se* was not an impediment to treatment, because of its small effect on psychological adjustment. Karnell et al. (2007) found that higher levels of social support one year after head and neck cancer treatment were associated with better health related quality of life (HRQOL). Higher social support scores were associated with less depressive symptoms and higher general mental health scores, but not with general physical health scores.

Post-treatment levels of social support correlated with HRQOL specific outcomes in speech, aesthetics, social disruption, depressive symptoms and mental health status. Karnell et al. (2007) also looked at clinically important differences and found patients with the highest levels of perceived social support had clinically important increases in HRQOL. They suggested that increased social support might enhance functional ability through encouragement from family, friends, and colleagues and assist with better attitudes or self-management after treatment. Evidence from HRQOL studies, however, is equivocal. Katz et al. (2003) did not find a correlation between perceived social support and depression; while perceived social support was associated with improved measures of well-being, this was found to be the case for female and not male patients, six months after treatment.

Howren et al. (2013) built on these themes in a prospective HRQOL head and neck cancer study, investigating whether perceived social support before treatment predicted HRQOL outcomes 12 months later. They found greater perceived social support present at diagnosis significantly predicted more favourable global and head and neck cancer specific HRQOL at three month and 12 month follow up. The greatest effects were in the head and neck cancer specific areas of speech, aesthetics and social disruption (but not eating). Perceived social support was the lone predictor of mental health scores at 12 months. In relation to clinically important differences, they found those with the lowest perceived social support at diagnosis, compared to those with higher, had worsened HRQOL scores at a clinical level of significance. In the head and neck cancer specific domains of the HRQOL measured social disruption was also higher. They argued that more attention needed to be paid to the head and neck cancer specific domains of HRQOL, mismatches in support and the roles of naturally occurring and created systems of social support.

The role of self-efficacy has been investigated in two studies (Hagedoorn and Molleman, 2006, and Deno et al., 2012) but these used different definitions and measure of self-efficacy. Hagedoorn and Molleman (2006) looked at the role of social self-efficacy in moderating links between facial disfigurement and psychosocial distress in head and neck cancer patients. They defined social self-efficacy as the extent to which patients believed they were capable of exercising control over the reactions of other people; this, they suggested, was likely to increase feelings of confidence in difficult social situations and reduce inclinations to withdraw. They used two measures of disfigurement: a rating of visibility of disfigurement by the patient, and facial disfigurement defined by impairment of facial expression diagnosed by the physician. Perceived social self-efficacy moderated a positive link reported between degree of facial disfigurement and psychological distress, distress being in relation to unpleasant behaviour of other people, and social isolation. Lower self-efficacy was related to higher distress and they argued that self-efficacy is an important asset for people with facial disfigurements.

Deno et al. (2012) explored the processes of how social support works with head and neck cancer patients with facial disfigurement. They looked at the buffering effects of perceived social support and self-efficacy on the relationship between social distress and emotional distress. They measured self-efficacy in relation to perceptions of ability to control or cope with symptoms, and reported that self-efficacy strongly buffered negative influences of social distress on emotional distress. However, perceived social support from family members did not have an influence on emotional distress, whilst perceived social support from friends was related to lower social distress, but higher emotional distress. In other words, different sources of social support seemed to play different roles in mediating social distress on emotional distress. These findings about support from friends did not support the researchers’ hypothesis. Deno et al. (2012) wondered if in some circumstances the effect of social support from friends exacerbated emotional distress, even if the support they provided was sympathetic. They suggested that social support and self-efficacy are complementary; higher self-efficacy creates a sense of mastery and a perception of high social support.

The other finding they had not expected was that support from the family only indirectly had an influence on emotional distress through self-efficacy. They suggested that family support enhances self-efficacy but does not necessarily ameliorate emotional distress.

The head and neck cancer literature found that the effects of facial disfigurement on emotional distress, as measured by medical aspects, have much less of an effect than at first supposed (Vickery et al., 2003). Yet, as indicated by burn studies, greater effects in perception of change in appearance and body esteem may have been masked as the measures used in the study were not based on respondent self-assessments. Greater use of subjective approaches may aid development of support and adaptation processes for those living with facial cancer scarring and their families (Semple et al., 2008).

3.6.3 Importance of personal relationships

This theme identifies how personal relationships have been explored in relation to social integration, and are affected by changes and pressures associated with living with, or adapting to, visible difference.

3.6.3.1 Social integration

Peter et al. (1975) investigated patterns of social integration of adults living with cleft lip and palate conditions, comparing these with age and gender matched non-affected adults and siblings. They explored geographic mobility, friendship patterns, participation in community groups and degree of ‘interdependence’ within their extended family. ‘Interdependence’ was measured by whether respondents resided with their family. Regardless of marital status, adults with cleft conditions were found more likely than the sibling or control groups to be living with relatives. Peter et al. (1975) suggested those with visible cleft differences were supported by their family through mutual aid, social activities and greater social and economic security. The researchers interpreted these patterns as signs of lower social integration, and regarded these relationship patterns as bordering on financial or social dependence on their family, because of the frequency of residence with relatives, in both single and married groups. However, the associations found were weak. It is highly likely that these patterns will have changed, as the study was carried out almost 40 years ago in the USA, and it used the idea of a nuclear family as a benchmark for normality in family arrangements.

Over this time there have been important social changes in relation to disability within the UK: introduction of equalities legislation, policies aimed at promoting inclusion in education of children with speech and language difficulties, and promotion of independence of people with disabilities. There have also been improvements in knowledge and treatments for cleft lip and palate, and their associated difficulties (Mouradian et al., 2006). Although no directly comparable study has been found, more recent cleft lip and/or palate literature has not identified living in the parental home as an adult as an issue or indication of lack of social integration, for example, Berk et al. (2001) and O’Hanlon et al. (2012).

Social integration was explored by Knudson-Cooper (1987) in a study of long-term adjustment of young adults with burn scars. She found, in general, respondents seemed well-adjusted, as measured by self-esteem indicators. In relation to social engagement, Knudson-Cooper found her respondents did not differ substantially from that expected from a general population of the same age. Respondents were active users of community organisations and only a small minority of the sample (2%) reported feeling socially isolated. The study suggests that social and emotional support from family and friends is more important than burn severity, age or gender, in relation to emotional adjustment outcomes. Respondents did recognise people (outside their circle of family and friends) treated them differently and worried whether they would be accepted by other people; they had concerns about self-acceptance and the role this plays in gaining acceptance from others.

In their sample of adults living with craniofacial conditions, Roberts and Mathias (2012), found positive perceptions of HRQOL and higher self-esteem when compared to normative data. They found significantly lower mean scores on emotional role limitation, mental health and social functioning. The ‘appearance concern’ scores were in the category of ‘a little’ but this was greater than general population scores. While social support was perceived as positive, respondents had significantly lower scores on ‘friends’ than did the general population. This indicates that respondents believed they received less support from friends than the general population believe themselves to receive; however, this was not the case for relationships with family, significant others or social support overall.

The researchers concluded that although functioning was at a similar level to the general population, their respondents were less likely to be married and women were less likely to have children; they were also more likely to be living on disability pension, although there were no differences in rates of unemployment. They did not differentiate in their sample between how many people were, or were not, living with developmental learning disabilities. The issues identified as important to quality of life were about being able to get along with life, rather than health-specific issues. The authors explained their findings by reference to a socio-political model of disability and suggested differences might be due to the impact of other people's negative reactions and attitudes towards people with craniofacial difference.

3.6.3.2 Social circles

Although studies mapping affective personal communities have not been undertaken, the notion of valued social circles has been employed. In studies of people with genetic conditions, social circles are associated with success in life and positive outcomes (Eiserman, 2001; Meyerson, 2000; Uttjek et al., 2007). Meyerson (2000) explored perspectives of people living with Moebius syndrome and reported that some people develop companionship from their extended family, and others have developed an informed coterie of family and friends who see beyond facial paralysis. Uttjek et al. (2007) found people affected by psoriasis linked a good quality of life with having a close social circle of friends and family, who accepted them the way they were. Those who reported not having a close friend reported a fear of loneliness and feelings of depression. Perceptions of restricted social networks were identified by Patel et al. (2011) among adults living with neurofibromatosis type 2. Some respondents limited their social networks to those they felt understood their situation and knew them well. Linkages are made between limited networks and feelings of social isolation through avoidance of crowds, social situations and being unable to work.

3.6.3.3 Changes in relationships and networks

Several studies describe how acquisition of visible facial difference has impacted on quality of relationships within a network, including loss of relationships.

Changing priorities in life, recognising the value of relationships and increased closeness have been identified as some of the factors affecting change in quality of relationships (Williams et al., 2003; Semple et al., 2008). Re-structuring of life priorities has been interpreted as flexible and constructive responses by individuals and their close others to forced and unwanted changes associated with disease or injury. Röing et al. (2009) identify how people adjusted to changes to their mouth after surgery for oral cancer. They focused on three areas: feelings about their body, how others saw them, and their relationship with others. They found a variety of relational processes in these areas of adaptation. These included adjusting to changing life priorities, developing an increased awareness of self as dependent on support and love, dealing with feelings of abandonment in some relationships, and difficulties in communicating how they have changed in different relationships. The study identified the continuing impact of oral cancer on everyday lives and raises questions about the emotional and existential nature of support people continue to need after the effects of medical treatment.

De Boer et al. (1995) reported changes to everyday life following head and neck cancer surgery several years before. They compared three types of treatment, each varying in treatment burden. Personal contact with a partner was found to have improved since treatment in all three treatment groups. 38% of the laryngectomy group reported a decrease in personal contacts with family and friends, 47% of these reporting tensions and difficulties in the family as a result of the disease, and 67% of reporting that the problems remained unresolved. Less than a quarter of patients in the other groups reported these problems. Undergoing a laryngectomy was related to decreased perceived abilities in swallowing and eating, communication with others and feeling hindered by their disfigurement because of a stoma. Furthermore, this group reported long lasting uncertainties in finding access to help, finding solutions and managing emotion. Everyday life was more strongly influenced by disease and its treatment for the laryngectomy and commando procedure patients, than for the ‘T1-larynx’ group, and activities were restricted to a close circle. However, open discussion in the family, social support and perceptions of adequate information were reported as the features most correlated with positive rehabilitation outcomes.

Open communication was also identified by O'Brien et al. (2012) as the means of building trust and negotiating changing sexual and intimate contacts; the effectiveness of this relied on the nature (or quality) of pre-existing intimacy in relationships. Methods of re-establishing social networks varied greatly, those who were able to return to work, and those who reported fewer intimacy problems found social networking easier; than those who experienced change in their drinking or eating habits.

Gamba et al. (1992) interviewed patients between six months and eight years after head and neck cancer surgery and found the greatest social impact was on friendships. 27% of the participants said friends did not visit as they used to do, and this effect was significantly greater for those classified as having extensive disfigurement. However, most respondents (62%) credited friends with boosting morale and encouraging them to start a new social life. About half the sample reported that their desire to meet friends had diminished. Overall, most respondents felt they had a good relationship with their partner and family. In relation to impact on their relationship with their partner, a stronger negative impact was found in the extensive disfigurement sub-group, who also felt their body image had changed.

Ciofi-Silva et al. (2010), investigating rehabilitation from burn injuries, suggested that reduced interaction with friends reinforces the need for support from family. The impact of burn injuries in some families disrupted already fragile relationships, while in other families this change was experienced as a tightening or closening of ties. Rossi et al. (2009) reported family support as facilitating coping through provision of a range of practical and emotional support: maintenance of the household income, being close during pain, assistance with self-care and activities of daily life, helping cope with others reactions, understanding and accepting difficulties faced, and understanding changes in their sexual life. Reduced interaction with friends during the rehabilitation period placed greater need for support on families.

3.6.3.4 Social pressures on families

In addition to the pressures of adapting to changed relationships and roles, consequences of progressive illness have been reported. In exploring impacts on family life, Patel et al. (2011) notes one respondent felt the effects of the disease impacted on their immediate family, as she could not do as much as she used to. The respondent described how she could not stand being looked at as a 'freak' and this increased her reliance, at times, on her husband to do everyday activities such as shopping. Explicit links between stigmatising social effects and pressures on family life and relationships were made.

Rossi et al. (2009) reported diverse responses as to how burn survival impacted on partner relationships. For some, relationships got worse, for others they improved; some met a new partner, some split up. Rossi et al. (2009) identified the family was a crucial source of protection in a society which was:

> '…segregating and rejecting those regarded as not having abilities, appearance or knowledge required of those who live in it' (Rossi et al., 2009, p.718).

They identified the cultural dimensions to quality of life as: autonomy, family harmony, and taking part in work and leisure activities. Support from the family was regarded as fundamental post-hospital, because health-care reduced and relatives were expected to support the burn survivor through this stage of their recovery. They needed the kind of support from family that would encourage independence, combined with the flexibility to deal with changing personal, financial and social circumstances. Family and cultural values were discussed in Rozario's (2007) case study of a Bangladeshi woman living with neuro-fibromatosis 1 (NF1) in the UK. Family shame about appearance difference was interpreted as being responsible for the family limiting social and educational opportunities early in her life and compromising her marriageability in later life. The narrative Rozario reported shows how the protagonist managed to overcome barriers associated with her appearance, but not in a way acceptable to her family and cultural milieu. She, however, described herself as happy. This paper illustrates how beliefs about appearance, in some contexts, connect to moral judgements of life-shaping significance. The family is construed as not separable from its cultural context.

Thompson et al. (2010) explored perspectives of British South Asian women with vitiligo. The participants discussed a range of personal and social identity issues. Awareness of family shame was heightened with family members from older generations or when visiting relatives in Pakistan and these became more painful when reproduced by closer family members. Complexities around personal identities were apparent in respondent discussions of iatrogenic depigmentation which lightened the skin; some perceived this positively because of the higher cultural value placed on lighter skin, but others perceived this effect as a threat to their ethnic identity.

Some studies have reported that friends and family do not always understand emotional aspects of living with visible facial difference. Semple et al. (2008) noted that some respondents viewed their supportive relationships as over-protective, and as another barrier to negotiate. Murray and Rhodes (2005) reported feelings of frustration among adults living with facial acne - sometimes reassurances felt hollow rather than helpful. This sense of isolation was echoed in Dures et al. (2011); the hereditary nature of epidermolysis bullosa (EB) could lead to blame in families. The disease affects each person differently and respondents identified desires to develop skills of self-management for their particular situation and experiences.

3.6.3.5 Mobilising support

Semple and McCance (2010) identified that close family members have an important role in mobilising support from wider networks and community. Most respondents shared knowledge of their diagnosis with their child’s school teachers in order to access support for their child. Some respondents used the church, other colleagues or workplace counsellors for support. Some felt they received insufficient advice from health professionals about how to deal with their parental role, which was affected by the disease and its treatment. Issues of parental stress, upset though separation, help with age appropriate preparation for their child’s visit to the hospital, struggles with balancing roles of parent and patient, and fear of not being a good parent were all reported. The authors suggested some patients need health professional encouragement in order to mobilise members of their core support community.

Similar findings were reported by Phillips et al. (2007) in relation to burn injuries. Some participants felt burn units did not provide services that helped with managing upset in the family after an injury to a family member. The authors identified roles for health professionals in encouraging families to mobilise support and develop patients' and families' self-management skills in post-burn care**.**

3.6.3.6 Family and friends are not enough

Dures et al. (2011) identified unmet needs in facilitation of self-management of the disease and in dealing with social consequences such as difficult encounters. Family and friend support was considered important, but not enough to support all the needs that could arise over the life-course of living with epidermolysis bullosa. Respondents valued others who they felt understood although this was tempered by a wariness of the effect that living with epidermolysis bullosa could have on relationships. Interviewees cautioned that even though friends could be very supportive, the long term severe physical nature of the disease was seen as limiting opportunities for friend making and keeping. A lack of social support personalised to the individual's situation and a lack of coping strategies have been noted (O'Hanlon et al., 2012). Other studies have noted low levels of emotional support from health care professionals to both patients and families (Furness, 2005; Phillips et al., 2007; Semple and McCance, 2010).

3.6.3.7 Resuming normal life

Getting back to normal life is viewed as an important element in recovery and adaptation to injury or disease, and is described as resuming previous activities and relationships. Rossi et al. (2009) and Ciofi-Silva et al. (2010) explored the dimensions of everyday life affected by burn injuries: work, leisure, intimacy, relationships, religious ties, education and personal or social habits. The importance of being able to resume employment and/or work in the home and maintain their role in the family were seen as central to quality of life, successful recovery and future prospects. Work not only alleviated financial problems, but also provided a sense of normality and important connections to the wider world. Returning to work is viewed as pivotal to moving beyond acute cancer experiences.

Semple and McCance (2010) reported problems in re-finding ‘ordinariness’ in the tangle of chronic illness disruptions, including the change in partner role to that of a carer.

3.6.3.8 Struggle for autonomy

Studies focussing on genetic conditions have not identified ‘resumption’ of normality as a theme. In studies of people living with visible facial difference from birth, the notion of normality is used in a different way.

It is related to questions about how social responses interact with personal identity to produce feelings of deviance or of not being normal. Dures et al. (2011) noted frustrations with not being seen or treated as normal which enhanced feeling unaccepted by society. They noted respondents living with epidermolysis bullosa wanted to be able to take their own risks and not be infantilised by care workers.

The bodily impacts of disease were seen in some studies as contributing to reducing choices in work, social life, personal relationships and education (Ablon, 1996; Dures et al. 2011; Patel et al., 2011). The lifelong presence of unpredictable and predictable negative responses from other people emerged from everyday ideas about what is acceptable as normal appearance (Hawkesworth, 2001). They require continuous adaptation and take their toll, in effect reducing choices in all areas of life.

3.6.3.9 Partners

Close family members were reported as important sources of emotional and practical support, with partners often as the main source (Bonanno and Choi, 2010; Semple and McCance, 2010; Bonanno and Esmaeli, 2011; Lau and van Nierkerk, 2011). Both Lau and van Nierkerk (2011) and Semple and McCance (2010) regarded a partner’s unconditional love and acceptance in the context of a supportive network of family and friends, as an important foreground to processes of positive adjustment. Although partners were seen as the most important source of emotional and practical support, emotional support was also valued from other close bonds, as this could reduce over reliance on their partner.

Looking specifically at relationships between partners, Vickery et al. (2003) investigated the impact of facial disfigurement on quality of life with head and neck cancer patients 6-18 months post treatment. Patients did not necessarily report a poor quality of life and in some instances greater distress was reported by their partners. The researchers separated the patients into two groups receiving different types of treatment, with varying degrees of treatment burden. No correlations were found between level of disfigurement and self-reported dyadic adjustment, psychosocial adjustment to illness, or quality of life. No significant differences were found in the patient groups on the quality of life measure, except for one sub-scale, 'Trouble with social contact' which included questions about physical appearance. The difficulties reported on this subscale were at low levels. This study indicated that patients with greater treatment burden reported greater difficulties with social contact; however, facial surgery was not an impediment to rehabilitation, despite the burden of disfigurement. The researchers concluded that there was no simple relationship between levels of disfigurement, dysfunction and quality of life. The experience of head and neck cancer illness and treatment was found to affect partners significantly. However, the study also indicated that surgical treatment was not placing additional burden on partners. The researchers suggested that the quality of the relationship between the patient and their partner may have buffered the psychosocial aspects of head and neck cancer. This study supports the view that more specific and sensitive subjective measures are required to explore the effects of facial disfigurement connected to head and neck cancer treatment. The use of subjective assessment of comfort in social contact seems to be an important element of any attempt to disentangle disfigurement from functional effects of head and neck cancer treatment.

3.6.3.10 Parent and child relationships

Two studies have explored parental roles using quite different perspectives (O'Hanlon et al. 2012; Semple and McCance, 2010). O'Hanlon et al. (2012) took a unique approach to the parental role of adults with cleft lip and/or palate, by looking at the contribution made from having a family history of cleft lip and/or palate syndrome. They investigated parental adaptation to the diagnosis of cleft lip and/or palate in their child. Experiences of non-affected parents were compared with those who had a diagnosis of cleft lip and/or palate.

Both groups of parents scored high on measures of social support, suggesting that parents of children born with cleft lip and/or palate did not lack social support in a general sense. The main differences between the two groups were the tendency of parents with a family history of cleft lip and/or palate to draw on their personal resources, and for unaffected parents to seek information and support from health professionals. Both groups of parents had support needs, but they differed in how these needed to be addressed. Findings from this study support the notion that situation specific coping mechanisms are used by parents dealing with childhood illnesses; these are often missed by general coping inventories. Qualitative research would be useful to adequately investigate situational processes.

Semple and McCance (2010) explored experiences and support needs of patients with head and neck cancer who were caring for young children. They identified how thoughts and feelings in relation to their children changed at different phases of a ‘cancer journey’. At diagnosis, the overriding emotions were fear coupled with awareness that the diagnosis affected the whole family. Some parents considered not telling their children, but realised that the hospital appointments, and emotional and physical changes, meant they had to give their children an explanation of what was happening. Telling the truth was thought of as a way of reducing mistrust, and they tended to use an upbeat language of hopefulness. Stays in hospital would be needed during treatment, and this led to a need to prepare the child for their first hospital visit. For adult patients, visits from children could be a useful source of emotional support. The debilitating effects of treatment impacted on family activities especially eating; side-effects were rarely isolated and influenced a number of aspects of intimacy such as eating, speaking, and not being able to pick up their child because of weakness. Each of these could affect relationships and feelings of closeness. The whole family had to adapt to changing roles, and partners particularly had increased care responsibilities. Role change was perceived as especially challenging for fathers, although it allowed opportunity for greater closeness to their children. Support from the wider family such as grandparents was regarded as helpful in caring for young children. Semple and McCance (2010) noted that open communications within families allowed space for negotiations about changing roles to take place.

Adults with visible facial difference described their parents' responses as formative in terms of their adjustment. Eiserman (2001), Meyerson (2001), Cadogan and Bennun (2011), and Egan et al. (2011) reported that respondents with visible facial difference since childhood spoke of their parents treating them 'not differently' as helpful. Some participants were able to interpret a lack of family support positively, as it meant they developed their independence. Eiserman (2001) identified how having a person in the family with a visible facial difference contributed to the quality of community life, for instance, by increasing awareness of the nature of discrimination and encouraging involvement in promoting acceptance of diversity.

3.6.4 Coping, time and resilience

Qualitative studies have looked at support from personal relationships as facilitating coping. Thompson et al. (2002) identified their role in facilitating self-acceptance of facial difference. Other studies have looked at coping with visible facial difference in terms of long-term adaptive outcomes or resilience (Eiserman, 2001; Meyerson, 2001; Williams et al., 2003; Strauss and Fenson, 2005; Lau and van Nierkerk, 2011; Stavropoulos, 2011). Roles for family members and friends have been identified in re-integration after an acquired visible facial difference, during the processes of recovery and over the longer term, as part of a journey of emotional adjustment (Knudson-Cooper, 1981; Thompson et al., 2002; Semple et al., 2008; Thompson and Broom, 2009; Konradsen et al., 2012).

Coping has been conceived as an individual, dynamic, and iterative process which can draw on a wide variety of strategies (Thompson et al., 2002; Furness et al., 2006; Uttjek et al., 2007; Thompson and Broom., 2009; Konradsen et al. 2012). Williams et al. (2003) distinguish between resilience and coping. They define resilience as an adaptive outcome in response to crises or stress, and coping as psychological or behavioural responses which reduce physical, emotional and psychological impacts of stressful life events (Williams et al., 2003). Relational contexts are explored as a buffer for those exposed to risky environments and resilience has come to be conceived as a common response and an ongoing process.

Lau and van Nierkerk (2011) employed a social constructionist approach, which considered processes of life management and resilience as fluctuating and never-ending, rather than being a single or fixed outcome.

3.6.4.1 Role of relationships

There are differences in how adaptation and coping is described in the accounts of people with lifelong visible facial difference and acquired difference. Eiserman (2001), Meyerson (2001) and Strauss and Fenson (2005) identified that selected and valued relationships play a role in creating a culture of acceptance and achievement in life. Thompson and Broom (2009) found social support could help with stigmatising situations and one respondent explained this was because these people accepted and shared her battles. Stavropoulos et al.'s (2011) respondents living with Crouzon syndrome identified a need to 'make the best of their situation'. They developed strategies since childhood to handle difficult situations and to enhance their sense of wellbeing. Some respondents constructed positive identities and did not see their adversity as a personal failure, but rather a socially mediated phenomenon that could be resisted. Resistance to stereotypes and appearance-related discourse is seen as a type of resilience. However, the respondents reflecting on their teenage years felt they had been excluded from dating processes and many had not found a 'love partner'.

The literature on acquired viable facial differences describes disruptive impacts on relationships as well as their potentially healing or supportive powers. These impacts are described as variable according to individual and family circumstances (Knudson-Cooper, 1981; Williams et al., 2003; Rossi et al., 2009; Lau and van Nierkerk, 2011).

3.6.4.2 Re-integration after surgery for head and neck cancer

The support of family and friends is emphasised as important in social re-integration. Semple et al. (2008) reported that managed re-entry into social situations appears to improve social confidence after treatment for head and neck cancer. They described useful strategies as combinations of a fighting spirit, social support and openness of friends, active planning in how to manage situations, and, where possible, immediate re-integration into usual social activities after treatment.

Konradsen et al. (2009 and 2012) looked at processes of ‘interactional re-integration’ after head and neck cancer surgery. Their first study was carried out with people shortly after surgery and looked at how presence of disfigurement was managed in interactions within nurse and patient dyads. They observed that processes, whereby ‘silencing disfigurement’, are triggered by responses of nurses and are then maintained within the dyad. These processes, they claimed, start before surgery, where the potential for disfigurement was seen as less of a problem, and survival the most important matter. When this continues after surgery it creates further barriers to communication, such as how to raise an issue considered less important. Assumptions by the nurse that the problem was minimal led to barriers in assessing whether or not there were issues that needed discussing. Another communication norm that developed was the idea that an issue should not be brought up unless raised by patients first, in order to prevent the patient getting upset. These silencing processes were located as arising from implicit and unverifiable professional assumptions made by nurses about their role. They identified a subtle distinction between making an extraordinary situation seem ordinary through normalisation, and covering-up strategies which hid emotional difficulties for both patients and nurses. An example of relevance to social support was of a nurse who assumed that a patient was managing because they had visits from family members. However, the patient, who had previous experience of disfigurement, emphasised her feelings of isolation, and talked about how she felt imprisoned by her large scarf, which she wore to cover her disfigurement outside her home. The study highlights how professional assumptions need to be questioned, in order to help address patients’ perhaps unspoken values, concerns and needs.

Konradsen et al.’s (2012) follow-up study explored nurse-patient interaction over the first year after surgery, and identified how silences around disfigurement were broken during interaction processes outside the hospital (Konradsen et al., 2012). They theorised three stages: becoming disfigured; being a disfigured person and becoming a person with a disfigurement. The second stage had two sub-processes: noticing and dissociating. Other people could not help noticing the disfigurement and often responded with silence. Patients noticed this response, were concerned it was a sign of an upset emotional state in others, and as a result started dissociating. This could create a space where they could temporarily forget, or where they felt protected.

These states appeared to alternate, although the pace of alternation was not established. Transition to the third stage occurred through the silence being broken, either by the patient, or by someone else. This stage was considered unstable and external events triggered going back to the second stage. The authors regarded these as social processes which contributed to identity change and adapting to facial disfigurement.

3.6.5 Social support and demographic factors

This section considers how gender, age, ethnicity and socio-economic status affect contributions of personal relationships and social support in the context of visible facial difference.

3.6.5.1 Gender and sex differences

Attempts have been made to search out correlations between gender and psychosocial difficulties relating to appearance. Studies have investigated whether there are sex differences in terms of self-esteem. These are based on the assumption that women experience greater social pressures in relation to facial appearance. Bowden et al. (1980) found differences in that, generally speaking, males had higher levels of self-esteem than females, including within a small sub-group of men and women in their sample who they classified as severely and visibly disfigured. Furthermore, they found no differences in self-esteem between the respondents classified as disfigured or non-disfigured, nor when comparing the location of burn injuries. Rumsey et al. (2004) found females showed higher levels of depressive symptoms, social anxiety and avoidance activity related to appearance concerns than men. Their findings showed both small effects sizes and also considerable variability in the scores. They also found no significant effects on quality of life scores based on observer rated degree of disfigurement. Only marginal effects on social anxiety scores were found for those rated as having least disfigurement. The rating of disfigurement was only carried out on a portion of the sample and the components of this rating are not reported, including location of the disfigurement. However, evidence of correlations based on sex differences has not been found within other studies (Brown et al., 1988, Knudson-Cooper, 1981, Lawrence et al., 2006b).

Studies which have incorporated perceived social support as a variable have found correlations indicating some gendered differences. Brown et al. (1988) found both males and females reported adjustment to burn injuries. The only significant difference found between males and females in relation to psychological adjustment, was that females reported greater disruption in their vocational adjustment than males. The measure of vocational adjustment included activities of homemaking and parenting as well as other employment and returning to work. Psychosocial adjustment for the whole sample was best explained by less functional impairment, belonging to more recreational activities, greater friend support, less use of avoidance coping and more use of problem solving. Brown et al. (1988) used these findings to challenge the idea that men were more concerned with bodily function and work, and women with their appearance. Bodily function and being able to carry out one's occupational activities were important to both genders. Women's perceptions of greater family support, and men's of greater friend support, were the specific social support variables contributing to psychosocial adjustment and greater participation in recreational activities for both genders. These associations led Brown et al. (1998) to suggest that different sources of social support for men and women might promote adjustment. Orr et al. (1989) reported perceived social support, particularly from friends, accounted for most of the variance in body image, self-esteem and depression scores in young adult burn survivors. They found that for the women in the sample associations between feeling less supported with higher levels of depression and lower levels of body image. They suggested there might be differences in the importance of 'social support' for young men and women. Katz et al. (2003) also investigated this area, they found women reported greater depression than men and, as well as less perceived social support. Perceived social support had a 'main effect' on wellbeing for women, but not for men. Women and those with low levels of social support, reported lower life happiness than did men, or those with higher levels of perceived social support. They concluded that social support seems to act as a buffer for women, as the women in their sample reported less social support, and more depressive symptoms, but perceived they benefitted more from social support than men.

Roberts and Mathias (2012) compared psychosocial functioning of adults with congenital craniofacial conditions with normative data, and found similar results between the populations. Adults with craniofacial differences were less likely to be married, or have children if female. Women reported more perceived general and friend social support than males, and had lower self-esteem scores than males in the sample, but not in comparison to the general population. O'Brien et al. (2012) reported gender differences in the expression of intimacy. Females tended to describe intimacy as providing a sense of emotional security and desirability, while males' sense of intimacy was denoted by their role as provider, ongoing virility and willingness to listen. The importance of female to female friendships and continuing social expectations of taking the role of care provider (in the case of women) are constructed along gendered roles.

When perceptions of social support is added to studies differences between men and women are detected, which has lead researchers to suggest that women and men may have different needs in relation to support. However other researchers have pointed out that perceptions of the relative importance of perceived social support are shaped by gendered social expectations. Ablon (1996) suggested that the manifestation of sexism and ableism in society at the time of any study will affect views presented of gender, disfigurement and disability.

Ablon found more experiences of social withdrawal reported by single males than single females in her sample, which she suggested developed from poor responses in educational and home environments towards children who do not fit with normative ideas about sporting and academic achievement. Disfiguring conditions challenge self-image and life-style of both genders by impacting on appearance, education, earning and economic status and ability to have children without perceived dangers.

Rozario's (2007) approach was inspired by Ablon's work and she also looked at cultural facets of neuro-fibromatosis 1. She identified that the high value placed on appearance was linked to gendered ideas about marriageability within a single case study from a UK Bangladeshi family. In order to achieve educational and other goals, Rozario's protagonist moved outside of her originating sub-culture in order to be able to achieve educationally and to have her own family.

Rozario (2007) interpreted cultural values of appearance as the uppermost factor in negatively affecting her interviewee’s life. It was from these judgements that other restrictions flowed.

3.6.5.2 Age

The review has revealed very little evidence about whether greater age enables better coping with visible facial difference, or whether appearance is similarly important for younger as for older people. None of the studies looked at whether perceptions or experiences of facial difference changed as a person ages. These findings highlight that within any visible facial difference condition there have not been any studies of age related differences in perceived stigmatisation. Consequently, the picture revealed is inconsistent and incomplete.

A HRQOL study found indications that a younger age at time of burn, and levels of social support, were the strongest predictors of improved mental quality of life after a massive burn injury (Anzarut, 2005). Lawrence et al. (2006b) did not find a significant relationship between either age at which the respondent was burned, or time since burn, and depression symptoms in people with burn scars, when using sex as a variable. However, in a study comparing paediatric burn survivors and adult survivors, Lawrence et al. (2010) found some interesting differences between age groups. Adults had a significantly lower ‘latent mean’ than the paediatric group on the investigators’ social comfort questionnaire, while perceived stigmatisation did not differ between children and adults. These findings do not support the assumption that children experience bullying or teasing more often however. The adult group had a lower average level of social comfort, a finding which can be used to question the assumption that people become accustomed to uncomfortable interactional situations over time. The researchers suggested that perceived stigmatisation and perceived social comfort were so strongly related that they possibly reflect different aspects of another overarching construct, and the need was to explore further the social context of living with difference.

Roberts and Mathias (2012) found no age related differences in psychosocial outcomes in their sample of adults living with craniofacial conditions. Leading them to suggest that even though surgical procedures have improved and discrimination decreased, this lack of difference might be accounted for by society becoming more focussed on appearance.

3.6.5.3 Ethnicity, cultural differences and socio-economic status

Cross cultural responses to visible facial difference and personal relationships have been largely under-investigated. Five of the studies reviewed were carried out outside Europe, North America or Australia. Berk (2001) examined social anxiety among adults with cleft lip and/or palate in China; Rossi et al. (2009) and Ciofi-Silva (2009) studied burn injuries in Brazil, Lau and van Nierkerk (2011) looked at burn injuries in South Africa; and Deno (2012) investigated head and neck cancer patients in Japan.

Cultural effects on responses to visible facial difference from the self, and significant or generalised others have been detected in this review, with differing strengths of perceived stigmatisation and restricting social practices. Differences in family practices and friendship patterns are highly likely, given a viewpoint that these are historically, socially and culturally shaped. However, these differences have not been studied in the papers included in this review.

There is a general absence of studies exploring ethnicity or race in relation to visible facial difference in the UK, particularly in relation to identifying contributions and support from family and friends. Rather, studies have identified stigmatising attitudes in relation to appearance within British Asian minority cultures (Rozario 2007; Thompson et al., 2010).

No studies were found to use the concepts of social or economic capital. Socio-economic status tends to be used to check distribution of the sample. However, some studies on burn injuries have noted that injuries were more likely among those in manual jobs, with low income or working class backgrounds and particularly so in lower income countries (Lawrence, 2006b; Ciofi- Silva, 2009; Rossi et al., 2009; Lau and van Nierkerk, 2011). The latter three studies indicate that the social impact of burns was ‘classed’ as physical impairment and could more greatly inhibit return to manual jobs than to white collar occupations.

These three studies also emphasised the presence of global inequalities in access to treatment. For example, in South Africa and Brazil where these studies were carried out, specialised burn facilities, provision of rehabilitation and psychosocial services were neither well developed nor widely accessible.

3.7 Summary

Facial appearance and other facial functions are hard to separate. Impairment of a particular facial function can also affect appearance as a human body moves and appearance is not static. One of the challenges in this review was identifying how papers from across a range of conditions investigated the occurrence, or consequence of visible facial difference. Many studies used the presence of a condition which requires changes in facial appearance to indicate visible facial difference, but they do not necessarily separate out the consequences of this in their findings.

Part of the reason for this might be the low numbers recruited. Studies that do seek to clearly separate out disfigurement effects are hampered by measurement issues and conceptualising the multi-dimensional aspects of visibility, severity, and of facial functions. The importance of subjective self-assessment has been identified as their most valuable means of accessing understanding of their effects of becoming used to or living with difference.

Studies looking at acquired differences have not found severity of visible facial difference *per se* to be an impediment to psychosocial adjustment; however it does have a role to play, albeit with much still to be understood. From a surgical perspective, these studies have served to support the development of important treatments involving the face. However, they also indicate that visible facial difference presents challenges for the individual and those around them and indeed much of this challenge appears socially generated. These extend beyond medical issues into interpersonal areas where a focus on the physical aspects of appearance change becomes untenable, and the complex, multi-dimensional involvement of social and subjective factors become apparent.

Studies that have focussed on the experiences and perspectives of those who have visible facial difference since birth indicate that adaptation and adjustment occur within disabling or stigmatising social contexts. As well as presenting evidence challenging the notion of severity as a single, sufficient predictor of psychosocial issues, the literature presents a discourse seeking to shape health professional responses to visible facial difference, by questioning a direct association between low medical severity and low psychological need. This has important implications for providers of health care, as low severity cannot be equated with no or low need. There are also access challenges in how to meet needs of dispersed populations, and where measurement and intervention resources need further development.

Family and friend relationships have been conceptualised as valuable sources of social support. There is a body of work that indicates that ‘perceived social support’ plays a fundamental role in aspects of psychosocial adaptation. Studies have found indications that different types of support, and different sources of support, may play different roles for women and men, at different times in the life course, or at different points in the processes of recovery, adjustment and in developing and sustaining life chances. Other studies indicate that social and emotional support from significant friends and family members are more important in the complexities of emotional adjustment than severity, age and gender, for example, Lawrence et al. (2006b).

Impacts on everyday life have been found in work, personal relationships, interactions with others and negative social attitudes persist across a range of visible facial difference conditions. Few studies have explored the perspective of the person with a visible facial difference on their specific social roles, with one exception being O’Hanlon et al. (2012) who compared experiences of parents with a diagnosis of cleft lip and/or palate with those of non-affected parents, looking at cleft lip and/or palate effect on the parental role.

Studies indicate that age, position in the life course, and gender shape experiences of visible facial difference and that there are significant gaps in knowledge of these factors. There is a dearth of studies looking at ethnicity and incidence, or impact of work-related difficulties.

Others have proposed an interactional approach which recognises multiple factors involved in bodies, contexts and environments in producing difference (Shakespeare, 2006 and 2014; Rhodes et al., 2008). Yet these approaches give rise to questions of social justice and also ask for an informed focus on the complexities of adaptation experienced by different people with varying conditions in different times, contexts and places.

A number of areas identified through this literature review have shaped the study questions. A strong case has been made for rejecting the notion of direct association between severity of visible facial difference and adjustment, and for measures based on medical characteristics, or observer only based assessments. The complexity of experiences when living with visible facial difference call for more focussed qualitative studies, to capture detail of changes in lives. There is a need for exploration of how social contexts, such as personal communities, are utilised by people living with visible facial difference. It would be useful to look beyond how people deal with perceptions of appearance, into how experiences of living with difference enhance or complicate life roles. Perceptions of stigmatisation and perceptions of social comfort seem so strongly related that they suggest a need to explore further social contexts of living with difference. The literature underlines a need to explore perceptions of personal social environment which promote living with difference. There is therefore, an opportunity to investigate in greater depth the roles that relationships with friends and families play in a range of life situations. Families are part of individual adaptation, and some studies indicate that friend relationships may be a stronger feature in social acceptance. The literature paves the way to a qualitative approach in understanding the contributions of personal relationships and how these are structured to provide love, social support and other qualities important to well-being in the experience of visible facial difference.

Chapter 4 Methodology

4.1 Introduction

This chapter discusses the methodological approach that has informed the design and choice of methods adopted. The study aimed to increase understanding of how relationships and social connections contribute support to adults with visible facial difference. This study asks whether Spencer and Pahl's (2006) concept of personal community has currency in understanding the personal communities of relationships of people living with facial difference:

- What are the characteristics and value of these personal communities of people with visible facial differences?
- Do personal communities contribute to resilient adaptation and protection against stigma for people with visible facial difference?
- What roles do people with visible facial difference play within their personal communities?

As noted in Chapters 2 and 3 relational and social aspects of living with visible facial difference are under-explored. A relational interpretive framework was constructed to develop enquiry into this area.

4.2 Pragmatism

Conceptions of interacting, thinking, feeling, embodied selves are underpinned by ideas from the philosophy of pragmatism. The idea that an active social self in interaction is mutually constituted through its context draws on the pragmatic ideas of knowledge as a practical achievement (Coffey and Atkinson, 1996). Knowledge developed about the world comes from reflection, practical engagement, and activity, and is always both partial and conditional. However, this does not mean that interpretations are only subjective, or that all interpretations are equally useful. Human beings develop meanings from living in the world, and these are based on practical knowledge and reason. Subject and object are entwined. To explore this requires methodology and methods that bring together object, and subject and which are capable of producing interpretations of these meanings in a credible way (Crotty, 1998).

A pragmatist’s view of the world holds that knowledge can be gained from theory as well as from inductive experience. Coffey and Atkinson (1996) described this as ‘abduction’ which is dialectic between ideas and experience. The generation and testing of ideas are required in order to develop knowledge. This interplay between generation and testing comes about through interactions in the social world and in the processes of building knowledge. Truth is connected to the processes of problem solving. As an epistemology, pragmatism is therefore sceptical of a single truth, viewing reality as open to multiple interpretations. Truths are fallible, provisional, and perspectival, but in the way we respond to truths, they can appear to have practical value.

4.3 Values

This study does not take an uncritical view of social and cultural meanings in relation to visible facial difference. Facts and values are not distinct, and findings are influenced by both the researcher’s and the respondent’s values and perspectives (Snape and Spencer, 2003). This line of thinking has developed from consideration of the value of looking at the world from the perspective of a ‘critical humanist’ (Plummer, 2001) which locates the complex, diverse, embodied, feeling and contingent human being as nested within multiple contexts. In this perspective, there is a continuous tension between the specificities of any particular time and place, and the universal potentials found in all humans (Plummer, 2001).

A universalism of human rights based, on shared, embodied vulnerability, was developed by Turner (2006). His argument was that the concept of vulnerability forces all people to need social dependency and connectedness. It is vulnerability that drives the need for social support and legal protection, because humans cannot ultimately respond to their own bodily and moral vulnerability by individual acts in isolation. Collective arrangements are required and these include an approach to human rights protection which includes those whose lives might be more precarious. Ethical commitments of care, fairness, respect, and minimising harm have been used in this study (Plummer, 2001).

4.4 Postmodern times

The study explores the situations of individuals, and their perspectives on their micro-social world, and what it is to be among others in this world. The approach adopted is influenced by an understanding of modernity, in which over-arching frameworks are loosened and meanings of categories such as family or friends become more fluid or liquid (Bauman, 2003).

The epistemological critique of the self and the knowledge on which it is based arising in postmodern times does not necessarily undermine the existence of selves, which emerge from the social and moral interactions of everyday life. The study sits within a type of ‘affirmative postmodernism’ (Gibbins and Reimer, 1999; Plummer, 2001), a sociology of postmodern times rather than a postmodern sociology. Context is important as are points in time and history. These serve to situate research and provide a different version of objectivity to the research process; this is a socially and historically relative position (Scheurich, 1997). The study’s focus is on exploring diversities of patterns and responses embedded in everyday relationships of people living with visible facial difference.

4.5 Interpretive approach

This enquiry is situated within the interpretative tradition, drawing on foundational interactionist writers such as Cooley, Goffman, and Mead, and more contemporary proponents such as Coffey and Atkinson (1996), Denzin (2001), Plummer (2001), and Burkitt (2008; 2012; 2014). Many of the ideas discussed in Chapter 2 are derived from interactionist ideas about the development of social worlds through action and interaction within a dialectical relationship between self and context. The approach applied here focusses on understanding the meanings of, and negotiations within, the embedded, relational, biographical, moral and embodied social and personal worlds of people living with visible facial difference.

A key lever in developing this approach was recognition that narrated lives do not only report personal experience. Plummer’s (2001) writing on ‘coming out’ stories demonstrated this by showing how selves and social worlds interact to produce, change or reinforce identities, actions and choices.

Rather than revealing the intimate personal worlds of people with visible facial difference, this study explored how people develop particular ways of construing social realities, within social and cultural situations, that personalise visible and embodied difference.

The ‘actor’ developed within an interactionist approach is capable of conscious, reflexive thought with emotions central to meanings of actions (Burkitt, 2003; Burkitt, 2014). Neither social shaping nor individual choices alone are sufficient to explain what becomes of a person, as there is complex interplay between reflexive and emotional selves and their contexts. Persons are seen as gaining a sense of self from interactions and from being in relationship with other people, from being relational. Accounts of these can be used as a means of understanding lives and are part of how respondents make sense of their lives and connections. They can be construed as having a social ontology in that they constitute experience rather than just represent it: what is seen as ‘real’ is produced and then interpreted.

4.6 Methodology

4.6.1 Qualitative methods

The study design used qualitative methods, based on Spencer and Pahl’s (2006) personal community approach. The methods developed by Spencer and Pahl (2006) were adapted to explore perceptions of contributions made by important personal relationships in relation to living with visible facial difference. Qualitative methods were used, because of their exploratory nature, and because of the interest in eliciting rich descriptions through narrated accounts of personal communities. The approach taken was considered to be a valuable means of enabling respondents to express their own definitions of what was important about relationships. Indeed, Spencer and Pahl (2006) developed this approach because of a predominance of quantitative approaches used to understand personal communities and networks, which leave under-explored the meaning and significance of relationships (Smart, 2007).

The study was cross-sectional in design, taking a ‘snap-shot’ in time from a range of people. This was combined with the collection of respondent accounts as a means of creating detailed descriptions of particular lives and experiences. The narrated accounts were used to understand aspects of the personal communities constructed. The cross-sectional approach enabled perspectives to be gathered from a diverse range of people with visible facial difference in order to identify personal communities.

4.6.2 Interviews and personal community maps

More than one qualitative method was utilised, as this was seen as useful in addressing questions about social experience and developing understanding of complexities and contexts of everyday life within lived multi-faceted realities (Mason, 2006; Mason and Dale, 2011). This combined approach to data collection (through use of more than one method) and analysis (through use of horizontal analysis and vertical analyses) was used to acquire an understanding of the complexities of personal life and, by extension, personal communities, making connections between spatial and temporal dimensions in biographical, personal and social data (Smart, 2007; Gabb, 2008). Personal relationships were approached in two different ways. First, the creation of personal community maps helped make sense of these relationships, how they combine and how they were placed by the individual in relation to each other. Second, personal accounts were created through interviews in which respondents were asked about these relationships, how they arose and changed over their life-course. The methods chosen and analyses undertaken aimed to identify interplay between these different viewpoints and to develop understanding about how respondents conceived of their personal communities as contributing to experiences of living with visible facial difference. A third perspective was sought from a person close to the original respondent, a friend or family member, to hear their views on how being close to someone living with visible facial difference affected them. Chapter 5 explores in greater detail how these methods were developed and applied.

In summary, visual mapping methods charted respondents patterns of personal communities and semi-structured interviews (incorporating a lifetime line) (Sheridan et al., 2011) explored perspectives of individuals with visible facial differences.

The approach to personal communities developed by Spencer and Pahl (2006) is a form of affective mapping which looks at subjective dimensions of social relationships and how they are positioned in relation to each other. Some commentators have classified this as a social network methodology (Phillipson, 2004). The method has an affinity with the concept of a ‘social network’ because it explores the interplay between many different types of relationships which provide sociability, support, and a sense of belonging. However, in developing their qualitative approach to personal communities, Spencer and Pahl (2006) moved away from a network methodology *per se*. The personal community of Spencer and Pahl (2006) does not just capture one network, but rather a subset of relationships important to the individual. The personal community includes within it parts of other networks which may not be connected, other than through the individual (Pahl and Spencer, 2004). Rather than concentrating on a quantitative assessment of the strengths of ties or network density, the production of the personal community is used as an interview elicitation tool, exploring the meanings and patterns generated. Friend and family relationships were initially explored, non-categorically, from the point of view of the personal significance of specific people, rather than exploring the ideal categories of friend or family. This required an open-ended approach to allow the respondents to determine, in the first instance, those they regarded as important, rather than assuming that either family or friends would have predominance.

Interviews can be seen as producing narrated accounts which approach people’s lives from a subjective point of view. This complemented the mapping technique, which might be seen as having a more ‘structural’ perspective, since relationships are ordered by the respondent according to their own considered degrees of importance. There are diverse understandings of the same phenomenon, rather than one true account.

Personal and social worlds were explored using the respondent’s and the researcher’s understanding in the praxis of interviewing. The understanding of the relationships between the respondent’s account and the social world, and the relationship between the researcher and the respondent are considered, as they are both actively engaged in constructing meaning (Crotty, 1998; Plummer, 2001; Silverman, 2006).

Narrated accounts are regarded as embedded in webs of relationships, and these webs of relationships are explored as they are narrated. The methods provide different insights into an apparently stable phenomenon, such as family or friend relationships, and explore how these are put together and work in everyday life, from the perspectives of some of those involved (Spencer and Pahl, 2006).

4.6.3 Analysis

Interviews are treated as both a resource and a topic, which means as well as the content of the interview, 'the what', *how* the interviewee constructs what they talk about is also incorporated into analysis (Coffey and Atkinson, 1996; Plummer, 2001; Silverman, 2006). Both the 'situated' and 'narrated' aspects of accounts are analysed in order to produce 'plausible accounts of the world' (Silverman, 2006, p.271). As resources narrated accounts are used for the insights they bring to understanding social worlds; that is, by focussing on the content and stories within the accounts. Whereas when looked at as topics, the content is less significant, and how they are produced and the purposes they serve come to the foreground. These purposes include individual identity work within the interview interaction, and more cultural work exploring why such stories are told in the way that they are (Plummer, 2001).

As well as the words spoken, notes have been kept of observations on interactions between interviewee and interviewer, and these are incorporated into the analysis. Some situations and interactions may be emotionally charged. The points of emotional change were used by the researcher as an indication of where care should be taken in use of the particular interview extract. Observations about the feelings of the interviewer, and the noticing of such points as these, may contribute to a better understanding of the challenges involved in addressing facial differences that are not often talked about or are difficult to put into words.

A thematic framework approach was taken to the analysis (Ritchie and Lewis, 2003; Ritchie et al., 2003b, Ritchie et al., 2014). This approach has some commonalities with grounded theory approaches particularly in relation to coding. Of particular note is its ability to work within a constructionist epistemology and its interest in remaining data-near within the interpretivist continuum.

The framework approach, however, maintains a balance between deductive and inductive modes of analysis and thus can be typified as a case-theme method of analysis (Barnard, 2012). The analysis undertaken used both thematic and narrative approaches, as did the way the findings were written up (Riessman, 2008). The methods of analysis are described in Chapter 5.

4.7 Developing the conceptual framework for understanding personal communities

The framework developed for this study used five overlapping concepts to explore personal communities and relationships with people with visible facial difference. Figure 1 below depicts the framework which is explained in this section.

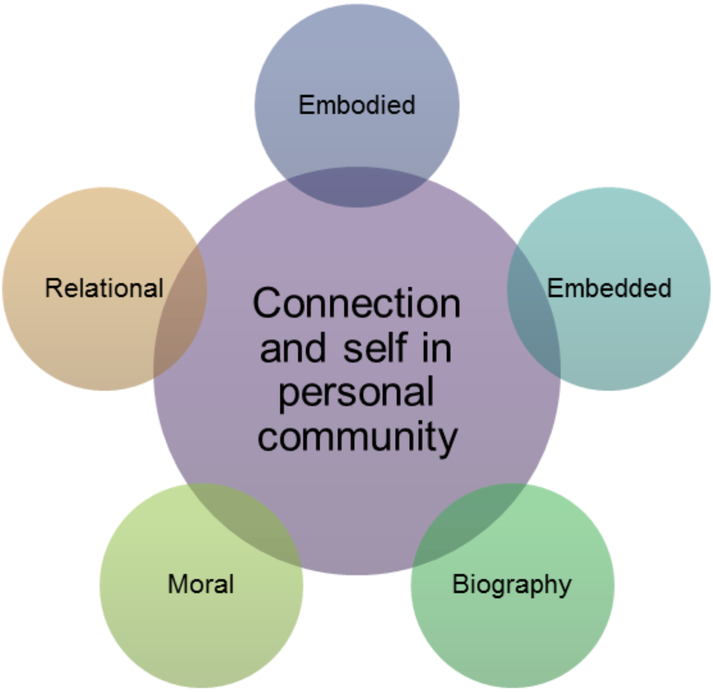


FIGURE 1: OVERLAPPING CORE CONCEPTS

4.7.1 Embodiment

Embodiment is a central component in this exploration of how people with visible facial difference live everyday lives in relational worlds. In intimate settings of relationships with families and friends, a person with visible facial difference is often the only person with visible facial difference. This may also be the case for those who live with genetic conditions.

How a person is treated, regarded, and accepted by families and in other close relationships, will have an impact on adaptation in relation to other types of relationships. All these interactions will affect the composition of personal communities and may also change members' views of embodied difference and how people should be treated by others (Valentine et al., 2014). Bodily existence provides a basic grounding in reality and exists prior to, simultaneously with, and after language in one's understandings (Black, 2011).

Following Burkitt (2003), the view has been taken that language is not the only medium to understand the world. Drawing on the work of the phenomenologist Merleau-Ponty, Burkitt (2003) uses the notion of embodiment to extend ideas of social construction of the self to recognise the mutual existence of the natural body with linguistic and social articulation. Together, they can bring about transformations of cultural and historical reality. Burkitt explains that, for Merleau-Ponty, humans are a part of the 'field of Being'; the perceiving human body belongs to the world. Through sense perceptions we can touch and be touched and, rather than being conceived as a spectator, we are a dimension of the field we are 'in':

> "I do not look at chaos, but at things – so that finally one cannot say if it is the look or if it is the things that command" (Burkitt, 2003, p.328 quoting Merleau-Ponty, 1968, p.133).

The world is full of latent meaning accessed through the senses, which invites interpretation and which needs no rigid separation between subject and object. All human beings and human things (such as social practices and discourses) are part of the 'sense world' and this makes possible belonging to a shared world which is perceived from different perspectives by each person. This type of understanding requires a multi-dimensional world where bodies exist before intersubjectivity between persons, and language develops from the human need to describe and share the world. In this sense, language can be seen as an embodied act. Language does not fully capture human experience, but articulates it alongside other types of understanding, meanings, and symbols gathered, learned, or constructed through history and culture. The implication for this study is that systems of discourse additional to language are seen as relevant data for analysis, such as feelings and in particular sensitivity to feeling of judgements.

4.7.2 Embeddedness

The constitutive nature of relationships and the self highlights the importance of embeddedness (Figure 1) within generational and current family relations. These linkages underline the difficulties involved in separating individuals from their context. The bonds of family occur through longstanding processes of socialisation and shared events over a life course. As Smart (2007) points out, embeddedness is not of itself necessarily a ‘good thing’; it can take many forms, offering multiple qualities from ontological security to stifling and restricting environments. Smart argues that studies of personal life are not just about intimate relationships and private worlds; they have something to say about the everyday worlds in which they are embedded.

4.7.3 Relationality

A commitment to relationality (Figure 1) draws from a recognition of the negotiated nature of family and friend relations (Finch and Mason, 1993). Relationships are conceptualised as developing through a history of interaction and reciprocity. They are not just based on obligation. Relationality uses interactionist ideas combining thought and action, and it contains negative forms as well as loving ones. Smart (2007) delineates two themes in relationality in personal lives. First, social individuals are constituted through their relationships with others and they derive their identity from their location in social relations which are seen as dynamic and unfolding processes (Burkitt, 2014). Second, these significant close ties in personal lives need not be with those related by blood but also include those who ‘occupy the same place in emotional, cultural, locational and personal senses’ (Smart, 2007, p.46). Spencer and Pahl’s (2006) concept of personal community can be viewed using this approach, with its aim of opening up examination of the categories of ‘friend’ and ‘family’ through subjective ideas of commitment and choice. The difficulties with taking this approach are the limitations of methods which capture ‘snap shots’ of processes in time, and it becomes difficult to convey the sense of continuous change. A stance is taken of seeing processes as never-ending but which, through social processes of communication and learning, come to form relatively enduring and recognisable patterns (Burkitt, 2014).

4.7.4 Biography

Biography (Figure 1) emerges as respondents identify and describe their important current relationships. Memories and stories about particular relationships and how these relate to the present give a sense of the shared processes and contexts around the challenges and achievements of living with visible facial difference. Pahl and Spencer's (2004) mapping individual perspectives incorporated a biographical aspect using the idea of a 'social convoy' (Antonucci and Akiyama, 1987). The 'social convoy' refers to the idea that relationships with important others change though social and geographic mobility. Intimate relationships are made and broken and can be explored through interview around how, at significant life transitions, relationships have changed.

Personal communities give a sense of a 'biographical anchor' (Spencer and Pahl, 2006, p. 56). The inclusion of people known since earlier times in the life course provides a sense of continuity and a shared history. They can be people who know you and 'accept you for who you are' or 'as you are', and these continuing presences provide a sense of belonging which appears to hold even when there is little current contact. However, the framework of belonging used by individuals when they map a personal community may not be visible to one's self as it is derived from the individual's biography rather than from membership of a readily identifiable social group or one on the ground. Ideals about family and friends get into people's minds and influence how they think about relationships and patterns of connection on a personal community (Pahl and Spencer, 2004). In narrating accounts about how relationships have contributed to living with visible facial difference, other types of importance are identified, for example being a colleague and being a partner.

4.7.5 Moral dimension

A moral dimension has been included in the conceptual framework. Yang and Kleinman's writing on moral dimensions of stigma within local networks identified that, in stigmatisation 'what matters most' to people is affected (Yang et al., 2006; Kleinman and Hall-Clifford, 2009). Families, friendships and personal relationships can contribute to feelings of social support and connection as well as to feelings of exclusion. In personal communities when people talk about *who* is important to them, they also say something about *what* is important to them.

Through drawing on memory and story what is important in life is identified in relation to the important person. This also connects to valued activities, roles or memberships. This can also be used to see the actor as an active subject in their relationships: they are not simply someone who is supported, they may also support others.

Garland-Thomson's (2009 and 2011) body of work based in critical feminist disability theory identifies that a focus on 'what people want in life' is as important as identifying how others can contribute and how barriers can be shifted. Her work on staring provides a backdrop to understanding the complexity of interaction in relation to embodied difference and the moral significance of how both starers and starees respond in emotional and evaluative situations brought about by staring.

Individuals' personal communities have an ecological and an imagined aspect. A personal community need not be situated in any one particular location. In a sense they are 'communities in the mind' (Spencer and Pahl, 2006, p.45) rather than communities on the ground. There are a range of levels and dimensions which individuals can use to describe their important relationships: biographical, geographical, relatedness, cultural, occupational, and political. Additionally supportive or social contacts and connection may not only be with living people or with other humans (Smuts, 2001). The imagined and the ecological are present at the same time within a personal community. In order to conceptualise how these different ways of constructing a personal community might fit together, the present study draws on Bronfenbrenner's (2005) ecological model (Figure 2).

The personal community of an individual can be situated within the micro-system but may draw from any of these 'systems' depicted below. The multiple systems in the model interact bi-directionally. This conceptualisation moves the focus from individual psychological factors to looking at person-environment interactions which facilitate human development. These changing environments are embedded within wider social contexts which change over time. The time dimension is represented by the chronosystem which includes historic time and biographical life course time.

The model does not imply a reductionist hierarchy of influence of any one of the systems. The value of the approach is that the influence of an individual on their personal community can be looked at, as well as influence from others in a personal community. Ungar (2013) applied this ecological model to resilience; resources that assist positive development can be influenced by many different systematic interactions.

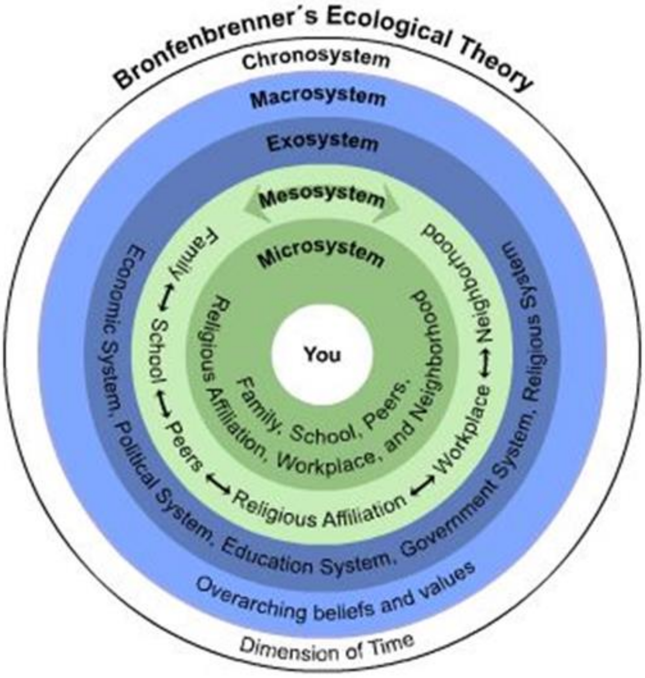


FIGURE 2: BRONFENBRENNER'S MODEL OF HUMAN DEVELOPMENT

(Source: Small et al., 2013)

Protective or promotive factors have different influences in different times and contexts as a result of the perceptions of resources available and the ability the person has to navigate opportunities. These negotiations and navigations are influenced by culture and exhibited as everyday beliefs, practices and values.

4.8 Reflexivity

Interviews are not just the product of the interviewee being asked questions by a neutral interviewer in an information gathering exercise. Interviewing is an active process (Atkinson and Coffey, 2002); it is a situation in which meaning is produced through the processes of interaction. As a result of this there is a need for researchers to be reflexive and attend to how the interview is carried out as well as what it produces (Fontana and Frey, 2005; Silverman, 2006).

The perspectival nature of the research process requires interpretation of the researcher's own participation. Reflexivity about how research is conducted is required of the researcher as part of the process of research design, data collection, analysis and write up (Spencer et al., 2003; Byrne, 2004; Mason, 2002). Following the advice of Plummer (2001) a research journal was kept of reflections on the process of researching this topic. Aspects of self-development work were involved in learning the craft of social research. This also included deliberations about ethical and methodological commitments and how they have been applied and developed during the process of research, and with the respondents. The researcher started out with certain presumptions about what it might be like to live with visible facial difference, about how visible embodied difference might shape social worlds and relationships. These assumptions have directed the reading undertaken and the approach developed in the study. An early reading of the visible facial difference literature identified the phenomenon of 'peer shields', where friends of young people affected by cancer 'protected' their peers in social and educational situations (Larouche and Chin-Peuckert, 2006). However, friendships cannot be appointed; instead relationships develop and change over time in relation to changing circumstances and social locations, and there may be situations in which the making of friends is inhibited. The exploration of friendship by Spencer and Pahl (2006) identified under-recognition of friend relationships as a source of social connection and belonging. Their work provided the researcher with ideas for a methodology which could explore with individuals the meanings of family and friend relationships. Adaptation was not seen as only an individual characteristic or as a set of cognitions about appearance. From here the approach developed a biographical aspect about how social support and friendship arise in the context of everyday relations over time.

These ideas were also informed by reading disability studies literature and were influenced by ideas that have emerged from the social model of understanding disability (Shakespeare, 2006; Thomas, 2007; Garland-Thomson, 2009). The study further developed through connections with people with visible facial difference and in discussion with *Changing Faces*.

A greater understanding was acquired by the researcher of the delicate balance between the needs of addressing political and ethical issues of prejudice and exclusion, and the needs to enable individuals and their families to find ways to live everyday lives in a world where judgements about what facial appearance might mean are commonplace. This questioning and shaping of the study has continued through the processes of interviewing, analysis and writing. Meeting the respondents who volunteered for the study gave an insight into worlds that were both imaginable and unimaginable. These opened up both personal and intellectual challenges to ideas about difference, disability, normality, resilience and diversity. Central ethical issues which arose thereof are discussed in Chapter 5. Kvale and Brinkmann (2009) suggest that a valid qualitative account can contribute to the public discussion about values in society. Through continuing a dialogue with the charities and support groups who supported the development of this study, the researcher aims to make a contribution to an understanding of diversities in the lives of people with visible facial difference.

4.9 Trustworthiness and credibility

Credibility refers to the ‘truth-value’ of a research project (Seale, 2012; Silverman, 2006). The concept of credibility is part of the socially and historically constructed world. Under these conditions credibility and trustworthiness acquire several dimensions with ethical commitments as well as methodological ones. Mason (2002) stresses that researchers need to satisfy themselves and others that their data have not been invented or misrepresented. This type of validation of knowledge is not a separate stage of a study but something that flows throughout the process. While sets of procedures can provide useful ideas about how to maximise credibility, simply following procedural guidelines is not sufficient. This final account of the processes used spells out how the accuracy for the claims made was achieved, provides detail of the methods of data collection and analysis, and how these contribute to the credibility of the interpretations made. This means that methodological choices are to be explained and justified (Chapter 5). They will show that nothing has been taken for granted. The processes and logics developed that have led to the conclusions drawn have been presented.

The study aimed to produce high quality contextual data that may lead to credible interpretation of social situations. While there may be no rules as such to follow, there is methodological craft to be learned (Seale, 1999; Silverman, 2006; Kvale and Brinkmann, 2009). The criteria devised by Lincoln and Guba (1985) about trustworthiness of qualitative research were used to stimulate ways of thinking about how the study could be designed and carried out to improve its quality and ethical credibility. The concept of trustworthiness has four components:

4.9.1 Credibility

Credibility refers to how a researcher carries out their enquiry relates the findings about the multiple realities being studied. In order to enhance the credibility of the findings significant engagement in the field was undertaken, even though the method of enquiry used was interviews. This included undertaking more than one interview, where agreed by respondents, and using the second interview as a means of checking understandings developed in the first. Other ways of learning about the milieu was an engagement, where agreed, with some of the charities involved. This component was carried out before the start of the study in terms of consultation and public engagement, during the study in terms of engaging with people with life experience of visible facial difference and after the study through feeding back to the respondents and charities involved. A detailed account has been provided of the methods used in Chapter 5. Key methodological elements include: piloting of the interview guides; digitally recording and carefully transcribing all the interviews in full by the researcher; using a method of low inference description to build up the interpretations; including extended extracts of data in the findings to show some of the questions asked which provoked the answers given; analysis of all the cases including negative cases and outliers (Silverman, 2006).

An ethical commitment was to ensure the researcher was skilled in qualitative interviewing and analysis through undertaking training. A further strategy employed to enhance credibility of the findings and interpretations was to engage with peers as a ‘critical friend’ and also to take part in a regular Action Learning Set with research student peers. These encounters were used to debrief aspects of the research process including discussion of the basis of the recruitment methods and outcomes, ethical challenges, particular interpretations of data, effects of different styles of writing.

4.9.2 Transferability

Transferability refers to the extent the findings can be found in other settings by other researchers. Lincoln and Guba (1985) identify that the transferability of a study is difficult for the researcher to establish as they cannot know the contexts in which it might be re-applied. The researcher therefore needs to provide enough descriptive information about the study in order to enhance the possibility of future transferability. In order to achieve this, detailed descriptions of recruitment, sample and findings have been provided. (An important ethical commitment adopted was to confidentiality and privacy and these have influenced the extent to which personal information about recruitment and the respondents have been reported). In addition, the theoretical background of the study and a systematic, integrative review of the relevant literature have been employed in order to inform the reader about how and where the research study was intellectually situated (Chapters 2 and 3).

Lewis et al. (2014) extend the discussion of transferability to a consideration of the different types of generalisation that can be made by a study. It may be argued that the study does reveal some of the diversity of patterns of relationships in the personal communities constructed; the diversities and ranges of views are likely to be found in a wider population of people with visible facial difference and therefore this study may have some symbolic representational value. While the sampling strategy endeavoured to achieve diversity, there were significant restrictions in achieving this as it was a volunteer sample mainly recruited online through advertisements.

4.9.3. Dependability

Dependability refers to establishing the merit of the research methods and their relationship to the findings. To these ends, an audit trail process was used; a record was kept of all communications and processes and tracked using an Excel spreadsheet; notes were kept about the interviews and throughout the transcribing and analysis processes. The interviews were transcribed accurately and in full. A ‘critical friend’ was asked to provide feedback on how the quality of a sample of transcriptions was achieved, and patterns of error were rectified across the transcriptions. The whole data set was analysed and an account of the research process and data analysis decisions are provided in Chapter 5.

4.9.4. Confirmability

Confirmability refers to the ways in which personal values or theoretical perspectives of the researcher are interwoven and separable from the research and its findings. The use of low inference descriptive techniques described above and analysis of outlier cases rather than anecdotalism were also used to assist in this process (Silverman, 2006). Records were kept of all the research processes including those associated with data coding; matrices used in data synthesis and narrative summaries of each case. The researcher critically examined her role and how this may have influenced data collection; this was recorded in a reflexive journal.

4.10 Summary

This chapter has examined the study’s methodological commitments and how these influenced the practice of research. The next chapter goes into detail about the methods used and how they developed during the course of the study.

Chapter 5: Design and methods

5.1 Introduction

This chapter describes the study design, including negotiation of research relationships, recruitment of respondents, methods of data collection and processes of data analysis. The purpose of this chapter is to provide sufficient detail of the methods used to enable assessment of the trustworthiness and credibility of the findings. The interactive model of qualitative research design (Maxwell, 2013) has been used to reflect the iterative nature of the processes involved. This chapter describes how methods were developed to address the research questions outlined in Chapter 1, based on the theoretical perspectives discussed in Chapter 2, the literature reviewed in Chapter 3 and guided by the methodological and philosophical issues discussed in Chapter 4.

The study used qualitative methods to explore the perspectives of adults with visible facial difference. The combination of semi-structured interviews with creation of personal community maps provided the opportunity to explore the interplay between respondent accounts and the pattern of relationships in which people are embedded. On-going methodological reflection was employed to address ethical, or practical issues as they arose, and to enhance the process of learning the craft of qualitative research and interviewing (Brinkmann and Kvale, 2015). Insights from these reflective processes are incorporated throughout this chapter.

5.2 Negotiating research relationships

The importance of developing ethically informed relationships with respondents was clear from the start. Preparatory work was undertaken to develop an ethical approach, and to establish relationships with organisations, and people who live with visible facial difference. Links were developed with a small group of key informants local to the University of Bradford, who had personal or professional experience of visible facial difference and an interest in research design. They were able to provide advice on areas to explore, suitability of materials and questions, and insight into preferences about the terminology of visible facial difference. Relationships were developed with *Changing Faces*, who supported the study in principle, provided expertise and commented on the study design, publicity and other materials developed.

Contacts were developed with other charities and support groups who were interested in the aims of the study and were prepared to offer space on their website to publicise the study. A commitment was made to feedback findings from the study to the organisations, who were interested in, and facilitated, the study, as well as to the respondents (Appendix 28: Research summary).

The study was shaped by recognition that, broadly, within health research, the perspectives of adults with visible facial difference risk being ‘seldom heard’ (Beadle-Brown et al., 2012). Concerns about well-being in everyday life can become submerged under pressing medical and psychological issues, which focus on recovery. However, in lived realities, boundaries between what constitutes the ‘health world’ and ‘social world’ are porous. An issue explored with informants was the perception of a ‘gap’ between medical and social realities. The ongoing and changing nature of learning to live with difference was perceived by respondents as rarely addressed within the medical setting. Living with visible facial difference can affect individuals and their interactions with others for many years after initial diagnosis or treatment, with support often coming from informal sources such as family and friends. The complexity the person with visible facial difference must reconcile in belonging and relating ‘normally’ within different relationships and contexts, does not fit readily with contexts focussed on treatment outcomes. These discussions initiated an interest in the parts played by personal relationships within these social spaces, where health and social worlds have overlapped and effects remain in the form of visible facial difference.

5.2.1 An ethical approach

Following professionally and institutionally recognised ethical procedures was important, and approval for the study was obtained from the University of Bradford (Appendix 15). This account describes both procedural approaches developed before the field work stage started and reflections on how these were experienced during key times as the study progressed. Ethical issues and practice were considered throughout the course of the study. In developing an ethical approach, it was important to consider whether the topics were of a sensitive nature and if there was potential for vulnerability in the sample.

Discussions with informants indicated that the topic of personal relationships and support was important. The study was designed in order to create a respectful research environment, which was mindful of potential vulnerabilities. However, it was not assumed that vulnerability was necessarily a feature of the experience of living with visible facial difference. The sensitive nature of views about facial appearance and their moral significance was explored in the public engagement event described below.

5.2.2 Public engagement event

In order to explore some of the public views about visible facial difference, a public engagement event was arranged in July 2012 at the Sheffield Children's Festival. This involved thirty-nine children and their parents or carers, and other members of the public. Participants in the event were asked to choose a name for a *Changing Faces* teddy bear, which has asymmetrical colouring on its face.

FIGURE 3: PHOTOGRAPH OF *CHANGING FACES* TEDDY BEAR

Typically the names chosen had pleasant associations; some children named the bear after a friend, or a quality of its fur or its bear nature, something they liked, and some were drawn to the asymmetrical markings. Examples of the names were: Ruby, Fluffy, Paws, Bubble-gum, Pink Splodge, and Funny. During this activity, the parent or carer interacted with the child prompting or negotiating a name, and sometimes querying the child's first choice of name. The adults were aware of the moral context of the game and some used this as an opportunity to talk with their child about the significance of naming, and the extent to which it is acceptable to use physical attributes in this process. The naming of a cuddly bear was taken seriously, aroused social sensitivity, and prompted some parents or carers to explore moral issues about naming and appearance with their children.

5.2.3 Reflexivity

The development of ethical practice is part of the craft of research and involves reflexivity. Gabb (2010) points out that contemporary family and personal world research draws on a feminist ethic of care, which connects the researcher to the construction of knowledge. It places a responsibility on the researcher to act with integrity above and beyond adopting the necessary procedural ethical approach required by ethics committees. Ali and Kelly (2012) define reflexivity as the ability to reflect on experience and use the learning derived during the research process, from initial conception, to research conduct, through to dissemination. Part of the purpose of researcher reflexivity is to ensure non-harmful practices and an awareness of the relationship between researcher and respondent (Kvale and Brinkmann, 2009). The process of reflexivity serves to address ethical dilemmas as they arise, promoting understanding of the effects of researcher values and constructions on the interview process. The practice of keeping a research journal to capture these processes and observations, relevant to methodological decisions, has been incorporated in this chapter.

In order to understand better the emotional and evaluative processes involved in mapping a personal community, the researcher constructed her own personal community before carrying out the pilot interviews. This heightened her awareness of the close connections between important relationships, the roles she valued, and how she viewed herself as a person.

The ‘snap shot’ nature of the pattern produced was evident; completing this activity at other times would have produced different patterns of relationship in the personal community. The personal community assembled was a crafted product, which sought to reflect the current ‘reality’ of relationships with others. It brought to the surface thoughts about whether this was the ‘truth’, or perhaps a reflection of ideas, or imaginings, about what an ideal personal community would look like. Reflecting on the activity highlighted a potential for judgement about to what extent having particular types of friendships was a sign of social inclusion and social capital. This activity highlighted the possibility of making assumptions about whether experiences of friendship or close relationships with another are beneficial, or indeed something that everyone will necessarily have. It highlighted the importance of grounding the study in the perspective of the respondent, as making a personal community map might open up narratives of worlds very different to those experienced by the researcher (Cooper and Burnett, 2006).

5.2.4 Informed consent

In order to minimise risk of harm to respondents, the study used informed consent procedures. These require that respondents are informed about the purpose of the study and what taking part in the study will involve. The process aims to address issues of confidentiality and anonymity and give potential respondents an opportunity to ask questions about the study. The respondent has a right to withdraw from the study at any time, without giving reason. In this study, the process started at first contact with a potential respondent. It involved sending formal information to the respondent about the study. The researcher was available to answer questions over the phone and by email. If the initial expression of interest became a desire to volunteer to join the study, then a meeting was arranged and consent forms were sent for information. At the first meeting, the study was discussed further and the consent forms completed and signed. Appendices 16, 17, 18, 19 and 20 provide details of the letter to respondents, examples of the information sheets, consent forms and the procedure developed to obtain informed consent.

The process and meaning of informed consent is not a simple, unproblematic procedure. It is not possible to know in advance exactly how an interview study might proceed. Questions about outcomes were difficult to answer in a study with an exploratory element and this researcher chose to be open about this to respondents. Consent and desire to remain in the study was checked with respondents at second interview, and when materials developed in the interviews were sent to them.

5.2.5 Confidentiality, anonymity and privacy

Gabb introduces a concept of ‘responsible knowing’ (Gabb, 2010, p462). This requires commitment to ethically advancing understanding of meaning of inequalities rather than suppressing the nature of dangers that lie in unequal social worlds (Back, 2007). One of the tensions involved was how to respect the respondent’s account, balance a risk of revealing their identities with a risk of obscuring uncomfortable ‘truths’ which they might tell. This tension was present throughout the process of data collection, analysis and write up.

The interviews explored issues that might contain sensitivities, namely, the issue of exploring feelings about living with visible facial difference in the context of feelings about relationships with family members and friends. Although the primary purpose of the interviews was not to explore events surrounding acquisition or diagnosis, it was likely these would come into the interview. Respondents were likely to be concerned about the confidentiality of their personal data and the content of their interviews. They were assured that any requests not to write something down, or to omit using a quote, would be respected. Personal data and interview materials were stored securely according to the policy and procedures of the University of Bradford. Care was taken to protect respondent identities and data collected through anonymisation. Pseudonyms were used for file labels, the interview transcripts and extracts of the interviews used in the thesis. Reporting of qualitative research involves verbatim quotes and therefore identifying names and place names were taken out. Aspects of personal profiles were disguised in terms of respondent’s name and age. The type of visible facial difference included in respondent profiles was at a generalised level of description (Appendix 1: Key to respondents).

Furthermore, details such as place names, names of other people and companies were removed from interview extracts and pets' names were changed.

It was important to be careful in protecting respondents' privacy, as the study potentially involved talking to people who knew each other. The consent form and related information highlighted this risk and particular care was taken when interviewing people from the same social circle. It was possible that respondents might tell the researcher something they did not want their friend or family member, also involved in the study, to know and a clear line was taken that information provided by a respondent was not to be disclosed to another respondent.

Gabb (2010) teases out additional issues that arise when case studies are used in addition to a cross-sectional thematic analysis. She identifies that:

> '…it is relatively easy to ensure the family's anonymity is protected. It was much harder to prevent close intimates and family members from gleaning this mother's identity from the analytic portrait I presented and in doing so find out previously 'private' information' (Gabb, 2010, p.468).

In these circumstances, care was taken in selection of narrative material to balance maintaining the integrity of the research, with the trust involved in the researcher/interviewee relationship.

5.2.6 Potential for distress

There was a risk that respondents might become distressed in the process of talking about past or present relationships. It was important to consider whether this could be a source of harm to respondents and to ensure the researcher was prepared and skilled enough to deal with such possibilities. Gabb (2010) problematises the conflation of distress and harm in qualitative social science studies, arguing that distress is not necessarily harmful. Sometimes people want to talk about issues that arouse emotions. Emotional responses are present in interactional situations, and interviews are a particular type of interaction. This position highlights the constant need to consider this balance between these issues in presentation of findings. In relation to the interview situation, sensitive ethical practice is required. The researcher needed to prepare for the possibilities of responding empathically to upset.

The process did not seek to silence distress. This included undertaking training in interview skills and developing a practice of de-briefing in the research journal (Corbin and Morse, 2003). Selection of interview settings, in negotiation with the potential respondent was undertaken in order to locate a place where they would feel comfortable. These issues signalled the importance of establishing a respectful co-relationship between respondent and interviewer in the interview practice.

A process was developed to use in the event of a respondent becoming upset (Legard, 2003). Fundamentally, this was about the interviewer listening to the respondent, being responsive and guided by them. Some people might want to continue talking about a subject, whilst others might want a break or to change the subject. The interviewer had to consider whether too much was being asked of the respondent. If a respondent’s eyes became wet, the interviewer would pause and wait. At these points, the focus of the interaction changed in response to the presence of sad emotions and enquiry took second place. The interviewer would ask if they would like a break, and if so switch the recorder off. The decision to take a tea break was made within one interview. Following the break, the respondent wanted to carry on with the interview, feeling their upset came from reflection about matters they were already aware of and they wanted to continue to tell their story. During the process of listening to the recordings, other moments of emotional change were noted and used to guide sensitive selection of quotes in the thesis.

An additional element of the process was to create a leaflet for each respondent, which provided information about local and national external support agencies and details of how to contact them and the researcher (Appendix 21).

5.2.7 De-briefing for respondents

As well as building a respectful relationship before and during the process of interviewing, attention was paid to how each interview ended. Interviewing respondents about relationships was tiring and, at times, emotionally stirring for both parties. An interview relationship is one-sided, however sensitively the interview has been conducted. At the end of an interview there may be tensions, as the respondent will have talked about personal and emotional experiences and will have given a great deal of information.

Kvale and Brinkmann (2009) advocate minimising these tensions and suggest providing an opportunity for their expression. The end of each interview was signalled and rounded off by asking the respondent if they had anything else to say after which the recorder was turned off. The interview was followed by de-briefing to reflect on and summarise the interview. The interviews were detailed and patterns in the personal community would not be apparent until after analysis had taken place. The practice of summarising the content of the interview was hard to maintain and often becoming more of a conversation about parts of the interview, rather than a summary. Some respondents used the space to ask about the interviewer's personal experience and these were often in relation to being in a family, being a student, and experience of disability and ageing. These were questions that followed on from processes within the interview interaction. Talking about these gave the respondent greater understanding of the researcher's perspective and motivations in the research relationship and process.

5.3 Selection of respondents

This study sought to recruit adults who self-identified as living with visible facial difference, either from birth, or acquired later in life. Adulthood was defined as aged 18 years or over. A guideline of minimum time period of one year after treatment was put in place in order to encourage interest in exploring longer term experiences of difference. In recognition of the potentially sensitive nature of the topic, volunteers were asked to consider their willingness to talk about support from personal relationships, in relation to visible facial difference. The selection strategy sought a diverse range of respondents within the two broad categories of born with and acquired visible facial difference. A broad sample was sought to include men and women, of differing age, race and ethnicity (Spencer and Pahl, 2006; Ziebland and McPherson, 2006).

The challenge was to gain access to such a dispersed group of people within the general population, who are not identifiable through their use of medical services. The literature review (Chapter 3) revealed little epidemiology of prevalence of visible facial difference. Even within specific medical conditions, information about the incidence of altered and visible facial appearance was scant. Therefore it would be hard to build a sampling frame formed from an evidence base.

The importance of subjective assessment of the visibility of facial difference indicated the value of pursuing a strategy based on self-definition. The use of a voluntary, self-selecting sample of people attracted to the study was regarded as appropriate, given the exploratory nature of, and the potential for sensitivity within, the topic area. Whilst the intention was to seek as much diversity as possible in the recruited sample, the strategy was best described as convenience sampling (Weiss, 1994).

A range of means were employed to increase the size and diversity of the sample (Weiss, 1994). Snowball sampling was used, as some of the respondents suggested people they knew who might be interested in taking part. These people could then, if they were interested, make first contact with the researcher to find out more about the study (Seale, 2012). A number of charities and support groups were approached to see if they would be agreeable to advertising the study on their websites. Those who agreed were *BLESMA*, *Changing Faces*, *Cleft Lip and Palate Association*, *DEBRA*, *Let's Face It*, *Mobius Research Trust, Paddington Survivors Group*, and *Treacher Collins Family Support Group*. These charities and groups are involved in campaigning, fundraising and providing support services. Appendix 22 provides an example of the online advertisement used.

5.3.1 Recruiting a friend or family member

The study aimed to recruit a friend or family member of the volunteer respondents. This element was optional and reliant on the respondent wishing to invite someone they knew to also volunteer. This element was introduced at the start of the study, and discussion about whether or not they wanted a friend or family member to join the study was carried out after the second interview. The reason for this design was that it was felt that only a few people would wish to take up this option, because of the greater intrusion that might result.

5.3.2 Sample size

The number of required respondents was not set in advance. There are few guidelines for determining non-probabilistic sample sizes and the samples are usually quite small. Ritchie et al. (2003a) indicate that samples in qualitative studies are usually fewer than 50 for single individual interviews.

The rationale was to have a large enough sample to gain a picture of the diversity of patterns of personal communities, balanced against a realistic sample size for recruitment of a geographically dispersed group. As the intention was to interview each respondent twice, it was judged that between 12-20 respondents living with visible facial difference would be sufficient to carry out the different elements of the method and analysis. The maximum sample size planned was 40 respondents (up to 20 people living with visible facial difference and up to one friend or relative each). The maximum number of interviews planned to be carried out was therefore 60, comprising of two interviews with 20 people living with visible facial difference, and 20 of their friends or relatives. A time period of eleven months was set for the process of recruitment, in order to achieve these numbers. No geographical boundaries were set on recruitment, as it was felt that potential respondents would be dispersed across the UK.

5.3.3 The respondents

The dispersed nature of the population required significant travel throughout England and Scotland, from the University of Bradford, to meet with respondents at a place convenient to them. It was found to be logistically difficult, within resources, to travel to a distant town on three separate occasions to complete the three interviews separately, as some of the interview locations required an overnight stay. Through email or telephone negotiation with potential volunteers, the researcher devised a method of carrying out the two interviews on consecutive days in instances where interviewees were based at a location over 3.5 hours rail journey from the University of Bradford.

This process was further complicated by the optional interview with a friend or family member. It had been envisaged that discussion about recruiting a friend or family member would happen after the second interview. However, for long distance locations it proved unfeasible to be at the location long enough after the second interview to allow consent and contact of the friend or family member to take place. For this reason, this aspect of the study was curtailed in January 2013. In the final sample, two respondents were recruited who were friends or family members, and among those with visible facial difference, three people had family members who were also affected, but were not respondents. Nineteen respondents were recruited.

Table 1: Socio-demographic profile of sample

Socio-demographic profiles	Total = 17 respondents (plus 2 respondent friend/family members)	
Gender	Women	7
	Men	10
Age	20s and 30s	4
	40s and 50s	10
	60s and 70s	3
Educational qualification	Other qualifications (trade, GCSE, ‘A’ level, professional)	8
	Degree or higher	8
	Not known	1
Occupation	Employed or self employed	11
	Retired	3
	Not working	3
Ethnicity	White UK	16
	Not disclosed	1
Current relationship	Single	4
	Cohabiting with partner or married	11
	Divorced or widowed	2
Household	Lives on own	5
	Lives with partner/spouse &/or children	12
Geographical mobility	Largely stayed in same area	4
	Moved as child and/or adult	13
	Not disclosed	1
Visible facial difference	Acquired through injury, illness, surgery	8
	From birth	9
Range of linked causes of visible facial difference	Burn	4
	Cerebral palsy	1
	Cleft lip and/or palate	3
	Eczema	1
	Haemangioma	1
	Head and neck cancer	1
	Moebius syndrome	2
	Skin cancer	2
	Treacher Collins syndrome	2
Not affected family member or friend		2

This recruitment and advertising strategy had an advantage of attracting people living in the community, rather than attached to a medical service. The self-selecting nature meant that very little was known about each respondent prior to then joining the study. The use of this selection strategy meant that the final sample was biased by the accessibility and willingness of the respondents. There was limited ethnic diversity within the final sample. The majority of volunteers were recruited through charity networks and this sample profile may be indicative of the reach of the organisations concerned. The structure of the sample through the network of activist and support organisations may have favoured those who are living more confidently with visible difference, and this connection might limit the extent to which findings might be relevant to people who have no contact with such organisations.

5.4 Data collection materials and processes

5.4.1 Choice of methods

A visual method to map a personal community was combined with a semi-structured interview. Interviews were shaped partly to reflect the themes identified in Spencer and Pahl’s (2006) study, and partly to capture living with visible facial difference in relation to a personal community. The decision to carry out two interviews with each respondent was seen as having several benefits: completing a personal community map was found in the piloting stage to be a lengthy process and one with which people were unfamiliar. It was considered overly demanding to ask respondents to carry out the whole process within one interview. Two interviews allowed greater opportunity for the respondent to have an input into the pace of the interview and depth of disclosure, and to make an informed decision about whether or not to invite the inclusion of a friend or family member.

Other types of interview method were considered but not chosen. These were: telephone interviews, interviews using electronic media, or focus groups. Face-to-face interviews were favoured, because the mapping of a personal community is both a physical and visual task, involving moving bits of paper around on a series of concentric circles. This could not be achieved over the telephone or electronic media. In addition, interviewing using electronic media were ruled out because software has not been developed which could capture personal communities electronically.

Focus groups were not chosen, partly because of the practical difficulties involved in recruiting respondents who were likely to be scattered geographically. It was also felt this would not be a suitable method to collect personal community information, as the strength of the method lies in its ability to generate interactional data about how social and cultural meanings, knowledge and opinions, are produced (Tonkiss, 2012). Participant observation was not chosen because personal communities are to some extent ‘communities-in- the-mind’ (Pahl and Spencer, 2004) and not necessarily place-based, although they may contain both types of features. The relative isolation of people living with visible facial difference excluded this design option.

5.4.2 Pilot interviews

The purpose of the pilot interviews was to become more familiar with how the method generated personal communities in an interview context, and the ease of use of personal community mapping tools for respondents. The pilot interviews were used as an opportunity to try out the topic guides, check out how pilot volunteers understood or responded to the questions, and to make modifications in the light of experience. Four pilot interviews were carried out, two with volunteers from the researcher’s personal networks, and two with a health professional with experience of disfigurement, together with their friend. The process of incorporating life course information into the interviews was piloted with another volunteer from the researcher’s personal network. It was found that completing a personal community map was a lengthy process which could take up to two hours. The technique was effective in producing personal community maps however, and pilot volunteers were able to understand and follow the process. The pilots were a valuable way of practising interviewing using the planned questions. Different sizes of blank personal community maps and labels were piloted. It was found that respondents needed quite a lot of space to write down the descriptions of their relationships and sometimes wanted to be able to move them around, to different parts of the diagrams. The combination found most satisfactory was drawing a blank diagram on A1 size paper, with post-it notes for the labels (Figure 4).

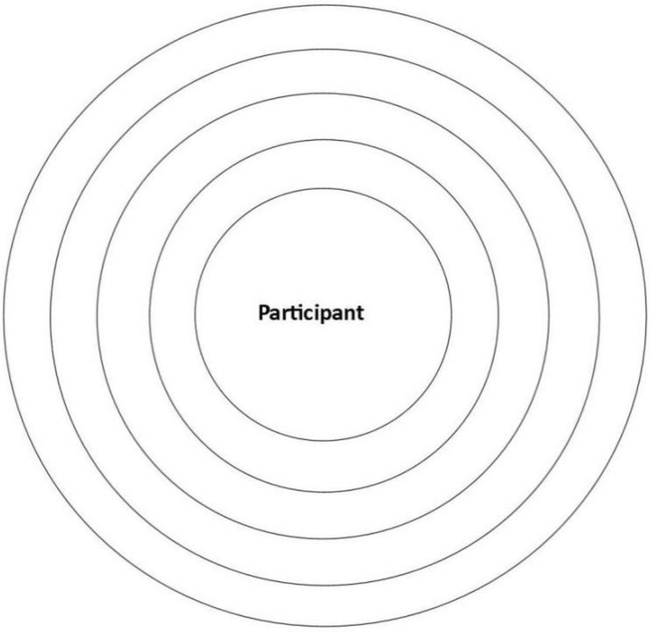


FIGURE 4: BLANK PERSONAL COMMUNITY MAP

5.4.3 Processes of interviewing

The methods designed by Spencer and Pahl (2006) were adapted for this study in the following ways. First, two interviews were carried out rather than one. Spencer and Pahl's (2006) design had asked respondents to carry out preparatory work prior to the interview, by identifying people who were important and completing a questionnaire about their personal history. The University of Bradford Ethics committee did not approve this design, preferring instead that identification of important relationships should take place within the interview. As the pilot interviews indicated that creating a personal community map required up to two hours, it was decided to carry out more than one interview with each respondent, so that the pattern could also be discussed. Life course information was collected in a 'life-time line' rather than a questionnaire (Sheridan et al., 2011). This diagram captured when important current relationships came into a life course and was used as an elicitation method in the second interview. This method was developed through the process of piloting. A further adaptation was that the topic guides reflected the study's focus on visible facial difference. The ordering of the interviews was also influenced by the Ethics Committee's concern with respondent attrition and the burden of multiple interviews. Therefore, as the primary focus of the study was to generate personal communities, this was situated in the first interview rather than the second.

Fourteen respondents with visible facial difference were able to attend two interviews, while three respondents preferred one interview. The process of interviewing did not always follow the order described above. The second respondent felt that it would be more helpful to the researcher to know about their experience of visible facial difference first and then explore their current personal community. They wanted to tell their story first. They felt there was a relationship between their experience of visible facial difference and their patterns of relationships. This was indication of linkage between views of normality, visible facial difference and personal community patterns. The interview process was modified in the light of negotiations with respondents about preferences for attending one or two interviews and the extent to which they expanded upon the initial question about their account of living with visible facial difference. Over the course of the process of interviewing, the following pattern developed: in the first interview, accounts of living with visible facial difference and mapping of the personal community onto paper was started, and in the second interview this process was completed and the relationships within it were discussed in greater detail.

5.4.3.1 Interviews with respondents with visible facial difference

Development of the topic guides was influenced by discussions with informants described in Section 5.2, piloting the interview schedules and Spencer and Pahl's body of work. Another source used for development of the questions, and for guidance, was the Social Capital Module of the 2000/1 General Household Panel Survey (Coulthard et al., 2001; Harper and Kelly, 2003). The topic guides for the first and second interview with respondents can be found in Appendix 23 and for family or friends in Appendix 24.

Eighteen of the interviews were conducted with a single respondent as envisaged in the design. However, one of interviewees was joined by this partner who contributed to the discussion about his personal community. The change to plan was accommodated within the consent process. His partner assisted him in the interview but they were clear it was his personal community rather than one shared by the couple.

Respondents were asked about their experience of living with visible facial difference. This was followed by the main personal community question: “Who is important to you now?” They were asked to identify people who were important to them now and then to arrange the names on a map. The names were arranged in order of importance in a series of concentric circles, with the respondent situated in the centre (Figure 4). Respondents were given 20 post-it notes and invited to write on them the names of important ties, their age, and occupation, how relationships are described, and how they met. They were not expected to use all of the post-it notes or be limited by that number.

The interviews explored how the idea of importance was interpreted and the basis for including particular relationships. The term ‘now’ provided a time frame, and allowed respondents to make comparisons between relationships by focussing on current circumstances. The topic guide was used flexibly. The interview covered the following areas:

Generating personal community members: respondents were asked how they interpreted the phrase ‘important to you now’ - the criteria they used in deciding whom to include.

Comparing importance: respondents were asked to compare the people they had identified and place them in order of importance on the map. They were encouraged to use as many rings as they wished and to talk through their basis of allocation.

Comparing relationships: differences between relationships in the various circles were explored, whether there were different types of friendship, how relationships with friends compared to those with family or partner, and to whom they would turn in a range of situations.

Describing quality and content: key relationships were explored in greater depth. Respondents were asked how long they had known the person, how the relationship had developed, how frequently they had contact and the basis of the interaction, and about changes over time within the relationship.

Checking recognition of personal communities: reflections on their map and how well it represented their personal social world

With those who selected to attend one interview, the focus was on capturing and talking about the personal community within one interview, and these lasted for longer than one hour.

The second interview was shaped by the first interview and explored the meaning of the relationships chosen and how these relationships had developed over life-course time of living with visible facial difference. The second interview provided an opportunity to add detail to the initial map, discuss meanings of the relationships involved and explore how these had developed over time. Additions or other changes could be made. In between the two interviews, the researcher plotted the personal community relationships onto a lifetime line (Sheridan et al., 2011). She listened to the interview and charted the relationships from the personal community onto a lifetime line. The length of time that respondents had known the people on their personal community was mapped against a life-line ranging from birth, or from when their narrative of living with visible facial difference started, to current age (Figure 5 below). This was then used as a method of elicitation in the second interview. It also served as a means of allowing the respondent to check the researcher’s interpretation of key relationships on the map. The lifetime line was hand drawn in pencil and given to the respondent to draw on, alter or add to during the second interview.

0-10	*11-20*	*21-30*	*31-40*	*41-50*	*51-60*	*61 plus*

Figure 5: Blank life-time line diagram

This second interview focussed on meanings of the personal communities in relation to experiences of living with visible facial difference. It had the personal community map and the lifetime line as resources. The areas explored in this interview were:

Accounts of challenges and successes in living with visible facial difference: respondents were asked about earlier or other contexts of their lives, for example, school, college, job changes, having children.

Support: role of members of the personal community in providing different kinds of support and checking out whether the respondent felt supported.

5.4.3.2 Interviews with friends and family members

This element of the study was curtailed (Section 5.3.3) however, two friends or family members were recruited. The purpose of these interviews was to explore how being close to someone with visible facial difference affects that person. The nomination was made after the second interview with the respondent, who agreed in principle and then approached their family member or friend to see if they were interested. These interviews were carried out in a place of the family member or friend’s choosing.

The notion that awareness of appearance differences may change at different points or events was explored. For example, does appearance become irrelevant once a relationship is established? What kind of situations may bring perception of difference to the foreground again? These interviews explored changes over time, responses of others from within their personal worlds or from outside it, and how the friend or family member would deal with these, should they occur.

5.4.3.3 Presence of the researcher in the interviews

This section reflects on the presence of the researcher in the research process, from interview through to analysis. There are asymmetries to power relations in interviews (Brinkman and Kvale, 2015). The researcher sought to emphasise that the respondent was the expert with their knowledge and with ownership of their information. She sought to support the respondent’s position through choice of interview location, how the researcher presented herself and her openness to being asked questions.

The interviews were between a person, who did not describe herself as living with visible facial difference, and respondents who did. There are pervasive social norms that shape behaviour in this area (Garland-Thomson, 2009). It is a sensitive matter referring to another’s facial appearance, and how or whether this is done is context and relationship dependent. (Some of these norms were on display in the interactions between parent and child over naming the *Changing Faces* teddy bear (Section 5.2.2).)

Prior to meeting for the first time, there had been contact via email, sometimes telephone, but rarely face-to-face contact. The first interview was a meeting of two strangers. Both respondent and researcher found strategies to build safety into meeting a stranger. The first was about increasing knowledge about who was being met. Information was provided for respondents about who they were meeting and the nature of the study. There was a searchable page on the University of Bradford website which contained information about the researcher, so her identity and the authenticity of the study could be checked. Some respondents also provided similar information about themselves, so there was fore-knowledge about their work, websites, books, policy work, charitable work or film work. These pre-interview moves by respondents increased researcher understanding that while some respondents might be ‘seldom heard’ within a health research context, they were prominent actors in other contexts.

The location of the interview was another consideration. The interviews were carried out at several locations over the UK. The type of location was chosen by the respondent and the exact setting negotiated before the first meeting. The researcher was concerned, at the design stage, that public areas such as cafes might not provide sufficient privacy for the respondent and was surprised that so many respondents had this preference. Five respondents came to University of Bradford interview rooms; four respondents invited the interviewer into their home and eleven respondents suggested meeting in quiet or private areas in public places such as workplaces, cafés known to respondents, private areas with in the public parts of the hotel where the researcher was staying, and so on. The decision was based on a combination of criteria, such as convenience to the respondent during a busy working day, and feeling comfortable because they were known there. During the pilot interviews one of the respondents, who was also a personal contact of the researcher, offered their home as a potential interview location. However, they felt that if the researcher had not been known to them they might have chosen a more public environment. The choice of a public location put the interviews on a semi-professional, semi-public footing and gave the respondent more control about how much of their lives was brought into the view of the researcher.

It was considered how two people who did not know each other would identify each other. Several ways of dealing with this issue were employed, such as letting people know one of her identifiable visible features, sometimes what she was wearing, and sometimes her age, hair colour, type of spectacles. Another strategy was to let respondents know where the researcher would be precisely situated at the appointed time and location. The strategy of identification by issues such as age and hair colour made the researcher more conscious of what it might be like to be recognised by a visible feature. One respondent pointed to the irony of her meeting someone who could use her visible difference as a means of identifying her, as this was a means of identification she would not normally use or encourage. It is probable that by exchanging visible identifiers the process was felt more consciously by the researcher. Hovering near the entrance of the meeting place looking expectantly at everyone who went past seemed to work as no-one else was behaving in such a fashion. Once the first meeting was negotiated, a place suitable for the respondents was found in which to talk privately.

The opening moments of the meetings were taken up in discussion about the study and checking out further the researcher’s credentials and motivations. Some people had conducted online searches prior to the interview, others came to the interview with a friend, partner or colleague, who left when it was agreed to go ahead with the interview. While everyone came to the interview to discuss topics related to ‘visible facial difference’, preferences in language use were explored, as there are many meanings for each of the words in the phrase. For some ‘visible’ may not be ‘visible’ anymore, but rather related to their history of dealing with facial change; ‘different’ might mean ‘deviant’ for some and for others ‘diverse’; and ‘facial’ might be used to refer to any part or organ on the head, face or neck.

Empathy risks reducing differentness to sameness (Lincoln, 2010) and rapport require a moral honesty. In relation to the interviews, the researcher was open to questions about herself, her stance, and her experience of disability (Oakley, 1981). These conversations were encouraged, by the researcher, to take place outside of the interview and were often picked up at the end of interviews by the respondent.

Most respondents did not ask the researcher questions during the interviews. However, when they were answered briefly, rather than leading into a conversation about the researcher. Most of the respondents met with the researcher on more than one occasion. The second interviews differed from the first as they were developing a conversation about personal communities and their value rather than starting afresh.

Within the researcher’s reflexive diary, the role of the researcher co-creating the content of the interviews was explored. The researcher noticed her signs of discomfort and reflected on how these signalled the kind of identity and emotional work she was carrying out in the interviews. This included tensions between being: a student and an academic, a psychologist and a sociologist, a person new to the area of visible facial difference and someone who could meaningfully co-create knowledge about others’ experience, a person with family experience of disability, but not direct experience. Some of these tensions would come directly into conversation when respondents asked the researcher questions, but others had a less conscious, more embodied, presence. Different identities of the researcher were felt more fully in the relation to different respondents. These were numerous such as being a woman in relation to both women and men in the study, someone older than some respondents, younger than others, someone who did not share an occupational background with any of the respondents, someone who was a mother, and as someone who did not describe herself as having a visible facial difference.

Prior to starting the study the researcher had presumed there would be an awkwardness at times in relation to differences in facial appearance, having read other researcher encounters, such as Cole (2001). However, it was the researcher’s other identities which were more often gave rise to assumptions based on similarities or differences in age, education, being a parent or gender; and noticing a greater awareness of these during the more conversational times at the start and finish of interviews. Cole (2001) suggests that those with visible facial difference may not experience an ‘attentional absence of oneself’ (p.56) because of awareness of their visibility, but do experience other absences of confidence and sometimes relatedness and relationship with others.

These effects were not directly apparent in interview interactions, although many of the interviews do include references to times and situations when they felt under-confident. Some respondents identified they had difficulties in social interaction, such as talking about themselves with other people. The researcher returned to these expressions to explore how these experiences compared with the current interview interaction. In those cases, respondents responses were that this was a different event, as the difficulties identified stemmed from situations where the other people were not interested in understanding them and they had not voluntarily agreed to. Conversely, the interview interactions were based on interest and communication with the researcher. A key motivation respondents gave for joining the study was often about wanting other people to become more aware of what it was like to be treated as ‘different’. Awareness of this desire expressed by some respondents has shaped how the researcher has analysed and written up some sections of the study, particularly Chapter 7.

The multiple identities of the respondents were in the foreground of the interviews. Through talking about who was important, respondents also talked about what was important to them, what roles they valued, and how they felt they had achieved these. The idea of normalities was co-constructed in the interviews, rather than being a part of the researcher’s initial framework. Normalities within everyday lives first emerged in conversation with a respondent who felt that their current personal community was ‘normalised’ in comparison to that which they would have constructed in more difficult times. They were concerned that looking at their current personal community would say little about their experience of living with facial difference. Other respondents regarded their personal community as something that might differ from one constructed by someone who had not experienced as many disruptions or difficult experiences as they had. These observations between respondents and the researcher were captured in Chapter 6, with its emphasis on normalities and valued roles. The notion of ongoing processes involved in achieving these was the basis of the thinking behind Chapter 7, with its interest in resilient voices. Chapter 8 was most clearly defined by the original research question, with its focus on the role of personal communities.

A persistent theme present in the literature (Lau and van Nierkerk, 2011) was that a visible facial difference obscures other facets of identity in interaction with others. The reflexive diary tried to explore this from the perspective of the researcher. One facet that some facial differences obscure was found to be age. Scars and surgical reconstruction can produce an unlined skin. The researcher became aware, at times of initial meeting, how much she used signs of age to gauge how to pitch amiable conversation. The researcher learned it was more conducive to establishing a rapport to observe and gain the required information gradually, rather than make assumptions or ask direct questions too early on. The notion of intrusiveness as an expression of curiosity raises issues about to what extent people have the right to express their curiosity. The researcher was aware that in trying to work out a person’s age over a few seconds would most likely be noticed by the other, and unless the reasons for the scrutiny was acknowledged, they could construct the reason as being one of many possibilities, amongst them, an intrusive interest in the visible facial difference. The researcher reflected that in order to live comfortably with a distinctive appearance, one might need to become a student of looking and noticing as well as staring (Garland-Thomson, 2009).

In talking about difference, the pressures on an individual to be seen to be coping with difference seemed to be strong. This may have made it difficult to capture the anxieties and thoughts of those affected, particularly in the context of wanting to preserve the privacy of the respondent. This risked making less visible the experiences of those who may not be coping so well. The methods used went some way to providing a space where the contributions of others could be acknowledged and explored. It was painful to the researcher to look at how hard some aspects of life can be and how difficult it might be to live with contentment and some hope for the future. Pain and sadness were present in some of the interviews. However, without this space being made to consider relational aspects of living with visible difference, these issues might be further obscured. Tensions came up in finding a balance between the right words and saying nothing, realising that views expressed in the thesis will combine ‘insight and blindness’, constructing and reporting accounts, denying and intruding (Back, 2007, p.12).

Getting to grips with the interpreted and partial nature of knowledge present in all accounts, the researcher came to see the personal community maps constructed as ‘fragile precious gifts’ (Back, 2007, p.104) simultaneously partial, displayed and true.

5.5 Strategies for data analysis

Some of the processes of data analysis started with the first interview and continued through write-up. An approach was developed which could analyse visual and interview data. Both within case and across case, thematic methods were used to analyse the content of the interview transcripts and diagrams. Analysis was supported by the use of NVIVO10, a computer programme that stores, manages and displays data.

5.5.1 Initial stages of analysis

Each respondent was given a pseudonym, and the interviews were transcribed by the researcher after the interview. During the process of transcription, notes were kept about temporal sequences, along with tentative ideas about categories and relationships emerging in the data (Maxwell, 2013). After transcription, the texts were read again to make notes about what was happening and the researcher’s reflexive response to what was being said (Gilligan et al., 2003). The transcripts were then uploaded to a NVIVO10 database.

Identification of codes was based on comparison. Four interviews were explored in the first instance, in order to build an understanding of respondents’ perspectives individually. Both ‘top-down’ and ‘bottom-up’ strategies were used (Bazeley and Jackson, 2013). A short description was created for each code. The initial coding framework was a response to the areas suggested by the research question and also those areas that arose from the interview context. Each part of the interview was looked at to see what it might mean; anecdotes, metaphors, situations, events, and relationships were all looked for. In the processes of coding the researcher asked how concepts or ideas were similar, and how they differed, so they could be grouped in similar places on the database. When the process moved to the second, third and fourth interview, comparing and contrasting came into play.

After coding the second respondent’s interviews, the codes coming from the data had proliferated to the extent that a higher level of coding was needed, in which similar and smaller elements of the codes could be grouped. These processes of comparison and grouping were continued until four respondents’ interviews had been scrutinised.

The codes were arranged into the larger categories (Appendix 25) and served as a basis for coding the rest of the interviews. The codes developed at this stage were mainly descriptive and were close to the data. Some of these used terms from within the interviews and others were based on the researcher’s descriptions (Maxwell, 2013). All the transcripts were prepared in this way.

The substantive categories developed were: structures of personal communities; significance of visible facial difference; importance of relationships in personal communities; roles of respondent in personal communities; qualities of personal communities; particular types of relationships; other people’s responses; effects of other people’s responses; situations; developing resilience and protective strategies; life outcomes; social location and interview processes. Thirty-three different types of relationship were named in personal communities and they were all cross-referenced within the database, in terms of degree of importance.

This process captured the ideas in the interviews and formed a basis for a retrieval system. The process of coding had the benefit of increasing awareness of the content of all the interviews, and of seeing the bigger picture in terms of themes. These processes were the start of the development of understanding the meaning of personal communities specific to each respondent. However, the cross sectional approach did not prove favourable to understanding the form of personal communities. A within case approach was taken in order to develop each respondent’s personal community patterns from the transcripts and each respondent’s interview text was examined as a case (Bazeley and Jackson, 2013).

5.5.2 Constructing personal communities from visual and interview data

This stage of the analysis considered how to capture the paper versions of the respondent's personal communities, for the purpose of comparing them with the patterns produced by Spencer and Pahl (2006). This required several stages. For each respondent an electronic version of the paper and post-it note personal community was created in 'Publisher' (Figure 6). The numbers within the shapes denoted the circle within which they were placed. The circle numbers began from 'one', representing those regarded as closest by the respondent, represented by the letter 'P'.

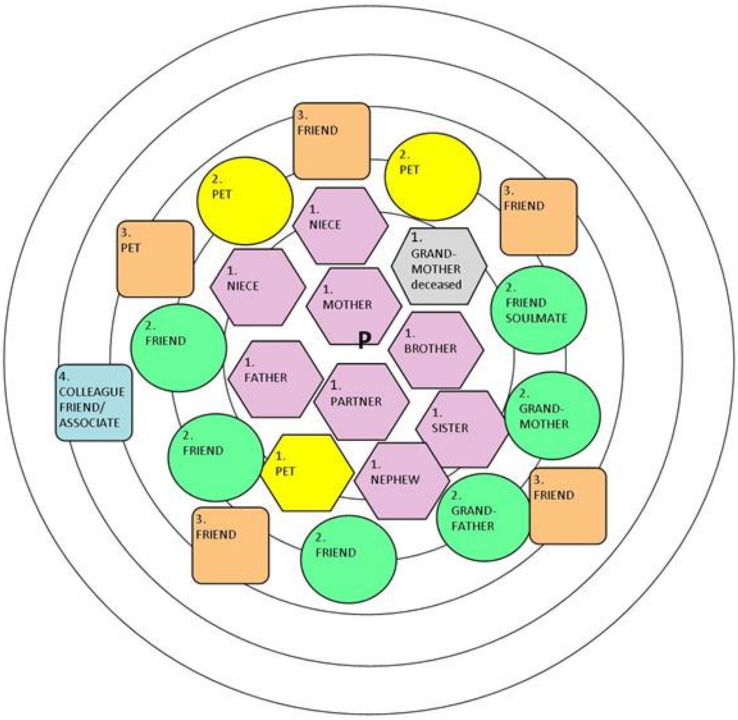


FIGURE 6: EXAMPLE PERSONAL COMMUNITY

The next stage was to identify the relationship types for each family and friend relationship on each personal community. Spencer and Pahl's (2006) typology of friendship and relationships (Appendix 3) was used as a framework. When this analysis was completed for each respondent, a matrix was developed to construct their personal community pattern.

For each relationship placed on a respondent’s personal community, the following categories were compared: name of relationship (e.g. mother, grandmother); their age; time known; proximity; frequency of contact; type of relationship based on Spencer and Pahl’s (2006) typology of relationships in relation to friendship types and whether ‘given’ or ‘chosen’ (Appendix 3), and finally the type of support relationship enjoyed with this person.

These developed iteratively through consulting the interview accounts and diagrams. The process was greatly enhanced by the ability of NVIVO 10 to locate specific relationships by name, relationship type, or circle, within each interview. Once the matrices were completed, they were compared to the dimensions within Spencer and Pahl’s typology of personal communities and the respondent’s pattern checked for degree of match (Appendix 2). Differences with Spencer and Pahl’s categories were noted, whilst retaining awareness of the possibility of ‘no fit’ at all, or different types of patterns. Appendix 26 depicts an example matrix used to capture the components of each of the personal communities.

The coding described in Section 5.5.1 chopped the data, making it difficult to retain an understanding of each respondent’s account. As each respondent’s account related to their personal community map, it was decided to retain a within case process in writing up. Keeping the within case approach was potentially more revealing of identities, and signalled caution in the quotes used. However, it enhanced the sense of how the respondents were situated in terms of gender, age, biography, type of difference, and personal community and in relation to other themes discussed. For each respondent a summary was constructed, which captured more of the interplay in each account between relationships, contexts and time. The summaries followed, through time, the respondent’s life course and key relationships, roles and events to do with living with visible facial difference. They sought to retain the contexts of important relationships and stories linked to them, and to this end, made use of quotes and linkages back to the transcript. They included the respondent’s perspective on how they live with visible difference, using the notion of ‘voice’ taken from a reading of Gilligan’s Listening Guide (2003).

Once the personal communities were established the coded data was returned to and was grouped according to the analytic categories of:

- Personal community type
- Friendships types
- Friendship modes
- Friendship repertoires
- Combinations of ‘given’ and ‘chosen’
- Presence of sustaining, managing in some areas, or developing voices

The next phase of the analysis aimed to explore the coded data in greater depth, by using matrices. In the last stage, 22 matrices were developed, enabled comparison between thematic content and the constructed personal communities to explore linkages within the different categories (Appendix 27). This method was used extensively to detect patterns. It was necessary to move backwards and forwards between the different kinds of data display (Maxwell, 2013). This included the researcher’s reflexive response to the interviews and the narrative summaries for each respondent, as well as the thematic coding and matrices. The database continued to be useful as a support to the analysis, because of its extensive search and retrieval abilities.

Matrices were constructed to explore the data and to capture the different dimensions within the main thematic areas selected for reporting:

- Personal community patterns similar to Spencer and Pahl
- Variations on Spencer and Pahl’s patterns
- Role of inner circles
- Role of pets
- Role of continuing bonds
- Important respondent roles in a personal community
- Unpredictable responses of others
- Sustaining, managing and developing voices
- Support specific to living with visible facial difference

The thematic areas were derived, in part, from the research interest and developed further during the course of exploring the interviews and other data.

5.6 Summary

This chapter has described the research approach developed and describes the methods and analytic approaches used. The ethical issues relevant to this study have been incorporated into the design. The next three chapters introduce the respondents and the main themes analysed.

Chapter 6: What is important?

6.1 Introduction: recovering, developing and sustaining

The starting point for this study was to explore if and how important relationships contribute to a sense of being connected to others. This chapter identifies findings about identities and roles derived from narrated accounts about important people in respondent’s lives. It presents an analysis of what is seen as making life meaningful and purposeful, drawing directly on data from the study to explore these dynamics. A sense of the narrative of respondents’ accounts has been retained within the themes. Examples have been used from the respondents using their own words, however, personal details, including names and places have been anonymised and some of the quotes have been ‘tidied up’ for greater readability (Plummer, 2001).

This chapter was inspired by a reading of Kleinman and Clifford-Hall (2009) which focussed on how stigma affects that which matters most in people’s lives. Connections within personal communities extend beyond micro-systems of ‘family’ to connections with friends in worlds of work, education, activities and healthcare and then into worlds of surrounding communities. Being a partner, a parent or a friend, for example, are important aspects of self-identity. Connections with particular relationships extend back in time from current personal communities through memories of earlier relationships. Visible facial difference has many causes and varying impact in terms of how it is life threatening, life changing or life shaping. To help understand the complex processes involved in different embodied experiences, the categories of recovering, developing and sustaining have been developed as themes guided by the data. Emphasis varies according to individual perspective and can shift and change over time for someone. At different points in time, the individuals focus might be on recovery of the body, sustaining what has been developed in the context of challenges in social worlds, or developing chances and choices in life. Recovering, sustaining and developing chances and choices are interdependent and are not clearly defined as distinct stages.

The term ‘chances and choices’ has been used to indicate the effects that facial difference might have on the chances people have access to in their social worlds, and on the choices made. These choices are influenced by relational and contextual factors. The emphasis in this study is on the longer term rather than recovery issues, and on dealing with ‘continuities’ in life (Williams, 2000). Difficulties in navigating aspects of personal and social worlds are identified which intersect with experiences of visible facial difference.

The study has used an interactionist perspective. A person’s sense of self is developed in interaction with other people. This sense of self develops relationally, partly on the basis of whom we feel we belong or do not belong with (May, 2013). An interactionist perspective holds that the process of becoming a fully participating member of society requires the person to develop the idea of the ‘generalised other’ through the development of symbolic capacities, thereby becoming able to see things from the viewpoint of other people (Mead, 1967). Inter-relations with others are seen as having a role both individually and communally, with space for agentic adaptation (Emirbayer and Mische, 1998) over a life course within a social, ecological system.

Psychology studies concerned with visible facial difference have found that differences in adjustment outcomes are to some extent mediated by self-perceptions of the importance of appearance or body image (Rumsey and Harcourt, 2005; Rumsey and Harcourt, 2012). These perceptions are thought to have arisen through internalisation of appearance norms and through experience of negative interactions with others. In terms of psychosocial outcomes people with a visible facial difference can and do adjust well, but there is substantial variation within samples (Rumsey and Harcourt, 2005; Rumsey and Harcourt, 2012). These studies indicate that a lack of severity of a visible facial difference is no bar to psychosocial difficulties and adverse feelings about appearance (Rumsey and Harcourt, 2012). Newell and Marks (2000) propose that fear of other people’s behaviour has a role to play in social avoidance observed among some people with visible facial disfigurement.

These findings have been linked to the development of interventions to enable individuals to overcome social barriers through increasing a sense of agency. However, social and situational contexts which also contribute to avoidance remain underexplored (Corry et al., 2009; Newman et al., 2014).

From an ecological, constructionist perspective (Bronfenbrenner, 2005; Ungar, 2013) adaptation to challenging or changing circumstances is seen as taking a life course rather than having a fixed endpoint or outcome. Previous experiences of challenging circumstances influence future ones. Experiences of overcoming, or of being set-back from throughout one’s life, can exist in the present through memories and *habitus*. Family and friends can be seen as ‘resources’ for negotiation within new and different types of situations and they can also act as constraints. It seems that it is the ability to continually adapt and, having the right people around confers advantage, and also that having the right people around impacts on the ability to adapt.

Data from this study indicates that recovering, developing and sustaining processes generate differing needs for the individual, unsettling established relationships, selves and identities, and bringing changes. Furthermore, those with whom a person is connected have their own biographies, processes and needs. The constant flux and change of relational worlds needs to be grasped. Support from others might be needed at some points more than others. Importantly, although particular connections might change or be severed, a sense of connection and belonging has longer term impact on lives.

When respondents talked about what was important in their lives, the idea of wanting a ‘normal’ life was brought up, but being normal is complex. Respondents want what society expects people to want. This is learnt from experiences and socialisation and respondents recognised there was no such thing as a singular ‘normal’. Social worlds are replete with all sorts of normalities for appearance, health and achievement and these different sorts of normal have material, symbolic and moral dimensions. Experiences vary in relation to age, gender, socio-economic status, and geography. Some experiences directly relate to having a visible facial difference, and these shape and influence feelings about self and identities.

In respondents’ accounts, ideas of ‘normal’ could be used as a source of standards against which to measure accomplishments, and as a source of information about how to proceed. Living with visible facial difference could be understood as a complication in realising self-goals and meeting (or fitting in with) social and normative expectations. Certain relational interdependencies appear to be supportive of dealing with complications associated with visible facial difference. The gateway to full participation in society is available for many people with visible facial difference. However, the boundaries to full and equal participation may be constrained for some, and this may indicate a lack of acceptance of living with visible facial difference as a social achievement.

6.2 What is important to people living with visible facial difference?

Respondents talked about the significance of having visible facial difference at different times, places and situations in their lives. Visible facial difference, while it may have a bodily reality, is also a social construction. Symbolic meanings revolve around ‘ugliness’, cognitive, physical or emotional deficiency, and instability following trauma. Respondents’ accounts emphasise the importance of resisting negative meanings.

Most respondents felt that having visible facial difference had the potential to affect their life chances and to impact on how they felt about themselves. They talked about their continuing experience of using resources and support to help in the construction and re-construction of selves and identities. They narrated accounts about dealing with the challenges of living with difference where they may have been severely tested, experienced losses, depression, and insecurities. Important areas of life discussed were working, having partners, establishing a family, having friends, taking part in sports or voluntary activities, and having a feeling of freedom of movement. Respondents described how they incorporated having visible facial difference into various settings in their worlds and how relationships with other people contributed to, or constrained, these processes.

Dave explains that he thinks the combination of his scar not being highly visible or affecting his facial functions, his age and his achievements in life contribute to a belief that his visible facial difference has not made much difference to his relationships:

> *Dave: Oh I think it's the fact that it's late in life and it's not going to affect, er, you know, affectionate relationships if I can call them that, or work relationships, or friendships. Most of the people, all of the people I know on here [Dave refers to his personal community map] erm, have come after, have come before, rather, the situation*

In his interviews Dave sometimes says the opposite of what he means to say and then corrects himself. Employment, friendship and partner relationships are picked out as important areas. He highlights the existence of supportive social and familial networks in which he has been embedded since before his visible facial difference occurred. However, elsewhere in his accounts, further complexity is revealed. Firstly, in recalling his experience of visible facial difference he found the condition and associated surgery as less intrusive than his experiences with another form of cancer. He regards his scar as minor and indeed as an interesting talking point. While he experiences occasional self-consciousness, it has not prevented him doing things. In this sense he has integrated his new appearance into his everyday life. The awareness in his family of his health situations, and the role of his partner, daughters and friend were prominent in enabling him to be part of a wider group even when his illness was more evident. For example, at a family social event, questions about his appearance or health were routed through his daughters rather than directed straight to him. These supportive interactions have enabled him to deal with his medical treatment and integrate his feelings about his scar into his everyday life. Factors such as loss, lack of everyday company, financial worries and other health conditions have been more significant changes to deal with as he ages.

None of the respondents, even those who felt their relationships had been deeply affected, claimed that visible facial difference had a straightforward or simple influence on life chances and choices.

The difference visible facial difference made was contingent on changing situations, responses of others, individual's own responses to bodily difference, and complications in worlds of work, valued activities, and relationships. Developing a degree of ease with one's own appearance might be complicated by interactions within any of these areas.

In relation to impairment, a dimension was whether physical healing had occurred and the body was in a state of being 'as well as it could be'. The significance of separating out the processes of bodily healing and repair, and the complications in developing and sustaining the life lived, are referred to by respondents whose visible facial difference were connected with ongoing illness or changes associated with medical treatments. The issue of the body being 'as well as it could be' seemed to be played out differently depending on the trajectories of the underlying condition. For some respondents born with a condition that required surgical intervention, points in their life could be identified where a decision was made - by themselves or others - not to continue with surgical options because it was felt that it might not bring any further improvements in appearance or facial function. These possibilities were balanced against the disruptions to making progress in everyday life, education and friendships. Whether happy or not with their appearance, there was a sense in which they had to face the issue that the body was 'as well as it can be'. This was noticeably more difficult to manage in the narratives of those who had a condition which re-occurred. There were similarities in the accounts of those born with conditions that required interventions over several years and those who had acquired a visible facial condition through physical trauma:

> *Lewis: Just accept it, you are not going to change it, you are not going to come up with a revolutionary idea. I could have new hands and I could have a new face but I don't want them. I don't want to go into hospital; I don't want to take immune-suppressants, I don't want to shorten my life by five or ten years. Cos I have seen immune-suppressants, no thank you, no. Fought hard enough to be here and I don't want to go down another road. So you know it is really what more do I want in life, I have got pretty much everything I need. I don't want too much out of life. Just want it on my terms.*

For respondents who had an acquired condition as a result of disease, issues of concern over facial function and appearance were complicated by both the need to tackle the underlying disease and concerns about whether they would be able to return to a previously established ‘normal’ life. These complications can be played out over many years:

> *Carl: The journey for me was. I had two journeys, that is how I split it. I had the medical journey that was nothing to do with me, that was clinical. And that went one way I was in the hands of someone else which is probably something, I don’t like being dependent on anybody. And the other journey was a life issue and that was dealing with loss of income, loss of respect for myself, you know, shame, guilt, anger, all the collapsing bits and probably now probably this last two years we have got back to Square One, where we are free, our life is free of illness, and where we are able to attack things, don’t you? We are able to attack things and look at things realistically.*

Carl refers to the chaos in his life that ensued after his unexpected and forced unemployment brought about by a life-threatening condition which required facial surgery. Having to cope with major life change at the same time as major bodily changes left him and his partner very exposed. They had to make choices in *“survival mode” (Holly)* with little professional support in the area of life change. A state of approximate embodied normality was important. Overlapping processes of learning to live with visible facial difference and changed ability to work became more prominent over the longer term. Alan identifies the difficulties he has had in learning how to control bodily processes which continually generated visible facial difference at points in his life:

> *Alan: But the trouble is I have basically detached myself from the world in normal terms a long time ago. Yes. It would be nice to get back into the world, but I haven’t got a clue about how to go about it. (Laughs) Sorry. That’s the other side of having a disadvantage nobody asks…if you have…if I was a victim of a crime there would be instantly counselling to help me get over it. But as a victim of disadvantage there is not counselling to help you get over it*

> *Rose: Would counselling help?*
>
> *Alan: No, it's something you have to learn to live with yourself. And because it's something you have to learn to live with without any help at all. I mean, even my family hasn't helped me on this one. I was the only one going through it after all. They didn't know anything about it. I know a lot more than them. In some ways I know more than the doctors that treated me. The, this is the trouble you are so totally on your own. Nearly all of us end up incredibly self-reliant, incredibly insular, incredibly alone. Most of us claim that we are happy that way, because we have learned to adjust to it over the years.*

This extract identifies an alternative to the normalising story of the majority in the sample. Resignation and constraint can be read into this account; however, Alan also recognises his agency and accomplishments in tackling aspects of life that others know little about. He connects his current insularity with processes of not learning how to form sustainable relationships with others. Effects are cumulative over the course of time. Although the goal of 'normality' might be viewed as a social and cultural product, there is often little in the way of practical guidance about how to produce this in your own life:

> *Bridget: Now, my accident happened many years ago and the support definitely was not there then. But I am hearing people say the same. So there is a gap between leaving hospital and finding support in the community. Because the biggest lesson to be learned is how to live your life being different, and if you are not getting it from the hospitals that starting process, then how are you going to start that? If you have got all your own inhibitions coming into play. If you are an 'out there' person, it probably won't matter so much, but if you are thinking this is a traumatic event and how do I deal with this and that support is not forthcoming it's left to them to find it, erm, and a lot of people don't do that.*

The idea of being on your own, marginalised or isolated, was accompanied by a sense of not knowing how to do something or get something. In the two extracts above, the sense of not being able to deal with multiple difficulties present was not confined to the individual.

The wider set of family relations experienced difficulties in managing strong emotions and relationships within the family as well as issues of social integration which accompanied the complex embodied experiences of one of their members. In contrast others discussed how they could see their marginalisation by observing what those presumed ‘normal’ had access to. In the extract below Isobel explains how she sees herself as ‘normal’:

> *Rose: So how did that come about?*
>
> *Isobel: I don’t know I think it was quite early really because I was always you know, my parents made me go and join things and be part of the community really. I think it started quite young and they really didn’t see me as having a disfigurement which really helped. I wasn’t disfigured to them and by not talking about it I think that made it, do you know what I mean, that you weren’t and so I grew up with this. And I think that’s why I found it difficult, you were maybe on the periphery, do you know what I mean, of these people who seem to be having a good time and everything and you think that’s essential for me as well, and you think “I want that”, yes.*
>
> *Rose: and so you figured out “How am I going to get it”?*
>
> *Isobel: yes, yes, and I think it’s just as important, you know for disabled people, its jolly difficult when you have a disfigurement, mental handicap, mental illness, do you know what I mean? It’s just being part of this world. It’s complicated because I had never met anybody with a disfigurement. There is no one in [name of place]. Until I went to a [name of charity] meeting in August I had never spoken to anyone with a disfigurement before, never really met anyone or anything.*

This sense of normality seems to be about wanting to be part of the social world. In other parts of account Isobel talks about how little she disclosed to her parents about the extent of the bullying she experienced in some of the schools she attended. The idea of being part of a ‘normal’ family that ‘gets on with it’ and was committed to forming relationships with others became part of the resources she took to other life stages and challenges - it was part of the family culture.

The tension between being cocooned by the family, as Isobel puts it *“wrapped in cotton wool”,* and being encouraged or pushed into wider social worlds, is echoed by other respondents.

Not everyone aspired to an everyday sort of normality. Lewis talks about the problems of returning to ‘normal’ life, after adventurous and traumatising experiences, in quite a different way:

> *Lewis: And really all that you need to know for yourself is that you can gain a level of normality that has abandoned you for a time being in your mind, because there is no such thing as normality, there is just tedious complacency, you know, that is normality to a lot of people, you know. Tedium and mediocrity to a lot of people that is normal, to me it’s abnormal and I don’t like it. I spend hours and hours on the phone working up deals and creating situations and creating positivity, creating openings because I am good at that. And that’s why I do it, it creates working, it creates finance, and it creates business, and it gets employment for people, and that’s why I do it. I can’t settle for mediocrity just can’t it’s not where I live; it’s not what I want in life. I have to create, well; no-one has ever given me anything.*
>
> *Rose: You are really out there?*
>
> *Lewis: Yeah, I am doing my own thing and I am marching to the beat of my own drum.*

Lewis goes on to explain that his family and children are central in his life, and his purpose is meeting his and their emotional, financial and material needs. The links between material factors and family life are strong in this account and this is a dynamic also reflected in the accounts of other respondents.

Now rating his health ‘as good as it can be’, Alan reports that he has spent such a large portion of his life focussing on gaining control of his body and dealing with physical and mental pain, that other areas in his life have been negatively impacted:

> *Alan: For me it was a conscious decision rather than a change of life. I suddenly realised I was getting older and I never really had any prospects of having a serious money or a regular income. I do OK. But you know it's a different thing to do OK as a single man than to do OK as family man. You need a lot more money than I had and I realised that it wasn't going to happen and even if I had a kid now by the time that kid got interesting, fifteen plus, I would be how old. So at that point I stopped looking.*

Alan brings in gendered aspects of life chances, highlighting expectations on men to be a 'breadwinner' in a family context or on boys to 'stand up for themselves'. These are roles that have proved elusive and he has had to carve a different version of 'normal'.

6.3 What is important about work?

Respondents' accounts identified a range of experiences in the world of work, from significant achievements, to experiences of difficulty in accessing work commensurate with their abilities, to protracted periods of unemployment. In summary, twelve respondents with visible facial difference were employed, self-employed or business owners; two respondents were fully retired; and three were unemployed. Nine respondents in employment said they were satisfied with their current employment or their employment history within the constraints of their age, gender or class. The younger respondents in their twenties and thirties were all employed, were seeking to develop their careers, and none of them had their own family responsibilities.

Career pathways varied by gender. Four respondents were mothers of adult or near-adult children and had carried out the main childcare responsibilities when their children were young. They had either looked after their children full-time or worked in paid employment around their childcare roles. Re-entry into the employment market involved negotiating the world of work, and also the world of re-education through tackling deficits arising from their earlier education or employment breaks.

One respondent had undertaken a role of full-time carer for her father in the years up to his death; however, none of the respondents with visible facial difference described themselves currently as a home-worker or carer.

Four of the respondents were fathers of dependent children and felt responsibility for earning for the family and caring for their children in collaboration with their partner.

Work provides the means for material inclusion in the world, identity development and a source of connection in which colleagues can become future partners or friends (Priestley, 2003) Particular colleague relationships may also provide an important type of friend relationship, as work cultures can be a source of identity through shared occupation or interests. Work also has symbolic significance and can be seen as a part of being ‘normal’ (Shah and Priestley, 2011; Friend and Rees, 2013). Achievement in the world of work varied between respondents.

The female respondents who were keen to hold well paid jobs or roles that could develop into a career; however, for some this has taken second place when they focussed on caring for their children:

> *Rose: So when did you start working again or did you start working through out?*
>
> *Fiona: Well I was, I didn’t, I worked voluntary all the way throughout because I had to as soon as [child’s name] was born actually we joined the [name of charity] and immediately got elected onto their committee doing a newsletter, or secretary, or something, and so I always did something, and I think when I was having, erm. Then I became a national local rep still when [child’s name] was born and before [child’s name] and then I think part time paid work came when the boys were, [child’s name] had just started school, I think. I worked from home for that it was about telephone support and supporting families with deaf children and stuff. Erm so yes, I have really always worked but I have wanted to. Obviously part time and at home when the boys were little and not until they were twelve-ish, thirteen-ish it was full time and out of the home and so that was quite handy.*

Fiona found a connection between the communication and advocacy skills she developed through her parenting experiences and eventually finding paid employment. The route from full or part-time parenting varied.

Connections between childcare and routes into employment were found in other respondents' accounts; for example, Jane enrolled on a degree programme after hearing about opportunities at a family centre. Her family of origin was not supportive of her education during childhood. She found that it was not until she achieved financial and residential independence from her family of origin in her late twenties, in part through marriage, that she was able to undertake higher education. After gaining her degree her employment prospects improved. Jane talks about a reunion with contemporaries from her school some years later:

> *Jane: But it was interesting that reunion because they all sort of went to [name of school] and all the girls I was working towards a BA at the time. But lots of lots of them either had degrees or were working towards them or were doing some similar kind of thing maybe a nursing qualification or something along decent higher educational qualification, and I looked round and I thought what a waste. We could all have left school with these things we were working towards or done or had achieved and we hadn't and I thought what a waste. Really they sort of had about 20 odd years of working life by then, we were in our, no about 10 years, we were in our 30's or so and yeah, I thought you know that decade we could have spent well and I thought, yeah, but the middle class people that organised it would have thought we would have been competing with their off spring and so if you look at it in a broader context of that and how it's all organised.*

Gender and class expectations surrounding the respondent and her family of origin shaped her view of her life chances and choices. Her experience was further complicated by limiting assumptions and stereotypes present in her family and school about her visible facial difference. This was seen as a sign that she had fewer prospects in either developing her education, work or family forming prospects. Jane typifies the school's approach to gender as one which aimed to produce docile employees for the local economy and for the women to be marriageable. Her experience of visible difference meant that she was regarded at times as having 'special needs' and was severely bullied. This was not dealt with by the school who failed to recognise these problems. What she held onto was her own interest in gaining knowledge through reading. Some adults recognised this and afforded her the protection of the library at times.

For Jane, her subsequent achievements in higher education are an important part of her self-identity, but this is accompanied by the sense that she could have achieved more if she had the early start in life which she knows other people can have. Distinctions in opportunity can be seen in terms of class and gender, but her experience of visible facial difference also shaped her experiences of schooling. The priority for Jane became one of keeping herself safe within the hostile school environment. Her emphasis on safety and the lack of adult support combined to reduce the chances available to her within the school.

Other respondents reflected on the problems of ostracism and the quality of schooling. Isobel provides a different perspective on social limits and how they interact with life choices. She suggests that her ‘realism’ about what she could achieve developed from self-knowledge of her capabilities, and of limitations which emanated from the interactional contexts in which she was living:

> *Isobel: And it’s building up in your own mind what you are capable of doing and what you know works for you really*
>
> *Rose: Where you are now, what would you say your capability is in that respect?*
>
> *Isobel: Well, I wouldn’t say get a job on a beauty counter or anything like that. I would never put myself in that situation, do you know what I mean, because I know I would be rejected. And it is knowing your limits, and other people’s reactions sometimes. I know you have got to go and push back boundaries, but again you have got to be realistic about it. That’s what I find and I find that mine are going out and making friends and I enjoy the job that I am doing and yes I would say I am happy. And people, maybe would sort of say you are not adventurous enough, but then again sometimes it is just about being happy with what you are doing and who you are.*

A tension appears between keeping safe and pushing boundaries through being adventurous. This tension has implications for the self as well as for relations with others.

Respondents talked about the importance of achieving suitable employment from which they could construct or maintain a valued identity, and from which they could gain a sense of achievement. Roy describes how, through the finding of two areas in which he could excel, one work and one in sports, he was able to build a life he felt he belonged to:

> *Roy: Just wanted engineers and they didn't care what you looked like they just wanted attitude and people who would try and do as good as they can. I would work really hard…I used to love my work, but I couldn't wait to get out of work because I was going to [name of a sport] that night. Crack on and get it done and then I would go off and do training and go and compete somewhere.*

An important means of reducing the symbolic social powers of visible facial difference was to minimise its relevance. Ken relates how he decided to act as someone not defined by visible facial difference; rather, he identified himself as someone who was good at something. Early in his life after his accident, he realised that he had two choices: giving up or getting on with it. However, this was a question that confronted him a number of times over his life course. Ken discussed his aversion to being defined by a particular employer as 'disabled'; he associated his resistance to this with feeling punished by his then line manager. However, he felt that he had demonstrated that he was as good as the next person at his job and he went on to build on this self-knowledge:

> *Ken: The connections what I remember thinking was I ready to do the London thing, I think, yes, the fact that and again it's all retrospective stuff that I didn't let my disfigurement kind of define me. That going for a job, going for an interview and particularly after [name of company] and I knew I was going to be quite good. I knew I could repair cameras and I was quite good at it, the same line I used with the manager, there was nothing in skills that would stop me. I was confident in my skills to repair cameras and that was the beauty of it.*

Ken's talk about seeking to not allow his disfigurement to define him could be read as a denial of his difference. For example, in his interviews he uses metaphors such as the process of *"bottling up"* to describe how he suppresses his emotional responses.

However, alongside this he also describes how he learned over many years to minimise the distraction of his appearance by emphasizing other aspects of his identity particularly in gaining interesting employment. Learning to live with visible facial difference requires being able to work out how to deal with the unpredictable nature of social environments and connecting collaboratively with others it is these times that can provide both safety and opportunities for movement.

Ken and Roy explain how becoming a skilled employee within a career structure was an important aspect of the process of having a life and identity not defined by visible facial difference. Both respondents perceived themselves as people who have learned to go forward into the world and who found ways they could achieve in the world of work with its important keys to financial independence and social connection. This was despite a number of setbacks from early in their life relating to aspects of appearance and bodily function:

> *Roy: I love my work my advice to young people find a job you enjoy and can do every day and all day. 10 out of 10 for work and I couldn’t have accidently have fallen on my feet any better. I have achieved at education that I am very happy with, I had a very poor education when I look back. At secondary modern which I loved, but they didn’t push you, I left with five ‘O’ levels. You can do this if you want. They never saw you going to university, some did, but it was who wants to do French ‘O’ level, not me, English, oh I will do that. You did what you put your hand up for rather than because you had a career in mind. I remember doing economics because the teacher was good. Relationships are way beyond my wildest dreams and I couldn’t imagine having a greater group of friends.*

A recurrent theme in respondent’s accounts was that they did not want to be known for something not worthy, and some respondents would see being known for having a different appearance alone, as an example of this. Roy in the quote below re-frames his visible facial difference as giving him an advantage:

> *Roy: People always remember me*
>
> *Rose: And you use that to your advantage?*
>
> *Roy: Oh absolutely, it means I can't get away with anything. Which again I used to my advantage with my children when they were growing up "You can't hide in a crowd, you will be the one", and so their attitude to being a bit mischievous at times was good. Because they were the one that was going to get spotted out, because they look that little bit eye catching different*
>
> *Rose: How does being remembered, how does that become an advantage?*
>
> *Roy: So how does that become an advantage, well obviously, you want to be remembered for good things and not bad things. So when I stood for being a school governor we had to go in and give a talk and I give my talk, I stand up and give my talk. I got twice as many votes as all the others put together because the advantage was because firstly I got that little bit more attention because I don't speak that clearly and I look different and it wasn't the only thing I was the leader, because I had better things to talk about but it just makes you stand out in that environment if you want it to.*

Roy maintains that having indistinct speech and looking different can increase listener's attention to what is being said but this needs to be set in a context of having other well developed skills. The linking of a visibly different appearance with an achievement or ability can be viewed as a means of escaping the negativity of being known only for the uniqueness of one's appearance.

Tensions were present in accounts between the dangers of defining yourself by facial difference and others defining you as different. These processes are intertwined and difficult to separate. Threads of defiance from being defined as being symbolically different by others were woven into respondents' accounts. However, it was seen as something that could not be easily evaded because of cultural norms that appearance is actually important.

It was perceived as one thing to downplay the importance of your appearance to yourself, but another matter to convince everyone around you, your family and friend networks, and the social and cultural institutions in which you are embedded, that this was indeed the case. A danger of being misperceived runs through accounts. It is particularly emphasised in situations where people know they are being judged or assessed. The extract below brings into stark relief how difficult choice is within the welfare benefit system:

> *Bridget: People assume because I am different I lack physical ability and mental ability. I think it goes hand in hand for some people. Not for everyone. But I think for some people they think if you are physically different you are mentally different and I have felt that. I still feel that, but like the Job Centre, now they go on about the caring. You know I have got a caring side to me and they have been trying to look at jobs in care homes and that sort of stuff. I know my limitations and there's, um, the health aspect around handling stuff which I can't do because they wouldn't insure me for it. And it's almost like the job centre don't acknowledge that aspect. So they are trying to treat me as if I am absolutely normal and I can have any job, where I am the one that's saying well, actually I have limitations. But then when I go for a job interview for something that I feel that I can do I often feel like they are putting limitations on me that are not there...So it's a difficult one is that, it's their concept and my concept of what my differences or whatever they call it are erm the word disability I don't like that. I am limited in use. Am I disabled? Well what's disabled? What is a disability?*

Those who have experienced unemployment explain how difficult it can be to escape from it. As well as placing material limits on chances and choices, it introduces another system of institutional judgements into one's life. Steve talked about how his father's family business has been a source of support to him in terms of employment, accommodation and providing a sense of belonging to a community with which he has been able to align himself. He says he does not know what he would have done without this, even though his experience is one of apparent marginalisation within this community.

With the retraction of work in the family business, Steve has found it difficult to secure alternative continuous employment. He struggles with whether or how to disclose his condition and is worried that he will be judged as not capable if he uses a medical label. However, he attributes part of his difficulties at work to his attitude of standing back and not being competitive. He does not like mixing with other people, he just wants to do the job and not be involved in social interaction with work teams:

> *Steve: Everybody says "You are laid back". People say I am a nice person to know but I am not a, I am not competitive, yeah. I just, you know, people who, well I understand to be, competitive to get high up in your job or whatever. I don't like being in the limelight. I like being in the background. I don't like being forward. I mean it's like working, I am probably , I know what I am doing I know me job, but I am better off working on myself than working in teams.*

Steve sees his difficulties in fitting into the work environment as partly a product of his identity as a farmer and as someone used to working in solitary conditions. He does not want to explore whether aspects of his facial difference contributed to his marginalisation. Instead, he wants to be taken for the person he is, rather than in terms of his appearance or his past employment. He sees this as a matter of his disposition and upbringing rather than his birth condition. He relates that he has stopped competing with or caring about the perspectives of the others, and wants to be able to be left to get on with his own life. He says if he is upset with someone or upset about something he may not speak for a week and tends towards being a hermit at these times. However, he also recognises his need for company and, while he does not like talking to people he likes them around in case he wants to talk. He regards his withdrawal as adaptive and developed over the course of his life and describes this as a *"Catch 22 situation"*.

The discomforts that can be brought about by taking part in the selection process to get work are described by Eve. Her talk highlights the possibility of an extra dimension of judgement present in the job selection process:

> *Eve: I went to this place and I knew the receptionist and so that was nice and I thought “Oh this is a lovely place to work” and I got chatting to her. Went up and I had to do a presentation. It was actually when I put in my application to work at [name of an employer] as well. And I could see instead of looking at like my slides, rather than just saying to me “Oh I can see you have got a different set do you mind explaining that and we can continue”, the woman who was interviewing just stared at me. I could clearly see, she wasn’t interested in and I thought I was just talking for the sake of it because all she was doing was looking at me and she probably wasn’t taking note of what I was showing her or what I was saying. It was really bizarre and I got the job and during the question and answer session another woman came in to ask questions and I felt that she genuinely listened and chatted. And I came out and felt that was absolutely awful, I just felt awful and I felt it had gone so badly and I thought I don’t know whether I am right or wrong but I just thought that the first woman had judged me. And when I got offered the job I was so shocked I just said to my Mum and it was like seven grand more than this job pays I just thought I am not putting myself there...I turned it down because even though just because I refuse to put myself in a situation where I feel uncomfortable.*
>
> *Rose: Did you tell them that?*
>
> *Eve: I didn’t, no; to be fair I had been offered this job as well.*

This extract indicates the difficulties involved in deciphering of the meaning of staring. This resonates with the work of Garland-Thomson (2009) which produces a typology of different acts and motivations for staring. Eve describes her personal sense of unease or lack of confidence produced. She talks about her refusal to accept employment in situations that make her feel uncomfortable. In other circumstances this refusal could be construed as an act of withdrawal. However, in her situation she had alternatives to pursue. She continues describing how difficult it can be to avoid the sense of being judged beyond what one would usually expect in an interview environment:

> *Eve: It’s more professional ones that I worry about more because I feel that there is almost an expectation from your CV about what this person is going to be and how they are going to perform and I think sometimes without realising it I can, because I know my face doesn’t show how I am feeling, my face can’t express how I am feeling. I never look happy, I never really look sad, and I am quite aware that sometimes my hand gestures or body language can be more, what’s the word, can be more in general than other people would use. Does that make sense? So I might do bigger actions and I am quite aware how that comes across. But I can’t help doing it.*

As a response to her lack of facial mobility and as a means of improving her communication skills, Eve has learned to use gesture to express emotion. She voices concerns about how this conflicts with normative ideas about what use of hand gestures might mean in an interview environment. She feels her communicative accomplishments run a risk of not being recognised as such. However, these challenges do not necessarily go away once established in an employment environment for Eve because of the necessity to keep meeting new people. Ease at work is something that is negotiated and below Eve talks about a positive employment experience:

> *Eve: Like one of my best experiences, ever, was actually my last role. I don’t know if I told you this already but I went for an interview there for a job and I had not met one of the directors and so it was my maybe third day at work. And she called me into a meeting room and she just sat me down and she was a German lady and I am still really good friends with her actually I am meeting her for tea tonight. And she sat me down and she just said, look I notice there is something different about your face what is it? Are you on any medication? Is there anything we need to know so we can look after you? And I just thought that was amazing because I could tell her then and she knew. And she knew it wasn’t anything, she knew it was something that I live with, and it wasn’t anything threatening or something that I needed medication for.*

> *And she understood and since then she never blinked twice. And that was the best, for me, if someone would rather stare or look or glance, I would rather they just ask. And that was a really good experience. Very fresh and it's the only time that has happened when someone has actually said, "What is it?"*

The requirements of some work settings can be seen as assisting with the process of regulating colleague's and other people in their workplace's behaviour. Eve explains that an expectation of professional conduct within some workplaces ensures that negative behaviour, commonplace on the street, is not encouraged:

> *Eve: It's because I think it's because in a professional environment people can't make a snap judgement, I think. So they can't look at me and think "Oh she looks weird" or whatever it is that someone might think. Even if they do think that they could not have a nudge and wink at somebody else because it's just not acceptable behaviour in a professional environment, I think. And because of that they are almost forced, the people you work closely with, almost forced to get to know you and not be act from first judgement. Does that make sense?*

However, the uncertainty about other people's reactions does not entirely disappear. In the course of her work Eve has to meet new people in other companies. She carries with her a residue of unease about potential negative responses or judgements into these situations:

> *Eve: And then meeting people like, part of my job is I go out to other businesses and try and sell [name of company] products and services that we can offer. Sometimes that can be quite daunting as well because you never know how people are going to react. Not that they ever say anything but you can see the looks and just little things that you get used to and pick up on really. So it's quite hard. Inside my friends and family I don't think about it but then outside it can become quite uncomfortable.*

Issues in relation to work were not just about gaining employment. Achieving a sense of ‘normality’ at work was linked to being in an environment that understands that signs of unease or under-confidence may not be a sign of inadequacy for the task, but could be to do with how individuals are treated by other people. Many of the important relationships that respondents placed on their personal community map were with people who they had met through work. These were colleagues who then became friends or partners and range from people who had become close intimates to those with whom they socialised with during or after work. The sharing of mutual interests such as a hobby or sport could be used to connect with people at work, and professional affiliations might enable access to other areas of interest and new social networks. Work can be seen as reducing everyday isolation and as a source of company even if you do not bond with your colleagues. It is potentially a means of increasing social resources and connections.

6.4 Significance of partner relationships

Most respondents have had at least one experience of an intimate partnership, although two respondents had not had such a relationship. Thirteen respondents described long lasting intimate relationships. Most lived with their partner, but two respondents had non-residential partners. All partners were placed in the inner circle of their personal community. For many, these relationships were interconnected with other aspects of their lives, and were centrally located within their personal communities. For some these were of equal importance with their relationships with their children and were mostly described as having greater importance than friends. Some of the current ‘enduring’ relationships are second or third relationships that have formed after the loss of a partner, separation or divorce. On personal communities, partners were variously described as a respondent’s best friend, intimate, confidante, companion, lover, and depending on the couple’s circumstances, boy/girl-friend, co-parent, business partner or carer.

The metaphor of working as ‘a team’ was often used to describe their partner relationship. This involved describing the relationships as being with someone who knows you better than anyone else and which needs negotiated commitment, loyalty and love in order to work. Although the narrated accounts tended to display the positive aspects of these relationships, difficulties were present as well. Embeddedness is not viewed in this analysis as solely positive (Finch and Mason, 1993; Jamieson, 1998; Smart, 2007).

Fiona describes how her partner has supported her not only in how she feels about her appearance, but also how they have worked and cared together to bring up their sons:

> *Fiona: Yeah and so [partners name] takes precedence because he is the most important person in my whole life and I wouldn’t be doing what I do today or feel as good as I do today if it wasn’t for him. And so we met as teenagers and erm and so we have known each other an awful long time erm and I couldn’t imagine life without him really. Obviously he loves me for who I am and erm he has supported well of course he would support, but he has been so good with the boys, having the boys, and it’s just, and having them and all we have been through with them has just brought us closer together. Erm, the longer we live together I think the happier we are. So he’s just, yep, he’s just the most important person in the whole world really erm. He’s such a lovely man, a laid back, a quiet man and just puts up with everything bless him, erm, yeah. So and I know he, well, I always keep in my mind and I tell him, he would have said that anyway. But when we first met and went out with each other he said that he thought I was out of his league and that he wouldn’t stand a chance with me and so if ever I am feeling a little bit low I always think back to that and that cheers me up a bit, so yeah (laughs) that’s why he is there.*

Most of the partnerships described by respondents were made when they already had visible facial difference. Lewis describes how love of a partner changed his life significantly, he talks about this as not something he was looking for, but was something that he was glad to have come to him:

> *Lewis: Let's start with the easiest ones then. There's [name of partner] my wife. I don't really need to say too much about her though; she's the love of my life. She's what she is, she is my wife. We are not just husband and wife, we are mates as well, best friends and er I just love being with her, so er you know you fall in love, you fall in love don't you? So it's an odd thing to do in life, it really is odd falling in love. A pain in the arse really, well it is.*
>
> *Rose: Why is it a pain in the arse?*
>
> *Lewis: erm because you fall in love. Love is one of the greatest emotions in the world along with hope, but love means that you take on major commitment. It means you take on all the responsibility, and you will do anything for that person, and it is irrational love. That's what's wrong with love that's why it's a pain in the arse, because it is so irrational. Erm, because you never stop loving people, you may not always like them, but you never stop loving them.*

Not all of the couple partnerships described came after visible facial difference. In these relationships the concepts of dealing with disruptions associated with illness or trauma came to the foreground. A prominent relational issue was about negotiation of the partner's role in provision of nursing-type and other types of care. In this sample, two marriages have survived and one broke up by mutual agreement after the initial crisis and question of survival had abated. The problem of the assumption of a compatibility of the roles of being both an intimate partner and carer were discussed. Becoming a carer is seen as a role that is taken on out of necessity, often in a time of heightened anxiety, and where there are uncertainties about the prospects of survival of one of the partners. Tom expressed ambivalence for the word carer:

> *Tom: Well for me, it's something that's bandied around and you think, well, they are doing that for us, so they must be my carer, erm, no partner in crime really more it is, than a carer. She's caring because she's my wife that's, you know, she wants to make sure you are OK.*

> *Erm, I always think it's an unfair word, it's branded that all they do is take you to your hospital appointment and bring you home again or make you a cup of tea when you need one. Yeah it's fine but it's everything else as well.*

The necessity of care may be the most important thing for the person affected by the presence of illness or accident related disruption. However, partner relationships are established on a different mix of negotiated roles and responsibilities, particularly when disruptive events or illness situations are unexpected and relatively early in life (Ketokivi, 2008). The change of roles, significant financial pressure, or threat to survival can put the couple into *"survival mode"* (Holly). The extract below is particular to the relationship of Carl and Holly where the idea of mutual interdependence is a strong theme within their interviews:

> *Carl: But it also impacted later in life when it hit us. I started to get ill. I suppose I didn't let you, I didn't want you to stay at work.*
>
> *Holly: Well, it wasn't just that…*
>
> *Carl: It wasn't just a question of that but…*
>
> *Holly: He was so ill; it was a case that I would have to forfeit the work to make sure that Carl in those early days survived. And that was as basic as it was, wasn't it?*
>
> *Carl: Yes it was income driven. I mean we were two cars, two good salaries and like most people living up to that salary. And then all of a sudden a joint income of [large number] becomes £68.75 per week. You know it's whoof…big house, big rates, big oil bills…so all of a sudden phoof and I suppose in the end we decided it was better for you to leave work, we found out it was cheaper in the long run for Holly to leave work and to become my carer.*
>
> *Holly: Trying to balance work and look after Carl at the end of the day what I was bringing home was gobbled up any way.*

This quote signifies a recurring theme in Carl and Holly’s accounts which they typify as one where they have worked together in their business and marriage and also during the period where Carl’s survival became the priority. Carl’s illness was a significant turning point in their lives and a start of their new life together. They strove to adapt with dignity to a different set of circumstances over the next ten years.

Other respondents were single, either following divorce or because they had never been in a partner relationship. For Bridget while her marriage did not work out, it gave a physically intimate relationship and children which she had thought she may never otherwise have experienced. In breaking away from the relationship she was able to prioritise love and care in her relationships with her children:

> *Bridget: Erm and although I look on it and think how sad that is, he actually gave me something that I never thought I would have and that was erm a loving physical relationship and two kids. Because I was 28 when I got married and I never thought anyone could look at me in that way and so he did that and he wasn’t a bad man. Just sometimes he lost his way when it came to drink, erm. So I don’t regret ever marrying him because of what I got from that.*

The significance of her relationship was that it brought her new purpose, intimacy and relationships with her children. Living outside of a partnership (whether co-resident or not) might for some mean more space on the personal community for the inclusion of friends (Spencer and Pahl, 2006). However, this was not the case for all respondents, and within this grouping there was a self-described degree of isolation.

The importance of partner relationships was highlighted by the presence of doubts in some accounts about whether they would attract a partner because of their visible facial difference. Ken describes continuing to feel thankful to his first girlfriend who he credits with giving him confidence in developing intimate relationships. The extract below signifies how for him having a thriving social life outside school contributed to him being able to start to re-connect to ‘normal’ aspects of teenage life:

> *Ken: So as I say, never going to get a girlfriend, but part of this group of friends that were all out and know each other quite well and were starting to go to pubs, although none of us really drunk a lot of alcohol, maybe a half of lager and lime. It was just that whole friendship group and I became at one point. I remember one girl who was, every time we were in a group; she would come and unburden herself on me. Tell me all her woes and she said, and I remember her coming, and I quite liked her, and saying "You are so good to talk to you are such a good listener". I can remember thinking I don't want to be a good listener, I want to be your boyfriend. That was never going to happen, but around that time one of the other girls had come and sidled up and I thought, oh this listening stuff again. It turned out that her friend had wanted to know if I would go out with her. And that was quite a ((can't hear word)). I had lost all that self-pity stuff, but I remember I had become quite resigned to the fact that I can't see how I am going to get a girlfriend.*

Ken was part of a nurturing family and a caring community and was moving on from what he terms his *"self-pity"* phase. As well as a close friend who is still on his current personal community, his mother, brothers and sisters played varying parts in enabling him to become independent and be able to move beyond the family home. Youth clubs and sporting organisations were meeting places for other respondents in enduring relationships within the sample. The nurturing family was seen as having encouraged his connection to an including part of the local community. Other respondents also describe how establishing a partnership had opened up worlds they thought might be barred to them on the basis of appearance and crossing this boundary represented a turning point in life. The long lasting nature of the partnerships in this sample is notable, as are the qualities attributed to many of the partner relationships. In addition to providing connection and belonging, a partner relationship can also been seen as a means of displaying normality, and producing a sense of safety within a highly couple-focussed culture (Ketokivi, 2008).

6.5 Significance of being a parent

Becoming a parent for respondents who have children was a significant source of self-identity development, connection and not least to say responsibility, love and pride. Four mothers and six fathers shared the importance of their children and parental role in their lives. Two of these respondents had experiences of being single parents, and two others had children who were also affected by visible facial difference. Although exploring parent-child relationships was not the focus of this study, the central importance of parent-child relationships in personal communities reveal these relationships as critical for those who have children to their sense of purpose in life. Becoming a parent could also be a valuable source of linkages to new relationships and route to generating new relationships.

Isobel carefully entwines her account about becoming a parent around concerns related to her embodied difference, with her perspective on how encouraging independence had become one of her important parenting values:

> *Isobel: They mean the world to me they really do, do you know what I mean, and they have added another dimension to my life really. You know at one time I thought, "Will I have children if I don't marry?" And it's just been absolutely fantastic. And when I had the skin graft I thought what if it won't allow the baby to grow but they just said "No its fine" and the doctor said "I've seen people with far worse scarring and they have had children." It's just added a whole new dimension to my life and I have met so many people through the girls. I really have. No I haven't lived my life through them, and they are very independent. I always wanted them to be independent, but you know it is just something that I had always hoped so and it just means really everything. I just love them to bits, yes, (laughs). Not all the washing and everything else but.*

Valued connections with other parents and families were often made during the childcare years, particularly for some mothers in the sample. In the quote below Jane talks about members of her current circles, some of whom still live locally and who she met during the childcare years:

> *Jane: I see them on a weekly basis, we got to know each other; I have known both those twenty-two years as well, from school and 'Mums and Tots'. Their kids went to the same primary school and me and [friends name] lived in the same road and we used share childcare and [friends name] was a home help and I was doing strange little packing jobs so that the kids. I'd look after me own kids, you see, and not put them in nurseries and things so I could pack in my little packing jobs or do them at home in the evening and look after [friend's son's name]. And if I had to have an early start I would drop mine off at [friend's name] and she would drop them off at school and so it worked do you know and neither of us had to pay any childcare fees which were astronomical.*

Peter, Roy and Tom found joint interests in their son's enjoyment of football. Peter talks about the reciprocal connections made with wider community-based groups through mutual enjoyment of football:

> *Peter: They are enabling us, but also are people who we give our time and energies to as well so it is not just one way. The [name of local football club] for instance, it's a major part of [name of son]'s life and so that feeds into that, but we equally we feed into that by supporting it and doing our bit.*

Fiona talks about an important friend she made through her local toy library. They have lost contact because of geographical moves, but they were very important to each other when their children were young and when they most needed a particular type of childcare connection. This experience combines the importance of finding someone who 'gets it' in terms of challenges but also with the importance of finding a place where you can be comfortable with your children who have disabilities. Fiona had found the 'normal Mum's and Tots' groups *"horrendous":*

> *Fiona: I think we were friends because of what we were going through with our children because she had a little girl who was autistic and deaf and really bad autism and we met at a toy library for disabled children and I have got [name of son] and we became really good friends for a long time, for about twelve years while the children were little and growing up.*

> *Really good friends we would see each other on a weekly basis and we would phone each other and one of the reasons for that, she, other people found it really difficult to accept her little girl, she was so, you just didn't know what she was going to do from minute to the other. She hit other kids, she would throw her food and whatever. Other people didn't really know how to approach me with my children because of the way they looked and so we both had our barriers but both of us, because of that, we didn't worry. Our kids played together and we understood that and it wouldn't have worried me if her daughter had, if [name of friends child] had pushed [name of her son] over or whatever because I would understand and vice versa and I was the only one she would invite round to her house because there was stuff all over the walls because [name of friends child] had thrown her dinner at the wall and she would have been horrified to see that. But because I understood that was OK but also we shared a love of painting. And we went on a painting course together which was really nice. So we had an awful lot in common.*

Roy was able to draw on his own experience to enable his sons to avoid some of the *"pitfalls"* he came across in his early life. Roy's children also had visible facial difference. He guided them in terms of preparation for dealing with the behaviours of others but also in terms of making sure his sons had access to therapies that were helpful. His view is that health service provision is very disjointed and he was able to ensure connections for his sons because of his personal knowledge:

> *Roy: I made sure he started speech therapy earlier, made sure he knew exactly why he was different and how he could explain how he was different and look after himself when people gave him a hard time. Rightly or wrongly being a judo expert and he started judo as soon as he could and at four years old he was beating eight year olds in competition and so when he went to school my rule was: you explain it the first time, you explain it a second time, and third time you tell them to go away, and the same with bullying.*

Roy's support for his children included proactively going into the schools to make them aware of the risk of their being bullied.

Jane emphasises that supporting her children was about enabling them to have opportunities that suited their interests and abilities and also about making sure the school knew that she was an involved parent. She wanted to make sure the school was clear that she expects her child to be able to meet their educational potential and leave school either employable or ready for higher education. Respondents talked about how positive and negative experiences from their childhoods contributed to how they brought up their own children, building on their knowledge of how to live with visible facial difference and passing this to their children whether they had a visible facial difference or not.

6.6 Summary

This chapter has explored important identities and roles identified by respondents through the relationships they hold within their personal communities. These are put forward as presenting an analysis of what is seen as making life meaningful and purposeful. Kleinman and Hall-Clifford (2009) suggest that stigmatising social contexts affect ‘that which matters most’ to people’s lives. The roles and relationships, of which respondents are a ‘part of’ within their personal community, extend beyond family into worlds of friendship, heath care environments and employment. Respondents described that which mattered as suitable work environments, being able to take part in activities they valued, relationships with partners, friends, and as parents if they had children. This suggests that like families (Finch and Mason, 1993) personal communities might be regarded as a conduit for support and belonging.

This chapter has explored respondents’ views on the importance of constructing ‘normal’ lives. But being ‘normal’ was complex and respondents recognised there was no such thing as a singular ‘normal’ within any particular context. Social worlds are replete with all sorts of normalities for appearance, health and achievement and these different sorts of normal have material, symbolic and moral dimensions. The contexts identified indicate multiple ways, in which people have become, to varying degrees, embedded outside family circles. Respondents wanted what society expects people to want, but on their own terms, and with others identified through the medium of personal communities (Kittay, 2006).

These relationships within personal communities were not conceived as a place of retreat or even of safety. Instead the themes of a dynamic between safety and movement (or pushing at boundaries) emerged. Personal relationships could contribute to the processes of balancing safety and movement simultaneously within a number of different normalities. Problems could occur when this dynamic balance became static. Data indicated that recovering, developing and sustaining processes generated differing needs for the individual, unsettling established relationships, selves and identities, and bringing changes and possibilities of new important relationships. These occurred in lives in singular ways, although team-like partner relationships and relationships with children had most commonalities in how they were valued, when they were.

Living with visible facial difference threw up particular challenges. The presence of visible facial difference in the important aspects of life was negotiated with differing levels of ease. Learning ways to differentiate between different ways people notice and assess was important for a sense of personal security. Having relationships with others who were able to understand or provide a sense of solidarity in relation to similar challenges was an important aspect reducing isolation and of becoming part of a more of a shared normality (Kittay, 2006). A central challenge voiced was about wanting ‘life on their own terms’, rather than determined by other people’s responses to their appearance (and what they imagine this might mean).

Limits to support were identified in relationships in personal communities. One of these was about how individuals can find help and support when it is not present among those they have around them. These experiences appeared to intensify in cases where lack of knowledge or support over a particular issue combined with difficulties in helping navigate to other resources that might help. Some respondents identified situations where there seemed to be little help at all for an individual who was isolated

Institutions, and the attitudes and practices of gatekeepers within these, are shaped by class, gender and visible facial difference intersected with these. This could affect the processes by which experiences in the setting was experienced as encouraging, including, constraining, or limiting an individual and which had long lasting consequences.

Chapter 7: Stigma and resilience in everyday life

7.1 Introduction

This chapter connects two areas of enquiry: contexts of stigma, and the development of resilient orientations within these. First, potential difficulties are posed for some people with visible facial difference in stigmatising contacts and situations, with attention drawn to the responses of strangers and acquaintances (Goffman, 1963). They can affect an individual's sense of freedom in going about their everyday world, particularly when developing ways of dealing with high levels of intrusive responses by others (Garland-Thomson, 2009).

Second, the concept of resilience has been used to explore how psychological adaptation translates into fulfilling lives in potentially stigmatising social contexts. Voices of resilience emerged from accounts and are explored in relation to dealing with assumptions from other people when getting on with matters of everyday life. As explored in Chapter 6, different aspects of a 'desire for normality' shape realities for people living with visible facial difference. In this context the opportunity to take chances or make choices was highly valued. Voices of resilience provide a linkage between what is important in life (Chapter 6) and personal communities of important relationships (Chapter 8).

7.2 Complicating responses from others

Everyday encounters with acquaintances and strangers contribute to who we feel we are and how we feel we belong. Strangers and acquaintances are often a valuable source of future close connections and belonging (Morgan, 2009). A person develops strategies, the means of maintaining what Goffman (1982) called 'poise', in social encounters. However, when a glance in a public space turns to that of unwanted or special curiosity the loss of 'civil inattention' can result (Goffman, 1982; Garland-Thomson, 2009). These interactional processes enhance the experience of stigma, which is attached to visible embodied difference (Goffman, 1963). De-stigmatisation strategies are developed relationally, and individuals will vary in the degree of access they might have to these social and cultural resources. For example, a strategy of celebrating visible facial difference is only viable in some situations and for some people.

Having to learn how to deal with the less palatable or puzzling actions of others was an important feature of some respondents' accounts. These can be seen threading through Chapter 6, when respondents talked about their important roles and relationships and how they negotiated chances and choices with a 'different' facial appearance.

Visibility, or rather noticeability, had a role to play and was associated with experiences of noticing, staring or other intrusive behaviours from other people. This can change over time through healing processes or with corrective surgery, as for example, in Peter's account (Section 7.6) about the initial period following his injury. He was aware of greater reaction to his appearance from other people during these times. When experiencing severity in facial difference people had to learn ways of dealing with complications in interaction and find ways of protecting themselves from feeling diminished. Changes in visibility were seen in the accounts of both those whose facial difference was apparent at birth, and those who experienced injury or illness.

Others construed their scar as quite minor, though they were aware of it was not very noticeable and in looking back they felt this had not had a disruptive effect on their lives. The accounts of Dave and Vera reflected this position. Experiences of being noticed as having a scar could be fleeting, or involve one-off inappropriate comments that reminded them of their scar. Respondents who rarely linked comments or noticing behaviour to facial difference included both those with acquired and born difference. One commonality was a sense of outrage at the idea that someone might (dare to) comment on their facial appearance, something they would consider inappropriate, rude or socially inept.

Visibility is not constant in other ways. Familiarity seems to reduce the noticing behaviour of other people. This could be valued by respondents and was an essential feature of important friend and family relationships. Acquaintances who act as if they have not noticed could also be appreciated. Familiarity was not necessarily always a 'good thing'. If the assumed meaning of the 'difference' was connected to other judgements about the respondent these could become embedded within family, community or institutional contexts and become limiting.

These mostly troubling assumptions explored by respondents were when they were seen as ‘not normal’. Respondents articulated that feelings of negative judgements could come with a feeling of being assessed about whether they had a mental health problem, cognitive deficit, or were mentally unbalanced as a result of a trauma. The presence of their visible facial difference was interpreted as signifying these possibilities. Where these viewpoints became locally embedded they were seen as affecting choices, opportunities and sometimes developing trusted and valued relationships (Yang et al., 2006).

Some accounts focussed primarily on past events and contexts. These accounts identify various ways respondents developed strategies to deal with interactional intrusions, as well identifying perceived impacts framed as types of judgement or discrimination. Others talked about ongoing experiences ways they lived with these and ways they affected them. Some people were better placed than others to embrace visible facial difference by incorporating their knowledge into either their paid or voluntary activity. Despite the diversity of the sample, everyone was able to retell one example over the course of their life where they had experienced some sort of interactional disturbance or inappropriate occurrences that they linked to their visible facial difference.

7.3 Present time experiences

This category describes ongoing experiences of being noticed. These were described by respondents who had lived with visible facial difference for their entire life, and in the cases of acquired difference from their childhood or early adulthood. What respondents thought was being noticed varied and, it could be a difference in speech, losing balance, eating or drinking differently, not eating or drinking in a situation where this was expected, not smiling, walking a Hearing Dog, a noticeable nose, uneven skin colouration, sores, or using gestures. These aspects were connected to their embodied visible facial difference, ideas about noticeability, and whether there was anything they could do about it that would not further enhance the experience of feeling different. The judgements felt to be present in some situations, were about level of intelligence, mental stability, and whether the respondent belonged in that situation. That is to say, classic elements of stigma:

> *Mark: I think you see I have always kind of thought, erm, along the lines of racism. In that if someone is racist towards a black person, it’s more that’s seen as worse than it is for someone to be say discriminative of me because I look different. It’s more than it should because I am a, because people with facial deformities are smaller group than Black people or Chinese or whatever. So I have always thought maybe there are people who are out there who are worse off than me, but I have always thought, I don’t know, maybe if someone has, I dunno I have lost my train of thought there. I think it is worse than racism because it’s not recognised as not being a rights thing. If someone was racist to a black person everyone would go ‘Oh that’s really bad, you shouldn’t do that’. But if someone was nasty to someone with a facial deformity it’s not spoken about, it’s not seen as a bad thing and therefore it’s worse than racism, if you know what I mean.*

In order to live with staring, noticing, looking and comments some respondents talked about how they have learned ways of ignoring it, not noticing it all, or learning a suitable socially acceptable response to the situation. Ken uses a metaphor of developing ‘blinkers’ in order to enable him to be amongst people who look at him. He uses the ‘blinkers’ as a means of enabling him to have mobility in social worlds. As part of getting used to his changed appearance he developed over many years an understanding of the inevitability of other people’s responses. His family and friends also had to learn similar interactional strategies, but people new to his social world could be shocked. He described travelling on a tube train with some new work associates:

> *Ken: They said I don’t know how you put up with it. Put up with what? You know all those people? What people? I don’t see them. I didn’t see the people who stare. Sometimes I do and sometimes when I am not in the right mood, I get cross and I’ve got blinkers on. I can remember developing those blinkers but so you normalise everything. The friendships, the relationships you are going to see are first and foremost about people who are there. There are things about my family obviously, they’ll have to deal with the, er, people who stare, people who look, but they have done the same kind of things, the switching it doesn’t bother them anymore.*

The processes of adaptation to a ‘noticing environment’, particularly for those affected in their childhood or youth, occurred over time and with experience in a family context. There is an active nature in these processes of learning social expectations:

> *Mark: Here at work there is quite a few people in and out and because they know me they are used to the way I look. Therefore they don’t stare. People that don’t know me will stare because I am, I guess, I am new, something new for them. So they, but it’s not everybody. Some people will just kind of treat you normally by not looking. Erm, but I think having that happen, obviously all my life, I think I have got used to it. To a point where in my, I suppose, in my head, I can dislike them in my head, and say that person’s a whatever in my head or just feel like that in my head rather than getting annoyed or maybe when I was younger I would be getting annoyed or avoiding situations that had I been older and having a lot of experience of it, it’s more, it’s easier to put up with.*

This type of learning is social and sometimes very public in nature, potentially producing an accompanying awareness that how they are seen to respond in an interaction was also part of the judgement process. Techniques for dealing with the unpredictability of other people can be to develop a ‘front’ (Goffman, 1990). While this may be protective in some situations, such as at the bus stop, it can get in the way in situations of meeting new people, friends of friends or dating:

> *Eve: Or meeting new people, say friends of friends that I have not met before. I am always like on guard. I feel like I can’t totally relax, like if I went out with one of my best friends and one of their friends I have never met I probably wouldn’t be my most relaxed.*
>
> *Rose: So how does that affect you in the situation?*
>
> *Eve: I think I can come across as quite hard faced. One of my friends was talking and she told me, and I am really close now actually, but she once said that we didn’t like each other because she thought I was really hard-faced. And I think that is probably my guard. Because she thought I was quite, probably a bit rude, because I didn’t make much conversation.*

> *I didn't really seem interested in her. But it's not that, I just need to feel comfortable to be able to kind of relax and communicate as I would with friends.*
>
> *Rose: How do you prepare yourself, do you need to?*
>
> *Eve: I think I probably used to, and I think a lot of it is I prepare myself for rejection, I think if I am honest. But I think it's probably the wrong way of doing it, I find that for example when I didn't have [name of partner], when I was dating. I used to set myself up for rejection thinking well not everyone can handle someone that is you know visually different. That's how I used to say in my mind, well it's probably not going to go well and then if it did it was a bonus. And so that was how I was keeping my guard up and so if it didn't go well then it was almost though you expected it. Does that make sense? It's bizarre, it's bizarre but obviously I would still be hurt and upset if I liked them. It's difficult especially dating or going out with new colleagues that don't know me.*

Eve uses the term 'hard-faced', which for her has a double meaning. It could be descriptive of her facial immobility or it could refer to her strategies of self-protection and not allowing people to get too close in the first instance. There is recognition that self-protective behaviours can have a counter-productive edge in social encounters. There is a balancing act between self-protection through developing low expectations, or appearing not to care about how others might respond. There is recognition of a risk misperception of herself as a person. Eve is aware of these issues and talks about feedback related to her 'hard face', from someone who eventually became her friend. She changes to the past tense during her talk about this self-presentation strategy. The past and present are entwined as she describes how some experiences have become part of the past, but the presence of future unease remains because of the unpredictability and situational nature of these encounters.

Several accounts feature ongoing experiences resonating with bullying and name-calling behaviour at school; experiences of being perceived as 'other' are not confined to the school environment:

> *Rose: I mean if it made you who you are now, do you mean you got your confidence back or*
>
> *Gina: No, I think I am quite a shy quiet person, yes, I mean it was all bullying based around my being different and so you know it more like psychological than physical, but it still stays with me and stuff.*
>
> *Rose: Makes you feel sensitive to it happening again?*
>
> *Gina: Yes, I mean now around about town and stuff, I get the odd comment and stuff. Which is really hurtful and it takes me quite a long time to get over it and stuff. You kind of think when you leave school, oh that'll be it over, but it isn't, you know.*

The effect on confidence varies as does the type of situations that are associated with unease, and the extent to which feelings of ontological insecurity are produced. Respondents who experience ongoing noticing behaviour over-time developed ways to deal with it. Some strategies are emotional-cognitive techniques, such as learning to ignore people, or thinking of the starers as 'other'. There were also strategies which were more relational in technique and consequence, such as developing a group of people with whom they felt at ease.

The sense of ease and confidence that respondents talk about can be conceptualised as a spectrum. Movement along this spectrum is described by Ken whose, his level of ease has changed to such an extent he has become involved in providing educational interventions that aim to extend cultural knowledge about living with difference:

> *Ken: I would also like to develop a programme where I can bring people who are at risk of disfigurement or acquired disfigurement or who are struggling maybe a bit to shadow me and come into schools and I mean to be honest, I think I was at a point when I wouldn't have done this probably 30 years ago maybe 20 I am not sure. I have always wanted to do it because of the impact you can have on kids because of how abusive kids can be and so I want to go in and say look it's OK to look different.*

> *Yeah I had to get through that the physical stuff pales into insignificance really I can go through 20, 30, 50, 100 operations and I had 120 different interventions to get to look like this. Erm but to do the mental stuff, to come to terms with it, putting up with people, the sheer loss of confidence, the loss of self-esteem that's the tough stuff. That's really hard, that's when you need family and friends, good people. That's why I go into schools, and that's why I wanted to let kids know because you can imagine my going back to school.*

This journey to 'developing confidence' can be seen as lengthy, complex and arduous, rather than a simple passage of time. Development of a relational context of *"good people"* contributes to its achievement. What is being talked about is not just a matter of getting used to facial difference. Others, who have also had many years living with facial difference, have found they increase their ease by another route, placing social distance between themselves and others.

7.4 Past experiences

This category of experiences was related by respondents who described the more unpredictable reactions of other people as largely confined to their past. Respondents in this group had acquired and born visible facial difference. They regarded their difference as being less noticeable because the condition had subsided in its severity, or their scars had healed and were not particularly prominent. Past experiences could still resonate through life stories and for some were felt to have contributed to cumulative disadvantage. Jane talks about the disruption she experienced in her school education, where her priority was to keep herself safe. She learned that part of this involved not making a 'fuss' or pursuing a legitimate complaint:

> *Jane: …of course people did attack me. I used to try and complain, I mean, I give up by the last year because I got told to keep a low profile. So I didn't talk to anybody at all. And on my last school report I got that I had settled down and got used to school. In other words I had stopped complaining and that suited very nice. I still got kicked around inside of the place but I didn't complain.*

Respondents report different time-frames for their processes of getting used to being noticed by others. In Chapter 6 Alan talked about the dangers present in waiting until you have learnt to ignore or minimise it, since this can take a life-time and, meanwhile, opportunities pass by.

De-stigmatisation strategies are as a source of management to help get on with life, rather than something that makes the problems disappear. There are links between marginalising experiences and perceptions of discrimination and under-achievement. However, it is difficult for respondents to know whether discrimination is going on at the time of its occurrence. This ‘not knowingness’ is manifest in accounts of trying to work out the motivation of the people who respond negatively to difference. There are many possibilities for the meanings attached to noticing. These vary according to context, situation, social position of the respondent, and also the symbolism given to a particular visible facial difference, and the way these meanings then affect other roles in life. Noticing becomes discrimination when judgments are linked to practices in social environments (for example, school and employment situations).

Fiona described how difficult it was as a young mother being in public with her children who had a born with visible facial difference, and how she found support within a toy library set up for disabled children. However, she says that ‘difference’ is not enough to deter them from being out and about. She discusses how being known and recognised by a greater number of people within a given geographical area aided the family’s sense of security:

> *Fiona: We’d also sort of brought it on ourselves. We had also been in the local paper because as part of the Group we campaigned for because its [name of condition] you are born without ears which the boys were. There is a new hearing aid that has been developed in Sweden, a bone anchored hearing aid which [name of son] has. And at the time in order to get things on the NHS they have to be approved and you have to make people aware of them. And so we took part in a campaign to make the NHS aware of this new brilliant hearing aid and they could get it on the NHS. It’s not that they wouldn’t, it was just making them aware of it. And so obviously the local paper picked up on it and there is a lovely picture of us so, you know, yes, and so people knew of us even more.*

> *But in a way that's, in a way that has a positive effect as well because our community in [city] know us and they know the boys and a lot of people talk about the boys even now. You know "Ooh I saw your boys" I don't know who they are and almost gives us, it almost gives us a little bit of security and comfort in that they know us and they know the boys as 'The Boys' and they almost see them as part of their family. And so they are not going to get any negative feedback as much, apart from looking at them.*

Fiona's account distinguishes looking from potential threat. She uses the idea of increasing acquaintanceships to increase her sense of security for her sons' safety (Morgan, 2009).

Respondents described how they have integrated 'difference' into their lives and found ways of using it to their advantage, including its potential use within education. They recounted ways of challenging the behaviour of others. One respondent identified situations in which they made a legal challenge to being singled out. Jane recounts how she was able to use disability legislation which was introduced in the 1995 Disability Discrimination Act (DDA) to successfully challenge a complaint made about her voice at work:

> *Jane: I got out of that with my dignity intact but you know I wouldn't have done that, I don't think you know, before I got my degree and done a bit of a better job.*

A growth in confidence through educational achievement and improved job prospects, and knowledge about legal changes contributed to her being able to act in a more proactive way:

> *Jane: It helps me be proactive in dealing with stuff now. I'd still spot stuff and identify stuff but no there was nothing I could do. Now we have got the Disability Act we can we be proactive and say this that and the other. Can we sit down and have a meeting with the trade union and discuss it? I would have been quite happy to, well look we have got it wrong and we are going to a couple of [name of charity] workshops and sort it out, but they didn't and I kept hanging on.*

This is an example of how an individual was able to utilise and mobilise community resources to advocate for herself. The development of feelings of confidence have come about through a multi-faceted process requiring tenacity, knowledge, experience, education and support from knowledgeable community and workplace resources.

7.5 Voices of resilience

This section explores respondents' perspectives about how relationships in personal communities contribute to a resilient orientation within environments that can be stigmatising. Respondents' discussed processes of resilience and how they have drawn on these in order to achieve what they have identified as important in life. Personal community patterns are examined in greater detail in Chapter 8. Ungar defines resilience as:

> 'The capacity of individuals to *navigate* their way to the psychological, social, cultural, and physical resources that build and sustain their well-being, and their individual and collective capacity to *negotiate* for these resources to be provided and experienced in culturally meaningful ways'. (Ungar, 2013b)

The concept of resilience in the literature has changed over time as have conceptualisations of 'good' and 'bad' outcomes. These are historically, contextually and culturally constructed (Ungar, 2003). Runswick-Cole and Goodley (2013) caution against accepting normative assumptions of particular successes in life as equated with resilience. They argue from a critical disability perspective that in some lives resilience differs from normative definitions of success in an achievement oriented society. Failure to recognise this can risk misrecognising achievement. What we see as successful outcomes are best characterised by negotiation, as being self-defined, rather than having a fixed or pre-determined nature.

While recognising diversity, Ungar (2010) maintains that nurturing and including relationships assist individuals in navigating access to resources that enable them to self-define as having well-being. Person-environment interdependence is emphasised as people need communities that are able to provide what is required to develop. This is variable and subjective.

An ecological focus decentres the individual and avoids blaming them for not flourishing when there are few accessible or contextually relevant resources (Ungar, 2013). The respondents’ accounts presented describe challenges emanating from situations, institutions, experiences and interactions with other people that are complicated by visible facial difference. However, some respondents did not experience visible facial difference as a source of adversity. There is no simple or necessary connection between having visible facial difference and poorer life chances. Any connection is mediated by personal histories, resources and other stressors in their environments and relationships.

7.6 Acquired and born with visible facial difference

The accounts reported are from adults’ living with visible facial difference long after acquisition, and the focus is on everyday life (Lenette et al., 2012), these lives are seen as normal to those narrating them. Adversities associated with visible facial difference included negative reaction from others, lack of support from family, or poor management by family or educational environments. Other people’s reactions to one’s appearance could trigger negative feelings about one’s appearance. Individuals develop various strategies for dealing with such responses. These responses could, in turn, further affect people’s relationships to situations and environments (Kent, 2000).

Acquiring visible facial difference can be seen as a ‘risk’ to well-being as the events or illnesses surrounding acquisition can be catastrophic and can be biographically disruptive (Bury, 1982). For those born with visible facial differences ‘risk’ may be more related to resources and relationships as the person develops (Ungar, 2013). The accounts of people with acquired and born with difference took different forms during the interviews. Those who acquired difference later in life tended to start their account just before this time in their life. Those who were born with difference or acquired difference in their childhood started their account with early memories. They talked about their family of origin, schooldays, further education and training, work, career or business development leading up to the present time and current personal community, family and activities. A sense of continuity (Williams, 2000) was developed and visible facial difference was seen as part of who they were.

The help or hindrance they experienced was linked to a sense of under-response to people who are presumed different in some way. For Mark this was not so much bullying but a lack of interest in including him:

> *Mark: I think that's the main obstacle but it's quite a large obstacle because you are looked at all the time or commented about and so you don't necessarily do the best that you can in social situations which probably effects, well it affects the rest of your life because maybe in school if I had been accepted more, maybe I would have learnt more.*

He found being looked at and being noticed discouraging to his participation in activities. He talks about how he and his small group of friends at school saw themselves and were seen:

> *Mark: I think we were happy enough with ourselves. Occasionally we had, it sounds a bit silly, but occasionally we added someone to our group like they came along or no I just think we were happy enough in ourselves. If we wanted to do something we would have done it despite other people, if we wanted to go and play football we would go and play football…and I don't think because we were generally excluded. We felt that way because we were just different, it didn't matter we just got on. Because we were different anyway being excluded was just a (pause) not reaction, what's the word, oh, we were different therefore we were excluded. Not excluded and therefore we were different. So because we were the way we were we wouldn't make an extra attempt to fit in with everyone else because we were happy with the way we were.*

They became friends early in their school years and had being 'different' in common and not fitting in with sporty or popular groups in the school:

> *Mark: And I think because they were the same age as me when we at school and we first became friends and so I think there's a respect that from the first instance they must have seen me and known I was different but they were still my friends at that point and basically we all kind of stuck together through the whole school.*

This group of friends made his schooldays more bearable. Notions of resilience were developed in terms of how they were able to negotiate outcomes that they wanted.

Respondents considered whether the presence of visible facial difference hampered access to environments or relationships, whether these generated discomfort or negative experiences and how they approached such challenges. The family of origin played a significant role. Respondents were also concerned about the cumulative effects of social limitations on chances in areas of work, education, partner or intimate relationships, family forming or friend making environments.

The accounts of those who acquired difference were different in their emphasis. They tended to start at the point when visible facial difference entered their lives. The seeds of resilience, however, may be set long before such an occurrence. Carl recollects difficult times from his childhood and makes connections between the dispositions he developed then with his approach to fighting illness and disability now:

> *Carl: I think ironically looking back at what I have just said to you, I think that might be why I strive to achieve all the time because I had to do very early doors.*

Resilience was strongly tied to recovery and a return, or change, to what was seen as ‘normal’. Peter identifies a strong focus on recovery and highlights the importance of the support of others, in his case his workplace and key relationships he had around him at the time:

> *Peter: And so that to me perhaps shows an overdrive in terms of what I was going to do in terms of my own recovery. But also the effect what my appearance would have on others, let alone how people would look at me at the time, it was not in thinking. Atypical probably, but it does prove, however…that if you have a clear and achievable focus on recovery and you know people at the other end will support you and be there to welcome you. If you have got that, then nothing else really matters, the wreckage that has on everyone else.*

None of the respondents described personal communities where all connections were damaged or lost and for many there was continuity in the form of close family, partners and very close friendships.

Many respondents' personal communities continued to develop and change and for others their resilience was manifest in adaptation of their relationships and resources to different purposes in life. This was particularly the case for those experiencing life threatening disease where the ability to continue in employment, and survival itself was at risk. Some respondent's appear to have decided that their body is as 'good as it can be'. This was most striking among those whose condition had stabilised. They have had to 'get on with it', whatever the reactions of others or others' conceptions of normality, or even their own reaction to their body:

> *Ken: So you walk into a shop and you see that image coming back at you and it goes into your guts and you get a kick and it knocks you down a peg or two because inside of you, I keep using this it's me in here, I'm in here, and that's what kept me going through… once you get used to that image, the image that looks back at you, once the brain clicked as soon as you looked in a mirror or the one that you catch yourself looking back and you know that the image is the image that you have now been left with, the new image. That's when you have started really on that road to recovery…I can pretty well say that it took six years for that to stop and that was, if I had known that had to take place then I would have been a little, and it would have been so much easier. But so what you do is build everything around that and your self-confidence goes up and you know that what people are seeing is the image that you have got in here now and then you build relationships and friendships around the fact that it's not that important and the importance of the scarring and disfigurement goes down and down and down.*

Reaching 'stability' for some conditions can take considerable time; some people have to live with an active condition for many years. People have ups and downs, no-one is continuously 'optimally functioning' (Ungar, 2013a).

Some respondents noted that they would not have wanted to explore the issues discussed in the interviews at times when they were experiencing difficulty.

The presence of visible facial difference did not seem to necessarily cause adversity independently of other circumstances, experiences and relationships in people's lives. Gaining access to resources and experiencing nurturing relationships in their respective communities contribute to how people feel they had 'done' in life and to how they felt they had coped.

7.7 Three voices

This study has identified three voices used within respondent's accounts when describing how they managed their successes and challenges: 'sustaining', 'managing in some areas', and 'developing my way'. The voices have a time dimension. It is difficult for an individual to know, how they are going to get through a difficult period when they are in the middle of it, and in what ways they are going to succeed in achieving what is wanted most from life.

7.7.1 'Sustaining' voices

This voice was used by ten respondents who describe themselves as having success in several areas of their life, and sometimes explicitly using the idea of resilience. This is described as a process. Ken's perspective on his experience of success shows how his disposition and his response to his disfigurement inter-relate with aspects of his ecological system, in particular employment, business development, and relationships with his wife and family:

> *Ken: Success to me, I look back on what I have done and feel I have been a success. I have managed under some extreme conditions to keep, I had a dip around the time my Mum died, and despite knock backs and despite kicks, I have developed in here somewhere, developed a positivity that has kept me kind of upright.*
>
> *I feel very proud of what I have achieved from a career point of view, from a family point of view and particularly in coming to terms with my disfigurement. I am, when I divorced my first wife, I was quite happy to feel that I don't have the need to get married again, I am quite happy in my job and was not bothered.*
>
> *When [name of partner] and I did get together and that progressed and we decided to get married and I look back on the twenty odd years we have had together, that has probably been despite having some serious setbacks, the most successful period of my life.*

> *I am really proud of what we have done with the two kids and that we have managed to run a business from home and still stay sane and we are not alcoholics, and we have two lovely kids who are well adjusted and, yes, I think in general I can leave this world and think, yes that's been OK.*

As will be seen in Chapter 8, Ken keeps his relationship with his mother in his personal community as a continuing bond (Klass et al., 1996). He needs to keep her by his side as part of his construction of resiliently living with her death. Her support was fundamental to his survival after his accident and instrumental in initiating his learning about when to protect himself and when to go forward into challenging situations.

Fragility and toughness reside together in individuals and in groups of people in personal communities. Lewis describes his most important connections in terms of living with visible facial difference as coming from within his family:

> *Lewis: He would never ever let me down, not ever. I know that and I have a lot of friends like that. But the people I keep closest to me are my family, if I lose a friend I lose a friend, I won't lose family. Friends you can make if you are lucky and if you are of a good enough character, you will always make friends, but you can't make family.*

The family membership is based on relationships of commitment and love. His family has a history of toughness and resilience, and persisting in the face of significant difficulties:

> *Lewis: I would get a pair of boots made out of my mother because she is tough. My god is she tough, but she's as frail and fragile as most women and she's a wonderful person. But there is an awful lot of that in my family tough people*
>
> *Rose: Your sister too?*
>
> *Lewis: Yeah, resilience, yeah, resilience is there. We are not the hardest people in the world and we never could be. But we are resilient we are tough, erm, and we, family, and we are emotional as well, but there's a lot of love in my family. A huge amount of love, you know you can't go anywhere without love.*

His analogy to boot leather conjures up an image of tough armour over a loving centre. Similar ideas can be seen in other accounts where respondents have described toughness as a part of their resistance to being affected by negative assessments by others. The development of this aspect of resilience needs to be contained, as loving, supportive relationships co-exist alongside toughness.

Relationships from families, partners and friends are important influences in understanding resilience. They can provide a structure, and a way of guiding or supporting (Ungar, 2004a). In addition they provide a narrative about the kind of family one comes from, as in Lewis's account.

The family story and role model influences are bound together. The structures of a family can enable connections to be made to those who have the resources they need. Fiona describes how supportive her grandmother was when her children were young. Her grandmother provided the understanding and respect she needed as a young mother and served as a role model through her tenacity. She understood the pressures in caring for an unwell child within a family. Her grandmother lived as a single parent of four children while her husband was away at war and she cared for one of her children who had serious illness:

> *Fiona:…she had a lot to deal with medically wise that she was an incredibly strong woman I mean it's a cliché and what have you, but when my Grandpop's came back she still ruled the roost. You had to, you had to get on with it then, and I think so she's very much the type, well you have to get on with it, you have to make the best of what you have got. Erm, very resilient woman, but understood how difficult that was as well. Because she had to go through it and so I am not saying she was broad minded, she definitely wasn't broad minded or open about things. I think she was just more supportive of me and understood because of medical aspect more of what we went through I think and probably of how difficult it was for her.*

Her grandmother, although deceased, continues as part of her personal community, and is still regarded as a valuable resource in her life.

Isobel sees herself as having resilience and sees this as a type of determination to tackle potentially difficult situations and connects. She links this to a hardiness she developed when she was younger from her exposure by her family to establishing relationships outside of the core family:

> *Isobel: I know it's hard but I think you are better out in the community. There are some lovely people, some really good lovely people. There are some horrible ones but you are always going to get those. Yes. Yes.*

Similarly to Fiona, she identifies her relationship with one of her sets of grandparents. Visiting them provided a respite from a bullying school environment and access to alternative environments in which she developed her love of animals. Her grandparents provided a nurturing relationship in addition to that of her parents. She describes learning strategies for withstanding the prejudices of others from her grandfather:

> *Isobel: I mean home was fine, I couldn't talk to my parents about it but, erm but, then going to stay with my grandparents it was a completely different environment. My uncle had a farm and we went and helped out on the farm and things and the great thing is with being with animals. You realise that animals don't judge you do you know what I mean? And that it is probably why now, and it has probably come from my grandfather because he was always worked a lot with animals. And he was illegitimate, my great grandmother decided she didn't want to get married which was fair enough but in early 1900s there was a fair bit of stigma and my grandfather had been bullied quite a lot. So he was sort of developed this love of animals and this is where mine has come from, do you know what I mean?*
>
> *Rose: When I was listening to your tape he comes out as a very important figure?*
>
> *Isobel: Oh he was yes, he was very, very important. He could just identify, he didn't say a lot, it was just his different experiences. I mean he had a brother and his brother wasn't bothered but Grandad hated being called a bastard or whatever, you weren't a love child in 1905. But that was his mum's choice she didn't want to get married, so I mean it would have been fine today, wouldn't she? But then he just didn't like it.*

> *He did have some contact with his father but they just lead separate lives. She was a very feisty woman and very determined was my great grandma*
>
> *Rose: He had got some experience of dealing with stigma?*
>
> *Isobel: Yes, he had and that sort of helped me. It wasn't direct, it was indirect and when you look back now, it was sort of little supportive strategies really, if you analysed it.*
>
> *Rose: Can you think of one?*
>
> *Isobel: Erm, I mean he always used to say, and a lot of people don't agree with this, sticks and stones, that saying, sticks and stones will break my bones but calling me names won't hurt me. And I know a lot of people say that isn't the right phrase to use, but at the time it helped me. And my grandfather used to say there is always someone worse off than yourself. That's probably the one more, but he always used to say you think your life isn't fantastic, but when you look around you can always see somebody who is in a worse situation than you are. And that's and one that I often think about.*

Isobel feels this guidance has enabled her to regard her visible facial difference as a small part of her person. Through her commitment to forming relationships outside the family, she learned there are many people with whom one can establish either casual or close relationships. She sees her challenge as keeping open to new experiences with new people.

Relegation of concerns about visible facial difference to a secondary issue features in some accounts. After a traumatic accident, Peter's focus was on recovery and getting as close back to his normal life as he could. He prioritised returning to work and did not feel a need to worry about how other people might respond to his appearance. His priority of meeting his return to work target was supported by his workplace, and his recovery was supported by his partner and several close friends and family members. Peter describes how he was able to ignore the responses of others to his facial appearance but this experience has changed how he looks at other people. He recognises how his 'normal' behaviour of looking at a disfigured person is now underpinned by a different sensibility:

> *Peter: Well I have always had to look relatively smart because of the job I have done and even with no hair and bits hanging off I still tried to look as smart as I could. But it's not a great issue. Unless [name of his wife] and I are going out and I know she is making herself very smart then I will too. I will put a suit on and that sort of stuff but I don't really worry about appearance at all. I mean I will stare at someone who has got a serious disfigurement the same as you would do when you first see them, but probably through different eyes than I would do before, because the recoil isn't there. You know that people can recoil away from someone who is much disfigured, some people do, crossing the road on the other side of the road to avoid someone with a mental health disorder but someone with a broken leg doesn't bother them at all.*

A fighting and competitive spirit combined with a concern for others can be heard in some accounts:

> *Roy: I was much better at secondary school because by then I could always stand up for myself. I used to stand up for other people and I mentioned that racist thing we had at that point in the late sixties, early seventies and I was always standing up for people who could not stand up for themselves, because I could. I was number one in the county by twelve. And we had a fantastic games teacher, but despite the fact that I was having operations he would always help me when we were having cross country he would let me start off a bit earlier. He would give me a five minute start and make sure he used to encourage me with the rugby and judo and get me involved. I meet him fairly recently we still have time for each other.*

For Roy it is important to connect his ability to stand up for himself with a commitment to standing up for others too. He has been helped by others which enabled him to develop his physical ability and toughness and he shares this with others whom he sees as part of his community. He sees commonalities between experiences of racial prejudice and prejudice against people with different abilities and appearances.

Roy and Carl have described success in dealing with their bullies, and this was not just explained as an individual characteristic. The ability to stand up for oneself can develop from harsh beginnings. Jane also described her fighting spirit. Her account highlights how differences in situation, degree of support and gender can make what could have been advantage into a problem. She recounts a conversation with a friend about their schooldays:

> *Jane: Any trouble in school over my appearance or socially interacting she said it didn't come from me at all. She was absolutely adamant. Can't be moved on it, [name of friend], whatsoever. So I think if, you know what I mean, if someone walks up behind you and punches you hard on the back of the head and calls you for your face and walks off as one of the lads. Or maybe one of the girls would go for you and you would have no choice you would have to fight. You really would.*

Jane was categorised as aggressive by her school teachers, whereas her view was that she was seeking to protect herself from unwarranted physical attacks. The fighting spirit appears more acceptable in some environments than others and this account identifies gendered perceptions of acceptable behaviour.

Neither Dave nor Vera felt they have experienced limitations in their life chances or choices based on having a visible facial scar and suggest that this is in part due to its lack of severity and in part to their highly supportive relationships. Vera notes that the surgery she had as a child did not disrupt her education. She wonders what, in her 'normal' upbringing and education, has resulted in her having no significant memories of disturbances connected to her facial scar. She concludes that her experience signals that it does not have to be like that:

> *Vera: And that makes me sad that that is the case because it doesn't have to be the case and I don't see any relation between the facts that I have, had, I was born with something that affected my face. I genuinely think that it is not normal, or the standard, or generally the way people are born; and my parents and the medical profession decided something needed to be done to right that wrong, and so therefore I have a scar.*

> *In my brain there is absolutely no logic between those things happening and getting a worse paid job and doing worse educationally and having trouble developing relationships and things like that it is just doesn't compute and so I start to get on my box and think that shouldn't be like that and think I have to save the world and I have to change everything.*

Vera's search for an explanation brings in appearance and functional severity, childhood socialisation and experiences in educational and health care institutions and also a sense of unfairness that some people experience their lives as affected. These accounts indicate that the presence of a physical visible facial difference is not viewed as an independent risk to development, but that the 'risk' resides interactively in the relationships and ecologies in which the individual is embedded. The presence of visible facial difference may be so well absorbed that the contributions of these relationships and ecologies are almost ordinary.

7.7.2 'Managing in some areas' voices

Four respondents primarily used the 'managing in some areas' voice. This voice reflected those times, places and experiences where respondents' felt they managed some areas, whilst other areas of life were more problematic. Respondents using this voice tended to see themselves as survivors - they have come through some very difficult times and this has required strength and resource but the outcomes may differ from what people might normally regard as successful. Although some of these voices contain accounts of depression and resignation they also have resilience within them. Bridget's frames her account as one of managing rather than breaking down:

> *Bridget: …it very difficult to say breakdown because I don't think I had that. I think I hit low points and I think I managed. How someone else might see it I don't know. I think I managed.*

Bridget talks of her long hard work of learning to live life *"being different".* This involved learning that other people's reactions to her appearance were part of a social process rather than necessarily personal.

> *Bridget: I was somewhere in my thirties, late thirties, probably even early forties when I started to actually think more about it. I think the counselling actually helped like they say when you have a client, what's going on for that client is going on for that client, but is not necessarily going on for you. I think that itself made me think deeper…I started to fully understand, no, I don't have to accept it. It's not my issue it's what is going on for them.*

Her professional training in counselling enabled this learning:

> *Bridget: …this last few years there has been a lot of mental and emotional activities brought on by events, starting the counselling really made me turn round and have a look at myself which is a good thing. I have learned more about myself and I am sure there is a lot more to learn and I think I need to look at myself and the counselling has helped me do that. Because how can I look at a client if I am not able to look at myself? There was a huge gap in that section, got married left home, went with that, that gave me space to look at where I was, finally gaining something that I really wanted that I never thought I would have.*

Bridget talks about how she found purpose and love in her life through her relationships with her children. She was also able to achieve healing in her relationship with her father. She describes valued connections with a small number of very important relationships, most specially her children and pet dogs. Bridget has spent many years as a carer within her family and the opportunity to locate paid work using the skills she values is difficult to achieve. Her greater understanding of the processes of interaction has not been sufficient for Bridget to experience ease in social situations. She feels that her protective mechanisms of keeping other people *"at bay"* and her limited trust of other people hinder development of relationships. She attributes this to how her acquisition of visible facial difference was bound up with her childhood experiences, rejection within her family, and school environments:

> *Bridget: I think for me, my difference came and I was impacted by other people's reactions to me, which played a huge part in how I viewed myself as a person and the struggle that goes with that. If you are not accepted in society and you are not accepted in your own small group then where are you accepted?*

She raises important questions about the types of assistance needed to help some people living with visible facial difference. She believes that approaches that are valuable to those with an *"out there personality",* may not be the kind of assistance that would help those who missed out on guidance early in life. Her account seems to ask how achievements of those who seem not to be doing so well, recognised.

Managing in some areas means there are difficulties in others. The resilience seen in 'managing in some areas' can co-exist with resignation about those times, situations and experiences where there are limitations:

> *Alan: That's surviving not thriving, it's like I've created a situation where I can cope with anything. But I can't plan to do anything.*

He describes his early years in terms of no-one expecting or encouraging him to be anything, in part due to his health problems and in part due the circumstances of his family:

> *Alan: I had no ambitions. No preselected path. No nothing. And as a teenager it just didn't happen. No one gave me any advice.*

However, he holds to his ability to manage in some areas through his achievements of developing unique ways to manage his skin condition. This learning overlapped with developing an interest in a sport through which he became physically fit:

> *Alan: This was different. It was socially acceptable…and at that time I started to get the skin worked out, the diet worked out and so all at once I had become healthy…the skin cleared up, the insomnia vanished. The first time I had had sleep in donkey's years and my life started to sort out. And that's when I realised what a mug I had been most of my life, because when I looked back at all these things I was doing just to distract myself from pain.*

His enjoyment of sport has led to other benefits, a confidence to be who he is and to not be so afraid. The experiences of training with others, being trusted by his coach and becoming competent enough to teach are valued:

> *Alan: I was all shallow, and now I am a lot deeper so I have realised I can be myself and if people don't like it, fair enough they just don't like it. A lot of that has come from [name of a sport] though. Now I am physically confident I have no reason to be afraid of anyone. A lot of my life I was very afraid.*

Alan, as discussed in Chapter 6, feels this realisation has come too late in his life. He believes the protective mechanisms he has developed limit his ability to trust other people and to weather ups and downs in relationships:

> *Alan: [name of relative] in the meantime spends an awful lot of his time alone.*
>
> *Rose: Do you?*
>
> *Alan: Yes, oh yes, for all my life – this is a very interesting city and there is a lot going on, but I have no friends' only acquaintances*
>
> *Rose: You used the word friend here…*
>
> *Alan: Yes, no friends up here, and it's been like that for a good four years now. I did have some friends up here but they, I could see a tragedy going to happen and I ducked out before it happened.*

He feels he has found come ways which help him manage his loneliness. He engages in activities and hobbies which sustain his interest and help him avoid becoming as insular as he has seen other people become:

> *Alan: I set myself nearly impossible goals on a regular basis. Most people specialise, their lives get narrower and narrower. Mine gets wider, it's this distraction thing where I am trying not let myself become truly emotionally aware just how empty my life is.*

Tom’s account of ‘managing in some areas’ differs from others. He is in the process of dealing with changing health conditions which are a source of stress and pain. He has rich sources of support in his personal community and is developing new supports for his health care needs at the same time as finding distancing among his social contacts, including a close friend. His current desire is to retain as much of his previous normality as he can, but there are many *“not knowns”* to do with his health and employment. He describes a time of transition in which he is seeking to remain positive to as yet unknown outcomes.

Steve credits the support of his family for his current circumstances. He lives close to his family of origin and he has supportive relationships with carefully selected family members and family friends. He describes himself as someone who wants to (be left to) get on with things in his own way. He remembers painful experiences of realising that people talked about him behind his back:

> *Steve: Well it was gradually I think erm somebody told me once, whether it is true or not, you are not really adult until your mid-twenties when you have learned everything. And I thought, yeah, you know if they want to, I don’t care what the hell they say now-a-days just, you know, you have got to get on with your own life. It’s also if you start thinking about that again, you would lose your confidence again, and get all upset about it. I thought well you know it’s their loss. If you don’t like what you see, stuff it.*

He has learned to listen to how people talk and not engage with those who talk about others in negative ways, and feels this strategy works for him. He identifies himself as someone who has little need for sociality, preferring the company of a trusted few. However, he resists seeing this as a deficit and identifies his preference for a certain degree of isolation with his valued identity of coming from a farming background. He sees farmers as used to spending long periods of time of their own with *“with a radio on in the background”*. He regards his greatest problem as finding long term employment and he is currently considering whether disclosing his disability would be helpful to him. His concern with taking this step is about experiencing a further loss of privacy.

The approach of his family has been one of not acknowledging his condition and he did not learn about his diagnosis until his middle adulthood and then only indirectly. He does not currently have access to resources in his personal community to help him address these issues of disclosure.

7.7.3 ‘Developing my way’ voices

A ‘developing my way’ voice was associated with three of the younger respondents who have lived with visible facial difference from birth. Common to all three was having at least one person in their family who fought for them. This was often their mother, but fathers also played a role. The respondents talked about developing aspects of their lives such as making new friends, moving to a new city, developing their role at work, dating, or getting married. For these respondents developing confidence was a central theme. Confidence can be seen as important genesis in developing resilience as it is associated with seeing themselves as having capacity to deal with the challenges they face (Ungar, 2004a):

> *Gina: You know I hope to develop in my career and stuff and hopefully start a family and stuff but later on. But, erm, you know build my self-confidence*

Gina talks about the challenges of making friends in a new work setting:

> *Gina: I mean quite a lot of my friends have had like maybe they are disabled and stuff and I think it’s like people who are like that don’t judge you and stuff. It’s easier than making friends with someone who has not had any disabilities. So like I always think, like because my brothers and sister have been brought up with me and stuff then I don’t think they would judge anyone like, yes, hopefully like you can make friends with people who are different and stuff.*

Eve notes that she has found some people are not interested in associating with people who look ‘different’. However, she has also learned that there are others who will be friends:

> *Rose: You are a bit more confident?*
>
> *Eve: Yes I think so and now I kind of feel like, if something, a facial difference or a disability of any kind puts someone off another person then that's someone I don't want to be friends with anyway.*
>
> *Rose: Do you think that does put people off?*
>
> *Eve: Oh yes definitely I think there is some very, very, what's the word; I don't know what the word is. Shallow, very shallow people, definitely*
>
> *Rose: What do you think they are worried about?*
>
> *Eve: Being seen with someone that's different*
>
> *Rose: About how it reflects on them?*
>
> *Eve: Yes, that's what it boils down to*

Eve describes how she has been able to find new connections through mutual interests, and she has learned how people from different backgrounds can share world-views:

> *Rose: You value friendship?*
>
> *Eve: it's just the support, the support you can give and it's nice to feel you can support others as well and nice to know if other people have a problem like. For example my gay best friends went through quite a bad time because one of their parents really didn't agree with them moving in together, because of the sexuality aspects of it. It's nice to have someone to support because you know if ever something does go wrong someone is going to be there unconditionally for you as well. I think that's what it is, the leisure activities as well, socialising, being able to talk and enjoy the same interests together.*

There is a relationship between difference and having a limited social space in which to develop. For Mark, being noticed and stared at is a commonplace experience and he prefers environments where people have become used to his appearance in order for him to feel comfortable. He describes his process of developing acceptable ways of dealing with his anger at the behaviour of strangers. He examines how a relationship between exclusion and difference has produced avoidance and sapped his confidence:

> *Mark: yes if I had been if I wasn't as excluded, if I was treated better or treated as everyone else maybe I would have done more at school or I would have maybe attended more clubs or had the confidence to do what I want. Maybe. That I mean because I am like this from birth I think I must have got used to not wanting to be the centre of attention or wanting to be included as much as other people. I think that's the same kind of scenario is maybe if I was walking thought the city I would get looked at quite a lot and that would annoy me. In the same respect, in the same type of way, if I was in school if I was to join a club or to try out to play or something then I would be looked at quite a lot. Then I wouldn't have done that yes.*

Finding suitable employment has helped, as well as providing the financial resources with which to live independently. Mark has recently started an interesting job in an environment where people are used to his appearance and he can feel comfortable. His account shows how facets of his developing confidence are built around experiences through which he has learned he can develop interests and take opportunities:

> *Mark: I think because college isn't like school, college is voluntary and you choose to go and learn. I think because of that I think maybe my confidence grew a little bit and I think if there was anything I wanted to do I would do it.*

His processes of developing confidence is one with ups and downs, having experienced a 'dark time' when he was unemployed after he left college:

> *Mark: They told me they needed a cleaner and I said OK because I needed the money. I didn't see that as wanting to do anything but now I think after doing the cleaning work and I think after having that dark patch of waking up and there is nothing to do. And lonely and I suppose because at the time I was living on benefit I wanted to change that. I wanted a job and I wanted to go out and earn money and I wanted something to do. Yes. But yes. But I am, but from that in the middle of that dark patch I think I did apply for quite a lot of jobs and I did go to the job centre and sign and all this lot and try to get a job. And now I am here.*

He became aware of other opportunities within the same organisation through encouragement from his family. The development of a close friendship was central to seeing himself in a different light as someone who could act. He sees this as coming from the mutual experience of being able to help each other with their different challenges in life:

> *Mark: I think maybe since [name of best friend] my confidence has grown a lot more therefore if there is a situation or an opportunity I erm handle it a bit better as it were. It's certainly now it's been a bit more erm more of a…what's the word…I have felt certainly now I feel like I can do that. There will always be the not wanting to be in that situation with other people and feeling the awkwardness but because my confidence has grown then I feel like, yeah, I can do that if I really try.*

He can see the possibility of developing further in his new job with the support of his best friend and family.

7.8 Summary

This chapter connected two areas: contexts of stigmatising and negative responses from others, and developing a resilient orientation within these. The kinds of 'assessments' respondents feel they can be subjected to can be stigmatising particularly when connected to assumptions about cognitive abilities or mental health status. They could lead to the misperception of the individual's personhood. There is a sense that presence of 'assessments' contributes to feelings of settling for less or experiencing constraint on agency. The idea of fear playing a role in avoidance to the extent that this can become part of ones 'normal' experience has been explored. However, it can become hard to tell the difference between 'normal' avoidance and that which is more limiting. Nurturing and encouraging support from close relationships have important parts to play in this area: balancing safety and movement, enabling adventure outside a family 'cocoon' are played out in family settings.

Uniqueness can bring with it a sense of not knowing how to deal with consequences, and for some, this promotes a search for greater knowledge. Some respondents recognised 'automaticity' in another's perceptual acts of noticing, whereas other respondents felt that these notions naturalised staring and could be used to mask processes of discrimination or prejudice.

Garland-Thomson (2009) has argued that it is not an either/or matter. She has identified there are generative aspects in staring encounters such as: catching interest, recognising another’s personhood, creating knowledge as well as an oppressive side. What respondents seemed to be saying was however, the positivity, negativity or uncertainty of these encounters is highly contextual. They require a range of responses and alternative interpretations. In Chapter 8, the role of personal communities as acting as sources of alternative responses and interpretations is further explored.

This chapter has identified three voices of resilience in respondents’ accounts. The voices were not fixed but depended on context, and a different voice may have therefore come to the fore as life changed. Even in more difficult circumstances efforts were being made to mitigate some of the less desirable aspects of lives, in particular isolation. The importance of supportive relationships was described by those with visible facial difference. This was often with parents, and particularly (but not exclusively) their mother. In addition finding other connections in a personal community who had experienced stigma in any form could be a helpful developmental resource. Several respondents described such relationships with grandparents.

Cognitive-emotional coping processes were described, by some respondents, as a part of developing socially acceptable way of dealing with the behaviour of others. Some respondents found their protective mechanisms could become a barrier in making new friendships. Personal communities, particularly the roles of close family members, were discussed in terms of identifying supportive resources, role models and supportive family cultures. The presence of three resilient voices indicates that a resilient orientation is an ongoing feature of adults living with facial difference whatever their perspective on how well they have done in life chances. They indicate the necessity of balancing fragility and toughness in developing and sustaining their chances and choices.

Chapter 8: Personal communities

8.1 Introduction

This chapter presents and analyses the personal communities constructed. The analysis explores how different personal communities ‘work’. Typically, respondents talked about immediate family, people from their family of origin, friends from school days, college days, work environments, churches, clubs or sporting associations, connections with healthcare professionals and involvement in charities. Some respondents included pets and others relationships with the deceased. While many of these accounts indicate a richness of connections and resources within people’s social worlds there is also considerable variation. No simple relationship was found between type of personal community and type of visible facial difference or voice of resilience.

8.2 Constructing personal communities

One of the aims of this analysis was to examine the relevance of Spencer and Pahl’s (2006) understanding of personal communities to those communities constructed by people with visible facial difference. There was diversity found in the personal communities of people living with visible facial difference. The size of personal community described ranged from ten to thirty-three relationships. Unlike Spencer and Pahl (2006), none of the patterns described were too small to include in the analysis.

Twelve respondents’ personal communities mapped relatively easily onto Spencer and Pahl’s (2006) types namely ‘family-enveloped’; ‘family-like’; ‘friend-enveloped’; and ‘friend-like’. Five respondents’ personal communities did not fit readily into Spencer and Pahl’s (2006) typology indicating new interpretations of personal community. A feature of all the personal communities was that their central ‘structure’ was based on family relationships. Friendships seemed to interweave with family relationships. Three of Spencer and Pahl’s (2006) types were not constructed in this sample, namely ‘partner-based’, ‘neighbour-based’ and ‘professional-based’. The value of using Spencer and Pahl’s (2006) analysis was that it gave a comparative yardstick.

They sampled a larger population with diverse characteristics. They were clear that it was unlikely they had found all permutations of patterns. This study found patterns largely similar to those of Spencer and Pahl's (2006) respondents, indicating that the personal community of people with visible facial difference are 'normally diverse'.

8.3 Family-like personal communities

The 'family-like' personal community was the commonest personal community constructed, described by nine respondents. Exploration was carried out to check whether other characteristics of the respondents were in common in this pattern (Fuhse, 2009). No correspondences were found with type of visible facial difference, age of acquisition, gender or age group.

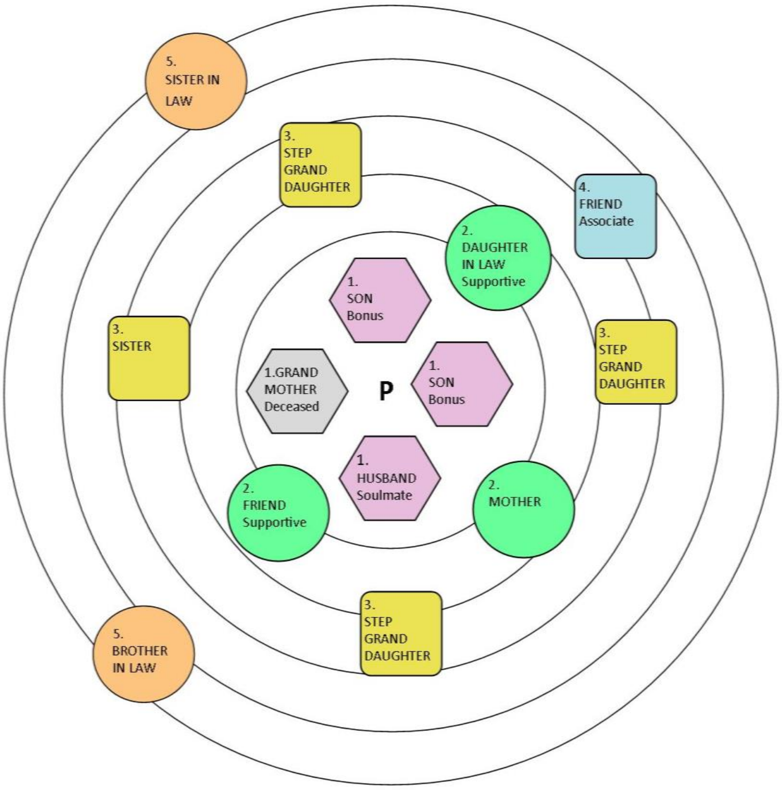


Figure 7: Example of a family-like personal community

The 'family-like' personal community, as conceptualised by Spencer and Pahl (2006), was based on primacy of the family and one of its features is that family members outnumber friends. Family-like personal communities include a few key 'chosen' ties but these tend to be placed further out in the circles than family members.

Figure 6 in Chapter 5 and Figure 7 above provide examples of family-like personal communities. Respondents with this type of personal community had a strong cultural belief that family come first. One respondent put all their important relationships, all of whom were valued family relationships, in their inner circle:

> *Lewis: Yes, they are the closest people in the world to me. That's my whole family, not including my grandson's mother, because my cousin was brought up like a sister to me, my sister, my sister's three children, my father and mother in law and that's it, not even my friends. These people are all the centre of my world.*

The priority is given to family, but they may also form strong attachments to friends:

> *Eve: So family to me, there is nothing more important than my family. Like, they be, they are more important than anyone to me and that includes my partner, my dad, among my immediate family, they are more important than anyone. My sister and my mum I am extremely close to, my mum is my best friend. And my sister is another best friend. I am really, really close to them. My dad and my brother, that's a strange, that's quite a strange relationship, because the men in my family don't tend to show emotions. So although we are not close, we are, if that makes sense, because I know that they would always be there for me no matter what. They just don't show it, if that makes sense.*

Where friends become close they are often described as 'like family' or, as Spencer and Pahl (2006) put it, 'honorary family'. Carl describes one of his close friends who lives locally and with whom he has a long standing friendship, developed from when they were colleagues about twenty-eight years ago:

> *Carl: We're really close, we are close without that and with that we are even closer. I put her [name of friend] very high. Yes, I would say she is as close as [name of sister in law]. She's very close; she's one of those, you don't have to see her to be friends, if you know what I mean.*

His partner, close friends and his sister and sister-in-law are important sources of emotional and practical support as well as day-to-day companionship.

They are people with whom he enjoys a relaxed social life. His wider social circles include less close family and friends who have biographical connections and keep in regular contact. There are connections to people who can provide knowledge, information and health resources that can be activated if required. Carl's network is evolving, even though it has been strained by illness and geographical moves. The people who are new are connected to his changing health. Carl sees himself as having two sets of important people; one he calls a 'health circle' and the other his 'life circle'. The personal community he constructed supports him in sustaining his recovery and down-sized life-style. He calls his relationship, with the two lead nurses of his local support group, *"professional friends"* and with a degree of ambivalence, tends to think of some of these as friends rather than 'just' professionals. He would contact them with a health care need, they provide back up support for his wife, and they contact him for help as he works as a volunteer providing a 'patient voice' between professionals and patients.

In Fiona's personal community a new member of her family, her daughter-in-law, is becoming a friend. Fiona describes how her close-knit family grouping has extended since her son's marriage:

> *Fiona: She's an incredible person, not only for taking my son on, but clearly not seeing his, she has seen his facial deformity, but seeing past that and seeing [name of son] for who he is. And loving him for who he is, and not putting any obstacles in the way and I get along with her so well. We are very similar in a lot of things really, which is uncanny I suppose and yeah. She's really friendly, and she gets it, and she understands, and we can talk about anything, and I feel really close to her because I feel she understands the whole thing, and so yeah, she's really important because she has brought into our life a whole new set of, erm, obviously a way of living because she has brought three girls with her as well, but also it's impacted on us in such a positive way.*

The potential insularity of their nuclear family grouping has been opened up by these new sets of relationships, and given them a *"new sort of hope"* for the future.

This hope is about the possibilities of family renewal that arises from a person without visible facial difference marrying someone with facial difference:

> *Fiona: You don’t have to be disabled too; disabled people don’t have to stay together, kind of thing.*

Practical and emotional support is primarily through family relations. However, close complex friendships with people who ‘get it’ (understand living with difference and disability) are included in Fiona’s personal community.

8.3.1 Family-like with a supportive friend in inner circle

Four of the ‘family-like’ personal communities placed a close friend in the central ring, although family outnumbered friends and accounts indicated that family was their primary focus.

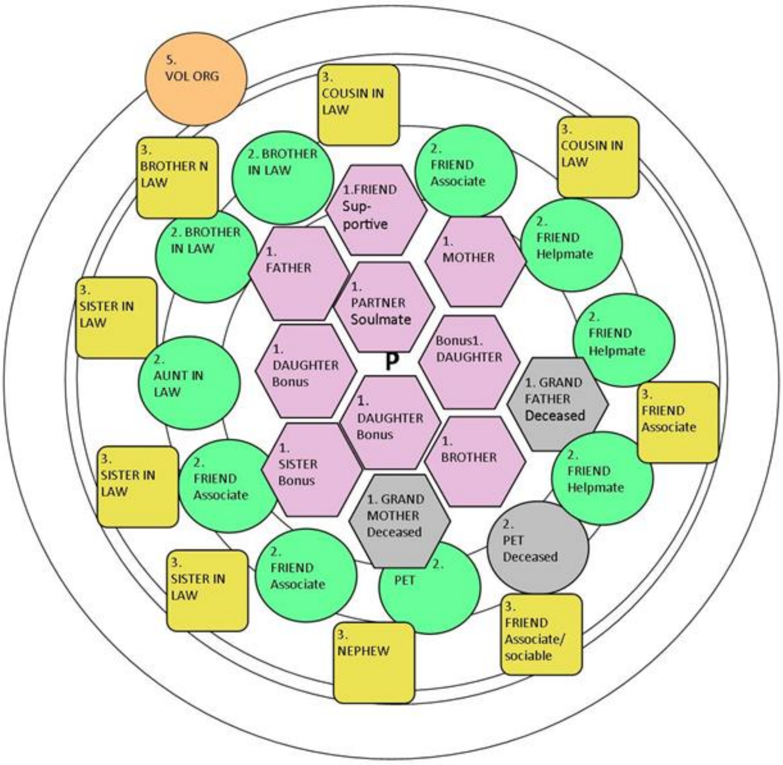


FIGURE 8: EXAMPLE OF FAMILY LIKE WITH A SUPPORTIVE FRIEND IN INNER CIRCLE

In Spencer and Pahl’s (2006) typology, a friend in the inner circle was used to indicate a ‘friend-based’ rather than a ‘family-based’ personal community. However, in Spencer and Pahl’s (2006) ‘friend-based’ personal communities friends outnumber family relations.

In the current study, some respondents have constructed their personal community slightly differently. They have placed a friend as central, within a personal community dominated numerically by family members. This distinction indicates a new type of 'family-like' personal community that is 'family-like with a supportive friend'. The supportive friend offers a complex friendship which is supportive, intimate and/or confiding and is in addition to close relationships with family members or partners. Dave describes his 'best friend' as being like a sister, and she is placed along with his partner, adult children and his deceased wife in his well-populated inner circle. All his practical and emotional support is associated with this central grouping:

> *Rose: If I asked you to give a name to circle one, what would it be?*
>
> *Dave: Erm a loving relationship, because it's my two daughters and it should be natural that you love them, but you don't always like them. Love them or hate them. [Name of partner] again she's love and [name of friend] it's sisterly.*

His 'sisterly' friend was a friend of his deceased wife and an important source of support for him in living with this loss:

> *Dave: Well there's one person up here. Totally along the lines we are talking of here, we sort of since [name of his wife] died, since moving here, I moved here when [name of his wife] and I got married. All the friends of mine were through her. I am not saying they have gone, but a lot have died and so on.*

She is one of the few friends he is still in touch with from this earlier time, in part because of their affinity. His current make-up of relationships included in his personal community is different to ones he might have described in the past and he associates these changes with ageing.

This new personal community pattern was not exclusively associated with ageing; younger respondents also constructed this pattern. Mark has included his best friend in his inner circle and describes this relationship as like a sister and is both a confiding friendship and a mutually supportive relationship:

> *Mark: I think her having done that and her being really the only kind of friend in my life who sees, who has seen my problems, and helped me deal with them, and has also been a friend without seeing those problems. She can recognise that I am different and she is allowed to make jokes about it because she is my friend. She can joke about it but she can also say how are you feeling about this, how are you dealing with this?*

In this type of personal community, while practical and emotional support comes from family and friends, the family predominates.

8.3.1 Family-like with a professional in the inner circle

A personal community with a professional placed in the inner circle was named 'professional-based' by Spencer and Pahl (2006) as reliance for support was placed on health or social care professionals. Although healthcare professionals were placed in some of respondents' personal communities, they were not regarded as the mainstay of support; this came from family.

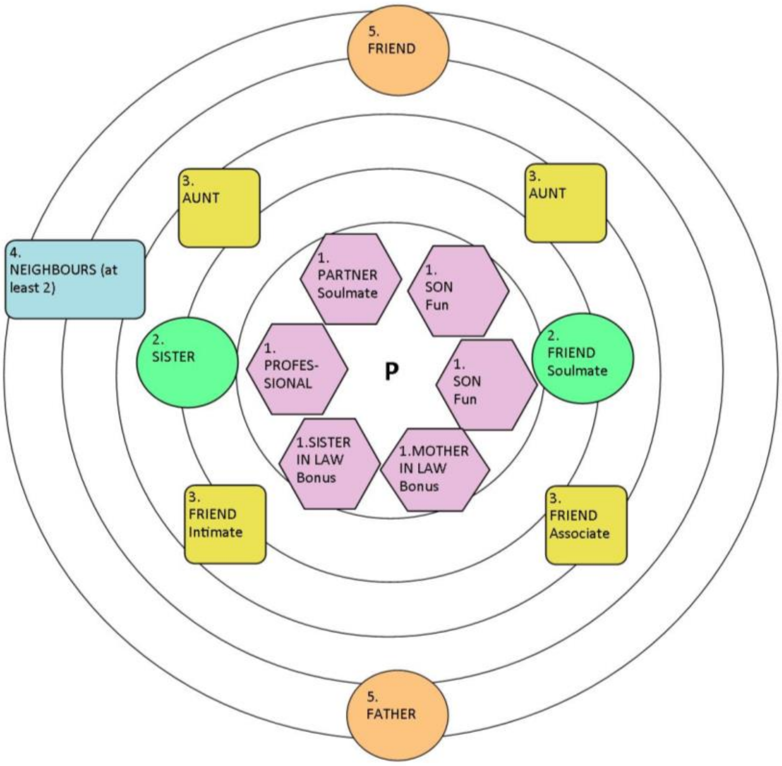


FIGURE 9: EXAMPLE OF A FAMILY-LIKE WITH A PROFESSIONAL IN INNER CIRCLE

This personal community seems to fit more readily into the ‘family-like’ pattern, rather than a ‘professional-based’ personal community. While the healthcare professional was seen as important in terms of providing health information and access to psychological support during difficult times for both the respondent and his partner, they were not the mainstay of their everyday support. This came from family members. Tom talked about feeling disappointed with a close friend who, he felt, was distancing himself. He noted that his social life stopped when he became unwell, and he had almost ceased to function as a social person, which was a source of sadness to him. The reasons for this are complex: some are related to his illness, pain and energy levels, but other changes are about others’ attitudes and the experiences of loss related to cancer and to the impact of his illness on his family, who have also withdrawn socially. Members of the wider family are working at holding the family together, in particular his aunt and sister-in-law, by providing support to his partner and trying to mobilise other less responsive members of the family. This personal community could be in transition from one that was surrounded by friends to one that has become family focussed because of the pressure of illness. This may be a temporary phenomenon, rather than a lasting change. This personal community with its central placement of a healthcare professional seems to provide an indication of the importance of support from healthcare professionals and how, at certain times and situations, they may be incorporated into the centre of personal worlds.

Spencer and Pahl (2006) envisaged that the types of professionals included in personal communities would be counsellors, therapists or social workers. However, respondents who had taken up a sport talked about how their sports coaches enhanced their sense of belonging and self-worth. For one respondent their relationships with their sports coaches were regarded as professional rather than as friendship. The support provided was in relation to health and fitness improvement and being a member of a socially accepted club.

8.4 Family-enveloped personal communities

In contrast to ‘family-like’ personal communities, ‘family-enveloped’ personal communities lack close friendships. People with this type of personal community, according to Spencer and Pahl (2006), have a narrow friendship repertoire, which includes simple friendship types only.

Family members on the other hand play a wider range of roles and are seen as the mainstay of social support. Figure 10 below provides an example of a family-enveloped personal community. Three respondents constructed this pattern.

In Steve's personal community selected members of his family are his main source of emotional and practical support, and companionship. He also is close to another family who live nearby. They are an older couple who are friends of his parents and have children of his generation.

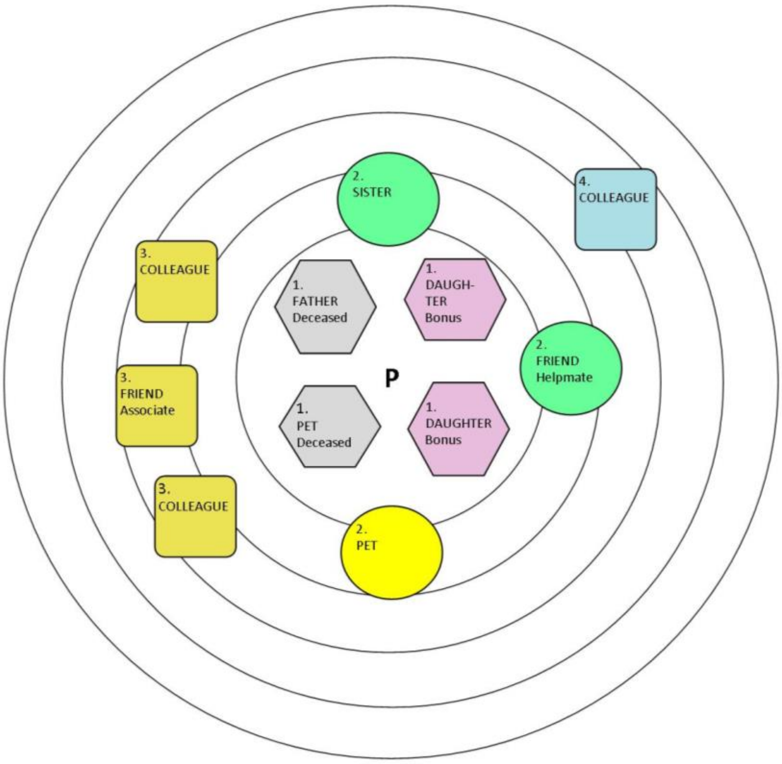


Figure 10: Example of a family-enveloped personal community

He thinks of this family as 'family friends' as the two families 'look out for each other' and have been connected through friendship since the respondent was young:

> *Steve: They are people I can rely on*
>
> *Rose: Yeah, is it one person who is the main person or are they equal?*
>
> *Steve: They are all equal, it's the whole family. [Name] and [name] are Dad's age and [name] and [name] I went to school with or were in Young Farmers.*

> *Rose: There are the parents on one and the brothers on another*
>
> *Steve: They put, well they were my Mum's best mates and they put me up and they knew*

Steve explains his personal community pattern in cultural terms, describing how people from a farming background may make particular types of connections with others on a neighbouring farm. They *"stick together".* Steve cared for his wife up to her death and he describes himself as seeking to *"move on"*. The loss of his wife may account for the ruptures in his friendship repertoire and his current reliance on family ties. However, Steve also describes how difficult he has found it over his life to meet people he trusts and who treat him with respect.

Other respondents who constructed this type of personal community also had experienced ruptures in their friendship repertoires associated with adverse life events. Spencer and Pahl (2006) noted that this personal community pattern was associated with those they considered to be vulnerable in their sample.

8.5 Friend-like personal communities

Spencer and Pahl (2006) characterised this personal community as one in which close friendship relationships are placed in the inner circle. In addition friends outnumber family members in the personal community (Figure 11)

This personal community most closely resembles 'families of choice' discussed by Weeks et al. (2001). One respondent constructed this type of personal community. Vera placed close friends and some family members within her central circle. Most of her practical and emotional support came from her boyfriend, close friends and sister who were dispersed over the three inner circles of her personal community. She has a broad range of simple and complex friendship types with an evolving repertoire. Although she retains some friendships from earlier times, new people are added as she moves through life. Vera describes her positive reasons for comfort with making and developing friendships.

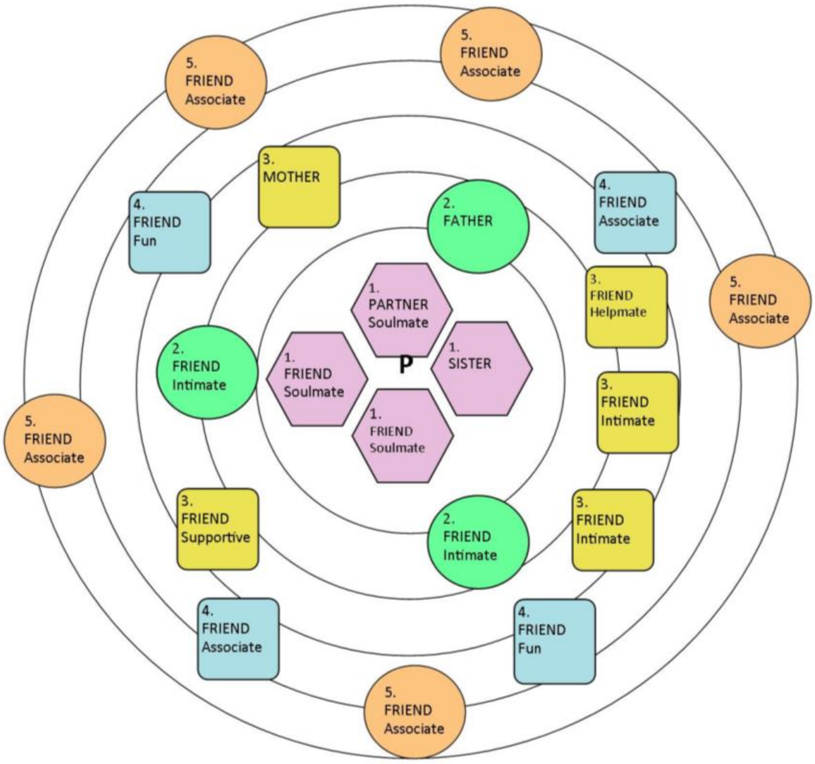


FIGURE 11: EXAMPLE OF FRIEND-LIKE PERSONAL COMMUNITY

Her friends are important as they encourage her to do things as opposed to the more cautious approach of her parents:

> *Vera: So when I lived in [name of a country] for two and a half years, "You can't do that because what about your house, your job whatever", whereas my friends, "Hey you are twenty-five go and see what happens it will be great fun you may come back you may not and I might visit you. Send us emails let's talk on the phone", a lot more positive about it. Whereas they were very practical but they saw the practicalities as things to stop me doing it and not problems to solve and so I could still go and do it. I think I wouldn't have achieved half of what I have achieved if I had just listened to them and they had been the only place where I got interaction and value. And with my friends bring a lot more diversity.*

Vera's personal community emphasises 'choice', with four close friends in the inner two circles, and whilst she is strongly connected to her immediate family, through her ability to make friendship connections she feels able to access a wider range of opportunities.

This aspect of friendship is described by other respondents, particularly those who have personal communities that emphasise friendship.

8.6 Friend-enveloped personal communities

The friend-enveloped personal community described by Spencer and Pahl (2006) reserves the inner circle for family, usually a partner and children. The key feature of this type of personal community is that although family are at the centre of people’s lives, core friends also play a supportive and day-to-day role and outnumber family members. Four respondents constructed this type of personal community.

Jane’s personal community fits closely with Spencer and Pahl’s friend-enveloped pattern. Her immediate family are central, and her second circle is made up of close local friends with whom she has practical and emotionally supportive friendships.

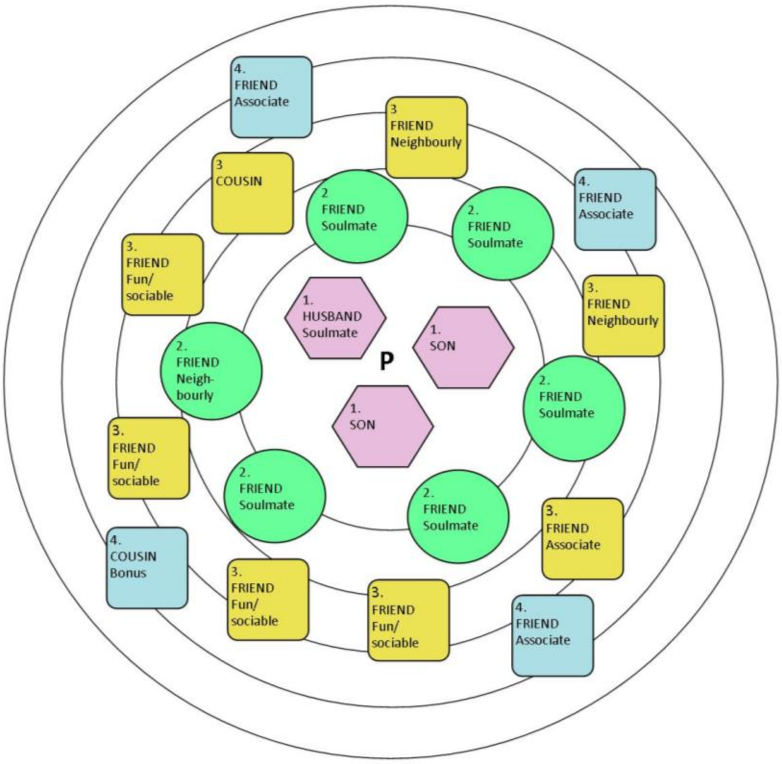


FIGURE 12: EXAMPLE OF A FRIEND ENVELOPED PERSONAL COMMUNITY

She met most of her friends locally, some whilst bringing up her children and sharing childcare, and others, more recently through her work. This supportive circle is surrounded by circles of sociable and neighbourly friends.

Jane includes few other family members outside of her immediate family of husband and children. Her parents are deceased and she has disengaged from wider family ties. Her personal community appears rich with friends, but Jane talks about how she does not see herself as central as she is not an organiser of social events:

> *Rose: The last question I have is, when we looked at this before, when you were talking about it and you said right at the very end that you were quite pleased with the way it was and it looked layered and complex and what you wanted. You did say "I thought I was more marginal"?*
>
> *Jane: I did, I don't see myself as the centre. No. Yes, I still feel that you know. I was surprised that I'm where I am in that friendship network because I always feel that I am on the periphery and always was. Do you know what I mean? So you always see yourself that way. But I am actually not, now I have realised I will have to see myself as more central in things, yes*
>
> *Rose: So you wouldn't use the word marginal?*
>
> *Jane: Not anymore, no*
>
> *Rose: When did that change?*
>
> *Jane: I think when I had a look at that, and I have seen that we were not quite as marginalised as I felt I was. I think you carry feeling through from being young as well. Yes. It's been quite a positive experience for me. Yes.*

Jane reflected that she has developed a layered and complex network of connections, which in a way substitutes for her less satisfactory family relationships.

Roy's personal community can be seen as either friend-enveloped or family-like. He has placed an equal number of friends and family in his personal community. Roy is firmly established within his local community and has important ties going back to his childhood through shared involvement in sports and his role as a coach.

His friendship repertoire is broad including both complex and simple friendship types and his relationship with his partner and two friends is comparable to the ‘soulmate’ category of Spencer and Pahl (2006). These are everyday confiding relationships which mutually provide practical and emotional support. Although many of his connections were established early in life, his friendship mode is evolving. Roy’s personal community is one in which his friends have become like family, and his family like friends:

> *Roy: Slightly, on the wider family you have got the common interests - grandchildren - but it’s more rigid and you will meet up with them on anniversaries and birthdays and therefore quite a regular pattern when you are going to meet them. But with friends it’s more ad hoc and you will meet them when you want to. It’s never a thing I have got to do.*
>
> *Rose: You have described several of your friends as being family?*
>
> *Roy: Yes, because it’s more of I care so much, so much about everything that happens to them and if they have a problem I will go out my way to help them resolve it and if I have a problem they will go out their way to help me resolve it. If I have a problem with at home would I call my brother, no he’s not that helpful with that sort of thing. I’ll call [name of friend]. If I had an emotional problem I would probably talk to [name of another friend] first, or my brother*

The bonds with family are depicted as more rigid than those with friends (Spencer and Pahl, 2006).

8.7 The inner circles

The idea of ‘inner circles’ has been used to identify the most important current relationships in a personal community. Both partner relationship and relationships with their own children, when looked at across different respondents’ lives, show more consistent categorisation of importance and centrality than other types of relationship. All respondents who were co-resident with others (with partner or children) put these people in their inner circle. The primacy of partner relationships in terms of central placement was also found among those who did not reside with their partner.

Several levels of interdependency were described by couples particularly those co-resident, such as shared material bonds, homes and financial arrangements; common activities and purposes in life; and care of children (Finch and Mason,1993).

About half of the respondents with partners placed only their partner and their children in their inner circle. The other half included other relationships in their inner circle as well. These included parents, mother and father-in-law, sister-in-law, niece, nephew, sister, cousin, grandson and relationships with important people who were deceased. Three respondents included a close friend and another respondent, a nurse. This indicates that for a number of respondents' close and important relationships with their partner and children do not exclude other close, important relationships.

Some respondents described how some of their relationships were so close they were almost part of themselves. This sounds like constitutive bonding described by Cooley (1965), where the other is expressed as part of oneself, as might happen with someone we love:

> *Bridget: People I want to continue as part of my life, those people I would struggle to live without. They are my purpose.*

Most often referred in this way were partners and/or children. The relationships were more than support, invoking loyalty, love, mutual respect, and emotional closeness that had developed through time, experiences and events. Differing metaphors were used, *"rocks"* (Eve; Peter); *"partners in crime"* (Tom); *"shared lives"* (Vera). This type of bonding could also include very close friends:

> *Mark: I think all my friends and family, on those lists and paper, I have a strict loyalty to. In fact if they need help I will help them, and if they are in trouble I will help them, and that loyalty is the same for all of them. [ ] So if someone is a family member immediately they have that loyalty because they are my family. If someone is a friend, if we have that connection and they are that close, they get that loyalty if you like.*

Other accounts emphasised the earned nature of inclusion of people into the inner circle. Steve only included people who he could rely on, who understood his ‘illness’, could be trusted to not talk negatively about him behind his back, and took him for who he is rather than what he had got. He included no personal friends within his personal community. His inner circle comprised members of his family of origin. Experiences over his life course of being let down by friends, he says, had led him to being cautious about making friends.

8.8 Inclusion of pets and deceased people

Six personal communities included deceased relationships among current important relationships. Eight of these relationships were included in the inner circle and the rest in circle two or three. Relationships included father, mother, wife, grandmother, grandfather, daughter, friend and pet dogs. The largest category was pet dogs closely followed by grandmothers. The majority of losses were between five and twenty years previously and one had occurred recently. Both genders included continuing bonds (Klass et al., 1996), and while most respondents were aged over fifty, one respondent was in their thirties. All the respondents who included a deceased grandmother were female.

Continuing bonds were with people or pets that were valued, loved or had played an important role in their life, one which they wanted to retain:

> *Eve: …and then I have got my grandma on here. She was one of, while she lived, one of the most important people in my life. And she died before five years ago now, and I still think of her every single day, and I think there is still a lot of qualities in me that I saw in my grandma.*
>
> *She would always, if I had had a daft argument with my mum and dad when I was growing up, she would always say “Come and stay over and you are going to be fine”. Very affectionate and she literally thought the world of her grandkids she would do anything for them. One of the things I respected her for was rather than being like “My grandchildren can do no wrong”. If you had done wrong she would tell you and she would say.*

> *Like for example I had had a massive fall out with my mum over one of my boyfriends and we had not spoken for three months and my grandmother was the one to come over to Uni at [place name] and basically said like look this isn't on. Like your mum is your family and no matter who's right and who is wrong you had better sort it out. You can't be as stubborn because one day you will regret it. She was kind of she was like a second mum.*

Eve continues her grandmother's commitment to family values and regards her as a role model in her life. Isobel includes her grandmother and grandfather:

> *Isobel: They were brilliant. They really were and they were just so loving and things. And you know sometimes your parents probably do get stressed and there probably were under currents at times but you know, you couldn't talk about things. But you went to grandparents and I think they have a different view on things don't they.*

The grandmother relationship was also experienced as an alternative source of understanding in Fiona's account:

> *Fiona: My nan well she was really important to me because my sister, bless her, obviously doesn't have any facial deformity, she's blond and beautiful, younger than me, and my nan understood a lot. I don't really know why, because she didn't have any facial deformity, or anything like that neither, but she really got me and really understood how I felt as a child, with my sister being Okay.*

The relationship with her grandmother continues into the present, in the form of a dialogue and Fiona feels she continues to be there for her:

> *Rose: Do you still relate to her now?*
>
> *Fiona: Yeah I do, I still talk to her now even though she has gone, yes, and I do think she is still there. And she is a very strict, very strait-laced woman and a lot of the things in life we wouldn't agree with at all.*

> *Yeah, but in terms of I don't know, just always being there for me, just to chat with and I know I used to go indoors and have a cry and how I'd feel and she would be so good, she never put my parents down or anything. She just would just be a shoulder to cry on I didn't ever feel I would be like that with my mum. So, it's interesting really, yes.*

Dave also talks about an ongoing conversation with his wife who died eighteen years ago. Dave sees the connection as one-sided he is the one who is talking. His current partner knows of her presence in his life:

> *Dave: Do you, can I consider a dead person?*
>
> *Rose: Yes you could, but you don't have to. It can be, I mean it's up to you how you define important?*
>
> *Dave: She's out of my mind most of the time but there are times now and again when you will think [name of wife] would have loved this, if [name of wife] had been here this job would have been done.*

Ken keeps up a conversation with his mother. He was devastated when she died:

> *Ken: I decided in order to deal with the loss I had to keep her here. So I used to take the dogs, go out for a walk with the dog, my old dog, she's here somewhere, and just talk to her about, and I found that really cathartic, and I really needed to just explain to her about a lot of that stuff that I didn't know she did. I think I suppose because I got that much from her she still stayed close she's still around here somewhere. So I can still talk to her.*
>
> *Rose: What do you talk to her about?*
>
> *Ken: Just how things are, nothing in particular, just general garbage particularly with the dogs. That, I've got to say, it isn't as usual, I don't do it as often as I used to. But I can still just walk up the road maybe walk up and have a smile, and I can have a smile.*

There is a connection between the loss of his mother and his experiences of visible facial difference. He talked about how she cared for him unconditionally while he was in hospital and for the remaining years of his childhood.

When she died, the depth of his love for her hit him hard. He talked about how she (and his brothers and sisters) both protected him and extended him to face situations he found difficult in the years after his injury:

> *Ken: It was mainly the exposure and I think, what's the word I am looking for, protection. I think she kind of shielded me once I had got fed up with visitors coming and I didn't want to see any more. I think it she started to realise perhaps that I needed a bit more protection from people coming to the house but didn't do it in any overt kind of fashion. The stuff I talk about and what I mentioned last time was how she would go out around the streets when the town was quiet. And I often wonder how much she appreciated the stares I really regret never discussing it at any length with her because I think she was just working on instinct. She had got a sense of what I was uncomfortable with*
>
> *Rose: But she didn't hide you?*
>
> *Ken: No, she was determined to get me out. She was determined, you know, that's it; I didn't want to see any visitors. She wouldn't stop anyone coming into the house that would normally come into the house.*

In looking back he recognised the effectiveness of the actions she had taken intuitively out of love and generosity. Although the family did not 'know' what to do, what they did was consistent with what he knows now to be effective means of supporting someone adapting to facial change. He found the best way he could survive her death was to keep her connected as an important person in his life and as a continuing bond (Klass et al., 1996).

The deceased pet dogs in personal communities were remembered in different ways. Rather than having a continuing conversation, they seemed to serve as a symbolic reference point to a significant period of Bridget's life where she needed love or protection and this came from her dogs:

> *Bridget: She was the caring dog, the nurturing dog, just like Dottie was a listening one and was there. Ellie was there always by my feet when I was there, fantastic with the kids*

These pets are remembered with fondness and were a source of support during difficult biographical events, for example divorce, times of isolation or depression. Somehow, remembering the love of the animal counters the memory of the difficult times, providing solace in the biographical story.

This compares to Isobel's reasons for including of one of her dogs as a continuing bond. She talks about her deceased and living dogs in a similar way:

> *Isobel: Yes, put Sammy and Barkley down. Sammy died a few years ago and then we had Barkley. And we go out dog walking and it's amazing who you meet. You talk about dogs, I mean you don't talk about the fact that I have a disfigurement or they are old or whatever, that they are struggling or a stick or anything. Like you talk about your dogs, same with children, you sort of talk about your children for so long. You know, my dog has done this and has your dog done whatever, it's things like this. And it's amazing the number of people, and nice people, I have met through dog walking*

She values them for the fun and recreation they enjoy together and helping make social connection to other dog lovers, making strangers into acquaintances.

8.9 Dynamics of support

All respondents identified important relationships and most identified these as supportive as well. They talked about how relationships were sources of practical and emotional support, people they might turn to in a crisis, or if they needed advice or comfort, friendship, or companionship. Different types of support were associated with particular relationships, rather than a relationship category. Family relationships with either family of origin or family of their making were consistently seen as a fundamental source of various types of aid and support.

Respondents defined the significance of important relationships as people who: cared for them, they cared for, they loved and liked, loved and liked them, and they saw on a regular basis and did things with. Other qualities were respect, loyalty, trust and acceptance, and being part of wider circles.

Respondents described how their current personal community was supportive in different ways. Those who constructed ‘family-like’, ‘friend-enveloped’ and ‘friend-like’ personal communities generally had resourceful personal communities which could be reached into to address particular needs and with whom a biographical history of supportive interactions could be traced. Those whose constructions were interpreted as ‘family-enveloped’ personal communities reported the least types of feelings, or types of support, in the interviews.

Respondents varied in the degree to which their relationships offered comfort or emotional support. Those who felt they had few connections which provided such comfort also described difficulty in developing trust with other people, especially when harms they experienced in life had come from family members. These types of experiences were recalled on a number of occasions in these accounts, and were often associated with examples of times, when, as a consequence, they distanced themselves from people or let a relationship drift as a way of protecting themselves. This highlights a tension between not wanting to be alone, but finding that sometimes this was a less painful option:

> *Bridget: The problem is with me is that I don’t tend to turn to people. My kids see me because I am at home and they can see the look on my face they can see everything about me and I can’t really hide it. But if they weren’t there I probably wouldn’t turn to people. I’d talk to the dog.*
>
> *Rose: So does that make you isolated?*
>
> *Bridget: Self-isolated erm and that’s lack of trust, people are painful. They can inflict pain and so why would I ever trust them. So it goes back to that childhood stuff [ ] I am easily let down. If I start to trust someone and they do something, it’s why have you done that and if they can’t sit down and talk about it and get it out in the open then I feel generally let down. And it’s why are they being like this, why are they being like that, erm trust is hard work and to keep that trust is hard work erm but people make mistakes and if people make a genuine mistake that is fine erm but trust erm funny*

These feelings were more likely to be expressed by those who constructed a narrow friendship mode, comprised of simple friendship types, and who had also experienced a rupture in their life associated with health. The ‘narrow’ friendship mode is part of ‘family-enveloped’, ‘neighbour-based’, ‘partner-based’, and ‘professional-based’ which Spencer and Pahl (2006) identify as the least robust types of patterns.

Respondents who had personal communities with ‘complex’ friendships could turn to those friendships, as well as family, for particular practical or emotional support. Emotional and practical support tended to be drawn from the inner three circles, but not exclusively so by all respondents. Someone who is a valuable source of support may not be placed in the innermost circles but may be turned to in a particular situation, for example, someone with whom they have a strong connection but they may see only infrequently. One of the reasons for a lack of correspondence between personal community patterns and how people experience support could be the negotiated nature of support (Finch and Mason, 1993). The personal communities represented importance in terms of connection and aspects of self, rather than support. People were not placed on personal communities for their ability to provide support; support was seen as an emergent element of these relationships and not their whole rationale.

Personal communities change over time, they are dynamic constructions but connections are not readily unmade particularly with family members. It is hard to capture processes of change in personal communities in a cross-sectional study. Two respondents at the time of the interviews were in processes of significant change. Tom talked about his changing health as affecting friend relationships:

> *Tom: I have got a mate who has always been there. First time round he was always knocking on the door, but this time I think this second time around he doesn’t know how to deal with it. Because he thinks it’s not good news, you know, coming a second time and yeah it’s weird, weird, disturbing. I should like him to come knocking on the door especially when you couldn’t drive. I like to get around but earlier I couldn’t and you would expect them to come and see you. The absence has been noted.*

His wife’s social circles have been affected, and support functions are drawn from a tight family circle. This has intensified his relationship with his wife:

> *Tom: Since I have been like this like even the little network of Mums that my wife has got who would round all the boys up and girlfriends up and live near us we used to get together and stuff on Saturday night and stuff in the garden and have a drink at somebody’s house. We have noticed that we don’t get invited now or if we do get invited it is like a very late thing. Because they know that obviously I couldn’t drink and I was tired all the time. And then there were nights when all the girls got together and they didn’t invite [name of partner] along. It’s like we have just been put out of the circle slightly because of the way I am.*

Tom was feeling sad it was difficult to retain friendly social contacts. His practical support needs were being met and additional psychological support from the health service was useful to both himself and his wife.

8.9.1 Local care and support

Personal communities can be looked at in terms of whether there is access to people who could provide practical emergency help. Most respondents’ accounts of support indicate they felt they could access help in emergencies, such as when ill in bed, needing help at home, or needing an urgent lift. Where they lived alone and had few such connections, respondents reasoned that they would deal with these situations on their own. Greater lack of local and practical support was associated with those whose lives were characterised by some degree of insularity at the time of the interviews.

8.9.2 Distant and virtual connections

Respondents talked about how important connections were maintained over geographical distance and time. There were descriptions of processes whereby people drift away, grow apart as life priorities change, or as people move. There were also processes whereby some of these connections were maintained virtually by telephone, Skype, social media, or email, interwoven with less frequent face to face contact. Virtual means were described as a way of keeping up with people already deemed as important. Two respondents gave examples of making important connections with new people using online means:

> *Eve: I met [name of boyfriend] through online dating but not in the usual dating websites. Because we both are really into computer gaming and there is like a play station games console, there is a forum online. Or you can go and talk about games and I have been a member on that website and so you basically become friends with people and then add them so you can play games with them. There was one time when I struggled to connect my play station online and so I was asking for help. And [name of boyfriend] replied and we became friends and started playing together and we just talked more and more and more. Until eventually we said "Shall we meet up?" "Yes" and we did and that was it. So it was kind of online dating but not through the traditional routes*.

This indicates that on-line connections are a way some people use to make important connections. Neither respondent who used the internet this way used 'traditional' dating websites rather they established connection through a mutual interest online. Most respondents used social media and email as an additional means of keeping in touch with people with whom they already had a relationship. It was useful over long distances and was used by some to re-establish family connections that had become lost though complex series of events and geographical moves.

8.10 Processes of social support

This section identifies particularities of support relating to living with visible facial difference. It considers specialist contributions that people with visible facial difference make, which are assistive in their personal communities.

8.10.1 Talking about appearance issues

Respondents discussed who they would turn to if they had appearance related difficulties in the present time. It emerged that there were many varieties of 'appearance-talk', some light-hearted, some serious, some only shared with closest relationships. These were felt to take place in much the same sort of ways that anyone would discuss, for example, haircuts, weight, what to wear for an event, tie choice. Linked to this perspective was the feeling that appearance talk about visible facial difference in everyday conversation was a topic that required sensitivity in an analogous way to conversation about someone else's skin colour, body shape or size. Invited, reciprocated and practically oriented appearance conversations were readily shared.

But where there was an emotional element; respondents who discussed these aspects, did so only with those they were close to, such as partner, a close friend, or a very close family member. There were differences in whether or not respondents allowed support from their close, intimate relationships about their feelings and/or insecurities about their visible facial difference:

> *Eve: Because if you asked everyone I knew I think only a tiny percent that truly know me would actually know that, because I can tend to put on quite a front. And [name of partner] is the one person that can see straight through that. [Name of partner] and my Mum and my sister and my Dad and brother, they know exactly what I am like; [ ] some of my best friends know that as well.*

Within close knit groups there was an awareness of the importance of how to discuss issues relating to appearance because of the different types of sensitivity each person has to their appearance at any one particular time. One person’s way of thinking about their appearance might be adaptive, constructive or helpful to them, but might not be felt so by the person they are speaking to. Respondents reflected on who they would talk to about negative incidents associated with visible facial difference and most commonly this involved close friends and family. When respondents discussed whether or not they might talk with particular people about their appearance concerns, or about difficult situations, a number of different factors were considered: who the person was; whether bringing up this kind of matter fitted in with the dynamic of the relationship; whether it was relevant to that particular relationship or whether it might make them vulnerable in the relationship or cause concern or worry to their friend or family member.

8.10.2 ‘Getting it’ cultures

The term ‘getting it’ has been borrowed from Fiona who used it to describe the importance of relationships with people who understand the difficulties faced in the ‘work’ and emotional experiences associated with living with disability and with appearing facially different. Experience of being able to deal with stigmatising attitudes and behaviour was an important element as discussed in Section 8.7 about the inner circles. It is not necessarily enough for a friend to have become used to the appearance of someone with visible facial difference.

> *Fiona: When they get to know you and they don’t see the facial disfigurement any more but that has an additional impact because they don’t necessarily realise what you are going through. I find that a lot with friends and family because there becomes a point when your face is the norm, so then which on the one hand is great, but on the other hand they don’t recognise that you are still living with this every day and still going through everything because it’s just Fiona. [ ]. So that’s sometimes quite hard because sometimes they don’t realise for that person they are still dealing with that every day. Just because you have accepted it is great, but then you then don’t often realise it is still on-going. But there is still for everyone else that you meet for the first time, and then suddenly you have got that inside you and you cannot get away from that. So if someone looks at me I automatically think they are looking at me because I look a bit different and not because they might think “Oh she’s quite nice”.*

The people who understand the personal work involved do not forget about the possibility of underlying work required to face the next issue. Fiona explains it is not just a question of having close, confiding everyday relationships, but also other types of relationships that contribute to feelings of security:

> *Fiona: They are my brother in law and sister in law and they were when we had the boys they had been more accepting and understanding I think than anyone else in our family and so we have seen them a bit more often but not terribly close but just they are important just because they get it and we know they will always be there for us. [Name of partner] and his brother have had to work as a team quite a lot because we have lost [Name of partner] parents and also his sister over the last few years and so the two of them have had to deal with everything and so in terms of we don’t see them on a daily basis or go out together or anything but we are still quite close with them and we know we are there for each other.*

> *And I've always felt that if anything had happened to [name of partner] I, they are the ones who would look after the boys in the right way and would understand where we are coming from and understand the needs of the boys and so we don't need this now because the boys are adults but they have been important in our life because we have felt they are back stops.*

Fiona has had a series of important friendships at different life course stages with people who have had similar but not identical experiences. With these people issues about visible facial difference may not feature in everyday interaction, but they appreciated the issues involved and they could share in the pleasures and work of bringing up their children.

Steve talks about how he has to select the people with whom he relates carefully and draws his sense of closeness from those who understand his life experiences:

> *Steve: well as you know he [referring to his brother] has got his disability and I have got mine and we help each other out. Then there is [name of ex-partner] again with her background she understands about illness and this that and the other and so I think also it's like when [name of wife] died, no when you go to funerals in the past and you say oh I know how you are feeling and you realise when it happens to you, you don't know how they are feeling. Because you don't until something really happens to you, you don't know. I mean when she went I was quite surprised that no-one came round that weekend. I had to go to them. Not anyone come to me. I was a bit disappointed about it but I just sat in watching T.V. and….no.*

Shared understanding can be a source of support and connection with close others. In some circumstances it can also be a source of limitation, if the range of relationships that can 'get it' is tightly drawn. Establishing 'a getting it culture' seems fit with Kittay's (2006) notion of a 'new normal' in relation to how the family sees itself. In Chapter 7, some of the family narratives of resilience were shown. Respondents whose experience of visible facial difference had started within their childhood spoke of the emotional challenges to themselves, their family and in wider contexts.

Some respondents felt that their family had accepted them and fought for them in educational and health environments. Conflicts between family members, a lack of resources to deal with emotional turbulence accompanying injury or arising from rejection from other family members, reactions from others or difficulties in educational environments were also identified. Respondents who narrated their experience in these ways did not report having lasting high quality relationships with some of their family of origin.

8.10.3 Facilitating access to new relationships and resources

This happens in different ways depending on the context and people involved. Several respondents who had experienced traumatic injuries described how family members and friends mobilised resources which contributed to their recovery processes. Some friends and wider family members became more important within personal communities because of the highly valued help they offered at difficult periods in respondents' lives. Ken has described how he has moved geographically, developing his career. Friendship connections were a resource in making new connections, in pursuing job opportunities and in having the courage to move to new places. Vera describes how new friends develop from friends of friends and have enhanced her ability to set up in new places. She describes her friend making technique as 'infiltrating', which is the meeting, and making of new friends through other friends and developing affinities of her own:

> *Rose: When you use the word infiltrator you are not using in a way of feeling marginal?*
>
> *Vera: No, it's more like I have managed to wiggle my way in or have really become a part of group and I don't feel they are thinking what the heck is [surname] doing there? I feel like I…Like [name of friend] who is on there somewhere, who is someone who, yeah, he's someone who is really someone else's friend but I have now become his friend as well. We go out and have lunch together, or go on holiday together, and, you know, there was only a group of six people that I invited to go out on my birthday, and he was one of them, so, yeah, I have infiltrated but I have also managed to, I am now part of those groups*

Eve also recognises the value of friends of friends but describes how not knowing how things might proceed when she meets new people is unnerving:

> *Eve: Or meeting new people, say friends of friends that I have not met before. I am always, like, on guard. I feel like I can't totally relax, like if I went out with one of my best friends and one of their friends I have never met, I probably wouldn't be my most relaxed.*

She describes this process as situational:

> *Eve: I think it might be different in different situations. Because in work everyone is like, I am really lovely, and people have said that you sound really lovely on the phone; you were really lovely when we first met, but outside a professional environment I seem to have a different, different kind of erm*
>
> *Rose: Experience?*
>
> *Eve: Yeah, experience I think, and I think because in a professional environment I know, people wouldn't be allowed to react in the way that there would in a social environment like the hints and the nudges. They would either have to ignore it or say is there something wrong?*

The combination of situation, relationships and familiarity serve to act as a support for Eve at work. She has been able to increase the number of situations in which she can feel ease with support from within her personal communities.

8.10.4 Alternative interpretations of situations

This type of support describes how other people can help by providing alternative reflections of self and interpretations of other people's behaviour. In Chapter 7 respondents discussed the unpredictable responses of others and linked this to a sense of unease and a potentially erosive effect on confidence. This section examines how familiarities and connection can ease some of the negative feelings. It is illustrated with quotes from respondents using the 'developing my way' voice, described in Chapter 7, where these situations crop up regularly for respondents. Eve talks about a situation where she felt unease at a stranger's behaviour:

> *Rose: yes, it does make sense, is it specifically about appearance?*
>
> *Eve: That's where it stems from I think, yeah, yeah. And even and I think I am quite I don't know if paranoid is the right word. But for example if somebody is in a bar and they look at me for example and like my partner might say "Oh that man, like, fancies you" or something daft like that. Whereas I have not seen it like that I think they are looking because of my facial impairment. I may not be right but that's what I assume.*

Relying on situations in which a combination of people and place create an individual's experience of ease and feeling safe. This seems to need to be balanced with not allowing this to become too limiting where a person may not feel able to leave a safe 'cocoon'. Having people around who encourage taking steps into new areas, or seeking help for a difficulty, are valued. Gina talks about the encouraging perspective of her boyfriend:

> *Gina: Like when we first went out he didn't judge me or anything and he thinks personality is more important than looks and stuff and does a lot for me like and encourages me a lot just to go out and do things that normal people would do*
>
> *Rose: What sort of things has he encouraged you to do recently*
>
> *Gina: Like erm before like I got my job, I was working in a supermarket and he encouraged me to go to the interview and I didn't want to go because I don't like interviews.*

Mark elaborates on how differently he and his brother interpret staring behaviours:

> *Mark: And so I am not sure if he interprets the stares as, they have seen me on telly or I have lived around here quite a lot, I have lived here all my life and they know me. That's why they are looking or I have taught at that school and that's why they are looking or I taught sign language. Whereas I see stares as*
>
> *[Interruption from a knock on the door for Mark to deal with]*
>
> *Rose: Interpreting staring differently?*

> *Mark: I see staring as I don't like being treated differently and that is what they are doing by staring at me. So I feel like a victim, I feel like I am being, attacked is a strong word, but I feel like a bit of a victim when they do it. Whereas I think my brother is more, either he sees it as attention which he genuinely likes or he just handles the situation really well.*

The plausibility of the interpretation offered by the other person is highlighted as an issue. People make different interpretations of situations based on combinations of life experiences. Not all alternative interpretations are welcome though, or can be made to 'fit' the individual's particular frame of mind or current challenges. A related set of observations was about the advantages and disadvantages of 'shielding' behaviour by others. Both Eve and Gina recount how they have to be careful what they tell their father and brothers about their experiences, or they may become angry on their behalf, and possibly unnecessarily intervene in a social situation.

8.10.5 Demonstrating and displaying belonging

Friendships can also be a way of displaying belonging to a group and in having a right to be in a place:

> *Isobel: Like when you are out with a group of people you will notice someone staring sometimes. But one of my strategies now is, not to stare back or anything, ignore them and just be in your group chatting away and everything and show that person you are cool about it, your friends are cool about it and you're having a nice evening. And sort of take a positive against their negative. But sometimes it is difficult some people just blatantly stare and it is hard and you do feel a pang, it upsets you. And sometimes you maybe think about it longer than you should do but eventually you do move on and the person, who stared this morning, becomes the person who stared yesterday and then by the end of week do you know what I mean you have forgotten about it.*

An orientation towards belonging and the presence of friends who endorse this serve to create a different type of interpretation in a public situation; these people are with me and I am with them. This is not a lone activity, as the friends are aware and they have some knowledge about dealing with the situation.

Other respondents talked about how, in the past, people had taken on a role of protecting them in public situations such as pubs. Ken described his self-appointed *“wing men”* who challenged the staring behaviour of others.

8.10.6 Recognising specialist contributions

An important quality of relationships discussed by respondents was the establishment of an active role within relationships and situations. This has been highlighted in the themes identified and discussed in Chapter 6 through being a partner, friend, or parent and contributing love, care and inclusion. Respondents discussed examples of how experience of visible facial difference can become a specialist resource in their personal community in dealing with consequences of difference and diversity. Some people extend their specialist knowledge and skills into the civic arena of the charitable sector. This study attracted respondents associated with support groups and campaigning charities. The recruitment methods will have contributed to this emphasis. The data does offer insights into the importance of being involved in community services.

However effective or appropriate hospital services were judged to be, ‘gaps’ were identified between medical worlds and social worlds. Charities were seen as operating within this gap between health care and the worlds of dealing with difference with one’s families and friends. Some of these gaps were about a lack of knowledge concerning a rare condition. Other gaps were about how to support families making decisions about everyday aspects of their lives which intersected with medical aspects of their lives. Parents of children with visible facial difference, who themselves had a visible facial difference, noted specific issues in these areas. They highlight dealing with the individualised nature to their situations, and access to few cultural resources to help with specific and general aspects of difference. Some respondents identified that this shortfall extended to availability of technical information about particular conditions, especially rare ones:

> *Fiona: Well I suppose probably because we've run a [name of a support group] which is the syndrome I have for twenty-five, twenty-six years since my first son was born. So it's really important for me to create as much awareness about the syndrome and how people react to facial differences and I am quite passionate about that really and I think anything that we can help with that will help people understand that can only be beneficial*.

Roy highlighted a lack of continuity in health and related services and a need for resources for families struggling with problems new to them. He has been involved in providing such help to people who have approached him personally from his wider networks and also in relevant charities. Carl discusses how his visible facial difference is symbolically a *"badge of honour"* which he uses in his work with head and neck cancer 'survivors'. Within these descriptions of activism, there is a coincidence of civic duty and knowledge of human vulnerability.

It is also a means of reciprocating within one's own networks and maintaining a sense of contribution. Carl discussed how, after his illness, he trained as a volunteer welfare benefits advisor, and he assisted friends with the knowledge learned. Those he helped in this way did not have to be important people to him. But, through being able to advise people connected to those who are important to him, he was able to maintain a reputation of having valuable knowledge and the ability to provide aid. Other respondents described similar dynamics in relation to their condition which gave them specialist knowledge about relatively rare problems, as well as insights into the range of different kinds of support families and individuals new to these situations may need.

8.11 Critical associations

A personal community brings together important people and highlights connections with people from outside the family. This quality of the personal community leads Spencer and Pahl (2006) to suggest that friend and friend-like relationships are a type of 'social glue' as they can extend and connect the individual to other social worlds, in personally situated layers of micro and meso systems. However, Spencer and Pahl's (2006) typology mainly explores the positive sides of friendship.

In order to explore more difficult areas associated with friendship that emerged in the interviews the idea of critical friendships (Smart et al.,2012), has been utilised. Having friends can be seen a form of showing ‘normality’. Friendships (like families) can be ontologically unsettling, particularly when important and trusted bonds are broken, because connections between people are linked to a sense of self (Burkitt, 2008). People can become unsettled and develop the idea that they lack judgement in others. This can affect confidence in abilities to form new friendships and can be experienced as a type of social incompetence. Self-knowledge can be affected, for example, distancing by a friend could be read as a sign that there is something wrong with you Smart et al. (2012) identify that unsettling experiences are connected particularly to difficulties within complex friendships.

In one of the personal community patterns ‘family-enveloped’, the friendship repertoire used was ‘narrow’ which Spencer and Pahl (2006) defined as including simple friendship types only. The value of close friendship in providing support was noticeable with this friendship mode, which has developed over time and life experience. Steve explains he wants company, he wants people around him:

> *Rose: There is a much wider community?*
>
> *Steve: Yeah you don’t really talk to when you go and see you don’t really go out the fifth league. But that’s probably me as well I, I mean, I don’t socialise I want to think of a reason to go and see them and not just go there because I think well I am probably invading their space, you know. Because when I was living on my own the only reason why I probably went to the pub was because there were people there. I didn’t really want to speak to them but the company there instead of sitting watching TV every night. I don’t know, I am not a socialiser, I don’t mean, I mean I am not a talker. I talk, I can’t think of anything to say really, I haven’t got, well I just listen and join in conversations when I feel whatever, yeah.*

Friendships are not seen as readily made or supportive in this account and exploitative relationships were described. These experiences seem to have become internalised and associated with a sense of deficit.

Difficulties in the processes of friendship are not confined to this type of pattern. Those who had developed a range of complex friendships also recounted experiences of unsettling friendship processes:

> *Gina: Like at university there was this girl, like, she was, you know, she was really popular. She was really pretty and stuff and she did try to get to, like, speak to me and stuff but, like, I suppose I, like, just brushed her off. Because I thought, you know, why would you want to hang about with me? I know it sound silly but.*
>
> *Rose: Would you give a pretty person the time of day now?*
>
> *Gina: Yes, I would try to but there would be all these things in the back of my mind, why are you wanting to stick to me because you have obviously got lots of other friends and stuff and, but you know maybe I think it's maybe partly my fault why I didn't have a large group of friends and stuff.*

Eve describes the breakdown of a relationship with a close friend as they moved in different directions after leaving school:

> *Rose: How long did it take, all that process?*
>
> *Eve: I am not sure it has ever finished really. From going, because literally we spent every single spare minute together, so from going from that and seeing and knowing things were going wrong and not knowing how to salvage it and then to nothing was just absolutely horrendous. It really was. It sounds really petty but it was almost worse than, like, a death because it is, like, they are still there but they are not in your life anymore. And it's like death, I suppose, is like a finality and you can understand that it's nothing you have done that has caused the…whereas as that. I still don't understand to be honest what happened. And I lost countless nights of sleep and it made me ill thinking of it. The tears I shed and I just could not do it anymore but it was probably one of the saddest times of my life.*

The significance of friendship and self-identity emerges. Unsettling friendship accounts were not only associated with the past. Tom described a distancing process that has started with a close friend since he became unwell.

There is a feeling of helplessness in trying to stop the friend drifting away, a feeling of being ‘dumped’. These accounts underline the complexity of processes in negotiation of complex friendship.

8.12 Summary

A diversity of personal communities were constructed by respondents with visible facial difference. Twelve of these mapped relatively easily onto Spencer and Pahl’s (2006) types namely ‘family-enveloped’; ‘family-like’; ‘friend-enveloped’; and ‘friend-like’. Five personal communities, however, a variation within the ‘family-like’ pattern, in which in intimate relationship, additional to the core family relationships, was central. A feature of all the personal communities was that their central ‘structure’ was based on family relationships. Friendships seemed to interweave within these family relationships

Personal communities can be viewed as accounts about social space and of the self. The personal communities included families and friends and also other important relationships with health professionals, pets and deceased people. These were sources of love, support, understanding and connection. The closer these relationships were to the centre of personal community, the greater degree to which they might be spoken of as part of the self. Six themes were identified which related across personal communities in relation to supporting living with facial difference: sensitivities in talking about appearance, accepting cultures, ability to facilitate access to new relationships and resources, providing alternative interpretations of situations, demonstrating and displaying belonging and valuing and encouraging specialist contributions.

Respondents defined important relationships as those who: cared for them, they cared for, they loved and liked, loved and liked them, and they saw on a regular basis and did things with. Other qualities valued were that respect, loyalty, trust and acceptance, and being part of wider circles could be generated from these patterns. One of the reasons for a lack of correspondence between personal community patterns and how people experience support could be the negotiated nature of support (Finch and Mason, 1993). Connections to others and the kinds of resources that people might reciprocally seek are not equitably distributed.

Personal communities cannot be viewed as neutral they show processes of exclusion as well as inclusion. The personal communities represented importance in terms of connection and aspects of self, rather than just support. People were not placed on personal communities for their ability to provide support; support was seen as an emergent element of these relationships and not their whole rationale. Shared understanding can be a source of support and connection with close others. In some circumstances it can also be a source of limitation, if the range of relationships considered able to ‘get it’ becomes tightly drawn. Establishing ‘a getting it culture’ seems a component of Kittay’s (2006) notion of a ‘new normal’ in relation to how the family sees itself.

The majority of respondents’ personal communities centred on their partners (whether co-resident or not) and, for those with children, their offspring. This suggests that for those living outside a partnership options for finding connection are harder. The presence of an individualising discourse appears to add stress to those in these situations, as the source of the problem shifts to the individual. This can lead to feeling ‘not normal’ and leave particularly isolated those who struggle to deal with social aspects of visible facial difference and are enmeshed in a personal community that also struggles.

The chapter has tried to identify valued aspects of personal communities, rather than highlight rejection and distancing. One personal community type, in particular, with its lack of complex friendships and distances with some family members showed greater signs of isolation from, or avoidance of, relationships which were seen as a possible source of harm.

Chapter 9: Discussion and conclusion

9.1 Introduction

This chapter discusses the main findings in relation to the research questions. Connections are made with the relevant published literatures, highlighting where agreement is found and where differences have been identified. Chapters 6, 7, and 8 presented the findings and an analysis of themes. These emerged from the interviews and were shaped by the researcher’s developing knowledge and understanding. Particular areas explored were: respondents’ perspectives on what is important in their lives, perceptions of other people outside of personal communities, voices of resilience and how relationships (also viewed as patterns of personal community) made contributions and connected people in social worlds. Dynamic support processes were identified within personal communities. These were positioned as an intermediary social structure within a more complex and interacting ecological system (Bronfenbrenner, 2005). The identification of processes lends support to the relational lens which has been used to view this study. This chapter connects these themes to a broader theoretical context and to the starting points of the study.

9.2 Overview of the main findings

The findings chapters discussed four areas. The first area is **the importance of belonging and participation in everyday life.** This was highly diverse and contextually specific but themes of employment through paid work, engagement in valued activities and being in relationships with others as partner, parent, friend or a family member were highlighted and discussed. Second, a sense of **being able to move freely around in one’s environment** was explored. Accounts of living with visible facial difference include examples of being seen as ‘not normal’ in some way. Different aspects of ‘desire for normality’ shape realities for people living with visible facial difference. In this context the opportunity to take chances or make choices was highly valued. The third area explored **voices of resilience** which provided a linkage between what is seen as important in life and personal communities of important relationships. This provides a view of how respondents talked about their orientation in negotiating social worlds and accessing resources.

The accounts indicated that the presence of a visible facial difference was not viewed as an independent risk to developing and sustaining life chances, but that the ‘risk’ resided interactively in the relationships and ecologies in which the individual was embedded. The fourth area explored how **personal communities were constructed**. It identified supports particular to living with visible facial difference. Personal communities played a role in creating ‘new normalities’ where people could feel safer, connected and valued.

A range of personal communities were found, rather than a specific pattern associated with type of visible facial difference. Relationships and personal communities build over time and are shaped by events and life-course transitions. They are sources of a range of relational resources including, but not confined to, social support. They enable individuals with visible facial difference in a number of ways: having a sense of belonging with friends and family, developing sustaining narratives and social spaces. These communities are not a one way process with the individual with visible facial difference on the receiving end of support from others. Respondents are active actors in their personal communities, playing important roles, such as parent, friend, partner or colleague. There are indications that families and friends in personal communities are also changed through dealing with the attitudes of others, responding to changing needs of their relative or friend and communicating inclusion actively.

The diversity of patterns of personal community found is one of the study’s significant findings. Some needs related to visible facial difference were identified and personal communities were seen to be sources of significant resources. The diversity in the findings raises questions about how coping strategies found useful by some people can be applied by another in differing contexts, situations and with differing qualities of relationships, histories and personal communities. The diversity and richness of personal communities challenges stereotypes of people with visible facial difference as ‘damaged and isolated loners’.

9.3 Gaps in the literatures

The research literature discussed in Chapter 3 reported that in general a majority of people with visible facial difference adapt psychologically, whether the difference is acquired or from birth, albeit with different concerns and processes. Visible facial difference is viewed as a personal and social challenge, but one which can be met. A gap in the literature concerns how psychological adaptation translates into fulfilling lives within potentially stigmatising social contexts. Pre-existing circumstances such as social support appear to aid adaptation, possibly through buffering against stress. However, there has been little research looking at the particularities of relational patterns in which selves are embedded and how these might contribute support and belonging. Chapter 3 revealed that many studies about visible facial difference focus on individual psychology. There is comparatively less research looking at how support and connection with family and friend relationships interact with and shape resilient voices.

This study focussed on the social in exploring personal relationships of people living with visible facial difference, drawing on the sociology of personal life (Smart, 2007). The methodology developed by Spencer and Pahl (2006) was influential and a review of the literature found it had not been applied in the field of visible facial difference. With this in mind, the study took an exploratory approach to applying this in a new area. The focus was placed on listening to perspectives of people living in situations where visible facial difference has become normalised outside periods of diagnosis, treatment and recovery.

Since Macgregor et al.’s work (1953 and 1974) considerable psychological research has developed an understanding of psychosocial aspects of visible facial difference (Chapter 3). There have also been changes in how the family is construed, with contemporary sociological concerns about loss of social connection (Chapter 2). The sociology of personal life has focussed on changing family practices with little emphasis on disability (or on visible facial difference). Accounts of people with visible facial difference have been lacking in debates about whether or not an ‘individualising’ society is breaking down social bonds and creating greater isolation, although concerns have been expressed about such processes in disability studies (Shakespeare, 2006 and 2014).

According to commonly held stereotypes, people with visible facial difference might be considered to be at some risk of social isolation in the context of a consumer society which amplifies the importance of appearance, a society in which 'ableist' assumptions about bodies and faces are engrained (Garland-Thomson, 2009 and 2011). The present study sought to contribute to rectifying this imbalance and it does this by seeking comparisons with the work of Spencer and Pahl (2006).

9.4 Contribution of findings to visible facial difference literature

This section compares the findings of the study to literature reviewed in Chapters 2 and 3.

9.4.1 Social interaction and stigma

Well-established findings of the potential for disturbances in social interaction in encounters, particularly with strangers and acquaintances are confirmed (Macgregor et al., 1953 and 1974; Partridge, 1990; Clarke, 1999; Newell, 2000; Thompson and Kent, 2001; Rumsey and Harcourt, 2005). The study confirms that staring and negative comments can be experienced by people with visible facial difference for many years (Knudson-Cooper, 1981; Lawrence et al., 2010). There will always be people you meet or who see you for the first time. Building on the work of Goffman (1963) and his conception of stigma, this study described situations where respondents felt judged by others and these judgements revolved around their looks, cognitive ability and mental health. However not everyone, including some respondents who felt their visible difference was very noticeable, 'noticed' or felt affected by such behaviours. Staring and commenting incidents were not just confined to school experiences earlier in life. These social experiences added to self-feelings of being 'different', feeling unacceptable and unaccepted at times. Supportive relationships played a role in neutralising some of these effects. A number of processes of support within personal communities were identified: sensitivities about how appearance differences are talked about, enabling accepting and anti-stigmatising 'getting it' cultures, facilitating access to new relationships and resources, providing alternative interpretations of situations, demonstrating belonging and enabling specialist contributions. These findings provide a relational view of anti-stigmatisation strategies which adds to observations of individual impression management strategies (Kent, 2000).

Rossi et al. (2009) discuss social judgements which stigmatise people on the basis of appearance, ability and knowledge. The dimensions of negative judgements that respondents incorporated into their accounts were about situations in which they felt as though they were being judged. Judgements revolved around expectations of lower cognitive ability, greater mental fragility and in some cases ugliness (or lack of attractiveness). These judgements were perceived as invisible, particularly when they were embedded within practices in social institutions such as the educational system. They were perceived as having a range of consequences depending on the social or economic importance of the situation, for example, job interviews, or interviews to assess welfare benefit entitlement.

Hawkesworth (2001) introduced the idea of a spatial dimension in the marginalisation of people negatively perceived as ‘visibly different’. Some situations or places demand the presentation of a ‘good face’. These ideas could be applied to some of this study’s findings, particularly respondents’ observations about their experiences at interviews or in large social gatherings. The ways respondents approached these situations varied within and between accounts. Those who had a tendency to avoid such situations might find themselves able to over-ride this when a greater obligation, for example to their family, did not allow avoidance.

There is an adaptive facet to noticing something within one’s environment which arouses curiosity or draws one’s attention. However, staring is regarded as a form of ‘improper looking’ (Garland-Thomson, 2009, p.22). In some accounts a tension was noted between processes of looking or noticing and instances where these processes went too far for the individual who felt singled out. Respondents understood the embodied urge to stare and discussed how their experience of living with visible facial difference has led to the development of a different sensibility (Shusterman, 2012). These findings indicate that ethical noticing (in looking and staring behaviour) is not fully realised within our culture (Garland-Thomson, 2009). Respondents described other negotiations in identity work with particular focus on those involving important relationships in their personal community - a perspective that goes beyond impression management strategies of ‘passing’ (Goffman, 1963, Kent, 2000).

Furthermore some respondents embraced visible exposure and were able to use it to their advantage. This finding accords with Garland-Thomson's (2009) view of the potential for 'visual activism':

> 'By putting themselves in the public eye, saying "look at me" instead of "don't stare"…might be called visual activism' (Garland-Thomson, 2009, p.193)

Garland-Thomson argues that an alternative ethics of looking is required in which visually distinctive activist's influence *how* staring takes places, rather than focussing on *whether* it takes place. In the present study, situations of increased visibility were provided to illustrate when relational support could be valuable.

As discussed in Chapter 2, complications with social connection can be exacerbated by discursive formations which emphasise the importance of appearance as both an indicator of healthiness, and normality (Garland-Thomson, 2009; Garland-Thomson, 2011). Discursive formations can be regarded as types of realities which, over time, have become grounded in the actor's habitual social world or *habitus* (Bourdieu, 1989). Situations or instances within the narrated accounts which tap into these complex representations of the wider social world have been identified and thematised. The findings are not so much about reporting individual experience but are concerned with what individuals say about their social worlds that are to some extent shared experiences.

Garland-Thomson (2011) uses the idea of misfitting to understand when an environment or situation does not sustain harmonious interaction with a particularly shaped or functioning body. She argues that the experience of misfitting can re-position the embodied person as a 'misfit'. Although misfitting is a common place experience, it occurs on a spectrum of consequences. The sense of unease discussed by some respondents when entering new social environments, the presence of interactions where one is noticed as 'one of a kind' can be seen as examples of these processes at work. In this study 'being noticed' situations are those which could stimulate protective processes used by respondents and their families or friends.

As these tend to be context specific, they may continue having an effect long after the person, their families, and friends feel they have understood the nature of their supposed difference. These experiences contribute to fluidity in feelings of acceptance, which can also become a source of ontological insecurity. For those whose visible facial difference is not accompanied by high social visibility, experiences of being noticed are perceived as more temporally limited or something that was reduced to irrelevance.

Some of the accounts of the younger respondents (particularly those in their twenties) convey a higher degree of threat in staring incidents in unregulated places such as the street, or where there are many unknown people such as pubs and clubs. The accounts presented were reminiscent of bullying more commonly associated with educational environments, and were accompanied by feelings of powerlessness. Respondents who discussed this found it to be an ‘almost normal’, though not acceptable, facet of public places for someone whose appearance is different. Incivilities in everyday life to people of difference can be seen as both enactments of attitudes held in wider communities and opportunism arising situationally. These link difference with heightened vulnerability.

Feelings of being judged by others were heightened when it was felt that an ‘assessment’ was being carried out into what appearance difference might mean. ‘Assessments’ were thought to have a component concerned with attractiveness, but respondents focussed most of their concern on judgements of cognitive ability and mental health status. Accounts which featured assessment processes identified personal and social consequences. These included disturbances in interactions, feelings of not belonging, fear or anger at being not properly recognised as a person. They seemed to be a source of ontological insecurity and challenge processes of confidence development. Indeed several respondents encountered few other people with visible facial difference in their everyday lives.

Personal communities can be viewed as relational spaces where the effect of being different could be neutralised and where a range of alternative interpretations for noticing or staring behaviour from other people can be generated. Social pressures on the family from stigmatising attitudes and rejecting attitudes within the family were found.

Dealing with social pressures became something that members of the personal community also had to learn to live with - where these were experienced; living with visible facial difference was not contained within the individual.

9.4.2 Contribution of social support

The literature discussed in Chapter 3 has identified perceived social support as a key pre-existing resource in adaptation in a range of visible facial difference conditions. Interrelationships between perceptions of social comfort, stigmatisation and social support are found in studies about disfigurement following burn injury. Lawrence et al. (2004) found subjective measures of visibility or severity of disfigurement had a low/moderate correlation between social and emotional outcome variables, in particular, more frequently perceived stigmatisation by others. Lawrence et al. (2006b) found a prominent role for perceived social support, in combination with fewer concerns about body esteem and higher levels of social comfort in predicting fewer depressive symptoms in long-term burn survivors. Head and neck cancer and social support studies also indicated an important role for pre-existing social support, focussing on the medical and physical dimensions of disfigurement. Different sources of social support and roles for different sources have been identified by Deno et al (2012) in mediating distress. They suggest that family support may enhance feelings of self-efficacy on the part of the patient. The studies indicate that strengthening people’s ability to deal with social situations, questioning beliefs that link self or social worth and appearance and encouraging people to develop systems that enhance social comfort, would be a valuable part of rehabilitation processes. It is in this area that using a personal community approach to exploring support and belonging is found by this study to be of value. The method of identifying people of importance allowed a selective view of family and friend relationships. The identification of all friend or family members might have obscured the nuanced nature of, and different types of, ‘importance’. It is suggested from the analysis of these findings that belonging to a personal community that has features of ‘getting it’ enhances a particular feeling of belonging. Many of these individual personal communities were also functional for wider social support in various forms and a number of types of support were identified in relation to dealing with visibility and difference (Chapter 8). Friendships as well as family relationships were important parts of these supportive cultures.

What this method demonstrated was that personal communities with a similar number of members may have quite different potential for support and belonging. Asking practical questions about their meaning, distance, role and history are necessary to obtain a fuller picture.

9.4.3 Social integration and social circles

This value of social circles of people as a potential positive outcome for people living with visible facial difference was confirmed (Meyerson, 2000; Eiserman, 2001; Uttjek et al., 2007). Richness of contacts, diversity and being valued as a person were reflected in the present study. Further evidence of contributions made by people with visible facial difference to their personal relationships and communities, as originally found by Eiserman (2001).

This study extends understandings of social circles by exploring them in depth. It found a diversity of patterns rather than a typical ‘normal’ pattern to aspire to. The occurrence of an ‘almost dependent’ family pattern found by Peter et al. (1974) was not identified in this study. Arguably, one respondent constructed this type of pattern, as he lived in accommodation provided by his neighbouring family of origin and had, in earlier times, found employment with his family. However, this seemed unlikely to be an effect of his visible facial difference as his unaffected siblings also lived in a similar arrangement, indicating it was part of their family tradition, culture and influenced by availability of material resources. In the forty years since Peter et al. (1974) much has changed medically, socially, legally and attitudinally, although there is little in recent literature on long term outcomes and contributions from families and friends of adults.

The findings from this study confirm the observations of Knudson-Cooper (1981) that over the long term people living with visible facial difference are actively engaged in social networks, with similar aspirations to their peers and that, for many, this continues alongside being treated by others, particularly strangers, as different. The study adds to the work of Knudson-Cooper (1981) by identifying patterning within social networks and their importance over the longer life term.

9.4.4 Changes in relationships and networks

The literature review identified the dynamic and changing nature of personal relationships, particularly after a facial appearance changing event or with the progression of a disfiguring illness. Patel et al.'s (2011) respondents reported that their interactions had become limited to members of their immediate family. They linked this to progression of the illness that brought with it tiredness, difficulties in communication due to hearing loss, and changes to facial appearance. Support came from partners and family. The authors reported avoidance of social situations and suggested this led to social isolation; however, the nature of this linkage was not investigated. Other studies have indicated that some friendships changed after treatment (Gamba et al., 1992; de Boer et al., 1995; Rossi et al., 2009; Ciofi-Silva et al., 2010). These changes were seen as putting increased pressure on the immediate family to deal with changes in health and capabilities of their relative. The current study did not focus on the time period surrounding acquiring difference or periods of treatment; its interest was in living in the longer term with visible facial difference. However, two respondents were undergoing significant life events at the time of the study, one in relation to separating from their partner and the other due to changes in their health status. Significant changes in important relationships were evident in both these respondents' community patterns and were described as painful losses of particular relationships, although not necessarily loss of the ability to find support. The findings in the present study indicate that personal communities changed in make-up over time and in relation to specific events. At the time of the interview size *per se* was not a dominant feature in whether the personal community was perceived as supportive. Events associated with acquiring visible facial difference could both disrupt and mobilise relationships in personal communities. Over the longer term, personal communities were not generally restricted, although some were.

The literature indicates situations where family and friends were not able to provide the support needed for an individual to learn long-term condition self-management or to deal with particular crises. Dures et al. (2011) found involvement in self-care groups both to be useful contact for personal support for themselves or their close family, and for providing resources to others in similar situations. Some of these connections featured in current personal communities.

Experience of living with visible facial difference can be shared with others with similar experiences. For some respondents meeting with these other people with similar experiences had also developed as a source of social connection.

This study focused on developing understanding of social patterns of personal communities. This approach has encouraged an emphasis on relationships in those personal communities. Assembling a paper version of a personal community can be viewed as a form of ‘family display’ (Finch, 2007). Family displays contain an evaluative element about the positive character of these relationships:

> ‘…my current family relationships work, however little they resemble those of other people’ (Finch, 2007, p.70).

Respondents assembled personal communities of relationships and made decisions about who to include and who to exclude. From the accounts, inclusion did not necessarily mean the relationship was inherently positive, but rather that the differences or disagreements were, at their least extent, workable in the flux and flow of everyday life. Where relationships had become unworkable, respondents discussed placing them further away from the centre than they might have been at another point in time or excluding them altogether. Family members identified as rejecting the facially different respondent, did not appear to be included on personal community maps. However, parents who appeared less supportive than a perceived ideal might continue to be included within the personal maps although the relationship was identified as containing aspects of obligation and duty.

9.4.5 Resuming normal life and struggle for autonomy

A number of studies have emphasised the importance of getting back to normal life as much as possible after an injury or surgery (Rossi et al., 2009; Ciofi-Silva et al., 2010; Semple and McCance, 2010), whilst other studies have identified changing priorities towards new versions of normal life (Semple et al., 2008; Röing et al., 2009). This is not however a duality. The idea of life as normal was found to be a prominent theme. The idea of normal drawn on by respondents was about adapting to the changes that one faces in life, rather than seeing normal as a particular set of achievements or a fixed state of being (Eiserman, 2001).

Studies of people living with visible facial difference from birth use the notion of normal in a different way (Ablon, 1996; Hawkesworth, 2001; Dures et al., 2011; Patel et al., 2011). Descriptions of how they are viewed or treated as ‘not normal’ come to the fore. Themes identified illustrated the kinds of pressures people experienced from others, reduced life choices and struggles in achieving autonomy. This study found similarities in the range of current personal community patterns whether people had acquired or were born with visible facial difference.

The literature has identified a gap in support between health care and everyday life. Dures et al. (2011) identified a need for resources which encouraged self-management and address the changing needs of people living with long-term changing conditions that affect appearance. Others identified the gap as the provision of emotional support by health care (Furness, 2005) and family and friends (Murray and Rhodes, 2005; Semple et al., 2008; Dures et al., 2011). Over-protection was thought to erect more barriers; advice, affirmation or comparisons may be unwelcome. Respondents in this study also identified gaps in support between healthcare and returning to the everyday world, lack of continuity of knowledge in services, or challenges in how to get information when they need it (Cartwright and Magee, 2006; Heron et al., 2007). It was noted by respondents with unsupportive families of origin, and those whose difficulties in interaction with others persisted later in life that it was hard to find appropriate types of support. This appears consistent with Kleve et al. (2002) who identified a group of respondents with more complex histories, whose benefit from the intervention described in their study was less sustained. Some of the respondents were actively engaged in developing or campaigning for improvements in services and some recognised the need for a focus on the family or friend network as well as on the individual.

A number of studies have focussed on social re-integration after surgery for cancer. This work is relevant because it makes clear the link between health worlds and social worlds and identifies important roles for healthcare professionals in re-integration. For example, Konradsen et al. (2009 and 2012) have explored, in depth, breaking silences specifically around facial disfigurement. They implicate interpersonal interactions in hospital for setting up ‘silence’ as a norm.

Breaking the silence, which often occurred outside the hospital, is construed as part of a process of adapting to changed facial appearance. Further exploration of the overlaps and gaps between hospital and social worlds is required, as also pointed out by Semple et al. (2008), Bonanno and Choi (2010), Semple and McCance (2010) and Bonanno and Esmaeli (2011)

9.4.6 Partner and parent-child relationships

Relationships with partners were central to the experience of feeling supported and cared for during treatment and rehabilitation phases (Vickery et al., 2003; Rossi et al., 2009; Semple and McCance, 2010) and to mobilising different types of support from their family or community (Phillips et al, 2007; Semple and McCance, 2010). Other studies identified roles for partners and very close relationships in maintaining or developing social contacts (Bonanno and Choi, 2010; Bonanno and Esmaeli, 2011). The centrality of the partner relationship, whether co-resident or not, was identified in this study. For those who had required care it was their partner who had become their 'carer' by providing a range of aid in response to their changing health condition. The stress associated with carer roles was identified and some friends in personal communities were regarded as important because they played a part in mitigating these circumstances.

The literature on partnership relationships and visible facial difference focusses on acquired difference (Vickery et al., 2003; Bonanno and Choi, 2010; Semple and McCance, 2010; Bonanno and Esmaeli, 2011; Lau and van Nierkerk, 2011). Vickery et al. (2003) find an association between greater treatment burden and difficulties with social contact. It is hard to make comparisons with the findings in these studies because the current study did not focus on the period surrounding treatment. Although some respondents looking back to their past did recount difficulties with social contact following cancer treatment. These were associated with having to make major life style changes, deal with pain and disability and having to de-prioritise other needs.

More generally, the centrality of the partner role was found to be widespread within the personal community patterns. Stability in this relationship, whether co-resident or not, was notable in many of the respondents' personal communities.

While these relationships were perceived as an anchor for many types of support, and whilst many roles were undertaken jointly, they could be surrounded by a variety of differing combinations of relationships with friends, other family members and sometimes professionals. The data indicates that lack of a partner relationship was not necessarily substituted by intimate relationships with friends. This finding is consistent with Ketokivi’s (2008) studies of disruptive life experiences in relational configurations. She found that those without a partner and intimate relationship with others (for example friends and children) had relationship patterns driven by hardship and characterised by social isolation.

There are few studies in the literature which look at how having visible facial differences affects the role of being a parent (Semple and McCance, 2010; O’Hanlon et al., 2012). This study’s findings are consistent with O’Hanlon et al. (2012) who identified how the parent (with a cleft diagnosis) of a child (with a cleft diagnosis) felt they contributed a particular sensibility and knowledge to the situation. Respondents who were parents of children with the same condition discussed how their experience affected how they dealt with aspects of the child’s diagnosis and subsequent socialisation and education. The absence of support or information geared towards the needs of parents with relatively rare conditions was a spur to setting up in such resources and being involved subsequently.

9.4.7 Coping, time and resilience

The literature reviewed in Chapter 3 indicates that a number of studies have looked at how relationships and social support contribute to coping strategies. The emphasis in the literature has largely focussed on individual processes of recovery (Bonanno, 2004). While coping and resilience are closely connected concepts, coping essentially is studied as an individual feature with little attention to social context and social influences (Rutter, 2013). Current resilience theory, on the other hand, emphasises process and does not assume the presence of static individual traits (Ungar, 2013). Furthermore constructionist, ecological based conceptions focus on dynamics between personal resources and environmental opportunities (Porcelli et al., 2014). Phenomenological approaches have added further to an understanding of the social and cultural production of resilience (Ungar, 2010; Aranda, 2012).

By theorising a social self, articulated relationally (Burkitt, 2008), resilience is not seen as an individual characteristic. Rather it is seen as residing in relationships, meanings and opportunities in ecological contexts.

The visible facial difference literature has tended to focus on resilience of children and adolescents (Feragen et al., 2010) and few studies have explored resilience of adults. The increased recognition of the long term importance of adaptation to visible facial difference within a number of conditions was identified in Chapter 3. Social contexts in which are enacted a range of negative attitudes, discriminating practices and fixed views of normality present further challenges. Recognition of the processes of social comfort (Lawrence et al., 2004, 2006a, 2006b and 2010) coupled with evidence for the importance of social support would indicate that exploration of social and ecological contexts is timely.

There has been some use of a processual model of resilience particularly within the field of burn injury (Holaday and McPhearson, 1997; Williams et al., 2003; Moi and Gjengedal, 2008; Lau and van Nierkerk, 2011). Holaday and McPhearson (1997) identified that their respondents did not see resiliency as an endpoint but as a continual effort in their everyday lives. They described the co-presence of social, physical and psychological problems alongside a determined and optimistic spirit. Resiliency, they argued, did not imply high behavioural competence or emotional health. They identified the development of a ‘secure base’ (p349) as a key resource grounded in personal, familial and community support. Likewise, Williams et al. (2003) focussed on resilience and adaptation to processes of loss to identity, life style, relationships and physical functioning following severe burn. Lau and van Nierkerk’s (2011) study of narratives of resilience among people with severe burn injury explored meaning-making processes beyond the injury event. Experiences of burn injury led to reconstructions of self and a shift in thinking about others and the world. These studies revealed co-presence of resilience with severe distress, need for acceptance and recognition alongside counter narratives of positive, transformative and resilient aspects of healing. Narratives of self-identity and relational contributions were construed as social pathways in the search for meaning and psychological healing. Lau and van Nierkerk (2011) identified three processes in the renegotiation of identity.

The first was a struggle for recognition of and reconciliation with their self. The visibility of their burn was typified by awkward interactions and the visibly disfigured self obscured expression of ‘me’ as a normal human being. These types of interactions can be seen within respondents’ accounts in the current study. Although not specifically about burn injury, it has considered how relationships with important others contribute to processes of ‘developing’ and ‘sustaining’ what the respondent sees as important in life. The second process highlighted by Lau and van Nierkerk (2011) was rediscovering the self as either re-constructed or continuous. This was an embodied process in which a changed appearance was reconciled with an underlying sense of self. These aspects can be seen in the current study through the different voices of resilience: ‘developing’, ‘sustaining’, and ‘managing in some areas’. Lau and van Nierkerk’s (2011) study was dominated by narratives of positive transformation, possibly akin to this study’s ‘developing’ and ‘sustaining’ voices. Some of Lau and van Nierkerk’s (2011) respondents adopted an attitude of resigned acceptance in parts of their narrative and to some extent this corresponds with the voice of ‘managing in some areas’ found in this study.

Eiserman (2001) and Meyerson (2001) found important relationships with friends and family members were seen as a valuable outcome for people living with visible facial difference. Relationships were spoken of as conferring elements of belonging, allegiance, support, othering, like-mindedness and, sometimes, support for activism. However, the current study did not just view relationships in terms of personal outcome; they are implicated in the production of the self. They also say something about the nature of society. Not all the respondents were able to include friends in their personal community, not everyone talked about their family of origin as supportive. Societal expectations of individuality pervade explanations of why some people can cope but not others. These can potentially leave the others with a personal sense of lack and isolation, a burden of individuality. Feelings of being ‘outside’ can be emotional and powerful and some people may take actions that allow them to avoid experiencing such situations. Negative emotions can become regarded as a source of personal failure for those not able to ‘control’ their emotions. However, it may be the case that the person has more stressors to deal with than others.

This study has identified different meanings associated with appearance difference which implicate assumptions of mental stability and cognitive ability as well as attractiveness. Being perceived as different in a negative way is a potential stressor. Resilience emerges in narratives as an ongoing process. It is about achieving ordinary things in difficult circumstances rather than focusing on extraordinary achievement. It is also about the ability to take part in social discourse about the meaning of resilience (Ungar et al., 2013). As pointed out by Clarke (1999) there is much unknown about how normality and resilience are enacted in the context of everyday lives. Respondents discussed what was important to them in the context of their personal communities. They explored their experiences of employment, education, finding a partner, making friends, or bringing up a child. The question of what might be ‘normal’ was thrown into a spotlight and some respondents suggested there were few signposts at some times and in some situations.

9.4.7.1 Cultures of acceptance

Ungar et al. (2013) emphasised the importance of adequately resourced environments. Nurturing relationships and inclusive communities have been found to be components of coping and adaptation over time and part of the processes of resilience (Ungar, 2010 and 2012). Relationships are negotiated and through these negotiations over time, different kinds of assistance emerge and develop as interdependencies embedded within particular social and cultural contexts (Finch and Mason, 1993). Relationships played a role in creating a personal culture of acceptance portrayed in the theme of ‘getting it’ identified in Chapter 8. According to respondents’ accounts, important relationships could develop understanding of the emotional work of living with visible facial difference, recognise how some situations can throw a person off their balance, and enhance empathic and semiotic skills in working out when to address issues (Peacock et al., in press). They may not always get this right. Relationships need to have capacity to buffer a wide range of unknowns and emotional challenges. The balance is in the negotiation within the relationships and the allegiances formed within them over time and through experience.

These relationships are talked about as having the key constituents of belonging and togetherness (McCarthy, 2012). The notion of the family was strong and central within personal communities. Different ways of assembling a personal community could constitute a ‘getting it’ culture that was supportive and in which the respondents played active roles.

9.4.7.2 Balance between movement and safety

Balancing between safety and movement emerged as salient in the accounts. Safety primarily meant emotional safety, but not exclusively, while movement refers to new encounters in the world and risk-taking in trying new experiences. From an individual perspective these were explored in terms of how people evaluated taking chances or making choices in developing and sustaining ways. Respondents explored how to extend into new environments, they recounted experiences of steeling one’s self in order to extend and of achieving comfort in new environments. Relationships with others were integral to these processes. Movement and safety were not thought of as oppositions but as two important elements that are both needed as part of the social self. People were simultaneously evaluating aspects of safety in relations to the choices they were facing (Valentine and Skelton, 2007). These became particularly noticeable when the responses of others had to be taken into account. They were particularly active in accounts discussing employment choices and decisions. The cumulative effect of only emphasising safety was connected to a feeling of limitation and sometimes underachievement.

9.4.7.3 Voices of resilience

Chapter 7 explored ‘voices’ of resilience within respondents’ accounts, illustrating how they see their way of managing aspects of their life in relation to experiences of visible facial difference. Three voices emerged pertaining to ‘developing my chances and choices’, ‘sustaining’, and ‘managing in some areas’ and were all construed as part of the social self. A respondent might use more than one of these voices, depending on the challenges they were considering. ‘Managing in some areas’ might be used to resist judgements others make about their achievements: given the number of stressors they have faced and continue to face, they were doing well, however unconventionally, and how others might see them.

Some ‘managing in some areas’ voices included resignation which related to looking back on problematic times, invoking feelings of not quite having accomplished their desires or goals. This was invoked in contexts of stressors such as partner loss, never having met a partner, prolonged unemployment and depressive illness. ‘Sustaining’ was used by those with more confidence in the stability of their achievement and life position. All these positions have been interpreted as voices of resilience (Porcelli et al., 2014).

Respondents had agency, they were not just acted upon by social forces. Agency might be constrained, choices limited and directions in life diverted; however, through practices and relationality, people endeavour to find ways to protect themselves and negotiate their way to living a ‘good enough’ life. This interpretation is consistent with the constructionist, ecological and embodied approach to resilience theorised by Ungar (2010 and 2012). However, it adds to his work by combining these voices with patterns of personal communities.

9.4.7.4 Resistance in narrated accounts

Constraint in life chances and choices is difficult to assess from personal accounts (Bolam et al., 2004). Resources are neither similarly nor evenly distributed between individuals, and respondents recounted when seeking to make use of what was available to them. They tended to assess their level of success against standards of someone of their class with a similar upbringing, or from their family or peer group, rather than against a universal normal. There were tensions in accounts when talking about co-presence of the possibilities of living well enough with visible facial difference and describing how bad times could be. The challenges respondents either set themselves, or feel they aspired to, these ‘normalities’ indicated a certain distancing from the notion of disability (Davis, 2013). However, respondent positions in relation to normalities can also be seen as resistance to being classified as different or disabled by others based on the others definition of difference or disability (Watson, 2002).

Respondents discussed ways in which they resisted seeing ‘assessing’ behaviour as a sign of being other than normal, whilst knowing their faces showed signs of ‘difference’. These claims on normality included the view that the person did not have to become normal, because they already were.

Kittay's (2006) deconstruction of the complexities and evaluative aspects of the concept of normality are useful in understanding these findings. It is possible to satisfy a desire for normality without acquiescing to the norm implied within the idea of a standard 'normal'. This is not about a rejection of difference. It rests on an understanding of the social and relational nature of values and the dialectical relationship between a need to be included within normal and a desire to be loved, accepted and to belong.

The moral, physiognomic model of difference still resides within culture (Chapter 2) and is present within value judgements about normalcy within medical approaches that claim objectivity. To be judged as not normal entails being placed in positions which are not valued, not desirable and are stigmatised (Goffman, 1963). So the desire to be normal (when it is understood as a value judgement) becomes clearer: to be normal is to be something desirable. Normality as a value is desired because of its important effects on a person's own self-regard, on others' willingness to accept one's worth and on acceptance within one's communities.

Kittay (2006), in drawing on the scholarship of Canguilhem (1991), considers why normal, when taken in a statistical sense of being something frequently found, should also be desirable. This is relevant to the construction of visible facial difference. The first consideration is whether the condition is an anomaly because of the social attitudinal environment, or whether it is 'pathological' and needs to be fixed. The category of anomaly can be further broken down into those which are 'simple' and those which are more 'questionable'. The 'questionable' variation can become regarded as 'pathological' because of its lack of fit (Garland-Thomson, 2011) with functional requirements of socially constructed practices. Once an anomalous condition starts to have functional consequences, because of social intolerance of that anomaly, then the desire for normalcy can be seen in part as a desire to be included within, and have access to, functionally relevant and valued social norms.

Visible facial difference is experienced as a functional limitation largely due to intolerance, and the functional consequences arising from a lack of social value and stigma. Kittay (2006) argues that when non-pathological anomalies are not tolerated, the desire for normality is in part a desire to establish 'zones of safety' (p.98) as well as 'zones of value' (p99).

Kittay's account can be used to illuminate why personal communities are so important. Values are socially established. While it is possible for an individual to reject a social value and its associated normalcy, a rejection of norms *per se* could result in the rejection of those necessary for survival or result in a situation where the suffering of some is considered acceptable (Turner, 2006). Rutter (2013) makes a similar argument in relation to post traumatic stress disorder. He says some resilience researchers argue for de-pathologising some stress reactions because they are 'normal'. He disagrees, as it would involve a return to outmoded body/mind dualisms and there is evidence that some extreme effects of stress are pathological to the body.

It is possible to construct new norms, but because they are socially established it cannot just be done at an individual level. Values are not just a private matter, they are within *habitus*, a shared set of dispositions, structuring structures, constraints and practices from which ideas of what is normal are derived (Bourdieu, 1989). Kittay (2006) suggests that families and social circles are a key part of the establishment of new senses of normality and their attendant zones of safety and value for the individual with an anomaly and those around them. It is possible to reject some aspects of what it means to be a normal family and to establish new norms of being a parent which can encompass the love, care and support of a distinctive child. This new normal has both continuities and discontinuities with the old ones. This desire to be recognised as a family and as such:

> '…to be part of a social configuration, to share the lives of others not as an individual but as one with ties and responsibilities' (p. 103).

However, there needs to be enough of a community who recognise the new normal as including the values of love, protection and care. Kittay (2006) argues that all parents adopt a set of norms with respect to their child and are also aware these are not the only set of norms their child can be judged by. This drives a desire to enlarge the community that accepts the new norm. This process can be seen in respondents' accounts through who they select as part of their personal community, as well as more overtly through involvement in charities which challenge meanings of appearance norms.

This argument was developed in the context of the family. The desires for recognition, inclusion and acceptance can, however, be generalised to other valued identities such as, being a partner, or a friend. People see themselves as partner or friend and want to be so recognised by others. Therefore one can fall outside some social norms but not necessarily others. The more norms that people fall outside the greater the extent to which they risk becoming identified as an anomaly and lacking in value (Kittay, 2006)

Other identities were seen to be drawn upon and used to counter excluding elements within accounts. Normalities associated with class, gender or age could be conceived as having protective features, describing oneself as ‘being one among many’ of having this kind of advantage or disadvantage or of being someone ‘who went to this type of school’. Some respondents viewed disability legislation as a useful tool and one which, in some situations, was part of a new normal which they had seen come into practice over the course of their working lives. It enabled the possibility of voicing objections to suspected discrimination or poor treatment within work settings. It put pressure on work environments to be more mindful of areas of potential discrimination.

Very few people directly attributed life successes to visible facial difference, seeing it as an additional source of stress or complication in the negotiation and navigation of their lives. Although respondents claimed they did not want to be known for their distinctive appearance alone, some were able to find protective identities within visible facial difference. For example, one respondent highlighted how they were able to use their distinctive appearance as a ‘badge of honour’ symbolising their survival of severe facial skin cancer and as a metaphor for the possibility of living with bodily chaos. Further, neutralising noticing behaviour can be seen as an example of successfully drawing on a wide range of strategies, relationships and ways of feeling valued.

9.4.8 Social support and demographic factors

The literature has made little headway in understanding how demographic factors intersect with visible facial difference. Findings appear inconsistent; however, this is not surprising given the complexity of interactions between embodied, personal, social and cultural realities.

It is an indication of the need for greater knowledge to aid understanding of the complexities involved (Klinge et al., 2009). Complexities are obscured by issues of research design and the heterogeneity of people with visible facial difference both between and within medical conditions. The work of Vickery et al. (2003), Lawrence et al. (2004), O'Hanlon et al (2012) and Flexen et al. (2012) has highlighted issues with developing sensitive condition-specific measures; sampling and recruitment issues arising with conditions having relative low levels of incidence and the consequent issues of lack of statistical power to investigate the multiple factors involved (Newell, 2000). There is also a need for specialised qualitative studies to identify meanings of social and personal processes involved in recovery, rehabilitation, adjustment or adaptation (Thompson and Kent, 2001; Thompson, 2012).

The embeddedness of gender and visible facial difference can be seen in the literature pertaining to social support. Perceived social support is thought to play a greater role for the well-being of women than of men (Orr et al., 1989; Katz et al., 2003; Roberts and Mathias, 2012). Specifically, friend support was more important (Orr et al., 1989; Brown et al., 1988). O'Brien et al. (2012) argue that men and women express intimacy and seek support differently. Ablon (1996) has critiqued these ideas and proposes that differences found between genders rest within a sexist society in which people are embedded. Men and women living with disfiguring and disabling conditions may view themselves as having, more or fewer, options because of the low expectations placed on them. Depending on the perspectives they develop of the chances and choices they legitimately have within their grasp, they may conceive of their situation as better, worse or about the same as others.

Smart et al. (2012) question findings which indicate a linear relationship between gender and how people 'do' friendship. From the perspective of the social self, friendship becomes one of the mirrors of reflexive self-gendering:

> '…because doing friendships is part of the performance of the self, then we cannot disentangle friendship and gender' (p.106).

These thoughts accord with Ablon's (1996) observations and are evident in this study.

Patterns of personal community were scrutinised to see if they mapped directly onto sex, age or educational achievement. Both male and female respondents presented rich, varied and diverse social connections on personal community maps. There were gendered findings in relation to acceptable ways of challenging the behaviour of others, in expectations within educational environments and in roles taken in life. Some male respondents described the expectation to be a ‘breadwinner’ and female respondents to undertake caring roles.

Age of respondent did not affect the overall pattern of personal community assembled, although the younger respondents tended to use the ‘developing’ voice with imagined futures and possibilities, and older respondents used all the voices. Perceptions of stigmatisation, or emotional effects of negative experiences, did not seem to be something that respondents ‘grew out of’ with age. The impact of age and gender are areas worthy of further exploration.

9.5 Contribution of findings to developing an understanding of personal communities

A diverse range of personal community patterns were identified. There were connections to families, friends, neighbours, colleagues, professionals and pets. There were continuing bonds with deceased relatives and pets. Most respondents’ personal communities corresponded to patterns identified by Spencer and Pahl (2006). But some constructed variations and some of Spencer and Pahl’s patterns were not used at all.

9.5.1 Similarities to Spencer and Pahl

The four main types assembled in this study were ‘family-like’, ‘family-enveloped’, ‘friend-like’ and ‘friend-enveloped’ personal communities. Spencer and Pahl (2006) identified the most robust types as ‘family-like’, ‘friend-like’, or ‘friend-enveloped’ on the basis of the degree of flexibility within these patterns. The ‘family-enveloped’ pattern was identified as potentially less robust because the practice of establishing ties outside of family relations was limited. This pattern was typified by a narrow friendship repertoire with a restricted range of relationships and a lack of complex friendships. There were indications of greater social isolation among some respondents who assembled ‘family-enveloped’ personal communities.

Personal community robustness, as theorised by Spencer and Pahl (2006), is related to degree of suffusion and redundancy. Suffusion describes overlaps in role of family members and friends, and redundancy to a complexity where a range of ties provide similar resources. Neither suffusion nor redundancy is conceived as a form of interchangeability of important relationships. They argue that suffusion without redundancy could lead to vulnerability, if too much is invested in one or two key relationships. In this way, vulnerability is not due to individual circumstance alone, but is also connected to a lack of robustness in personal communities.

9.5.2 Differences to Spencer and Pahl

Some respondents included a close friend as well as their partner in their inner circle. However, unlike Spencer and Pahl's study, this was not confined to those who had friend-based personal communities. For some of the respondents it indicated the development of very close friendships outside the partner relationship, named by Ketokivi (2012) as 'alternative intimacies within a family setting'. Unlike Ketokivi (2012) this type of pattern was not associated with gender. Ketokivi (2012) suggests this is a sign of disembedding from the family context through formation of alternative intimate relationships which serve needs of the individual. Semple et al. (2004) have suggested that some people develop alternative sources of emotional support to take the pressure off their partner. The presence, roles and social meaning of these close supportive friendships require further exploration in the context of living with visible facial difference.

Spencer and Pahl (2006) thought 'partner based' and 'professional based' personal communities were less robust because they lacked diverse sources of support and in their sample were associated with those in more vulnerable life situations. 'Partner based', 'professional based' and 'neighbour' based personal communities were not assembled in this study. This finding was possibly a product of the method of recruitment (Section 9.6 Limitations of this study).

Volunteers for the study might represent those with more robust personal communities. Two respondents did include relationships with health professionals in their personal communities alongside family and friends. However, their presence did not seem to be an indication of lack of other support. These relationships had arisen in response to a serious and ‘long running’ health problem and, in one case, developed into a type of friend relationship. Involvement in condition related support groups appear to be a part of social connections as well as a part of health care. This area is worthy of further exploration in the context of the growth of such groups.

9.5.3 Components of Spencer and Pahl’s typology

Spencer and Pahl’s (2006) typology of personal communities is layered and composed of distinctions between patterns of ‘given’ and ‘chosen’ relationships, family and friend relationships, friendship repertoires and friendship modes (Appendix 3). These are discussed in turn below.

Spencer and Pahl (2006) problematised the dualities behind how close ties are thought of in discourse concerning family and friend relationships. They theorised that both family and friend relationships can be ‘chosen’, and that friends might come to be seen as ‘given’, as well as those more conventionally associated with the idea of ‘given’ friendships, such as with neighbours, or family members. They introduced, (using a grid analysis) a dimension of commitment into the categories of both ‘given’ and ‘chosen’. This allows the analytic possibility of locating relationships that might be ‘chosen’ but have high commitment, rather than only being seen as fleeting, insubstantial ties. In doing this, they introduce two additional ways of conceptualising important relationships: ‘given-as-chosen’ and ‘chosen-as-given’. The meanings of relationship in a personal community are seen as based on combinations of commitment and choice, rather than on the categories of relationship or ideals about family and friends. The use of this typology showed the presence of suffusion in particular relationships, and the extent to which a personal community was comprised of both given and chosen ties.

Spencer and Pahl (2006) further distinguished between types of relationships, particularly focussing on friends (Appendix 3). These distinctions were useful in the analysis as they enabled identification of a range of friendship types in respondent accounts. This was used to explore ideas about how friends might have single, or multiple roles in relation to the person. Both the categories of ‘given’ and ‘chosen’ and the typology of friendship had value when exploring the diverse configurations of friends within the personal communities. Furthermore they played a distinguishing part in Spencer and Pahl’s overall typology of personal communities. ‘Friendship repertoires’ (Appendix 3) identified different combinations of ‘simple’ and ‘complex’ friendships. These repertoires were used to indicate suffusion where members play multiple and overlapping roles.

Applying the ‘friendship mode’ typology (Appendix 3) however was less rewarding. This required identifying different patterns in friendship-making over life course and life events. Conceptually, the idea of ‘friendship modes’ was useful; however, the practice of identifying a ‘friendship mode’ which had occurred in the past was difficult to find within cross-sectional interview data. While the idea of modes was helpful in it bringing a time dimension into developing relationships, these distinctions did not play a defining role in comparing respondents’ personal communities with Spencer and Pahl’s (2006) typology.

Similarly, patterns of ‘suffusion’ or ‘specialisation’ were not a distinguishing feature between different personal community types in the analysis. In some respects Spencer and Pahl (2006) might have combined too many concepts into their personal community typology. This study found a simplified version more useful in composing personal communities which still had a high degree of comparability to the work of Spencer and Pahl (2006).

This more limited conception of personal community did not apply notions of ‘friendship mode’ or patterns of suffusion or specialisation within the personal community typology.

9.5.4 Supportive relationships

Respondents' personal communities included different combinations of friends and family which inter-dependently provided love, safety, encouragement, companionship, friendship and help. Family relationships were central components in all the personal communities, in many cases providing strength and solidarity. Support was negotiated in the context of relationships, obligations and histories. Finch and Mason (1993) found families delivered care with differing patterns of support and obligation emerging in relationships. The family group was particularly valued for its capacity to provide a network of support in crisis situations. Reciprocity was about achieving balances between dependence and independence in family relationships developed overtime.

A personal community is not the whole of a person's social network; rather it is made up of those who are considered important *now*. Where respondents saw their relationships as a source of 'social support', it was also described as shifting in response to changing situations and relationships. It was not described as a property of the individual, but rather as something experienced relationally with combinations of people that change according to situation, place, or time. These findings are consistent with parts of the relationally oriented social support literature (Feeney and Collins, 2015).

Not all personal communities were equal in the availability of supportive resources and while many respondents had found ways to thrive, some had had greater difficulty. A lack of intimate or social connections in a personal community was not necessarily associated with the 'choice' it was linked with. It combined with sources of stress, such as unemployment, illness, depression or a general distancing from certain types of social contact.

Those in the inner three circles were mostly relationships that people turned to for various types of aid, whereas those in rings four and five were more about social connection than intimacy. These findings seem to have consistency with Binder et al. (2012) who found differences between core (or inner) ties and significant (or outer) ties in supportive transactions and behaviours used to maintain relationships within personal communities. They found social loneliness was unrelated to the number of core ties but was associated with a decreasing number of significant ties.

They suggest significant ties have a role to play in providing a general feeling of social connectedness. A ‘romantic partner’ appeared to buffer against this, such that the association between number of ties and level of loneliness became weaker.

9.5.5 Importance of partners

Spencer and Pahl (2006) argue that the partner relationship is the most significant suffused relationship. When people talk about their partner they combine ideas from family and friend discourses. In the current study, partner relationships were found to have primacy, whether they were co-resident or not. Respondents with co-resident partners often used the metaphor of ‘working as a team’ to run households, businesses, or to raise their children. Partner relationships were sometimes valued where they had not worked out because of what else they had given the respondent, such as experiences of a close and intimate relationship, and children.

As well as the personal benefits of partnership intimacy, this study highlighted a cultural emphasis on the importance of the couple relationship in belonging and in support processes. These findings seem consistent with the case made by Ketokivi (2012). She identified that in developed Western democracies, for those living outside the couple model (whether co-resident or not) there are few ideal forms of connectivity to draw on. She argues that this restricts options for those who live otherwise. This applies whether living with visible facial difference or not, and if lives are complicated with adverse events this can be a source of isolation.

9.5.6 Combinations of friends and family

This study enabled a view of how family relationships and friend relationships are combined in a personal community. Examples of suffusion of family and friend relationships were found (Spencer and Pahl, 2006).Some respondents expanded who they thought of as family through including relationships with important friends, and including people from previous family arrangements. Distinctions were found in respondents’ accounts about these family-like friendships, for example, a person could be ‘like a brother’, but they were not a brother. Jamieson (1998) argues that the isolation of the nuclear family has been overstated in discourse concerned with the changing role of the family.

Examples were found of suffusion where family members were seen as a source of friendship. Close relationships with family members could be ‘chosen’ and these required relational work to develop and maintain them. This also fits with the observations of Jamieson (1998) that wider family relationships contain some selectivity, and might be relied on as possible sources of friendship, where the choices of people available are limited, for example, because of living in a rural setting. ‘Suffusion’ describes overlaps in roles between family members and friends, indicating that boundaries between the ‘nuclear’ family and other relationships might have been overstated (Jamieson, 1998; Spencer and Pahl, 2006).

This study found suffusion between ‘given’ and ‘chosen’ relationships based on relational qualities, such as identifying ‘honorary’ family members, or where a particular family member was regarded as important and sometimes as a ‘best friend’. The data indicated that friend relationships regarded as ‘close as family’ were longstanding, sources of confiding intimacy and in some cases provided support at a time of disruption. The selection was based on the nature of the relationship they had with that person, which may have developed over several years. Particular friend relationships were found to play significant, enduring and supportive roles in lives (Allan, 2008). Friend relationships could have formed at particular life course stages, such as having children, and played an important part in social identity as well as providing companionship, mutual aid and social contact. This indicates a distinction between complex and simple friendships, as suggested by the friendship repertoires described by Spencer and Pahl (2006). Commitment was found within both family and friend relationships. However, expectations of relationships were higher for those seen as long-lasting and very often these came from within the family of origin or family of one’s own which had built up over a history of interactions and events (Finch and Mason, 1993).

Spencer and Pahl’s (2006) analysis proposed that friendships make a contribution to social solidarity, acting as a type of ‘social glue’. They base this viewpoint on their findings that personal communities have a social dimension as well as a personal one. Although social patterning was diverse and variable on a number of dimensions including embeddedness within localities, family or other settings, degrees of commitment, life course stage, and durability.

It was not simply a consequence of individual choice (Pahl and Spencer, 2004, Spencer and Pahl, 2006). Social changes in family structures and increasing importance placed on friendships (Allan, 2008) indicate that social bonds are adaptive to changes in social circumstances (Spencer and Pahl, 2006).

Relationships from which social support emerges are often already in place before a ‘face changing’ event (Partridge, 1990). This study found respondents who had acquired visible facial difference reported that support often came from previously established relationships, although it was difficult to predict at the time which relationship this might come from. There could be surprises; sometimes friends felt to be close avoided contact. Some relationships were able to make a transition from, say, being a friend with whom you socialised, to someone who helped out in a crisis and who could be depended on over the longer term. To Spencer and Pahl (2006) this variability indicates that the most supportive of personal communities are likely to be those that have a greater redundancy and suffusion of relationships in their personal communities. This ‘extra-ness’ is seen as maximising the possibility of people being around in a time of crisis who may have the time and capability to help out.

Failure at a time of need may change the placement of the friend relationship from an inner to outer circle in a personal community - if they are retained at all. Even while the quality of close family relationships varied, greater expectations were placed on them than on friends to help out. Indications of these kinds are found. In addition, the personal communities of some people with visible facial difference often identify ways in which supportive gaps and lack of connection are manifest. The individual may appear surrounded by a number of relationships, but these relationships may not function in a supportive fashion.

A range of caring, and practical types of support were found as well as confiding intimacies. The importance of company and being able to feel familiar or safe in places was a feature of increasing a sense of belonging (May, 2013). Those respondents who described themselves as socially isolated found ways to increase their contact with others, although they might not have developed close relationships.

This is consistent with Shakespeare’s (2006 and 2014) discussion about the importance of companionship. Getting companionship from clubs or sitting in a pub for the company, without having to engage in conversation, are social achievements. They are potentially signs of self-defined resilience.

The literature (Chapter 3) identifies that the birth of a child with visible facial difference may require the family to invest a great deal of time and emotional input to contribute to the child’s survival. O’Hanlon et al. (2012) challenge the idea that such families necessarily have difficulties with finding social support. They identified resources that a parent with the same condition as their child could bring to the discussions about the child’s treatment. In the current study, development of significant specialised knowledge was narrated by respondents who were parents of children with the same condition. Some of the respondents have made contributions to their communities, initially based on trying to meet their own needs (Ryan and Runswick-Cole, 2009). Realising their child’s difference, they had to find ways to go forward with love and care through the many different interpersonal, situational and institutional contexts they would encounter.

Most of the respondents who were born with visible facial difference were the sole member of the family with visible facial difference during their childhood. Retrospective accounts of family life variously described ways in which some families were perceived as supportive and some were not. Respondents talked about what was useful or unhelpful in the various responses made by their family members and, very often placing their reactions within a historical framework. The analysis undertaken did not distil these into ‘top tips’ or coping strategies that could be generalised to others, as they were seen as having value within a specific relational, temporal and historical biography. A sense of understanding different kinds of help that could be drawn upon were seen to evolve through relationships.

9.5.7 Inclusion of pets in personal communities

This study did not prompt respondents to include pets into their maps of important personal relationships, but several people chose to. Research informed by attachment theory has identified that human-animal bonds are similar to those found between humans (Field et al., 2009).

The inclusion of pets has been found in studies of families, social networks and personal communities where people regard their pet as part of their family and support network (Charles and Davies, 2008; Morris, 2011; Brooks et al., 2012).

Respondents talked about relationships with particular pets in positive terms, such as being fun, loving, and, notably, non-judgemental. There was also a role for pets in the dynamics of human relationships within a personal community, sometimes adding friendship or protection when it was needed. The respondents talked about how the animal-human relationship was companionable, a presence through very difficult times, and a means of readily developing acquaintanceships alongside an aspect of shielding from unwelcome types of attention. There is a growing body of evidence associating relationships with pets with human health and social benefits (Ryan and Ziebland, 2015). The relationships described go beyond one of pet ownership. They are linked to finding purpose, protection, non-judgement and fun, which could even continue with some particularly special animals after their death. This finding demonstrates the value in putting at the centre of the account the respondent's perspective on what is important to them. The varying roles pets play in the lives of people with visible facial difference would be worthy of more focussed attention.

9.5.8 Presence of continuing bonds

Some respondents included continuing bonds with deceased people on their personal community (Klass et al., 1996) and some respondents also included some of their deceased pets (Field et al., 2009). Klass (2006) maintains that continuing bonds are not best viewed as indicators of either better or worse adjustment to loss but rather as:

> '…a component of an inner reality and as part of a family system.' (Klass, 2006, p.848).

McCarthy and Prokhovnik (2014) theorise continuing bonds as having an embodied relationality experienced by the living person through practices, felt experiences and cognitions. The continuing bonds narrated in accounts were connected to significant human or animal relationships, which continued to have an important place on the current personal community often many years later.

The study did not explore the nature of the continuing bond and its relationship to grief. However, respondents described some of the ways in which these bonds were important in their lives.

The continuing bonds were with key figures who had provided support through difficult past times associated with coping with stigma, depression, bodily injury or getting out into the local area. These seemed to fit with the roles identified by Marwit and Klass (1996) of acting as a role model, a source of situation specific guidance, a way of clarifying one's values and as a type of remembrance. The placement of relationships with deceased humans and animals in a personal community requires exploration beyond individual adjustment to grief, by looking at whether, or how, these types of bonds serve as ongoing resources and contribute to resilience.

9.5.9 Usefulness of personal communities

The method of personal community mapping has proven helpful in identifying a range of personal relationships and in acting as an interview elicitation tool. It provided respondent generated diagrams, through which interplay between accounts and patterns of connections could be explored. A benefit of the method is that different relationship patterns could be explored, rather than relying on ideals of what families or friends *should be* like. For example, the sociological literature of the contemporary family has identified diversity within family patterns: 'families of choice' (Weeks et al., 2001) in which relationships are viewed as more likely to be 'chosen' than 'given', with blood ties as only one way of securing continuing relationships. 'Family of choice' patterns could be captured in Spencer and Pahl's (2006) 'friend-like' personal communities.

Relationships included in a personal community were not assumed to be necessarily continuously benevolent. The process of generating names for the personal community encouraged focussing on importance in relationships and this could be seen as emphasising positive aspects of the relationships. In contrast, respondents' accounts included stories of negative experiences in their life course with strangers, acquaintances, former friends or distanced family members.

Past difficulties with primary relationships, such as a parent, might not definitely exclude that person from being part of a respondent’s personal community. This could perhaps be because a sense family duty remains, despite the quality of the relationship (one that could be described) less than ideal (Finch and Mason, 1993; Spencer and Pahl, 2006). The combination of narratives and personal communities allows an examination of some of the critical associations within relationships (Smart et al, 2012). Spencer and Pahl’s (2006) typology has a built-in assumption that friendship is a form of social good. That assumption was questioned by this study. Some respondents saw friendship as too painful, hard work, or of questionable benefit. Some did not include friends on their personal community, with the underlying viewpoint that those who were most likely to be there for them in a reliable way were valued family members. Spencer and Pahl (2006) saw a role in increasing the visibility of personal communities and an awareness of the embeddedness of the individual arguing:

> ‘understanding personal community as a collectivity, might help people appreciate the support that hitherto they had not recognised or had taken for granted, while at the same time becoming aware of the efforts that have to be made to keep it in good repair’ (p.208).

Spencer and Pahl (2006) suggest the concept has a role in encouraging greater awareness of one’s relationships in order to take steps to value and maintain important connections and bonds. To an extent, this is supported by the data as some respondents found assembling a personal community gave them a different view of themselves. Both Spencer and Pahl (2006) and this study have emphasised the contributional aspects of relationships, however this is only one part of the picture. Within family and friend narratives are stories of painful difficulties and ones not easily changed, particularly in relation to family of origin or one’s own family. A contributional and supportive context would be helpful to ensure that these pictures were not interpreted as fixed. But they are difficult to change.

This would suggest that in order for the personal community method to be useful as a self-educational tool, developmental work would be required, possibly building on the history of the use of sociograms and eco-maps in social work and family systems therapy (Kiser, 2015).

9.6 Limitations of this study

The sample recruited was small and volunteer based, via advertisements posted on the website of charities, biasing the exploration towards those in touch with campaigning or supportive charities. It is possible that the people who volunteered for the study are those who are better ‘networked’. People living in isolation or in situations where they are more ‘dependent’ on their family may not have been recruited. These recruitment issues are likely to have shaped the findings to reflect the perspectives of those who are possibly socially involved, or who recognise a role for research in increasing understanding of how visible facial difference affects lives. Some respondents identified that they would not have volunteered for the study at times in their lives when they were experiencing difficulties. Thus, it is likely that the study reflects the perspectives of those who are in a more reflective phase of their life course.

The use of convenience sampling has other limitations, such as reducing the ability to maximise the diversity of the sample. One strategy employed to encourage diversity was to advertise in a range of organisations. The sample achieved within these constraints was demographically diverse particularly with respect to types of visible facial difference and self-perceptions of severity and lifestyle disruptions. There was a fairly even balance between those born with and those with acquired facial difference and between genders. People aged over fifty years were more predominant in the sample, as were those with higher education qualifications. However, none of the sample came from ethnic minority backgrounds. This further underlines the known gap in the field about experiences of people from ethnic minorities with visible facial difference in the UK. The decision to not continue with recruitment of a friend or family member has meant that relationships and personal communities have been largely explored from the perspective of people living with visible facial difference.

This study was exploratory, as the methods used had not been applied in this field before. A wide form of generalisation was not sought in this study. The narratives and maps have been used to guide the reader between the specifics of particular lives and generalities found within theories, in particular Spencer and Pahl’s (2006) conceptualisation of personal communities.

The particularities of individual situations and narrated experience have pointed out some of the ways in which the ‘theory’ is too general (Plummer, 2001). The accounts of personal communities shows some of the variations and ranges in which lives are situated and have provided a fertile ground for developing further ideas to understand these contexts for people with visible facial difference.

The cross-sectional design has meant the study was not able to track how changes occur overtime, giving a ‘snapshot’ of processes viewed as dynamic. The ‘data-set’ produced was rich and decisions were made in the analysis stages about which areas to concentrate on, guided by the originating research questions. Focus was placed on, exploring aspects of relationships engaged in by people with visible facial difference, rather than network effects or life histories. The decision to apply the full personal community typology of Spencer and Pahl (2006) may have obscured the roles of the constituting typologies of friendships, friendship repertoires, and development of friendship modes overtime. Further exploration of these areas within this data would be a fruitful area for post-doctoral research.

9.7 Implications of the study for further research

The method of personal communities has proved feasible and fruitful and could be usefully applied in a number of research areas, some of which are detailed in this section. The study found a simplified version more useful in composing personal communities, which still had a high degree of comparability to the work of Spencer and Pahl (2006).

9.7.1 Influence of social support

The literature (Chapter 3) has identified the importance of the influence of pre-existing social support over a number of psychosocial outcomes connected with visible facial difference. Personal communities provide a means of exploring the complexities of the personal social context and how these interact with development in important areas of life. Together these points indicate that future studies need to take into account perceived social support, in order to get a fuller picture of how support affects well-being and perceptions of appearance.

Social support is not a passive background variable. Cultural beliefs about disability and appearance are embedded within personal social worlds and these affect and create feelings of social comfort, social connection and social support.

9.7.2 Friendship, belonging and isolation

Friendship was found to have important roles beyond social support. Friendships are implicated in processes of belonging and making connections between the self, families and wider social worlds. They were found to be a key feature of social normalities. This is an under explored area in the field of visible facial difference. Further exploration of the processes of the evolution, making and breaking of adult friendships could add valuable insight into how these relations contribute to processes of belonging.

Those who did not have intimacies with friends and have ruptures within their family relationships are at risk of isolation. Further exploration of how isolation is relationally produced would be of value.

9.7.3 Disruptions and continuities

The method of personal communities would be a useful means to further explore processes surrounding biographical disruption (Bury, 1982) and continuities (Williams, 2000). This study found appearance concerns tended to be shared with close and intimate connections. However, this did not necessarily mean that their personal communities were generally restricted. Those who were placed further out on personal communities could provide something else valued, such as sociality, connections to other worlds, and a sense of relational history. While connections and priorities might change at time of difficulty they might re-connect at a later date or new bonds might be formed. An understanding of how these connections are made (or not, as may be the case) would be valuable to those with an interest in processes of rehabilitation, and to those interested in developing greater knowledge of personal communities of those living with visible facial difference from birth.

9.7.4 The role of health professionals

This study found that under certain circumstances, such as cancer treatment, a healthcare professional was centrally placed as an important relationship. This gives an indication of the importance of support from healthcare professionals. In certain times and situations, they may be incorporated into the centre of personal worlds. The use of the method of personal communities would be a means to understand further the tensions implicit in professionals engaging closely in personal worlds and their implications for addressing support needs and other aspects of professional practice.

9.7.5 Diversity of family and friendship patterns

It is a question for further exploration whether, or under what circumstances, people with visible facial difference construct ‘almost dependent’ family patterns, as identified by Peter et al. (1975). It may be that the development of equalities legislation and the encouragement of independence have reduced the occurrence of ‘almost dependent’ family patterns in adulthood for people living with visible facial difference from birth. Exploration in this area could identify support needs of families and individuals in these situations.

This study did not recruit people from black and minority ethnic communities. The literature review (Chapter 3) indicated a dearth of studies looking at contributions of ethnicity and ethnic identities to living with visible facial difference. Some studies indicate that stigma may be higher within UK South East Asian populations ((Rozario, 2007; Thompson et al., 2010). This area is poorly understood and research into implications for delivery of psychosocial services has been overlooked. Part of the difficulty may lie in the individualistic approaches favoured in the field (Vickers et al., 2013). Family practices vary in relation to dynamics of protection and movement. There is a risk of conflating differences within family practices as the source of difficulty if the wider context of ethnic disadvantage and poorer access to culturally appropriate services is not taken into account (Mir and Tovey, 2003). In relation to adults living with visible facial difference, it might be fruitful to explore how self-identities in relation to visible facial difference are combined with needs to live within specific cultural and religious contexts.

There would be a need to consider the benefits, as well as the difficulties, associated with cultural and traditional practices, in relation to facial appearance. The personal community method could play a role in providing an ecological and relational dimension to such a project.

9.7.6 Development of new ‘normalities’

The findings of the importance of ‘getting it’ cultures of families and friends merits further exploration. The significance of this finding resonates with the ethics of care theory of Kittay (2006). Deeper exploration of this area could increase understanding of the range of ways people with visible facial difference and their families and friends adapt ‘normality’ to achieve a sense of value, safety and also adventure in important areas of life such as education and employment as well as care.

Some respondents had better resourced personal communities than others. The risk of social isolation within some personal social worlds suggests this should be a priority for policy and practice development. Furthermore some personal communities which were experienced as supportive appeared restricted in their reach outside of their family. This suggests that support for the ‘personal communities’, as defined by the person themselves, would be worth investigated as part of developing support to families. It is possible that the presence of apparently more restricted personal communities might be a matter of personal preference; alternatively they may indicate a wider issue that the family are also experiencing difficulties in making resourceful or wider connections.

9.7.7 Experience of employment

There were indications of overlaps between ‘managing in some areas’ and protracted periods of unemployment or under-employment. Within the other ‘voices’ the approach taken by a workplace in relation to inclusion was narrated as important, and workplaces could, in these circumstances, be a source of social contacts and positive relationships. Inclusion in worlds of work for people with visible facial difference merits further attention, not least because of its importance to current social policy.

Severe disfigurement is a protected characteristic under equalities legislation. A systematic review could establish what is known about gaining and retaining employment, and experience of work contexts which foster inclusion and support diversity (Hays-Thomas, 2012).

9.7.8 Development of resilience within relational ecologies

There is potential to develop deeper understandings of adult resilience, employing an ecological, embodied and relational approach (Ungar, 2013). This study found interplay between individuals' processes and their relational and social ecology. The processes of 'developing', 'sustaining', and 'managing in some areas' could be built upon. Conceptualising resilience as an aspect of everyday life would be a valuable way to encouraging a nuanced approach to understanding the relativity of resilience. Enabling a greater recognition of the pathways to a resilient orientation within a stigmatising environment, taken by some people with visible facial difference, would be valuable. It would provide potential for recognition of the resilience of those viewed as 'less well adapted' or with less well-resourced ecologies (Runswick-Cole and Goodley, 2013). This would enable an understanding of responses to stigmatising social contexts, going beyond impression management strategies. It would also enhance people with visible facial difference taking part in social discourse about the meaning of resilience (Ungar et al., 2013).

9.8 Conclusions

This study represents an original approach to exploring visible facial difference. The sustained focus on social contexts has contributed to greater understanding of how personal communities can value, protect, stimulate and support people living with visible facial difference.

A conceptual framework was developed which theorised an embodied social self within relational environments, to enhance the concept developed by Spencer and Pahl (2006). This enabled an exploration of the interplay between the self and the ecology of important relationships. As a method, it has proved useful in identifying and understanding current relationships embedded in a variety of settings.

Subtle changes in the quality of a relationship could be identified, for example, failure in a prior time of need could realign the placement of the friend or family member from an inner to a less centric area of the personal community.

The findings indicate that many respondents with visible facial difference are situated within rich and diverse personal communities and have relationships embedded in a number of different social settings. The accounts indicated that the presence of facial difference was not viewed as an independent risk to sustaining and developing chances, but that the ‘risk’ resided interactively in the relationships and ecologies in which the individual was embedded. Respondents described how, to a greater or lesser extent, they had integrated reactions to their facial appearance into these worlds. Resistance to being seen as ‘not normal in some way’ was evident and some respondents described how certain members of personal communities contributed to their development of this.

This study explored how personal communities contribute to a person’s sense of belonging and connection as well as providing sources of support. A personal community is not a single network but a selection of people important to the individual who may come from a range of other networks to which the individual is also connected. Family and friends associated with the inner circles on the personal community could be the mainstay of a number of supportive relationships, with the partner relationship being primary.

Personal communities were a useful means of capturing a range of relationships, and their relative importance. The typology developed by Spencer and Pahl (2006) was difficult to apply in full, and a modified version was used (Section 9.5.3). Distinctions between the types of personal community offered some insight into differences in social experience of people living with visible facial difference but only when the interplay between the maps and the narrative accounts were considered. Components of the typology were useful in their own right, particularly centrality of ties, considering quality of family and friend relationships, the friendship typology, and friendships repertoire.

Spencer and Pahl (2006) did not consider size of a personal community a defining feature; however they also decided not to analyse some of the personal communities they identified because they were too small. In the current study there were indications that the number of important relationships would have some analytic leverage and would be worthy of further consideration.

The study can be seen as contributing a different perspective to the field of visible facial difference. It will not be surprising to people living with visible facial difference that much of what is wanted in life centres on belonging, worthwhile activity, financial resources and relationships with family, friends and others. However, many quality of life studies focus on the individual aspects of adjustment or adaptation and fewer studies have looked at familial, community or friendship contexts. While the formation of networks might be seen as a basic human activity, it is not open ended or a given; people are not in a position to devise a supportive social network just because they see a need for it. Instead, they have to draw on, or withdraw from, what is available to them. The negotiations that occur within lives were the primary interest of this study. This study contributes to the understanding of social support, something identified as most important in many studies of adaptation or adjustment. It does this through a deconstruction of the meaning of support and connections in people's lives.

The way in which people see themselves depends on their relationships and experiences, rather than visible facial difference alone. These experiences are not just about the face, qualities of connections also count. However, the primacies of family and partner relationships are apparent in this study. These connections and relationships are understood as nested within a system (Bronfenbrenner, 2005; Ungar, 2012, 2013). Relationships in a personal community link the person with other settings, making links dynamically between micro and meso systems. Individual experiences of resilience are developed as a part of this system. The voices of resilience developed in Chapter 7 identify a range of responses to living with visible facial differences, which link to past and current experiences of relationships.

In addition, a number of processes of support were identified within personal communities around talking about appearance issues, enabling accepting cultures, facilitating access to new relationships and resources, providing alternative interpretations of situations, demonstrating and displaying belonging, and making specialist contributions (Chapter 8).

Respondents identified that negative attitudes are not only about descriptions of physical differences. They involve value judgements about ability and disability, and, in turn, these were linked by some to processes of discrimination in schools or workplaces. In this study, these judgements were most overtly described with strangers and acquaintances, and the personal community was explored in relation to its ability and resources to provide protective qualities. Balancing between safety and movement indicate that families are deeply affected and a sense of uncertainty pervades narratives about the meanings of experiences and behaviours encountered. The personal communities maintained a coherence, but in the ‘family-enveloped’ pattern, the narrative voice contradicted this coherence with emotionally distant or absent relationships, and a sense of isolation.

The hope that Spencer and Pahl (2006) expressed about the value of greater cultural awareness of personal communities in lives needs to be handled with care and sensitivity at the personal level. For respondents, it seemed valuable to identify the complexity of their connections and to see themselves at the centre of a larger whole. However, this may not be the case for those who have limited connection with others and whose experience is one of isolation and rejection. The importance of employing the method in a sensitive, contributor focussed environment and via the interviewer-interviewee relationship, is an essential part of the method.

The study has focussed on two broad experiences of visible facial difference: acquired or born with and it has explored living with difference in everyday lives, rather than the processes of diagnosis, treatment or recovery. Resilience has been thought of as a metaphor to suggest ways in which people ‘do well’ under a condition of adversity. Doing well has been thought of as being about how people talk and about the ways in which they are achieving what they believe is important in life.

The study has used the idea of a personal community to look at how relationships, with combinations of family and friends, develop and sustain the individual as a social self. The socially embedded nature of personal resilience is emphasised. It is complex and hard to foresee because of its basis in embodiment and relationality. Visible facial difference is not readily categorised as disability or illness and is a highly variable presence. It can occur with other types of disadvantage or with none at all. The respondents described vastly differing life experience, types of visible facial difference and ages when affected.

This study has looked critically at what is normal and important in lives and found a significant voice among people with visible facial difference. Personal communities can be viewed as a significant resource in developing and sustaining what is important in life. They are an important means by which people contribute to the personal lives of their families, friends, neighbours and colleagues. They also provide avenues for connection to local communities and wider society through work, sporting activities and hobbies, parenting, neighbourliness, and involvement in organisations which provide consultation, advocacy and support services. Some people utilise their experiences of health services and self-help groups to recognise how services could be strengthened to provide support when needed by people affected by difference. Personal communities also need nourishing as they are an important part of a person’s social ecology providing networks of support and sources of solidarity. These are examples of ways valuable contributions are made by people living with difference to a society which has a strong focus on appearance.

Friendships are important in relation to social identity, connecting to settings of work, valued activities and neighbourhoods. Solidarity and altruism are not confined within the family for people living with visible facial difference. This study has shown how different aspects of desire for normality shape realities. Diversity was found in how people lived their lives and in the extent to which visible facial difference was thought to have had negative shaping effects.

However, for many people with visible facial difference much of their everyday lives in their personal community are not dissimilar to the lives of other people. This challenges a cultural representation of disfigurement and visible difference as pathological or tragic. Lives set not set apart: personal communities play a central role in creating new normalities where people can feel safer, accepted, encouraged and valued.

Appendix 1: Key to respondents

Name	Age	Visible facial difference	Born with or acquired facial difference
Alan	30-60	Eczema	Acquired
Bridget	30-60	Burn	Acquired
Carl	60 and above	Cancer of head and neck area	Acquired
Dave	60 and above	Cancer of head and neck area	Acquired
Eve	30-60	Cranio-facial condition	Born with
Fiona	30-60	Cranio-facial condition	Born with
Gina	Under 30	Cranio-facial condition	Born with
Isobel	30-60	Cranio-facial condition	Born with
Jane	30-60	Cranio-facial condition	Born with
Ken	60 and above	Burn	Acquired
Lewis	30-60	Burn	Acquired
Mark	Under 30	Cranio-facial condition	Born with
Peter	30-60	Burn	Acquired
Roy	30-60	Cranio-facial condition	Born with
Steve	30-60	Cerebral palsy	Born with
Tom	30-60	Cancer of head and neck area	Acquired
Vera	30-60	Cranio-facial condition	Born with
Holly	30-60	Partner of a respondent	
Nigel	60 and above	Friend of a respondent	

Range of conditions within the sample

Burn*	Injury to tissues caused by heat, flame, chemicals, electricity, or radiation. Burn injuries vary in degree, area affected and in extent of injury to the body.
Cerebral palsy*	Affects muscle control and movement, usually caused by injury to the brain before, during or after birth. Can affect body movement; muscle control, coordination, or tone; reflexes, posture and balance and varies in severity.
Cleft lip and/or palate*	A cleft is a gap in the upper lip, the roof of the mouth (palate), or sometimes both. It occurs when separate areas of the babies face do not fuse during pregnancy. The type, severity and effect on speech vary from person to person.
Eczema*	Affects the skin, in which patches of skin become rough and inflamed with blisters which cause itching and bleeding. There are different types of eczema which vary in degree, length of time the eczema is active for and areas of the body affected.
Head and neck cancer*	Includes cancers of the mouth and the throat, as well as rarer cancers of the nose, sinuses, salivary glands and middle ear.

Haemangioma**	A benign tumour of infancy often affecting the head and neck area.
Moebius syndrome*	Rare neurological disorder present at birth. Primarily leaves those with the condition unable to move their face or eyes laterally. There may be hand/feet anomalies, respiratory problems, speech and swallowing disorders, visual impairments, sensory integration dysfunction, sleep disorders, and weak upper body strength.
Skin cancer*	There are two main types of skin cancer. Non-melanoma skin cancer refers to a group of cancers that slowly develop in the upper layers of the skin. Melanoma skin cancer spreads faster in the body.
Treacher Collins syndrome****	Affects development of bones and other tissues of the face. Effects vary greatly from almost unnoticeable to severe. Most affected individuals have underdeveloped facial bones, particularly the cheek bones, and a very small jaw and chin. Some people are born with a cleft palate. In severe cases, underdevelopment of the facial bones may restrict an affected infant's airway, with potentially life-threatening respiratory problems.

Sources: *relevant charity website; **NHS website; *** professional association website; ****National Library of Medicine website.

Appendix 2: Spencer and Pahl's (2006) typology of personal communities

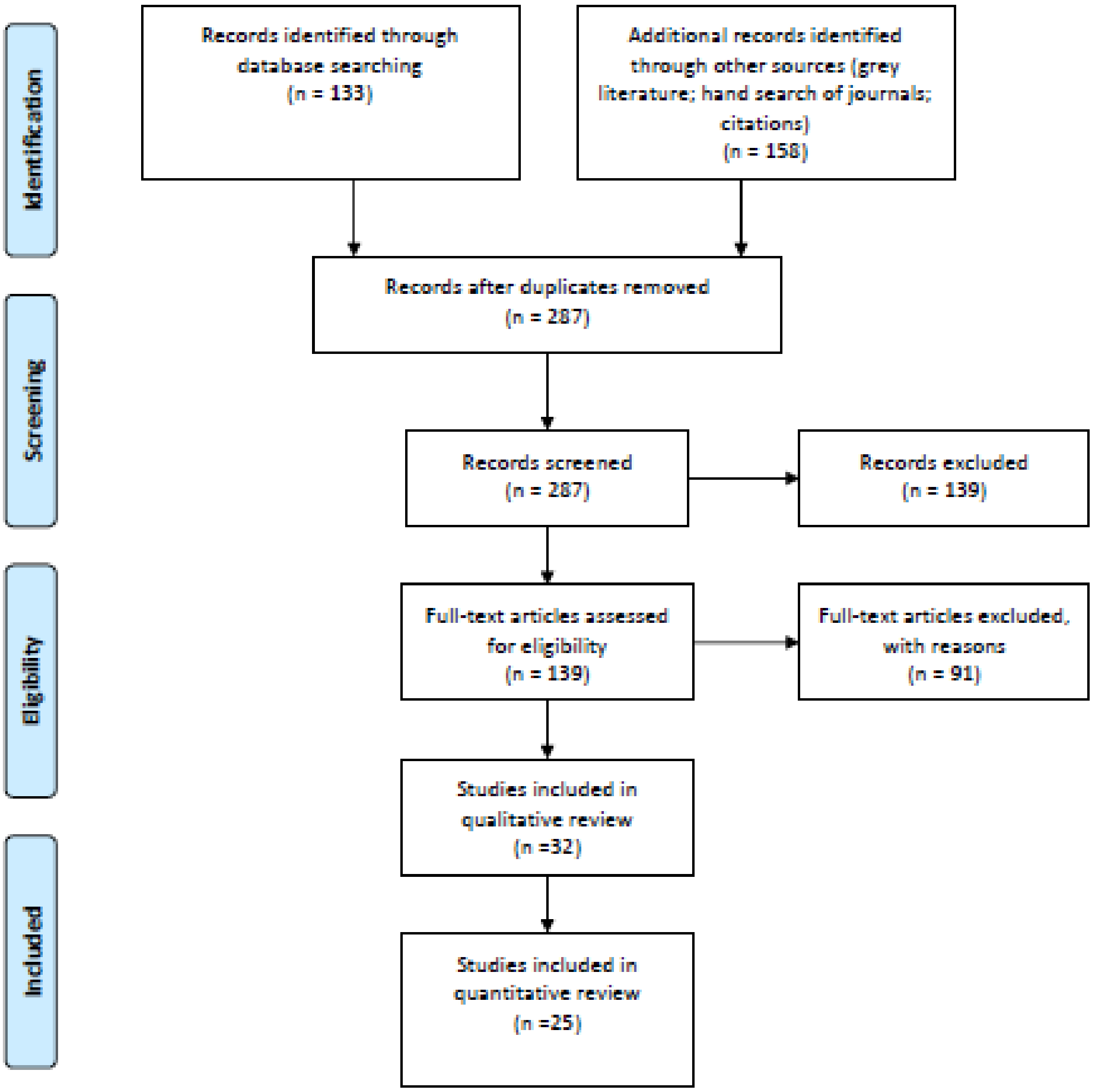
Personal community	Criteria for inclusion	Balance between kinds of tie	Central ties	Friendship repertoire	Friendship Mode	Suffusion or specialised
Friend-like	Mainly chosen	More friends than family	Friends in centre with close family	Broad or Focal	Evolving	Friends (or friends & partner) specialise in certain roles or in a suffused pattern
Friend-enveloped	Mainly chosen, some given	More friends than family or equal numbers	Family only in the first ring	Broad or Focal	Evolving or Ruptured	Friends (or friends & partner) specialise in certain roles or in a suffused pattern
Family-like	Mainly given, some chosen	More family than friends	Family only in 1st, & possibly 2nd ring	Focal or Intense	Evolving or Ruptured or Bounded or Serial	No clear pattern of suffusion or specialisation
Family-enveloped	Mainly given	More family than friends	Family only in 1st &/or 2nd ring	Narrow	Bounded	Family (or family & partner) specialise in certain roles or complete separation of roles between family & friends
NEIGHBOUR BASED	Mainly given	Neighbours equal or outnumber family & friends	Neighbours in 1st ring	Focal or Narrow	Bounded or Serial	Neighbours & friends specialise, separation of roles between friends & family
PARTNER BASED	Chosen & given	No clear pattern in balance of friends & family	Partner or partner & family in 1st ring	Narrow	Bounded or Serial	Partner specialises in certain roles, complete separation of roles between family & friends
PROF-ESSIONAL BASED	Mainly given	No clear pattern in balance of friends & family	Prof-essional supporter in 1st or 2nd ring	Narrow	Serial or Ruptured	Professionals specialise in certain roles, complete separation of roles between family & friends

Appendix 3: Spencer and Pahl's (2006) typologies of relationships

Type of friendship	Definition
Simple friendships	
Associate	Confined to a single activity or context
Fun/sociable	Socialise together, friend or family
Favour/neighbourly	Help each other in practical ways, live locally. May include useful contact
Helpmate/helpful	Socialise and help each other out in practical ways
Complex friendships	
Supportive	Socialise, help each other out and provide each other emotional support
Confidant/intimate	Enjoy each other's company, disclosure of personal information but may not be local
Soulmate	Confide in, provide emotional support, enjoy each other's company, often called best friends
Friendship repertoires	
Narrow	Includes simple friendship types only
Intense	Includes complex friendship types only
Focal	Includes simple and complex friendship types, but the range is narrow. For example, has a small core of soulmates and rest are fun friends
Broad	Includes simple and complex friendship types and a broad range of types
Friendship modes	
Bounded	Made most of their friends at a particular life stage or context, for example, school, but may add new ones when old ones fade. Often stayed in same area for a long time.
Serial	Friendship repertoires almost completely changed at new life stages or events. Often geographically mobile or sometimes have had a number of crises
Evolving	Elements of bounded and serial, new people added at life course transitions, but some retained from earlier stages.
Ruptured	Almost complete replacement of friendships following a dramatic change of circumstances. For example, serious illness, difficult divorce.

Patterns of suffusion on personal communities	
Suffusion	Role of family and friends overlap. Many relationships are sociable, helpful or confiding
Specialised	Roles of family and friends are separate. Interact with family and friends in different ways
‘Given’ and ‘chosen’ ties	
‘Given’	Ascribed ties, mainly family. Also neighbours and colleagues ascribed not described as also friends
‘Chosen’	Bonds which need forming and developing. Mainly friends, partners and particular family members.
‘Given-as-chosen’	Where a ‘given’ tie seen as having an element of choice. For example, a family member seen as a friend.
‘Chosen-as-given’	When a ‘chosen’ tie is treated as a member of family
Bonus relationships	Where given ties are seen as chosen. For example, a favoured sibling who is more like a friend

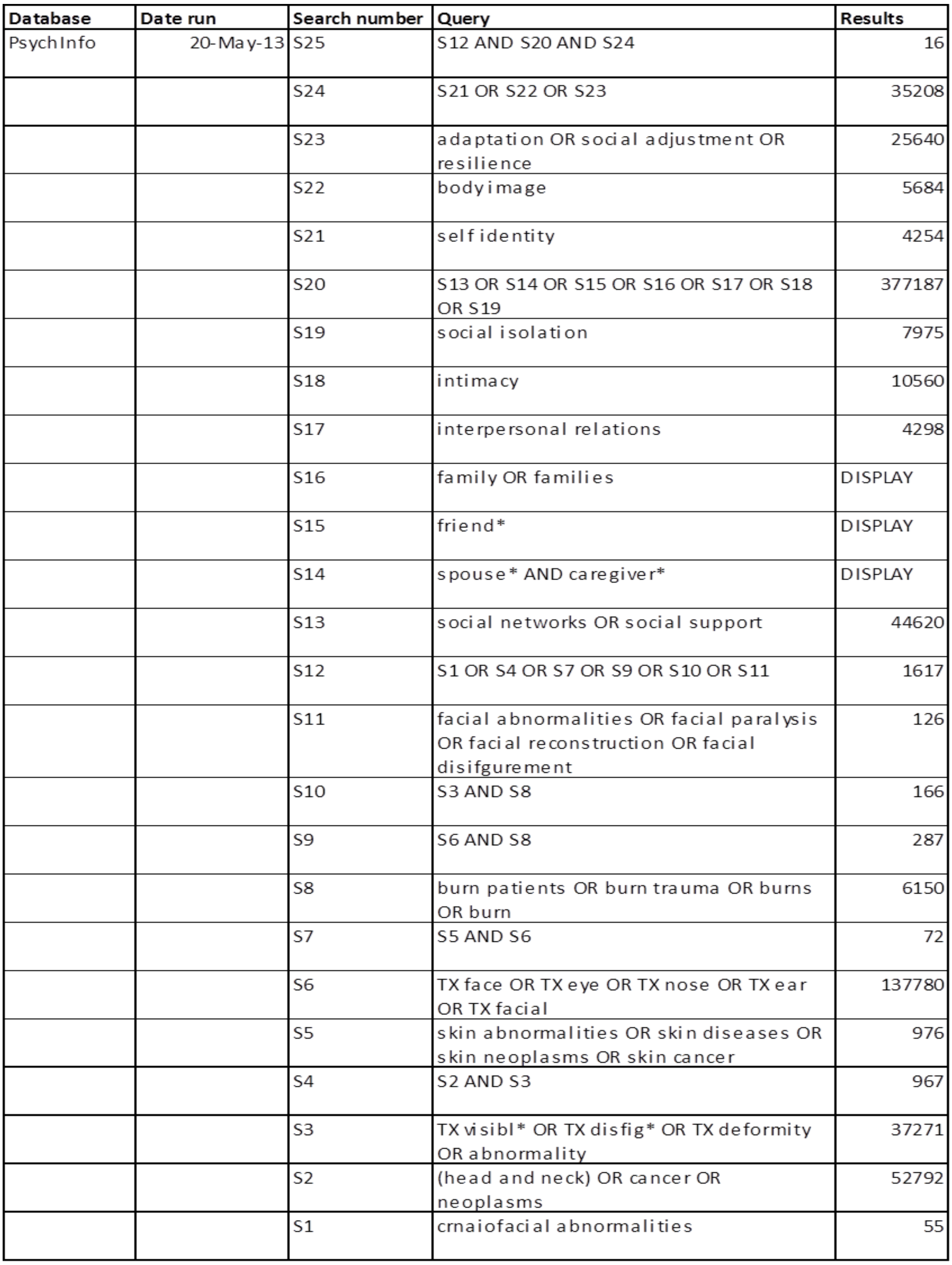
Appendix 4: PRISMA flowchart of search strategy



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

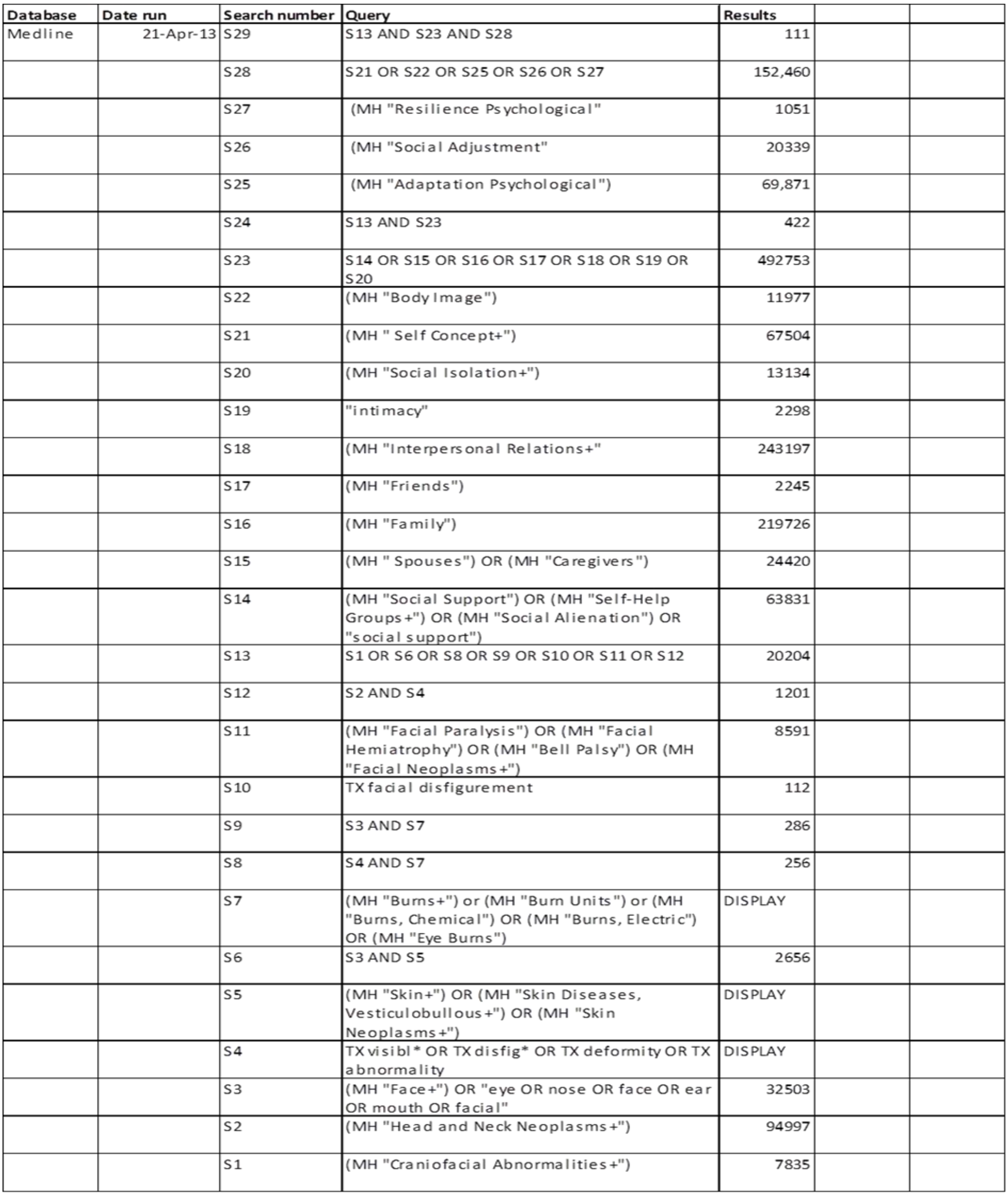
Appendix 5: Review search terms

5.1 PsychInfo



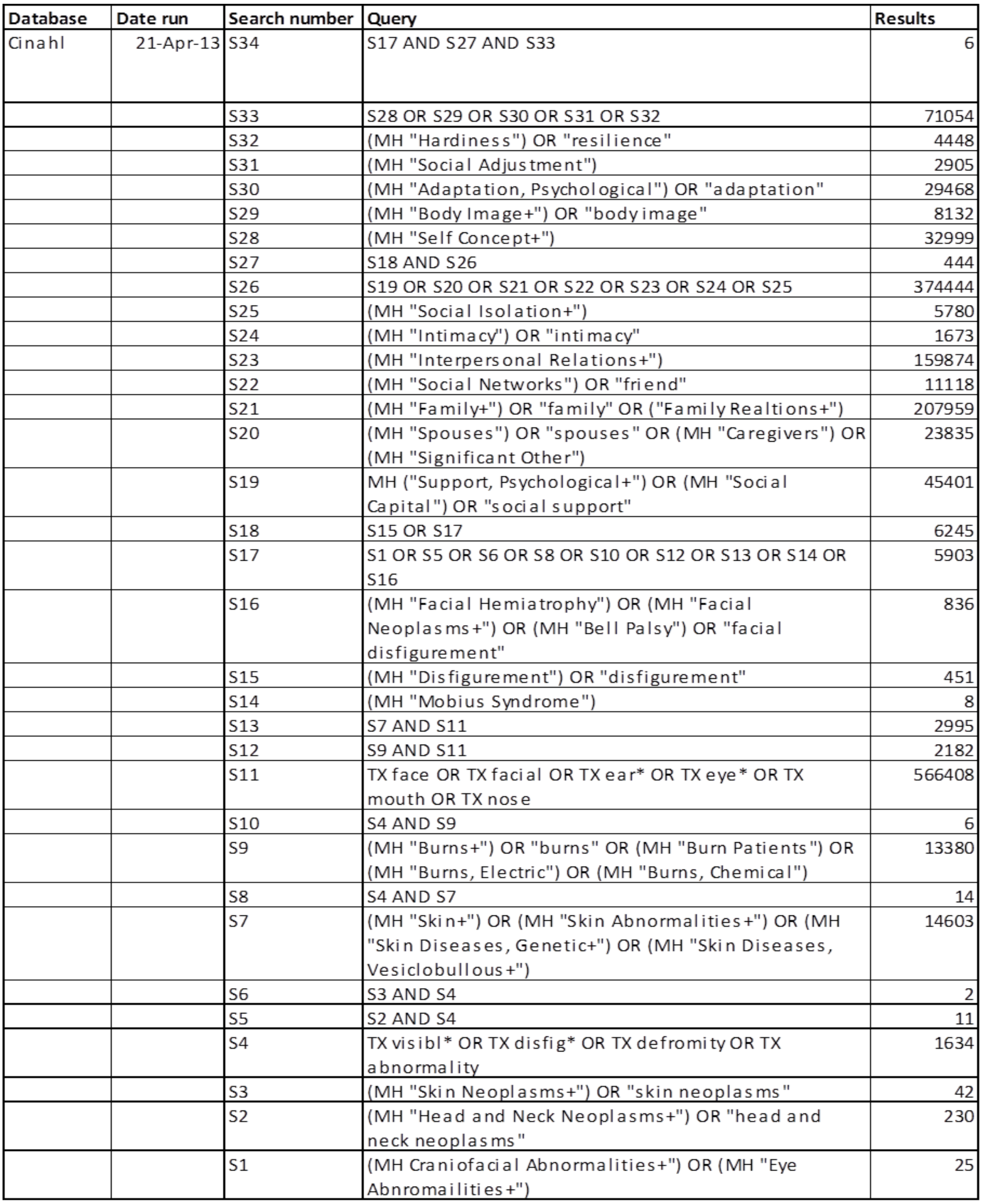
Database	Date run	Search number	Query	Results
PsychInfo	20-May-13	S25	S12 AND S20 AND S24	16
		S24	S21 OR S22 OR S23	35208
		S23	adaptation OR social adjustment OR resilience	25640
		S22	body image	5684
		S21	self identity	4254
		S20	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19	377187
		S19	social isolation	7975
		S18	intimacy	10560
		S17	interpersonal relations	4298
		S16	family OR families	DISPLAY
		S15	friend*	DISPLAY
		S14	spouse* AND caregiver*	DISPLAY
		S13	social networks OR social support	44620
		S12	S1 OR S4 OR S7 OR S9 OR S10 OR S11	1617
		S11	facial abnormalities OR facial paralysis OR facial reconstruction OR facial disifgurement	126
		S10	S3 AND S8	166
		S9	S6 AND S8	287
		S8	burn patients OR burn trauma OR burns OR burn	6150
		S7	S5 AND S6	72
		S6	TX face OR TX eye OR TX nose OR TX ear OR TX facial	137780
		S5	skin abnormalities OR skin diseases OR skin neoplasms OR skin cancer	976
		S4	S2 AND S3	967
		S3	TX visibl* OR TX disfig* OR TX deformity OR abnormality	37271
		S2	(head and neck) OR cancer OR neoplasms	52792
		S1	crnaiofacial abnormalities	55

5.2 Medline



Database	Date run	Search number	Query	Results		
Medline	21-Apr-13	S29	S13 AND S23 AND S28	111		
		S28	S21 OR S22 OR S25 OR S26 OR S27	152,460		
		S27	(MH "Resilience Psychological"	1051		
		S26	(MH "Social Adjustment"	20339		
		S25	(MH "Adaptation Psychological")	69,871		
		S24	S13 AND S23	422		
		S23	S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20	492753		
		S22	(MH "Body Image")	11977		
		S21	(MH " Self Concept+")	67504		
		S20	(MH "Social Isolation+")	13134		
		S19	"intimacy"	2298		
		S18	(MH "Interpersonal Relations+"	243197		
		S17	(MH "Friends")	2245		
		S16	(MH "Family")	219726		
		S15	(MH " Spouses") OR (MH "Caregivers")	24420		
		S14	(MH "Social Support") OR (MH "Self-Help Groups+") OR (MH "Social Alienation") OR "social support")	63831		
		S13	S1 OR S6 OR S8 OR S9 OR S10 OR S11 OR S12	20204		
		S12	S2 AND S4	1201		
		S11	(MH "Facial Paralysis") OR (MH "Facial Hemiatrophy") OR (MH "Bell Palsy") OR (MH "Facial Neoplasms+")	8591		
		S10	TX facial disfigurement	112		
		S9	S3 AND S7	286		
		S8	S4 AND S7	256		
		S7	(MH "Burns+") or (MH "Burn Units") or (MH "Burns, Chemical") OR (MH "Burns, Electric") OR (MH "Eye Burns")	DISPLAY		
		S6	S3 AND S5	2656		
		S5	(MH "Skin+") OR (MH "Skin Diseases, Vesiculobullous+") OR (MH "Skin Neoplasms+")	DISPLAY		
		S4	TX visibl* OR TX disfig* OR TX deformity OR TX abnormality	DISPLAY		
		S3	(MH "Face+") OR "eye OR nose OR face OR ear OR mouth OR facial"	32503		
		S2	(MH "Head and Neck Neoplasms+")	94997		
		S1	(MH "Craniofacial Abnormalities+")	7835		

5.3 Cinahl



Database	Date run	Search number	Query	Results
Cinahl	21-Apr-13	S34	S17 AND S27 AND S33	6
		S33	S28 OR S29 OR S30 OR S31 OR S32	71054
		S32	(MH "Hardiness") OR "resilience"	4448
		S31	(MH "Social Adjustment")	2905
		S30	(MH "Adaptation, Psychological") OR "adaptation"	29468
		S29	(MH "Body Image+") OR "body image"	8132
		S28	(MH "Self Concept+")	32999
		S27	S18 AND S26	444
		S26	S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25	374444
		S25	(MH "Social Isolation+")	5780
		S24	(MH "Intimacy") OR "intimacy"	1673
		S23	(MH "Interpersonal Relations+")	159874
		S22	(MH "Social Networks") OR "friend"	11118
		S21	(MH "Family+") OR "family" OR ("Family Realtions+")	207959
		S20	(MH "Spouses") OR "spouses" OR (MH "Caregivers") OR (MH "Significant Other")	23835
		S19	MH ("Support, Psychological+") OR (MH "Social Capital") OR "social support"	45401
		S18	S15 OR S17	6245
		S17	S1 OR S5 OR S6 OR S8 OR S10 OR S12 OR S13 OR S14 OR S16	5903
		S16	(MH "Facial Hemiatrophy") OR (MH "Facial Neoplasms+") OR (MH "Bell Palsy") OR "facial disfigurement"	836
		S15	(MH "Disfigurement") OR "disfigurement"	451
		S14	(MH "Mobius Syndrome")	8
		S13	S7 AND S11	2995
		S12	S9 AND S11	2182
		S11	TX face OR TX facial OR TX ear* OR TX eye* OR TX mouth OR TX nose	566408
		S10	S4 AND S9	6
		S9	(MH "Burns+") OR "burns" OR (MH "Burn Patients") OR (MH "Burns, Electric") OR (MH "Burns, Chemical")	13380
		S8	S4 AND S7	14
		S7	(MH "Skin+") OR (MH "Skin Abnormalities+") OR (MH "Skin Diseases, Genetic+") OR (MH "Skin Diseases, Vesiclobullous+")	14603
		S6	S3 AND S4	2
		S5	S2 AND S4	11
		S4	TX visibl* OR TX disfig* OR TX defromity OR TX abnormality	1634
		S3	(MH "Skin Neoplasms+") OR "skin neoplasms"	42
		S2	(MH "Head and Neck Neoplasms+") OR "head and neck neoplasms"	230
		S1	(MH Craniofacial Abnormalities+") OR (MH "Eye Abnromailities+")	25

Appendix 6: References identified by hand search

Author	**Reference**
Appearance Research Collaboration (2010)	Identifying the psychosocial factors and processes contributing to successful adjustment to disfiguring conditions. London: The Healing Foundation
Bellew (2012)	The role of the family. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press p 239-252
Bessell, Dures, Semple & Jackson (2012b)	Addressing Appearance-Related Distress Across Clinical Conditions. *British Journal of Nursing* 21(19) p. 1138-1143
Bessel & Moss (2007)	Evaluating the Effectiveness of Psychosocial Interventions for Individuals with visible Differences: A Systematic Review of the Literature *Body Image* 4 p.227-238
Bundy (2012)	Visible difference associated with disease: skin conditions. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press p398-413
Clarke (1999)	Psychosocial Aspects of Facial Disfigurement: Problems, Management and the Role of a Lay-Led Organisation. *Psychology, Health & Medicine* 4(2) p127-142
Feragen (2012)	Congenital conditions. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press p353-371
Jenkinson (2012)	Therapeutic interventions. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press p551-567
Moss & Rosser (2012)	Adult psychosocial adjustment to visible differences: physical and psychological predictors of variation. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press p273-292
Newell (2000)	*Body Image and Disfigurement Care*. London: Routledge
Partridge (1990)	*Changing Faces: The challenges of facial disfigurement.* London: Changing Faces Publication
Rumsey & Harcourt (2004)	Body Image and Disfigurement: Issues and Interventions. *Body Image* 1, p83-97
Rumsey & Harcourt (2005)	*The Psychology of Appearance*. Berkshire: Open University Press
Rumsey & Harcourt (2012)	*The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press
Thompson (2012)	Researching appearance: models, theories, and frameworks. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press p91-109
Thompson & Kent (2001)	Adjusting to Disfigurement: Processes Involved in Dealing with Being Visibly Different. *Clinical Psychology Review*. 21(5) p663-682
Williamson & Wallace (2012)	When treatment affects appearance. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press p414-438
Wisely & Gaskell (2012)	Trauma-with special reference to burn injury. In *The Oxford Handbook of the Psychology of Appearance.* Oxford: Oxford University Press: p372-397

Appendix 7: Inclusion and exclusion criteria

7.1 Inclusion criteria for literature review

- Adults with visible facial difference
- Adult defined as 18 years and over
- Published in English
- Empirical papers
- From inception

The studies included studies need to meet **BOTH** the following criteria:

- Visible facial difference defined by condition which causes visible facial difference or disfigurement. In addition the paper needs to explore the effect of visible facial/difference through;
  - Being addressed in the research questions
  - Use of a measure of facial disfigurement (such as studying groups by type of surgery; objective assessments or subjective assessment)
- Address contributions of personal relationships. This could be by
  - Addressing social support
  - Addressing social integration (clear criteria not fixed)
  - Addressing protection from stigma (clear criteria not fixed)
  - Addressing role in resilience (clear criteria not fixed)
  - Addressing role in coping (clear criteria not fixed)
  - Being about a personal relationship e.g. couples

7.2 Exclusion criteria

- Person with visible facial difference aged under 18 years
- Reviews
- Articles
- Personal testimony
- Intervention studies (not sure this was a justifiable decision on my part)
- Supportive relationships with health care professionals
- Supportive relationships with peer support groups

Appendix 8: Data extraction and quality appraisal

Author & reference	Aims of study	Methods used (quant or qual; details of approach, measures or tests, and how relationships were studied)	Respondents & sample size & data collection methods	Main findings: contribution of relationships to social support, social interaction, living with difference	Clarity of account of choice of measures, including outcome measure and justification for using these in relation to aims/objectives.	Clarity of conclusion in relation to method (sufficiency of data & suitability of method)

Quality criteria

Two quality criteria were applied to the papers:

1. Methodological rigour in terms of choice of measures and justification for using these in relation to aims and objectives
2. Theoretical rigour in terms of the clarity of the conclusion in relation to the method.

Tools were downloaded from the following websites to assist with the process.

CASP tools on case control studies and cohort studies checklists: Critical Appraisal Skills and Information: www.casp-uk.net

For surveys (including pre-test probabilities) checklist: Best BETS, Best Evidence Topics: Mackway-Jones et al. (2002-2012)

Questions for appraising qualitative research were obtained from: www.qualitysafety.bmj.com/content/13/3/223

Dixon-Woods, M., Shaw, R. L., Agarwal, S. and Smith, J. A. (2004) The problem of appraising qualitative research. *Quality and Safety in Health Care,* 13 (3)**,** pp. 223-225.

Appendix 9: Excluded papers with a reason

Author	**Reference**	**Reason for exclusion**
Adni et al (2012)	The psychosocial impact of chronic wounds on patients with severe Epidermolysis Bullosa. *J Wound Care* , 21(11), pp. 528, 530-6, 538.	Does not investigate facial disfigurement or difference
Agarwal et al (2010)	Coping strategies of African American head and neck cancer survivors. *J Psychosoc Oncology,* 28 (5), pp. 526-38.	Does not investigate facial disfigurement or difference
Akimbami et al (2007)	Psychological effects of speech disorders in an adult patient with untreated cleft palate. *Niger J Med*,16 (4), pp. 381-3.	Support from personal relationships not explored
Badger & Royse (2010a)	Adult burn survivors' views of peer support: a qualitative study. *Soc Work Health Care*, 49 (4), pp. 299-313	Support from personal relationships not explored
Badger & Royse (2010b)	Helping others heal: burn survivors and peer support. *Soc Work Health Care*, 49 (1), pp. 1-18.	Support from personal relationships and facial disfigurement or difference not explored
Badger et al (2011)	What's in a story? A text analysis of burn survivors' web-posted narratives. *Soc Work Health Care,* 50 (8), pp. 577-94.	Does not investigate facial disfigurement or difference
Baghi et al (2007)	Demands on caring relatives of head and neck cancer patients. *Laryngoscope,* 117 (4), pp. 712-6.	Does not investigate facial disfigurement or difference
Bergendal et al (2011)	Living with facial disfigurement—strategies for individuals and care management. *Spec Care Dentist*,31(6), pp. 216-219, 201	Healthcare service development
Bessell et al (2012a)	Evaluation of the effectiveness of Face IT, a computer-based psychosocial intervention for disfigurement-related distress. *Psychol Health Med ,* 17 (5), pp. 565-77	Support from personal relationships not explored
Bjorklund et al (2008)	Health promotion and empowerment from the perspective of individuals living with head and neck cancer. Eur J Oncol Nurs,12 (1), pp. 26-34.	Does not investigate facial disfigurement or difference
Bjornsson et al (1987)	A psychosocial study of Icelandic individuals with cleft lip or cleft lip and palate. *Cleft Palate J*,24 (2), pp. 152-7.	Support from personal relationships not explored
Bogart et al (2010)	Facial mimicry is not necessary to recognize emotion: Facial expression recognition by people with Moebius syndrome. *Soc Neurosci* ,5 (2), pp. 241-51.	Support from personal relationships not explored. Useful background paper
Bogart et al (2010)	Living with Moebius syndrome: adjustment, social competence, and satisfaction with life. *Cleft Palate Craniofac J*,47 (2), pp. 134-42.	Support from personal relationships not explored, Useful background paper

Author	**Reference**	**Reason for exclusion**
Bradbury et al (2006)	Psychological and social factors in reconstructive surgery for hemi-facial palsy. *Journal of Plastic, Reconstructive & Aesthetic Surgery* ,59, pp.272-278	Support from personal relationships not explored.
Brooker et al (2009)	A qualitative exploration of quality of life among individuals diagnosed with an acoustic neuroma*. Br J Health Psychol* ,14 (Pt 3), pp. 563-78.	Does not investigate facial disfigurement or difference
Broomfield et al (1997)	The orofacial cancer patient's support from the general practitioner, hospital teams, family, and friends. *J Cancer Educ* ,12 (4), pp. 229-32.	Does not investigate facial disfigurement or difference
Brown et al (2008)	The hidden cost of skin scars: quality of life after skin scarring*. J Plast Reconstr Aesthet Surg,* 61 (9), pp. 1049-58	Support from personal relationships not explored.
Brown et al (2010)	Skin scar preconceptions must be challenged: importance of self-perception in skin scarring. *J Plast Reconstr Aesthet Surg*, 63 (6), pp. 1022-9.	Support from personal relationships not explored, useful background paper
Browne et al (1985)	Psychosocial adjustment of burn survivors. *Burns Incl Therm Inj* 12 (1), pp. 28-35.	Does not investigate facial disfigurement or difference, does look at social support
Cella et al (1988)	Stress and coping in relatives of burn patients: a longitudinal study. *Hospital Community Psychiatry* 39 (2), pp. 159-66.	Age
Chen et al (2009)	Support Needs of Patients With Oral Cancer & Burden to their family caregivers. *Cancer Nursing TM*, (2009) Vol. 32, No. 6	Does not investigate facial disfigurement or difference, does look at social support
Chen (2012)	Life experiences of Taiwanese oral cancer patients during the postoperative period. *Scand J Caring Science,26* (1) pp.98-103.	Does not investigate facial disfigurement or difference
Cheng et al (1996)	Outcome studies for burn patients in Hong Kong: patients' satisfaction. *Burns*,22 (8), pp. 623-6	Does not investigate facial disfigurement or difference
Cheung et al (2007)	Psychological profile of Chinese with cleft lip and palate deformities*. Cleft Palate Craniofacial J* ,44 (1), pp. 79-86.	Support from personal relationships not explored
Cohn et al (1985)	Life response to Crouzon's disease. *Cleft Palate J*,22 (2), pp. 123-31.	Support from personal relationships not explored
Coleman et al (2007)	Influence of chin prominence on esthetic lip profile preferences. *Am J Orthod Dentofacial Orthop* ,132 (1), pp. 36-42.	Support from personal relationships not explored
Costa et al (2008)	The meanings of quality of life: interpretative analysis based on experiences of people in burns rehabilitation. *Rev Lat Am Enfermagen* ,16 (2) pp.252-9.	Facial burn not examined in measures, findings or question
Davidson et al. (1981)	Social support and post-burn adjustment. *Arch Phys Med Rehabil* 62 (6), pp. 274-8.	Severity focussed on and not location.

Author	**Reference**	**Reason for exclusion**
de Leeuw et al. (2000)	Negative and positive influences of social support on depression in patients with head and neck cancer: A prospective study. *Psycho-Oncology,* 9(1) pp. 20-28.	Does not investigate facial disfigurement or difference
Derks et al (	Elderly Patients with Head and Neck Cancer: Physical, Social and Psychological aspects after 1 year. *Acta Otolaryngol* ,124, pp. 509-514	Does not investigate facial disfigurement or difference
Drabe et al (2008)	Psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer. *Psycho-Oncology*, 17, pp.199–204	Does not investigate facial disfigurement or difference
Dropkin (1999)	Body image and quality of life after head and neck cancer surgery. *Cancer Practice*, 7(6), pp309-313	Support from personal relationships not explored
Fauerbach et al (2002)	Coping with body image changes following a disfiguring burn injury. *Health Psychology,* 21 (2), pp. 115-21.	Support from personal relationships not explored
Flexen et al (2012)	Identifying appearance-related concerns in routine follow-up clinics following treatment for oral and oropharyngeal cancer. *Br J Oral Maxillofac Surg*, 50 (4), pp. 314-20	Support from personal relationships not explored
Foxwell & Scott (2011)	Coping Together and Apart: Exploring How Patients and Their Caregivers Manage Terminal Head and Neck Cancer. *J Psychosoconcol,* 29 (3), pp.308-26	Does not investigate facial disfigurement or difference
Goldstein et al (2008)	Palliative care for patients with head and neck cancer: 'I would like a quick return to a normal lifestyle. *JAMA: Journal of the American Medical Association*, 9(15), pp. 1818-1825.	Support from personal relationships not explored
Gotelf et al (2007)	Cognition, psychosocial adjustment and coping in familial cases of velocardiofacial syndrome. *J Neural Transm*, 114 (11), pp. 1495-501	Support from personal relationships not explored
Haisfield- Wolfe et al (2012)	Perspectives on Coping Among Patients With Head and Neck Cancer Receiving Radiation. *Oncol Nurs Forum* , 39 (3), pp.249-57	Support as a coping strategy for dealing with side effects of radiation.
Havstam et al (2011)	Taking charge of communication: adults' descriptions of growing up with a cleft-related speech impairment. *Cleft Palate Craniofac J*, 48 (6), pp. 717-26.	Background paper about communications. Closely related topic.
Hodges & Humphris (2009)	Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncology*, 18, pp. 841–848	Does not investigate facial disfigurement or difference
Holloway et al (2005)	Psychosocial effects in long-term head and neck cancer survivors. *Head & Neck*,27(4), pp.281-288	Support from personal relationships not explored

Author	**Reference**	**Reason for exclusion**
Hughes et al (2009)	South Asian community views about individuals with a disfigurement. *Diversity in Health & Care*, 6(4), pp.241-253	Support from personal relationships not explored
Jenewein et al. (2008)	Quality of life and dyadic adjustment in oral cancer patients and their female partners. *Eur J Cancer Care*, 17 (2), pp. 127-35.	Does not investigate facial disfigurement or difference
Kent (2002)	Testing a Model of Disfigurement: effects of a skin camouflage service on well-being and anxiety. *Psychology & Health*, 17:3, pp.377-386	Support from personal relationships not explored
Kornhaber & Wilson (2011)	Building resilience in burns nurses: a descriptive phenomenological inquiry. *J Burn Care Res*, 32 (4), pp. 481-8.	Support from personal relationships not explored
Krohne & Slangen (2005)	Influence of social support on adaptation to surgery. *Health Psychol,* 24 (1), pp.101-5.	Role of support to reduce anxiety to facial surgery. Borderline looks at surgery anxiety
Kugaya et al (1999)	Correlates of depressed mood in ambulatory head and neck cancer patients *Psychooncology*, 8 (6), pp. 494-9.	Does not investigate facial disfigurement or difference
Lawrence et al (2006a)	The reliability and validity of the Perceived Stigmatization Questionnaire (PSQ) and the Social Comfort Questionnaire (SCQ) among an adult burn survivor sample. *Psychological Assessment*, 18(1), pp. 106-111.	Factor analysis of content of two new scales
List et al (2002)	An exploration of the pre-treatment coping strategies of patients with carcinoma of the head and neck. *Cancer*, 95 (1), pp. 98-104.	Does not investigate facial disfigurement or difference
Locher et al (2010)	Disruptions in the organization of meal preparation and consumption among older cancer patients and their family caregivers. *Psycho-Oncology*, 19(9), pp. 967-974.	Cannot clearly exclude, needs to be looked at again
Loewenstein et al (2008)	The art of coping with a craniofacial difference: helping others through "Positive Exposure". *Am J Med Genet A*, 146A (12), pp. 1547-57.	Peer support
Love et al (1987)	Adult psychosocial adjustment following childhood injury: the effect of disfigurement. *J Burn Care Rehabil*, 8 (4), pp. 280-5.	Does not investigate facial disfigurement or difference. Background paper on severity
Ma (1998)	Effect of perceived social support on adjustment of patients suffering from nasopharyngeal carcinoma. *Health Soc Work*, 23 (3), pp. 167-74.	Does not investigate facial disfigurement or difference. Longitudinal study of effect of social support on adjustment, visibility is not explored it is strong on support issues.

Author	Reference	Reason for exclusion
Magin et al (2008)	Experiences of appearance related teasing and bullying in skin diseases and their psychological sequellae: results of a qualitative study. *Scand J Caring Sci*, 22, pp.430-436	Effect of visibility of skin conditions and teasing, includes facial acne, not on support contributions
Magin et al (2010)	Sex and the skin: A qualitative study of patients with acne, psoriasis and atopic eczema. *Psychology, Health & Medicine*, 15 (4),pp. 454-462	Investigates sexual intimacy
Mah & Johnston (1993)	Concerns of families in which one member has head and neck cancer. *Cancer Nurs*, 16 (5), pp. 382-7.	Does not investigate facial disfigurement or difference
Malm et al (1988)	Port-wine stain--a surgical and psychological problem. *Ann Plast Surg,* 20 (6), pp. 512-6.	Support from personal relationships not explored
Mannan et al (2006)	Psychosocial outcomes derived from an acid burned population in Bangladesh, and comparison with Western norms. *Burns*, 32 (2), pp. 235-41.	Support from personal relationships not explored. Background, attacks are family and family related
Manne & Badr (2010)	Intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Psycho-oncology*, 19 (9), pp. 941-54.	Does not investigate facial disfigurement or difference
McGory (2011)	Communicating with head and neck cancer patients. *Head Neck Nurs*, 29 (3), pp. 7-11.	Support from personal relationships not explored
Moi et al (2008)	The experience of life after burn injury: a new bodily awareness. J Adv Nurs, 64 (3), pp.278-86.	Does not investigate facial disfigurement or difference
Moss & Carr (2004)	Understanding adjustment to disfigurement: the role of the self-concept. *Psychology and Health,* 19(6), pp. 737–748	Support from personal relationships not explored
Newell & Marks (2000)	Phobic nature of social difficulty in facially disfigured people. *Br J Psychiatry* 176, pp. 177-81.	Support from personal relationships not explored.
Ostroff et al (2004)	Interest in and barriers to participation in multiple family groups among head and neck cancer survivors and their primary family caregivers. *Fam Proces*, 43 (2), pp. 195-208.	Background paper because family intervention in HNC. But paper does not explore disfigurement or visible facial difference
Pallua et al (2003)	Psychosocial adjustments 5 years after burn injury. *Burns*, 29 p143-152 2003	Support from personal relationships not explored
Papadopoulos et al (2000)	The relationship between body location and psychological morbidity in individuals with acne vulgaris. *Psychology, Health & Medicine*, 5(4), pp. 431-438.	Support from personal relationships not explored
Penedo et al (2012)	Perceived social support as a predictor of disease-specific quality of life in head-and-neck cancer patients. *Supportive Oncology*, 10 (3), pp. 119-23	Does not investigate facial disfigurement or difference

Author	**Reference**	**Reason for exclusion**
Pertschuk et al (1987)	Psychosocial considerations in craniofacial deformity. *Clin Plast Surg,* 14 (1), pp. 163-8.	Support from personal relationships not explored
Peter et al (1974)	Sociological aspects of cleft palate Adults: I. Marriage.*Cleft Palate J,* 11 (0), pp. 295-309.	Support from personal relationships not explored
Picardi et al (2003)	Stressful life events, social support, attachment security and alexithymia in vitiligo: A case-control study. *Psychotherapy and Psychosomatics*, 72(3), pp. 150-158.	Does not investigate facial disfigurement or difference
Picardi et al (2005)	Stress, social support, emotional regulation, and exacerbation of diffuse plaque psoriasis. *Psychosomatics: Journal of Consultation Liaison Psychiatry*, 46(6), pp. 556-564.	Does not investigate facial disfigurement or difference
Precious et al (2012)	Head and neck cancer patients' perspective of carer burden. *British Journal of Oral and Maxillofacial Surgery*, 50, pp.202–207	Does not investigate facial disfigurement or difference
Rapp et al (2001)	Social coping strategies associated with quality of life decrements among psoriasis patients. *Br J Dermatol*, 145 (4), pp. 610-6.	Does not investigate facial disfigurement or difference
Richards et al (2001)	The contribution of perceptions of stigmatisation to disability in patients with psoriasis. *J Psychosom Res*, 50 (1), pp. 11-5.	Does not investigate facial disfigurement or difference
Röing et al (2006)	Ways of understanding the encounter with head and neck cancer patients in the hospital dental team--a phenomenographic study. *Support Care Cancer*, 14 (10), pp. 1046-54.	Support from personal relationships not explored.
Rosenbach et al (2008)	Positive change after severe burn injuries. *J Burn Care Res*, 29 (4), pp. 638-43.	Does not explore support from personal relationships
Rosenberg et al (2007)	The importance of family environment for young adults burned during childhood. *Burns*, 33 (5), pp. 541-6	Investigates severe burn does not differentiate location. Background paper on importance of family environment
Scheuerle et al (2004)	A report of behavioural data on three groups of patients with craniofacial disorders. *J Craniofac Surg*, 15 (2), pp. 200-8.	Support from personal relationships not explored.
Schmid-Ott et al (2007)	Stigmatization, coping and sense of coherence in vitiligo patients. *J of the European Acad of dermatology & venereology*, 21 (4),pp. 456-61	Support from personal relationships not explored. But withdrawal is identified
Sharp et al (2008)	Caregiver and patient reported outcomes after repair of cleft lip and/or palate in the Philippines. *Cleft Palate Craniofac J*, 45 (2), pp. 163-71.	Age

Author	**Reference**	**Reason for exclusion**
Sproul et al (2009)	Perceived sources of support of adult burn survivors. *J Burn Care Res*,30 (6), pp. 975-82.	Does not investigate facial disfigurement or difference
Thambyrajah et al (2010)	Cancer doesn't mean curtains: Benefit finding in patients with head and neck cancer in remission. *Journal of Psychosocial Oncology*, 28(6)	Does not investigate facial disfigurement or difference
Thomas et al (1997)	Satisfaction with facial appearance among subjects affected by a cleft. *Cleft Palate Craniofacial Journal ,* 34 (3), pp. 226-31.	Support from personal relationships not explored.
Thombs et al (2008)	From survival to socialization: a longitudinal study of body image in survivors of severe burn injury. *J Psychosom Res*, 64 (2), pp. 205-12.	Support from personal relationships not explored. However it is a step forward study in relation to role of pre-injury social functioning and body image, changes over time, gender & extent of burn injury
Titscher et al (2010)	Emotional associations with skin: differences between burned and non-burned individuals. *Burns*, 36 (6), pp. 759-63	Support from personal relationships not explored.
Tovetjarn et al (2012)	Children with Apert syndrome as adults: a follow-up study of 28 Scandinavian patients. *Plast Reconstr Surg*, 130 (4), pp. 573e-577e	Support from personal relationships not explored. Borderline because looks at living with family as a function of intellectual functioning
Turner et al (1997)	Psychological outcomes amongst cleft patients and their families.*Br J Plast Surg*, 50 (1), pp. 1-9.	Support from personal relationships not explored.
van den Elzen et al (2012)	Adults with congenital or acquired facial disfigurement: impact of appearance on social functioning. *J Craniomaxillofac Surg*, 40 (8), pp. 777-82. Date of Electronic Publication: 2012 Mar 27.	Support from personal relationships not explored.
van Dijk et al (2009)	Coping strategies of retinoblastoma survivors in relation to behavioural problems. *Psychooncology*, 18 (12), pp. 1281-9	Does not investigate facial disfigurement or difference
Verdonck-de Leeuw et al (2007)	Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope*, 117 (2), pp. 238-41.	Does not investigate facial disfigurement or difference

Appendix 10: Included qualitative papers

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Purpose of study**	**Main findings**	**Quality issues**
Ablon (1996)	NF1	Interviews. Anthropological approach	N= 30: 28 affected adults (14f) & 2 non affected parents	Visibility & severity rated by researcher & self-report	Explore patterns of gendered response to NF1	Life style & attitudinal difference found between genders. NF1 affects self-image of men & women. Presence or absence of visible tumours or other effects did not 'predict' a satisfying or fulfilling life, but self-reported learning disabilities: resulting in poor school achievement, poor self-image & job prospects. Some males were severely affected by these proposed processes	Large qualitative study for a rare condition. Clear account for topic, analysis used & conclusions. Theoretical perspective evident
Bogart, Tickle-Degnen & Joffe (2012)	Moebius syndrome	Focus groups. Qualitative content analysis	N=12 affected adults (6f). Aged 18-60	Observed by researcher & self-report	Explore perspectives of social interaction	Use of compensatory expressive gestures & strategies: vocal tone, & humour to express oneself & improve social functioning. Social support & stigma represented on a continuum at one end providing support to bullying, prejudice & discrimination	Clear account for topic, analysis used & conclusions. Recruitment bias discussed.

Author & date	Type	Study design	Sample	Facial difference	Purpose of study	Main findings	Quality issues
Bonanno & Choi (2010)	HNC	Interviews. Grounded theory.	N=14 affected adults (6f).	Adults with disfigurement after cancer surgery	Explore interaction patterns between patients & strangers & acquaintances	2 groups of patients identified always comfortable (n=4) & occasionally comfortable (n=10) in interaction. Discomfort in interaction used as an indicator of stigmatisation. 3 interaction patterns by others identified: intrusion, sympathy & benign neglect & degree of discomfort varies with groups size. Always comfortable patients do not experience discomfort despite interaction pattern or group size	Clear account for topic, analysis used but conclusions over general. Simple statistics reported, but numbers are too small to distinguish between always comfortable patients & occasionally comfortable patients.
Bonanno & Esmaeli (2011)	HNC	Interviews. Grounded theory.	N= 30. 15 adults at least 6 mons after treatment (8m & 7f), 1 family member per patient	Adults with disfigurement after cancer surgery	Explore interaction patterns between patients & strangers & acquaintances	3 patterns identified: intrusion, sympathy & benign neglect. Intrusion & sympathy fostered stigma but benign neglect did not.	Clear account for topic, analysis used but conclusions over general.
Cadogan & Bennun (2011)	Cranio-facial conditions	Interviews. IPA	N= 7 (4f) adults with operations 2-4 years previously	Adults who had orthognathic surgery.	Explore psychological impact of orthognathic surgery.	Themes: self-awareness of facial appearance, attitudes of others, treatment issues, impact of surgery & support & coping	Limited information about literature, or conduct of analysis. Conclusions formed on a weak basis.

Author & date	Type	Study design	Sample	Facial difference	Purpose of study	Main findings	Quality issues
Dures, Morris, Gleeson & Rumsey (2011)	Epidermolysis Bullosa	Interviews. Thematic analysis.	N=24 adults (14f)	Affected adults & self-report	Psychosocial impact of EB & identify support needs.	Themes: beliefs about containing impact of EB, understanding of the disease & disabling impacts of EB at intra-individual, inter-individual & sociocultural levels including stigmatising effects of visibility,	Clear account for topic, analysis used & conclusions. Theoretical perspective evident
Egan, Harcourt, Rumsey & ARC (2011)	Visible difference	Interviews & focus groups. Thematic analysis	N=12 adults (9f) with a range of visible differences	Self-reported visible difference (body & facial)	Investigate positive experiences & adjustment to living with a visible difference.	Themes: importance of appearance, personal growth, relationships with others, coping	Clear account for topic, analysis used & conclusions.
Eiserman (2001)	Cranio-facial conditions	Questionnaire & interviews	N= 22. 11 parents of affected children & 11 affected adults	Affected adults & self-report	Explore contributions of people living with difference to social & family worlds. Mixed methods	Positive contributions were communication abilities, service to others, observational skills, inner strength abilities to question society, a valued social circle, perceptions of being normal	Pilot study. Claims mixed methods, but findings reported as themes & simple descriptive statistics. Clear account for topic. Quotes reported as speaking for themselves
Furness (2005)	Facial surgery for a range of conditions	Interviews & focus groups. Grounded theory coding techniques	N=38 (16f). 29 adult facial surgery survivors & 9 partners/family members	Affected adults & self-report	Explore experiences of facial surgery patients & friends/family about support from health care professionals	3 categories of support: informational, practical & emotional. Found discrepancies between patients need for emotional support & provision by healthcare staff	Exploratory study. Clear account for topic, analysis used & conclusions.

Author & date	Type	Study design	Sample	Facial difference	Purpose of study	Main findings	Quality issues
Furness, Garrud, Faulder & Swift (2006)	Facial surgery for a range of conditions	Interviews & focus groups. Grounded theory	N=29 (c21f) adult facial surgery survivors	Self-rated appearance change	Investigate predictors & process of adaptation to facial surgery.	Themes: demands, resources, responding & managing & consequences which were developed into a model. Social support theorised as an influence & a resource	Clear account for topic, analysis used & conclusions. Theoretical perspective evident
Hawkesworth (2001)	Acne	Interviews, email, letters, self-made tapes & telephone communication	N=32 (22f) adults with facial acne	Affected adults & self-report	Explores geographies of people with perceived facial difference, who withdraw because of their acne	Identified problems of exclusion in attitudinal environment or places which emphasise people looks. Issues of visibility & safety identified.	Clear account for topic, analysis used & conclusions. Theoretical perspective evident
Kent (2000)	Vitiligo	Critical incident technique	N=514 (465 f) adults aged 16-81.	Affected adults & self-report with any part of body affected	How incidents which trigger appearance concerns affect living with difference	Triggering events were situations where appearance was central e.g. bodily exposure. Uncertainty in how to deal with others behaviour. Social & personal costs found	Clear account for topic, analysis used & conclusions.
Konradsen, Kirkevold & Zoffman (2009)	Surgical treatment for facial cancer	Taped conversations between nurse-patient dyads. Interviews. Grounded theory	N= 28. 14 dyads of adult patients (5f) & their connected nurse a few days after surgery.	Affected adults & nurse/patient interaction & self-report of visibility to another	Explain how disfigurement is addressed in interaction between patient & nurse dyads.	Developed a model with silencing disfigurement as core category. Nurse assumption about whether patient socially supported explored	Clear account for topic, analysis used & conclusions. Theoretical perspective evident

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Purpose of study**	**Main findings**	**Quality issues**
Konradsen, Kirkevold, McCallin, Cayé-Thomasen & Zoffman (2012)	Surgical treatment for facial cancer	Interviews. Grounded theory.	N=15 (6f) patients followed up from Konradsen et al (2009).	Affected adults & nurse/patient interaction & self-report of visibility to another	Explore patient experiences & transitions to everyday life in first year after surgery.	Patient concern was feeling isolated. Resolved through interactional integration. This starts when silence of disfigurement is broken. Adjustment is about progressing from a disfigured person to a person with a disfigurement.	Clear account for topic, analysis used & conclusions. Theoretical perspective evident
Lau & van Niekerk (2011)	Burn	Interviews. Narrative approach	N=6 (2f) with moderate/severe burns at least 2 years prior. Aged 14-24	Affected adults & self-report	Explore meaning of survivor's experience.	Found resilience alongside losses & deficits; lifelong (re)negotiation of identity, appearance, psychological adjustment & social reintegration. Identified significant others important to self & acceptance	Included under 18's; Clear account for topic, analysis used & conclusions. Theoretical perspective evident
Meyerson (2001)	Moebius syndrome	Telephone interviews	N=18 (11f) affected adults aged 29-over 70	Affected adults & self-report	Explore sources of strength & resiliency that enabled achievement professional & personal success	Strengths sources: family support, faith, humour, sense of self, special skills, determination & networking	Clear account for topic. Limited information about analysis.

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Purpose of study**	**Main findings**	**Quality issues**
Murray & Rhodes (2005)	Acne	Email interviews. . IPA	N=11 (4m & 7f) adults with severe facial acne for at a least a year prior.	Affected adults & self-report	Elicit detailed accounts of impacts of visible acne on lives	Themes; powerlessness & variable nature of acne; comparisons, self-image & identity; experience of social interaction; relationships with family & friends; gender, sexuality & romantic relationships.	Clear account for topic, analysis used & conclusions.
O'Brien, Roe, Low, Deyn & Rogers (2012)	Head & neck cancer	Interviews. Thematic analysis.	16 adults (4f) at least 1 year post treatment.	Affected adults & self-report	Describe experiences & perceptions of changes in intimacy.	Themes; personal identity; re-establishing social networks & intimate relationships. Perceptions of altered position in society, impacts on willingness to re-engage & degrees to which treatment altered abilities to resume intimate relationships	Clear account for topic, analysis used & conclusions.
Patel, Ferner & Grunfeld (2011)	NF2	Interviews. Thematic framework analysis	N=6 affected adults (2f)	Affected adults & self-report of effects on communication	Explore physical, emotional & social impacts of NF2.	Themes: impact of disease, emotional response to disease, awareness of NF2. Negative impacts on daily life, social isolation from avoidance of difficult situations. Partners & family relied on for emotional support. Frustration at limited awareness of NF2 among health professionals	Clear account for topic, analysis used & conclusions.

Author & date	Type	Study design	Sample	Facial difference	Purpose of study	Main findings	Quality issues
Phillips, Fussell & Rumsey (2007)	Burn	Questionnaire Content analysis	N=50 family members of adults & children with burn injuries & some scar permanence. Siblings group n=15; children group n=21; partner group n=14)	Affected adults & self-report of perception of burn severity & visibility by family member	Describe the range of psychosocial issues that psychosocial programme need to address.	Identified elements for family support programme: normalising family reactions to burn; advice, support & information regarding scar permanence, realistic outcome expectations, acceptance of altered appearance & potential after burn; support in understanding how burned person might change/respond after injury	Clear account for topic, analysis used & conclusions.
Röing, Hirsch, Holmström & Schuster (2009)	Oral cancer	Interviews	N=5 adults (2f) at a median time of 4 years after start of treatment in a hospital dental clinic	Affected adults & self-report of appearance & relational functions of mouth	Explore how consequences of facial cancer affect being-in-the world. Hermeneutic phenomenological approach	Being-in-world affected in 3 ways: existing as one self; exiting in eyes of others & existing with others. Mouth is central to human's identity & existence. One case about facial disfigurement discussed, difficulties related to changes in speech for this type of cancer. Love of family & friends intensified. A source of interdependence or abandonment	Clear account for topic, analysis used & conclusions. Theoretical perspective evident

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Purpose of study**	**Main findings**	**Quality issues**
Rossi, Costa, Dantas, Ciofi-Silva & Lopes (2009)	Burn	Observation in clinics & patient homes; interviews	N=30. 19 adult burn survivors (12m & 7f) & 11 family members	Affected adults, TBSA & burn visibility & self-report of burn & effects	Explore cultural meaning & dimensions of quality of life from the perspective of Brazilian burn patients	QoL related to autonomy & ability to work. Included: resuming work & functional ability; body image; having leisure & interpersonal relationships. QoL associated with concept of normalcy.	Clear account for topic, analysis used & conclusions.
Rozario (2007)	NF1	Single case study account from a larger study.	N= 1. Female, British, Bangladeshi with NF1	Affected adults & self-report of meanings of appearance & effects	Explore social & personal consequences of NF1 & whether the accounts represent a specifically Bangladeshi & gendered experience.	Darker skin & NF1 tumours led family to see her as unmarriageable. Appearance was a bar to social acceptability. Consequences of genetic disorders in cultures where social identity is entwined with appearance.	Clear account for topic, analysis used & conclusions.
Semple, Dunwoody, Kernohan, McCaughan & Sullivan (2008)	HNC	Interviews. Thematic analysis.	N= 10 adults (4 f) who had completed treatment 6-12 mons prior	Affected adults & self-report of meanings of appearance changes	Explore changes & challenges to lifestyle following treatment.	Changes & challenges in: social functioning, interpersonal relationships, work & activities, concerns about cancer, physical changes. Personal attributes helped or hindered coping & the need for specific information post treatment.	Clear account for topic, analysis used & conclusions

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Purpose of study**	**Main findings**	**Quality issues**
Semple & McCance (2010)	HNC	Interviews	N= 12 (1f) affected adults treated within previous 3 years & who have children aged under 16 years.	Affected adults & self-report	Explore the experience & support needs of patients with HNC who are also caring for their children	Themes focussed on phases: diagnosis, during treatment & living with consequences. Appearance changes forced telling children. Debilitating treatment effects in eating & changing role in family. Social networks important	Clear account for topic, analysis used & conclusions
Stavropoulos, Hallberg, Mohlin & Hagberg (2010)	Crouzon syndrome	Telephone interviews. Grounded theory.	N= 8 (2f) adults. Mean age 25.4 years	Affected adults & self-report of meanings of appearance changes	Provide insight on how young adults with Crouzon Syndrome handle their life.	Main concern: to make the best of their situation: commitment to activity, avoiding exposed situations, actively launching oneself, struggling with normalising appearance & lowering expectations of finding a 'love partner'	Clear account for topic, analysis used & conclusions
Strauss & Fenson (2005)	Cranio-facial conditions	Analysis of documents	Content from fiction, web-sites & first person accounts	Affected adults & self-report of appearance & well-being	Explore how people with a range of craniofacial conditions see quality of life & building sense of well-being	3 domains; personality & psychological; family, work & social interactive; cultural & societal.	Method of selection of documents & method of analysis not described. Not clear how conclusions reached.

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Purpose of study**	**Main findings**	**Quality issues**
Thompson & Broom (2009)	Visible difference	Interviews. IPA	N=8 (2m & 6f) adults with an appearance altering visible condition who managed reactions from others well.	Affected adults & self-report appearance & coping	Explore how people managed interactions from the perspective of those who felt they were coping well.	Intrusive reactions to disfigurement included being stared at, being ignored, & discrimination. Found difficulties & coping. Adjustment as an ongoing process. Supports stigma theory	Clear account for topic, analysis used & conclusions.
Thompson, Clarke, Newell, Gawkrodger & ARC (2010)	Vitiligo	Interviews	N=7 British South Asian women with vitiligo on visible parts of body	Affected adults & self-report appearance & coping	Explores beliefs in relation to vitiligo & how British South Asian women with vitiligo manage & adjust psychosocially	Descriptions of feeling visibly different & experiences of stigmatisation. Avoidance & concealment common. Stigmatisation associated with cultural values about to appearance & myths about condition.	Clear account for topic, analysis used & conclusions.
Thompson, Kent & Smith (2002)	Vitiligo	Interviews	N=7 (7f) affected adults	Affected adults & self-report appearance & coping	Explore experience of living with vitiligo to understand impact & the way people deal with it & reactions of others.	Found tactics to contain feeling overwhelmed. Social support seemed to facilitate development of coping strategies. Living with vitiligo is a continuous struggle	Clear account for topic, analysis used & conclusions. Theoretical perspective evident

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Purpose of study**	**Main findings**	**Quality issues**
Uttjek, Nygren, Stenberg & Dufåker (2007)	Psoriasis	Interviews	N= 18 affected adults (9f)	Affected adults & self-report of meanings of visibility	Understand individual's everyday life with psoriasis.	Visibility most difficult aspect. Coping strategies developed with age. Most had good QoL but nothing positive to say about psoriasis. Impacts on having a job &/or close friends or being of use & being well had most influence on QoL & facilitated coping	Clear account for topic, analysis used & conclusions.
Williams, Davy & Klock-Powell (2003)	Burn	Interviews. Phenomenology & ground theory	N= 8 (4f) adult burn survivors	Type & location of burn. Self-report of appearance, injuries & coping	Perceptions of experiences of surviving burn injuries.	Impacts on relationships; some supported others not. Resilience; determination, striving for independence, courage, compassion & spiritual change. Themes of loss & change. Attention needs paying to patients context, stage of recovery as well as their stage in their life cycles, exploring of family & friend supports & loss of occupational role on s sense of self worth	Clear account for topic, analysis used & conclusions. .

Appendix 11: Included quantitative and mixed method papers

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Anzarut, Chen, Shankowsky & Tredget (2005)	Burn	Prospective, compared to population norms	N= 47 (2f) adults who have survived massive burn injuries, 1980-2001	% TBSA; % total thickness of burn; hand/face involvement	Age at time of burn; injury work related & other medical variables	Part of HQROL measure	HQROL (Short Form 36 mental & physical components)	Facial location did not contribute to SF36 scores. PSS improved prediction of QOL.	Small study; under powered; response rate 40%, females under-represented; small effect found
Baker (1992)	Head & Neck	Cross sectional	N= 51 patients at least 6 mons after treatment	Based on surgical procedure & a score formed of total dysfunction		Perceived social support (personal resources questionnaire)	Rehabilitation (Sickness Impact Profile)	Facial disfigurement not significantly associated with rehabilitation outcomes. PSS & degree of dysfunction were. Rehabilitation more complex than severity alone	Small study; disfigurement measured by medical factors; convenience sample; standard measures used
Berk, Cooper, Liu & Marazita (2001)	Cleft lip & palate	Matched case control	N= 255 in 3 gps adults with cleft lip/palate; unaffected adult siblings; age & gender matched controls	Diagnosis of cleft lip & palate.		Perceived social support (Interpersonal Support Evaluation List)	Other psychosocial measures: social avoidance & distress; fear of negative evaluation; self esteem	Social support for affected & unaffected siblings significantly different. Higher levels of social avoidance, distress, fear of negative evaluation & lower levels of self-esteem among affected adults than siblings & controls.	Matched case controlled study; visible difference through diagnosis, not differentiated by degree of impairment; standard measures.

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Bowden, Feller, Tholen, Davidson & James (1980)	Burn	Retrospective	N=320 (75f) Average age 29	Researcher visible disfigurement. Compared effects of burns on other body locations; TBSA & full thickness of burn	Gender, age, age when injured, time since injury, marriage, employment status & alcoholism	Social support (composite, from friends, from family)	Self-esteem (Coppersmith's Self Esteem Inventory)	Size, locus or visibility did not affect self- esteem. Severely disfigured women self-esteem more affected than men. PSS correlated with self-esteem. Those not in work, retired, disabled or sick had lower self-esteem. Dip in self-esteem at 11-13 post burn & greater for women	Representative sample from regional burn centre; social support was not main purpose of the study; does not specify social support measure; burn severity measured by observer & medical characteristics
Brown, Roberts, Browne, Bryne, Love & Streiner (1980)	Burn	Retrospective	N=260 (51f) adults burn injuries over a 12 year period in a regional burn unit	Disfigurement & functional disability rated by interviewer.	Gender	Participation in Social & Recreational Activities Scale. Perceived social support from friend, family, peers (Social Support Scale)	Psychosocial adjustment (Psychosocial adjustment to Illness scale) Coping strategies (Coping Responses Scale)	Females had greater disruption in vocational environment. Study refuted women are less concerned about physical function or cope differently. Social resources & problem solving useful to males & females	Large study; used validated measures; randomly selected with replacement until sample achieved; disfigurement rated by observer.

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Ciofi-Silva, Rossi, Dantas, Costa, Echevarria-Guanilo & Ciol 2010	Burn	Mixed methods, cross sectional	N=44 adult burn survivors discharged from hospital 6-12 mons prior, had reconstructive surgery in last year or were awaiting it	Burn characteristics (history of accident; locations affected; depth; %TBSA, visibility)	Demographics (age, gender, marital status, family income, education)	Interview about effect on personal relationships, dependence in care	Effects on leisure; relationships; religious ties; educational activity; habits	Majority reported changes in life associated with burn injury. Burns on lower limbs, neck & face associated with concerns about leisure activities	Small, descriptive study; regional burn unit; purposive sample; disfigurement measured by medical characteristics including locus
de Boer, Pruyn, van den Borne, Knegt, Ryckman & Verwoerd (1995)	Head & neck cancer	Cross sectional	N=110 HNC survivors treated 2-6 years prior	3 groups varying by treatment: T1: radiation only, T2: total laryngectomy & radiotherapy; T3: tumour excision & radiotherapy (called commando procedure)	15 rehabilitation process variables; illness related data.	Openness to discussion of illness in family; appreciation of info from the specialist	Rehabilitation (15 psychosocial or physical outcome variables)	Changes in social functioning in contacts with others; restricted to home or a close circle. Stronger affects for T2 & T3. Social support & information significant correlation with rehabilitation outcome variables. Openness to discussion of illness in family with 13 of the 15	Single treatment centre; convenience sample, some measures constructed for study. Small numbers particularly in T3 group.

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Deno, Tashiro, Miyashita, Asakage, Takahashi, Saito, Busujima, Mon, Saito, & Ichikawa (2012)	Head & neck cancer	Cross sectional	N=225 patients in 6 hospitals. Mean time since diagnosis 3.39 (+/- 4.1 years).	129 had facial disfigurement, self-rated by presence of scarring	Social distress (social distress scale); Self-efficacy (Self- efficacy for Advanced Cancer Scale & Activities of Daily Living) Demographic variables.	Social Support Scale.	Emotional distress, anxiety & depression (HADS).	Patients living with family had lower HADS scores whether disfigured or not. No medical variables related to HADS. Found social support & self-efficacy buffered influence of social distress on emotional distress. Social support from friends had a negative influence on emotional distress & social support from family did not significantly relate to social distress.	Power relatively low; convenience sample used validated measures; choice of measures limited by availability in Japanese; facial disfigurement self-assessed.
Gamba, Romano, Grosso, Tamburini, Cantu, Molinari & Ventafridda (1992)	Head & neck cancer	Cross sectional	N=66 patients 6-8 mons after surgery. 2 groups: 24 minor disfigurement & 42 extensive disfigurement	Degree of disfigurement rated as minor or extensive by interviewer. Type & site of surgery		Relationship with partner, family & friends	Body image, sexuality, relationships with family & social environment was gathered through interview.	Strong negative impact found on relationship with partner in extensive disfigurement group & more frequently by those who reported body image change. Most reported good relationship with partner & family, 33% reported improved relationship & 95% reported partner was not avoidant. 27% said friends did not visit as much & this was higher in extensive group.	Single outpatient clinic; convenience sample. Method of classifying into minor/major disfigurement not clear. Outcome measured by questionnaire, not validated measures. Disfigurement rated by observer & medical characteristics

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Hagedoorn & Molleman (2006)	Head & neck cancer	Cross sectional	N=76 adults (32f) post treatment	Disfigurement rated by patient report of visibility & physicians evaluations of patients' facial expression Medical variables about tumour cite, size & time since first symptoms	Medical & demographic variables (age, gender, education)	Social self efficacy in dealing with unpleasant reactions from others	Questionnaire social self-efficacy, distress in relation to others behaviour & social isolation & items from Spielberger's State- Trait Anxiety Inventory	Found degree of facial disfigurement judged by patients & physicians positively associated with psychological distress & unpleasant reactions from others but only when self-efficacy was perceived to be low.	Study under powered; convenience sample. Not validated measures.. Sample of relatively minor facial impairment only
Howren, Christensen, Karnell, Van Liew & Funk (2013)	Head & neck cancer	Prospective, longitudinal	N=364 patients assessed at diagnosis, 3 mons & 12 mons later	Cancer site & stage, treatment modality. Head & Neck Inventory (HNCI) has an aesthetics & social disruption component.	Demographic & disease characteristics .	Perceived social support (Social Provisions Scale)	HRQOL (Short Form 36 & Head & Neck Cancer Inventory, HNCI)	At 12 mons PSS was associated to a greater extent with HNC HRQOL for speech, facial aesthetics, & social disruption. It failed to meet significance in regression for eating. Found clinical significance levels as well except for eating	Large study; single hospital clinic; enrolled all cohort patients who have completed social support baseline assessments; validated measures; prospective longitudinal.

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Karnell, Christensen, Rosenthal, Magnuson & Funk (2007)	Head & neck cancer	Prospective	N=394 adults assessed at diagnosis & every 3 mons in first year	HCNI has aesthetics & social disruption component	Age, Gender, treatment characteristics, stage of cancer, primary or recurrent	Perceived social support (Social Provisions Scale)	HRQOL (HNCI) Beck Depression Inventory, Short Form 36)	Higher levels of social support at 1st year significantly associated with speech, aesthetics, social disruption (but not eating) & fewer depressive symptoms, higher general mental health but not better physical health. Highest levels of social support resulted in clinically imp differences.	Large study; selected from hospital longitudinal cohort; validated measures; Prospective. Measurement of facial difference only through effects on HCNI
Katz, Irish, Devins, Rodin & Gullane (2003)	Head & neck cancer	Cross sectional	N=82 (25f) adults 6 mons or more after treatment.	Observer rated disfigurement on a 9 point scale. Separate ratings made by surgical & nonsurgical personnel.	Demographic (gender, marital status, income, education, occupation status) Medical variables (T stage; diagnosis, type of surgery, comorbidities, time since surgery)	Perceived social support (Medical Outcome Social Support Survey)	3 measures of subjective quality of life: (CES-D; Bradburn Affect Scale; Atkinson Life Happiness Scale)	High levels of life happiness, low levels of depression & positive well-being. Women reported higher depression lower life happiness & those with greater disfigurement were more depressed. Social support indicated as buffering for women. Women with low social support & disfiguring treatment appear at greatest risk of psychosocial dysfunction	Small study; reduced statistical power; convenience sample from 2 hospitals; validated measures used; observer rated disfigurement

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Other factors studied**	**Social support /relationships contributions**	**Main outcome measures**	**Main findings**	**Quality issues**
Kleve, Rumsey, Wyn-Williams & White (2002)	Visible difference	Intervention study to evaluate effectiveness of CBT programme. Mixed method	N=36 (27f), aged 17-72, 75% with a facial disfigurement	Disfigurement severity rated by researcher & clinician; Appearance concerns (DAS); Visual analogue scale for noticeability. Semi-structured interviews	Demographic (age, gender)	Visual analogue scale for perceived social support & confidence with familiar people, strangers & meeting new people	Depression & anxiety (HADS); Positive & negative affect (PANAS); Satisfaction with life (SWLS); Appearance concerns (DAS); Social anxiety (Social Situations Questionnaire)	Found significant improvements in social support, confidence in meeting new people or stranger perceived. Reductions in perceived noticeability of condition to self & others. Found a sub-group with less improvement who had more complex social problems	Evaluation of specialist clinic programme; Validated measures used; disfigurement rated objectively & subjectively; Before & after study; no control; 6 month follow-up; evaluation of a programme at a specialist clinic
Knudson-Cooper (1981)	Burn	Cross sectional, used mixed methods	N=89 (45f) young adults aged 16-28 years who survived severe burn injuries.	Cosmetic impact assessment on 4 point continuum by a team. Date of burn, accident, number of reconstructive surgeries, physical condition in terms of scarring & functional disability & cosmetic impact of scarring.	Demographic variables	Social integration assessed from demographic data, participation in social networks & leisure activities.	Emotional adjustment (open ended questions) Self –esteem (Coopersmith Self-Esteem Inventory & Burn Related Supplement)	Did not differ substantially from general population in terms of social integration & self-esteem. Emotional adjustment linked to self-acceptance. Severity of burn, age or gender did not affect adjustment. Descriptions of how people felt they were treated differently by others & who helped them adjust	Descriptive study; specialist burn institute self-selecting sample; some measures were validated.

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Lawrence, Fauerbach & Thombs (2006b)	Burn	Cross sectional, (compared with population) Part of validation process for 2 new measures	N=311 adult burn survivors at least 3 years post injury	Self-rated assessment of burn visibility, burn effects of changing facial & overall appearance. Burn Characteristics (TBSA; number burn related surgeries)	Demographics: gender, age burned, race, education	Perceived social support (Interpersonal Support Evaluation List)	Depression symptoms (Short Mood & Feelings Questionnaire); Body Esteem; Importance of Appearance; Perceived Stigmatisation; Perceived social comfort; Worry about appearance	Depending on cut-off point 20-30% of sample reported clinically significant depressive symptoms. 59% variance of depression accounted for by burn characteristics, demographic characteristics & psychosocial characteristics. Perceived social support & social comfort accounted for majority	Large national self-selecting sample; only 23% completed questionnaire; those with large burns over-represented; used validated measures; measured burn severity & visibility subjectively & objectively.

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Lawrence, Fauerbach Heinberg & Doctor (2004)	Burn	Cross sectional Part of validation process for 2 new measures	N= 361 (181f) adult burn survivors. Average time since injury 18.5 years	Self-rated assessment of scar visibility, effect of scar in changing facial & overall appearance. Burn Characteristics (TBSA; number burn related surgeries; presence or absence of scars on body parts)	Demographics: gender, age burned, race, education	Perceived social support (Interpersonal Support Evaluation List)	Social & emotional outcome variables: Perceived Stigmatisation Questionnaire; Social Comfort Questionnaire; Body Esteem; (Importance of Appearance Scale; Body Esteem Scale; Worry about Appearance rated on a 5 points scale) Depression (Short Mood & Feelings Questionnaire)	Subjective rating of burn severity had low-to-moderate correlations with all social & emotional outcomes, including perceived social support & comfort & perceived stigmatisation. Severity & visibility unrelated to global social support & depression. In regression, burn characteristics accounted 19% variance of body esteem & lack of social comfort & depression accounted for more.	Large national self-selected sample; 20% completed survey of potential population; validated measures & 2 new measures; measured burn severity visibility subjectively & by medical characteristics. Social support not a main concept in a study & the specific contribution to regression not reported
Lawrence, Rosenberg, Rimmer, Thombs & Fauerbach (2010)	Burn	Cross sectional Part of validation process for 2 new measures	N=716. 369 paediatric & 347 adult burn survivors.	Subjective assessment of degree burns has changed appearance & Burn characteristics questionnaire	Demographics: gender, age burned, race, education	Not studied	Perceived Stigmatisation; Perceived Social Comfort SCQ	61% adults had facial burns. Adult sample had lower latent mean on SCQ than paediatric sample. Study supported construct validity of PSQ & SCQ	Large non-random sample; validated measures; measured burn severity & visibility subjectively & objectively.

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
O'Hanlon, Camic & Shearer (2012)	Cleft lip &/or palate	Mixed method; quasi-experimental causal comparative. Cases matched by children of same age, gender & diagnosis	N=54 parents of a child with cleft lip &/or palate: 27 cleft affected parents & 27 parents without cleft conditions.	Cleft lip &/or palate diagnosis. Focus of study on social support rather than appearance	Parental cleft lip &/or palate diagnosis	Perceived social support (Interpersonal Support Evaluation List)	Ways of Coping Questionnaire; Connor-Davidson; Resilience Scale; Posttraumatic Growth Inventory & researcher designed condition specific questionnaire	Parental diagnosis of cleft lip &/or palate impacts on how parents cope & adjust to their child's diagnosis, but have different support needs. No significant differences between parents with or without cleft on general perceived social support. Suggests general measures of coping not sensitive enough	Small study; parents of matched pairs of gender, age & diagnosis children ; used validated measures & measure designed for study
Orr, Reznikoff & Smith (1989)	Burn	Cross sectional	N=121 adolescents & young adults injured within previous 10 years. Aged between 14-27 years. Mean age=17.8	Burn related variables assessed from medical records & included location of burn. 75% with burn on a visible or socially sensitive area	Demographic (age, gender, age burned, in school or employment)	Perceived social support from family & friends (Perceived Social Inventory-Friends; Perceived Social Inventory-Family)	Body image (Semantic Differential Measure of Body Image); Self-esteem (Rosenberg Self-Esteem Scale); Depression (Beck Depression Inventory)	Relationship between modified body image scores & PSS from family & friends (stronger for friends) Cannot tell if this differs between adults & children in sample. PSS from friends & family related to self-esteem. Scores on body image were not correlated with locus (including face) of burn, number of years since burn or %TBSA. Suggests PSS bolsters self-esteem, mood & body image perceptions. PSS important for 'girls'	Specialist burn institute; self-selecting sample; validated scales, but body image scale modified. Sample includes respondents aged under 18 & results not separated by whether over/under 18; gender effect reported but number of m/f in sample not reported

Author & date	**Type**	**Study design**	**Sample**	**Facial difference**	**Other factors studied**	**Social support /relationships contributions**	**Main outcome measures**	**Main findings**	**Quality issues**
Peter, Chinsky & Fisher (1975)	Cleft lip &/or palate	Case comparison, matched by siblings and control group	N=594 adults. 195 affected adults; 190 siblings & 209 nationally drawn random controls	Cleft sub-groups: cleft lip & palate; cleft palate only Unaffected adults & siblings	Demographics (age, gender)	Social integration (place of residence; Initial Social Contacts; Friendship Patterns)	Social integration (Geographic mobility; Home Activities; Neighbour Integration; Voluntary Organisations)	Found more adults with cleft lip &/or palate resided with extended family, & tend to use family for mutual aid & social activities. Found those with visible cleft & females more likely to be extended this family support.	Historic study. Part of a larger study & full design not retrieved; does not seem to have used validated measures. Used case control design
Roberts & Mathias (2012)	Cranio-facial conditions (excluding cleft)	Cross sectional, compared to UK & Australian population data	N=93 adults (54f) aged 19-54	Wide range of craniofacial diagnoses	Demographic information (gender, age, education, occupation, relationship status, family status)	Perceived social support (Multi-dimensional Scale of Perceived Social Support)	HRQOL (SF-36); Depression & anxiety (HADS); self-esteem (Rosenberg scale); social anxiety (Brief Fear of Negative Evaluation Scale); Satisfaction with Life Scales; Appearance related concerns (DAS24).	Similar psychosocial function to comparison population; but less likely to be married, have children (females), more appearance concerns & less friend social support. More limitations in social activities & poorer mental health. Found global PSS was positive only lower on dimensions of friends in comparison to population norms on friends.	Wide range of conditions represented in sample; used validated measures. Compared data with UK & Australian population data. Some of the effects may be due to sample including facial conditions in which developmental intellectual functioning can be found

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Rumsey, Clarke, White, Wyn-Williams & Garlick (2004)	Visible dis-figurement on face &/or body	Mixed methods; cross sectional. Psychosocial outcomes compared with normative values where available	N= 458 adults (c266f) aged from 18-90 years	Diagnosis from medical notes. Noticeability of disfigurement rated a 4 point scale by physician for 193 of sample	Medical & demographic information (age, gender, ethnicity, employment)	Qualitative interview questions	Social anxiety & avoidance (DAS24); Anxiety & depression (HADS); quality of life (World Health Organisation Quality of Life Brief Scale) & qualitative interviews.	Caseness not found for anxiety or depression. Levels of anxiety were present judged by maximum scores & size of standard deviations. Reported generally good quality of life. Extent of disfigurement showed no QoL differences. Perceived social support linked with more favourable adjustment	Convenience sample from 2 hospitals; less than half sample were assessed for noticeability of disfigurement; may include disfigurement of hands & limbs; used validated measures.
Vickery, Latchford, Hewison, Bellew & Feber (2003)	Head & neck cancer	Cross sectional – dyadic design	N= 95 (6f) patients 6-18 months post treatment & their partner. 3 treatment types compared differing in degree of treatment burden/surgery	Dropkin Disfigurement & Dysfunction Scale classified surgical impairment. EORTC HN contains items on aesthetics	Demographics (age, gender)	Quality of relationship from perspective of both partners (Dyadic Adjustment Scale). Compared partner & patient outcome scores.	Anxiety & depression (HADS); Adjustment to illness (PAIS-SR); Quality of life (EORTC HN)	Partners reported greater distress than patients on some scales. Patients did not have a lower quality of life than other cancer populations. Treatment modality not predictive of psychological vulnerability	3 hospitals; convenience sample; Validated measures; EORTCHN is based on medical factors rather a subjective assessment. Sample were not severely impaired or disfigured

Author & date	Type	Study design	Sample	Facial difference	Other factors studied	Social support /relationships contributions	Main outcome measures	Main findings	Quality issues
Wallis, Renneberg, Ripper, Germann, Wind & Jester (2006)	Burn	Cross sectional, compared to population norms	N=55 (14f) adults in hospital for acute or follow up treatment	Medical data about burn (injury severity; face or hand involvement, need for amputation %TBSA, Partial or Full thickness of burn)	Demographic (gender, age, education, ethnicity)	Perceived social support (Social Support Questionnaire)	Physical & psychological symptoms & subjective pain; PTSD (Posttraumatic Stress Disorder Symptom Scale) Anxiety & depression (HADS); Coping strategy (Freiburg Questionnaire of Coping with illness); Optimism (Life Orientation Test); self-efficacy (General Self Efficacy Scale)	Significantly greater emotional distress than general population. High levels of resources such as general optimism, self-efficacy, PSS. No correlation found between severity of emotional distress & severity of burn injury found & patients with facial burns did not differ from other patients in anxiety or distress.	Small study, single burn unit; convenience sample; part of a larger study. Extent & location of burn assessed by medical variables.

Appendix 12: Thematic chart on visibility, contribution of relationships and social support

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Anzarut, Chen, Shankowsky & Tredget (2005) USA	% TBSA; % total thickness of burn; hand/face involvement	Facial location did not contribute to SF36 scores. PSS improved prediction of QOL.	Physical measurement of facial location did not predict QOL. Hand location did affect QoL. PSS at follow up did
Baker (1992) USA	Based on surgical procedure & a score formed of total dysfunction	Facial disfigurement not significantly associated with rehabilitation outcomes. PSS & degree of dysfunction were. Rehabilitation more complex than severity alone	Physical aspects of facial disfigurement not associated with rehabilitation outcomes. Degree of dysfunction was associated with outcomes. PSS was.
Berk, Cooper, Liu & Marazita (2001) CHINA	Diagnosis of cleft lip &palate.	Social support for affected & unaffected siblings significantly higher levels of social avoidance, distress, fear of negative evaluation & lower levels of self-esteem among affected adults	Those with diagnosis of cleft lip & palate differed from siblings & controls significantly on lower self- esteem & social support. Physical dimensions make a difference in China. Appearance not separated from functional issues such as affected speech
Bowden, Feller, Tholen, Davidson & James (1980) USA	Researcher visible disfigurement. Compared effects of burns on other body locations; TBSA & full thickness of burn	Size & body location or visibility did not affect self- esteem. Severely disfigured women self-esteem more affected than men. Perceived social support did. Those not in work, retired, disabled or sick had lower self-esteem.	Physical measures of severity did not predict self-esteem. Sub-group of disfigured patients identified (28 with facial disfigurement, but not clear whether this was the only location of disfigurement included). Comparing disfigured & non-disfigured group found ‘virtually no difference’, except disfigured women had lower self-esteem than men. PSS was found to predict self-esteem
Brown, Roberts, Browne, Bryne, Love & Streiner (1980) USA	Disfigurement & functional disability rated by interviewer.	Females had greater disruption in vocational environment. Study refuted women are less concerned about physical function or cope differently. Social resources & problem solving useful to males & females	Disfigurement measured by physical appearance did not play a great part in adjustment for women or men. Functional ability was an important variable for men & women. PSS from friends was important for men & from family for women, but important for both
Ciofi-Silva, Rossi, Dantas, Costa, Echevarria-Guanilo & Ciol 2010 BRAZIL	Burn characteristics (history of accident; locations affected; depth; %TBSA, visibility)	Majority (86.4%) reported changes in life associated with burn injury. A significant association was found between burns on at least 1 of the upper limbs & changes in ability to work.	Over half sample reported changes in work due to physical limitations. Significant correlations found between burns on upper limbs & changes in work, but not for %TBSA. Those with burns visible on lower limbs, neck & face reported changes in leisure activities, but %TBSA did not

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
de Boer, Pruyn, van den Borne, Knegt, Ryckman & Verwoerd (1995) NETHERLANDS	3 groups varying by treatment: T1: radiation only, T2: total laryngectomy & radiotherapy; T3: tumour excision & radiotherapy (called commando procedure)	Changes in social functioning in contacts with others; restricted to home or a close circle. Stronger affects for T2 & T3. Social support & information significant correlation with rehabilitation outcome variables. Openness to discussion of illness in family with 13 of the 15	Higher percentage of patients with laryngectomy or commando experience severe psychosocial distress between 2-6 years after last treatment (often related to communication) than those treated with radiotherapy for T1 carcinoma of larynx. Patients with 'commando' surgery had more problems with disfigurement & food. Open discussion of illness in family, social support & perceptions of adequate information were important predictors of rehabilitation outcomes
Deno, Tashiro, Miyashita, Asakage, Takahashi, Saito, Busujima, Mon, Saito, & Ichikawa (2012) JAPAN	129 had facial disfigurement, self-assessed by presence of scarring	Patients living with family had lower HADS scores whether disfigured or not. No medical variables related to HADS. Found social support & self-efficacy buffered influence of social distress on emotional distress. Social support from friends had a negative influence on emotional distress & social support from family did not significantly relate to social distress.	57% of sample had facial disfigurement. Self-efficacy buffered negative influences of social distress on emotional distress. Social support from family members did not have a direct or indirect effect on emotional distress. Social support from friends was related to lower social distress & higher emotional distress. They conclude that self-efficacy might confound relationship between social support & emotional distress & those different sources of social support might play different roles in the mediation of social distress on emotional distress.
Gamba, Romano, Grosso, Tamburini, Cantu, Molinari & Ventafridda (1992) ITALY	Degree of disfigurement rated as minor (MDG) or extensive (EDG) by interviewer. Type & site of surgery	Strong negative impact found on relationship with partner in extensive disfigurement group (EDG) & more frequently by those who reported body image change. Most reported good relationship with partner & family, 33% reported improved relationship & 95% reported partner was not avoidant. Partners described as somewhat ashamed of situation. 27% said friends did not visit as much & this was higher in extensive group.	Significantly higher impact in EDG in changed self-image, worsened relationship with partner, reduced sexuality & increased social isolation. 18% felt disadvantages of therapy outweighed advantages & 30& said difficulties encountered were 'too harsh'. Self-image was most important change by more respondents in EDG than MDG. Emotional distress re disfigurement was higher in EDG. Of those with major disadvantages with treatment (From EDG & MDG) 79% were accounted for the respondents who felt differently about self-image. Severity of disfigurement effects found, & also changes in self-image. Over 80% felt they perceived themselves as changed physically, emotionally & in self-image. Friends dwindled & they ask whether this is to do with less close bonds

Author & date	**Facial difference**	**Main findings**	**Visibility, personal relationships & social support**
Hagedoorn & Molleman (2006) NETHERLANDS	Facial disfigurement rated by patients self report of visibility & physicians evaluations of patients' facial expression (both are types subjective methods of rating) Medical variables about tumour cite, size & time since first symptoms	Found degree of facial disfigurement judged by patients & physicians positively associated with psychological distress & unpleasant reactions from others but only when self-efficacy was perceived to be low. .	Social self-efficacy moderates the positive link between degree of facial disfigurement & psychological distress, distress in reaction to unpleasant behaviours of others & social isolation. Patients with more severe facial disfigurement experienced more psychological distress in reaction to unpleasant behaviour of other people, more social isolation but only when they believed they were not very capable of exercising control over the reactions & openness of other people. Both subjective measures of facial disfigurement showed these results & associations for patient ratings were stronger
Howren, Christensen, Karnell, Van Liew & Funk (2013) USA	Cancer site & stage, treatment modality. Head & Neck Inventory (HNCI) has an aesthetics & social disruption component.	Greater perceived social support present at diagnosis significantly predicted global & HNC specific HRQOL of social disruption at 3 mon. But at 12 mons PSS was associated to a greater extent with HNC HRQOL for speech, facial aesthetics, & social disruption. Only for eating did it fail to meet significance in regression model. Also found these at clinical significance levels except for eating	At baseline, 3 mon & 12 mon HRQOL scores for SF-36 & HNCI follow general pattern of being lower in weeks nearest conclusion of treatment followed by gradual improvement at 12 mons after diagnosis. Although a general trend towards improved head & neck cancer specific HRQOL was seen at 12 mon, each of HNCI scores remained significantly lower than baseline indicating considerable condition specific deficits remain. PSS at diagnosis found to be a unique independent predictor of outcomes
Karnell, Christensen, Rosenthal, Magnuson & Funk (2007) USA	HCNI has aesthetics & social disruption component	Higher levels of social support at 1st year significantly associated with speech, aesthetics, social disruption (but not eating) & fewer depressive symptoms, higher general mental health but not better physical health. Highest levels of social support resulted in clinically imp differences.	Post treatment PSS correlated with HRQOL outcomes in speech, aesthetics, social disruption, depressive symptoms & mental general health status & higher levels of PSS resulted in clinically important increases in HRQOL scores. Possible pathways: help in special food preparations; encouragement from friends & colleagues aiding social function & possible sustaining a better attitude. Possible that better pots treatment outcomes affects perceptions of network, however they favour the other direction of effect

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Katz, Irish, Devins, Rodin & Gullane (2003) CANADA	Observer rated disfigurement on a 9 point scale. Separate ratings made by surgical & nonsurgical personnel.	Found high levels of life happiness, low levels of depression & positive well-being. Women reported higher depression & lower life happiness & subjects with greater disfigurement were more depressed. Women with low social support & disfiguring treatment appear at greatest risk of psychosocial dysfunction. Social support indicated as buffering for women.	Observer rated measures of disfigurement. Did not find a direct relationship between degree of disfigurement & well-being or happiness, although more highly disfigured women with low social support did report worsened well-being. Complex relationship between disfigurement & psychosocial well-being.
Kleve, Rumsey, Wyn-Williams & White (2002) UK	Disfigurement severity rated by researcher & clinician; Appearance concerns (DAS); Visual analogue scale for noticeability. Semi-structured interviews	Found significant improvements in social support & confidence in meeting new people or stranger perceived. Reductions in perceived noticeability of condition to self & others. Found a sub-group with less improvement who had more complex problems	About the intervention
Knudson-Cooper (1981) USA	Cosmetic impact assessment on 4 point continuum by a team. Date of burn, accident, number of reconstructive surgeries, physical condition in terms of scarring & functional disability & cosmetic impact of scarring.	Sample did not differ substantially from general population in terms of social integration & self-esteem. Emotional adjustment linked to self-acceptance. Neither severity of burn, age or gender affected adjustment. Descriptions of how people felt they were treated differently by others & who helped them adjust	Outcomes of adjustment found, social integration & self-esteem similar to population. Outcomes not influenced by physical variables relating to burn severity or variable relating to age or gender.

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Lawrence, Fauerbach Heinberg & Doctor (2004) USA	Self-rated assessment of burn visibility, burn effects of changing facial & overall appearance. Burn Characteristics (TBSA; number burn related surgeries)	The rating of burn severity with a subjective component had low-to-moderate correlations with all social & emotional outcomes, including perceived social support & comfort & perceived stigmatisation. Severity & visibility were unrelated to global social support & depression. In regression, burn characteristics accounted 19% variance of body esteem & lack of social comfort & depression accounted for greatest part.	Visible scarring & different aspects of body esteem had low but significant correlations (satisfaction with appearance, perception of others of appearance). Also had low but significant correlations with perceived stigmatisation but not depression. Other measures of scarring had low correlations with social & emotional outcomes. Used to regression to predict body esteem & found burn characteristics accounted <20% with social adjustment & depression accounting for 62% variance accounted for. Burn scar visibility & severity did not have a strong relationship with social & emotional adjustment variables. Subjective measures showed relationships. The relationship between burn severity & body esteem ranged from non-existent to modest depending on how burn severity was measured. Controlling for the effect of perceived stigmatisation found only low to non-existent relationships of burn severity & bun scar visibility. Introduces Social Comfort scale & places emphasis for future work on 'build[ing] a strong loving support system'
Lawrence, Fauerbach & Thombs (2006b) USA	Self-rated assessment of burn visibility, burn effects of changing facial & overall appearance. Burn Characteristics (TBSA; number burn related surgeries)	Depending on cut-off point 20-30% of sample reported clinically significant depressive symptoms. 59% variance of depression accounted for by burn characteristics, demographic characteristics & psychosocial characteristics. Perceived social support & social comfort accounted for majority	In regression psychosocial characteristics of such as social support & social comfort accounted for the majority of variance (total 59%) Stepwise: self rated change in appearance: 6% Education/cannot pay bills: 12% Social comfort/social support/body esteem: 59%
Lawrence, Rosenberg, Rimmer, Thombs & Fauerbach (2010) USA	Subjective assessment of degree burns has changed appearance & Burn characteristics questionnaire	61% adult sample had facial burns. Adult sample had lower latent mean on SCQ than paediatric sample. Study supported construct validity of PSQ & SCQ	Challenges age assumptions. Has details of social comfort questionnaire

Author & date	**Facial difference**	**Main findings**	**Visibility, personal relationships & social support**
O'Hanlon, Camic & Shearer (2012) UK	Cleft lip &/or palate diagnosis. Focus of study on social support rather than appearance	Parental diagnosis of cleft lip &/or palate impacts on how parents cope & adjust to their child's diagnosis, but have different support needs. No significant differences between parents with or without cleft on general perceived social support. Suggests general measures of coping not sensitive enough	Influences of cleft experience on parental role when having a child also with cleft. Suggests gross general measures of coping do not pick up the specific issues within population detected by more specific measures & there is a need for qualitative research
Orr, Reznikoff & Smith (1989) USA	Burn related variables assessed from medical records & included location of burn. Body image part of outcome variables	More perceived social support (friends more than family) had more positive body image, greater self-esteem & less depression. Women reported showing greater depression, lower body image & lower self-esteem	Relationship found between modified body image scores & PSS from family & friends. Correlation stronger for friends. But cannot tell whether this differs between adults & children in sample. PSS from friends & family related to self-esteem. Scores on body image were not correlated with locus (including face) of burn, number of years since burn or %TBSA. Suggests PSS bolsters self-esteem, mood & body image perceptions. PSS especially important for 'girls'. Medical dimensions of scars not correlated with modified body image scales
Peter, Chinsky & Fisher (1975) USA	Cleft sub-groups: cleft lip & palate; cleft palate only; & unaffected adults & siblings	Found more adults with cleft lip &/or palate resided with extended family, & tend to use family for mutual aid & social activities. Found those with visible cleft & females more likely to be extended this family support.	Found those with visible cleft & females more likely to be extended this family support.

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Roberts & Mathias (2012) AUSTRALIA	Wide range of craniofacial diagnoses	Similar psychosocial function to population; but less likely to be married, have children (females), more likely to be receiving a disability pension; have more appearance related concerns & less social support from friends. More limitations in social activities & poorer mental health. Lower outcomes found on Role Limitation (emotional), mental health, & social functioning & bodily pain. Low levels of concerns found about appearance, but had more appearance concerns that normative data. Found global PSS was positive & only lower on dimensions of friends in comparison to population norms on friends. No significant age or gender differences on most of measures. For gender the exception being PSS & self-esteem with females reporting moderately more PSS & lower self-esteem than males	Low levels of concerns about appearance but more than general population data. They note that even among participants aged over 40 a high proportion have never married or had children, & suggest may be related to genetic cause/fears of rejection. Neither gender nor age related to outcomes, age of interest because improvement in surgical procedures might have seen better outcomes for younger groups. Lower PSS from friends but not from family or significant others, & this perception is of concern but not known if it's about number of friends or quality. Suggest further work in this area
Rumsey, Clarke, White, Wyn-Williams & Garlick (2004) UK	Diagnosis from medical notes. Noticeability of disfigurement rated a 4 point scale by physician for 193 of sample	Caseness not found for anxiety or depression. High levels of anxiety were present in sample as judged by maximum scores & size of standard deviations. High scores on social anxiety & avoidance on DAS24. Reported generally good quality of life. Extent of disfigurement showed no QoL differences. Perceived social support linked with more favourable adjustment	Patient satisfaction with care high, but 71% had strong to moderate desire for a trained health care professional to help with their appearance concerns.No difference found between rating of disfigurement & quality of life domains: physical, psychological, social, environmental, social avoidance, distress or depression. Marginal differences in anxiety with higher levels for those with least noticeable difference. Life areas affected were: choice of work, social encounters especially strangers. Moderate levels of worry about appearance & noticeability & higher for 'non-whites'. Those who felt most supported thought appearance concerns had less effect on their lifestyle. Greater level of worry about appearance was associated with higher perceived levels of noticeability by others, desire for more support & less favourable ratings of self perceived coping & less ease in to talking about concerns in clinical setting

Author & date	**Facial difference**	**Main findings**	**Visibility, personal relationships & social support**
Vickery, Latchford, Hewison, Bellew & Feber (2003) UK	Dropkin Disfigurement & Dysfunction Scale classified surgical impairment. EORTC HN contains items on aesthetics	Partners reported greater distress than patients on some scales. Patients did not have a lower quality of life than other cancer populations. Treatment modality not predictive of psychological vulnerability	Impact of treatment for HNC on partners, higher anxiety. Found 'average' relationships with partners. Facial disfigurement has little impact on psychological adjustment & type of treatment is not predictive of psychological outcome & adaptation. However there were differences between patient groups on sub-scale 'trouble with social contacts' with S&R/B/C patients having low but significantly more difficulty. However those with most severe disfigurements were not eligible for the study & this may have affected QOL scores. No correlation was found between level of disfigurement & dysfunction & QOL scores. Also the scale does not measure the patient's own perception of their disfigurement; it only refers to operative procedure.
Wallis, Renne-berg, Ripper, Germann, Wind & Jester (2006) GERMANY	Medical data about burn: injury severity; face or hand involvement, need for amputation %TBSA, Partial or Full thickness of burn	Significantly greater emotional distress than general population. High levels of resources such as general optimism, self-efficacy, PSS. No correlation found between severity of emotional distress & severity of burn injury found & patients with facial burns did not differ from other patients in anxiety or distress.	Measured by medical severity no correlations were found between severity & psychological distress. No correlations between measures of psychosocial resources & emotional distress. With regards to locus of burn, patients with hand burns reported more anxiety & tended to be distressed but patients with facial burns did not differ from other patients in anxiety or distress.
Ablon (1996) USA	Visibility & severity rated by researcher & self-report	Life style difference found between genders. NF1 affects self-image of men & women. Presence or absence of visible tumours or other effects did not 'predict' a satisfying or fulfilling life, but self-reported learning disabilities did resulting in poor school achievement, poor self-image & poor job prospects. Some men in the sample were severely affected by these proposed processes	Presence or absence of visible tumours or other effects did not 'predict' a satisfying or fulfilling life, but self-reported learning disabilities did resulting in poor school achievement, poor self-image & poor job prospects. Some men in the sample were severely affected by these proposed processes. Visibility not the only issue at work. Although the term was not used 'ableist' expectation from families & schools appear implicated.

Author & date	**Facial difference**	**Main findings**	**Visibility, personal relationships & social support**
Bogart, Tickle-Degnen & Joffe (2012) USA	Observed by researcher & self-report	Use of compensatory expressive gestures & strategies such as vocal tone, gestures & humour to express oneself & improve social functioning. Social support & stigma represented on a continuum at one end providing support & the other bullying, prejudice & discrimination	Experiences with friend & family members who could 'see the real person behind the Moebius' was positive, but there were negative experiences sometimes in meeting new people. Stigmatisation & being judged relates to the facial difference & paralysis & leads to impression of lack of emotional or intelligence. Lack of public awareness concerned respondents. Tension between desire for privacy & talking about the condition with others in order to raise awareness noted.
Bonanno & Choi (2010) USA	Adults with disfigurement after cancer surgery	2 groups of patients identified always comfortable (n=4) & occasionally comfortable (n=10) in interaction. Discomfort in interaction used as an indicator of stigmatisation. 3 patterns identified: intrusion, sympathy & benign neglect & degree of discomfort varies with groups size. Always comfortable patients do not experience discomfort despite interaction pattern or group size	Distinction made between those always comfortable in interaction & those who are occasionally comfortable.
Bonanno & Esmaeli (2011) USA	Adults with disfigurement after cancer surgery	3 patterns identified: intrusion, sympathy & benign neglect. Intrusion & sympathy found to foster stigma but benign neglect did not.	Model of action for family members developed. At first disruptions experienced then a transitional phase when cancer diagnosed & treated & then a changed life. Responsibilities change including creating a supportive environment. Conflict found between shielding & encouraging membership in social groups.
Cadogan & Bennun (2011) UK	Adults who had orthognathic surgery.	Themes: self-awareness of facial appearance, attitudes of others & facial appearance, treatment issues, impact of surgery & support & coping	Unpleasant experiences perceived to be related to facial appearance. Parents & siblings identified as main sources of support.

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Dures, Morris, Gleeson & Rumsey (2011) UK	Affected adults & self-report	Themes: beliefs about containing impact of EB, understandings of the disease & disabling impacts of EB at intra-individual, inter-individual & sociocultural levels. Stigmatising effects of visibility.	Stigma of being visibly different could be socially & emotionally disabling. Unpleasant reactions from public & particular situations found difficult e.g. starting new school. Some reported how they managed staring & used clothing to cover up or minimise harm to skin. Appearance concerns & body image anxieties were difficult aspects of living with EB. Impacted on social life & loss of confidence & a sense of isolation & of being different. Information needs, self-management needs & peer support needs discussed
Egan, Harcourt, Rumsey & ARC (2011) UK	Self-reported visible difference (body & facial)	Themes: importance of appearance, personal growth, relationships with others, coping	Explored positive coping: found less significance placed on importance of appearance, other qualities valued more highly. Tried to overcome stigma by talking openly about disfigurement. Some felt attention by others not always negative. For those affected since childhood identified gamily as important in influencing their attitude, including a lack of support from family linked to resilience by one respondent. Consideration, support & acceptance valued from significant others
Eiserman (2001) USA	Affected adults & self-report	Positive contributions were communication abilities, service to others, observational skills, inner strength abilities to question society, a valued social circle, perceptions of being normal	Valued social circle identified, increased appreciation of diversity, community involvement Half sample reported they would want to remove the experience of facial difference from their lives & half said they wouldn't
Furness (2005) UK	Affected adults & self-report	3 categories of support: informational, practical & emotional. Found discrepancies between patients need for emotional support & provision by healthcare staff	Components of support helpful from staff as perceived by patients & their family/friends: staff approachability & positive attitude; awareness, education & training; long term follow up, time to talk. Largest individual variation in support was in emotional & psychological needs after surgery. Long term needs for information, practical help relating to locus of surgery suggested. Provision of prostheses to minimise aesthetic impact not routine & some patients report find it hard to manage post discharge adaptation required.

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Furness, Garrud, Faulder & Swift (2006) UK	Self-rated appearance change	Themes: demands, resources, responding & managing & consequences which were developed into a model. Social support theorised as an influence & a resource	Model of adaptation to facial surgery developed. Conceived as a process. Changes in appearance conceptualised as a demand, secondary demands were effects social roles & experiences. Attitudes to appearance social roles, life experience, demographic variables & financial resources were seen as internal resources. External resources included concurrent life events, social support & clinical interventions. Participants with facial cancer less significant appearance concerns. Social withdrawal reported. Social support interacted with demands & personal resources & there were variations in appraisal, emotion, coping & consequences. Social support intervened in the relationship between appraisal & coping. Appraisal is about weighing up the situation. Ineffective support was dismissive or over protective. Sometimes anxiety or introversion prevented people taking advantage of support. Benefit finding is suggested to occur through a combination of negative but controllable appraisals & active coping. Found avoidance to be used as a deliberate response to over whelming stress used by otherwise active copers to provide temporary relief in the early stages of recovery. Distinguishes between short term avoidance & longer term passivity. Short term avoidance not necessarily detrimental. Social support emerged as an important resource in adjustment process. Extension of current work in the area required from healthcare

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Hawkesworth (2001) UK	Affected adults & self-report	Identified problems of exclusion because of attitudinal environment or places which emphasise people looks	Sub-sample of people with severe consequences which they attributed to facial acne identified. Stigmatising experience found among adults with facial acne. Marginalisation & exclusion arises from attitudinal environment or those places that emphasise peoples' looks. Feeling of shame & embarrassment can result in withdrawal from mainstream spaces. Visibility a key factor, societal expectations of smooth faces & a specific time in life i.e. adolescence; Safe places identified such as own home, accepting people in work environments. Putting on a normal veneer discussed. Acne perceived as aesthetic even though it is also a breakdown/impairment of skin function.
Kent (2000) UK	Affected adults & self-report with any part of body affected	Triggering events involved situations where appearance concerns were raised e.g. bodily exposure. Uncertainty found in how to deal with others behaviour. Social & personal costs found	Integrates 4 theoretical models. Body image disturbance theory, triggering incidents where appearance concerns raised due to bodily exposure or enacted stigma, promoted vigilance & attribution of event to their appearance. Social anxiety theory for use of impression management strategies of avoidance & concealment. Avoidance & concealment had personal & social costs (loss of valued activities, reluctance to develop intimate relationships & anxiety). Social skills models & sociology of stigma can also be used to understand respondents' experiences. Interventions likely to need to address all 4 elements
Konradsen, Kirkevold & Zoffman (2009) DENMARK	Affected adults & nurse/patient interaction & self-report of visibility to another	Developed a model with silencing disfigurement as core category. Nurse assumption about whether patient socially supported explored	Responses to immediate effects of facial surgery. Identifies implicit & unverified professional assumptions about addressing the issue of disfigurement which became an underlying character of interaction & of silencing disfigurement. these pre-conceptions need to be challenged in order to help patients adjust to changed appearance after surgery

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Konradsen, Kirkevold, McCallin, Cayé-Thomasen & Zoffman (2012) DENMARK	Affected adults & nurse/patient interaction & self-report of visibility to another	Patient concern was feeling isolated which was resolved through interactional integration, which starts when the silence over disfigurement is broken. Adjustment is about progressing from a disfigured person to a person with a disfigurement.	Main concern of patient was feeling isolated. This could resolve using a process of interactional reintegration. Begins by breaking the silence to enable person to move from a disfigured person to a person with a disfigurement. Adjustment conceived as a process with varying temporal dimensions depending on experiences & responses of those around them.
Lau & van Niekerk (2011) SOUTH AFRICA	Affected adults & self-report	Found resilience alongside losses & deficits; lifelong (re)negotiation of identity, appearance, psychological adjustment & social reintegration. Identified significant others important to self & others acceptance	Explores meaning making processes beyond injury events. Identifies reconstructions of selves & shift in thinking about others & the world. Heightened self-awareness, need for acceptance & desire for recognition found alongside counter narratives of positive, transformative & resilient healing. Resilience & deficit reside alongside each other. Shift to person centred meanings beyond immediate wound care towards lifelong re-negotiation of identify, appearance, psychological adjustment & social reintegration argued for
Meyerson (2001) USA	Affected adults & self-report	Strengths sources: family support, faith, humour, sense of self, special skills, determination & networking	Degree of severity or visibility not studied. Strengths sources: family support, faith, humour, sense of self, special skills, determination & networking
Murray & Rhodes (2005) UK	Affected adults & self-report	Themes; powerlessness & variable nature of acne; comparisons, self-image & identity; experience of social interaction; relationships with family & friends; & gender, sexuality & romantic relationships.	Severe adult acne studied, respondents self-selected. Severe equated with visible, use of particular medications, being a member of an internet support group, having had symptoms for at least 1 year. Perceptions of personal & social relationships being affected found.
O'Brien, Roe, Low, Deyn & Rogers (2012) UK	Affected adults & self-report	Themes; personal identity; re-establishing social networks & intimate relationships. Perceptions of altered position in society, impacts on willingness to re-engage & degrees to which treatment altered abilities to resume intimate relationships.	Patient definitions of intimacy are multi-faceted & related to type of relationship that existed prior to treatment. Sexuality discussed. Concerns & challenges faced by patients need to be addressed supportively as part of the rehabilitation process.

Author & date	Facial difference	Main findings	Visibility, personal relationships & social support
Patel, Ferner & Grunfeld (2011) UK	Affected adults & self-report of effects on communication	Themes: impact of disease, emotional response to disease, awareness of NF2. Negative impacts on daily life, social isolation resulting from avoidance of difficult situations to communicate in due to hearing loss. Partners & family were relied on for emotional support. Frustration at limited awareness of NF2 among health professionals	Appearance changes (inability to smile) as well as hearing loss identified as communication problems. Restrictions in ability to carry out everyday activities affected partner & family. Experience of being treated like a 'freak' because of facial weakness. Social isolation experienced. Partner & family key support resource
Phillips, Fussell & Rumsey (2007) UK	Affected adults & self-report of perception of burn severity & visibility by family member	Identified elements for family support programme: normalising family reactions to burn; advice, support & information regarding scar permanence, realistic outcome expectations, acceptance of altered appearance & potential after burn; support in understanding how burned person might change/respond after injury; advice to enable all family members deal with potentially uncomfortable social encounters.	Support needs identified by adults with burn injury, parents of burned children & family members & developed into a family support programme proposal. Visibility or sight of burn injury caused reactions in family members when first seen. Study is about care immediately post-burn. However longer aspects term identified in relation to appearance of scar, its physical discomfort & effect on their partner. Example given was about how partner hated seeing others stare at their partner. Partner concerns were about their partner physical discomfort, pain & appearance.
Röing, Hirsch, Holmström & Schuster (2009) SWEDEN	Affected adults & self-report of appearance & relational functions of mouth	Being-in-world affected in 3 ways: existing as oneself; exiting in eyes of others & existing with others. Illuminates how mouth is central to human's identity & existence. One case relating to facial disfigurement discussed, difficulties related to changes in speech for this type of cancer. Love of family & friends intensified, or a source of interdependence, but for some abandonment	Existing in eyes of other affected in different ways. For example, a respondent with facial disfigurement talked about dealing with encounters with new people. Her familiarity of her life world & experience of being with others disappeared, her being-in-the-world was affected. Questions from a child helped her feel visible again. This was categorised as self as confirmed. Other selves were 'as pitied' & 'diminished'
Rossi, Costa, Dantas, Ciofi-Silva & Lopes (2009) BRAZIL	Affected adults, TBSA & burn visibility & self-report of burn & effects	QoL was related to autonomy & ability to work. Included: resuming work & functional ability; body image; having leisure & interpersonal relationships. QoL associated with concept of normalcy.	Body image concerns discussed in context of negative responses from other. Patients & family members reported that when they think of themselves or the patient they do not see the image of a burned person. Relationships affected in many ways. Sexuality discussed.

Author & date	**Facial difference**	**Main findings**	**Visibility, personal relationships & social support**
Rozario (2007) UK	Affected adults & self-report of meanings of appearance & effects	Darker skin colour & NF1 tumours led family to see her as unmarriageable. Appearance was a bar to social acceptability by Bangladeshi men & women. Consequences of genetic disorders in cultures where social identity is entwined with appearance.	Family of origin narrated as limiting her chances in education & marriage. After marrying outside of her culture & gaining an education her appearance was still a bar to social acceptability within her family of origin kinship network. Cultural aspects of appearance discussed & it is argued that greater pressures are on Bangladeshi women with respect to appearance than in UK more generally.
Semple, Dunwoody, Kernohan, McCaughan & Sullivan (2008) UK	Affected adults & self-report of meanings of appearance changes	Changes & challenges in: social functioning, interpersonal relationships, work & activities, concerns about cancer, physical changes. Personal attributes helped or hindered coping & the need for specific information post treatment.	Appearance changes had significant meanings for patients such as increasing self-awareness & social anxiety, especially first few months after surgery, but adaptation & acceptance came over time for most. Strategies for minimising noticeability identified. Specific post treatment concerns should not be viewed as discrete aspects of life, but need to be addressed with the patient holistically. Some found personal relationships helpful & supportive especially where they responded in a 'normal' fashion & were not over protective. Some people benefitted from gradual exposure to social settings, eating out noted as an area of difficulty.
Semple & McCance (2010) UK	Affected adults & self-report	Themes focussed on phases: diagnosis, during treatment & living with consequences. Appearance changes forced telling children. Debilitating treatment effects in eating & changing role in family. Social networks important	Changed appearance forced telling children. 3 main networks of support: 'family & friends', 'community' & 'professionals'. Main source of emotional & practical support came from family & friends especially partner. Community was about telling people who could support children e.g. school. Professionals were relied on for information, however emotional or coping information was not readily available e.g. how to deal with telling your children.
Stavropoulos, Hallberg, Mohlin & Hagberg (2010) SWEDEN	Affected adults & self-report of meanings of appearance changes	Main concern: to make the best of their situation. Included commitment to activity, avoiding exposed situations, actively launching oneself, struggling with normalising appearance & lowering expectations of finding a 'love partner' & finding someone who also had had exposed life situation or vulnerability	Visibility & staring noted as an issue & avoiding exposed situations because being stared at creates feeling of being not normal. Surgical operations to normalise appearance very physically & psychologically difficult. Discussion of lowering expectations of finding a 'love partner' & finding someone who also had had exposed life situation or vulnerability

Author & date	**Facial difference**	**Main findings**	**Visibility, personal relationships & social support**
Strauss & Fenson (2005) USA	Affected adults & self-report of appearance & well-being	3 domains; personality & psychological; family, work & social interactive; cultural & societal.	Visibility of the face is an issue. Many adults with craniofacial conditions find ways to live with difference & succeed using the methods they construct
Thompson & Broom (2009) UK	Affected adults & self-report appearance & coping	Found difficulties as well as coping with adjustment. Adjustment seen as an ongoing process.	Examined how people positively manage intrusive reactions to disfigurement. Not all reactions interpreted as negative. Social support helped with coping with other people's reactions. Two processes managing internal impact & managing external impacts. Normalising other people reactions involved the belief that people who stare are curious rather than motivated by malice. Supports stigmatisation theory.
Thompson, Clarke, Newell, Gawkrodger & ARC (2010) UK	Affected adults & self-report appearance & coping	Descriptions of feeling visibly different & experiences of stigmatisation. Avoidance & concealment common. Stigmatisation often perceived as associated with cultural values relating to appearance & myths linked to the condition	Cultural associations of stigma explored, effect on ethnic identity in skin colour changes. Feel of rejection or of being exposed affected intimate relationships. Some spoke of rejecting cultural practices & having to find their own way. Support from a variety of sources identified: family, friends, Vitiligo Society, dermatologists. Support helpful in seeing things differently & acceptance, & medical help.
Thompson, Kent & Smith (2002) UK	Affected adults & self-report appearance & coping	Found tactics to contain feeling overwhelmed. Social support facilitated development of coping strategies. Living with vitiligo as a continuous struggle	Experience of becoming different & becoming preoccupied with difference explored. Social support from significant others helps in a variety of ways encouragement to enter anxiety provoking settings, reassurance they are accepted regardless of appearance, & development of adaptive cognitions both problem focussed & emotion focussed. Maintaining 'good' adjustment to having an unusual appearance could continue to be a significant issue years after initial diagnosis

Author & date	**Facial difference**	**Main findings**	**Visibility, personal relationships & social support**
Uttjek, Nygren, Stenberg & Dufåker (2007) SWEDEN	Affected adults & self-report of meanings of visibility	Visibility most difficult aspect. Coping strategies developed with age. Most had a good QoL but nothing positive to say about psoriasis. Felt impacts on quality of life, having a job &/or close friends or being of use & being well had most influence on quality of life & facilitated coping	Visibility of psoriasis (rashes & joint changes) conceived as a mark of difference, especially for young people in sample. Most people adjusted but could nothing positive about condition. Adjustment involved dealing with the condition & the marking process. Suggested this evolved overtime. Learning to live with it typified as not bothering what people outside the closest social network thought about them. Felt impacts on quality of life, having a job &/or close friends or being of use & being well had most influence on quality of life & facilitated coping.
Williams, Davy & Klock-Powell (2003) USA	Type & location of burn. Self-report of appearance, injuries & coping	Impacts on relationships; some felt supported others disappointed. Identified factors for resilience; determination, striving for independence, courage, compassion & spiritual transformations. Themes of profound loss & change. Attention needs paying to patients context, stage of recovery as well as their stage in their life cycles, exploring of family & friend supports & how loss of occupational role affects survivors sense of self worth	Burn injuries present challenges in recovery on a physical, emotional & spiritual level. Influences that existed independent of injury separated & their impact on meaning making traced. Their construction of reality & memories of themselves, time since injury & age when injured including developmental stance of adult & point in family life cycle. Injury & recovery impacted on relationships with family, spouse, friends, new friends & helping professionals. Some felt disappointment in support received & others felt sustenance. Argues for greater understanding of patients context, stage of recovery, stage in their life cycles, exploring of family & friend supports & how loss of occupational role affects survivors sense of self worth

Appendix 13: Summary of review themes

Author & date	Social interaction & stigma	Social support	Personal relationships	Coping, time & resilience	Demographic factors
Ablon (1996)	X		X		X
Anzarut et al (2005)		X			X
Baker (1992)		X			
Berk et al (2001)			X		X
Bogart et al (2012)	X				
Bonanno & Choi (2010)	X	X	X		
Bonanno & Esmaeli (2011)	X	X	X		
Bowden et al (1980)		X			X
Brown et al (1980)					X
Cadogan & Bennun (2011)			X		
Ciofi-Silva et al (2010)			X		X
de Boer et al (1995)			X		
Deno et al (2012)		X			X
Dures et al (2011)	X		X		
Egan et al (2011)			X		
Eiserman (2001)			X	X	
Furness (2005)			X		
Furness et al (2006)	X			X	
Gamba et al (1992)		X	X		
Hagedoorn & Molleman (2006)		X			
Hawkesworth (2001)	X		X		
Howren (2013)		X			
Karnell et al (2007)		X			
Katz et al (2003)		X			X
Kent (2000)	X				
Kleve et al (2002)	X	X			
Knudson-Cooper (1981)	X		X	X	X
Konradsen et al (2009)	X	X		X	
Konradsen et al (2012)	X	X		X	
Lau et al (2011)	X		X	X	X
Lawrence et al (2004)	X	X			
Lawrence et al 2006(b)	X	X			X

Author & date	Social interaction & stigma	Social support	Personal relationships	Coping, time & resilience	Demographic factors
Lawrence et al (2010)	X				
Meyerson (2001)			X	X	
Murray & Rhodes (2005)	X		X		
O’Brien et al (2012)			X		X
O’Hanlon et al (2012)	X		X		X
Orr et al (1989)		X			X
Patel et al (2011)	X		X		
Peter et al (1975)			X		
Phillips et al 2007			X		
Roberts & Mathias (2012)	X	X	X		X
Röing et al (2009)	X	X	X		X
Rossi et al (2009)	X		X	X	X
Rozario (2007)	X		X		X
Rumsey et al (2004b)		X			X
Semple & McCance (2010)	X		X		
Semple et al (2008)	X	X	X	X	
Stavropoulos et al (2010)	X			X	
Strauss & Fenson (2005)	X			X	
Thompson & Broom (2009)	X			X	
Thompson et al (2010)	X		X		X
Thompson et al (2002)	X			X	
Uttjek et al (2007)	X		X	X	
Vickery et al (2003)		X	X		
Wallis et al (2006)		X			
Williams et al (2003)			X	X	

Appendix 14: Studies by visible facial difference type

Visible facial difference	**Quant**	**Qual**	**Total**
Congenital conditions (cleft lip &/or palate; Crouzon syndrome; Moebius syndrome; NF1 & NF2)	4	9	13
Injury (burn)	10	4	14
Cancer treatments (head and neck; eye cancer)	9	8	17
Facial surgery (range of causes)		2	2
Skin conditions (acne; epidermolysis bullosa; psoriasis; vitiligo)		7	7
Visible difference	2	2	4
Totals	**25**	**32**	**57**

Appendix 15: Ethics approval letter

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Research and Knowledge Transfer Support
Richmond Road | Bradford | West Yorkshire | BD7 1DP | UK
Tel: +44 (0)1274 233223
Fax: +44 (0)1274 236090
www.bradford.ac.uk/admin

Rose Peacock
School of Health Studies
University of Bradford

10th July 2012

Hi Rose

Ethics Application E.227
Title: Exploring relationships of people with facial differences

I passed the amendments to your ethics application to the Chair of the Research Ethics Panel together with Reviewer 1 and they have both confirmed that they consider you have made a big effort to thoroughly address all the points raised by the Panel and the Reviewer.

I can therefore confirm that Andy Scally, Chair of the Humanities, Social and Health Sciences Research Ethics Panel is happy to take Chair's action to approve your ethics application on behalf of the Research Ethics Panel.

Can you please add a sentence on any information given out to participants that this study has received ethics approval from the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford on 10th July 2012.

With all good wishes

Lynda

Lynda

Lynda Nuttall
Research Support/Ethics Administrator
Research and Knowledge Transfer Support
Room C.21, Richmond Building
University of Bradford
BD7 1DP

Tel: 01274 23 3170
l.d.nuttall@bradford.ac.uk<mailto:l.d.nuttall@bradford.ac.uk

onfronting Inequality: Celebrating Diversity

Appendix 16: Pro-forma letter about study

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[Insert date]

Dear

Exploring relationships of people with facial difference

Thank you for considering taking part in the study. I look forward to meeting you on ....at……………………………………………………………

Please find enclosed an information sheet about the study for you to hear more about the study. I have also enclosed a consent form for the study. Please take time to take look at the form and if you agree please complete and return to Rose Peacock otherwise please bring it with you to the first interview.

I would like to assure you that your views will be very valuable to this study and that they will remain confidential and you will not be named or identified in anything I write.

If you have any queries, please don't hesitate to contact me at the University of Bradford or email me at: r.e.peacock@student.bradford.ac.uk

Ethics approval received from Humanities, Social and Health Sciences Research Ethics Panel at University of Bradford on 10/07/2012. School of Health Studies, University of Bradford, Richmond Road, Bradford, BD7 1DP.

Thank you very much indeed.

Yours sincerely

Rose Peacock, PhD student, School of Health Studies, University of Bradford

Appendix 17: Participant information sheet

PARTICIPANT INFORMATION LEAFLET

Exploring Relationships of People with Facial Difference

Thank you for considering taking part in this research project. This leaflet explains more about the research.

What is the purpose of the research?

The study aims to find out more about how relationships contribute to the lives of people living with facial difference. Relationships can be an important part of support as well as promoting health and well-being. The study is interested in your views about how they can help you adjust to visible difference and how they contribute to you accepting or resisting pressures coming from other peoples' beliefs about appearance. I am interested in talking to people who live with visible facial difference, and also if possible, someone important to you such as a friend or family member.

What will happen if I decide to take part?

You will spend some time talking to me about who is important to you now and at earlier points in your life. This will mean meeting with me twice at a place at a suitable place to carry out an interview, this may be at a private room at the University of Bradford, a place in the community such as a café or another suitable place local to you. The interviews will involve making a diagram of your important relationships. I will guide you through this process, and provide pens and paper. You will not be asked to give the full names of any of the people you mention.

I will ask if you are willing for me to speak to a friend or family member. If you do not want me to talk to any of your relatives or friends, that is fine. However, if you are willing, after the first interview I will ask you to choose whom and to ask them, on my behalf, if they would be willing to talk to me about the study. The purpose of their interview will be explore how being close to someone who lives with visible facial difference impacts on them.

The interviews will be recorded with your agreement. I will also make some notes based on what you tell me in order to make sure I am accurate in my understanding. Each interview will last about one hour.

Do I have to take part?

It is up to you to decide whether you would like to take part. To help you decide I will explain the research to you, and will answer any questions you may have.

If you decide to take part, I will ask you to sign a consent form and give you a copy. You can change your mind about taking part at any time, without giving a reason any information that has been collected can be safely destroyed. I will make sure I respect your privacy whilst I am spending time with you. I will keep checking that you are still happy to take part.

Will taking part be kept confidential?

I will be the only researcher that will know the names of people who took part in the study. The information you give me will be kept confidential from other people taking part in the study. In addition, no names will be associated with your information and it will be assigned an ID number. Information about you will be kept safe, stored in a locked filing cabinet or on a password protected computer. If you have given me any personal details (e.g. your name & address) these will be destroyed after three years.

What are the possible disadvantages and risks of taking part?

There are no risks in taking part, but some people might find it upsetting to talk about facial difference and relationships.

How will I benefit from taking part in this research?

By taking part in this research you might help improve understanding about contributions relationships make to the lives and well-being of people living with facial difference.

How will the results of the research be used?

The findings of the research will be written up into reports and research articles. If you agree, some of the things that you tell me may be quoted in these reports. I will never use your name or the names of your friends and family. If you wish, I can send you a copy of the research findings.

Who has given permission for the research?

The study has been approved by the Humanities, Social and Health Sciences Research Ethics Panel at University of Bradford on 10/07/2012. The research forms part of a course of study for a doctorate degree funded by the University of Bradford, School of Health Studies.

What if there is a problem?

If you are worried about the research or have any questions, please speak to me. If you would like to contact me please use the details below. The mobile number is for this study only. It will receive calls Monday-Friday 10am-4pm for the purposes of study until June 2013.

Thank you, Rose Peacock

PhD Student: Voicemail: 01274 23 6372; Study mobile: 07584 924171
r.e.peacock@student.bradford.ac.uk School of Health Studies, University of Bradford, Bradford, BD7 1DP

Appendix 18: Friend and family information sheet

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FRIEND OR FAMILY MEMBER INFORMATION LEAFLET

Exploring Relationships of People with Facial Difference

Thank you for considering taking part in this research project. This leaflet explains more about the research.

What is the purpose of the research?

The study aims to find out more about how relationships contribute to the lives of people living with facial differences. Relationships can be an important part of support as well as promoting health and well-being. The study is interested in your views about the role of appearance in relationships and effects of other peoples' beliefs about appearance. I am interested in talking to people who live with visible facial difference and also people important to them, such as a friend or family member.

What will happen if I decide to take part?

You will spend some time talking to me about how being close to someone who lives with visible facial difference impacts on you and the importance of appearance in people's lives. If you decide to take part, this will mean meeting with me once at a place where you feel comfortable.

The interviews will be recorded with your agreement. I will also make some notes based on what you tell me in order to make sure I am accurate in my understanding. The interview will last one hour.

Do I have to take part?

Your friend or family member has agreed that I can contact you to see if you would like to take part; however, it is up to you to decide whether you would like to take part. To help you decide I will explain the research to you, and will answer any questions you may have. If you decide to take part, I will ask you to sign a consent form and give you a copy. You can change your mind about taking part at any time without giving a reason. Any information that has been collected can be destroyed. I will make sure I respect your privacy whilst I am spending time with you. I will keep checking that you are still happy to take part.

Will taking part be kept confidential?

I will be the only researcher that will know the names of people who took part in the study. The information you give me will be kept confidential from other people taking part in the study. In addition, no names will be associated with your information and it will be assigned an ID number. Information about you will be kept safe, stored in a locked filing cabinet or on a password protected computer. If you have given me any personal details (e.g. your name & address) these will be destroyed after three years.

What are the possible disadvantages and risks of taking part?

There are no risks in taking part, but some people might find it upsetting to talk about facial difference and relationships.

How will I benefit from taking part in this research?

By taking part in this research you might help improve understanding about contributions relationships make to the lives and well-being of people living with facial difference.

What will you do with the findings of the research?

The findings of the research will be written up into reports and research articles. If you agree, some of the things that you tell me may be quoted in these reports. I will never use your name or the names of your friends and family. If you wish, I can send you a copy of the research findings.

Who has given permission for the research?

The study has been approved by the Humanities, Social and Health sciences Research Ethics Panel at University of Bradford on 10/07/2012. The research forms part of a course of study for a doctorate degree funded by the University of Bradford, School of Health Studies.

What if there is a problem?

If you are worried about the research or have any questions, please speak to me.

If you would like to contact me please use the details below. The mobile number is for use for this study only. It will receive calls Monday-Friday 10am-4pm for the purposes of the study until June 2013.

Thank you,

Rose Peacock

Researcher and PhD Student, University of Bradford

Tel/Voicemail: 01274 23 6372 Study mobile: 07887 399 567

r.e.peacock@student.bradord.ac.uk

School of Health Studies, University of Bradford, Richmond Road, Bradford, BD7 1DP

Appendix 19: Consent procedure

1. Adverts are placed websites of consenting charities or self-help groups and including researcher contact details so people can find out more about the study or give an expression of interest.

2. Researcher follows up the expressions of interest as soon as possible with the potential participant. Respondents expressing interest were asked to provide a telephone number, and either an email or postal address so the researcher could send further information. The participant is sent the study information sheet (Appendix 4: Example Participant Information Sheet) and thanked for considering joining the study. A minimum of 24 hours will be allowed for interested potential respondents to reflect before arrangements are sought for interview.

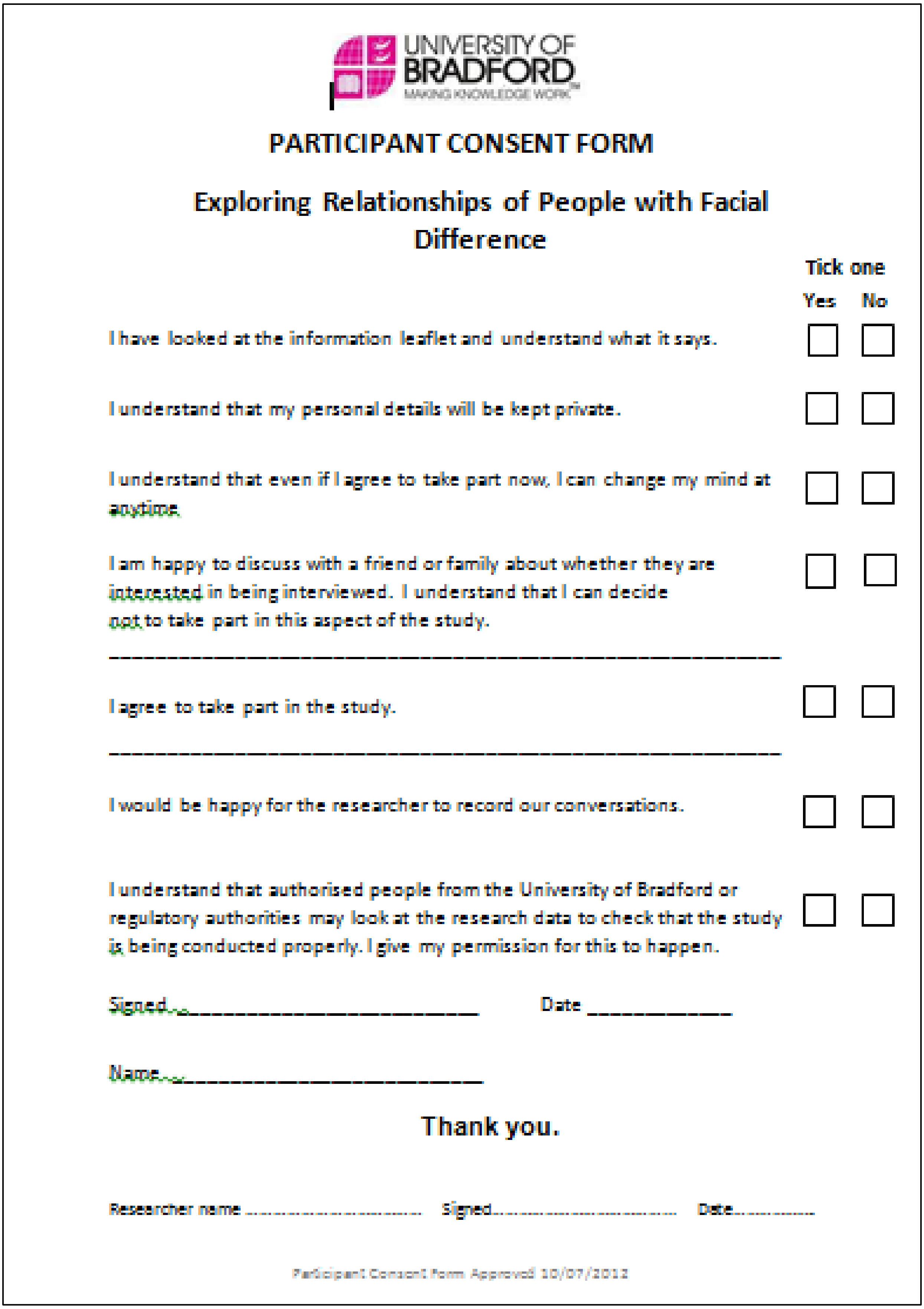
3. Then the researcher makes contact, explains what the study involves, the process of informed consent and provides an opportunity for the participant to ask questions about the study. The researcher checks whether they meet the study criteria. Respondents are asked whether they are willing to talk about important relationships. If the potential interviewee would like to volunteer for the study, the interviewer seeks suitable times, dates and locations for the interviews to be held. A minimum of a week will be left between interviews unless the interviewee opts for a single interview or more closely spaced interviews.

4. At this point verbal consent will have been reached but not fully informed consent. The interview arrangements will then be confirmed in writing by letter or email. This will include a consent form to sign and return to the researcher or bring with them to the interview if they prefer.

5. Before the interview commences the participant will be asked to read the consent form and sign if they agree, if it has not already been returned to the researcher. A further opportunity for questions will be provided.

6. At the second interview or when repeat contact is made with the participant, the issue of consent will be revisited verbally to ensure they are still prepared to participate.

Appendix 20: Consent form



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PARTICIPANT CONSENT FORM

Exploring Relationships of People with Facial Difference

	Tick one	
	Yes	No
I have looked at the information leaflet and understand what it says.	☐	☐
I understand that my personal details will be kept private.	☐	☐
I understand that even if I agree to take part now, I can change my mind at anytime.	☐	☐
I am happy to discuss with a friend or family about whether they are interested in being interviewed. I understand that I can decide not to take part in this aspect of the study.	☐	☐
I agree to take part in the study.	☐	☐
I would be happy for the researcher to record our conversations.	☐	☐
I understand that authorised people from the University of Bradford or regulatory authorities may look at the research data to check that the study is being conducted properly. I give my permission for this to happen.	☐	☐

Signed...___________________________ Date _____________

Name....___________________________

Thank you.

Researcher name .... Signed.................................. Date...............

Participant Consent Form Approved 10/07/2012

Appendix 21: Pro-forma support agencies leaflet

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Information about Support Organisations

Changing Faces

Are you worried about other people’s reactions to your appearance? Are you struggling to accept the change to your appearance after surgery or an accident? Whether you were born with a condition that affects your appearance, or you acquired a disfigurement more recently, Changing Faces will try to help.

You may also have questions about your medical condition and want to access more medical information? Changing Faces can advise you how to find out more and signpost you to other services. Changing Faces can help you find a local self-help or support group. They provide skin camouflage services and run training events and workshops.

If you are looking for support and would like to talk to someone, contact:

Changing Faces on **020 7391 9282** or email support@changingfaces.org.uk Calls are accepted between 10am – 4pm, Monday to Friday and messages can be left if they are not available.

Let’s Face It

Let’s Face It is a support network for people with facial disfigurement, their families, friends and professionals. The organisation aims to offer friendship on a one-to-one basis; link family friends and professionals; assist people with facial disfigurement share their experiences and help them build courage to face life again.

Contact information for the support network is:

Email: chrisletsfaceit@aol.com or julialetsfaceit@talktalk.net

Telephone: 01843 833724

Local Service

[Insert name, and contact details of relevant local service or support group once the details of where the person to be interviewed is based]

Access to Psychological Therapies or Talking Therapies

Your GP can refer you for talking treatment that is free on the NHS, usually a short course of counselling or Cognitive Behaviour Therapy (CBT) from the GP surgery's counselling service. If counselling or CBT aren't available at the surgery, your GP can refer you to a local counsellor or therapist for NHS treatment.

You may also be able to refer yourself for counselling. The NHS Improving Access to Psychological Therapies (IAPT) programme means that some NHS areas are introducing the option of self-referral. The service is available in some parts of England. To find out what's available in your area, search for psychological service available in your area on the NHS Choices website. The link below will take you to this part of the website:

http://www.nhs.uk/Livewell/counselling/Pages/Accesstotherapy.aspx

The link below will take you to the page on NHS Choices website where you can search for services in your post code: http://www.nhs.uk/ServiceDirectories/Pages/ServiceSearchAdditional.aspx?ServiceType=PsychologicalTherapyservices

Samaritans

You can talk to the Samaritans any time of the day or night for confidential support. Common reasons to call the Samaritans are: relationship and family problems; loss of a job, or friend, family member through bereavement; financial worries; job related stress or over-work; college or study issues; body image issues. **To talk to someone in confidence at any time, call: 08457 90 90 90**

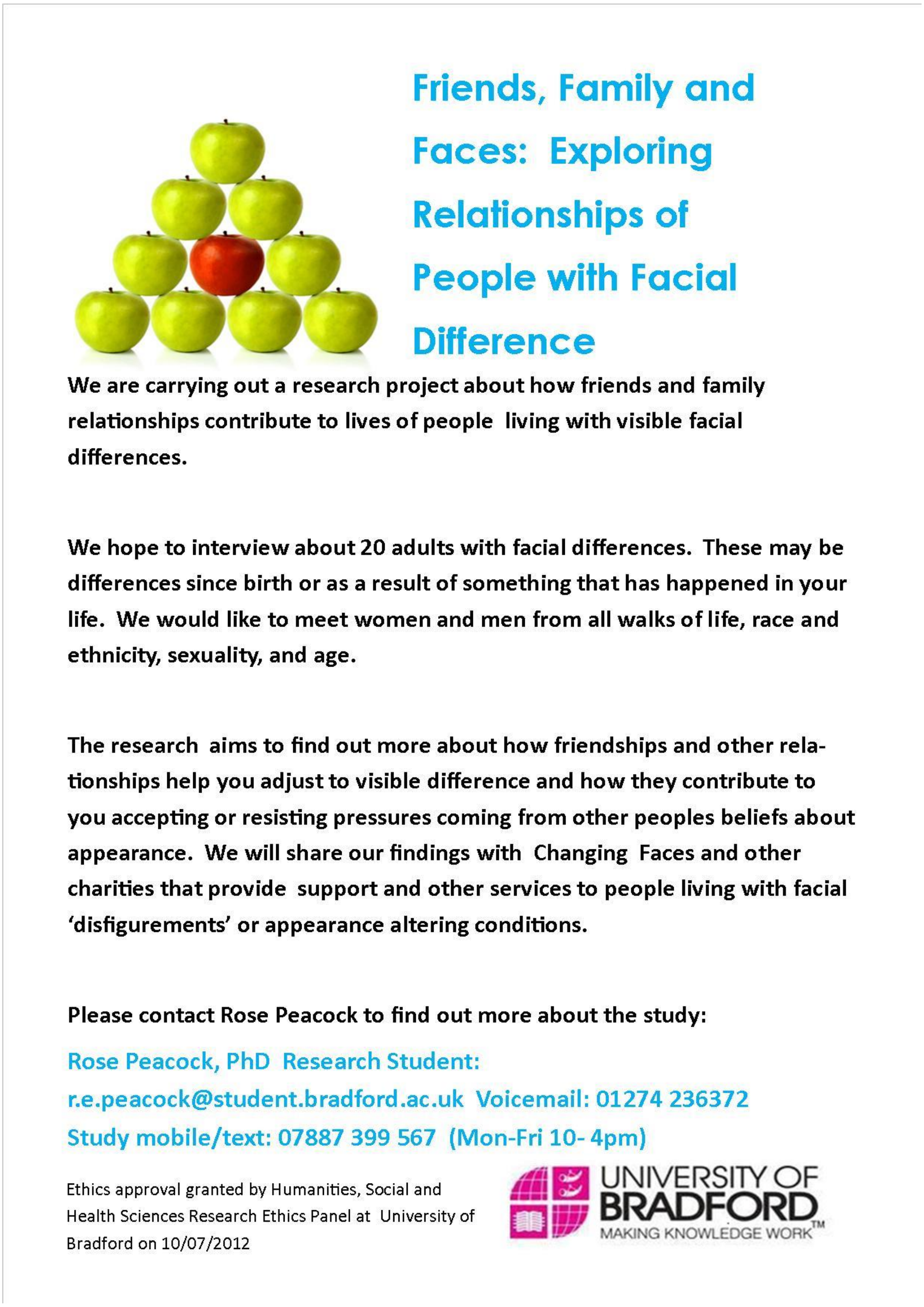
To Contact the Researcher:

Rose Peacock: r.e.peacock@student.bradford.ac.uk

Tel/Voicemail: 01274 236372 Study Mobile: 07584 92417 (Mon-Fri 10-5pm)

School of Health Studies, University of Bradford

Appendix 22: Example on-line advertisement



Friends, Family and Faces: Exploring Relationships of People with Facial Difference

We are carrying out a research project about how friends and family relationships contribute to lives of people living with visible facial differences.

We hope to interview about 20 adults with facial differences. These may be differences since birth or as a result of something that has happened in your life. We would like to meet women and men from all walks of life, race and ethnicity, sexuality, and age.

The research aims to find out more about how friendships and other relationships help you adjust to visible difference and how they contribute to you accepting or resisting pressures coming from other peoples beliefs about appearance. We will share our findings with Changing Faces and other charities that provide support and other services to people living with facial 'disfigurements' or appearance altering conditions.

Please contact Rose Peacock to find out more about the study:

Rose Peacock, PhD Research Student:
r.e.peacock@student.bradford.ac.uk Voicemail: 01274 236372
Study mobile/text: 07887 399 567 (Mon-Fri 10- 4pm)

Ethics approval granted by Humanities, Social and Health Sciences Research Ethics Panel at University of Bradford on 10/07/2012

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Appendix 23: Topic guides for respondents with visible facial difference

Exploring relationships of people with facial differences

Topic Guide/Aide Memoir for First Interview

Introduction

Introduce myself; talk about confidentiality and aims of the project; living with difference and role of relationships.

Please could you tell me a bit about your experience of living with facial difference

Identifying Important People

Think of people who are important to you now. Emphasise it is for them to define important, as I want to know how they see the world.

Provide 20 post-it notes for them to write down the first name and initial of people they identify. Put the following information on the post-it notes as they identify names:

- Their age (approx)
- Kind of relationship you have eg friend, relative, colleague, neighbour
- How far away live in miles (approx)
- Number of years you have known each other (approx)
- How often are you in touch

Ordering relationships

- Are some of these people more important than others?
- Put these in the central circle and work outwards to the fifth circle.

As each label is being stuck on ask: Why have you placed them here? Explore

How do you think of relationships – friends, family and others

You have described some people on the map as a friend: what does it mean to have a friend?

Do you have a best friend or best friends? What is a best friend? Explore

How do friends compare to family relationships?

Do you get something out of friendship you don't get out of family relationships?

Do you get something out of family that you don't get from friends?

Turn to relationships: when you need something

Who would you turn to if you:

- Wanted to socialise
- Needed a lift somewhere urgently*
- Were looking for work
- Were in financial difficulties and needed to borrow £100*
- Were called names
- Were treated with disrespect
- To talk about appearance related difficulties
- To talk about health issues
- If you had a serious personal crisis, how many people (if any) do you feel you could turn to for comfort and support*
- You are ill in bed and need help at home, could you ask anyone for help*

Why these people in particular?

Who do you tend to confide in? Explore

Who do you feel you have most in common with? Explore

Do any of these people have their own experience of difference? Explore

Are there people who make things more difficult re appearance? Are there any on you diagram?

Other colleagues, friends, relatives were not included, why? How are they different?

Characteristics of Relationships

Select relationships for in-depth exploration. For friends explore:

How often do you keep in touch? How do you know each other?

What kinds of things do you talk about and/or do together?

Has the relationship developed and changed?

What keeps it going?

In what situations have you/would you turn to this person for support? Do they turn to you?

For family relationships

Describe relationship

How often do you see each other/or are in contact?

Do you have a friendship/friend-like relationship with any members of your family?

Explore

Comparing circles

What is the difference between relationships in the different circles?

How would you describe the different criteria you have used?

Give each circle a name which describes it

I asked for important relationships at the start of the interview, which describe your supportive relationships

Ending interview

Looking at the map. Are you happy that this represents your social circle?

How do you feel about where you have put people, now that we have talked about them a bit more?

We are coming to the end of the interview do you have anything else to say?

Interviewer gives a summary of the interview and invitation to comment.

Biographical details: note as they come up during interview

Topic Guide/Aide Memoir for Second Interview

Introduction

Have a look at the chart made at the last interview. Reaffirm confidentiality that they are happy to continue

Experience of living with facial difference over life course events

Using a life-line mapped with the important relationships from the first interview. Explore life events, associated appearance issues and people important at that life stage:

0-10	*11-20*	*21-30*	*31-40*	*41-50*	*51-60*	*61 plus*

Talk about each person, examples of prompts below:

- Appearance related issues at that stage, have you changed in how you think about this?
- Are there people from this stage who were important at the time who have not already been mentioned? Who?
- What happened to that relationship?
- Check whether they want the name added to the circles map
- Have you had fewer or more friends at different stages of your life? Explore
- *(If not mentioned parents*) Would your parents have been on the map? Where?

Role of others

Before and after acquiring difference (if relevant)

Comparing your people vs those to make it more difficult

Staring or other similar experiences

Shielding by friends/others

Breaking friendships

Contact with health professions or voluntary organisations

Structures of the Personal Community

Do any of these people know each other?

Ending Interview and recap

Looking at the map, are you happy that this represents your social circle?

We are coming to the end of the interview do you have anything else to say?

Interviewer gives a summary of the interview and invitation to comment

Appendix 24: Topic guide for family and friends

Exploring relationships of people with facial differences

Topic Guide/Aide Memoir for Interview with Friend or Family Member

Introduction

Introduce myself; talk about confidentiality and aims of the project. The emphasis of this interview is to explore how being close to someone who lives with visible facial difference impact on perceptions about appearance and its importance.

Biographical details (note as they come up during interview):

Explore how they describe their relationship

Establishing your relationship - How long have you known each other; how did you get to know each other; first impressions; changes in your relationship since it was first established; amount of contact you have *(probe for examples, stories, accounts)*

Chronology of the relationship – can you take me through a timeline of relationship including significant moments or events *(probe for examples, stories, accounts)*

Positive aspects of the relationship – what you share, what you have in common, what is special *(probe for examples, stories, accounts)*

Challenging aspects of the relationship - *(probe for examples, stories, accounts)*

Reactions from other people – from family members, friends or others than you don't know relating to appearance; people who comment or stare; dealing with these providing support for your friend or yourself *(find examples, stories, accounts)*

Perceptions about social world in relation to appearance – when is appearance important, how important is appearance; what situation or contexts; have your views changed over time *(find examples, stories, accounts)*

Ending interview: *We are coming to the end of the interview do you have anything else to say? Interviewer summarises interview and invites comment.*

Appendix 25: Coding frame

Initial codes	**Definition**	**Sub-codes**
Background	Demographic information about each respondent	- Sampling details - Household composition - Relationship status - Employment history - Type of visible facial difference - Childhood and education - Interests and activities
Acquired facial difference	References particular to acquired facial difference	- Dealing with difference of body and face - Experience of returns to school, work - Changes in life priorities and normalising - Re-connecting difficulties - Support from family, friends in the past - Support from family, friends now - Appearance talk - Gaps in services
Born with visible facial difference	References particular to born with facial difference	- Body normal for me, not for others - Experience of school days - Experience of making friends, meeting partners, finding work - Support from family, friends in past - Support from family, friends now - Appearance talk - Gaps in services
Structure of the personal community circles	Names of people within the circles, type of contact, how long have they known each other and descriptions of how they met	- Circle 1 - Circle 2 - Circle 3 - Circle 4 - Circle 5 - Wider circles

Initial codes	**Definition**	**Sub-codes**
Importance relationships in personal community	Type of relationships in personal communities, descriptions of why they important then and now	- Aunt and uncle - Best friend - Colleague - Cousin - Daughter, son, mother and father in law - Daughter or son - Deceased people and pets - Ex-partners - Friends - Godmother - Grandchildren - Grandparent - Health professional - Neighbour - Niece or nephew - Organisation - Parents - Partners - Pets - Siblings - Sports coach and organisation
Roles of the respondent in a personal community	Roles respondent uses to describe their relationship to people in their personal community	- Being a parent - Being a partner - Being a colleague/ worker/ volunteer - Being a friend - Being a grandparent - Member of a family - Member of an organisation/club - Source of advice - Source of care - Source of intimacy
Qualities of a personal community	References to qualities of personal community and comparisons with other contexts	- Acceptance - Getting it - Recognition of emotion work - Caring/comfort - Safe haven/cocoon - Difference between important people & others - Comparing family and friends - Practical support - Emotional/Interpretational support - Advice/information support - Companionship - Social contact - Biographic contact - Role of inner circles - Role of outer circles - Getting used to unwanted attention - Demonstrating normalities - Becoming closer - Becoming more distant - Demonstrating belonging

Initial codes	**Definition**	**Sub-codes**
Particular relationship types	Descriptions of significant relationships	- Significance of partners - Having children with or without visible facial difference - Intimate friendships - Important grandparents - Important pets - Important deceased people - Use of clichés
Other people responses to visible facial difference A	Descriptions of situations, events and responses from other people	- Being used by others - Bullying, name calling, teasing - Fear of disease - Intimacy and care - Other getting used to you - Protective role by others - Evaluation of ambivalent assessments - Evaluation of negative assessments - Evaluation of positive assessments - Staring incidents
Effects of other people's responses to visible facial difference	Effects of the behaviour of other people	- Avoiding some things/some times - Feeling left out/marginalised - Feeling comfortable/uncomfortable - Feeling judged - Feeling angry - Feeling lonely/isolated - Lock out manner - Not knowing what the assessment means - Prepare for rejection - Family and friends have to learn to deal with it - TV and celebrity
Situations	Discussion of different situations associated with experience of visible facial different	- At work - Out in public - Present time situations - Past situations - Hobbies, interests, clubs

Initial codes	**Definition**	**Sub-codes**
Developing resilience and protective strategies		- Anaesthetised/ silencing pain - Avoiding some things/some times - Being upfront - Blinkers/put on a front/ get used to it - Bodily movement in communication - Cannot be beaten attitude/stubbornness - Choosing when or if to disclose - Deal with things myself/self control - Disfigurement does not define me - Fighting spirit - Find identity and community - Positivity - Right to normality - Taking opportunities - What I think of bullies/starers/judges - Work out what's going on
Life outcomes	Expression of how respondents felt they had done living with visible facial difference in their selected areas of importance	- Big footprint - Feeling resilient - Feeling good at something - Making a family - Making friends - Normal and handling normalities - Qualifications and education - Under achievements
Social location	References to effects race, age, gender, class, education	- Comparisons between race and visible facial difference - Comparisons with disability and visible facial difference - Effects of gender - Effects of class
Interview processes	References to taking part in the study	- Emotionally changing moments - Motivation for volunteering - Relationship with interviewer - Perceptions of their PC

Appendix 26: Example of personal community coding

Table filled in for each circles used in the personal community

Circle 1: [as defined or described by respondent)

Who	Relationship	Age	Time known	Proximity	Contact	S&P typology	Given/chosen combinations	Turn to questions and supports
Ivy	Mother	67	All life	Local	Most days	Mother	Given as chosen	Socialise in a family way; Lift; £100; Being called names; treated with disrespect; Appearance issues; health issues; serious personal crisis; emotional support (comfort & support); other
Caroline	Friend	43	9 years	Local	Monthly	Friend Supportive	Chosen	Socialise; treated with disrespect; favours; emotional support in crisis
C1: total	2							

Summary table: example only

Friend/family interpretations		**Other interpretations**	
Number of friends (living)	7	Friendship repertoire	Intense (nearly all friends are complex types)
Number of family (living)	11	Friendship mode	Evolving, has friend from school, university and work. New people added some retained from earlier stages
		Specialisation in support roles	Different types of support distributed through both friends and family relationships
God-parents or god-children		Given	5
Neighbours		Given as chosen	2
		Given and chosen	2
Deceased &pets	4	Chosen	9
Professionals, vol orgs		Chosen as given	0
Ratio of friend to family	7:11	Organisations/deceased/pets	4
PC Size	22	Total	22

Appendix 27: List of matrices

Number	Name	Description
Matrix 1	Identity voices	Resourceful, resigning, managing, surviving, developing
Matrix 2	Association with visible facial difference organisations	Links to charities, and health services, roles
Matrix 3	Interactional experiences	Incidents, memories, situations, turning points
Matrix 4	Work & activities	Types of work/activity; paid or voluntary; retirement, visible difference issues
Matrix 5	Importance	Meaning of importance from circles & interviews
Matrix 6	Employment, childcare & parenting role	Roles and issues connected to visible facial difference of either self or child
Matrix 7	Difference	Symbols, disability, normality, normal
Matrix 8	Interaction strategies	Examples from self and other
Matrix 9	Resilience	Risks, protections, dynamics
Matrix 10	Success in life	Descriptions of self-assessments in relationships, employment, education, boundaries with class & gender
Matrix 11	Importance & support	Meaning of importance in terms of roles played by self and relationships
Matrix 12	Support and modes	Perspectives on support & modes
Matrix 13	Support and repertoires	Perspectives on support & repertoires
Matrix 14	Continuing bonds	Deceased relationships and pets
Matrix 14	Pets	Living pets, roles and importance
Matrix 15	Inner circle	Composition of inner circles and kinds and support
Matrix 16	Partnerships	Partnership status, inclusivity of inner circle, significance of relations
Matrix 17	Support & PC types	Feeling about support types and personal community types
Matrix 18	Negotiating support now	Types of support in relation to visible facial difference
Matrix 19	Geographical connections	Local, distant, virtual contact
Matrix 20	Reactions from other people	Detailed themes from reactions of other people, known & unknown
Matrix 21	Identity voice and PC	Comparing patterns in voices, PC types and feelings of support
Matrix 22	Protection and display	Friends and family

Appendix 28: Research summary (draft)

Relationships, Personal Communities and Visible Facial Difference

People with visible facial difference often experience other people reacting negatively to their appearance. This can affect experiences in work, education, and all everyday situations. Personal communities are people around you who are important to you. This study asked how personal communities contribute to how people adapt to living with visible facial difference.

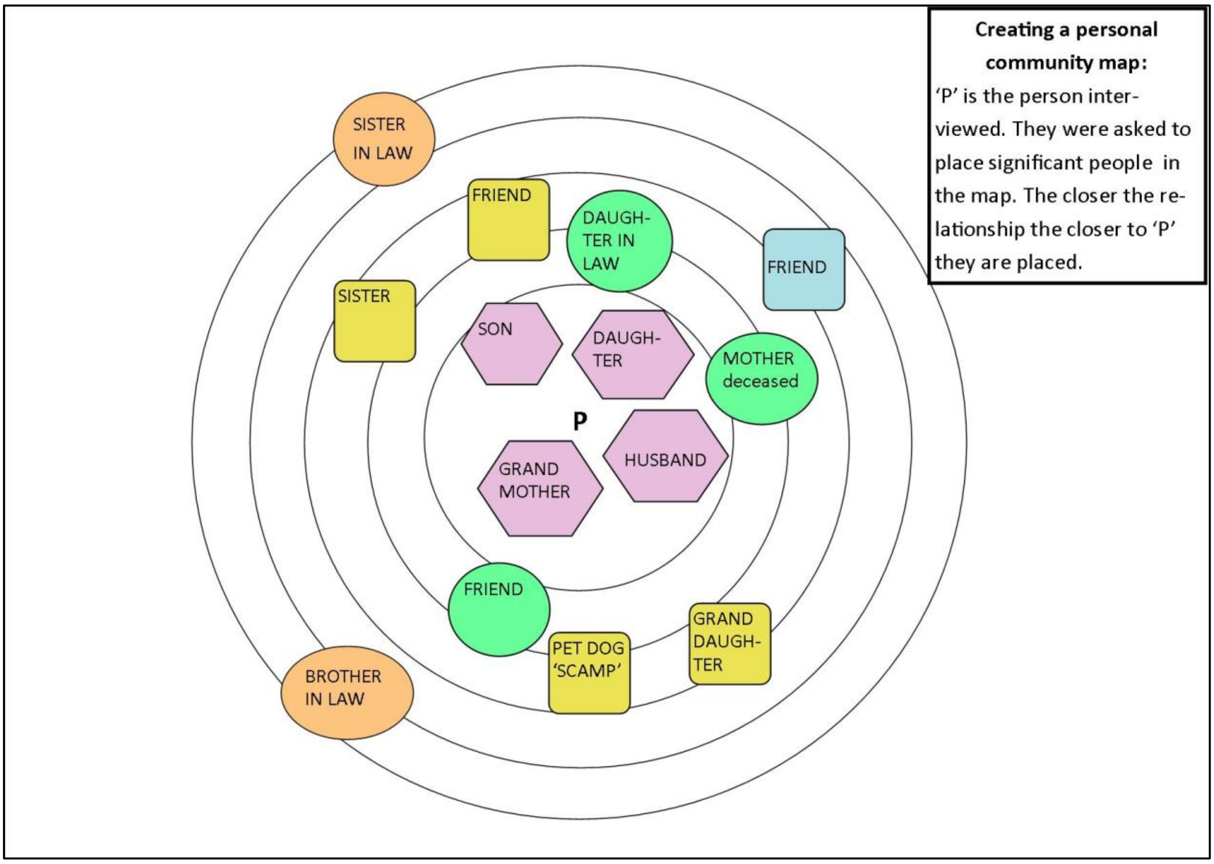
Introduction

Changing Faces and similar other organisations challenge the perception that people with visible facial difference are ‘damaged’ or ‘bad’ or that they have a life of ‘poor prospects’. We know there are these perceptions in society and that people with visible facial difference are sometimes stigmatised. Whilst it is known that social support is crucial for adaptation and adjustment during processes of diagnosis and treatment, less is known about how personal relationships, with both friends and family, are affected by stigmatising attitudes. Personal relationships develop and change over life-times, influenced by many factors. They are also influenced by age, ethnicity, gender, class and life stage needs. This study focused on how people develop personal communities, how they feel supported by them, and how people within them respond to the challenges of living with visible facial difference.

How the research was carried out

Nineteen people took part in the study, seventeen with facial difference and two others identified as significant within the personal community of someone with visible facial difference. They were eight women and eleven men, aged from their 20’s to their 70’s, from England and Scotland. Their facial difference had a range of causes: conditions people were born with, skin conditions, injuries, accidents and surgical treatment for cancer. The people who joined the study were interviewed and helped to create diagrams of their personal communities (Picture 1 for an example) and gave their perspectives about the roles different people had in their lives. The interviews and personal community maps were analysed for themes.

Picture 1: An example of a personal community map



Key findings and implications

Types of personal communities

The study found personal communities provide a sense of belonging and of being valued, as well as many different types of friendship and support. They played a role in helping combat negative and stigmatising attitudes to visible facial difference and they helped enable feelings of comfort and hope for the future.

Personal communities included a wide range of important relationships: family members, friends, neighbours, colleagues, health professionals. Some people included pets or relationships with the deceased.

People with visible facial difference are active contributors to their networks. They might be parents, partners, developing careers or businesses, supporting their families and friends - materially, emotionally or practically. Some people were involved in voluntary work to aid others with facial difference.

A range of resources were accessed through personal communities. The most important relationships were placed in the inner circle and regarded as the most intimate. This status was often reserved for partners or children. Some people included other relationships in this circle, typically a supportive friend, parents, or grandparents. The circles further out represented valuable connections to workplaces, to supportive organisations, as well as to a range of friends. The more opportunities people had in terms of work, education, community or voluntary work, the richer peoples experience was of developing varied personal communities.

Some people were at risk of isolation especially where there were few or no close friends and relationships and where families were more distant.

Challenges and resilience

The sorts of challenges people encountered included ones where assumptions seemed to be made about mental stability or intellectual ability as well as about attractiveness. These social experiences added to feelings of being ‘different’, of feeling unacceptable and unaccepted at times. Supportive relationships played a role in neutralising some of these effects through:

- Displaying sensitivities about how appearance is talked about.
- Establishing personal community cultures that were flexible and accepting, a space where you could feel understood and protected.
- Facilitating access to new relationships and opportunities.
- Providing alternative interpretations of negative situations.
- Recognising specialist contributions made by people with visible facial difference to their personal communities and wider society.

Resilience was an important theme. This was seen as “achieving ordinary things in difficult circumstances” rather than extraordinary achievement.

Three sorts of ‘voices of resilience’ were identified: ‘developing’, ‘sustaining’, and ‘managing in some areas’. Some people felt they had not done as well as they might have done in life. There is a need to understand achievements of those perceived as doing less well than others, they may be faced with a particular stress or be have less supportive environments and relationships.

Some personal communities were supportive, but were quite small, worsening health, loss of valued connections as one ages, or family difficulties in developing trusted relationships outside of the family all might contribute to this. This suggests it would be worth investigating the kinds of supportive and community services beyond the family which people find helpful in maintaining their personal communities through difficult periods and over time.

Being able to find a rewarding job or achieve in education was important to feeling ‘normal’ for many people. Despite successes in these areas, for some people a sense of unease was found when meeting new people, attending an interview or being in public situations. Inclusion in work is an important area for social policy as ‘severe disfigurement’ is a protected characteristic under equalities legislation. Research about work experience which foster inclusion would be a valuable resource for professionals with an interest in diversity for people living with facial difference and their personal communities.

Conclusion

Each personal community is unique. They are a valuable way of learning more about what matters to a person, they can show how these things are affected by ‘difference’ as well as provide insights into sources of support. They can show how a person sees their linkages and connection to social worlds.

The findings indicate there is not an overall ‘problem’ of poorly resourced personal communities for people living with visible facial difference despite the continuing presence of stigma. Many of the respondents in this study had rich, diverse and supportive personal communities. However, some respondents did not, and this was linked to adverse relationships with families, a lack of close friendships and the presence of prolonged periods of unemployment. These differences are sources of inequality for people living with visible facial difference.

It is important to focus on the social and relationship context when seeking to understand how people live with visible facial difference. These findings provide a view of how personal communities and valued relationships are an important part of an individual’s anti-stigmatisation strategies.

Appendix 29: Publications and conference papers

Publications

Facial difference, consumer culture and being ‘normal’. (In press, 2016) Peacock, R.E., Sargeant, A., and Small, N. In Valentine, G., Vieten, U. (eds) *Cartographies of Difference*. Peter Lang Publishing

Conference papers

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