A life lived: experiencing an acquired facial ‘disfigurement’ and identity shift

Thesis submitted in accordance with the requirements of the University of Liverpool for the Degree of Doctor of Philosophy by

Anne-Marie Martindale

8/22/2014
Abstract

With the advent of facial transplantation some academic authors have suggested that faces are significant for humans and that identities are located corporeally within faces and therefore transplantable. However, there has been little evidence to support these claims, particularly from a qualitative, theoretically informed social science background. Responding to this hiatus, in this thesis I set two interconnected research objectives:

- to examine socio-cultural values associated with human faces in predominantly Western societies using secondary sources;

- to explore the relationship between acquired facial ‘disfigurement’ and embodied identity shift using a narrative methodology.

The first objective was addressed in full through an analytical review of largely Western secondary sources. It has become clear that faces, as part of bodies, are imbued with a variety of socio-cultural meanings on multiple levels. Individually people experience the world through their body and their face, making it a significant site for perception and sense making. On a societal level, faces and facial appearance have been associated with social reproduction (Giddens, 1991). For example, inaccurate and harmful historical associations between facial appearance and moral character still pervade British society. And, utilising the concept of faciality (Deleuze and Guattari, 1987, p.168) Twine (2002), Dudley (2002) and Benson (2008) have illustrated that the faces of people in sub-sections of society, generally those with very little power, can be conceptualised negatively and used to serve the interests of powerful elites.

In terms of the second objective, most facial ‘disfigurement’ research has been completed using quantitative methods, resulting in partial knowledge and the disconnection of persons. Through the use of a phenomenological epistemology, embodiment position and a narrative methodology I have put the experiences of the 13 participants at the heart of the research. The analysis chapters focus on the participants’ embodied identities before, during and after an acquired facial ‘disfigurement’. In terms of conclusions, I have found that faces are important however, identities are not located within them but created and reshaped through embodied life experiences. I have also found that the relationship between embodied identity shift and acquired facial ‘disfigurement’ is one of contested negotiation between wider socio-cultural facial values, transitional/liminal identity states during and after the event(s) and the aim of previous identity restoration.
Acknowledgements

Firstly, I would like to send a huge vote of thanks to my three supervisors. Dr Pamela Fisher and Dr Susanne Langer have provided unwavering support, in-depth subject knowledge and critical commentary, which has helped enormously, especially in a new field of study. A huge thank-you also goes to Dr Gabe Mythen for his careful and considered input during the write-up and refinement stage. The thesis has become a much stronger document with the support and input of all. A second raft of thanks goes to my friends for their amazing support throughout. Thirdly, I would like to thank three people who have been specifically involved with the verbal development of ideas; Dr Grant Gibson has been invaluable, as has Dr Martin Whiteford and Dr Anne Rannard. Fourthly, I would like to thank my family for their total support over decades. Especially: Donnah Martindale for endless tea, meals and for enduring all my late night PhD conversations; my parents Sylvia and James Martindale and my sister Gillian Martindale; Auntie Marie; Auntie Doreen; Uncle John and even Uncle Bernard who have always been there for me in everything. Without the periodic herculean labours of my parents and watering and weeding by Margaret Devaney I would have lost my allotment due to weeds and neglect. Finally, I would like to thank all of my participants for coming forward and for sharing their lives and experiences with me. Without them I would have nothing to say.

For their unending support over all my years of study I would like to dedicate this thesis to all of my family, both the living and the ancestors, including the much-loved and much-missed Auntie Marie. Cheers everyone.
# Table of Contents

<table>
<thead>
<tr>
<th>Heading</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title Page</td>
<td>0</td>
</tr>
<tr>
<td>Abstract</td>
<td>1</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>2</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>3</td>
</tr>
<tr>
<td>List of Tables and Figures</td>
<td>10</td>
</tr>
<tr>
<td>List of Acronyms</td>
<td>11</td>
</tr>
<tr>
<td><strong>Chapter One</strong> <em>Faces, transplants, ‘disfigurements’ and theories</em></td>
<td>12</td>
</tr>
<tr>
<td>Chapter Outline</td>
<td>12</td>
</tr>
<tr>
<td>The research context: faces, questions, bodies and theories</td>
<td>13</td>
</tr>
<tr>
<td>Faces, questions and journeys</td>
<td>13</td>
</tr>
<tr>
<td>Faces, identities and theories</td>
<td>14</td>
</tr>
<tr>
<td>Theoretical and conceptual background influences</td>
<td>15</td>
</tr>
<tr>
<td>Biographical disruption</td>
<td>15</td>
</tr>
<tr>
<td>Emotion and embodiment</td>
<td>18</td>
</tr>
<tr>
<td>Gender and performativity</td>
<td>19</td>
</tr>
<tr>
<td>One in eleven: naming and identifying facial ‘disfigurement’ in the UK</td>
<td>21</td>
</tr>
<tr>
<td>Research objectives</td>
<td>23</td>
</tr>
<tr>
<td>Thesis chapters outline: from knowledge gaps and design to working</td>
<td>25</td>
</tr>
<tr>
<td>conclusion</td>
<td></td>
</tr>
<tr>
<td>Chapter Summary</td>
<td>28</td>
</tr>
</tbody>
</table>
Chapter Two Methodology Narratives, photos and a framework for analysis

Chapter introduction and research focus

Applying phenomenological theory

Starting with situated experience

Viewing experience through an embodied lens

Disrupted embodiment: absence and revealment

Methods: stories, identities and artefacts

The need for a phenomenologically embedded method

Narrative approaches and social science

Artefacts of desire: thickening description with material objects, i.e. photographs

Praxis issues: from form filling to face-related fieldwork

Overview

Sampling frame

Sample

Recruitment

Constructing and conducting narrative interviews

Narrative analysis

‘Contexts and conditions’

Stages of analysis

Doing emotional work

Subjective reflexions: My PhD mountain

Chapter Summary
Chapter Three Ethics Beyond face value

Chapter overview

From Nuremberg (1948) to Liverpool (2011): the rise and application of research ethics and audits

Ethical frameworks and the protection of facially ‘disfigured’ people

Chapter Summary

Chapter Four Mapping existing facial research: Socio-cultural contexts, positivist paradigms and biographical complexity

Chapter overview

Part one: what socio-cultural values are associated with embodied faces in predominantly Western societies?

Introduction: situating faces

Symbolic faces: structures, semiotics and subversion

Don’t judge a book by its cover: two thousand years of reading faces

Embodied facial senses and socio-cultural associations

Part one summary: the powerful phenomena of embodied faces

Part two: what the literature says life is like for people with a facial ‘disfigurement’

Overview: findings; issues and biographies

Facial ‘disfigurement’ findings: individuals and relationships

Facial ‘disfigurement’ findings: public reactions and attitudes

Summary of key ‘disfigurement’ findings

Part three: biographical accounts; persons and place
Introduction
A life in context
Experiencing facial ‘disfigurement’: emotions, motivations and actions
Chapter Summary

Chapter Five Analysis Before facial ‘disfigurement’: bodies and previous identities

Introduction to the analysis chapters
A baseline for bodies: diverse becomings and the myth of boundedness
Previous body-faces, imagined futures: the gendered telling of identities pre-disruption
Narrative context
Gendered narratives in the pre-‘disfigurement’ life
Men
Women
Chapter Summary

Chapter Six Analysis Facial appearance: disruption; transition and liminality

Chapter Introduction
Foregrounding faces: embodied disruptions and unhabitual body-facial appearance
‘Disfigurement’ as unhabitual facial appearance through cancer
‘Disfigurement’ as unhabitual facial appearance through accidents
‘disfigurement’

Renegotiating embodied identities in the aftermath of an acquired facial ‘disfigurement’

Theoretical overview

Bodies, loss of control and ‘narrative wreckage’

Ripples

Waves

Tsunamis

Chapter Summary

Chapter Nine Conclusion *Findings, implications, reflexions and next steps* 177

Chapter outline 177

Findings and implications 177

Beyond Descartes and ‘Disfigurement’: a call for complex, contextual research 177

Socio-culturally embedded body-faces 180

Disrupted and dynamic identities 181

Reflexive reflections: macro and micro considerations 184

Overview 184

The knowledge economy 184

Evaluating narrative interview methods 185

Enhancing the ethnographic snapshot 188

Representing and matching 188

Next steps 190
# List of Tables and Figures

<table>
<thead>
<tr>
<th>Table number</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Fourth stage of analysis: the narrative analysis framework</td>
<td>44</td>
</tr>
<tr>
<td>2</td>
<td>Examples of James Bond foes with body-facial differences or ‘disfigurements’</td>
<td>69</td>
</tr>
<tr>
<td>3</td>
<td>Embodied functions located within the facial region</td>
<td>71</td>
</tr>
<tr>
<td>4</td>
<td>A summary of biographical details</td>
<td>85</td>
</tr>
<tr>
<td>5</td>
<td>Timeframes: period of facial ‘disfigurement’ and the research interview</td>
<td>95</td>
</tr>
<tr>
<td>6</td>
<td>Participants’ unhabitual body-facial appearance and ‘disfigurement’</td>
<td>109</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Figure number</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Summary of factors influencing adjustment to a facial ‘disfigurement’ (drawn from the literature)</td>
<td>82</td>
</tr>
<tr>
<td>2</td>
<td>Factors influencing visual transition/liminality in the aftermath of acquired facial ‘disfigurement’</td>
<td>141</td>
</tr>
<tr>
<td>3</td>
<td>Acquired facial ‘disfigurement’ and embodied identity shift: a summary of influences</td>
<td>183</td>
</tr>
</tbody>
</table>
## List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASA</td>
<td>Association of Social Anthropologists (UK-based)</td>
</tr>
<tr>
<td>BBC</td>
<td>British Broadcasting Corporation</td>
</tr>
<tr>
<td>CF</td>
<td>Changing Faces</td>
</tr>
<tr>
<td>ESRC</td>
<td>Economic and Social Research Council</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner (medical doctor)</td>
</tr>
<tr>
<td>IAT</td>
<td>Implicit Attitudes Test</td>
</tr>
<tr>
<td>ITU</td>
<td>Intensive Therapy Unit</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>ONS</td>
<td>Office for National Statistics (part of the UK Government)</td>
</tr>
<tr>
<td>PhD</td>
<td>Doctorate of philosophy</td>
</tr>
<tr>
<td>RAF</td>
<td>Royal Air Force (part of the British military establishment)</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>US</td>
<td>United States (of America)</td>
</tr>
<tr>
<td>WW2</td>
<td>World War Two</td>
</tr>
</tbody>
</table>
Chapter One

Faces, transplants, ‘disfigurements’ and theories

Chapter Outline

This short introductory chapter will provide a framework for the thesis. I will begin by describing the context and formation of the research questions; consider relevant background theoretical influences; discuss research involving the numbers of people with a facial ‘disfigurement’ in the UK, and finish with an outline of the thesis. These are the mechanics of the chapter, in terms of the semantics of the thesis, I want to illuminate the experiences of a group, whose experiences have been somewhat academically and medically hidden, and to explore the relationship between faces and identity. In the recent past, living with a facial ‘disfigurement’ has come to wider public attention in the west since facial transplantation began to be discussed just over a decade ago (Hettiaratchy and Butler, 2002). However, contextualised and embodied academic research exploring the relationship between people, faces and identities within western societies remains limited. Through the production of the thesis, I am aiming to reduce the lack of knowledge in this area and to suggest new areas of future research. However, before this occurs I want to locate the work, starting with my use of the word society.

The concept of society has been widely contested and critiqued over recent decades. Strathern (1996) in particular has argued that the concept is ‘theoretically obsolete’, because societies have been conceptualised as bounded units and reified as ‘real things’ beyond the reach of individuals and their relations with others and environments (1996, p.61-66). I take Strathern’s comments on board, however, my understanding of society is not one which incorporates bounded, reified units where relationships are placed secondary to individuals. As Spencer (1996, p.81) argues, the term has plural meanings and contexts and can be used to refer to the ‘collectivity of human relations’, without diminishing the complexity. Whilst acknowledging the contestations associated with the term, I will be using Spencer’s description and placing relationships at the centre. Having said this I do not want to place too much emphasis on the concept of society during the
thesis, my main concern is how the participants construct their narrated identities and lifeworlds

The research context: faces, questions, bodies and theories

Faces, questions and journeys
I first became fascinated with faces after watching a television program in 2005 on the world’s first partial face transplant recipient, the Frenchwoman Isabelle Dinoire. The process of transplanting a face from one human to another raised so many questions. What roles did the face play in human sociality? What was the relationship between faces and identities? What impact would a facial transplantation have on individual identities? At the same time I was looking for a suitable PhD topic in a qualitative health social science area, something which was grounded in anthropological and sociological conceptualisations of the human condition. The thesis is the story of that six-year research journey.

My initial aim was to explore embodied identity formation and its prospective shift in people who were on the British facial transplant waiting list. To learn more about the topic I had exploratory talks with three transplant surgeons located in different teams (US and UK). After further inquiries, I was informed that it would not be possible to gain access to prospective patients in Britain, so I amended the research design (which is explained in Chapter Two). I decided to focus on identity shift in people with an acquired facial ‘disfigurement’ using a qualitative methodology, as very little work had previously been done in this area. During the course of secondary research, I discovered the field of facial ‘disfigurement’ studies. Overall, the field has provided many informative findings. For example, research has illustrated that people can find facial appearance change difficult to adjust to, and that they can be treated less favourably by others purely due to their appearance (Dropkin, 1989; Rumsey et al., 2004; Rumsey and Harcourt, 2004; Changing Faces 1). However, I found that a great deal of this research appeared to be methodologically positivist in nature and applied a biomedical model of disability to the framing of the research questions. To illustrate, studies were mostly constructed using quantitative methods of data collection and analysis, focusing on the diminished psychological health of disembodied persons in their role as patients, in largely but not exclusively clinical settings. Though, some studies did consider how living with a facial

---

1 Changing Faces is a British national facial support and equality campaigning charitable organisation.
‘disfigurement’ impacted on everyday experiences in the community, e.g. walking in the street or at job interviews (Rumsey, Bull and Gahagan, 1982; Stevenage and McKay, 1999).

I did not wish to challenge these findings, but I did want to know more about the people involved and their experiences. In particular I wanted to know what the application of sociological and anthropological theories, concepts, research methods and analysis could bring to bear on our understanding of unhabitual or unexpected (Leder, 1990) facial change and embodied identity shift. I wanted to put the participants at the heart of the research and to consider how they made sense of the potential disruption (Bury, 1982; Frank, 1995) to their body-face. Body-face is a term I have developed to stress the embodied nature of faces, as parts of bodies and therefore of persons, who are historically and culturally located (Mauss, 1938, pp.26-45). Too often during the ‘disfigurement’ part of the literature review process I found that faces were considered apart from their bodies and in isolation from their embeddedness within cultures, temporalities and epochs. Applying the term body-face reminded me of those existential conditions. Consequently, I chose a phenomenological epistemology to understand how individuals within the west constructed and renegotiated their lifeworlds and identities (Chapter Two examines this in depth), rather than a positivist approach, which can dissociate the person from their experiences and tends to focus on the researcher’s rather than the participants’ interests.

**Faces, identities and theories**

I started by exploring how the authors of facial transplantation papers had conceptualised the relationship between faces and identities. They generally concurred that the face was indeed a highly significant site of the body for humans, involved in various key aspects of life, such as self and other identification; taking on board sustenance; and communication between humans and humans, and humans and animals (Perpich, 2010). The authors of some papers have made bolder claims. Carolessa and Pradeu (2006) asserted that ‘The transplantation of visible organs [such as a face] provokes more serious questions for the recipient. Visible organs are components of an individual’s identity...’ (p.183). Whilst Swindell (2007) suggested that facial transplant recipients had ‘the potential to feel that their identity is a mix between their own and the donor’s (p.449) adding later that with ‘facial allograft transplantation, the person is gaining an identity, whereas in the case of severe facial disfigurement, the person is losing an identity’ (p.451). Building on these conceptions Modgil (2011) has proposed a model to assess the likely extent of identity
change occurring in facial transplant recipients based on their ‘*underlying craniofacial morphology*’ (p.171). These sentiments are also echoed by non-academic writers. For example Reid (Mail Online, 2010) argued that faces were ‘*sacrosanct*’ and posed the question ‘*Can the world’s first full face transplant patient live with his new identity?*’ The ensuing article examined the circumstances of the recipient’s facial injuries, an accidental gunshot blast to the face, and the details of his facial transplantation, which had taken place in Barcelona, Spain. This had involved the transfer of facial and muscle tissues, bone, nose, lips, eyebrows and eyelids from donor to recipient. Continuing in this vein, Carty et al. (2012) have suggested that blind recipients of a facial transplantation may not have so many difficulties adjusting to a new face, since they cannot see the results and the identity transfer, which is assumed to have taken place.

What these accounts have in common is a conceptualisation of identity as something which is simultaneously visual and corporeal, located within and on the external boundaries of the face, for example, in the configuration of features such as eyes or nose, and their recognition by self and other. When this corporeal capacity is disrupted or diminished, identity is reduced, when the face is replaced through transplantation, identity is ‘restored’.

In a rejection of these conceptualisations, social science theory and research has illustrated that identities are not located within visually evident body parts or their surfaces, but in the dynamic, embodied experiences and storied narrations over the life course (Merleau-Ponty, 1962; Leder, 1990; Csordas, 1994; Frank, 1995). In keeping with this disciplinary approach, I take an embodied position throughout the thesis and reject the idea of identity as a purely corporeal, visual and externally located phenomena within the facial region. Even so, I acknowledge that issues pertaining to identity are complex and that it cannot be understood from a single disciplinary or epistemological position.

**Theoretical and conceptual background influences**

**Biographical Disruption**

The focus of the thesis is on identity shift in the aftermath of an acquired facial ‘*disfigurement*’. Consequently, theories and concepts relating to embodiment, bodily appearance (Leder, 1990), biographical disruption (Bury, 1982; Frank, 1995) and narrative identity repair (Frank, 1995) will be explored throughout the chapters. During this sub-section I will explore the origins of biographical disruption and evaluate its merits and utility within the context of this research project. Bury (1982) argued that
‘Illness, and especially chronic illness is precisely that kind of experience where the structure of everyday life and the forms of knowledge which underpin them are disrupted’ (p.169).

This argument is also relevant to the process of acquiring a facial ‘disfigurement’. As I explore in chapter five, the participants become ‘disfigured’ through an illness such as cancer, through being involved in accidents and through one case of acne rosacea. These experiences have presented ongoing impairments to health and therefore to the structures of everyday living and identification. Let me explain. Bury (1982) suggests that illness involves a recognition of suffering and pain, which are usually only seen as remote possibilities to one’s self, though they may be present in others. When illness, or I would argue ‘disfigurement’ occurs it not only disrupts the body, but also the relationships and networks of the person involved. Bury (1982, p.169) argues that these combined disruptions lead to uncertainty as the impact and course of the unexpected health event together with its influence on relationships cannot be known. ‘Medical knowledge and practice is becoming a central feature of modern society’ (1982, p.178). However, people find medical explanations and treatments simultaneously relieving and limited. There is an explanation of symptoms and a justification for concerns. However, a diagnosis or treatment does not necessarily reduce the extent of biographical or relationship disruption. In an effort to maintain normality in the early stages after the event usual activities or appearances become deliberately conscious acts (Bury, 1982, p.173). This may become frustrating and/or tiring and individuals may begin to restrict their environment in order to avoid the gaze or verbal inquiries of acquaintances or strangers.

Bury’s (1982) paper was seminal, however, ideas underpinning the premise have not gone unchallenged. This paragraph lends some contents from a critical review paper published by Williams (2000). Though concluding that biographical disruption was still relevant, Williams argued that it needed revising due to its limitations. I want to consider a few of those limitations here. Firstly, postmodernists have challenged the concept because of its modernist premise of bodies as selves. Williams (2000) draws on Fox (1993) who argues selves are created through discourse, not necessarily through bodily location, and therefore internalised pain and suffering has no implicit meaning. Williams finds this critique less convincing, he argues that life, illness, disability and death exposes the ‘matter’ of bodies and the limits of discursive identities (2001, p.47), adding that the ‘playful deconstructions’ of post-modernists are only applicable to healthy people with choices, who are not constrained by their bodies. I agree with Williams (2000), biographical disruption is related to bodies. Persons are embodied, cognisant, cognitive and corporeal agents (Grosz, 1994).
not merely created discourses (Fox, 1993 cited in Williams, 2000). Denying a cancer diagnosis discourse does not diminish its potential to threaten health, facial appearance and life. Unfortunately if ‘I’ am my body, and my face, then I am also my cancer. Secondly, Williams raises the concerns of some disability theorists. Followers of the social model of disability have argued that biographical disruption and limitations are the result of ‘social oppression’ (2000, p.47) and inequality within society rather than bodily impairment. I do not doubt the oppressive nature of comments directed at facially ‘disfigured’ people however, I disagree that biographical disruption can be viewed as a wholly societal phenomena. Some activists and researchers have re-problematized bodily impairment as an issue relating to disability and social inequality (Coleman-Fountain and McLaughlin, 2013). Looking in the mirror and not recognising oneself, or being unable to chew or swallow certain foods could be as disruptive, or limiting as being stared at by others.

Thirdly, it is argued that researchers utilising the concept of biographical disruption do so to explain the impact of illnesses which occur in middle to later age, making it adult-centric. It might be more appropriate to apply the concept to adults, but this does not necessarily weaken the idea, it just makes it less relevant to some studies. Adults more experiences to assess, they can be more verbally articulate when describing disruptive moments. Though, equally, depending on the illness, they might not have the cognitive or verbal capacity to explore disruption, nor might they want to wax lyrical. It is also possible to explore biographical disruption which occurred in childhood, or young adulthood, and equally something which occurred in later life through asking adults. The age of the person is not important, what matters is their ability to talk and reflect. Using participants who have experienced facial ‘disfigurement’ across the life course has enabled me to develop a richer, deeper understanding of a complex issue.

Finally, Williams (2000) critiques the idea of ill health as a temporary aberration which leads to disruption, as it does not address congenital or childhood conditions, nor does it account for variations in health status. This does concern me. The idea that people may experience largely good health through life may only apply in western countries with high standards of living, education, health and social care. I conducted the research in England which fits within this western model. However, I did not have any assumptions concerning ongoing health when I designed the research. Through the use of an open biographical interview method I allowed the participants to describe and make sense of their own health status, which revealed that people thought differently about different conditions, including facial ‘disfigurement’. Williams (2000) concludes that in spite of these concerns the concept of
biographical disruption remains useful. However, its use has to be contextualised and its meaning understood, as individuals respond to events differently

‘...timing and context, norms and expectations, alongside our commitment to events, anticipated or otherwise, are crucial to the experience of our lives, healthy or sick, and the meanings with which we endow it’ (Williams, 2000, pp.51-52).

Taking these points into consideration I still find the concept of biographical disruption credible and useful. When used in conjunction with an open biographical method it can lead to the production of rich data. My research findings have allowed me to critique the idea that biographical disruption only results from illness, and that if it occurs, it does so in the same way for everyone. For example, a person with a facial cancer could experience disruption at the point of symptom recognition, diagnosis, during the treatment, and when living in remission afterwards. Where-as someone in a serious car crash might experience a more sudden sense of disruption in comparison to someone living with an episodic skin condition, which may disrupt their biography both in the shorter and longer term. These variations add to the richness of the concept and suggest new avenues of research rather than weakening it.

**Emotion and embodiment**

There are two themes that I wish to introduce here using the work of Hochschild (2003, 2007) as they will be developed later in the thesis. Firstly, I will introduce the idea of academic research as a type of emotional work. The concept of emotional work was developed by Hochschild (2003) who argued that all work involved not just physical or intellectual labour, but also emotional labour. Emotional labour ‘*requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others. This kind of labor calls for a coordination of mind and feeling...*’ (Hochschild, 2007; p.194). There are benefits and costs associated with emotional labour. The author uses the example of an air stewardess to illustrate. The stewardesses must maintain an outward appearance of happiness, involving smiling and remaining attentive to air passengers at all times during her working day. Even if they are rude to her and she feels upset or angry towards them she must not allow it to show through, thus maintaining a public façade, however ‘*fragile*’. This maintenance requires effort from the worker, in addition to their job. Although, as Hochschild (2007) notes; no-one wants to encounter a ‘*stroppy*’ member of staff who deals with the public. In research terms, the researcher aims
to develop a good working relationship with their participants to facilitate the production of accurate, detailed and complex data. This may not initially involve emotional work beyond the pleasantries and observances of polite stranger interaction. However, once they have agreed to take part and the interview starts; a great deal of emotional work may occur on both sides. For example, the participant may have to recount a painful period of their lives which may also upset the researcher who has to hear and analyse it repeatedly afterwards. I give an account of the emotional work I undertook during the PhD project in Chapter Two (Doing emotional work).

Secondly, I want to draw on strands of Hochschild’s (2003) work to introduce the idea of emotion as an aspect of embodiment. Hochschild (2003, p.214) observes that two broadly different models have been used to understand emotion, the organismic and the interactional. The organismic model has been proposed by scientists and psychological theorists, and is based on the premise that emotion is mainly a biological process, shared amongst all peoples. The management, labelling or expression of emotion is seen as independent to the emotion itself and is of secondary importance to the instinct which is thought to underpin it (p.216). Finally, emotion is assumed to have a ‘prior existence’ and is seen as separate process to introspection. Hochschild argues against this model in favour of the second, interactional model of emotional understanding. For interactionists who include social psychologists and sociologists, whilst there is some biological basis for emotion, what is significant is the meaning behind its creation. For interactionists, the experience or act which produced the emotion is not separable from the emotion itself. Therefore, emotion cannot be a fixed entity, since it can only be is understood within the cultural and temporal context in which it was located. If we apply this model to aid our understanding of the relationship between facial ‘disfigurement’ and identity shift it becomes clear that the participants emotional experiences before, during and after the ‘disfigurement’ cannot be separated from their bodies, nor from the context of the event(s). Consequently, during the primary analysis chapters I have selected quotations which include how the participants felt at particular times, as this helped me to understand their embodied identities and how these may have shifted over time.

**Gender and performativity**

This short introductory section has been informed using the works of Goffman (1959, 1968) and Butler (2004). Writing in the late 1950s Goffman argued that like a play being performed on a theatrical stage, much of human social life could be viewed and interpreted
as a considered performance, with social actors, roles, plots and props. ‘Life is performed with a stage, language, gesture, thought to what is being said...’ (Goffman, 1959, p.17). The performance is ‘moulded and modified’ to fit into the expectations and understanding of society and to create and maintain a favourable impression of ourselves to others. Of significance for this project, Goffman (1959, pp.42-43) argues that people may leave out aspects of their performance that do not give the impression they are trying to convey or manage. There may be gaps or inconsistencies in their story if it contains socially unacceptable aspects, such as semi-legal or physically unclean acts, or where the person was not as proficient at something as they currently are. In such cases, the end product may be emphasized instead of the journey. The idea of identity management based on the avoidance of recounting certain life performances is particularly relevant for people with an acquired facial ‘disfigurement’, as they will have had to manage periods of illness, injury and/or of looking different. I consider how people construct and narrate their identities in more depth during the Narrative analysis section in the next chapter (Methodology).

Butler (2004) develops Goffman’s idea that human social life is performed in conjunctions with others in her book Undoing Gender. She argues that identities are created and recreated through the performances of embodied persons. Performance involves both speech and bodily activity. From birth bodies become categorized and marked by gender, race, sexuality, and class according to the norms and expectations of a particular culture, for example the practice of hair dying amongst western women to maintain a youthful appearance. However, she argues that the performance of these cultural categories illustrates how unstable they are, for example the existence of homosexuality which exists alongside the expectation of heterosexuality. Butler’s example may be more suited to other societies. With the advent of legal civil partnerships (2006) in England and more recently the (equal) Marriage Act (2014), expectations of female heterosexuality are not what they would have been in England in the 1950s, 1980s or even the 1990s.

Focusing on the category of gender, Butler (2004, p.42) describes it as ‘the apparatus by which the production and normalisation of masculine and feminine takes place’ which involves hormones, chromosomes and the act of performance. Butler argues that gender has previously been understood in narrow, binary terms, for example, the seemingly opposite categories of masculine and feminine. In a rejection of this stance, she states that if close attention is paid to the complicated relationship between the performance of words
and actions, then categories like gender become disrupted and open to challenge. ‘...the very social life of gender turns out to be malleable and transformative’ (p.216). Butler suggests we pay more attention to how gender is actually performed during episodes where one loses some life control such as when grieving, as these make it easier to identify the instability of the category (pp.21-22). I want to return to this idea in Chapters Five and Six, to explore aspects of gendered identities in the remembered pre and post ‘disfigurement’ life.

One in eleven: naming and identifying facial ‘disfigurement’ in the UK

This section of the chapter will outline the prevalence of facial ‘disfigurement’ in the UK. Before I present some figures, I would like to say a little about my use of the term facial ‘disfigurement’. The complexities of life and its associated experiences are not always accurately represented through the medium of language. When I first started researching this topic I came across the terms facial difference and unique/altered facial appearance. I was inclined to use either or both of them instead of the negative sounding facial ‘disfigurement’. After all, ‘disfigurement’ is in the ‘eye of the beholder’ (Changing Faces, 2007). Changing Faces is a UK-based supportive and campaigning charity for people with facial ‘disfigurements’ and differences of every variety.

Indeed, as one facial equality campaigner said ‘everyone has a unique face’ (anonymous, personal communication). I tried using the term facial difference, but it was not something that was used by the two national facial support organisations in Britain (Let’s Face It, Changing Faces), nor was it used by the participants. However, after much deliberation I decided to re-use the term facial ‘disfigurement’, as it was widely used by both facial campaign groups and academics. And, in the way of language re-appropriations by vulnerable/stigmatised groups (Galinsky et al., 2013), I hoped that future searches using known key terms would list my work and that it would help to dispel myths and raise awareness about the hitherto ‘hidden’ lives of facially ‘disfigured’ people. To acknowledge the negative value judgements, which can be associated with the term, as well as my struggle to find one comprehensively useful descriptor, I have placed the term facial ‘disfigurement’ in inverted commas.

Not only are embodied, biographical accounts of people experiencing facial ‘disfigurement’ in the UK sparse, data on the number of people concerned is limited and outdated.
*Changing Faces* (2007) refers to the 1988 UK Disability Survey to present some early figures on the prevalence of people with a congenital or acquired ‘disfigurement’. Conducted by the Office for Population Censuses and Surveys (UK Government), it estimated there were at least 400,000 people with a ‘disfigurement’ to their face and/or body. A disfigurement was defined as ‘a scar, blemish or deformity which severely affected their ability to lead a normal life’ (*Changing Faces*, 2007, p.1). The definition is a starting place, which recognises the socio-cultural embeddedness of life; however, it is too simplistic and vague. Changing Faces commissioned their own research (2008) to provide more accurate estimates on the incidence and prevalence of facial ‘disfigurement’ in the UK. They proposed a working definition of ‘disfigurement’ as:

‘the aesthetic effects of a mark, rash, scar or skin graft on a person’s skin or an asymmetry or paralysis to their face or body’ (2008, p.1).

In the report *Changing Faces* (2008) recognise the need to incorporate a social element in a definition of ‘disfigurement’. The organisation also formally rejects the association between facial ‘disfigurement’ and the suggested inability to ‘lead a normal life’ (*Changing Faces* website). As I shall demonstrate in Chapters Seven and Eight, even the biographical accounts illustrate that diverse responses to life with a facial ‘disfigurement’ are possible. After experiences of shock, loss, grief and adjustment people can return to a revised ‘normality’ which can include experiences such as: maintaining an adult sexual relationship; having children; moving house and changing jobs. For example, Piff (1985) who was already married with three children, changed careers and set up *Let’s Face It*, a national support group and charity for facially different people. Whilst Partridge (1990) married and had three children in the years after he had received facial and bodily burns. In 1990 he set up the national facial equality and support charity *Changing Faces*. Whilst acknowledging that ‘disfigurement’ does not have to be a barrier to quality of life, I do not wish to downplay the widely reported physical and psychological suffering that people can experience in the immediate and longer-term aftermath of unhabitual facial disruption. However I want to contextualise, not pathologise.

Based on a thorough search of existing studies, data sources and websites *Changing Faces* (2008) reported that in the UK

- 542,000 people (or 1 in 11) have a significant\(^2\) disfigurement to the face

\(^2\) The term significant was not defined or explained in the report.
• 220,000 have disfigurements related to skin conditions like acne, vitiligo and psoriasis
• 100,000 have facial paralysis from stroke
• 92,000 have congenital or birth mark conditions, i.e. birth marks or cleft pallets
• 66,000 have disfigurements which arise from accidents such as burns and facial scars
• 40,000 have cancer-related ailments, from skin cancer surgery
• 1,345,000 people have a significant disfigurement to their face and body and
• 415,500 people are expected to acquire a significant facial disfigurement during a year, some transient, others life-threatening.

There is no definitive figure on the number of people who develop a facial ‘disfigurement’ during the life course. Though, it is evident that these tend to arise through accidents and cancer, something which is reflected in the experiences of my participants. Six had had a form of head and neck cancer, six had been in accidents (two of whom had been injured during wars as serving military personnel), and one was living with acne rosacea. It is also evident that a great deal of diversity exists, between the causes, consequences and the length of time a person may experience a facial ‘disfigurement’ (which is reflected through Chapters Five to Eight).

**Research objectives**

Given the research context, the thesis aims to explore aspects of the relationship between human faces and identities from a qualitative social science perspective. And given the problematic conception of identity as described in facial transplantation papers, social science evidence of embodiment, and the lack of embodiment research into faces and identities I decided to pursue two lines of inquiry. Firstly, as faces were considered to be deeply significant sites of human bodies, I wanted to know about the range of socio-cultural meanings and values that were attached to them. Secondly, I wanted to explore the relationship between experiencing an acquired facial ‘disfigurement’ and possible embodied identity shift. Consequently, I developed two research objectives, which have been addressed throughout the thesis:

---

1 I am not claiming that I have a ‘representative’ sample, merely that the experiences of my participants are reflected in the broader experiences of people in the UK with a facial ‘disfigurement’.
• to examine socio-cultural values associated with human faces in predominantly Western societies using secondary sources;

• to explore the relationship between acquired facial ‘disfigurement’ and embodied identity shift using a narrative methodology.

The first objective is addressed in its entirety during Chapter Four. I draw mostly on academic sources and some biographical materials. The second objective explores the relationship between facial ‘disfigurement’ and embodied identity shift over time using primary data. 13 narrative ethnographic interviews were conducted, which mostly took place in people’s homes or places of work. The interviews explored individuals’ experiences of life before, during and after the episode(s) of unhabitual facial change. (Chapter Two examines the methodology used in more depth.)

Overall, the role of theory in this thesis has been to provide a relevant framework for guiding the primary research and to aid explanations of the findings. The work of some phenomenologically influenced embodiment writers and researchers has been very influential (Merleau-Ponty, 1962; Csordas, 1994; Grosz, 1994; Shildrick, 2002, 2008 and 2010). In particular the work of Leder (1990), Gubrium and Holstein (2009) and Frank (1995) have underpinned the research design, methods of analysis and the framing of the findings and conclusion chapters respectively. Leder (1990) and Frank (1995) take a critical view of the Cartesian legacy (self as separated mind and body), which continues to influence biomedical framings of personhood, health, illness and disability (Wendell, 1996; Shildrick, 2002). Leder’s premise in The Absent Body (1990) is that the body is normally absent from view, whether alien, forgotten, uncontrollable or obscured. It comes into habitual (usual or expected) appearance in relation to the ebb and flow of daily life, for example the desire to eat, drink, to remove waste products or to reproduce. When these sensations are addressed the body goes back to its disappeared, background state. However, the onset of unhabitual bodily appearance for example, through illness, injury or in this case facial change, foregrounds aspects of the body/face and raises threats to previously known embodiment. Whilst in The Wounded Storyteller Frank (1995) has explored how individuals can respond to threats to their narrated embodied identities. He has argued that the advent of illness, injury or disability disrupts individual perceptions of
embodied capabilities and their associated past, present and anticipated future identities. This work has been invaluable in helping me to frame and explain the findings.

Within the context of exploring disrupted embodied identities, I drew on Gubrium and Holstein’s (2009) book, *Analyzing Narrative Reality*. The authors deconstruct assumptions surrounding the practice and analysis of narrative methods, advancing knowledge in this field. Though narrative interviews can provide a wealth of contextual and ethnographic data situating the participant at the heart of the account, the uniqueness of ‘their story’ can be over-exaggerated. I selected Gubrium and Holstein’s (2009) work as they aim to situate individuals within their networks of significance and consider the myriad of influences on what they chose, or chose not to disclose, who features in the story and how they identify in the account. This has been invaluable when considering how the participants chose to present and identify themselves.

**Thesis chapters outline: from knowledge gaps and design to working conclusion**

During this section I will provide short overviews of each of the chapters and outline how they help to answer the two research questions at the core of this thesis. During this first introductory chapter I have explained my reasons for conducting the research, alluded to academic knowledge gaps, contextualised the formation of the two research objectives and outlined the theoretical context of the work. Chapter Two explains how the research methodology enabled me to address the second research objective and therefore to reduce knowledge gaps about the identities of people living with an acquired facial ‘disfigurement’. Starting with situated experience, I take an embodied position within a phenomenological framework. The chapter introduces the idea of disrupted embodiment and the need for a phenomenologically embedded method, capable of eliciting lifeworld stories and experiences. Chapter Three is brief and considers the key ethical issues associated with the project. I considered adding an ethics section to the methodology chapter, however, I found this approach problematic. I did not want pertinent moral concerns to be seen as a methodological add-on. And though the chapter is brief, it covers the salient issues which are the growth of a professional research ethics audit culture and its influence on the project, together with a discussion on frameworks for the protection of ‘vulnerable’ groups, such as people with a facial ‘disfigurement’. Less complex moral concerns are dealt with as they arise to keep matters in context as far as possible.
Chapter Four is the first of five analysis chapters and is the only one to draw on secondary sources. The chapter is split into three parts, the first utilises a variety of social science and humanities resources to address the first research objective. The chapter starts by considering what a face is, how it can be defined and explores the socio-cultural roles and values attached to faces, largely within Western societies (Synnott, 1993). The second part of the chapter provides the results of a review documenting facial ‘disfigurement’ research and findings. It examines the impacts of having a facial ‘disfigurement’ on individuals and their relationships, and public reactions and attitudes to facial ‘disfigurements’. I found that there was a dearth of theoretically informed qualitative material exploring faces, and identitied embodiment. So, I supplemented the ‘disfigurement’ findings with four biographical accounts. The results are explained during the final third of the chapter. Three biographies are by people with a high media visibility and an acquired facial ‘disfigurement’: Christine Piff (1985) Chair of Let’s Face It; James Partridge (1990) Chair of Changing Faces and Lucy Grealy (1995) author, now deceased. The fourth was written retrospectively about the life of Joseph Merrick (Howell and Ford, 2009) known as the ‘elephant man’ who had a congenital facial condition, but who is arguably Britain’s most famous person with a facial ‘disfigurement’. I have included his biography here because I used the results to help finalise the two research objectives. In addition, his symptoms did not start to emerge until he was five years old. Overall, the biographies helped me to get a much-needed initial sense of the everyday lives, issues, concerns and complexities of living with a facial ‘disfigurement’ over time.

Chapter Five is the first of four primary data findings chapters which explore the relationship between acquired facial ‘disfigurements’ and embodied identity shift. Each utilises a wealth of sociological and anthropological resources to aid case study and wider theoretical/conceptual analysis. The aim is to locate ‘individual’ identity narratives within wider contexts. Chapter Five locates the participants within their pre-facial change lifeworlds or the combination of experiences, everyday life and the background through which all things are experienced and become meaningful (Schutz and Luckmann, 1974) and their identities, together with known pasts and anticipated futures. This chapter introduces the reader for the first time to the work of health phenomenologist Arthur Frank, in particular his book The Wounded Storyteller (1995), which I used to explain the findings in all four-analysis chapters. I consider his work in conjunction with other embodiment writers such as Grosz (1994), Wendell (1996) and Shildrick (2008, 2010). These authors alert us to the fact that bodies and faces are not abstract, autonomous and uniform entities, instead
that their natural state is one of diversity of size, shape and ability (Wendell, 1996), intercorporeality (Grosz, 1994; Csordas, 1997) and hybridity (Haraway, 1991).

The diversity of body-faces becomes clear in Chapter Six, when previously known lifeworlds and embodied identities become disrupted and threatened. The chapter explores experiences of unhabitual bodily appearance (Leder, 1990), embodied disruption, lifeworld and identity liminality and transition (Douglas, 1969; Frank, 1995) caused by cancer, accidents and in one case acne rosacea. I argue that all participants experience embodied change and therefore some identity change (Csordas, 1994). In addition, that all go through transitional, liminal periods as they negotiate lifeworld and identity shift. The chapter concludes that there can be no abstract, universal, homogenous experience of facial appearance change, as people are varied, connected, dynamic beings who are situated within temporal socio-cultural, political and economic networks. Though, there can be similarities of experience and response.

Chapter Seven continues the theme of disrupted identities and focuses exclusively on the idea of visual liminality. I argue that this has been overlooked as an area of study for qualitative facial ‘disfigurement’ research. The chapter explores the extent to which the participants’ sense of themselves shifted in the aftermath of visual change and the factors influencing this shift. Chapter Seven took the longest time to conceptualise. It contains new theory. I had not anticipated the extent to which the participants’ identities had remained in transition after the event(s), nor how complex and multifaceted they were. Participants took months, years and decades trying to reach states of health, visual and embodied identity restitution, which did not necessarily coincide with each other. The length of time this took related to the context of change and participants’ abilities to negotiate being, knowing and acting the same sort of persons in light of threats to embodied ‘control, body-relatedness, other relatedness and desire’ (Frank, 1995, p.29). Most narratives retained elements of liminality up to the period of the interview (2011-12). After much consideration and analysis, the chapter focuses on three related areas: health-related identity transition; the identity implications of facial appearance change and participant responses to shifting embodied identities.

During chapter nine I summarise the key findings and consider some implications of the research, reflect on the methodology and related issues, and consider future areas of research. As the chapter indicates, body-faces are located in epochs and symbiotically embedded in multi-layered relationships with other bodies and material cultures.
Therefore, I conclude that identities are not attached to or located within faces, but within persons, experiences, contexts and always in relation to others (Grosz, 1994; Csordas, 1994; Perpich, 2010).

Chapter Summary
There has been some debate about the role and value of faces to human sociality since the advent of facial transplantation. It is clear that faces are highly significant parts of bodies for humans (Synnott, 1993), which have implications far beyond the level of the individual (Rutter, 2007; Perpich, 2010). For example, faces allow us to recognise each other, to make sense of the world around us, to communicate and to recognise each other’s bodies. Some authors writing about facial transplant surgery have suggested that a person’s identity is located within the face (Carolessa and Pradeu, 2006; Swindell, 2007; Modgil, 2011); consequently when facial transplants occur, the recipient is likely to receive a new identity. The thesis will not be exploring identity shift in people after a facial transplant. Instead, it will explore the relationship between faces, corporeal and biographical disruption and embodied identity shift with 13 participants, using a phenomenological epistemology and a narrative methodology (Gubrium and Holstein, 2009).
A life lived: experiencing facial ‘disfigurement’ and identity shift

Chapter Two Methodology

Narratives, photos and a framework for analysis

Chapter introduction and research focus

During this chapter I will explain why an embodied approach has led to the research being framed within a phenomenological epistemology and why I selected a narrative methodology. As part of this discussion I will locate the research within the ethnographic tradition and explore some of the emotional work I engaged in as part of a wider reflexive endeavour.

Having identified and assessed existing facial ‘disfigurement’ research I discovered that much of the work had been conducted using quantitative methods (Thompson and Kent, 2001; Bessell and Moss, 2007) which, by their nature, sought answers to predefined researcher questions or hypotheses. In addition, very few facial ‘disfigurement’ papers had explored the relationship between facial change and identity shift using theoretically informed, qualitative research from the participant’s perspective. A body of social science work considering the relationship between faces and embodiment is emerging, though it is mostly of a theoretical nature at this time (Synnott, 1991; Rutter, 2007; Edgar, 2009; Perpich, 2010; Svenaeus, 2010). And yet the contents of the biographies of the facially ‘disfigured’ people I read to provide some context (Piff, 1985; Grealy, 1995) hinted at rich, complex lives and identifications both before and in the aftermath of facial change. Consequently, the focus of the thesis has been to address the second objective the relationship between acquired facial ‘disfigurement’ and embodied identity shift through the primary data findings. Relevant social science theories of health, methods of data collection and analysis have been utilised to provide a framework to explain and make sense of the data.
Applying phenomenological theory

Starting with situated experience

During this first section I will explain my choice of a phenomenological epistemology. Building on a substantial body of writing (Merleau-Ponty, 1962; Large, 2008) Schutz (1974) has illustrated how phenomenology can be reconfigured, from a philosophy to a methodology by utilising the key concept of ‘lifeworld’. The lifeworld is understood as the horizon of all our experiences, the world of everyday life and the background through which all things are experienced and become meaningful. It is the taken-for-granted, unconscious world of everyday meanings and practices, and the world which is experienced before we place a conscious interpretation upon it.

Van Manen (1997, p.101) describes the lifeworld as ‘the lived world as experienced in everyday situations and relations’. We each as individuals inhabit our own lifeworlds, constituted through our own meaning making; however, lifeworlds are not solely constituted by individuals. Meanings are shared amongst individuals according to their commonalities and experiences, becoming part of a ‘common sense’ reality, which leads to the construction of a particular everyday culture (Baumeister and Newman, 1994). The individual is located within the lifeworld via a number of biographical, social and cultural practices largely invisible to the person, but situated in their everyday actions and behaviours. Analysis Chapters Five to Eight explore the participants’ experiences of facial disruption within their situated lifeworlds.

Viewing experience through an embodied lens

Having touched on embodiment in the previous chapter I would like to explore it in more depth here. The theory of embodiment has been used by researchers to examine people’s complex and multisensory experiences of health, bodily change and illness. Developed in criticism of Cartesian theory, which separated minds from bodies, Merleau-Ponty (1962, p.173) argued that the lived body is not experienced as an object, broken down into discrete entities, such as rational thought or physical pain (Crossley, 2001). Rather, we are embodied beings, consisting of a conscious mind, a body-self, existing within a specific time and space (Toombs, 1993), connected to the surrounding physical and social world (Carel, 2011).

Toombs (1993, pp.51-57) states that there are six essential elements to experiencing a lived body. Firstly, being-in-the-world refers to our orientation to the lifeworld. Our bodies do not
exist purely as biological or psychological entities, rather they exist in relation to a physical space, oriented to particular social situations. Secondly, bodily intentionality refers to our body’s orientation to the world and its objects, ‘I can’ rather than ‘I think’. Thirdly, as newborns, we initially experience the world through pre-reflective perception and sensation, we know through the body. Conscious reflection is developed and overlays our experiences of the world. Fourthly, through contextual organisation, the actions of our bodies exist in the wider milieu. The act of smiling at the body of a passer-by is communicated and understood not simply through a moving mouth, but through the wider context of the person’s facial and bodily comportment and social situation. Fifth, body image refers to our implicit knowledge of the wider physiological position of our bodies - how we use our bodily comportment. Finally gestural display refers to our body’s ability to express itself in gestures and to comprehend the gestures of others – how we automatically come to know that the passer-by is waving as a gesture of friendship, rather than one of aggression or anger. These essential features are core features in our experience of the body as lived, the means through which we interact with our wider worlds through our bodies. The world shapes the physical, cognitive and cultural relations and boundaries of the body, but is itself shaped by the actions of the body. I access the world via my senses, which have a physicality and a presence within the body, many of which exist within the facial region, e.g. seeing, hearing, tasting and smelling. (Table 2, Embodied functions located within the facial region). The face is therefore a deeply significant site, as it provides a wealth of opportunities to experience the world, and in doing so plays a leading role in the creation of meaning, social life and culture. As such, anything that disrupts habitual perception and sense-making will lead to changes in a person’s embodiment and their lifeworld (Merleau-Ponty, 1962; Csordas, 1994). Therefore, the advent of an acquired facial ‘disfigurement’ will lead to shifts in embodied identifications.

**Disrupted embodiment: absence and revealment**

In his seminal text *The Absent Body* (1990, pp.18-20), Leder describes the body as being ‘absent’ from conscious thought whilst in good health, as we do not have to think about many of its physical acts. Instead, we focus our attention on the world as it reveals itself to our presence. Although, when facing a variety of emotional stresses we may become anxious, a reaction experienced physiologically through nervousness, shaking, palpitations, a dry mouth or sweating, such physiological and psychological symptoms, which make us aware of the present body. These experiences are usually fleeting, however; illness is one of
the key ways in which the lived body and through it, the lifeworld is disrupted and disordered.

‘Illness is consequently to be understood not simply as the physical dysfunction of the mechanistic body, but as the disorder of body, self and world’ (Toombs, 1988, p.202).

At such times the body ceases to be the unconscious medium through which we interact with the world. Successful treatment can bring about a return to health and bodily absence. However, where a person has acquired lifelong facial damage, for example through crush injuries, being burned, or the removal of a cancerous tumour (as some of the participants have), the body remains in a state of perpetual appearance. Even if the person comes to terms with the disruptive experience of living with the causes of facial change, they can continue to experience a body rendered present through its dysfunctions and disruptions (Toombs, 1993), for example through scar tissue, loss of vision, or altered ways of eating. I will examine three types of presence here using the example of unhabitual (unexpected) facial change.

Firstly, the lived body commonly reveals itself through the experience of pain, which at its most powerful leads to what Scarry (1985) described as the ‘unmaking of the world’. Within the lived body, pain, when severe enough moves from the afflicted bodily part to encompass the whole lived body and its place in the world, radically altering the way we live, even assaulting the fundamentals of human existence such as language, severe pain only being expressible via moaning, groaning and crying (Bullington, 2009, pp.104-106). The body as a site in the world shrinks in upon itself, in acute pain becoming focused only on itself, at the expense of everything else.

Secondly, the body reveals itself through dysfunction. The unconscious, habitual ways of moving through the world are no longer possible as the body, in this case the face, ceases to work properly. In the example of cancer, part of the face may have been removed leaving a scar or a hole, making seeing, eating or talking difficult. Thirdly, the body experiences alienation from the self and from the wider world (Svenaeus, 2009). Through our bodies we are beings immersed habitually in the world, rather than being simply a thing amongst other things (Svenaeus, 2010). When the body loses its place within the lifeworld it can take on alien-like qualities (Svenaeus, 2009, pp.57-58). For example, when looking in the mirror for the first time many participants related experiences of disassociation and visual estrangement (for further exploration see Chapter Seven Reflecting on reflections: some wider implications of unanticipated visual disruption). Facial ‘disfigurement’ literature
indicates that these feelings can lead to isolation and depression and a change in normal behaviour patterns (Dropkin, 1989; Callaghan, 2004). The act of leaving the house can become a threatening, complex task (Newell, 2000). People have reported leaving the house at night, when it is dark so they do not encounter others who may stare, or make critical comments (Rumsey and Harcourt, 2004). In summary, it is clear that ‘disfigurement’ through unhabitual body-face disruption and appearance can cause disturbances to lives and lifeworlds on multiple levels.

Methods: stories; identities and artefacts

The need for a phenomenologically embedded method
In a direct rejection of prevailing 19th Century positivist epistemology Husserl (Carel, 2011), a founder of phenomenology, argued that the social world is experienced through consciousness, and that this should be the focus of study, rather than the categorisation, measurement or recording of any positivist, ‘objective’ reality. I concur with these sentiments. ‘Disfigurement’ research findings have demonstrated that people can experience physiological and psychological suffering when they have an altered facial appearance. However, a number of the studies utilise quantitative, positivist data collection methods, which cut across people’s life narratives, resulting in fragmented accounts. Consequently, I selected methods congruent with the exploration of embodied lifeworld disruption in a participant-centred way. Utilising a narrative method of data collection and analysis, where participants recount experiences in their own way has supported the production of situated, dynamic and complex exploration of lifeworlds and embodied identities.

‘If stories express being-in-the-world, narrative recon structs not only an individual’s biography but their relationship to their place and history’ (Williams, 2000, p.139).

Narrative approaches and social science
Social science interest in narrative methods of data collection and analysis has grown significantly over the last few decades. During the 1970s a series of US academics capitalised on the works of European theorists like Roland Barthes (1974) and focused their attention on the ability of narrative accounts to illustrate how humans made sense of and organised their immediate and wider lifeworlds (Riessman, 1993). Since the 1970s, narrative methods
of interviewing and analysis have developed across different disciplines in relation to their own research needs (Huberman and Miles, 2002). Consequently, there has been a proliferation of accounts and considerable disagreement about the definition of narrative (Huberman and Miles, 2002; Riessman, 2008). Within the social sciences, many accounts describe or refer to narratives as stories (Josselson and Leiblich, 1995; Fisher and Goodley, 2007). Story telling is a universally acknowledged, elementary form of communication, rich in index. Stories can contain a number of varying plots, for example tragedy, comedy, romance and can be narrated chronologically, or thematically (Huberman and Miles, 2002), they can subvert socially expected norms (Fisher and Goodley, 2007), or they can be inspirational. Whatever the plot, every story needs a teller and an audience.

Though different opinions have been expressed on the role of narrative methodologies within the social sciences (Atkinson, 2010; Thomas, 2010), practitioners tend to share a number of commonly held beliefs, firstly: a rejection of hypothesis-based inquiry as developed through the natural/biomedical sciences, drawing on quantitative methods to define, measure and predict human social worlds. Included in this argument are more structured types of qualitative interviews, even those with open-ended questions, as they cut across the experiences and world-views of the participant and prevent them from giving their whole account (Chase, cited in Josselson and Lieblich, 1995). It has also been argued that non-biographical forms of interviewing merely express the personal and epistemological constructions of the researcher (Mishler, 1986). Secondly, many narrative approaches share a commitment to an open case study method, as they allow for the examination of identity shift across the life course and the examination of wider lifeworld influences, unlike more structured methods, which separate experiences, situations and relationships to offer up fragmented, abstract islets of meaning. Thirdly, narrative approaches share a commitment to the principle of active listening, to facilitate the unobstructed narratives of the research participant (Wengraf, 2004). Through drawing on ethnographic approaches, the aim is to ‘unearth what we did not expect’ (Josselson and Lieblich, 1995). Finally, practitioners have used the method to explore identity, through the telling of stories and the analysis of language, body language, utterances and silences. As Williams (1984, p.197) argued after he used a narrative methodology to explore identity shift in people who had experienced a chronic illness, it allowed him to explore the participant’s ‘attempt to reconstitute and repair ruptures between body, self and world’.
Artefacts of desire: thickening description with material objects, i.e. photographs

I was aware that the interview data was being gathered on one day, and that the responses could have been influenced by the participants’ mood, memory clarity or by a host of other factors, e.g. health status. To ensure that the encounter was as rich as possible I conducted face-to-face interviews at the participants’ homes where possible and asked them to bring a personal possession, which would help to explain their experiences. There are numerous advantages to be gained from using possessions, or material objects as research tools during interviewing. People and their objects are embedded within material cultures which they use on a daily basis, for example, to make life easier or to make statements about themselves in relation to others, owning an expensive car to convey higher wealth or status. What I want to do is to explore some pragmatic merits and challenges involved with the one type of object that people brought to the interviews, photographs, using Tinkler’s (2009, pp.173-194) book chapter and Prosser’s (2006) Working paper on researching with visual images. Nine participants out of eleven brought and used photographs during the face-to-face interviews. Both participants that I interviewed over the phone described specific photographs taken at seminal moments, but did not share copies with me.

By selecting photographs ahead of the interview the person may already be reflecting on the topic, which could lead to more considered and detailed responses and the multi-sensory memories attached to them would evoke richer responses (Tinkler, 2009). Likewise, the act of selecting some photos over others could help the participants to consider which stories they wished to highlight and prioritise, making their identifications clearer to the interviewer (Tinker, 2009). As Atkinson (2010) notes all verbal narratives are partial and deliberate; consequently, the choice of an object to illustrate a narrative, such as a photograph is also partial and deliberate. Finally, Tinkler (2009) points out that when talking, it might be easier for the participant to follow or elaborate on a conversational thread using a photograph, particularly if they are not used to engaging with professional strangers. Having interviewed most participants with their photographs and analysed their use, in conjunction with the field notes, transcripts and audio recordings, I can say that the photos did facilitate richer talk, memories and data. People can think of themselves in complex and contradictory ways, which may not be conveyed by talk alone.

Whilst the use of photographs has enriched the quality of the data, there are some caveats which Prosser (2006, pp.1-4) has acknowledged. I raise them here in the spirit of research reflexivity. Images do not stand alone, they require interpretation, in the same way as other sources. In this respect images are ‘polysemic’ (have multiple meanings); as material objects
in the world they gain their meanings from humans. Photographs are no different; they are constructed images created at a specific moment, which can be used to convey a variety of dynamic meanings and embodied identifications after the event.

Praxis issues: from form-filling to face-related fieldwork

Overview
In this context, praxis will be understood as the process whereby a theory or a skill is enacted. During this section, I will describe how I moved from designing the methodology to conducting the interviews. I will discuss the sampling frame and sample, methods of recruitment and locate the research field.

Sampling frame
The most rigorous data on facial ‘disfigurement’ prevalence stems from the now dated 1988 Disability Survey (Office for Population Censuses and Surveys, UK Government). It estimated there were at least 400,000 people (UK) with a ‘disfigurement’ to their face and/or body. Drawing on a range of data sources Changing Faces reported (2008) that 542,000 people in the UK (or 1 in 11) have a significant ‘disfigurement’ to the face at some point in their lives. Amongst this group, they note a marked variety of causes, which can be congenital or acquired, temporary or long-lasting, with variations in terms of facial form, function, and aesthetical appearance. My focus is adults with an acquired facial ‘disfigurement’ who speak English in Britain.

Sample
After much consideration, I decided to focus my research gaze on adults with an acquired facial ‘disfigurement’. I was interested in possible lifeworld and identity shift, incorporating the potential for a visual sense of identity. I conjectured it would be easier to explore facially related identity shift in a group who had experienced a ‘normal’ appearance before unhabitual alteration. I anticipated that asking people to take part in the research a minimum of two years after the event would provide some emotional distance and time for reflection. I was rather naive. In many cases events had occurred years and even decades
ago, although people still felt upset and emotional as a result of recounting their experiences.

Recruitment
In keeping with a phenomenological, person-centred approach I applied for University of Liverpool ethical approval, not National Health Service (NHS) ethical approval and I asked potential participants to self-recruit. Taking the former first, I wanted to avoid medical gatekeeping, through lengthy and cumbersome NHS bureaucratic approval processes, and to avoid ‘suitable’ participants being selected for me by NHS staff. Also, many of the facial ‘disfigurement’ studies were based on people in their role as ‘patients’. I wanted to get away from this partial identity, to encourage participants to explore their lives, lifeworlds and experiences. To consolidate this approach I also wanted people to register their interest to be interviewed if they self-identified as having an acquired facial ‘disfigurement’, not whether any medical ‘disfigurement’ rating scale deemed them suitable. With hindsight, self-selection was hugely rewarding. Though some people presented with seemingly ‘normal’ appearances, they had undergone years or decades worth of surgery. I learned quickly that the research was not going to be about how people presented (facially) at the time of the interview.

Having gained University of Liverpool ethical approval I developed three parallel recruitment strategies. My first and anticipated key strategy was to ask two national British facial support/equality organisations to publicise the recruitment materials either online or internally through their organisation. One circulated an advertisement in one of their quarterly journals. The other eventually published an advert on a quiet section of their website after I had sent a completed copy of the University of Liverpool ethics application. In spite of high hopes on both counts I received no replies after months of waiting. So, I asked and was granted interviews with one member of staff from each organisation. My second strategy was to recruit people via the internet who had a media presence relating to their experiences of gaining an acquired facial ‘disfigurement’. After an extensive search, several potential participants with a facially related media profile emerged. Unfortunately, this resulted in only one interview as I only received one reply.

My third strategy was to identify and contact supportive organisations for people with specific appearance-related concerns based in Britain. Between April and November 2011 I contacted approximately 70 organisations and individuals either by internet or letter. By
November of that year I had conducted only nine interviews and my list of participants had dried up. Attempts to elicit further participants through snowballing had also gone unrewarded, as had an appearance on a BBC Radio Merseyside programme on bodily appearance. For example, by October 10th 2012, my advertisement to interview people on the Cancer Research UK website had been seen by 1,491 people yet it had only resulted in one interview. So, in November 2011 I wrote letters explaining about the research to the editors of eight local and regional newspapers based across the North-West of England. These produced another four interviews and one final participant took part after reading about the research on a head and neck cancer charity website. According to the 2011 UK Government Census, 7.1 million people lived in the North-West of England (ONS, 2011). If the Changing Faces statistics on facial ‘disfigurement’ are correct, nearly 65,000 people or one in 11 live in the region with a facial ‘disfigurement’, and yet only four people came forward via advertisements in local newspapers. I must conclude then that the relevant people did not see the request or that they did not wish to take part. Though this is a sensitive issue, if people are not willing to come forward and take part, gaps in academic knowledge cannot be filled, shared and acted upon. Or perhaps, a more nuanced ethnographic approach is required, one requiring longer term immersion emersion within a charity or group?

Constructing and conducting narrative interviews

Wengraf (2004, pp.4-5), a widely published author on the narrative method argues that there are four stages involved with the design and implementation of a narrative interview. Firstly, reading is required to explore the field; secondly, questions are developed during the initialisation period. The questions are then asked during the main narration and finally, there is a questioning phase, after the interview, to clarify what people have said. Wengraf (2004) also adds a final option to the interview, the addition of semi-structured questions to specifically address the needs of the research.

There is general agreement that the interview has two key parts. The first starts with an open-ended question, which can be biographical in nature, usually something to elicit a life story and hopefully key events, like an episode of facial change. The rules surrounding this part of the interview are clear. The question or questions asked need to be few, open-ended and contain enough experiences for the person to talk unaided for some time. The role of

---

4 Office for National Statistics
the interviewer is to be a facilitator, an active listener (Wengraf, 2004), to ask the questions, tell the respondent that they will not interrupt, that they will take brief notes in addition to the voice recording and to merely encourage the speaker by non-verbally mirroring their embodied performance as far as possible (Riessman, 2008). A great deal of emphasis is given to instructing practitioners on how to move between questions. Wengraf (2004) advocates leaving the person to finish their response in as naturalistic a way as possible. Researchers are advised to respond to a silence with a silence, to ask are there any more experiences to relate here, to avoid a ‘fake’ ending, i.e. finishing when the researcher, not the participant wants to move on. Some practitioners (Wengraf, 2004, p.10) put forward the use of a single biographical question during the first part of the interview, to draw directly on participants’ notions of significance, expression and identity. I asked a biographical opening question followed by three open-ended questions:

1)  Could you tell me about your life from the period before your face changed up to the present day?

2)  Could you tell me what makes up your sense of identity, and whether this has changed or remained the same in the period before the accident/cancer/acne rosacea up to today?

3)  Could you tell me about your experiences of looking in the mirror, from the period before the accident/cancer/acne rosacea right up to the present day?

4)  Starting with the period before the accident/cancer/acne rosacea and finishing now, to what extent have you felt able to experience the type of life you wanted to live?

Elliot (Riessman, 2008, pp.17-20) argues that participants are more likely to find it easier to talk about specific events or periods, rather than being asked about very broad periods, i.e. decades. Having a question so general could lead to people saying less or simply filling the space as they forget what has been asked. She suggests giving participants a framework, not to influence their choice of content, but to ensure they cover key events/time periods.

I provided people with a written guide, which included the following instructions (which are also verbally given):

Start wherever you like, I won’t interrupt you, please take all the time you need

Could you include the following periods
before your face changed
the period immediately after
the period after that
the present day.

The second phase of the interview takes place after a ‘comfort break’, to allow the participant a little space and the researcher time to select meaningful or unexplained quotes to extract richer information (Riessman, 2008). These must be addressed in the order they are raised and using the language of the participant, to maintain the flow of the ‘conversation’. The researcher must not ask for any new information during this phase. Afterwards a third and final phase may be added, containing semi-structured questions directly addressing the aims of the research. I chose to ask two questions, to elicit material in a more direct manner and to compare the responses with earlier ones, to check for similarities and differences:

What do your experiences of life tell you about attitudes towards facial normality and difference?

Have any of these experiences ever motivated or inhibited you to think or act differently?

Wengraf (2004) states that this phase should take place at a separate time, to allow for a period of reflection, for both participant and researcher. I advertised nationally, across England to increase the chances of recruiting. As the interviews took place between Kent and Yorkshire (almost the length of England) and I was self-funding, travel costs alone prohibited me from conducting two visits per participant. Even if cost had not been an issue, people might not have been willing or available to undertake a second interview, which could have resulted in data gaps. Asking questions in one sitting meant that I obtained responses to all of the questions in all three phases. However, the data might have been richer if I had visited a second time. The participants would have had time to reflect on their responses and I might have developed a stronger research relationship, possibly facilitating greater openness? I interviewed people in their own homes where possible (11 visits, two phone interviews). I wanted to see how people presented themselves in relation to their surroundings and material objects. Participants surroundings and in some cases relations added an extra dimension to the embodied identities they were trying to confer.

At the end of the interview, there is agreement that the researcher should spend time writing field notes about the context and nuances of the interview and any conversation
before or after, to support the analysis of the narratives (Wengraf, 2004; Riessman, 2008). I wrote field notes about the research environment and the interview context immediately after the interview had taken place and kept them together with the final transcript. When I analysed each interview I did so in conjunction with the audio recording, the field notes, the transcript and an increasing awareness of the previous interviews.

**Narrative analysis**

*‘Contexts and conditions’*

Gubrium and Holstein (2009) argue that the study of narratives has moved in two distinct directions; firstly, a movement towards theorising the structures and functions of stories, which can involve the exploration of language, intonation, pitch, vowel length, emotion and repetition. The second direction has seen the development of narrative as a device to relate stories of identity. Analysis related to this type of research can focus on the content of what is said/left unsaid, rather than how it is conveyed (Gubrium and Holstein, 2009). However, owing to the diversity of narrative practice, researchers of both strands can now draw on a range of analytical approaches, including structure, content and performance (Wengraff, 2004). Though attention is paid to the data collection context, some narrative manuals minimise the role of field notes and prioritise that of the transcript during the analysis phase (Bauer, 1996; Wengraff, 2004; Reissman, 2008). There are two problems with this. Firstly, though it relates to dynamic experiences, the transcript itself is a static artefact, compiled during a specific period, reflecting how the person makes sense of their life on that particular day (Huberman and Miles, 2002). Secondly and more substantially, Gubrium and Holstein (2009, pp.3-7) have argued that some narrative accounts have focused too closely on the transcript as the key site of analysis, at the expense of a serious consideration of the environment and conditions, which influence both the narrative process and product. Using the example of Shaw’s *The Jack Roller - A Delinquent Boy’s Own Story*, Gubrium and Holstein (2009) argue for the development of what they call an ‘ethnographic approach’ to narrative, one which moves away from the prioritising of the transcript and the single voiced ‘self’ revealment story. Although twists occur in individual’s stories, they are patterned by social experiences, which are shared with others. Gubrium and Holstein (2009) define narrative as a combination of resources at hand, storied environments, experiences, story-telling and audiences. They argue that the purpose of what they term ‘narrative ethnography’ should be to provide:
‘the contexts, conditions, and resources of the storying process... to describe and explicate the storying of experience in everyday life... to capture through multifocal analysis, the contextual influences and dynamics that shape narrative’ (Gubrium and Holstein, 2009, p.262).

This is made possible through a consideration of narrative environments, embeddedness and control. An examination of narrative environments takes us beyond the internal organisation of stories, to consider the full socio-cultural and economic circumstances of their production and reception. Questions such as how to put it and what themes to highlight are relevant here. Regarding narrative embeddedness, the authors make use of a Russian doll analogy to explain; the smallest doll is embedded and enveloped within a nest of larger dolls. A life story is only fully understood when we take other related stories into account. Producing a multi-layered account can help to avoid the reductionist, romanticised aim of obtaining the person’s ‘own story, in his/her ‘own’ voice’, (Gubrium and Holstein, 2009, pp.5-9) as there is no single ‘voice’. Multiple voices reside within narratives, which reveal many phenomenal layers of meaning between the individual and society; individual accounts arise from both personal and social narratives. This pursuit leads us to consider the role of narrative control, how narratives are constructed, promoted or resisted within the environments of their telling. This is revealed in various forms and ongoing and competing concerns. It can be exercised ‘internationally’, through the give and take of the social interaction, or ‘institutionally’ depending on how interviewees frame or explain their experiences with reference to organisations. Whilst Gubrium and Holstein’s (2009) critical, complex understanding of narrative places the methodology within the ethnographic tradition the relatively short space of time that I spent with participants means that only an ethnographic snapshot is possible. The next sub-heading reveals how I incorporated these findings into the analysis phase of the project.

**Stages of analysis**

I undertook several stages of analysis, starting informally with the participants’ interview environment, demeanour, and initial conversation. The first stage of formal analysis commenced during the break, after the first series of open-ended biographical questions. I had noted timeframes, emotive topics, listened for silences, seminal moments or seeming contradictions, which could be explored further during phase two. The second formal phase took place after the interview had been completed and I had returned to the car or the
train. I wrote extensive field notes, describing and interpreting the location, the person and anything which struck me about their account or its focus, as suggested by Wengraf (2004). Thirdly, each interview was transcribed. Fourthly to critically analyse all of the field data I constructed an analysis framework incorporating various narrative, embodied identity and visual research analytical resources. The framework, which was applied to each case study, was organised around five themes. (Table 4 sets out the themes and sub-themes/questions and the academic resources that informed them.) Once the framework for each participant had been completed and checked over again for inconsistencies or gaps in the account, I sent it off to my supervisors for their inspection, responded to their comments and afterwards completed a one-page analytical summary.

I piloted the framework using the first interview, and I was happy with the results, even if it did take weeks to analyse a single narrative account. Initially I listened to this recording over 30 times and produced a 60-page analysis from listening, reading and remembering. Once the analysis had been completed for each case, I listened again to the recording as I read through it, to ensure that I had not missed anything, to check for accuracy and to ensure that it made sense. The more interviews I conducted the more I was able to analyse within and between cases. During this fifth stage of analysis, variations in seemingly similar cases led me to critically explore until I could reasonably explain how the person had made sense of their experiences and how the facial event and other unrelated experiences had influenced their lifeworlds and identities. As part of this process a number of cross-cutting themes emerged which influenced how the person perceived and identified with the experience. These included: the cause and context of facial change i.e. car crash or cancer; gender as an influence on the telling of the story; related life-threatening experiences; other life and ill health experiences and how they perceived the event after some years’ distance. On further reflection, it became clear that how people identified before the event had some bearing on how they identified afterwards, and though some spoke of a radical change in their lifeworlds and identities others did not, regardless of the severity of the facial alteration.
Table 1 Fourth stage of analysis: the narrative analysis framework

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme/question</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How do they speak about themselves?</td>
<td>Frank (1995)</td>
</tr>
<tr>
<td></td>
<td>How do they respond to biographical disruption? (focus on narrative wreckage, other relatedness, embodied control and chaos)</td>
<td></td>
</tr>
<tr>
<td>2 key themes arising</td>
<td>What is happening within the stories?</td>
<td>Gilligan et al. (2003)</td>
</tr>
<tr>
<td></td>
<td>What are the dominant themes?</td>
<td>Doucet and Mauthner (2008)</td>
</tr>
<tr>
<td></td>
<td>How are close relationships narrated and where does the balance of power lie?</td>
<td>Gubrium and Holstein (2009)</td>
</tr>
<tr>
<td></td>
<td>How do they talk about their face and facial change?</td>
<td></td>
</tr>
<tr>
<td>3 seminal moments</td>
<td>Are there any seminal moments?</td>
<td>Doucet and Mauthner (2008)</td>
</tr>
<tr>
<td></td>
<td>If so, how are these narrated and what are they trying to achieve?</td>
<td></td>
</tr>
<tr>
<td>4 contradictions, gaps, inconsistencies</td>
<td>Are there any contradictions, gaps or inconsistencies in each account?</td>
<td>Doucet and Mauthner (2008)</td>
</tr>
<tr>
<td></td>
<td>If so, what are they, where and why do these occur?</td>
<td>Gilligan et al. (2003)</td>
</tr>
<tr>
<td>5 use of photographs</td>
<td>How, why and when do they use photographs?</td>
<td>Tinkler (2009)</td>
</tr>
<tr>
<td></td>
<td>What aspect of identity are they trying to convey?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>How does this fit with the rest of their narrative?</td>
<td></td>
</tr>
</tbody>
</table>
A number of the participants had life-threatening experiences and suffered other injuries relating to their facial change, which were also meaningful in relation to lifeworlds and identities. Women were more likely to discuss relationships and emotions whereas men were more likely to narrate single author stories associated with higher degrees of autonomy and activity. All participants spoke of their medical experiences even though I did not ask for them. It became clear that for many the onset of facial and bodily change marked a transitional period, between the old and the new life, which required further analytical investigation. Identity was referred to directly and indirectly, and with some reference to individual appearance. I was encouraged by these interim findings but unsure of how to proceed with the analysis, so I stepped back to pause for thought and read up on gender health and illness, embodiment, and on illness, transition and lifeworld shift.

This sixth stage of analysis enabled me to think through the individual and thematic findings in relation to one another, and to provide thicker description to aid the formation and writing of the analysis chapters. One significant challenge was how to present the findings, as there were so many and they were all related in multiple ways; for example, should I select by cause of change, or by gender, or by response to the identity shift at the time of the interview? After much thinking and drawing with coloured pens on white boards, I decided to present the primary findings in four chapters, before, during, appearance related issues and life after unhabitual facial change, thus mirroring the broad chronology of the interviews. Chapter Five, the first primary analysis chapter provided a theoretical platform for understanding all persons as dynamic, vulnerable and diverse beings, prior to locating the participants within their lifeworlds and embodied identities prior to facial change. The second primary analysis chapter (Six) considered the various disruptions and transitions associated with the period of unhabitual facial change. The third analysis chapter (Seven) explored appearance-related liminality and the final analysis chapter (Eight) considered how people had made sense of their facial change and embodied identity experience in the years afterwards. As I wrote each one of them I referred back to the audio recordings and transcripts to ensure accuracy. In the final, seventh stage of analysis I have made amendments to each of the chapters, in the aftermath of comments from my supervision team and my partner, who was able to report on whether the chapters made sense to a non-specialist audience. My hope is that the thesis makes sense, that I have achieved the precarious balancing act of providing both individual case studies and wider thematic understanding in an area which is currently under-researched.
Doing emotional work

‘In order to be useful to other researchers, emotional accounts need to be discussed as data and in relation to the generally unspoken emotion rules of the setting under investigation’ (Lee-Treweek, 2000, p.114)

Humans are social animals and our emotions undoubtedly play a large role in helping us to make sense of our lives and maintain our relationships. However I am not entirely sure I agree with Lee-Treweek’s (2000) positioning of emotional work as data. Rather, I see emotional work as a normative aspect of human existence, and as both a tool and an outcome of the research process. To count emotional accounts as data without qualification seems to diminish the years of professional skills, training and research experience the researcher amasses and applies in the pursuit of socio-cultural understanding. I do however agree with Lee-Treweek (2000) that emotional work is part of the research process and that it can remain undiscussed in the final written product. The reflexive turn in the social sciences has come of age. Yet in spite of the recognition that research is subjective; that data is created not discovered and that the researcher plays a central role in its creation, there seems to be a limited amount of emotional work surfacing in published academic accounts (Lee-Treweek, 2000; Sampson, Bloor and Fincham, 2008). During this section I will use the works of Lee-Treweek (2000), Hallowell Lawton and Gregory (2005) and Sampson, Bloor and Fincham (2008) to inform a discussion of my PhD emotional work journey.

As I already worked in an academic environment I was able to view other research students’ emotional work at various stages of their PhD. I had an idea of what to expect. Though the fieldwork period with its new people, places and negotiations might be viewed as the most demanding period, I knew that emotional work started long before hand. Working and studying part-time, trying to maintain relationships in every sphere of my life as well as to have some time off created its own demands over the course of the six year PhD period. The more I learned about embodiment and the connectedness of people (Grosz, 1994, p.7-8) the more I became aware of its impact on my own body. Ongoing exhaustion coupled with the need to sit and write protractedly severely reduced my capacity to exercise, led to comfort eating and an excessive intake of caffeine as I pushed myself to remain alert and productive. In short I became more stressed than usual, put on weight and the quantity and quality of my sleep diminished. The more I read on embodiment the more disembodied I realised I had become; through prioritising the cogitations of the head at the expense of the body. I do not think that these experiences are in any way unique. Being in an academic environment by day meant that I was able to share and learn from others on similar
journeys. This became incredibly beneficial when I had to negotiate some upsetting aspects of the research.

Firstly, somewhat naively I had underestimated the extent to which people would open up to me about their lives when I had asked them about their faces. As Williamson (cited in Hallowell Lawton and Gregory, 2005, p.16) notes there are no ‘safe’ questions and no ‘safe’ participants. I was told about suicidal thoughts, thoughts of self-harm, feelings of inner ugliness and one episode of domestic violence, job loss and divorce. This was in addition to episodes of bodily, emotional and social suffering caused by the event of the facial ‘disfigurement’ its disruptions to lives, relationships, perceived futures left it its wake. As Lee-Treweek (2000, p.115) notes, great emphasis has been placed on safeguarding and supporting research participants. However, efforts to protect researchers have not been pursued with the same vigour. And until recently writings on researcher danger have largely focused on physical threats experienced during the fieldwork stage (Lee-Treweek, 2000, p.115). The advent of feminist research and reflexive discussions about the production of knowledge (Letherby, 2000, p.95) have by their nature opened up the topic of researcher risk and with it considerations of emotional investment and expenditure. These explorations are warmly welcomed, though unfortunately the findings of this work has not yet permeated its way into all higher education research processes. My family, friends and supervisors provided very satisfactory emotional support though I was left in no doubt throughout the official ethical approval phase of the research that the protection of my participants was of paramount importance. In the production of publicity materials I asked for a period of two years to lapse between the ‘disfiguring’ event and the proposed interview. I pointed out that if potential participants were in any way unsure about their mental health they were to seek medical advice before agreeing to take part. I developed information sheets with generic and specific facial ‘disfigurement’ support groups, explained in written documents and verbally that participation was voluntary and that participants were free to leave at any point. Prior to the fieldwork period I undertook a one day training course to become more sensitive to people living with a ‘disfigurement’. Whilst I wholeheartedly agree with these principles and actions; at no point did the writers of ethics forms require the same diligence be paid to the researcher’s own well-being.

As an aside a friend suggested that I attend the free staff university counselling service after I had conducted the interviews. I thought it a bit unusual and forgot about it. When I began to hear about suffering on a scale I had not expected I realised why this would be useful though I did not go. The interviews were spread over a twelve month period so I had time to
recover between each one. And, misguided or otherwise I imagined that feeling my way through the research was part of the PhD initiation process. However, when I undertook the analysis phase which involved several months intensive listening, reading and thinking I experienced the most challenging emotional work of the project. Not only were many episodes and emotional states upsetting to hear again, I completed the analysis in isolation, partly to maintain confidentiality and anonymity and partly because I needed to work on my own to concentrate. I am inclined to agree with Exely (cited in Hallowell Lawton and Gregory, 2005, p.17), that ‘the research world can be a very lonely place’.

An event occurred during the interviewing and analysis phase of the research which added an additional layer to the emotional work needed to complete the project. A much-loved Uncle died after a two-year battle with throat cancer. I chose not to tell the participants about this episode. Disclosure to the participants with a cancer diagnosis may have led to greater rapport and richer data. However I did not feel confident that I could control my own emotions. Secondly, I may have changed the trajectory of the participant’s narrative. I was there to hear their life stories, not mine. In addition, some participants were in remission, one with advanced (stage four) cancer. It would have been deeply insensitive to remind them of their mortality and that was not my role. Nevertheless, all of these emotional experiences aided my understanding of the participants’ stories and added depth to the analysis of the materials. I am not sure I would have gained the same level of understanding if I had not connected with the data in this way. In addition many of the participants had responded to adversity by trying to carving out a revised or new future for themselves. During my first interview, the participant had learned some valuable lessons about life and the shallowness of placing too much importance on outwards appearance in the years after the event. He had become very confident in his abilities and felt that he had now accomplished far more than if he had not been disfigured. I left his house feeling uplifted and inspired by aspects of his narrative.

**Subjective reflexions⁵: My PhD mountain**

Given the importance of the human face I had envisaged finding a huge body of pertinent secondary resources when I honed the research objectives; however, there were not as many as I had anticipated. The whole PhD project has taken me much longer than I anticipated and it has been quite a challenging endeavour, though it has also been hugely

⁵ Reflexions is a word I am using to combine the meanings of reflexive and reflections.
emotionally and intellectually rewarding. To use a mountain climbing analogy there have been a few gentle slopes, many steep learning curves, some sheer drops and seemingly insurmountable summits. Being indulgent, I have climbed this particular mountain for a number of reasons. As an academic researcher, I needed to learn from the apprenticeship that a PhD inevitably is. As a social anthropology master’s degree graduate and a teacher of health sociology I wanted to continue my combined exploration of these fascinating subjects in a way that would shed a little more light on the human condition. Whether they are related I do not know, but as a dyslexic person and someone who has never gained top marks in exams I also needed to climb the PhD mountain to prove to myself that I could.

Moving on to the research process, it was not until I started to read literature that I used to address the first research objective (Chapter Four) that I became consciously aware of the association between facial appearance and morality. As a James Bond film fan I knew that villains would be recognisable through having a scar or noticeable bodily difference of some kind. However, I was not consciously aware how influential the appearance-morality relationship still was in contemporary Western societies, nor how much it continued to detrimentally influence the lives of those with altered or different faces. Facial equality charity Changing Faces is doing much to challenge this inaccurate association. In terms of the underpinning theory, though I was taking an embodied approach to identity, I was unprepared for the connectedness of faces, bodies and experiences. Perhaps I was guilty of perpetuating false Cartesian ideas about the separateness of embodied persons. Relatedly, I was unprepared for what the participants revealed when I started interviewing them about their faces. A couple of participants had contemplated suicide, one hinted while another said it was a consideration though to my knowledge neither had acted on their thoughts. As a consequence of these sorts of disclosures I developed the term body-face to illustrate the connected, embodied nature of faces as parts of persons. On reflection, if I had not used a biographical methodology it is doubtful that people would have offered up these experiences, nor would I have gained such rich data. Consequently, I have been left with ambiguous feelings about the concept of vulnerability (Fisher, 2011). Vulnerability is a condition of all bodies (Perpich, 2010, p.178), though some are more vulnerable than others, and I did not want participants to suffer additionally as a result of reliving their experiences. However, if no one had agreed to be interviewed the complex lives and shifting embodied identities of these participants would have remained academically hidden, at least for the present.

All participants had received written and verbal information on supportive national organisations prior to and at the start of the interview.
In terms of writing up the chapters, I found it extremely difficult to convey the material in such a way as to convey the complexity and interconnectedness of the themes whilst meeting the conventions of the thesis. One key question that I kept asking myself during the primary research analysis phase and the subsequent writing of Chapters Five to Eight was how accurate is my representation of the participants and their experiences? Firstly, though I had made contact with all participants beforehand, I only had one face-to-face, or phone encounter to conduct a three-phase interview. I did this to ensure I gained complete data for each person and because it was the least expensive way of achieving it. I was a self-funding student, the field in this case covered Britain and I had offered to go to people’s homes (or somewhere they felt comfortable) to add additional depth. In spite of this pragmatism, I have probably not gained the same level of engagement and disclosure compared to if I had completed the three phases of narrative interviews on separate occasions as recommended by Wengraf (2004). Having said this, the participants did open up to a much greater extent than I was anticipating, and when analysing the data and writing and editing the thesis chapters I continually referred to my field data (transcripts, field notes and audio recordings). Consequently the PhD and particularly the fieldwork and analysis period lead to much emotional investment and expenditure. In spite of this expenditure and the several stages of analysis that were completed only 13 interviews were conducted during one research encounter. As such the thesis provides an ethnographic snapshot of a set of people’s experiences in a given timeframe.

In terms of which analytical themes to pursue, I had anticipated developing more on shifting gendered embodiment. However, it did not become prominent and there were other more pressing themes to consider. For example, I did not anticipate the degree to which the stories would continue to focus on disrupted identities in transition not just during the immediate phase of body-facial disruption but in the months, years, and decades following. Finally, I was unprepared for the length of time that I would have to spend confined in a quiet room with a pc, academic resources, field data and cups of tea. My hope is that the thesis accurately reflects the experiences of the participants and that the findings and conclusions can be utilised to shed new light on the relationship between faces and embodied identities, and to reduce ignorance on the issue of facial ‘disfigurement’.

**Chapter Summary**

As highlighted in the first chapter, some facial transplant papers had conjectured that a person’s identity was contained within their face, and that this could in theory be
transplantable, along with skin, tissue and bone between donor and recipient during the operation (Swindell, 2007; Carty et al., 2012). Yet, there was very little evidence to support this position. When evidence has been provided on what it is like to live with a facial ‘disfigurement’ it has been predominantly provided using quantitative methods, which cut across people’s narratives and fragment their dynamic experiences (Chase, cited in Josselson and Lieblich, 1995). The decision to conduct this PhD research stems from a desire to explore the embodied relationship between unhabitual facial change and identity shift using a social science methodology to fill in some of the gaps. Social scientists have been researching the relationship between (embodied) bodies and identities for decades (Merleau-Ponty, 1962; Leder, 1990; Grosz, 1994; Csordas, 1994; Benson, 2007), and they have much to contribute to the discussion about faces and identity. Locating this research within a phenomenological epistemology has meant that I have been able to prioritise the lifeworlds and experiences of the participants from an embodied perspective. I have been aided in my desire to understand by the choice of method, narrative interviews, with photographs, which again prioritise participants’ experiences and sense-making, rather than working to a purely researcher led agenda. Previous research has indicated that people with facial ‘disfigurements’ can be more likely to become socially isolated (Dropkin, 1989; Rumsey et al., 2004). The difficulties I have had in recruiting, in spite of varied methods of publicising the work seem to add weight to this finding.

I believe that I created a productive rapport with the participants, which has led to rich narratives, though this might have been enhanced if the interviews had taken place on more than one occasion. As it is, I will never know. What I can do is to offer up the four primary data analysis chapters for the reader to judge for themselves as to whether the interviews and the analysis have fulfilled the second research objective (to explore the relationship between acquired facial ‘disfigurement’ and embodied identity shift using a narrative methodology). Before that takes place, the next chapter (Beyond face value) will consider key ethical issues underpinning the project.
Chapter Three Ethics

Beyond face value

Chapter overview
Research ethics can be described as a form-filling process; a legal and peer-controlled gateway to be opened (Langer, 2005); a section of a PhD and as a set of moral codes to be adhered to regarding researchers and participants before, during and after the research is over (ASA, 2011). With this variety, I had a number of choices about where to locate ethical discussions within the thesis. I selected a two-pronged approach. Less complex moral considerations are addressed where they arise, to maintain the flow of the thesis, to enhance reflexivity through addressing issues in context and to illustrate that ethical issues, which arise, are present in all aspects of the research process (Hallowell, Lawton and Gregory, 2005). More complex issues, specifically the rise of a professional research ethics and audit culture and the support of research participants with a facial ‘disfigurement’ will be examined here, within this short chapter. The purpose of having a separate ethics chapter here is twofold: to present ethical issues as equal in value to the other chapters; and to prevent moral issues from being viewed as a methodological appendage.

From Nuremberg (1948) to Liverpool (2011): the rise and application of research ethics and audits
During this first section, I will take a step back and consider the socio-political development of research ethics on a wider scale before considering how these processes have influenced the project.

Historically, the large-scale consideration of ethical (moral) issues when conducting medically related research with humans can be traced to the development of the Nuremberg Code (1948). The Code was developed in response to the abuse and exploitation suffered by those who were subject to Nazi ‘quasi-medical’ experiments during the Second World War (Hallowell, Lawton and Gregory, 2005). It has since been followed by the Declaration of Helsinki (World Medical Association) initially in 1964 and more recently by the Council of...
Europe’s Convention for the Protection of Human Rights with Regard to the Application of Biology and Medicine (1997). Whilst medical and social science research aims may differ, the ethical guidance in both instances remains similar (Holman, 2005, cited in Hallowell, Lawton and Gregory, 2005). Their purpose has been to protect research participants from exploitation and harm and to give them freedom of choice and privacy. Whilst their aims may be congruous, the methods used to gain ethical approval are not. Qualitative social science researchers have been challenged by the rise of a politically motivated, audit-driven ethics culture within the UK National Health Service (NHS) and elsewhere, which has favoured the gathering of quantitative data (Langer, 2005), which is another reason why I chose to avoid NHS ethical approval processes. Anecdotally, I have heard colleagues’ tales of frustration, as approval of their proposed qualitative projects has taken longer, owing to the overrepresentation of clinical professionals on local NHS ethics committees, who are not trained in social science theories or related methodological issues.

Langer (2005) argues that NHS ethics committees (otherwise known as Local Research Ethics Committees) can be seen as a type of audit for a number of reasons. They emerged during the Conservative premiership of Margaret Thatcher she was influenced by a strong belief in laissez-faire policies for both the State and individuals (Pollitt, 1993; Farnsworth and Irving, 2011). The emphasis on self and State regulation through market-driven audit culture continued during the Blair administration of the New Labour government years (1997-2007) and became more intensified (Cutler and Waine, 2000; Davies and Tavakoli, 2004). Successive Thatcher governments also introduced management science practices such as auditing into the organisation of state-financed services. This has led to a large increase in the automation of information and self-management including the practice of applying for ethical approval to conduct social science research such as this PhD.

‘When it comes to ethics, a large proportion on social science is self-regulated’ (Hallowell, Lawton and Gregory, 2005, p.143).

Lengthy and complex guidance notes are provided in the belief that they will remove the researcher’s need to communicate with a member of the ethics committee. For example, The University of Liverpool ethics form (2010-11) that I filled in independently was 17 pages long. I had to provide participant information/consent materials for review by the committee at a meeting to which I was not invited. There were many opportunities to explain qualitative social science research designs in continuous prose on the form. However, other pages
required the researcher to reduce their study to a series of tick box categories with either yes or no responses. The following section is taken from pages five and six of the form:

SECTION C EXPEDITED REVIEW

Does the study involve participants who are particularly vulnerable or who are unable to give informed consent? Yes/no.

No working definition of vulnerability was supplied, making it difficult to know whether my participants were seen as ‘particularly vulnerable’ or not. Furthermore, given the tick box approach, there was no chance to explore the concept of ‘vulnerability’ (Fisher, 2011, p.6), nor to discuss how this may have related to participants with a facial ‘disfigurement’. In addition, the issue of whether a person could give informed consent or not and what this meant in practice was subsumed into the same question. Again, the only method of response was either a yes or no. As this hugely significant double question could be answered with a number of responses, a single overall yes or no tick gave a meaningless response.

Ethical frameworks and the protection of facially ‘disfigured’ people

Notwithstanding the previous comment, going through the ethical approval process has enabled me to become more aware of the general and specific moral and legal responsibilities I had towards the participants (Hallowell, Lawton and Gregory, 2005). The general responsibilities were crystallised in the Economic and Social Research Council’s (ESRC’s) Research Ethics Framework, which set out the following six principles to guide the conduct of its grant holders.

1. ‘Research should be defined, reviewed and undertaken to ensure integrity and quality.
2. Research staff and subjects must be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved.
3. The confidentiality of information supplied by research subjects and the anonymity of participants must be respected.
4. Research participants must participate in a voluntary way, free from any coercion.
5. Harm to research participants must be avoided.
6. The independence of research must be clear, and any conflicts of interest or partiality must be explicit’ (Gilbert, 2008, p.178).
This section will explore how I used these principles to guide the PhD research project. The first consideration refers to having defined and reviewed research to ensure quality and integrity. The research design was enhanced through continuous critical supervisory scrutiny by my supervisors and by the Sociology Department’s Ethics Committee (University of Liverpool) who awarded the project ethical approval. Statements two and four concern the principle of informed consent and the importance of gaining it. Informed consent refers to the practice of recruiting research participants by providing them with as much information about the project as possible, including its aims, their involvement, any risks, what will happen to the findings and how their rights will be protected. Critical to this concept is that once individuals have full knowledge, they choose to freely give their consent to take part in the research. According to the British Sociological Association (2011), this implies a responsibility on the researcher to explain in detail and in a way which can be understood by participants, the nature and implications of the research. To comply with these statements I have provided varied forms of publicity about the nature of the research, i.e. verbal and written, and participants have freely given their consent to take part.

Starting with principle two, before I could send any publicity material out, it had to be passed by the University of Liverpool ethics committee. Once I started recruiting I sent copies of the approved participant information sheet, ethical approval letter and publicity flyer to facial support and single issue health organisations where people with an acquired facial ‘disfigurement’ might belong. One organisation requested and was given a copy of the completed 17-page University of Liverpool ethics form to evaluate before they gave consent to publicise the research on their website. When individuals who had heard about the research contacted me, I sent them another copy of the information sheet, which explained why the research was being conducted, who I was looking to interview, the implications of being involved and what would happen to the data. Regardless of whether people took part, they were also provided with a list of supportive organisations and their contact details. I spoke to most participants on the phone before the interview, to reiterate the contents of the information sheet, to allow them to ask any questions and to arrange an appointment to conduct the interview if they are still interested. Immediately prior to the interview commencing, I talked the participant through the information sheet, the narrative interview process and the informed consent form, i.e. their right to pull out of the interview at any point without explanation. After this point, I asked them to sign both copies of the consent form if satisfied, and to retain one for their records. After the interview had ended participants were verbally debriefed. I told them that the interview would be transcribed,
that they would get an anonymised copy. I did this for three reasons. Firstly, I wanted to give them something in return for their time and input. One of the participants said she would use it as a basis to write her life story. Secondly, for reasons of accuracy I wanted participants to comment on the transcript, to confirm the account or to add further detail, especially since the interview had been completed in one sitting and was therefore only an ethnographic snapshot, rather than a tripartite narrative interview encounter as Wengraf (2004) recommends. Thirdly, in keeping with ethical guidance I needed to provide participants with the opportunity to withdraw elements of the transcript or the whole account. I received comments back from less than half of the participants. They were mostly grammatical, or to elaborate slightly on a story. No one withdrew or contradicted anything they had said during the interview. One participant commented that he had been amazed how open he had been, another had found it ‘therapeutic’. All participants were provided with a summary of research findings early in 2014. Those that responded were positive about the experience.

The third ESRC ethical statement asserts that confidentiality and the right to anonymity must be respected. In compliance I anonymised the digital audio recordings and transcripts and made it clear to participants that the research data were being stored securely (encrypted and password protected). Identifying features were removed from quotes and conference presentations, also from academic papers when they are written. Whilst the participants’ right to confidentiality and anonymity must be protected, it can be assumed in research ethics applications and guidance that everyone will want to remain anonymous. The University of Liverpool allocation for ethical approval form (2011) was written on the assumption of preferred anonymity, so I was unable to give participants the option. However, with the movement towards visual research methods (Prosser, 2006; Tinkler, 2009) and a greater awareness of the merits of co-production (power sharing) between academics and participants (Martin, 2010; Roberts et al., 2012) the time has come for a re-examination of assumed participant anonymity in ethical guidance and applications (Tilley and Woodthorpe, 2011). Some people might want to be identified via their photograph or name. Changing Faces, an organisation I approached to publicise my research uses the faces of some of its members in online and printed media campaigns, to present positive role models of facially ‘disfigured’ people and to challenge stereotypes, for instance that facially different people are isolated and live hidden away. Allowing people to own their voice and face might make the research process more accountable from design to publication, and return some agency to those on which our careers are built. Furthermore, better research visibility particularly by
those labelled ‘vulnerable’ may contribute to greater public visibility, reduced ignorance and support for their right to freedom of expression (Fisher, 2011, p.12).

Finally, the fifth ESRC statement asserts that harm must be avoided. Whilst I do not wish to harm participants there is a research tension here. As a social scientist, I want to enable a group of marginalised people who have been under-researched and deemed ‘vulnerable’ (Fisher, 2011, pp.5-9) to be heard. In this respect the research provides an opportunity for people to open up about their lives, experiences and relationships. For most participants recollecting memories of the period during and after unhabitual facial change was painful, as their stories involved cancer diagnoses, existential crises, mental ill health, disrupted relationships and in some cases the death of a loved one. After one interview, a participant told me that she would feel ‘drained’ later as a result of recanting her story to me. Another said that in spite of the number of times she had told her story, it was always upsetting to relive it again. Whilst I have been unable to avoid distress caused through the biographical nature of the narrative method, I have tried to avoid the possibility of inflicting more serious harm to participants.

Narrative interviews allow people to talk in their own time and words about their experiences which stops the researcher from cutting across them with direct or painful questions (Chase, cited in Josselson and Lieblich, 1995). If people wish to disclose painful or emotionally resonant experiences, they do so of their own accord. To reduce harm stemming from the immediacy of a facial change experience I required that people only came forward if a two-year gap had elapsed between their facial change and the research inquiry. The information sheet also politely stated that if potential participants were undergoing treatment for a mental health condition, they would be excluded from taking part, along with anyone diagnosed with a moderate to severe mental health issue, regardless of treatment status. Additionally, on the information sheet I asked those interested in taking part to talk to their doctor (GP) if they were in any doubt of their fitness to take part. I let potential participants know that they could be interviewed with a friend, colleague, or relative if they wished, which was verbally reiterated prior to the interview beginning. In addition the information pack provided multiple contact details of two national facial support organisations (Let’s Face It, Changing Faces) and supportive guidance for facially ‘disfigured’ people designed by Changing Faces. And to ensure that I did not inadvertently harm participants with inappropriate language I attended a training day delivered by Changing Faces on being sensitive to the needs of people living with a facial ‘disfigurement’ (16th March, 2011).
Whilst it is essential to recognise and mitigate against harm from occurring, there may be benefits from disclosing sensitive experiences (Wiles et al., 2007). As the authors note, the interviewee may not have had the opportunity to talk uninterrupted about what has happened to them and to have someone listen, either ever before or not for a long while. The process of telling might help them to make sense of their experiences or to explore a new chapter in their life. Telling a professional stranger could be cathartic and potentially improve their health/wellbeing. The interviewees know that the details of their story will be kept confidentially and there will be no personal reverberations, in the way that an exchange with a friend or family member might (Gilbert, 2008). Furthermore, taking part in the research and being able to add to knowledge and reduce social ignorance in the area of facial ‘disfigurement’ may leave the person feeling that they are contributing to the greater good in a research capacity or beyond. Stephen, who felt that his life had been ‘ruined’ by acne rosacea strongly desired that his story be told if it could help to alleviate the suffering of others (though making people more sensitive to appearance differences). Andrew said that if he hadn’t been burned and told his story publicly, about the struggles he faced afterwards, that two little girls and a mother might not be alive now, as the mother (who had also been burned), had written to him on the verge of killing herself and her children. She had later informed him that their correspondence had helped her through a period of deep depression and suicidal thoughts. Two more participants stated that they had found the encounter beneficial in the aftermath of the interview. When returning an annotated interview transcript with comments Clara wrote that she had found the encounter ‘very therapeutic as I let go of some things I hadn’t talked about’ (2012). Responding to a summary of research findings in early 2014 Jonathon hoped that the work would enhance public understanding:

‘Thank you for including us in your studies. It was a pleasure to help in understanding more about people living with facial disfigurements and your work can only further improve public opinion and understanding’.

Chapter Summary

To conclude, I concur with Hallowell, Lawton and Gregory (2005) who argue that the rise of a politically motivated, bureaucratic research governance/ethics culture has narrowed the field of ethical commentary. Issues such as the prediction of ‘unnecessary’ risk, discussions surrounding informed consent, and a concern with participant confidentiality have been awarded an elevated status. The authors (2005) argue that these issues are important, but
that we need to remain flexible, reactive, and accountable for all of our actions, not just as researchers but as morally responsible selves (Bauman, 1993, cited in Hallowell, Lawton and Gregory, 2005). My PhD project has been peer-reviewed and conforms to ESCR ethical guidance. However, I have argued that a discussion needs to occur about the assumptions underpinning research anonymity. In addition, that it is impossible to prevent the harm of reliving the experience from occurring whilst creating rich original data and completing the second research objective. In closing, I concur with the sentiments of Hallowell, Lawton and Gregory (2005), who argue that we need to see ethics as an integral aspect of the whole research process. This is why many of the less complex moral issues relating to this project are located throughout the thesis in context as they arise.

‘We need to see ethics as an integral feature of all aspects of our research, from dreaming up a research question, designing the study, securing funding, negotiating access, recruiting participants, gathering and analysing the data to reporting our findings’ (Hallowell, Lawton and Gregory, 2005, p.151).
Chapter Four Analysis

Mapping existing facial research: Socio-cultural contexts, positivist paradigms and biographical complexity

Chapter overview
This is the first of five analysis chapters and the only one to draw on secondary sources. During the chapter I review three strands of facial and facial ‘disfigurement’ related material to inform my background knowledge. To my knowledge a review of these three strands has not been conducted together before. The findings of this chapter provide a context for the next four primary research based analysis chapters.

The first part of the chapter addressees the first research objective, an examination of ‘socio-cultural values associated with human faces in predominantly Western societies using secondary sources’ in full. The objective arose as a distinct response to the facial transplantation ethical and discussion papers where faces and bodies were considered in abstract terms, isolated from their cultural and temporal location. Faces were felt to be socially significant for humans though very little evidence had been provided or considered. My subsequent review of humanities and social science material has illustrated that symbolic values and meanings have been attached to faces, and facial appearance for over two thousand years (Synnott, 1993) indicating that faces have played significant roles in social reproduction since antiquity (Giddens, 1991; Benson, 2008).

The second part of the chapter contains a review of facial ‘disfigurement’ research. A number of papers have revealed the existence of a largely ‘hidden’ form of discrimination, the negative treatment of people based purely on the existence of a ‘disfigurement’. However, most of these studies have been framed within a positivist paradigm, which has focused largely on people in their limited role as patients, in clinical surroundings, measuring anticipated mental health deficits. Consequently, it has been difficult to get a sense of how embodied persons have made sense of the ‘disfigurement’ as part of their
lives and lifeworlds. Therefore, in addition to the studies I examine the contents of four biographical accounts during the final part of the chapter. These have provided more complex, nuanced experiences of living with an acquired or congenital facial ‘disfigurement’. One biography explores the life of Joseph Merrick, known more commonly as the ‘elephant man’ during the 19th century (Howell and Ford, 2009). The other three accounts are autobiographical, explore acquired ‘disfigurement’ and were written during the latter 20th century (Piff, 1985; Partridge, 1990; Grealy, 1995).

Part one: what socio-cultural values are associated with embodied faces in predominantly Western societies?

Introduction: situating faces
To accomplish the first research objective I completed a literature review on the socio-cultural values associated with embodied faces in predominantly Western societies. To my knowledge, such a comprehensive review has not been completed before. If people were being treated negatively, as the facial ‘disfigurement’ literature had revealed, I wanted to know why, as this was not greatly discussed. The relevant resources that I identified were drawn from a variety of disciplines including: sociology; philosophy; history and literature, as there was also a dearth of social science materials on this theme. The materials I did identify were mostly written from a Western viewpoint and discussed Western examples.

In the aftermath of the review two phenomena have become clear; firstly, that there is no single, universal definition of the term face. Perpich (2010) states that philosopher Levinas recognised that face incorporated notions of facade, personhood, agency, interaction and cognisance. Taken together, these definitions simultaneously involve identification and appearance, self and other, activity and constraint, not just corporeal coverings as some facial transplant paper authors have suggested (Carolessa and Pradeu, 2006; Swindell, 2007; Modgil, 2011). Instead, they incorporate the body-self and its movements within the world, themes which are reflected throughout the primary data analysis chapters. Secondly, faces play multiple and significant roles in human sociality and its reproduction.

During this first part of the chapter, I will consider three areas of significance: I will outline the symbolic value of faces; discuss the history of values associated with facial
appearance in the West, and consider the role of the face in individual embodiment, perception and sense-making. As Benson (2008) illustrates faces are never simply bodily entities with features, they can act as powerful devices to convey cultural meanings through the practices of everyday life through to the ritualised practices inherent in ceremonies of social significance:

‘Human faces never simply signify in terms of phenotypical features... Amidst a transpersonal set of strategies operating throughout society... faces are actively coded as allegorical signs and invested with cultural meaning in practices of everyday life’ (Benson, 2008, p.596).

Symbolic faces: structures, semiotics and subversion

This section will outline three ways in which faces can convey symbolic meanings: through masking during rituals; through characteristics being associated to groups by economic and political elites, and through choosing how to dress and present individual body-faces. Firstly, I consider the significance of facial masking during rituals. Aspects of the identity of the wearer are concealed, thereby protecting them and presenting new values and/or the possibility of transformation (Sorrel, 1973 cited in Tseelon, 2001). One of the earliest examples of masking can be seen through the funerary practices of Egyptian royalty three thousand years ago (Tseelon, 2001). Elaborate golden masks were placed on the faces of the recently deceased to illustrate their high status (as both royals and gods) and to act as an intermediary device, to help negotiate a safe passage between the potentially difficult boundaries of this world and the afterlife (Tseelon, 2001). However, not all groups privilege the face in this way. Pollock (1995) noted that the Kulina, a Western Amazonian tribe studied by anthropologist Lévi-Strauss during the 1950s did not use facemasks during identity transition rituals, as they did not associate faces as being unique sites of identity change (1963, cited in Pollock, 1995). Likewise, the Kwakiutl (British Columbia, Canada) studied by Boas, regarded the whole body as significant, not just the face, in enacting and displaying ritualised identity transformation (1966, cited in Pollock, 1995).

Secondly, faces themselves can be used by political elites and individuals to create, maintain or subvert social and power structures. Anthropologist Benson (2008) has utilised Deleuze and Guattari’s concept of faciality (1987, p.168) to explain the perpetuation of structural violence towards migrant Mexican farm labourers in Brazil.
For Deleuze and Guattari (1987) faciality occurs when power and perceptions overlap. Benson (2008) uses the concept to explain how political elites could exploit their power by associating negative moral values with the facial appearance of marginalised societal groups, to benefit themselves. The soil and dirt amassed on the face and body of migrant farm labourers, through manual labour and the limited hygiene facilities of the labour camps, i.e. a lack of adequate toilet facilities, became associated with a kind of moral dirt, leading to their defacement, or dehumanisation and disempowerment. This defacement narrative has been perpetrated by political and media elites and used as a reason not to improve pay and working conditions, thus serving the interests of agricultural producers who supply the demand for cheap goods (Benson, 2008).

Finally, at the level of the individual, I will use the work of Broekman (2009) to illustrate how body-faces may be used to subvert Western gendered expectations of femininity. For Broekman, the face forms a type of cultural artifice, which lies at the heart of human semiotic encounters. This artifice is made possible in three ways. Firstly, through a cognitive component; the face is a thinking and expressive vehicle. Secondly, humans have the ability to interpret abstract meanings from facial expressions in others, i.e. sadness, anger and joy. Thirdly, as well as the ability to perceive facial meanings more generally, i.e. happy or sad, humans have the capacity to interpret specific meanings within a wider context. Broekman (2009) uses the example of Tilda Swinton, a British Actress attending the 2008 American film Oscar awards to explain. Swinton, who was nominated for an award and therefore receiving considerable media attention, chose to attend without any makeup and wearing a simple white dress. Swinton, it is argued, understood her face as a sign rather than a ‘natural’ entity, and chose to subvert gendered expectations of heavy makeup and glamorous dressing by appearing facially ‘nude’ in contrast to the women around her.

‘At the Oscar ceremony, she appeared brazenly pasty, unstained by rouge and bronzer, a white waif in an ocean of spray-tanned limbs and bobbing plastic torsos. Her asymmetrical dress exposed an ivory arm. The virginity of her unpainted flesh made everyone around her look like a crowd of aging, insecure hookers. I admired her for... braving the television lights without a whisper of powder of blush — for being what passes for naked in Hollywood in front of millions, if not billions, of people. On television, she looked like a fabulous alien’ (Kuczynski, 2008, cited in Broekman, 2009, p.50).
In summary, it is evident that within the context of their period, power structures and cultures, faces can be used as vehicles for: expressing ritualised social transition; political and economic legitimation, and for individual representation, belonging and cultural subversion. It has become evident that body-faces are embedded in the practices, processes, performances and politics of social reproduction.

**Don’t judge a book by its cover: two thousand years of reading faces**

Faces can convey a raft of coded signs and political agendas, conveying meanings beyond the phenotypical features of the individual. This next section charts the origins, contexts and implications of moral values associated with facial appearance through literature, religion, art and more recently through the media industries of film and television. This is important, to illustrate how faces have been used to convey societal meaning and to influence public perceptions of ‘disfigurement’. With a reported one in eleven people in Britain experiencing a facial ‘disfigurement’ at some point in their lives *(Changing Faces, 2007)*, the issue is of long-standing significance. Facial ‘disfigurement’ researchers (Rumsey et al., 2004) and facial equality/support groups *(Changing Faces, Let’s Face It)* have consistently reported that those who fail to meet normative facial expectations, e.g. by not having symmetrical features, can experience negative treatment from others including ridicule and ostracism. This finding is reflected in the experiences of most of the participants. Synnott (1993) argues that unlike other body parts, strong associations have developed between a person’s facial appearance and their supposed moral character. These associations can be traced back to ancient Greek authors, whose ideas have influenced European literature for the last two thousand years.

Sappho proclaimed that what is beautiful is good and that those who are good will soon be beautiful, while Homer equated evil with ugliness in the *Iliad*. Plato (cited in Synnott, 1993, p.76) added ‘beauty is good and the good beautiful, souls should not be wasted and destroyed by ugliness and evil’. However, there have always been critical challenges to this premise. Writing during this period Socrates wrote that true beauty was not something that was conveyed in the face, as the body was imperfect and contaminated (Synnott, 1993). While Diotima argued that moral and spiritual beauty should be ranked above physical attractiveness. During this period, Aristotle became fascinated with faces. Drawing on the idea that everything is present and expressed in the face, including the soul, Aristotle wrote *Physiognomics*, a manual for the study of
reading faces (Popovic, 2007). The idea that it was possible to determine someone’s mental capacity and moral character from ‘reading’ their physical facial attributes became popular and lived long after its cultural milieu had faded.

Within the Christian religion, early ideology also fed the notion that beauty is desirable and indicative of moral goodness. Genesis states that humans are made in the image of God, by God and that God is good. Much early and medieval Western Christian art is devoted to the glory of God’s beautiful creation. In the fourth century, Augustine argued that God is beauty and that beauty is God (Synnott, 1993). Therefore, those who are not beautiful or who are facially different in some way must be removed from God. At the same time, Christian mythology promotes the idea that people are weak and vulnerable to sin. Passages within the sacred text of Christianity, the Old Testament of The Bible put forward the idea that sinners will be punished for their un-Godly behaviour. One of the ways that God is supposed to enact his revenge is through punishing the body, including the face. For example, the book of Exodus reports that when the Pharaoh refused to comply with God’s wishes, He released a series of plagues, one of which involved covering Egyptians with boils. The association between bodily maiming and sinful activity has therefore ‘trickled down’ through the centuries, and though it has been overwhelmingly discredited, some people reportedly wondered whether they were being punished by God (Thompson and Kent, 2001, p.665).

‘And they took ashes of the furnace, and stood before the Pharaoh; and Moses sprinkled it up towards heaven; and it became a boil breaking forth upon man, and upon beast’ (The Bible, Exodus. 9:10).

Themes resonating from these early sources are evident in European renaissance literature. Dante’s Divine Comedy features a Satan who is evil and ugly (Synnott, 1993). Whilst Shakespeare’s character Miranda in The Tempest states that a good-looking man is a divine thing and therefore is good. Milton’s Paradise Lost features Adam and Eve who are beautiful in paradise before their fall from grace; afterwards they are punished by being thrown out and turned into ugly serpents. However, Firenzuela, a contemporary of Dante’s argued that physical beauty had no relationship to morality and contemporary writer Francis Bacon concurred, stating that ‘deformed persons are common even within nature’ (Synnott, 1993).
The cultural and moral value of faces became more pronounced during the late eighteenth and nineteenth centuries. Aristotle’s physiognomic premise that the moral and mental character of people could be gleaned by studying faces regained prominence. According to sociologist Giddens (1991), the growth of scientific rationalism and the progression of the industrial revolution had left people feeling ‘ontologically insecure’ about themselves and their known worlds. Being able to read someone’s face and therefore their moral and intellectual character allowed people to ‘know’ others during a period of rapid geographical and social upheaval. Consequently, the question who is my neighbour became a prominent literary theme during this period. Faces took on a heightened significance, as devices to explore the dichotomies of friend/stranger, country/city and ultimately good versus evil. In Jane Austen’s *Pride and Prejudice* written in 1813 heroine Elizabeth Bennet tries to decide which of her two (recently acquainted) suitors would make a better husband, by comparing their appearance and actions with her sister Jane:

‘There certainly was some great mismanagement in the education of those two young men. One has got all the goodness, and the other all the appearance of it’ (Austen, 1998, p.172).

In Mary Shelley’s (1969) enlightenment classic *Frankenstein*, published in 1818, a person known as the ‘monster’ is constructed from body parts and brought to life by creator Victor Frankenstein. The monster is created to be morally virtuous but becomes bad as characters within the novel reject him, partly due to his unattractive physical appearance. Charlotte Bronte’s moral heroine *Jane Eyre* (1994), published in 1847, only marries the man she loves after he has been physically disfigured through an act of moral redemption. The flawed male protagonist (Mr. Rochester) loses his sight after trying to rescue his ‘mad’ wife from a house fire that she started. With Jane eventually at his side as his new wife, not as the mistress he previously proposed, Rochester regains some sight having metaphorically learned to view things differently.

Stevenson’s *Dr. Jekyll and Mr. Hyde* (1994) published in 1886, is one of many gothic horrors to wrestle with the body-face beauty and morality theme. After consuming a potion of his own creation, the virtuous medical doctor, Dr. Jekyll transforms into the physically deformed Mr. Hyde and cannot control the immoral acts he commits during the night-time. Similarly, in *The Picture of Dorian Gray* published in 1891, Oscar Wilde makes the point that all that is beautiful is not good (Twine, 2002). The central character Dorian, an affluent gentleman, does not age through life unlike his friends.
Though the physical traces of his immoral actions throughout life, e.g. getting a girl pregnant and disowning her, become etched onto the face of a portrait painted in his youth, which he moves to the attic to avoid it being seen. When Dorian dies the facial deformities on the portrait dissolve and become etched on his face as the traces of his actions return to the body. There is no single way of viewing at the body-face here, but what all books have in common is the use of body-facial difference to discuss the morality of key characters.

Literary debates relating beauty with goodness and evil with ugliness/’disfigurement’ continued well into the twentieth century, long after the pseudo-scientific ideas underpinning them were seriously discredited (Synnott, 1993). Early in the century crime writer Agatha Christie drew on popular understandings of the discredited practice of physiognomy, to convey immorality in her characters (Twine, 2002). She described unpleasant-looking villains with shifty eyes, criminal jaws and low brow ridges. Elsewhere in Europe, the same device was being employed by political leaders for different ends. Jews were under attack on two facial fronts during the Second World War (WW2). In Mein Kampf Adolf Hitler drew on physiognomy to present Jews as physically and morally inferior beings with large noses (Twine, 2002). Whilst Nazi instigators used cartoons to create associations between the faces of Jews with those of animals (Dudley, 2002) whilst the faces of blond haired, smaller nosed, blue eyed, Caucasian Germans were portrayed positively. It appears that the practice of faciality (Deluze and Guattari, 1987) was being utilised by powerful elites to dehumanise people long before Benson’s (2008) work in Brazil.

In the years after WW2 Ian Fleming applied the same literary device as Agatha Christie to his James Bond books. The physically attractive moral hero, James Bond generally fights and always wins battles against bodily or facially damaged or diverse enemies. In The Man with the Golden Gun (United Artists, 1974), the head of a secret criminal organisation Scaramanga had three nipples on his chest. In Moonraker (United Artists Corporation, 1979) the seven-foot henchman Jaws had metal teeth. Whilst the iconic villain Blofeld who appeared in three Bond films, e.g. From Russia with Love (United Artists Corporation, 1963) had a deep facial scar running from his eye down to his cheek. In the 2006 remake of Casino Royale, (Sony Pictures) Bond fights and defeats a money laundering assassin (Le Chiffre) who has a facial scar and a tear duct anomaly, which leads him to shed tears of blood when he becomes anxious. Most recently, the main villain Silva in the film Skyfall (Sony Pictures, 2012) has to wear a facial obturator
to keep his appearance equal on both sides owing to an earlier acid burning incident and the loss of tissue, bone and teeth. Table 1 provides some visual examples of the many James Bond foes with body-facial differences or ‘disfigurements’ which audiences have come to expect.
### Table 2: Examples of James Bond foes with body-facial differences or ‘disfigurements’

<table>
<thead>
<tr>
<th>Photograph of James Bond foe and image source</th>
<th>Character and ‘disfigurement’</th>
<th>Film</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Silva](wikja, 2012)</td>
<td>Silva facial ‘disfigurement’ and missing teeth</td>
<td>Skyfall (Sony, 2012)</td>
</tr>
<tr>
<td><img src="james_bond_mm" alt="Le Chiffre" /></td>
<td>Le Chiffre scar through eye, cries tears of blood when nervous</td>
<td>Casino Royale (Sony, 2006)</td>
</tr>
<tr>
<td>![Jaws](filmsirkus, 2014)</td>
<td>Jaws he is over seven foot tall and has very strong metal teeth</td>
<td>The Spy who Loved Me (United Artists Corporation, 1977) Moonraker (United Artists Corporation, 1979)</td>
</tr>
<tr>
<td>![James Bond as Scaramanga](every_james_bond_movie, 2014)</td>
<td>James Bond as Scaramanga third nipple on chest</td>
<td>The Man with the Golden Gun (United Artists Corporation, 1974)</td>
</tr>
<tr>
<td>![Blofeld](pgcooper, 2014)</td>
<td>Blofeld deep scar running length of face</td>
<td>From Russia with Love (United Artists Corporation, 1963) Thunderball (United Artists, 1965) You Only Live Twice (United Artists Corporation, 1967)</td>
</tr>
</tbody>
</table>
Embodied facial senses and socio-cultural associations

Thus far, I have established that facial appearance can carry values and be involved in social reproduction. This final section will consider the role of individual faces in the process of embodiment, and outline some Western socio-cultural associations with facial parts. The theory of embodiment, a central concept here, has been used by researchers to examine people’s multisensory experiences of their bodies and bodily change. Developed in criticism of Cartesian theory, which separated minds from bodies, Merleau-Ponty (1962, p.173) argued that the lived body is not experienced as an object, broken down into discrete entities, such as rational thought or physical pain. Rather, we are embodied beings, consisting of a connected mind, body and self, existing within a specific time and space (Toombs, 1988), embedded within surrounding physical and social worlds (Carel, 2011). The lived body incorporating the lived face, is not simply an object in the world, but instead is primarily a way of accessing and experiencing it.

The world shapes the physical, cognitive and cultural relations and boundaries of the body, but is itself shaped by the actions of the body and face. I access the world via my senses, which have a physicality and a presence within the body, many of which exist within the facial region, e.g. seeing, hearing, tasting and smelling (Table 2, Embodied functions located within the facial region). Therefore, to understand embodiment comprehensively, it is necessary to consider the complexities of facial sensory perception and expression. As Rutter (2007, pp.285-56) notes:

‘Many of our most powerful human expressions come from facial behaviour, facial movements, facial gestures: we speak, we wink, we stare, we kiss, we cry... As a site of perpetual reception and existential expression, the face is a complicated place’.
<table>
<thead>
<tr>
<th>Function</th>
<th>Facial feature/action</th>
</tr>
</thead>
<tbody>
<tr>
<td>hearing</td>
<td>ears</td>
</tr>
<tr>
<td>sight</td>
<td>eyes</td>
</tr>
<tr>
<td>touch</td>
<td>facial skin, lips</td>
</tr>
<tr>
<td>breathing</td>
<td>nose, mouth, skin</td>
</tr>
<tr>
<td>smell</td>
<td>nose</td>
</tr>
<tr>
<td>taste</td>
<td>lips, mouth, tongue</td>
</tr>
<tr>
<td>conveying emotions</td>
<td>eyes, mouth, tongue, lips, nose, cheeks, eyebrows</td>
</tr>
<tr>
<td>communication, verbal and non-verbal</td>
<td>ears, eyes, mouth, tongue, lips, cheeks, eyebrows</td>
</tr>
</tbody>
</table>

Starting with the eyes, they can be seen as ‘the window to the soul’, enabling individuals to see and sense what another person is thinking or feeling. Eyes also play a key role in interaction (Synnott, 1993), allowing us to interpret others moods and intentions and to respond to them accordingly. Eyes can leak emotion through tears of joy, pain or sorrow; they also enable us to identify food, drink and shelter, to make sense of and navigate landscapes, and to lip-read. They can be dressed through the application of gender or sub-culturally appropriate makeup, sight defects can be aided through the addition of reading glasses, which are associated with intelligence in the West. Ears allow us to hear and communicate with others, sense danger, take on board new information and to make sense of environments that we inhabit and create. They can also be modified to become sites of differentiated socio-cultural significance (Broekman, 2009, pp.49-50). For example, during the late 1970s and early 1980s in Britain, the practice of wearing earrings for women could be seen as an act of gender conformity, through body enhancement. However, at the same time, this act was subverted by the sub-cultural group punk rockers (punks), who wore multiple, exaggerated piercings to illustrate their rejection of the political state. Simultaneously, gay men could wear one earring, to recognise each other in an era of social, political and physical hostility.

Noses not only allow us another way of breathing, they allow us to inhabit, make sense of and engage in another aspect of the world, that of smell. As well as appearance,
odour is one of the indicators which separate the self from the other; not having this sense can leave a person feeling muted (Synnott, 1991, pp.439-440). Synnott also asserts that we are socialised into which smells are acceptable and unacceptable from an early age and as with other areas of social life, these rules are embedded within existing power hierarchies (1991, pp.447-452). Supporting Deleuze and Guattari’s (1987, p.168) concept of faciality and Benson’s (2008) findings, Synnott (1991, pp.447-452) noted that people in less powerful societal groups, i.e. those from minority ethnic groups and in lower income groups could have distinctive and disagreeable odours attributed to them, which justified and perpetuated their poorer treatment by those with greater power. Whereas scents associated with power and high status were more likely to be described as pleasant and acceptable. It would appear that faces are equipped with a powerful socio-political tool, the ability to ‘sniff out’ power relations.

In addition to noses, mouths allow us to breathe and therefore to live. Through lips, tongue and teeth, mouths allow us to state our needs, moods, intents and to communicate with others, enabling the re-negotiation of both psycho-social and physical worlds. In terms of sustenance, the mouth region allows us to take in and taste food and drink, to break it down using our teeth and to swallow. Mouths, or rather lips touch, caress and kiss, which can incite powerful emotional reactions in others. Voices also play a critical role in the recognition of selves and similar and unknown others, through a combination of pitch, speed, intonation, accent (local, regional, national) and pronunciation. In England it can be possible to infer a person’s socio-economic standing from the words they use, how they pronounce them and the speed, confidence and fluency with which they are pronounced. Voices also take part in singing, enabling humans to develop their sense of individual and group identities. Moss (1998) has argued that communal wailing at funerals can serve as a vehicle to create or reinforce ethnic identity through the passing down of familial and ceremonial songs. Finally, Rudge (2009) has argued that skin has been overlooked as an object of social investigation, even though it plays such a significant role. Skin acts as a visible and palpable boundary, between the inner and outer worlds of the embodied self. Externally skin makes visible the boundary between self and other. We also recognise others through the touch of their skin and its feeling on our own. In cases of facial reconstruction, these boundaries are disrupted and re-written as a result of the exchange between self, surgery, bio-technology and other (Haraway, 1991; Shildrick, 2008).
'Skin is the embodied tapestry that... contains us, keeps us from leaking except at specific points, prevents infections, maintains our sense of embodiment... assists us with regulating our temperature, acts as a point of attachment, senses our environment, gives out messages and does some of our excretion’ (Rudge, 2009, p.234).

Overall, it is clear that faces play a powerful role in embodied and symbolic social reproduction. In addition, that socio-cultural associations can be attached to facial parts as well as facial appearances.

**Part one summary: the powerful phenomena of embodied faces**

It has become clear that faces, as part of bodies, are imbued with a variety of socio-cultural meanings on multiple levels. Therefore, I will be adapting Scheper-Hughes and Locke’s (1987, pp.7-8) tripartite notion of embodiment, based on the individual, the social body and the body politic to frame this summary. The individual body refers to the lived experiences of the body as self. The social body encapsulates representational uses of the body as a symbol of nature, society and culture, whilst the body politic explores the control and regulation of bodies. I intend these to be used fluidly and in association with each other.

On an individual, phenomenological level, people experience the world through their body and their face. Several senses are located in the facial/head region, including the eyes, ears, mouth and nose making it a significant site for perception and sense-making. Although, these experiences are filtered through many lenses including: epoch; culture; socialisation; ethnicity; gender and sexuality. For example, Tilda Swinton (Broekman, 2009) chose to illustrate her agency and subvert hegemonic gender expectations as a twenty-first century Western woman by arriving simply dressed and without makeup at a significant film award ceremony.

In terms of the social face, inaccurate and harmful historical associations between facial appearance and moral character still pervade British society through the works of influential Georgian, Victorian and twentieth century literary authors such as Jane Austen, Oscar Wilde and Ian Fleming as I have shown. However, on a more complex level, facial appearance has also been used as a device to consider social reproduction (Giddens, 1991). Being able to read the moral and intellectual character of your neighbour through studying their face and head became increasingly popular in a
period of great social upheaval, i.e. mass migration from the countryside to rapidly expanding British towns and cities. Whilst the masking of faces during ceremonies displaces the individual’s identity, enabling ritualised social reproduction to occur (Tseelon, 2001).

Finally, examples of facial politic go back for thousands of years with the head of the victorious or conquering ruler appearing on coins and the heads of the losers being displayed publicly on spikes. Even today, on English money, Queen Elizabeth II’s head features on both notes and coins. Utilising the concept of faciality (Deleuze and Guattari, 1987, p.168) Twine (2002), Dudley (2002) and Benson (2008) have illustrated that sub-sections of society, in this case those with very little power, can be conceptualised negatively and used to serve the interests of powerful elites. However, this is not a one-way argument. Groups wishing to change the status quo can use the faces of iconic leaders or individuals to muster support and to challenge orthodoxy. It is clear that faces can and do play a role in the perpetuation of power and inequalities. It is also clear that individual, social and political faces are embedded in the practices, processes and performances of social reproduction.

Part two: what the literature says life is like for people with a facial ‘disfigurement’

Overview: findings; issues and biographies

I have established that the body-faces of individuals and groups are embedded in social reproduction and that negative socio-cultural values have been associated with facial ‘disfigurement’. During the second part of this chapter, I will summarise the findings of two strands of work from the field of facial ‘disfigurement’ research. Firstly, the impact of having a facial ‘disfigurement’ on individuals and their relations (social interaction needs, the visual self and changes, and coping with difference). The second strand considers societal attitudes to ‘disfigurement’ (public attitudes towards difference and how and why people are treated differently). The findings have been illuminating. Researchers have identified that, in comparison to people who are considered to be ‘good looking’, people with facial ‘disfigurements’ can experience overt and covert discrimination and a reduced quality of life, such as reduced career and relationship opportunities (Rumsey et al., 2004). In addition, when someone’s appearance changes, either through reductive or reconstructive surgery, they have an
increased chance of becoming depressed and anxious, due to the shock and loss associated with facial change and the unwanted stares and critical comments from others (Callaghan, 2004). Whilst these studies have increased our knowledge, I have also found some gaps and tensions, which have been acknowledged within the ‘disfigurement’ field thus illustrating the need for this PhD. I outline four pertinent points.

Firstly, I had expected to find complex, qualitative accounts of identity shift in the aftermath of body-facial disruption. However, many studies within the facial ‘disfigurement’ field drew on a bio-medical model of disability, as a deficit condition to be treated and managed, which was informed by Cartesian conceptions of bodily dissociation (Grosz, 1994, pp.6-9; Wendell, 1996, p.117). Let me explain. In many studies, the participants were referred to in their role as patients rather than as nuanced and connected persons (Wendell, 1996). Minds and bodies tended to be considered separately in the field, with the focus on either physiological or psychological repair of the ‘machine’ (Leder, 1990, p.199) to enable a speedy return to ‘normality’ in a world challenged by corporeal difference (Shildrick, 2010). Ultimately, this conception of persons leads to their experiences and voices becoming subservient to the observation and measurement of symptoms (Barnes and Mercer, 2003). For example, some studies assume suffering from the outset and test associations for psychological deficiency with discrete variables such as depression using ratings scales. I do not wish to deny the suffering that people experience nor their desire to return to a revised physical and psychological ‘normality’. What I do wish to draw attention to is the partial and limited exploration of people’s experiences which was noted by Stricker et al. (1979, p.419) some decades ago:

‘It is possible to apply quantitative methods to behavioural characteristics, such as intelligence, learning, motivation, anxiety and frustration, in only a limited sense’.

UK-based facial equality campaigners (Changing Faces, Let’s Face It) argue that surgery and counselling is only one response to the issue of facial ‘disfigurement’ and that it has been unfairly prioritised. These groups point out that there has always been facial and bodily diversity, that it is part of life, and that society needs to understand and engage so that people are accepted and do not fear negative treatment from ignorant others (Wendell, 1996; Barnes and Mercer, 2003; Shildrick, 2002, 2010). The remaining three issues draw on the findings of Thompson and Kent’s (2001) review paper.
The second point refers to the weak design of some ‘disfigurement’ studies, as authors have relied on the use of un-validated survey instruments, so it is not clear how accurate the findings are (Thompson and Kent, 2001). Thirdly, many studies suffer from low sample sizes, without control groups for comparison (Bessell and Moss, 2007). Finally, the measures of adjustment to facial ‘disfigurement’ tend to be generic and may not be accurate or specific enough to assess the needs of facially ‘disfigured’ people (Thompson and Kent, 2001). These issues are not unique to the field of facial ‘disfigurement’ research, though some have argued that it has left conclusions open to question (Thompson and Kent, 2001; Bessell and Moss, 2007). These findings illustrate the need for a contextualised, phenomenological and embodied approach, which puts the participants at the heart of the research and explores which experiences are important to them in their terms. To inform my knowledge and help fill the gaps left by some of the ‘disfigurement’ methods and findings I drew on four published biographical accounts, which are examined during the last third of this chapter. The biographies concerned Joseph Merrick (Howell and Ford, 2009) known as the ‘elephant man’, now deceased; Christine Piff (1985) Chair of Let’s Face It; James Partridge (1990) Chair of Changing Faces and Lucy Grealy (1995) author, now deceased.

Facial ‘disfigurement’ findings: individuals and relationships
This first strand explores the impact of facial ‘disfigurements’ on individuals and people they have relationships with, focusing on social interaction needs, the visual self and changes, and coping with difference. In terms of social interaction needs I am going to summarise one seminally rigorous, large-scale piece of research conducted by Rumsey et al. (2004). A convenience sample of 458 outpatients at 15 head and neck outpatients clinics were asked questions on: appearance concerns; the perceived noticeability of their ‘disfigurement’; factors affecting lifestyle, coping, social support and level of care satisfaction. There was an 86% response rate, all were over 18 years of age and 55% were in employment. The results revealed that the mean scores for anxiety were below threshold levels, that patients attending burns clinics had the lowest anxiety scores, that women had higher levels of depression than men and that those in work were less depressed than those not working. Patients who avoided activities because of appearance-related concerns were more depressed. In terms of their appearance, 22% thought work opportunities had been affected, which potentially meant that 78% did not, or were not sure. Many thought friends did not notice as much as strangers. When asked if there was
anything they avoided, 63% reported a range of situations including sports and appearing in photos. This finding was also evident during the fieldwork. Avoiding being in photographs and looking into mirrors after facial ‘disfigurement’ is explored during Chapter Seven (Visual transition/liminality and identity shift) and Chapter Eight (Reflecting on reflections: some visual implications of acquired facial ‘disfigurement’). Rumsey et al. (2004) concluded that a high proportion of facially ‘disfigured’ people were experiencing physical and functional problems, but also difficulties with relating to other humans. Social interaction, exposing the ‘disfigurement’ and dealing with ignorance, gazing and negative comments were of particular significance. The size or severity of a ‘disfigurement’ could not predict the level of distress; indeed a variety of responses were evident.

Some discussion papers considered the visual self and associated facial changes. However, the research could be narrowly constructed, for example a reliance on psychological measures, which could be untested or lacking in social context. In an early and unusually large study, Lefebvre and Barclay (1982) examined changes in self-esteem before and after changes in visual appearance. 250 patients with severe craniofacial deformities were interviewed pre-operatively, as well as the parents of 215 children/adolescents. People were asked to rate their appearance according to a scale, with one for children and adolescents and one for adults. Participants were interviewed post-operatively one, two and four years after surgery. One year post-operatively 96 out of 125 had noted a psychosocial and emotional improvement, i.e. increased comfort in public places, diminished self-consciousness, an increase in appearance interest and feelings of being more appealing to others. In a discursive piece, Callaghan (2004) examined facial ‘disfigurement’ and sense of self in head and neck cancer patients. She argued that the face held both literal and symbolic functions, it was our presentation to the world and how we were remembered. She found that patients who had undergone head and neck cancer surgery reported distress, negative self-image, loss of self-esteem and diminishing sex drive (2004).

Finally, in terms of coping with difference, research findings have indicated that a number of factors can predict, but not determine, how well a person will adjust to being facially different. The initial reason why a person seeks surgery can have an impact on how well they cope afterwards (Van Doorne, Van Waas and Bergsma, 1994). Dropkin (1989), a research nurse with specialist cancer experience proposed that an inability to cope with facial ‘disfigurement’ at discharge could result in a wound infection, through non-treatment compliance due to denial, depression and social isolation. Fauerbach et al. (2002)
investigated body image changes in people following burn injuries and found that the severity of the injury did not completely account for the varying rates in post-injury, body image adjustment and hypothesised that this arose from the degree to which people utilised coping mechanisms.

Vickery et al. (2003) investigated the impact of post-operative head and neck cancer on the quality of life of patients and their partners between 1999 and 2001. 51 participants were recruited from outpatient clinics in England. Partners were assessed separately using five quality of life measures to determine anxiety and depression; the quality of partner relationship; quality of life in cancer patients and an assessment of the extent of the dysfunction and ‘disfigurement’. The study reported that the median scores for anxiety and depression for patients and partners fell within normal ranges. Both patient and partner scores fell below the clinical level for psychosocial distress. No difference was found between partners and patients regarding the perceived quality of relationship. In fact, partners’ scores were in line with the findings of non-‘disfigured’ population relationship measures:

‘... head and neck patients and their partners aren’t necessarily pre-disposed to psychological differences and lower quality of life’ (Vickery et al., 2003, p.295).

In summary, we can see that the focus of the research is on patients not persons, perceived and actual reductions in mental states, which has been conducted using quantitative methods, addressing researcher concerns. It is not possible to consider the embodied identity shift, which may have taken place as a result of an acquired facial change, thus necessitating the need for this PhD study. Nevertheless, a few themes have become evident from the review. It is clear that a change in facial appearance can negatively influence a person’s psychological state through being image-avoidant, depressed, socially avoidant and vulnerable to unknown others’ intrusive stares and comments. However, it is also clear that people will cope with the change differently according to a number of influences, including the reasons for the change and coping mechanisms in the aftermath of the health event, which was not necessarily determined by the severity of the injury. In addition, some expectations of depression or isolation in participants were overstated. As Vickery et al. (2003) note, the expectation of reduced quality of life does not necessarily materialise.
Facial ‘disfigurement’ findings: public reactions and attitudes

This second strand examines public attitudes towards difference using an early field experiment, a mock job interview experiment and an online survey. Early research by Rumsey, Bull and Gahagan (1982) examined the proxemic behaviour of the general public towards facially ‘disfigured’ individuals. (Proxemics is the study of measurable distances between people as they interact.) Previous research had found that people regarded less favourably were given more personal space. This field experiment explored whether facially different people were regarded less favourably and given more personal space. The distance between people who had to wait to cross a busy street and a supposed facially ‘disfigured’ person was measured. The results illustrated that there was a difference in the way that people responded to a person with a perceived facial difference. For both ‘disfigurement’ conditions (strawberry birthmark and temporary trauma) people chose to stand more frequently on the non-‘disfigured’ side of the person facing them. On average people stood 44cms further away from the person with the birthmark, when compared to the person with a ‘normal face’. When comparing the strawberry birthmark and temporary-looking trauma marks pedestrians were found to stand an average of 22cms further away from the person with the congenital marks. The authors concluded that the public may avoid facially ‘disfigured’ individuals (Rumsey, Bull and Gahagan, 1982).

Stevenage and McKay (1999) also found evidence of the unequal treatment of people with a facial ‘disfigurement’ through their research into the effects of facial appearance on recruitment decisions. Creating a mock interview experiment, they assessed three dependent measures: perception of personal qualities; job skills and job recruitment decision. 59 business and management undergraduate students and 57 recruitment personnel took part. The recruitment personnel had at least five years’ experience. Four conditions were assessed: an applicant of ‘normal’ appearance; an applicant with a facial ‘disfigurement’ only; an applicant with a physical disability only and a person with both a facial (port wine stain) and a physical disability (in a wheelchair). Mock assessments took place for a job position for which all candidates were qualified. A CV and a questionnaire, assessing personality and job skills were used to assess suitability. Photographs of all candidates were sent in advance, with either the port wine mark or the wheelchair clearly visible. Concurring with the results of the socio-cultural review, Stevenage and McKay (1999) found that the perception of personal qualities and skills was felt to be lower if the candidate had either a facial ‘disfigurement’ or a physical disability. The impact was greater for those with a facial ‘disfigurement’ and worse still if people were perceived to have both
a facial and a physical ‘disfigurement’. Though, the findings indicated that all of the recruitment consultants would still have hired all of the students. However, the candidates were never interviewed in person and as people were aware of the research setting they may have responded in the ways they felt morally obliged to, e.g. treating everyone equally rather than how they would in real-life circumstances.

An online survey\(^7\) (Changing Faces, 2008) to explore people’s responses to facial ‘disfigurement’ concurs with Stevenage and McKay’s (1999) earlier perception findings. Two types of questions were asked, conventional and an implicit attitudes test (IAT). The IAT survey was designed to reveal implicit, unconscious attitudes. 1,000 people over the age of 18 completed an online survey; the sample was reportedly representative, though no details of sampling frames or methods were given. No difference was revealed between the reactions of people with and without a ‘disfigurement’ to replies to the conventional questions. However, the IAT results revealed that ‘90% were shown to have unwitting negative attitudes towards people with facial disfigurements’ (Changing Faces, 2008). The IAT results revealed that people with facial ‘disfigurements’ were judged to be: less attractive; less likely to succeed; less socially skilled and less likely to lead happy lives. The authors conclude that this type of attitude is indicative of widespread facial prejudice, which can be summarised in three inaccurate beliefs. Firstly, the prejudice of the ‘second-rate’, where people are judged to be less successful in life, when compared with ‘good looking’ people who are thought to be more successful. Secondly, people are judged to be different, of low intelligence and can be excluded and finally, the prejudice of assuming that a surgical cure will make people happy by fixing the ‘disfigurement’ physiologically. In summary it would appear that people can be treated less favourably based on their facial appearance both directly and indirectly. However, the evidence also suggests that discrimination may not occur, though more research is needed to confirm these findings.

**Summary of key ‘disfigurement’ findings**

A few themes have become evident from completing the review of facial ‘disfigurement’ studies. Firstly, a gap between public and private perceptions towards facial ‘disfigurement’ has been found. Though people may claim to treat facially different people equally in public, they have been found to give them more space on walkways (Rumsey, Bull and Gahagan, 1982) and to perceive them less favourably to facially ‘normative’ people, as

\(^7\) Public Attitudes Survey.
indicated by the *Changing Faces* survey (2010). Secondly as much of the facial ‘disfigurement’ research draws on biomedical conceptualisations of disability, e.g. it takes place in clinical settings i.e. hospitals, and focuses on psychological using quantitative methods, it is not possible to assess how situated and embodied persons experience facial change and possible identity shift. This methodological gap has been reduced through the completion of my second research objective and the production of situated and contextualised research data. Thirdly, what is apparent from the literature is that there can be a relationship between changes in people’s facial appearance and their emotional and psychological states. It is evident that the degree to which people adjust to having an altered appearance is contingent on numerous factors, including pre-existing resilience, the cause of the ‘disfigurement’ and access to medical, familial and therapeutic support. In addition, the magnitude of the alteration is not necessarily an indicator of how well the person will adjust to life afterwards. Finally, some expectations of reduced quality of life in people with an altered facial appearance do not always materialise as Rumsey et al. (2004) and Vickery et al. (2003) found. Overall, the ‘disfigurement’ findings gave me some snapshots of understanding (Figure 1), though it highlighted some knowledge gaps such as the socio-cultural context of living with a ‘disfigurement’ or how perceptions shift over time. So, I completed a content review of four published biographies written by or about people with a facial ‘disfigurement’ to enhance my understanding of contextualised lives, experiences and sense-making. The results are now examined during the third and final part of this chapter.
Part three: biographical accounts; persons and place

Introduction
Very few facial ‘disfigurement’ studies have considered the identified experiences of the participants before, during and after unhabitual facial change using a qualitative methodology. So to help fill my knowledge gaps and suggest questions for phase one and three of the narrative interview schedule I drew on four biographical accounts of people with both acquired and congenital (inherited) facial ‘disfigurements’. I wanted to get a sense of how lives were lived in the ongoing aftermath, as persons within socio-cultural contexts, temporalities and relationship networks. The four were Joseph Merrick (Howell and Ford, 2009) who was popularly known as ‘the elephant man’; Christine Piff (1985) Chair of Let’s Face It; James Partridge (1990) Chair of Changing Faces and Lucy Grealy (1995) author, now deceased. As richly diverse as these accounts are, there are caveats. Firstly, they must be viewed with reflexive caution, as the product of partial, memory representations, literary license and media management. Secondly, the account of Joseph Merrick was not written by himself, but several decades after his death by people who did
not know him. Finally, this is an extremely small sample size and is in no way intended to replace research or to represent all facially different people’s experiences. Though what it does do is describe a dynamic life course, with critical events, identities, relationships and complexities, something which can be missing from abstracted facial ‘disfigurement’ research and conceptual debates about the relationship between facial damage, transplantation and identity shift theories). The findings are presented under two subheadings, firstly: A life in Context, which provides details of the person’s life and the reason for their unusual facial appearance and secondly Experiencing facial ‘disfigurement’: emotions, motivations and actions, which describes how the subjects felt and acted.

A life in context
Joseph Merrick, who was popularly known as ‘the elephant man’ is perhaps Britain’s most renowned person with neurofibromatosis (Howell and Ford, 2009). Born in 1862 in Leicester, he was the eldest of three born to Mary, a part-time Sunday school teacher and ‘cripple’ and Joseph, a cotton mill worker. One child died and another was born ‘crippled’. Joseph’s development was regarded as normal until the age of two when a slight growth became visible on his lip; by the age of five it was apparent that part of his head and two of his limbs were growing disproportionately to the rest of him. His appearance was explained as the result of an escaped elephant running down the high street near where his pregnant mother was walking. The family’s fortunes progressed and he was sent to school, which was unusual for the period.

During his childhood, Joseph’s mother died and his father remarried. The accounts suggest that Joseph was increasingly alienated from the new family and forced to fend for himself, living on the wages he earned selling millenary goods from the family shop and later from door to door. He was forced into the workhouse twice when he lost his income, because people would not buy from him as his deformities advanced. His family was not prepared to support him. Merrick spent two years in the workhouse before being offered paid work as the ‘elephant man’, a human curiosity in a travelling show. The work was reasonably paid according to the records and Joseph was reportedly treated well. He managed to save money on his travels, however it was stolen and he returned to England a broken man. Merrick moved into the London Hospital permanently. His surgeon physician, Sir Fredrick Treves, orchestrated a national charitable campaign through the media and using his society connections. Joseph was cleaned and made comfortable in private lodgings and became the charity cause of the day for rich socialite philanthropists, including senior
royals. Joseph lived for a period in a cottage on the private estate of a rich benefactor then moved back to the London Hospital in autumn of 1889. He died unexpectedly of asphyxiation in his sleep in April 1890.

Seven decades later Lucy Grealy (1963) was born in Ireland. Her family moved to America shortly after and she grew up in New York, becoming a lecturer in writing and literature. As a child of nine she developed a rare and potentially deadly cancer of the jaw, was treated with chemotherapy and had part of her lower jaw removed. She recovered though her appearance was altered and her whole life changed. Autobiography of a face articulately examines the period, its aftermath and its impact. The book is beautifully written. It lays bare the family and environmental context and the continuing dynamic that the cancer had on the rest of her life. In spite of its literary merits, the contents have been contested both by Grealy's sister and a close friend (Patchett, 2004). Grealy’s sister, Suellen, argues that the account is selective, and does not lay bare her sister’s ‘constant need of approbation and affection’ (Grealy, 2004). However, she has nothing but contempt for the book Truth and Beauty, written by her friend Ann Patchett (2004), which was published shortly after Grealy's death, examining their friendship and exposing Lucy’s personal flaws. The ensuing media debate revealed her mother’s lifelong battle with severe depression and her brother’s schizophrenia and early death by a car crash. It also says her sister revealed Grealy’s increasing despondency and inability to accept herself and her drug use, which led to the heroin overdose in 2002. So, her mental ill health was not just related to Grealy’s altered appearance, it was bound up in her life experiences and family background.

In 1976, Christine Piff (1985) became aware of a ‘soreness’ in her cheek. She went to the doctors and after a series of tests, it was diagnosed as a malignant tumour. She had to have radiotherapy and two operations to remove the cancerous sinuses. Her autobiography fleshes out the lived experiences of someone with an active pre-existing social life, a job and a family.

James Partridge’s (1990) account is split into two parts, starting with a short explanation of the accident. In 1970, aged 18, Partridge was driving on a Welsh country road, he lost control of the car, which burst into flames and he had trouble undoing his seatbelt. He was driven to a nearby hospital by onlookers, suffering from severe burns to the face, legs and hand and spent four months in hospital.
<table>
<thead>
<tr>
<th>Person</th>
<th>Reason for ‘disfigurement’</th>
<th>Area of residence</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joseph Merrick (1862-1889)</td>
<td>Joseph inherited a genetically inherited condition (neurofibromatosis), which started emerging from the age of five. He had surgery on his face and body to remove several tumours.</td>
<td>Joseph lived mostly in England between Leicester and London. He later travelled to northern Europe with a ‘freak’ show then back to London where he later died.</td>
<td>Joseph was a hawker of haberdashery; he spent five years in a poor house when he could not sell goods owing to negative public reactions. He then earned a living with travelling circuses and ‘freak’ show in England and Europe. Finally Joseph lived on charity as a medical curiosity in the London Hospital.</td>
</tr>
<tr>
<td>Christine Piff (1940s – present)</td>
<td>Christine had cancer and had part of her upper mandible and an eye removed; she wears a prosthesis.</td>
<td>Kent, England.</td>
<td>Christine was a nursery nurse before she married in 1962; after having three children she returned to work prior to the cancer. She set up and still runs Let’s Face It, a charity supporting people with facial difference.</td>
</tr>
<tr>
<td>Lucy Grealy (1963-2002)</td>
<td>Lucy developed a facial cancer in childhood. She had part of her lower jaw removed and reconstructed later.</td>
<td>Lucy was born in Ireland, grew up in New York, America and travelled widely, which included Europe.</td>
<td>Lucy became a poet and a teacher of literature and writing. She is believed to have committed suicide in 2002 through a heroin overdose. Lucy had several short relationships.</td>
</tr>
<tr>
<td>James Partridge (1950s – present)</td>
<td>James was burned in a vehicle fire when he was in his late teens and had years of skin grafts and reconstruction work.</td>
<td>James was from Bristol, went to Oxford University, and now lives in the South East of England.</td>
<td>He became a lecturer and researcher in economics and related fields, a campaigner for facial difference, and set up the charity Changing Faces in 1992. James married and had children.</td>
</tr>
</tbody>
</table>
Experiencing facial ‘disfigurement’: emotions, motivations and actions

Having given a chronological summary of how and why people came to appear facially ‘disfigured’ I want to describe how they report feeling and acting. There are several direct quotations in this section, to remain as accurate to the text as possible.

‘The word cancer was left unsaid, but nevertheless I had a tumour in my sinus... reality suddenly came back and kicked me hard in the stomach. Oh my God! I flung myself on the bed and wept. Then equally quickly ‘Christine’ took over again, confident and determined’ (Piff, 1985, p.14).

Christine Piff (1986) reported feeling like a glass that has been smashed by a hammer when she was told that her facial cancer would have to be operated on, then described the reassurances she gained from her husband. This is a pervasive theme, the love and support of her husband, children, family and friends are her world and are there each time something happens. The following quote explains her reaction the first time she looked in the mirror after surgery to remove part of her cheekbone and eye socket;

‘... for the first time I saw my reflection in the mirror. I could not believe it was me. I nodded in the mirror to make sure. It was unrecognisable... my face was red and swollen... It looked grotesque’ (Piff, 1985, p.37).

Lucy Grealy struggled to come to terms with her altered appearance, the reactions of others and her growing sense of isolation. The first half of the book describes the diagnosing of the cancer and its subsequent treatment. There is a palpable sense that she took her cues about how to respond to the impact of the medical treatment from her parents. It is also possible that Lucy led a disembodied, fractured life both before and after the surgery to remove the lower part of her jaw. There are many instances throughout referring to her living in her head, or becoming suddenly aware of the present. The second half examines how Lucy gradually began to slot back into activities and to interact with peers, initially school children. She describes feeling increasingly upset by their negative comments, but rationalised this by thinking that she was ugly and that this was what people would do and that she had to learn to deal with it. A few years later she had reconstructive surgery, to fill the gap where her jaw had been. This happened around the time Lucy went to university. She describes going to gay nightclubs with a male openly gay friend as a momentous occasion. The men were interested in meeting each other and left her alone; during this time she learned to dance, ‘never in a million years would I have been able to do
this in a heterosexual club’ (Grealy, 1995, p.203). Grealy may have felt less confident in a place where men would have paid much more attention to women.

During the final chapter, Grealy (1995) recounts her search for love. Admitting to consuming self-pity, she rationalised that finding love would ultimately make her feel lovable, and prove that she ‘was not too ugly’. After a difficult but sexually charged relationship and several lovers she reached the conclusion that she liked being loved, but felt not beautiful enough to be loved. Having moved to London to live with her sister, she then moved to Scotland to have some cosmetic procedures, to fill out the new cheek tissue. Having had various reconstructive procedures, she realised that she still felt incomplete, could not reconcile the person in the mirror with herself and did not know what to do about it, so she stopped looking in the mirror for a year. Grealy wrote:

‘The journey back to my face was a long one... Without another operation to hang all my hopes on, I was completely on my own. And now something inside started to miss me... And then I experienced a moment of the freedom I had been practising for (looking in a mirror)... As a child I had expected my liberation to come from getting a new face to put on, now I saw it came from shredding something, shredding my image’ (1995, p.222).

In stark contrast to the unhappy account written by Grealy, James Partridge spends little time exploring the cause or potential consequences of his impairment. The book was written to support people with a facial ‘disfigurement’. The first part examines looking at your face in the mirror, being a patient and evaluating plastic surgery. Based on these contents and the sentiments of Christine Piff I introduced a question about people’s experiences of looking in the mirror in the aftermath of facial change; it yielded rich results which are documented in Chapters Seven (Visual transition/liminality and identity shift) and Eight (Reflecting on reflections: some visual implications of acquired facial ‘disfigurement’). Part two explores reconstructing your life, through rebuilding self-esteem, being in a crowd and making new friends; the author offers no quick fixes:

‘This book is not going to offer any miracle cures, just as plastic surgery does not provide a total answer. Changing Faces in the fullest sense means being able to enjoy living with and in spite of your ‘disfigurement’. It does not happen overnight, you have to work very hard at it’ (Partridge, 1990, p.3).

To draw this section to a conclusion we cannot ignore the body of academic findings which indicate that facially ‘disfigured’ people can suffer, physically and emotionally through
personal adjustment to life with a ‘disfigurement’, or through the unwarranted stares and comments of known and unknown others (Dropkin, 1989; Clarke et al., 2006). However, much of this research takes place in clinical settings during or immediately after the period of change and is designed to look for emotional/psychological difficulties. The biographies illustrate that there are aspects of people’s lives and identities, which have been left out of research designs. Some facially ‘disfigured’ people have received an education beyond school-leaving age; had successful careers; travelled widely; experienced relationships, married and had children. Indeed, beyond the commonality of an altered facial appearance, there lies a marked degree of heterogeneity, both in personal lives and in relation to the causes, areas affected, degrees of severity and people’s ability to cope with the changes. This heterogeneity is reflected within the human condition (Wendell, 1996; Shildrick, 2002) and within the lives, experiences and identifications of the research participants.

Chapter Summary

A great deal of material from different epochs, epistemologies, societies and disciplines has been utilised to consider the socio-cultural significance of faces and to explore what life can be like for people whose do not conform to societal expectations. In short, it is evident that faces are a deeply significant aspect of human sociality and social reproduction on multiple levels. To summarise these findings I would like to re-apply Scheper-Hughes and Locke’s (1987) tripartite concept of embodiment (individual, social, political). The individual body refers to the lived experiences of the body as self. The social body encapsulates representational uses of the body as a symbol of nature, society and culture, whilst the body politic explores the control and regulation of bodies.

There is a lot going on at the level of the individual body-face. Unlike other animals humans are born with the capacity to move their facial features flexibly in ways that can be understood by others. Even before they can speak, humans have the capacity to recognise and remember specific faces and to communicate their thoughts and emotions through their facial features and utterances, i.e. crying or laughing. Not only can faces communicate, they also allow us to perceive and experience the world around us and in doing so, play a key role in embodied sense-making. Some sights, sounds and smells have the power to take us back to childhood and to specific memories (Synnott, 1993, pp.128-130).

8 with their caveats noted.
When facial embodiment becomes disrupted, so does our ability to perceive the world and our perception of who and what we are (Merleau-Ponty, 1962; Csordas, 1994). However, this epistemology is not reflected in the facial ‘disfigurement’ research papers. They tend to draw on positivist and Cartesian understandings of people as ‘patients’ with distinct minds and bodies, who are abstracted from their lives, identities, networks and social contexts. Consequently, the need for embodied, qualitative methodological research is pressing.

What we can say using the research and the biographies is that people respond in different ways to the advent of an acquired facial ‘disfigurement’ (Fauenbach, 2002; Rumsey et al., 2004). Though people may experience reduced quality of life, they can go on to lead fulfilled lives, get married, have children and develop careers. Drawing on the biographies, Christine Piff (1985) was already married with three children when she developed facial cancer. In the aftermath she founded a national facial support charity. James Partridge (1990) married some years after he had been burned, had three children and also created a facial support charity. Lucy Grealy developed a career and published a widely acclaimed novel, though she had relationship difficulties, possibly never came to terms with her facial appearance change and died after a drugs overdose (Patchett, 2004, p.234-38).

There is also much we can say about the social body-face. Faces can play multiple roles in social reproduction, for example through masking during ritual ceremonies to hide the identity of the wearer (Tseelon, 2001), and through dressing the face to express group allegiance (Blackman, 2008) or to subvert cultural expectations (Broekman, 2009). In addition, work by Giddens, (1991) and Synnott (1991, 1993) has illustrated the long and inaccurate association between facial appearance and moral character. Though its roots can be traced back to ancient Greece, every James Bond film fan knows that the villains and henchmen will be recognisable in part due to their facial and bodily flaws and that they will be defeated by the handsome hero. These arcane cultural tropes may help to explain why ‘disfigurement’ findings report higher levels of social anxiety, mental health disorders and social avoidance in people with altered facial appearances? The biographical accounts certainly document the distress caused through unwanted stares and comments from strangers (Grealy, 1995).

Finally, body-faces have also been used by powerful groups to justify and maintain the status quo. Drawing on Deleuze and Guattari’s (1987) concept of faciality, Twine (2002), Dudley (2002) and Benson (2008) have all illustrated how the attribution of moral values to the facial characteristics of societal groups can create and perpetuate their marginalisation and exploitation, to the benefit of those in power. If there were any doubts, body-faces are
powerful corporeal and societal entities conveying multiple meanings. Early in the chapter, I outlined the need for the development of social science informed, phenomenological, qualitative research. The next chapter, the first of the primary data findings explores the remembered pre-facial ‘disfigurement’ lives and identities of the 13 participants using this much needed methodology.
Chapter Five Analysis

Before facial ‘disfigurement’: bodies and previous identities

Introduction to the analysis chapters

Mirroring the biographical order of the interview questions there are four analysis chapters which explore life before, during and after facial ‘disfigurement’. Each chapter and sub-section builds on what is known about the experiences of the participants and about what this tells us about the relationship between acquired facial ‘disfigurement’ and embodied identity shift. This first analysis chapter is relatively short compared to the others. It has two aims; the first is to provide a theoretical baseline for the consideration of all bodies. It will discuss the diversity of body-faces (Wendell, 1996; Shildrick, 2002) as a precursor to facial change. The second aim is to establish participants memories of their pre-facial disruption identities, so these can be compared to how they identify during the period of ‘disfigurement’ and afterwards. The second analysis chapter (Chapter Six) considers the disruptive episode of body-facial ‘disfigurement’ in some detail. Anthropological concepts of ritual pollution (Douglas, 1969), transition and liminality (Turner, 1969; Little, et al., 1998; Philpin, 2007) have been applied to help explain participants’ experiences of disruption, chaos and transition. The third analysis chapter (Chapter Seven) continues the theme and considers visual identity liminality whilst the final one (Chapter Eight) considers lifeworld and embodied identity transition in the immediate and continued aftermath of the event(s). In Chapter Eight I introduce a new tripartite theory to explain how and why the participants have made sense of body-facial disruption, transition, liminality and lived with the aim of identity restitution (Frank, 1995, p.75). However, before the analysis chapters unfold, it is necessary to theoretically define what is meant by the term body for the purposes of this study. Though I have touched on this in earlier chapters this section of theory is being placed here and not in the secondary analysis chapter (Five) because it is the bedrock on which the analysis chapters are based.
A baseline for bodies: diverse becomings and the myth of boundedness

‘Where once the apparent truth of the Cartesian body as the unified and fundamentally unchanging material base of continuing existence could be taken for granted, the development of both contemporary biosciences and post-conventional models of theoretical inquiry have radically undone that illusionary certainty’ (Shildrick, 2010, p.11).

As Shildrick (2010) alludes, there is no single type of body to which experiences occur. In the West, the myth of the universal ‘body’ type has arisen with the development of the biomedical sciences and their increasing focus on normative form and function throughout the nineteenth and twentieth century’s (Wendell, 1996). The myth centres around the imperial, patriarchal ‘ideal’ of the young, white, able-bodied male which is self-contained, bounded from others and unlocated in time and space (Grosz, 1994; Wendell, 1996). Social scientists and disability rights activists have challenged the idea that there is a single ‘ideal’ body type, which should speak for all bodies (Haraway, 1991; Wendell, 1996; Shildrick, 1997). Consequently, there is no such thing as a universal, abstracted, or timeless face to which experiences occur. As ethicist Perpich (2010) states bodies are perpetually in a state of becoming, changing in size, shape, abilities and component part. In addition, there are many types of corporeality, for example transgendered people, those born with congenital conditions or those with acquired disabilities as well as people who undergo transplant surgeries (Shildrick, 2002). For Perpich (2010), to be a body is to be exposed, a solid mass but also to be vulnerable. This is true of faces, as they are always on show and generally uncovered. Shildrick (1997) goes so far as to suggest that bodily vulnerability is an essential condition of corporeality. Concurring with these sentiments Grosz (1994, p.19) argues that as bodies are always gendered, ethnically and sexually distinct and embedded in strata and cultural worlds, they are incapable of being incorporated into a single universal model to be generalised from. Not only are our bodies diverse, we are also subject to multiple identity influences. As Van Wolputte (2004) argues ‘we are all creoles of sorts’ (p.263).

Having rejected the idea of one universal body-face, I now want to challenge the idea that Western bodies, and by implication that faces are bounded and self-contained (Van Wolputte, 2004). Arthur and Marilouise Kroker (1987, cited in Csordas, 1994, p.180) have suggested that due to the destabilising effects of commoditisation, fragmentation and multiple images of body parts, the human body can no longer be considered a bounded entity, at least socially. Haraway (1991) has considered increasingly problematic boundaries between animals, humans and machines which have arisen due to medical advances such
as organ/facial transplantation, prosthetics (Sylvia has a facial prosthesis), pacemakers or cochlear (Agnes has one) implants. To reflect our increasingly complex relationship with bio-technologies and pharmaceutical products Haraway (1991) proposes it is more accurate to talk of cyborgs, rather than bounded individuals. We can therefore conceptualise humans as creoles or cyborgs with leaky body-faces (Shildrick, 1997) as technological developments, practices and treatments have become increasingly commonplace in biomedicine. For example, facial boundaries can be so easily transgressed, skin leaks through cutting, ripping, becoming infected or getting burned, eyes become infected or damaged necessitating removal, repair and/or reconstruction. When this occurs, argues Shildrick (2010) embodied boundaries, and I would argue identities are rewritten as a result of the exchange between self, surgery, bio-technology and other. (Participants’ experiences of corporeally rewritten boundaries are explored in the next chapter). Finally, bodies are not ontologically divisible from time and space (Adam, 2006) they are always culturally and temporarily located.

**Previous body-faces, imagined futures: the gendered telling of identities pre-disruption**

**Narrative context**

Having reviewed the strengths and weaknesses of using a narrative method in Chapter Two I want to introduce the participants and their storied pasts in the period before facial ‘disfigurement’. Though I had asked for a distance of two years between the critical facial episode(s) and the interview (to be sensitive to participants’ potential distress), in many cases decades had passed (see Table 5 at the end of this section). During the intervening period lives had been lived i.e. jobs/careers, accommodation and relationship statuses had changed, children and grandchildren had been born and bodies had continued to change and to age. Consequently, memories had faded and experiences had shifted in significance, though emotional journeys remained vivid. Hochschild (2003, p.216) has argued that emotions cannot be understood as separate biological processes, that they have to be understood as an aspect of embodiment, which are created and understood within a cultural and temporal context. Consequently, I have used participants emotional narratives to help explain how their embodied identities shifted and how they made sense of the shift.

Of the thirteen participants who took part in the research, six had received a diagnosis of head and neck cancer. Four of the six were aged between their thirties and their fifties
when it occurred and all had spouses, jobs, and children (Sylvia, Natasha, Marie and Jonathon). Two more were diagnosed in their sixties both were retired at the time of diagnosis (William, Doreen). Six had experienced a variety of accidents. Gillian and Martin had been in car crashes in their late teens, Andrew and Barney had been injured during the course of active military service in their late teens at a similar age and Clara and Agnes had experienced medical mishaps. Stephen had been living with acne rosacea for 25 years. Table 5 summarises the age at which the ‘disfigurement’ occurred, together with the decade and the participant’s approximate age at the time of the interview. Overall, the pre-facial ‘disfigurement’ accounts were constructed around a broadly positive past and imagined future, actively filtered through the lenses of age, culture, white British ethnicities, heterosexual sexualities and traditional notions of gender i.e. the male protagonist and the female nurturer. Although, gender related concerns mostly featured in the pre-change stories the narratives did not always follow traditional trajectories. Before I discuss the findings I want to say a little about the lack of theoretical input in this first data findings section. I want to prioritise the data and make it easier to compare participants embodied identities in the pre-, during and post-‘disfigurement’ phases. Theoretically informed analysis will figure significantly in the last two analysis chapters and the conclusion chapter.
Table 5 Timeframes: period of facial ‘disfigurement’ and the research interview

<table>
<thead>
<tr>
<th>Name and approximate age of first unhabitual face change</th>
<th>Decade(s) of facial disruption</th>
<th>Approximate age at time of interview (2011-12)</th>
<th>Name and approximate age of first unhabitual face change</th>
<th>Decade(s) of facial disruption</th>
<th>Approximate age at time of interview (2011-12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td></td>
<td></td>
<td>Male</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agnes 8</td>
<td>1940s</td>
<td>early 70s</td>
<td>Martin late teens</td>
<td>1970s</td>
<td>mid-50s</td>
</tr>
<tr>
<td>Clara 6 and 8</td>
<td>1950s-60s</td>
<td>early 60s</td>
<td>Barney late teens</td>
<td>1940s-50s</td>
<td>early 90s</td>
</tr>
<tr>
<td>Gillian 19</td>
<td>mid-1980s</td>
<td>mid-40s</td>
<td>Andrew mid-20s</td>
<td>1980s</td>
<td>late 40s</td>
</tr>
<tr>
<td>Natasha mid-to-late 20s</td>
<td>1990s+</td>
<td>late thirties</td>
<td>Stephen mid-20s</td>
<td>1980s+</td>
<td>late 40s</td>
</tr>
<tr>
<td>Sylvia mid-30s</td>
<td>1970s</td>
<td>early 70s</td>
<td>Jonathon early 50s</td>
<td>mid-2000s+</td>
<td>late 50s</td>
</tr>
<tr>
<td>Marie early 40s</td>
<td>2000s</td>
<td>mid-to-late 50s</td>
<td>William early 60s</td>
<td>mid-2000s+</td>
<td>mid-70s</td>
</tr>
<tr>
<td>Doreen mid-60s</td>
<td>mid-2000s</td>
<td>mid-70s</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Gendered narratives in the pre-‘disfigurement’ life

Men
The first open question I asked everyone was ‘Could you tell me about your life before your face changed?’ As I had asked an open question I had anticipated a set of varied responses relating to male gender roles, values, expectations and performances (Goffman, 1959, p.17; Butler, 2004, p.42). However, in the pre-facial disfigurement life, all of the men identified as having hegemonic masculinities, or culturally dominant, idealised forms of being men in the Western tradition, through the selection of their narrated experiences. Connell (2005) has stated that though hegemonic masculinity only speaks to the practices of a minority of men, it has appeared to embody the most ‘honoured’ way of being a man. Positive characteristics associated with hegemonic masculinities include bringing home a wage, being a father and sustaining a sexual relationship (Connell, 2005, p.840). In addition, traits such as dominance, autonomy, physical engagement with other men through sport or fighting, risk taking and emotional detachment have also been associated with hegemonic masculinities (Kimmel, Hearn and Connell, 2005). All of the male participants in this study
identified discursively and performatively with some hegemonic masculine attributes, even if they also narrated more subservient masculinities e.g. complicit masculinity⁹. For example, the men positioned themselves at the centre of their pre-disruption narratives; identifying themselves as active and agentic performers engaging with the world (Doucet and Mauthner, 2008); in control of their bodies and lifeworlds (Frank, 1995) with much to look forward to regardless of age. I refer to five characteristics during this sub-section.

Firstly, negative emotional states or difficulties experienced during the pre-disruption period were rarely mentioned, or if they were, they were not elaborated on. For example, Martin gave a glowing account of his early life, for example being ‘successful’ academically and performing at sports, though his body language and intonation became less effusive when he talked about being sent to boarding school at the age of six. It sounded like he was not happy with the arrangement but Martin did not expand. In addition, it did not conform to his largely positive, agentic narrative, so it seemed unlikely to be prioritised. In the immediate period before being burned Andrew spoke of being very happy. In an earlier story he mentioned but did not elaborate on the trauma of losing friends from his regiment who had been blown up in a tour of duty in Northern Ireland. There were sideways looks, vocal changes and pauses in his account. Secondly, four of the six men spoke of fighting in their former life. Barney was fighting a war, William had referred to an unarmed combat course when in the armed forces (decades earlier), to stop others picking on him for being smaller in height. This aspect was used to illustrate his problem-solving nature and physical resilience, as a precursor to facial cancer. Stephen said he was not afraid to stick up for himself or others if they were unfairly being picked on, which had changed since his acne rosacea had developed. It was not just the vocal expression of his body-self that Stephen mourned, but aspects of its performance (Goffman, 1959, p.17). In a somewhat contradictory statement, Stephen lamented the loss of his physical ability to address perceived injustices and unwarranted physical violence

‘... I couldn’t stand seeing kids getting knocked about, shouted at and there was one occasion where this guy, he has got this little boy with him, and he picks him up and he whacks the back of his legs so hard he nearly took his legs off and I thought hang on. So I went across and went, grabbed hold of him and I smacked him one. Right I said, don’t you ever hit that kid again right!... I just avoid them situations because my face is red, and

⁹ Complicit masculinity refers to practices and ideas associated with men who benefit from hegemonic masculinity but who do not associate with it (Connell, R. 2005).
confrontation would make it worse... I have just lost all my confidence to deal with situations like that’ (Stephen, 2011).

Andrew’s early account was full of traditional male-gendered performances (Butler, 2004). He described ‘getting into a spot of bother’ when he was younger and joining the British Army to give him some ‘discipline’ neither are elaborated on. Later on he described a play fight with a friend that had gotten them both into trouble whilst he had been a soldier. Thirdly, three of the men used their sporting performance to express their active, risk taking personas and bodily control. William referred to going potholing when he was much younger. It did not seem to play a large part in his earlier life, but it helped to identify him as an active, risk-taker. Andrew had been very sporty whilst in the British Army and was part of the athletics and rugby teams. He told me that a rugby club had offered to buy him out of the army so he could turn professional. Though he declined the offer, it helped to establish him as a competent, physically active sportsman with choices at his disposal. Finally, Martin’s narrative was building towards anticipated achievement based on early success.

‘I was quite a well I was quite a successful child I suppose in the sense that I was, always in the topish group in the class, and I was able to play sport and I was able to be quite a sociable lad about the place. So in terms of a school experience, mine was a pretty successful one I suppose, I felt quite strongly about myself, positively about myself’ (Martin, 2011).

These physical, visual identifications were also expressed through the use of pre-event photos by three men. Barney showed me an album of his achievements, the first half of which contained photographs of himself in various military guises. Martin prefaced the sharing of his pre-facial change photo by saying ‘You might have thought I had it made’, referring to his handsome appearance. Whilst Jonathon showed me a picture one of his friends had taken which had acquired significance after his diagnoses and two treatments for head cancer. Hosting a summer BBQ and standing in the large garden of his detached country house Jonathon looked rugged and relaxed, in control of his body and his life, and he had enough friends and resources to throw parties. That was to change later on.

Fourthly, all six men talked of either building, engaging in or remembering successful careers. Martin was looking forward to getting into an elite English university and to developing a high status and financially rewarding career. Andrew and Stephen were both in their early-to-mid 20s immediately prior to the event. Stephen had just gained his ‘dream
job’, a technical post with career potential that took him out on the road, illustrating Stephen’s pragmatic nature and love of travel. By the time Andrew had recounted his tours of military duty to Africa, Germany and Northern Ireland, with vivid, sensory descriptions, lyrical intonation and passionate tones I felt like I had been there with him. The joy of these new experiences and his youthful curiosity (Germany and Africa) together with the sad death of a friend on a tour of duty in Northern Ireland (described in muted tones with little eye contact) was building up to the moment when his life and body would change forever. In his remembered pre-facial change life Andrew wanted to convey positive emotions; a life full of experiences and career opportunities; that he is sustaining a sexual relationship that might lead to children; sporting prowess and being fully in control of his body. If biographical disruption involves the disruption of relationships (Bury, 1982), then pre-‘disfigurement’ narratives, for Andrew, Stephen, Martin and Jonathon were all about the development of friendships, work-based relationships and/or romantic/sexual relationships. Let me explain starting with a quote from Andrew

‘Even right up to the moment we got blown up I was as happy as a sand boy, loved being in the military, you know I was engaged, I was erm, I was just happy rabbit you know, everything that I wanted in life was coming together, I erm, yes, I erm (silence) my life was pretty full. (Big silence) That was my life you know, it was one of being a... a young bull in a china shop... enjoying his life... so much potential (silence) you know... erm (silence then thinking). I wasn’t sure whether I was particularly good looking or not...never really thought about it too much. I had my girlfriends like everybody did you know, some casual, some meant a bit more to me. Erm (thinking) but in order of looks and appearance you know, I felt I was as good looking as the next guy and not as ugly as some... (silence). But, it was never really that big of a relevance to us to be honest with you. (He talks more slowly) Playing rugby and being professional and doing the best I could was all that mattered to me really’ (Andrew, 2011).

Jonathon was mid-career and financially solvent before his diagnosis with cancer. He identified as an established trainer and fundraiser who was also actively involved in local and national voluntary organisations. His pre-story not only involved the control of his own body, lifeworld and future, but extended to community control through his involvement in various local and national charitable organisations, some of which carried high status positions.
‘... I can’t do anything by halves and if I join a football team I have to be the captain, club secretary, erm... and the same thing has applied most of my life. I have erm... been in Rotary I ended up being President of the Rotary club, erm... I have been in Masonry for many, many years and I have been the Master of the Lodge twice, erm... so that is the sort of character I am...’ (Jonathon, 2011).

The importance of former careers did not stop for the two men I interviewed who were retired men (75 and 91). On the contrary, previous employment experiences were used to identify positive characteristics, which were later used to limit the chaos of facial disruption and associated existential threats. William, who had taken the unarmed combat course in the British military, had later established a career as an industrial chemist. He used his work-related skills and attributes to identify as a pragmatic, well-travelled, problem solver with managerial responsibilities. This identification was to be used later in the narrative, when he applied the same approach to his treatment for mouth cancer. Barney had a strong claim to a hegemonic masculinity that developed in the period just before but mostly after his facial appearance changed. Barney had been in the RAF from his teens until his late 40s in the 1970s. His unemotional story started with active military service and the control not only of his own body, but of other bodies and in the engagement of life-risking activities whilst in charge of complex and powerful machines in wartime situations.

‘Could you tell me about the period of your life before you were in the accident or the injury that lead to facial change? (A-M)

I was flying, I was flying on operations over the Atlantic (Barney)

So you were in the Second World War? (A-M)

Yes’ (Barney).

Women
In general, the women’s pre-facial disruption accounts contained more direct references to emotional states, were narrated in greater emotional depth and in more complex, varied terms than the men’s were. Part of this complexity manifested itself in the acknowledgement of other influential actors or in the recognition of pre-facial ‘disfigurement’ bodily vulnerability (Shildrick, 2010). For example, Gillian was ‘not happy’ about going to her ex-boyfriend’s friend’s 40th birthday party, though she went along. The car crash which changed her face and her life happened later that night. As a child Agnes
reported ‘always crying for some reason’, which she later related to losing her hearing. In contrast to the men, who all positioned themselves as physical, agentic and autonomous central figures, the women were more likely to construct their identities through their relationships with other bodies, notably family members, partners, friends and children. More so than the male narratives, the importance of relationships was stressed in their pre-biographical disruption phase (Bury, 1982). Again, unlike the men, the women did not always place themselves at the centre of their stories. Doreen started her pre-cancer diagnosis story by relating the sudden and unexpected death of her husband: ‘well I found a small hard lump on my neck, and I thought I’d get it checked out, but that was just before my husband died’ (2011). Like all of the men, some women did identify as being successful in the pre-disruption phase. When describing herself in the period before she was diagnosed with sinus cancer Sylvia identified as being slim and pretty, whilst Gillian’s account illustrated facets of hegemonic masculinity (Connell, 2005), for example actively striving for success in career, financial and relationship terms. Having given an overview of the findings, I now want to explore how each of the seven women located themselves in their pre-facial disruption identities. The results are presented in three age-related groupings (childhood, early adulthood and middle age). These refer to the ages at which the event occurred and not the age of the women at the time of the interview, because the age at which the event occurred had a significant influence on how they perceived their lives and identities.

Two of the women were children (Clara, Agnes) in the period before unhabitual facial change occurred and their accounts reflect a lack of agency during this period. The narratives were predominantly concerned with domestic spheres, relationships with immediate families and friends, childhood hobbies and educational arrangements. In her pre-facial disruption account and using a family photo album as a prop Clara looked back to an idyllic childhood. As the only child of affluent middle class parents, with a nanny, a few close friends and a choice of hobbies, e.g. horse riding, Clara seemed to have it all: ‘My parents were quite well off, I would say they were quite middle class, middle class Jewish erm... and I have had everything...’ (Clara, 2012). However, further elaboration and specific second phase narrative questioning revealed a more multifaceted past. Clara remembered a doting father and a more complex relationship with her mother. She felt that her Jewish parents restricted her ability to form friendships because they did not want her to mix too freely with gentile children. This seemed to have restricted her ability to interact comfortably with her peers. Clara fell over twice whilst playing outside; both times they
resulted in scarring. The first time, aged six, she fell over her dog and lacerated her lip, which was hanging off. The second time, aged eight, she fell into a door and broke her nose, which was squashed out of shape and could not be operated on until she was 17 years of age. In Clara’s view she was already socially isolated, and with an altered appearance, and very poor esteem her ability to interact with others diminished along with her happiness.

‘I wanted but I never felt connected to my mom, never felt close, I did to my dad. Erm... I had a beautiful boxer dog who I suppose was my sister and I hadn’t had her long when I had my first accident, but that didn’t really affect me as badly as the second accident... Right so before that happy, after that not so happy’ (Clara, 2012).

In contrast to Clara’s small family and ‘isolated’ upbringing, Agnes was the youngest child of five, brought up in a supportive, loving and busy family atmosphere. She remembered playing with her brothers more than her sister and being clingy. She explained this through being the youngest child and because it was becoming increasingly hard to hear what was going on around her. In some contrast to Clara, Agnes narrated her account matter-of-factly and without emotion. Becoming deaf was narrated as something that she simply got on with, in keeping with the period she was growing up in just after WW2. This pragmatic, unemotional position was one Agnes narrated throughout the account, even though she eventually went deaf and had her facial nerve accidentally cut by a surgeon, whilst operating to remove a potentially fatal ear infection. The operation resulted in an asymmetrical smile that Agnes has been aware of from the age of eight, through to the time of the interview, when she was 72 years of age. However, unlike Clara, there was no simple dichotomous memory of before happy, afterwards unhappy. Life continued unabated.

In spite of the differences in which the stories were told the two accounts shared some similarities. Both were critical of the lack of control they had over medical procedures, environments and their consequences. Both felt that they did not have their voices listened to and both felt that they had been facially ‘disfigured’ through medical neglect and a lack of parental intervention, particularly fathers. Clara felt that her father could have intervened to prevent the formation of unsightly scar tissue and helped her to secure the right shaped nose. Whilst Agnes was angry at her father for not removing her from a scary, painful and isolating hospital.
‘Nobody was allowed to see me or come and hold my hand or anything... he (the surgeon) came and did the operation (for mastoids) on a Wednesday evening and so I was all prepared for it and erm... I fell asleep waiting for them (her parents) and then they came (medical staff) with the trolley and the nurse woke me up and she said, she said your father has been on the phone and he sends you his love. And I remember all this (laughs) and I remember thinking to myself, the stupid man! Why doesn’t he come and take me home?’ (Agnes, 2011).

Three more participants’ faces changed unexpectedly during early adulthood (19-36 years). Gillian was in a car crash at the age of 19; Natasha was 29 when she started to get facial lumps and a life-threatening head infection and Sylvia was diagnosed with sinus cancer at 36 years of age. All three remembered happy lives and as expected, the women in this age group reported more agency, choices and accomplishments in their lives compared to those who were children. All told their pre-facial change identity stories through their relationships, particularly close family and heterosexual romantic relationships. Gillian built up to the moment of the car crash by explaining how she came to be in the car. She had gone away for the weekend with an ex-boyfriend, to get some distance from her then current boyfriend troubles. The weekend was to be an opportunity to consider whether she wanted to continue the relationship or resume something with her ‘first love’. Very early on in the interview Sylvia defined herself through her relationships: ‘I was happily married with three young children’. Similarly, Natasha stated ‘most of my 20s were really nice, I met my husband...’. Though relationships were very important, the women did not define themselves exclusively through them.

Natasha related a happy middle class upbringing with a close family who still lived nearby. She had gone away to university where she had gained a degree in English and history. She met her husband-to-be at 25 years of age, went travelling with him and they purchased a bookshop which they ran and lived above at the time of the interview. Gillian identified as young, active and career focused; her narrative shared some similarities to the men’s in that she exhibited characteristics associated with hegemonic masculinities (Connell, 2005). For example, she presented herself as the central, partially independent, career motivated protagonist capable of sustaining heterosexual relationships. Though unlike the men, Gillian recognised the influence of close family relationships on her career and life.

‘... before the accident Christ only knows what I wanted. I think I wanted a you know, I wanted all the things that 19 or 20 year old girls want. Do you know what I think at
that time I wanted? To be successful as a woman as a female, because why can guys go out and buy a Porsche and be successful? I think I can do that, that comes from my dad probably, or my mum was like that as well’ (Gillian, 2011).

Sylvia had two traditionally female gendered jobs as a nursery nurse, one of which was at her children’s school. These positions and her associated activities, for example taking sports lessons, were used to reaffirm her strongly identified, joint roles of wife and mother. However, the way in which Sylvia related to these roles was to shift when her treatment started and in the years after the facial event. As Butler (2004, p. 216) argues ‘the very social life of gender turns out to be malleable and transformative’.

The final two women were older when their faces changed unexpectedly. Marie was in her early 40s when she was diagnosed with a head and neck cancer, whilst Doreen was in her early 60s when she was diagnosed with the same condition. In the life before diagnosis both women defined themselves through their relationships with close others and by their pragmatic unfussy, unemotional narratives. Marie’s husband was there at the start of the interview and they jointly answered questions. In the immediate pre-change life she described herself as ‘just normal’, married and living with her then 15-year-old son and husband. Doreen had worked in a shop for many years but had since retired and began visiting people at the local old people’s care home. Looking after others was something she had a lifelong identification with. Doreen remembered always having a relative or someone living with her and her husband. Her story of her cancer diagnosis and treatment started with the sudden death her husband of many years, not her own existential crises.

In both accounts there were no focal career-related identities, as with the men or Gillian, though Marie did talk about her role as a university administrator. Nor did either woman place themselves at the centre of their stories. Instead, both women gave traditional female gendered accounts focusing on nurturing. In the case of Marie, it shifted between her, her husband, work and her son. In the case of Doreen it was told through her close relationships such as her sister and her now deceased husband, and through her role as a carer and volunteer.

**Chapter Summary**

The chapter started with a rejection of the Cartesian legacy (Grosz, 1994). For the purposes of this thesis, I have used phenomenological and embodiment theorists to refute the
following conceptions: that persons have and are unconnected minds and bodies; that persons are objective, static, pre-cultural and bound, and that their lifeworlds and embodied identities can be researched using positivist methodologies such as rating scales. Persons are embodied, subjective, culturally embedded cyborgs (Haraway, 1991) who are varied in form and capability (Wendell, 1996; Shildrick, 2002), always vulnerable (Perpich, 2010) and always in a state of becoming and interconnectedness with other persons, even before an unhabitual life disruption (Leder, 1990; Frank, 1995) occurs. The purpose of this chapter has been to position the participants within this theoretical understanding of persons and to locate them within their remembered pre-facial ‘disfigurement’ identity narratives using the data findings. All of the participants produced partial, largely positive and gendered accounts of their pre-facial disruption lives. Those who were younger adults, who had career and family aspirations conveyed that they had the most to lose from the disruption in comparison to those in younger or older age groups. In summary the men narrated successful, career orientated, active and independent identities, whereas the women tended to tell their identity stories in conjunction with close family and romantic relationships. Life in most cases was glowing or good, in a few cases there were also pre-existing tensions, which played a role in how participants made sense of their lives and identities during the period of ‘disfigurement’ or unhabitual facial change and corporeal disruption. The causes and consequences of embodied identities becoming disrupted and undone, e.g. through surgical cuts, accidental wounds or being burned, are considered in depth in the next chapter. During the first half I focus on participants’ experiences of embodied disruption and ‘unhabitual’ body-face appearance using Leder’s (1990) text *The Absent Body*. I also draw on the work of Frank (1995) and his text *The Wounded Storyteller* to help explain the disruptions to narrative identities that facial appearance can cause. During the second half of the chapter, I step back from the individual as the unit of analysis to consider the wider societal implications of inhabiting disrupted embodied identities using a combination of anthropological and sociological research on ritual pollution, transition and liminality.
A life lived: experiencing facial ‘disfigurement’ and identity shift

Chapter Six Analysis

Facial appearance: disruption; transition and liminality

Chapter Introduction
As I stated in the last chapter, the participants relayed largely positive, gendered accounts of lives richly lived and performed in the pre-facial ‘disfigurement’ era. Using those conceptual and empirical findings as a starting point, this chapter explores how participants’ body-facial boundaries and embodied identities were disrupted and how they made sense of the disruptions at the time of the event(s) and in the initial period afterwards. As the chapter illustrates there can be multiple, simultaneous episodes of facially related embodied disruption. Firstly, the face can become altered in its sensory capacity, leaving the person less able to perceive and to engage with the world, for example through diminished: communication (verbal or non-verbal); sight; sense of smell or taste. Secondly, the person may no longer visually recognise their face and may struggle to come to terms with their appearance-related identity. Thirdly, the person may not recognise their body-face through its altered touch, contours and sensations. For example shock or pain may be catalysts in the unmaking of the world they know (Scarry, 1985). Finally, existential crises related to the facially traumatic event can disrupt the person’s sense-making of their past, present and future (Frank, 1995), for example, through a cancer diagnosis or being in a motor accident.

During the first half of the chapter I focus on participants’ experiences of embodied disruption and ‘disfigurement’ as unhabitual body-face appearance using Leder’s (1990) text The Absent Body. Leder (1990, pp.85-91) considers how we become more aware of aspects of the body-self when they behave unhabitually, for example through illness or disability. In doing so, they move from the background of our bodily awareness to the foreground of our attention, into a state of ‘appearance’. I draw on Leder’s (1990) work to help explain the participants’ facial appearance through cancer, accidents and acne rosacea. I also draw on the work of Frank (1995) and his text The Wounded Storyteller to help explain the disruptions to biographies and narrative identities that facial appearance can cause. Frank’s work (1995) will feature more significantly in the next chapter, life in the aftermath of facial
disruption. As with the first analysis chapter, I want the data and the participants’ identified narratives to stand out, and not become hidden through the extensive use of theory.

Developing ideas raised by Bury (1982), Frank (1995) argues that illness wrecks the sense of the known present and the perceived future. For Frank (1995), whilst infantile bodies are contingent and leak according to need, adults are expected to control their excretions or hide what they cannot control, or else face social ostracism. Illness leads to ‘narrative wreckage’ (1995, p.53), a process where the body is thrown into relief and chaos, and contingency comes to the fore, resulting in the loss of the life map. Illness is therefore, about learning to live with loss of control and predictability. Stories utilising selected actors, objects and events are needed to ‘repair’ the damage done to the person’s biographical coherence (Frank, 1995). The practical problem is to construct a story in which the past is still connected to a present and future in an ongoing project. Though the past cannot be altered, the sense of what was foreground and what was background can shift to recreate greater ‘continuity and closure’, creating a greater sense of cohesion, or not, in some cases (Spense, 1982, cited in Frank, 1995, p.61). These are told to one’s self as well as others, each telling unfolding within the other (Frank, 1995). Through re-storying pasts, presents and re-framed futures selves can be redrawn, as can relationships with the self and ‘other’. Through each nuanced telling and listening, the self retains its status as being worthy of voice and audience and each time a version is shared, it returns some control to the teller. To tell is to make sense of, in some way to carve through the contingency and the chaos (Frank, 1995).

During the second half of the chapter, I step back from the individual as the unit of analysis to consider the wider societal implications of inhabiting disrupted embodied identities. To help explain the findings I used a combination of anthropological and sociological research on ritual pollution, transition and liminality. I was unprepared for how significant the idea of identities in transition would be to the remainder of the thesis. I move beyond the individual to consider how and why these transitional, and in some cases liminal identities emerged. I explore the idea of facial matter ‘out of place’ (Douglas, 1969) as a form of ritual pollution, bio-medically influenced liminality, cancer as a liminal state and disrupted gender identities.
Foregrounding faces: embodied disruptions and unhabitual body-facial appearance

During this largely theoretical section I will use Leder’s (1990) work on bodily appearance to illustrate how faces can move from background to foreground. Leder (1990) asserts that we cannot understand the origins, orientations, or textures of our perceptual fields without reference to the ‘absent presence of the perceiving body’ (p.13). Absence refers to all the ways in which the body can be absent from view and awareness. Disappearance is a form of absence, as aspects of the becoming body are never shown, i.e. internal organs. Although, usually on show to others, the face can be seen as absent in two key ways. Firstly, when the body is functioning normally, it tends to disappear from the individual’s explicit awareness. For example, I may use many of my facial senses to perceive of and interact with others, but I am not necessarily aware of my eyes, nose or mouth working. Secondly, unless a person has sight and is looking in a mirror, they cannot see most of their face, even though they know it is there. Similarly, Leder argues that we tend not to notice habitual environments that we live in intimately. However, when something is desired by the body, i.e. food, drink, sex, we experience sensations which focus our activities and make us aware of our environments. These needs are experienced as habitual sensations, which return to the background when our emotional state changes or our needs are satisfied (Leder, 1990, p.79). For example, we may be aware of the food in our mouths through its taste, touch or smell, though once swallowed, it is removed from our attention. Although, when unhabitual sensations occur, i.e. pain, illness, emotional or mental distress, our attention is drawn to the body and the part causing distress, together with the environment, which shifts from absence into presence or appearance (Leder, 1990, pp.39-40). In this case, the causes of the participants’ unhabitual body-facial appearance and ‘disfigurement’ are through cancers, accidents and acne rosacea. (These are summarised in Table 6.)

‘The image of the skin as some kind of inviolable boundary no longer makes sense, for it is continually breached by a series of biomedical technologies in the interests of maintaining the illusion of a normative body’ (Shildrick, 2008, p.33).

Leder (1990) argues that when unhabitual bodily disruption occurs, it illustrates that the body and I argue - the face can no longer be taken for granted. As Shildrick (2008) argues, breached skin shatters the illusion of an unbreakable boundary between self, environment and other. When embodied disruption and appearance occurs, the body no longer expresses the individual’s personality, but the hegemonic will of an occupying force (Leder,
As the face is permanently on view and key to recognition and communication, skin breaching and unhabitual facial appearance are more likely to be noticed than other bodily injuries, which can be hidden by clothing. Therefore, there is always a strongly societal element to facial ‘disfigurement’. As most of the participants’ intimated curious, well-meaning, insensitive or negative comments by others could enhance the sense of biographical, emotional and visual disruption caused by the incident (Bury, 1982, p.173; Hochschild, 2003). Feelings of alienation towards body parts can occur as the individual feels they are no longer in control. This can lead to feelings of pity or disgust, within the self, or from others (Goffman, 1968; Leder, 1990; Frank, 1995). In light of my research findings, I would add that these feelings may also occur because the person is breaking norms of having a bounded face, incurring possible ritual pollution and because the person no longer recognises themselves through their appearance. The ideas of disruption, ritual pollution and identity transition/liminality are developed during this chapter. In the first section, I explore how participants’ faces appeared through having cancer, being in accidents or by having a diagnosis of acne rosacea and the environments that they occurred in.
Table 6: Participants’ unhabitual body-facial appearance and ‘disfigurement’

<table>
<thead>
<tr>
<th>Cause</th>
<th>Person, age, and decade of change</th>
<th>Summary of body-facial changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer and facial palsy</td>
<td>Natasha, late 20s, 1990s-present</td>
<td>In her late 20s Natasha had a life-threatening head infection and was treated in hospital; she nearly died, recovered, then convalesced at home. It took two years to heal. Eventually an underlying genetic condition was diagnosed, explaining her slightly unusual head shape and making her more prone to cancer. She has since been diagnosed and treated for facial and other cancers, and was in remission with advanced cancer (December, 2011). She has also suffered from facial palsy, as a result of the cancer treatments.</td>
</tr>
<tr>
<td>Cancer</td>
<td>Sylvia, mid-30s, 1970s+</td>
<td>Sylvia went to the GP with sinus problems. After two misdiagnoses a life-threatening sinus cancer diagnosis was given. Evasive surgical and other medical treatments occurred. The cancer returned within a couple of years. She survived after further surgery and cancer treatments. In the process of treatments she lost an eye and a substantial part of one side of her face. Sylvia wears a prosthesis.</td>
</tr>
<tr>
<td>Cancer</td>
<td>Marie, early 40s, 2000s</td>
<td>Marie noticed a small lump in her mouth and went to the GP. It was later diagnosed as cancerous, though it had been caught early. She had surgery to remove it, and it has not returned.</td>
</tr>
<tr>
<td>Cancer</td>
<td>Doreen, mid-60s, mid-2000s</td>
<td>Doreen noticed a small lump in her neck so she went to the GP. It was later diagnosed as cancer. She had surgery to remove it. It has not returned, though she has to blend her food in order to eat.</td>
</tr>
<tr>
<td>Cancer</td>
<td>William, early 60s, mid-2000s+</td>
<td>William noticed an ulcer on his tongue and went to the GP eventually. It was diagnosed as cancer and treated with surgery. William has had to adapt the way he eats food. The cancer has since returned twice, though it had been caught early and he was in remission.</td>
</tr>
<tr>
<td>Cancer</td>
<td>Jonathon, early 50s, mid-2000s+</td>
<td>Jonathon noticed a rapidly growing lump on his forehead. It was wrongly diagnosed by the GP before being diagnosed as cancer. He had surgery to remove it and lost an eye in the process. Jonathon had reconstructive surgery to replace the skin. The cancer has returned and been treated, though he had had to retire from work and was in remission at the time of the interview.</td>
</tr>
<tr>
<td>Accident</td>
<td>Agnes, 8, 1940s+</td>
<td>Agnes had suffered with deteriorating hearing and had gone into hospital to have a potentially life-threatening ear infection removed by surgery. The surgeon accidentally cut some of her facial nerves resulting in a loss of movement on one side. She grew up with an unsymmetrical/lopsided smile and for a while had to wear a facial brace from her inside cheek to her ear.</td>
</tr>
<tr>
<td>Accident</td>
<td>Clara, 6 and 8, 1950s-60s</td>
<td>Clara had two accidental falls whilst out playing as a child. They nearly ripped her top lip off and broke her nose. The initial treatment was poor and resulted in evident scar tissue. She had reconstructive surgery at 17 years of age to rebuild her nose though was unhappy with the results.</td>
</tr>
<tr>
<td>Accident</td>
<td>Martin, 18, 1970s+</td>
<td>As a teenager Martin was driving a car, he lost control and it caught fire. He received extensive burns to his face and body, lost some fingers and initially the use of his hands and legs. Martin spent months in hospital where he received extensive skin grafts and physical therapies. Over the next five years he spent time in hospital receiving reconstructive surgeries to his hands, face and back.</td>
</tr>
<tr>
<td>Cause</td>
<td>Person, age, and decade of change</td>
<td>Summary of body-facial changes</td>
</tr>
<tr>
<td>----------</td>
<td>----------------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Accident</td>
<td>Gillian 19 Mid-1980s+</td>
<td>Whilst out on a drive, her ex-boyfriend lost control of the car and crashed it into a wall. Gillian’s head and body were crushed. She nearly died twice, firstly due to her injuries and later from a related infection. She broke her back, lost an eye, her face had to be rebuilt surgically and she had to learn how to walk again. Gillian had a prolonged period in hospital followed by related surgeries over the next two decades.</td>
</tr>
<tr>
<td>Accident</td>
<td>Barney late teens 1940s-50s</td>
<td>Barney was a serving RAF Commander during World War II and afterwards. In the course of war operations, the aeroplane he was in command of crashed into the sea. He would have died but for being rescued. His face was lacerated on one side and his skull was crushed. Initial reconstructive surgeries took place in hospital, which were continued episodically by pioneering facial surgeon Archibald McIndoe.</td>
</tr>
<tr>
<td>Accident</td>
<td>Andrew mid-20s 1980s</td>
<td>Andrew was a serving soldier in the British military. At the start of the Falklands War the boat that was carrying his regiment was bombed. He received extensive burns to his face and body, lost fingers and nearly died. After a prolonged hospital stay including reconstructive surgeries to his hands, Andrew left the Army.</td>
</tr>
<tr>
<td>Acne Rosacea</td>
<td>Stephen mid-20s 1980s+</td>
<td>Stephen began to develop facial redness, burning and symptoms associated with acne rosacea from the age of 25 onwards, though it took years for an accurate diagnosis. During this period, the symptoms continued to worsen. Stephen has tried extensive medical treatments, from creams to tablets, to laser treatments, all with either none, or limited effectiveness.</td>
</tr>
</tbody>
</table>

‘Disfigurement’ as unhabitual facial appearance through cancer

Those who had had a head and neck cancer (William, Jonathon, Doreen, Sylvia, Marie and Natasha) all talked about the diagnosis. For some it was a momentous departure from known lifeworlds, for others it was not, or at least the significance was not verbally acknowledged. The following two cases illustrate the range of participant responses to the revealment of bodily vulnerability and potential lifeworld and identity chaos. Though he was married with adult children and close friends and neighbours, William presented himself as ‘the’ central, agentic mostly autonomous actor in his identity narrative. Even though his diagnosis had occurred after retirement, much of William’s story was told through the performance of his role as a former manager and industrial chemist, which involved much European travel. Bury (1982, p.178) argues that medical diagnoses and treatments only offer people a limited explanation of events. Whilst I would agree, William also used the medical narrative to enhance aspects of his pre-existing biography. He identified strongly as a pragmatic, unemotional problem solver, knowledgeable about the world, able to move freely within it and in control of his body. He tried to maintain this identification after
diagnosis and treatment, not only through his gendered bodily performances (Goffman, 1959; Butler, 2004) but though the way in which he constructed his account. Like one of his successful chemical problem solving stories, William’s narrative was broken into small sequences of technical action, such as of the type and length of treatment, leaving little room for any bigger picture and contingency, chaos or emotion such as fear. For example, his potentially life-threatening diagnosis, invasive operation involving splitting his jaw open and a yearlong recovery period were reduced to a couple of minutes. He did not verbally acknowledge the temporary and more permanent shift in lifeworlds, nor what he was unable to do during this period, though he did divulge more details later in the interview. Chaos was only hinted at towards the end of the cancer episodes once they had been ‘dealt with’ and controlled, which was signalled by his return to gardening (involving the physical control and movement of his body) as an indicator of habitual performance:

‘... The guy (a dentist) had a look at it (a mouth ulcer) and said I don’t like the look of that I want a second opinion. And so, Wednesday morning the hospital rang... The following day they did a biopsy and a week later I was told you have got mouth cancer and did quite a substantial operation... Just to give you a comparison on this, I have had three more tumours since then which were all detected very quickly, one hour in theatre, home the next day, pottering in the garden at the end of the week’ (William, 2011).

Like William, Sylvia started her story with an illustration of her bodily control and positive aspects of her identities, though her narratives were domestically orientated and conforming to traditional gendered notions of femininity for women in 1970s Britain. Her account focused on the control and appearance of the body, not like William, who was more concerned with its performance and movement in the world: ‘I had an idyllic life, I was blissfully happy, I was marginally attractive I had really good hair and I was very slim’ (Sylvia, 2011). Her diagnosis account was very different to William’s; there was no mechanistic focus on the details or problem solving. Instead, her growing awareness of embodied vulnerability and the chaos arising from the partial cancer diagnosis became evident from the emotional tone of her voice, description of the environment surrounding the disclosure and from the often emotional content of her story. For Sylvia, the diagnosis alluded to a point of biographical and relationship departure, not one of continuation (Bury, 1982, p.178)

‘... they (surgeons) did an exploratory op, did a biopsy and discovered that I had squamous cell carcinoma growing in my sinus and I can remember standing at the bus stop.
My friend had my three children after school and I went for this appointment. And I can remember standing at the bus stop and she told me to phone her and she would come over... and I can remember standing at the bus stop and... not wanting to phone her. I was going to get a bus home, I was going to be totally independent. I can do this! And it was dark and it was cold and I thought well all I have got is erm... actually they didn’t tell me it was cancer then, he just said that there was something sinister so, I thought I am just going to get on with this and get it sorted...’ (Sylvia, 2011).

Sylvia’s quotation has metaphorical and poetic qualities; like the environment, her lifeworld has suddenly become cold and dark, she had gone to the medical appointment on her own and due to the partial diagnosis could not see what lay ahead. In addition, the diagnosis threatened her bodily boundaries, lifeworlds and the performance of her identities such as wife, mother and friend. The bus became a vehicle for her continued independence. Sylvia could rely on a friend for a lift, but she did not want to rely on anyone physically or emotionally. In that moment, she conveyed her control over her body and its movement in the world, something that was to change in the months and years to come. Between the extremes of these accounts are Doreen and Marie’s, and Jonathon and Natasha’s diagnosis narratives.

Doreen’s and Marie’s diagnosis stories are similar to William’s, in that they are both diagnosed after the age of 40 and both conveyed relatively unemotional accounts with little room for chaos. At the time of her diagnosis Doreen was a retired shop worker in her 60s and had been a wife for decades (how many she did not state). Doreen had a daily routine, which involved visiting the inhabitants of the local old persons’ home, calling in on her sister who lived locally, having a small bet on the horses and keeping her house clean and tidy. She kept her mind alert and used her body to support the needs of others. Unlike any of the other cancer stories Doreen did not place herself at the centre of what could have been an existential crisis. Instead, she relayed the episode calmly and pragmatically as she presented for much of the interview. Like William there was no narrated threat to her future life or identities, however it was not because she was trying to mitigate the chaos through managing events mechanistically. Like William, she had already lived much of her life, though more so than William, she acknowledged the contingent nature of existence. Her diagnosis event was told through the sudden and unexpected death of her husband. There were short pauses and some sideways looks to illustrate that eight years on, the memory of this event, rather than the threat of her embodied facial appearance was still emotionally resonant. After her treatment she was able to return to her daily routine and to her much
prized role as a carer, which may also explain why she appeared to be so sanguine about events.

Marie’s account was similar to Doreen’s in some respects. Marie narrated herself to be a pragmatic, positive woman, a wife, mother and a worker (an administrator at a local higher education establishment). Like Doreen’s diagnosis story Marie’s was narrated matter-of-factly with little emotion; it concerned various medical encounters and her compliance with treatments. Again, like Doreen it was co-narrated through relationships, in particular her husband and son. Marie’s husband was present for half of the interview and co-created the narrative. However, where they differed was in the articulation of lifeworld disruption and chaos. The diagnosis did not seem to outwardly cause Doreen significant existential distress, compared with Marie. Firstly, she was much younger than Doreen when she was diagnosed and her son was a teenager. Though she did not say it, there was an implication that she had much to lose such as the opportunity to see her son become an adult and have his own family. In addition, rather than accepting the contingencies of life my understanding was that Marie wanted to maintain embodied control at all costs, even during the interview many years later. Remembering the episode she appeared to dissociate from her body, and view it as an organism to be mechanistically treated and cured (Shildrick, 2010):

‘I had this sore mouth, and eventually erm... this thing which I thought was an ulcer, appeared. Eventually I went to the dentist and he knew straight away what it was but didn’t tell me... basically (the dentist) told me that it was a growth, and I said to him, but it will be benign? And he said no, and that was it... So, from then on it was just erm... it was horrendous at first I have got to say, because I think my whole life passed before me, you know but I remember saying to him, am I going to die? And he said not if it’s treated, so because he said that, I decided there and then that you know I was going to fight this but, erm... I remember the GP telling me that they would just cut it out, sew it up and that would be it’ (Marie, 2012).

Jonathon’s and Natasha’s stories of diagnosis shared some characteristics with Sylvia’s emotionally evocative account. Both Jonathon and Natasha were in control of their lives and futures, they owned houses, had careers and families, which were mentioned prior to the diagnosis and treatment. With both accounts there is no one definitive moment of facial change. In Jonathon’s case he had been aware of a growing lump on his forehead for some time, which was initially wrongly diagnosed. During this period he received some curious stares and direct questions from unknown others, especially children: ‘Mummy why does
that man have a potato on his head?’ However, the altered appearance and unwanted attention was not as significant a disruption and threat as the initial and second cancer diagnosis and treatment was to his lifeworld and embodied identities. It took a while for Jonathon to talk about the initial diagnosis. Like Sylvia it was an emotionally resonant moment that he remembered clearly. Jonathon tried to enact elements of a hegemonic masculine identity (Connell, 1995) to help him manage his emotions in front of the (male) health professionals and his wife, and to mitigate the threats to his already revised embodied identity. He responded directly, pragmatically and unemotionally during the consultation, trying to instigate some control over the existential threat through asking for the cancer’s removal. However, the attempt at control and the illustration of a hegemonic masculinity was only partially successful; his body-self relayed the extent of his shock and distress in the car park where his knees gave way and he cried with his wife. Unlike a number of the other men who were married and yet presented themselves as autonomous agents Jonathon’s story is co-told through his wife’s influence and reactions and there are many references to ‘we’:

‘... but when they actually told me erm... I don’t know how you, don’t know how you are supposed to feel you know? I (pause) my wife just collapsed in a pile of... and I sort of stiff upper lip you know... remember my father (laughs). And he said (the oncologist) you have got cancer is there anything you want to ask? I said no, when are you going to take it off my head? And I walked out in the car park and my knees went and that was it, I would rather blub in the car park’ (Jonathon, 2011).

Using the example of Jonathon it is clear to see that identity is not located within faces as some clinical academics (Carolessa and Pradeu, 2006; Swindell, 2007; Carty et al., 2012) have suggested, but within the embodied identifications and activities of the person. For Jonathon, it is the threat to life, activity and overall loss of corporeal control that is much more meaningful than the alteration in facial appearance (a lump on his head, which became a noticeable skin graft, together with an eye patch). After the first round of treatment Jonathon could continue to control his body and his future, through continuing to work - for money, and for his charities by being on the committees of the Round Table and the local Mason’s lodge. However, when the cancer returned he required more invasive treatments; in the process he lost an eye and his hearing in one ear, developed temporary Bell’s palsy and lost the ability to concentrate or retain information. Other unrelated health conditions also became foregrounded, i.e. diabetes and a heart condition and Jonathon had to retire from both paid and charity work completely. The loss was keenly felt to his identity
as a successful material provider, an element of masculinity traditionally associated with
men, and as a committed volunteer with responsibilities and some control, such as being
the head Mason or Master of the (Masonic) Lodge on separate occasions:

‘As I say it was hard at 53 you know to... You are in your swing, there you are really
going. Both kids had left home, two nice incomes coming in, two cars and all of a sudden you
are on £68.90 a week you know, because your company can only keep you on, I think I was
on three months sick pay, but after then it was - what can you do?’ (Jonathon, 2011).

Jonathon’s response was to exert greater control over the things he could influence such as
his finances, particularly after the second course of cancer treatment. He and his wife sold
their large country house and moved to a low maintenance retirement flat, bought health
insurance and a funeral plan each. Tight control was also exerted over his daily income and
monetary outgoings in an attempt to quash some of the chaos resulting from bodily
vulnerability, existential threats and the unanticipated, unknown future:

‘We have been able to structure my life so much now... financially we know what is
coming in, we know what is going out... So that is it, so it’s very pigeon-holed but there is no
mortgage, you know because what we are in is a sheltered housing... you can stay when the
other partner has gone and so I feel comfortable there... It’s like paying your mortgage off,
and so I feel and perhaps the illness, the only plus side of it, was it’s made me I suppose look
at my vulnerability and try and make it less vulnerable...’ (Jonathon, 2011).

In Natasha’s case, she had experienced several health complaints and long since recognised
the vulnerability of her body, i.e. a serious infection on her head and facial palsy before an
underlying genetic condition was diagnosed, which entailed a significantly higher chance of
developing cancer. She talked about her advanced cancer diagnosis in relation to her life
and the hinted at, but did not expand on her future. Like Jonathon Natasha was in
remission, however her cancer was at an advanced state and her health varied on a daily
basis. However, as a book shop owner (with her husband) and with a family close by she had
more flexibility than most regarding employment and her income and career-related
identity did not suffer unlike Jonathon. The key disruption for Natasha was the one to her
perceived future, which she dealt with by compartmentalising her life into ‘boxes’, and living
it ‘in a kind of bubble’, and verbally through the use of unfinished sentences with existential
implications. There was a firm focus on the present and a recent marriage to her long-term
partner, which could be seen as a way to mitigate some of the legal, bureaucratic and
emotional chaos when events finally took their course. As with Jonathon and Sylvia the
existential threat from cancer and its potential to disrupt her identities of wife, mother, family member and bookshop owner were more meaningful than her altered facial appearance, partly for herself and as an illustration to her daughter that there was more to her life than appearance:

‘... My daughter is the big motivation for me, for not letting this (silence). I don’t want to see my face as kind of the defining thing about me’ (Natasha, 2011).

‘Disfigurement’ as unhabitual facial appearance through accidents

During this section, I will examine the participants’ experiences in pairs, as their cases have some similarities: Clara and Agnes, Gillian and Martin, and Barney and Andrew. Clara and Agnes both underwent facial change as young children approximately five decades ago and both experienced unanticipated and unwanted side effects of their medical treatments. They were both critical of their fathers for not standing up to medical authority and making things better, e.g. getting proper treatment, or being there at the hospital. However, their conceptualisations of the event and its influence during the immediate aftermath were markedly different.

Agnes’s appearance altered at the age of eight. She had an operation to prevent the onset of a potentially serious ear infection from becoming life-threatening. The surgery was a success and the infection was removed however afterwards she became aware of a pulling sensation when she smiled and realised that her appearance did not look like everyone else’s. It transpired that a surgeon had accidentally cut her facial muscles on one side. While she was still in hospital and feeling self-conscious a member of her medical treatment team told her off for not smiling. In addition to feeling upset, alone and frustrated that her parents had let her go through the operation Agnes said that not having a symmetrical smile had diminished her confidence all her life. However, it does not seem to have prevented her from achieving her desired goals.

Agnes was the youngest of five siblings with three protective elder brothers and an older sister. For a younger female sibling growing up during the 1940s, Agnes may have had opportunities that other girls of her age might not have had, for example she played pool and billiards with boys, beating them on many occasions. This appears to have left her feeling comfortable and confident being around male contemporaries, something that was to pay dividends in her working life. The family seemed to have been close, supportive and sociable, especially her mother; as children they ‘always had lots of friends home’. In many
ways, Agnes’s childhood sounded idyllic, apart from her asymmetrical smile which she was always conscious of. However, it was not the sudden appearance (Leder, 1990) of her smile that was the most significant facially related influence on her identity, but her gradual hearing loss which started to occur around the same time (and led to her becoming profoundly deaf for 50 years). Though it had been a challenge taking the large and heavy hearing aid around school, her family, friends and the school staff appear to have been supportive and Agnes did not appear to suffer from social isolation or diminished educational expectations unlike Clara. Agnes recalls being ‘10 and 11 years old, very happy really, with hearing aid and friends and school, I never got teased or bullied or anything like that’. In spite of increasing deafness Agnes achieved O-levels and A-levels at school and went on to complete a chemistry degree, develop a career in a scientific laboratory where she met her future husband and had two children. In spite of these achievements, Agnes did not present herself as the central, agentic autonomous narrator unlike some of the male accounts where career, intelligence, or sporting prowess was clearly stated, i.e. Martin, Andrew, William, Stephen. Agnes seems to have had a positive outlook on life, been engaged with the world through her family and friends and had a desire to succeed educationally:

‘Well apart from the operations and things I was fine, fine. I was getting better and making friends I think at school, the nuns and the teachers were very, they were very sympathetic they were very good. And I think the other children in the class - it became easier to make friends... But my hearing was definitely affecting me... in those days hearing aids were massive you know... heavy and erm... uncomfortable but erm... it helped me tremendously. I hated the thing you know, and I hated to be without it’ (Agnes, 2011).

In contrast to Agnes who felt supported by family, friends and teachers and who engaged with the world, Clara felt increasingly isolated after her two facially related accidents. Prior to their occurring (at ages six and eight) she had some close friends and participated in activities with other children, e.g. horse riding. However, as the only child born to Jewish parents Clara was not encouraged to develop friendships with gentile children. There were few Jewish children for her to mix with locally and her parents did not regularly attend a synagogue. So, when the accidents occurred Clara was left with facial scarring, a squashed nose and feelings of vulnerability. The mixture of curious, well-meaning and ignorant comments from contemporaries and strangers alike made her even more aware of her appeared facial difference, which in turn led to her becoming more socially avoidant,
introverted and isolated. This became more pronounced when her family moved house to a new area with a new school where she did not know anyone:

‘I was in such a state, there was blood everywhere, all down me. Dad took me to the hospital, and instead of doing it properly and suturing and everything they stuck it with these little butterfly strips you know that they put over sutures, and it grew back all deformed and everything... I had a lovely childhood... and then this happened... I have only just realised that you know since talking to you... that was the only time in my life I had a lot of friends’ (Clara, 2012).

For Clara the accidents mark a clear biographical and corporeal disruption (Bury, 1982) in her life between happiness and friendships and ‘ugliness’, unhappiness and reclusiveness. In her eyes she became ‘unlovable’ due to her facial change and she sought other positive embodied identifications such as intelligence: ‘... if anyone insulted my intelligence that was a terrible mega thing... because I thought well I can’t be pretty but I can be bright’ (Clara, 2012). From childhood onwards, Clara began to place a great deal of importance in the facial looks and bodily attractiveness of others, partly to compensate for something she felt she did not have. Hers was one of the clearer examples of the arcane cultural trope still in existence wrongly linking facial appearance with moral character (Synnott, 1991; 1993). It is an association which has remained with Clara throughout her life. However, now, as an adult some five decades later, she also acknowledged the role of other factors in how she perceived the facial change and its influence on her identifications and subsequent choices. In light of the then approaching interview, Clara had given the facial issue some consideration. She reflected that her upbringing and experiences of being Jewish had also shaped her understanding of her appearance and her body-self in the aftermath of the event and the ensuing decades. There was a recognition that Clara did not have a significant facial ‘disfigurement’ compared to some people, though its lifelong impact was felt to be deeply significant. This finding concurs with earlier research conducted by Rumsey et al. (2004). They discovered that the degree of facial disfigurement was not associated with the degree of suffering that the person experienced.

‘So I had a very happy childhood then, very carefree and then I had this accident and everything changed... You see these scars here on my upper lip, they have faded a lot now with age, but it grew back like great big clumps. I used to get people coming up to me on the bus there telling me ‘Excuse me do you know you have got chocolate round your face?’ And it was just awful... and really when you think, when you look at other people’s
disfigurements, that is nothing, but it was a lot to me growing up. It blighted my life this facial disfigurement...' (Clara, 2012).

In the next pairing, Gillian and Martin had both experienced car crashes in their late teens. Gillian was being driven through the countryside by her ex-boyfriend; he misjudged the road ahead and drove into a wall at speed. The car spun and smashed into the wall with the brunt of the impact on the passenger’s side. In the process her head was smashed against the windscreen, her back was broken and her eye was perforated. Gillian lost consciousness and had to be cut out of the car by the fire brigade, she lost the eye, nearly died and had to learn to walk again. Martin was driving at night when he lost control and turned the vehicle upside down. It caught fire and he was pulled out just in time, though he received extensive burns to his body, limbs and face. He lost fingers in the episode and also had to learn to walk again. In both accounts there was a strongly anticipated successful future, through the development of careers, relationships, marriage and the production of children. Martin was an active sportsman and trying to get a place at a prestigious English University. Gillian was at the start of a career in advertising. Both identified as bodily attractive and active individuals. Then the unexpected occurs and both spend many months in hospital due to the severity of their injuries.

The accidents suddenly threw known and perceived bodily abilities, presents and anticipated futures (Frank, 1995) including relationships (Bury, 1982) into relief. They both moved from social environments where they were active agents with relationships (Gillian was on holiday coming back from a meal at a pub, Martin was on his way to a party) to hospital environments where they had little bodily agency or autonomy for months. Unlike the participants with a cancer diagnosis there was no time between the diagnosis and the treatment to consider the possible disruptions and the future. The focus of the initial aftermath for both participants was on survival and their language reflected the immediacy of the shock, pain and suffering, all of which reflected the undoing of the previous lifeworld (Scarry, 1985). Family members and medical staff were present in the background of both stories, though both were given a limited role and the participants retained their role as central if partially isolated protagonists. In addition, both used photographs to great effect to illustrate the difference between anticipated and disrupted identities.

Martin described the six-month period in the immediate aftermath of the crash using a series of photographs of himself at regular intervals. They focus on himself and his changing corporeal appearance, from before to six months afterwards. Viewing burned skin, raw-
looking flesh and healing skin was not easy to look at. The suffering in his eyes was evident; I was looking at ritually polluted ‘matter out of place’ (Douglas, 1969) which I discuss later in the chapter, and it reminded me that I am a corporeally vulnerable being (Shildrick, 1997; Perpich, 2010). The emotional devastation was still resonant in his voice thirty years after the event. The chaos and suffering that had suddenly entered his body-face and life through being burned was not just spoken of, it was evident through his emphasis on specific words, lower pitch when he talked about the initial aftermath and through silent pauses and unfinished sentences:

‘... suddenly I was completely, completely swamped by a medical emergency. 40% of my body and frankly I didn’t think about my face for, well probably, I was sort of aware of people’s reactions to my face. But actually - rather the physical pain, enduring the endless operations, the unbelievable discomfort from skin grafts and donor sites and you know just the physical agony of going through what I was going through and heavy sedation. So for some months I was really out of it, I was surviving...’ (Martin, 2011).

Even so, Martin left the impression that he had not revealed the full emotional, psychological and physical impact of events. For example, he talked of a ‘medical emergency’, rather than existential threats, emotional pain or the loss of future anticipated success (Frank, 1995). In addition, the burn-related injuries, loss of fingers on one hand and having to learn to walk again challenged Martin’s conception of himself as a successful sportsman. This was something he touched on later in the interview but again, I was left with the impression that the full impact was not fully articulated. Martin did go on to state that he was no longer able to ‘trade’ on his good looks to attract women. Perhaps this was easier to disclose because his looks were less important to him than what he was able to achieve with his body?

Martin’s transitional, liminal state lasted for five years and was marked by many hospital stays, operations, and skin grafts, to reconstruct his body and repair the openings where matter had come out of place (Douglas, 1969). Though, this was not the only reason he was in a transitional state. Like Andrew, Gillian and Sylvia, Martin had lost the visual and performative recognition of his body-self. Like them, his transitional phase was about learning to identify with and through his revised embodiment, both physically and visually. To signify the end of this phase Martin changed his name, as the period of ritualised embodied transition ended and he began to focus increasingly on life outside of the hospital:
‘... although my name is Martin now, at school I had been known as ------- and I reverted during this year off to Martin’ (Martin, 2011).

Gillian’s account of the car crash which altered her body-face was similar. However, the threats to her body, lifeworlds and identities resulting from the car crash were more fully revealed than Martin’s. The early chaos remained palpable through her articulation, pitch and expressions, even though the crash took place 25 years prior to the interview. In the following quote Gillian articulates the alienness of her new situation through: the medical professionals’ appearance, actions and manner; the unhabitual hospital environment; her appeared unfamiliar body; the shock and pain of the unrecognisable face; the presence of multiple competing emotions, and through her growing sense of isolation. The word ‘foreign’ in the following quote does not just describe the woman sitting on her bed; it describes Gillian’s body, the pain she experiences, her visual appearance and the environment she finds herself in. I would argue that these indicate the loss of the anticipated life map (Frank, 1995) and lifeworlds and identities in temporary transition at the very least:

‘One day this lady came up to my bed and she was a foreign lady. I think she might have been Indian, and I just remember her having a long plait down the back of her neck and although she was very nice and came in and smiled, she dropped down a plastic bag, see through polythene bag of artificial eyes on the bed. And I just looked at this woman and looked at this bag and thought oh my God what is that... So I was absolutely shocked, and you know me being me just thought oh right well this is obviously what happens. She sort of opened my eye socket with her fingers which I thought was horrific and it was very painful, tried to get a prosthetic eye into my eye socket which was clearly very swollen, damaged all the rest of it. And of course she managed to get it in, and I didn’t know what all this was about, hadn’t seen the side of my face, I asked one of the male nurses to give me a mirror, oh my God’ (Gillian, 2011).

The final pair to be ‘disfigured’ by accidents were Barney and Andrew, who at that time were both serving members of the British armed forces. They were both military personnel involved with fighting wars and though the idea of gaining a body-facial injury was conceivable within the context of their profession it was still sudden and unexpected. Barney was a pilot in command of a plane and a crew during WW2; during one operation it crashed into the Atlantic ocean due to bad weather. Some of the crew died and Barney was rescued from the sea, initially presumed dead. Andrew was a soldier, on board a ship in the
southern hemisphere. His ship was bombed by an aerial bomber (plane) and it burst into flames killing approximately 50 men in the process. He received significant burns to his whole body including his face. Their accounts were similar; they both strongly identified as active and later ex-British military. Both maintained their links with their former professions via friendships and by becoming active members of ex-servicemen’s organisations. So, although events disrupted some relationships (Bury, 1982), they did not disrupt all of them, possibly because injuries can be an aspect of military life. Both told the story of how they gained their body-facial injuries using hegemonic masculine identities, such as emotional control, physical strength and functional independence (Connell, 2005, p.77) and incorporated their environments (Leder, 1990) into their disruption narratives. However, their accounts also differed slightly in ways that I will now explain.

From start to finish Barney’s story was quietly told; he narrated stories of self-improvement, hard work and achievement, whilst in positions of power. He had joined the RAF before the start of WW2 as a teenager with few qualifications and remained in it until the 1970s when he retired at the senior rank of Wing Commander having gained an economics degree from the London School of Economics. His narrative was one of control of his own bodies and those of others, continued physical and cerebral activity and worldly engagement (Frank, 1995). In keeping with his stiff upper lip attitude and risk-taking activities Barney’s account of the plane crashing into the sea (not for the first time), was both brief, unemotional and slightly humorously told. What he did three weeks after being rescued compounded these characteristics and illustrated his continued: commitment to the RAF; control over his body and lifeworlds; and illustrated some agency through the defiance of military medical authority and a sense of uniqueness, as no one else had reportedly defied medical orders. Barney may have been seriously injured but his biography as a military man was still firmly in place and being performed. In contrast to Gillian or Clara’s accounts, very little time or attention was given to the period (one year) that he spent in hospital when his body was additionally vulnerable (Shildrick, 1997; Perpich, 2010) as he was recovering from rounds of skull and facial repair surgery. The role of medical professionals in his recovery was absent from this part of his story, though their role in restoring his body-face was enthusiastically acknowledged later in the interview. The emphasis of the identity narrative was on Barney’s recovery and his being able to return to active military service as part of the British war effort. It was not related to his altered facial appearance and at no point during the interview did Barney intimate that his identity was located within his face.
‘Well, I had erm… several crashes and the one that this particular injury erm… I was captain of the aircraft, I was, sent off to look for a submarine between Iceland and Greenland, came back to Oban, bad weather and I crashed in the sea in the Atlantic and that’s the one. Mind you it was 70 years ago now so (Barney, 2011).

So what happened when you crashed, were you conscious? (A-M)

No I was unconscious when I crashed. I recovered consciousness underwater, and I don’t actually remember the erm… impact but I was underwater and fortunately in the boy scouts I had done swimming and rescue things, and so I paddled and erm… until I was picked up by some rescue boats and erm… They operated on March 15th, 1941 I went into East Grinstead in April ’41 and… because my skull was damaged, he couldn’t start the plastic surgery until the damage from my skull was cleared up… I was sent down to the Palace Hotel at Torquay for three weeks or a month before going on for more surgery… And instead of going down there I went to erm… the Head quarters and said that I had been let out of hospital to keep my hand in flying, and erm I was flying from Invergordon... (Scotland, hundreds of miles away). And then when I got back to East Grinstead, the plastic surgeon said, ‘Oh how did you enjoy the Palace Hotel?’ I said well, I haven’t actually been and he was very cross, very cross, nobody had ever done that before, and nobody has ever done it since’ (Barney, 2011).

Though Barney needed significant reconstruction work on his skull and down one side of his face stemming from the gash and the long, deep cut, Andrew had suffered more debilitating and extensive injuries leaving him with very little corporeal control and no opportunity to disobey orders. He was the most injured soldier to survive the bombing on his ship and had a related near-death experience. Andrew had been burned, lost his sight temporarily, nearly died, received an honourable discharge from the army and lost his much-prized identity as a British soldier, which he found incredibly difficult to adjust to. His account therefore had many layers of embodied, biographical and lifeworld disruption and contained some contradictions. As Goffman (1959, p.42) argues, aspects of stories which do not convey the identity that the person wants to present may be left out, or may contain gaps or inconsistencies. For example in the following quote it is Andrew’s mum that appears to be upset, not him, even though he had asked persistently to be sent home to her in the aftermath of his injuries. In addition, though his narrative was jokily told in places, as with Barney’s, Andrew’s was more emotionally resonant. Despite a focus on bodily vulnerabilities, physical pain and medical details his emotional response leaked out of the
narratives. This was evident from Andrew’s non-verbal body-facial language e.g. by looking away; and by what he said; how said it; the hesitations; the sentences he did not finish and by what he did not say:

‘Erm, I was blind for about a week, because my eyes had swollen up so badly because of the fire, (breathes deeply). Erm and then when I regained my eyesight my eyelids started to shrink, (silence). And they kept me on board for three and a half weeks because I erm, they thought I would die in transit. And in the end I was fretting so much to go home, they decided to send me and my heart apparently did stop twice so they resuscitated me, erm. They had to give me 100 mg of pethadine so they could clean my wounds with a brush, erm. (Silence) Got on the aeroplane to come back home and we were about to take off, plane was hurtling down the runway and the engine fell out the aircraft (told humorously). And I got back home and my mother didn’t recognise me (said in same voice). And I remember the upset it caused my mother at the time as well you know because she came in erm, (draws breath sadly) and then err it was just constant rounds of surgery really’ (Andrew, 2011).

‘Disfigurement’ as unhabitual facial appearance through acne rosacea
In this final case before considering the transitional/liminal nature of disrupted, embodied identities I summarise the experiences of Stephen who developed acne rosacea as an adult. Stephen’s preamble to developing the facial skin condition defines him as a physically orientated man in his prime, one of action, independence and full bodily control. He had friends and a strong sense of morality, though somewhat contrarily he used to get into fights defending himself and others. Stephen began to develop facial redness, burning and symptoms associated with acne rosacea from the age of 25 onwards, though it took him years to gain an accurate diagnosis. During this period, the symptoms continued to worsen. And in spite of his trying various treatments they did not work and the focus on the body-face and controlling the environments which triggered his symptoms intensified. Stephen sacrificed his beloved post office job and moved to a new employer to avoid the extremes of heat and cold and to avoid the curious and sometimes critical comments of his work colleagues when his face became red and swollen. He felt that no one took a person with a red face seriously: ‘people associate people with red faces with having something wrong with them and clowns’ (Stephen, 2011).
Bury (1982, p.173) has argued that in the aftermath of illness and consequent biographical disruption, that individuals may begin to restrict their environments, to avoid inquiries or gazes by others. Stephen’s narrative echoes these sentiments. He attempted to regain some of the lost body control by withdrawing from his lifeworld, for example avoiding friends at the pub, colleagues at work, and not challenging unfairness when he saw it. The life map had become lost, chaos had set in (Frank, 1995) and he did not know what to do to make life better; increasing environmental control was not working. As with Andrew, his emotional response was present, but was initially quashed using humour. However, unlike Andrew, Stephen cannot draw on an explanation for the rosacea, nor is it serving any greater good, i.e. by fighting for your country in a popularly regarded war. Nor is there a positive societal aspect to his condition leading to positive identity management (Goffman, 1959, p.18). Stephen does not receive media interest, or any unsolicited messages of support from the public. There was no burned mother of three writing to express her thanks for sharing his stories of suffering as they prevented her from taking her own life and that of her children. Consequently, his suffering and state of identity chaos continued long after the initial diagnosis took place.

‘And then I stopped going out erm… at weekends, because the… my face it was getting worse. It was getting redder it was getting all pimply and it was, I was getting these veins on my nose, right and I would walk in a building like say a pub and first of all it’s warm right, and especially like in the autumn and the winter straight away the heat would hit it and bang it’s bright red. Erm… and I just knew to avoid them situations, you know erm… then alcohol on top of that, that would make it even worse, so I was becoming socially isolated. I stopped going out to shops… I have got two older girls, they are both in uni (university). I used to try and send them to the shop because I wouldn’t go in. I would sit in the car… so that was like 20 years (laughs)’ (Stephen, 2011).

Disrupted body-faces: transitional and liminal socio-cultural identities

‘Betwixt and between’: Overview

‘Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial’ (Turner, 1969, p.95).
Having explored individual reasons for facial appearance (Leder, 1990), ‘disfigurement’, identity disruption and transition, I will now examine four socio-cultural types of transition/liminality that the participants may have experienced.

Firstly, I utilise Douglas’s (1969) classic text *Purity and Danger* to consider the idea that liminal states can be caused through matter, particularly bodily matter being ‘out of place’. Liminality can also be described as a stage in a process, which leads to a limen or threshold and the possibility of moving to a new state (Turner, 1969). Secondly, I draw on Turner’s (1969) work to consider the idea that being treated for an illness or injury in a Western biomedical institution can create or enhance a liminal identity state (Jackson, 2005; Philpin, 2007). Thirdly, I use the work of Little et al. (1998) to argue that receiving a cancer diagnosis can lead to the inhabitation of a liminal state. Finally, I explore aspects of the relationship between gender identity disruption and acquired facial ‘disfigurement’. Though I am presenting these threads in a linear fashion for academic clarity, in reality the participants experienced more than one thread, sometimes at the same time, sometimes not. For example, Martin initially had matter out of place, spent five years in and out of a biomedical institution repairing and reconstructing his body-face, all of which left him feeling ‘damaged’:

‘This was actually taken a month or two after (the crash). This was still scabby and these were not healed up...it was extraordinarily red, and vividly red and gaping and you know this scab was revolting and it was hard not to feel revolted, frankly. I felt tarnished (pause) I felt damaged beyond repair...’ (Martin, 2011).

‘Matter out of place’

In the classic anthropological text *Purity and Danger* (1969), Mary Douglas argued that individuals who did not inhabit clear identity statuses could be considered as ritually polluted, which state could threaten the legitimacy and continued existence of societal classificatory systems, e.g. power structures. This could happen in one of two ways; firstly people could inhabit marginal societal positions, which were not clearly defined, or alternatively, individuals could go through a dangerous transitional phase on their way to a new role or identity. The participants did not inhabit marginal statuses: all presented as ‘white’ British heterosexuals who spoke English as a first language; all had clear roles as either a current or previous partner (mostly a spouse), employer or employee; most were parents; most were connected to other family members and most had hobbies. Therefore,
the relevant type of transition leading to ritual pollution in this instance arises from an unexpected, acquired facial ‘disfigurement’. When pollution occurs individuals have the power to disrupt convention and to pollute others, especially when their bodily matter is considered to be ‘out of place’, through having broken its own boundaries (Douglas, 1969).

‘Matter issuing from them is marginal stuff of the most obvious kind. Spittle, blood, milk, urine, faeces or tears by simply issuing forth have traversed the boundary of the body. So also have bodily parings, skin, nail, hair clippings and sweat’ (Douglas, 1969, p.121).

Facial conventions and/or aspirations in Western societies include the pursuit of youth, beauty, facial symmetry, and bodily boundedness (Synnott, 1993). People with acquired facial ‘disfigurements’ subvert these aspirations/conventions. In the case of the participants, body-facial matter has definitely become ‘out of place’ (Douglas, 1969). Facial skin has been burned, torn, removed and sown back together. Blood has leaked out. Disease has been identified. Bones have been shattered, removed or replaced. Glass, bone and dirt have been embedded and removed from three skulls. Sinuses and muscles have been removed. One eye has perforated and along with two others removed, two more have leaked discoloured fluid and dirt resulting from an explosion. Two lips have nearly been ripped off. Many, many tears have been cried, noses have leaked and vomiting has occurred. Therefore, it is possible to view all of the participants as being ritually polluted, at the very least during the period of ‘disfigurement’ and in the aftermath prior to bodily repair or reconstructive surgery. I want to be clear that in reaching this conclusion that I do not intend to add to the suffering of a group who can experience enhanced social anxiety and depression simply because of their altered appearance (Rumsey et al., 2004). Applying the theory of ritual pollution to the analysis of the data adds an extra dimension to our understanding of the participants’ individual and social experiences as inherently connected. In some cases language did express these dynamic, leaky and polluted states. For example Martin reported feeling ‘tarnished’, after being burned, while Gillian stated that she felt ‘horrified’ by her newly altered appearance. The participants did not always express these sentiments directly, they were also hinted at through words, emotions, uneasy looks and pregnant silences.

Douglas (1969) has argued that during this transitional phase people can be ostracised by others, to mitigate the risk of contagion or to express their disquiet at the threat to convention. I would add that in this case, ostracism can also occur because facial ‘disfigurement’ is omnipresent unlike other bodily injuries/disabilities and that others do
not always respond with sensitivity. As conveyed in Chapter One, a number of social science and humanities scholars have already illustrated the inaccurate historical association between having a damaged or different facial appearance and a person’s supposed moral character (Synnott, 1993; Dudley, 2002; Benson, 2008). This harmful historical trope is still in existence. The recent James Bond film, Skyfall (2012) features a main villain with a prosthetic palette; the character Silva had suffered from internal acid burns and lost some of his own teeth and part of his jawbone. It may be more subtle than the villain Blofeld, a character in You Only Live Twice (1967) with his deeply scarred face, but the association and the implication is the same, this man is facially damaged and therefore morally damaged, do not trust him. It was against this socio-cultural backdrop that my participants reported unwanted looks and comments, either from work colleagues or strangers in pubs, supermarkets and other public places. In the weeks after the car accident Gillian was sacked from her dream job and found it difficult to gain employment in the years afterwards, which she thought was related to her altered visual appearance. She also reported an upsetting encounter in a pub on a night out with friends. An unknown ophthalmologist had walked past and said ‘eye, eye’ to her then proceeded to ask intrusive questions about the episode which she felt obligated to answer. Clara dreaded her mobility scooter breaking down in town as she had been subject to local youths calling her ‘Miss Piggy’. Shortly after her cancer treatment Sylvia reported being rudely stared at in a supermarket. Even during this period of transition, she still identified strongly with her identity as a mother:

‘I was still wearing an eye pad and I looked pretty terrible, I had lost most of my hair, and I had three beautiful children with me, and we were in a supermarket in Wales and everybody, but everybody stared at me. And in the end I wanted to take a can of baked beans and chuck it at one woman because she was walking round looking and watching, and I think that was my toughest experience of being stared at’ (Sylvia, 2011).

Biomedical influenced liminality?
During this next sub-section, I will be considering claims that Western biomedical environments, cultures, practices and treatments can add to a person’s liminal state. This is relevant because all of the participants’ stories contained biomedical narratives and all accessed biomedical treatments for their accidents, cancers, or acne rosacea. To be specific, twelve of the thirteen talked about hospital stays and operations relating to their facial ‘disfigurement’. Of those twelve, seven had experienced multiple operations, over months,
years or decades after the event(s). Five of those seven had had life-threatening experiences in hospital (Gillian, Natasha, Martin, Andrew and Sylvia). Others may have had intensive care experiences, in the aftermath of invasive operations, though chose not to share them. In addition, those with cancer or in remission have continued to have periodic episodes as patients, to check their health status and to review the wear on their artificial parts such as palettes, or prostheses or themselves. The remaining participant (Stephen) had been a day patient at a local hospital, to receive laser treatments for his acne rosacea.

Firstly, I am going to say a little about the academic research findings then in the following paragraph I am going to apply them to the participants’ experiences. Little et al. (1998) found that fear and pain, and the management of illness and pain with strong biomedical drugs could lead to ambiguous states, through creating confusion over place, chronology, and memory. Reporting on an ethnographic study of an Intensive Therapy Unit (ITU) involving interviews with nurses, Philpin (2007) found that hospitals in their entirety were liminal environments, with some areas more liminal than others, for example in locations where the most vulnerable patients were treated. She found that the ITU environment was within a sequestered (bounded and controlled) area, separated from the rest of the hospital and the outside world with restricted access to staff and visitors alike. She concluded from the study that health status ambiguity was present on several levels; at the boundaries between life and death; at the boundary between consciousness and unconsciousness; at bodily boundaries, i.e. by blood being outside of the body either contained (intravenously) or uncontained and through matter being out of place. Methods to reduce and manage the contagion stemming from ritually polluted and ambiguously statused patients in ITU included: extensive checking of procedures and practices; wearing hospital clothing and plastic aprons, gloves, to avoid skin on skin touching and the transmission of dirt, and cleaning rituals. These findings concur with Lawton’s earlier research (1998, cited in Philpin, 2007) into hospice care, that patients with unbounded leaky bodies were viewed as an anomaly and sequestered away from others.

These ideas and experiences are evident in a number of the accounts. Martin describes his initial transition into liminality through the unfamiliar feel and appearance of his body (Leder, 1990) in through being in an ‘alien’ hospital environment (Philpin, 2007), somewhere between consciousness and unconsciousness and in significant pain, the unmaker of lifeworlds and identities (Scarry, 1985). He described matter being out of place (Douglas, 1969), for example a burned body-face, disrupted and leaking bodily boundaries (Shildrick, 1997), a lack of mental clarity and left with uncertain capabilities in contrast to his
earlier assured ‘sporting capacity, prowess, physicality...’. He described the episode as being in ‘a foreign country’. As such Martin had no familiar lifeworld bearings to make sense of events or his environment; he may also have had little understanding of the clinicians’ professional language and difficulty in identifying and making sense of how he felt:

‘... just the physical agony of going through what I was going through and heavy sedation. So, for some months I was really out of it, I was surviving... and I was thrown into a, well into a completely foreign country basically. I had no idea where the hospital was, I might have just as well been in space you know, Mars it could have been...’ (Martin, 2011).

Martin’s story of perceptual, bodily aware status and hospital-based liminality shared some similarities with Gillian’s account. She was taken to hospital immediately after the crash and placed in intensive care, a sequestered environment (Philpin, 2007) where Gillian spent the first ten days in a coma. Her parents had to make medical decisions for her, for example the decision to remove a perforated eye, as she could have lost them both if it remained intact. As a result of the impact Gillian not only had matter out of place, for example her eye was perforated, but her exposed tissue was covered in dirt and bits of broken glass and bone fragments. During her three-month stay in hospital Gillian developed a life threatening infection and had to be nursed in isolation, to prevent the risk of infection to herself and others in her very vulnerable and emaciated state. During this episode she nearly died, experiencing a ‘flat line’ (temporary heart failure) and an out-of-body experience (she felt she was floating, watching from the ceiling), clear indicators of being in a transitory, liminal state encompassing life and death, consciousness and unconsciousness and this world and the next. In the following quote we see that Gillian experienced a Cartesian mind-body dissociation; her mind was given primary agency, desire and control, in contrast to the vulnerable and passive body which had let her down. One element of her liminality ended when she lived and regained consciousness:

‘So back into intensive care... I had an out-of-body experience, which at the time I didn’t realise I was having... I was arched, hanging from this ceiling looking down at my bed. It was absolutely fascinating, total calm, total peace, and I could see everyone that was sitting around my bed, my parents and it was just blip, blip, blip of the life support machine. Whilst I was in there I had a flat line (temporarily died) which was probably again quite horrific for those there. I don’t recall any of this, so it was looking pretty grim. For some reason, this brain in there decided it wasn’t giving up, and erm, I obviously had a lot more
trouble to cause down here, so I think I knocked on the pearly gates and he (St. Peter or God) told me to sod off, you have got a lot more to do’ (Gillian, 2011).

After the first part of her cancer diagnosis Sylvia describes a parallel version of ‘normal’ life until the treatment started, though with the anticipated future suspended (Frank, 1995) she becomes ‘two people’, one ‘confident’ the other not clearly defined, but more hesitant, meeker with authority figures and more compliant with treatment regimes. Her ambiguous state becomes more pronounced when she undergoes chemotherapy and radiotherapy treatment. In the process, Sylvia does not recognise her altered body-face physically or visually. Gone was the early bodily confidence associated with having/being a ‘slim’ figure and ‘really good hair’:

‘... now I had finished the treatment and the only thing I had in my favour were my long fingernails because I lived on raw eggs and milk, and I couldn’t get any other food down and, so I had lost most of my hair and I weighed about 5 stone, and my clothes just hung on me. My boots, I can remember at winter time, they just rattled around my ankles’ (Sylvia, 2011).

If we take Philpin’s (2007) study as a starting point, it is evident from Sylvia’s narrative and Natasha’s, Gillian’s, Clara’s, Stephen’s and Andrew’s that embodied identity transition and liminality continued during and long after the initial biomedical treatment period had finished. In Sylvia’s case it was brought about through iatrogenesis associated with the cancer treatment, i.e. sickness, weight and hair loss, which led to a state of exhaustion, increased bodily vulnerability and a lack of visual and somatic recognition, which in turn disrupted her lifeworld, identified performances and relationships (Bury, 1982)

‘I wasn’t on medication, I wasn’t on anything and just eating to try and build my strength up which I found really, really difficult, and I wouldn’t speak on the telephone because I didn’t sound the same. I was nasally and my voice had changed, the whole Sylvia had changed and gradually that half of Sylvia (the ‘confident’ one?) had slowly disappeared, and for weeks, the character, this other person who I didn’t recognise (appeared), because I was so withdrawn from everybody and everything’ (Sylvia, 2011).

Though all participants could be said to have gone through a state of bio-medically related liminality, not all of them recognised this or gave it precedence in their accounts. I offer three examples. Barney was in hospital (after his plane had crashed) for just under a year, but it was not something he dwelt on. He mentioned it in a sentence. Being hospitalised,
dependant and vulnerable did not fit with his overarching narrative as an agentic, autonomous and physically performative military figure. William underwent an operation to remove his mouth cancer. He did describe being in hospital after the operation though his narratives did not contain references to liminal, transitional or emotionally dependant states. To do so would have interfered with his identity as a problem solving autonomous being and his return to a normal, if amended lifeworld.

‘... the day after I came out of intensive care and I was laid in bed I had 11 drips and drains attached, and my wife and daughter came to see me. And just to give you an idea of my daughter’s sense of humour she said you know dad I think they have made a distinct improvement, which made me laugh and that was the most painful bit’ (William, 2011).

Doreen’s account was one of unconscious philanthropy. Now as a pensioner, she valued her independence and her ability to leave the house every day ‘even in winter’, to undertake caring duties by visiting her sister and people in the local old persons’ home. Giving credence to a liminal emotional or physical state would have threatened her identity as an independent, active older person and carer:

‘I can’t change the results of the cancer, I have to get used to it live with it, and I don’t think it’s so noticeable, my sister kept telling me to wear a neck scarf, or a high neck jumper - but I don’t bother... I’m still me, I just have a different appearance. Well, if you take the apple, if it’s bruised you peel the skin off and the core is fine, people need to accept others for what’s inside’ (Doreen, 2011).

Cancer as a liminal state?
Six participants had experienced at least one episode of cancer resulting in facial change. From their narrative research conducted with ten people with cancer Little et al. (1998) concluded that liminality could be a significant aspect of people’s cancer experiences in three respects: ‘cancer patientness’; ‘communicative alienation’; and ‘boundedness’ (pp.1486-1489) as these experiences placed them somewhere between health and illness, life and death, boundedness and unboundedness. Therefore, I am proposing that people with a facial cancer can experience an additional strand of identity liminality in the immediate and longer-term aftermath of unhabitual facial change.

The theme of ‘cancer patientness’, (Little et al., 1998, pp.1486-7) started at the initial diagnosis, included its immediate impact, e.g. existential crisis, and ‘persistent identification’
as a cancer patient, regardless of time since treatment or the presence or absence of the
disease. Acute liminality began at the point of diagnosis and was associated with loss of
control, disorientation and uncertainty. Sustained liminality followed after an indeterminate
period, when people had been treated, but lived with the knowledge that the cancer could
return along with its existential implications. Doreen, Sylvia, Jonathon and Marie all had two
experiences of being diagnosed and successfully treated. William had had multiple episodes
as had Natasha. Sylvia experienced acute liminality in the form of an existential crisis during
her treatment phase:

‘… and she looked at me and she said, you will be pleased to know that it is working and it’s
shrinking and do you know I just didn’t believe her. And I don’t… had I been in any other
situation I would have just jumped up and kissed her, but I just knew she was lying…’ (2011).

Sustained liminality was evident in some of the participants’ narratives, through continuing
to be medical patients of various kinds and by worrying about their health status years after
treatment. As Frank (1995, p.8) argues, we live in a remission society where health status is
increasingly ambiguous, for example after a cancer diagnosis and treatment a person can
feel better but is not considered to be cured. Some years after being twice treated
Jonathon said of the cancer, ‘it’s there, it’s parked in my body somewhere and certain
conditions and circumstances will make it wake up again’ (2011). William also expressed
similar sentiments. Even if the person in remission is no longer worried about a relapse,
close family members may be: ‘it is quite frightening because at first and for a long time,
you wonder is it going to come back, now it has been 18 years for me now I don’t think that
now, but George (her husband) does’ (Marie, 2012). Marie no longer had to return for
check-ups though Jonathon, William, Doreen and Natasha did. In addition, the direct or
indirect effects of the surgery and/or chemotherapy/radiotherapy meant that most
participants had to undergo physiotherapy or speech therapy. Two participants spoke of
having their jaw cut open to reach the tumour. William, Doreen and Sylvia had to re-learn
how to eat. Marie had some speech therapy. Doreen made a point of telling all new
members of the cancer support group she attended to, ‘do what they (physical therapists)
tell you’ (2011). Even when the recovery phase was over some continued to be patients,
through the replacement of their artificial parts, for example, palettes and obturator’s to
provide artificial jaws and teeth, to enable speaking and chewing and artificial eyes to
maintain a normal appearance. Through worrying about an uncertain health status future,
returning periodically to biomedical institutions (Philpin, 2007) and by engaging with out-
of-place bodily matter (Douglas, 1969), sustained liminality can be seen to occur.
‘I am going up again next Tuesday to have new facial prosthesis and a new obturator and that is a tough cookie with facial cancer, if you have reconstruction with your bionic parts as I call them. It’s an ongoing process you know they wear out, so every couple of years you have to go and you are back to being that patient again’ (Sylvia, 2011).

Little et al. (1998) found that ‘communicative alienation’ (pp.1487-8) could occur early in the illness, from an inability to communicate the person’s experience of the illness, from the diagnosis to the treatment and afterwards. This could be caused by the participant not fully knowing what to expect. Marie stated ‘They don’t (the medical staff), well they might have explained it, but until you have actually had it (the operation to remove the cancer) you have no idea what it’s like’ (2012). However, I was of the impression that that was not Marie’s only experience of communicative alienation. During her treatment phase, she had been overwhelmingly positive. Marie’s husband said ‘You wouldn’t have anybody being negative in your presence would you? Your sister came (laughs) and your mother was crying, and you said well if you are going to be like that go home’ (George, 2012). However, some of her unfinished sentences and the many distant yet absorbed gazes suggested that Marie had also experienced some non-positive emotions, which remained uncommunicated, or which she did not want to share with me:

‘… We had to get back to normal, a normal life basically. I was off work four months. Once I went back to work we were back more normal I suppose. But erm...’ (Marie, 2012).

Little et al. (1998) describe the theme of ‘boundedness’ (pp.1488-89) as one where the world shrinks for the ‘patient’ through an awareness of limits to time, space and empowerment. After years of seemingly unrelated ill health conditions Natasha was finally diagnosed with a genetic condition and related advanced cancer. Though in remission at the time of the interview, Natasha was deeply aware of the boundedness of her life. She responded by creating her own ‘bubble’ and trying not to think about her (ill) health or her future. Natasha had responded to the threat of boundedness by focusing on living in the present, for example by recently (2011) buying a puppy and by getting married to her long-term boyfriend. The latter also helped to establish some financial clarity for her daughter in the event of Natasha’s death. In William’s case, though he had retired before his cancer diagnosis and subsequent treatment, he talked about the increasing boundedness of his world using examples from earlier life. William had reported driving across Europe with his former job. After the surgery he said that he no longer had the confidence to do that, instead preferring to drive at home in England. His world had become a smaller place.
addition, since the cancer treatments William had developed acute claustrophobia, though he could not explain why. It is arguable that like the small spaces, the illness had the power to constrain his body and its movements and to frighten him.

**Gendered identity disruptions?**

So far I have argued that gender identities can be constructed through the narrating of life stories and the performances of the body-self (Goffman, 1959) and that gender can become undone in the event of a serious illness (Butler, 2004). The participants talked about themselves and their embodied performances in gendered ways in the pre-facial ‘disfigurement’ life. Men placed themselves as central, successful agents within their accounts and were more likely to talk about active bodily performances such as engagements in sports, wars, travel, military operations or fighting. While the women’s stories did include performative, agentic aspects they were also concerned with nurturing, with relationships and they spoke more openly about emotional states. Gendered identities did shift in the aftermath of facial disruption; however, they were not undone (Butler, 2004), consequently, there was less of a gendered element to the post-‘disfigurement’ narratives.

‘A traditional masculine identity requires men to demonstrate that they can deal with the challenge of illness in a similar way to how they deal with other challenges of the material world – as another problem to be ‘fixed’’ (Charteris-Black and Seale, 2010, p.55).

Charteris-Black and Seale (2010) argue that many of their male participants drew on traditional notions of masculinity to cope with the biographical disruptions that illness had presented. The men did this in various ways including employing linguistic strategies such as talking in the abstract, distancing themselves from the event, not discussing emotional states as this was considered to be a feminine trait, and by trying to re-establish control of their stories by finding solutions to the disruption (2010, p.53). However, as Charteris-Black and Seale (2010) found these strategies are not always successful, as experiences of reduced bodily control influence men’s perceptions of who they are. The authors also found that gendered identities could not always be repaired through talk alone. These findings echoed my own. In the aftermath of an acquired facial ‘disfigurement’, all of the men initially had less control over their body-faces. However, only Barney was able to return to talking about himself in hegemonic ways. Verbally, he did this by minimising the disruptions associated with a year spent in hospital to one sentence as his patient
experience did not conform to the identity he was constructing (Goffman, 1959). Performatively, Barney was able return to his hegemonic identifications through his role as an RAF pilot and leader of men during the Second World War and afterwards.

‘I enjoyed it, I loved flying. And then when I eventually finished in hospital in about March 1942, I was posted straight back from hospital back to flying, doing exactly what I had been doing before’ (Barney, 2011).

Though the other male participants had also identified with hegemonic masculinities in the pre-‘disfigurement’ life (Connell, 2005) the effects of cancer, burns and acne rosacea meant they were unable to continue the association to the same extent afterwards. There were recognitions and disclosures of bodily vulnerability, reliance on others, talk of important relationships and articulated emotional states. However, their stories also retained traditional masculine elements such as chaos resolution and emotional management (Charteris-Black and Seale, 2010). The varied ways in which these elements interacted gave the stories more diversity of content and ending than in the pre-‘disfigurement’ life. For example, in his post-diagnosis and cancer treatment life Jonathon referred to his wife as ‘me, myself and I’, his account became more emotional and he tried to manage the existential chaos and reduced bodily capabilities and performances by exerting a much tighter control over his finances. Andrew tried to talk about his post-burns life in the same confident light hearted tone but it did not work, his tone, pitch and language changed ‘Erm...but I never (silence) that’s a lie, say never affected me unduly (silence) there was a huge amount of issues...’. Decades later Andrew espoused confidence in his revised embodied capabilities and also reported career success, though he was unable to provide a definitive narrative fix ‘(Draws breath in meaningful way) The thing is (silence) it’s not erm, it’s not a story that just sort of ends really it’s one that is continuing...’.

There was one area of convergence between some of the younger participants. For Gillian, Martin and Andrew, experiences of bodily and biographical disruption were sudden, all-encompassing and life threatening. One aspect of the disruption was to anticipated relationships, they were concerned that a damaged facial appearance would render them unable to find a future spouse and have children. Even with this shared concern, their talk was still gendered. The two men both presented an emotionally contained, condensed account of this difficult period which finished with stories of marriage and children (Charteris-Black and Seale, 2010). Gillian’s relationship stories and emotional states were not so neatly packaged. The challenge of finding a partner continued as an ongoing thread
which ended positively nearly two decades later, she had married and they were going through the process of adopting children.

‘would I meet a girl, would I have a relationship, shouldn’t have self-doubted really I mean because I had such a great time you know. Girls are a lot less shallow than men’ (Andrew, 2011).

‘(when meeting a burns survivor whilst Martin was in hospital) and that was the moment when I started to think on my God, you know this might not be rescuable, I might not get back my looks…so that’s 7 years after until I met my wife, I had had a few relationships before then but I had never really thought that that would be anything possible and then I met her and you know, we ended up getting married and we ended up having kids…’ (Martin, 2011).

‘I can’t look at anybody looking like this, how am I going to live my life at 20 years old? Who is going to love me? Who is going to want to speak to me? All of these emotions, and then it’s just tears, tears, tears…’ (Gillian, 2011).

The narratives told by the women in the aftermath of facial ‘disfigurement’ shared some similarities and differences with the men. Most of the men constructed stories about diluted forms of hegemonic masculinities in their post-facial ‘disfigurement’ life. Stories included strands of vulnerability, revised physicality, narrative repair and control. The women’s stories also shared these strands, however, there was no sudden realisation that they were vulnerable, interconnected beings, as this was already present in their accounts. Nor were the women’s stories as obviously, or uniformly gendered. In some cases i.e. Doreen, Agnes and Marie, the women did not talk about gendered disruptions. In Natasha’s case, some concern was raised that her facial appearance change had left her further away from the facial beauty ideals of magazines. However, it did not seem too disruptive, as she reported being more concerned with continuing to be a book shop owner, wife and mother in the context of living with advanced cancer. Natasha felt that womanhood was constructed and that she had a number of choices, including as a consumer, about how to construct one. Constructing womanhood around consumer choices rather than on the appearance of her (unreliable) body-face gave Natasha an element of control in her life of existential cancer chaos.

‘when I was growing up you know, how you watch other women, what they wear and what they… I got sick enough that I had no clothes and my hair fell out, my face swelled up, every layer you put back on is, it’s a construct you decide how you want to present
yourself, and then that’s what you do and whether that’s... that’s I don’t know, bovver boots or high heels or [31.33] you do get to choose that and I don’t get to choose my face but I do get to choose the other stuff. And you can’t... you know I am not going to look normal and / or like Elle McPherson that there is a load of that stuff that I still do get to choose which is probably why I spend too much money on clothes [laughs]’ (Natasha, 2011).

Two women, Gillian and Sylvia had both identified in part with traditional female gender norms. In the pre-facial event world, both identified as slim, attractive and as having had a male partner. Gillian had gone away with her ex-boyfriend and looked forward to a future of marriage and children. Sylvia was married with three young children. The associated disruptions stemming from a car crash and sinus cancer (respectively) shattered their associations of femininity based on an attractive body-facial appearance. The story of Sylvia’s shrinking body, lack of energy and hair loss was told along-side her alienation from her body and from her roles as a wife and mother. Gillian felt the loss of her good looking facial appearance would impact on her ability to get a future life partner and blamed a ‘shallow’ appearance based advertising industry from preventing her establishing a much desired career. These gender based associations were significant, though not the most important aspects of Gillian and Sylvia’s lifeworlds. Though their disrupted and transitional identity states lasted for years and continued to an extent, both went on to identify as emotionally stronger, more resilient, confident, successful career women, as well as being wives or mothers. It was not so much that gender was undone, more a case that it was never told or performed in binary ways (Butler, 2004) and it was only one aspect of the women’s stories and embodied identities.

Chapter Summary

The first primary data analysis chapter (Chapter Five) placed the participants within their lifeworlds and embodied identities prior to the episode of ‘disfigurement’ through unhabitual body-facial change. This second analysis chapter has explored these experiences and their capacity to disrupt known lives, lifeworlds and identities and replace them with transitional and liminal states in the aftermath of change, and in some cases for decades afterwards. The disruptions have both individual and socio-cultural reasons (which have been artificially separated for the purposes of thesis explanation). I started by considering individual experiences of facial appearance (Leder, 1990) through cancer, accidents and acne rosacea. Even with a small sample size, it has become clear that there is no universal
experience of gaining or living with an altered facial appearance though there can be similarities. Another significant finding was the extent and breadth of reasons for participants to experience identity transition. Socio-cultural reasons for identity transition and liminality have included: having ‘matter out of place’ (Douglas, 1969); experiences of bio-medically influenced liminality (Little et al., 1998); cancer as a liminal state (Philpin, 2007) and through gender disruptions. As all of the participants have experienced some of these forms of disruption and transition, I have concluded that experiencing an acquired facial ‘disfigurement’ does not only lead to embodied identity disruption but to identity liminality and transition. And that these differing but related strands do not necessarily occur simultaneously. During the next analysis chapter I consider the related strand of visual transition and liminality occurring at the time of the ‘disfigurement’ and beyond. I argue that the extent of visual identity transition is influenced by the participants’ lack of ability to recognise themselves visually, bodily, historically and performatively.
Chapter Seven 

Analysis

Visual transition/liminality and identity shift

Chapter Introduction

In order to fully address the ethical issues and dilemmas that arise in a study such as this, I devoted a full chapter to these considerations. Similarly, given their significance, I wish to consider the visual transitions that participants described here in a concise standalone chapter, to avoid it being overlooked and to emphasise its equal importance with the other chapters. Drawing on the concepts of ritual pollution (Douglas, 1969), transition and liminality (Turner, 1969; Little et al., 1998; Philpin, 2007) developed during the last chapter, I propose a new and additional strand of liminality, visual liminality which is caused by the disruption of a person’s visual perception of their embodied identities.

Through this research I have found that embodied identity shift in participants with an acquired facial ‘disfigurement’ can occur through: the cause and context of the facial event; disruptions to the body-face, its performance in the world and to anticipated futures. I have argued that these disruptions can lead to the inhabitation of transitional and liminal identities, as old certainties can no longer be taken for granted (Frank, 1995). I had asked people to use their own photographs during the interview to help illustrate their stories. It soon became apparent that having a photograph taken and/or looking in the mirror after facial change could add an additional layer of identity transition and/or liminality. Through the final sub-section of this chapter, I will explore how identity shift can occur through disruptions to the visually identified body-face. For the purposes of this thesis, I am describing visual identity as the dynamic relationship between body-facial embodiment and its visual appearance, within a socio-cultural context and always in relation to/with others (Grosz, 1994). Visual identity transition or liminality occurs when the person no longer visually recognises who they perceive themselves to be.

As with my findings and previous facial ‘disfigurement’ research (Rumsey et al., 2004), the severity of facial change did not wholly explain the extent of identity disruption. I have found that visual identity transition/liminality is influenced by the cause, context, and
extent of body-facial disruption, as well as the extent to which participants are able to recognise themselves in the aftermath of change (Figure 1). Briefly, the causes of ‘disfigurement’ through body-facial disruption are cancer, accidents and acne rosacea. The context of disruption includes both societal and individual circumstances surrounding the event, for example socio-cultural values about facial appearance and episodes of ritual pollution. An example of individual circumstances would be employment status, i.e. military personnel or civilian. As a serving soldier, Andrew knew there was a possibility of becoming injured, whereas Gillian was not expecting to receive extensive crush injuries the night she stepped into her ex-boyfriend’s car. The extent of embodied disruption refers to unhabitual changes to the face and the rest of the sentient body, incorporating emotional and psychological states. Finally, recognition refers to the extent to which the person is able to recognise their body-face in the aftermath of disruption, including its performance (Butler, 2004) and associated identities when they look at their image. I placed the participants into three groups according to the extent of their transition and liminality none to limited visual disruption, relational visual disruption, and substantial visual disruption. The findings form the last sub-sections of the chapter. As with the previous types of transition and liminality, none should be considered exclusively; together they form part of a dynamic package to help explain identity disruption and transition during and after the period of acquired facial change. As such, group affiliation could be transient or multiple as I will explain.

Figure 2 Factors influencing visual transition/liminality in the aftermath of acquired facial ‘disfigurement’
Visual liminality?

None to limited visual disruption
Upon analysis this first group of participants (Doreen, Barney, Jonathon, Marie and William) did not appear to be too concerned with the alteration in their facial appearance, nor did it seem to lead to significant identity shift or dissociation. At the time of the interview Doreen, William and Marie had little noticeable facial alteration, though all would have looked different in the aftermath of head and neck cancer treatment. Barney’s scar, running from his head down to his chin had also faded with age, though it would have been evident for decades. Jonathon did have an eye patch and a white patch of skin on his forehead, which had been transplanted. The reason for their responses can be explained using Frank’s (1995) Wounded Storyteller. This group appeared to be more connected with their bodies than the other two groups, to accept a degree of contingency in their lives and to be desirous of a return to their usual roles and performances (Butler, 2004) in the world, even if this was not always possible. As a group they were all in their forties at least when their faces changed, in comparison to younger participants they had already achieved life goals, such as careers, long-term relationships and for some having children. In addition, due to the cancerous cause of the facial disruption, Doreen, William, Marie and Jonathon had existential concerns. For Doreen, appearances were not so important, even before she was diagnosed with cancer. By way of contrasting herself with her sister, who was appearance-concerned Doreen stood up during the interview and did an impression of her sister looking in the mirror ‘When we went to the club she would stand in the doorway waiting for people to notice her, I told her, get in and stop messing about, silly woman…’(2011). In Barney’s case, being a pilot during wartime one had to anticipate becoming injured and then minimise the potential impact. Though his injuries were life-threatening at the time, after a year in hospital he was able to continue corporeally and militarily as before. As with the other participants, context is key here; these pragmatic unemotional sentiments expressed by Barney were encouraged during WW2: ‘I think it’s all in the mind. As far as I was concerned, I had this crash and if you are flying aeroplanes it’s what you expect to have really and erm… you just get on with it’ (Barney, 2011).

Relational visual disruption
The term relational visual disruption refers to participants who were experiencing additional corporeal conditions such as deafness or cancer. Their visual identification and
shift was viewed in relation to the other conditions, not just their body-face. Agnes disliked her unsymmetrical smile and avoided being in a photograph where possible. However, she had had bigger corporeal issues to make sense of since the age of eight when her facial muscles were accidentally cut during an operation. Becoming profoundly deaf during childhood and most of her adulthood had been more of an identity issue for Agnes. Though even this had not stopped her from achieving A-levels, a chemistry degree and a marriage and subsequent children. As with Sylvia, Natasha had experienced cancer and expressed the same sentiments, ‘my face is the price I pay for being here’ (Natasha, 2011). Like Sylvia, she had dissociated from events in order to cope with them including avoiding being in photographs. Being in a photograph or looking in a mirror reminded her of events and of their future implications. After the onset of the head infection, the cancer diagnosis and subsequent genetic underlying condition Natasha preferred to keep her life ‘in boxes’, to mitigate the existential threat to her lifeworld and future as a mother, wife, family member and bookshop owner. It would appear that having an acquired facial ‘disfigurement’ is not the only, nor necessarily the most important influencer of embodied identity shift in adults.

Substantial visual disruption
Some participants (Gillian, Andrew, Martin, Stephen, Clara and Sylvia) narrated significant identity disruption based on an inability to recognise themselves, their lives, careers, activities or anticipated futures when they looked in the mirror in the aftermath of the face-changing event. Those who had experienced sudden, accidental body-facial injuries resulting in existential crises found the process of looking in the mirror particularly emotionally challenging (Gillian, Andrew, Martin, Stephen). However, similar sorts of embodied emotional reactions (Hochschild, 2003) were evident in participants treated for cancer (Sylvia) and those with lesser facial damage who did not experience existential crises (Clara, Stephen).

The shock of the corporeal and biographical disruption to Gillian, Andrew and Martin’s lives was reflected in their accounts of looking in the mirror for the first time. Gillian nearly died in the immediate aftermath of the car crash and developed a potentially fatal illness during her stay in hospital. She lost an eye, broke her back and had had her hair shaved to have lifesaving head surgery. Gillian felt that she was not psychologically supported to see her altered appearance for the first time and was deeply traumatised when it occurred, thus marking an additional embodied, identity shift (Hochschild, 2003). As like Martin and Andrew, she no longer recognised her body-face or her perceived future of attractiveness,
economic and romantic success. It was the start of a period of emotional dissociation that was to last for decades.

‘Oh Jesus Christ what is that that is looking back at me because it’s not me? You look at the other side of your face which is clearly knackered as well but it’s you, and then you are looking at this other side going what the hell is that? ... I am just looking at it thinking the elephant man has arrived in my mirror it’s not me... And then it really hit home, then it was inconsolable tears, it’s the first time probably three weeks into it that I had, that I had actually seen the devastation of it. I just couldn’t believe what I was looking at and then all of these emotions just come flooding through...’ (Gillian, 2011).

There were strong similarities with Martin’s account, though he did receive some psychological support when he came to look at his altered appearance, a few months after receiving burns to 40% of his body. Previously, Martin had been the central agentic figure in his account, using his body to win at sports, education and in conjunction with his face, to attract women. Looking in the mirror marked the recognition that this aspect of identity was disrupted temporarily at least. Family and others became foregrounded as they support him to look at his altered appearance. During this early period Martin began to realise that bodily control could not be quickly resumed and emotional chaos ensued; suicidal thoughts were alluded to. He drew on the Western saying- the eyes are the window to the soul- to express the fact that he not could find the successful embodied identities that he had previously recognised, performed (Butler, 2004) and managed (Goffman, 1959, p.42) when he looked in the mirror

‘Anyway so the moment came to look in the mirror... And it was one of those shocking incidents that you know, you think oh my God, wait a second how can I possibly deal with this? I suppose there were a few things about me that immediately struck me, one was that I was still there somewhere, but I didn’t find it easy to look into my eyes... but I remember thinking I am not sure that I know where I am in this picture, I am not sure that I am there. And yet, and yet, you know there was something that said look, don’t don’t write it off, don’t, erm, don’t get to the point (silence)... And I suppose you have got two processes going on... I really needed my mother not to and my family not to think that I was going to go down into the pits because she was so supportive and damn it this is my fault you know... Erm, and yet inside I was, the other process was this ghastly grinding of all the emotions of loss and anger and self-blame and self-pity...’ (Martin, 2011).
Andrew’s account of looking in the mirror was similar. As Goffman (1959, p.42) argues, aspects of stories which do not convey the identity that the person wants to present may be down played or left out. For example, he described the action of looking as ‘not the most pleasant’. However, greater emotional significance was evident during the interview through intonation changes, the silences and contrast to later in the narrative when he became more emotionally open. As with Gillian and Martin, when he looked in the mirror for the first time Andrew was deeply upset and concerned with the possible life world repercussions of his body-facial change. Similarly, one of these was a shared anxiety that future identities as spouses and parents were now uncertain

‘there was a huge amount of issues, but they were psychological issues, they weren’t just to do with the disfigurement, there was a lot to do with the disfigurement erm you know would I meet a girl? Would I have a relationship?’ (Andrew, 2011).

Andrew was engaged to be married prior to the ship being bombed, though they did not marry and no details were given. When recalling the event Andrew did acknowledge his vulnerability, but it was something that was associated with his body not his emotions. Andrew’s vulnerability was measured by weight loss and compared to his recent identification as a rugby player, and though he does not say it, he is possibly alluding to the loss of hegemonic masculine characteristics and the loss of performance associated with rugby playing such as physical fitness and toughness, agency and hard drinking.

‘... and I was lying in a hospital bed and (long silence) a guy called Moses came in and err... showed me a picture... and I remember having a real (emphasis) upset time after that because I realised then I was going to be completely disfigured. (Thinking) That sent me into a downward spiral but I was already in a very vulnerable place anyway (silence) you know I was weighing about eight stone at the time, from 18 stone prop forward (long silence)...’ (Andrew, 2011).

Though her bodily change was not unexpected, Sylvia had a similar emotional reaction to Andrew, Gillian and Martin. The sinus cancer returned and she had to have more evasive surgery to remove it; survival was doubtful. Sylvia did survive but lost an eye, a cheekbone, her upper palate including teeth and some sinuses. ‘When I take my glasses off, I take my face off’ (Sylvia, 2011). After the treatment, the loss of facial parts and her hair and weight loss, Sylvia did not recognise her former glamorous body-self in the mirror, one where she was in control. The event enhanced her pre-existing feelings of loss and shock and she continued to feel dissociated from herself and from others for several years afterwards. In
this quotation we see that Sylvia has trouble adapting to her newly reflected cyborg status (Haraway, 1991) and that her children, which were central characters become locked out of her emotional lifeworld. Sylvia’s quote illustrates Bury’s (1982) argument that people can hide themselves away partly to avoid the stares or comments of others.

‘I went home and I went to the mirror in the bathroom... and I had to take out this obturator, because I had lost my teeth. The obturator is an artificial part for the palate and enables you to speak, and I had to go and clean this thing and I just was in total despair thinking how can I live the rest of my life with this? This is unimaginable, I just can’t do this. And then I heard the children coming up...the door was never locked, but I locked the door. From then on I started locking the door and I was aware that that image that I saw of myself wasn’t one that I was familiar with...’ (Sylvia, 2011).

The final two participants (Clara and Steven) did not have severe disfigurements or life threatening conditions, though they had strong negative reactions to their appearance at the time of disruption, which continued to influence how they identified with themselves decades later. Clara and Steven were very influenced by the negative and well-meaning facially related comments of others. They also became dissociated from themselves and withdrew from family and friends and developed a strong aversion to having their photograph taken (Bury, 1982). Clara felt that the childhood accidents which resulted in a scarred lip and an asymmetrical nose, or in her words an ‘ugly beak’, left her looking ugly and ‘feeling ugly’ and ‘unlovable’. She was the only participant to directly identify with the incorrect historical trope linking appearance with morality as discussed in Chapter Four (Don’t judge a book by its cover: two thousand years of reading faces). To compensate for her appearance Clara began to develop a strong desire to be around facially attractive people, especially boyfriends which lead to some unhappy relationships (this is explored in the next chapter). From an early age this perception of herself as ugly and unlovable led Clara to avoid being in photographs wherever possible. However, somewhat contradictorily Clara had a different perspective on seeing her image in a mirror than a photograph. Her strong belief in the value of a beautiful appearance and a desire to avoid being noticed had led to an elaborate highly gendered make-up performance ritual (Butler, 2004), which included seven coats of mascara and the extensive use of colour co-ordinated clothing, including accessories to hide behind.

‘I could not go out without my make-up on. I have very, very occasionally but I feel awful, I feel like everyone is staring at me and thinking how ugly I look without it. I am
very pale even my best friend says I just look totally different, it takes me about an hour and a half now to do it’ (Clara, 2012).

As Stephen’s acne rosacea symptoms increased he began to avoid environments where his face would go red and swell and he began to avoid having his photograph taken. He became increasingly unable to control his appearance and the environment’s which influenced its appearance. Stephen thought that no one took a red face seriously as it ‘looked like a clown’. He did not have any photographs of himself or with other family members on view when I interviewed him. He reported only owning a few photos of himself together with his family, which he had altered from colour to black and white to hide his facial colour. Like Clara, he identified strongly with the outward appearance of his body and struggled with his lack of control over it. Altering his image and withdrawing from his lifeworld was the only way Stephen could exert some control in a contingent world.

Chapter Summary

It has become clear that there are multiple strands of embodied identity disruption, transition and liminality, such as altered performance (Butler, 2004) which occur with the phenomena of an acquired facial ‘disfigurement’. All participants experienced identity shift in the immediate and latter aftermath, what differed was the extent to which they were influenced by their appearance change. What was also apparent was that the strands did not necessarily coincide with each other. When the participants looked in the mirror or at a photograph in the immediate and longer aftermath of the phenomena they no longer saw the past self or the future anticipated person or lifeworld. Factors influencing visual transition/liminality in the aftermath of acquired facial ‘disfigurement’ included the cause and context (individual and social) of the facial event; disruptions to the body-face and its performance in the world (Butler, 2004), and to anticipated futures. Through the analysis of the data, I distinguished three types of visual identity disruption and transition: none to limited visual disruption; relational visual disruption, and substantial visual disruption. As with the previous findings, the context was key to understanding how the participants had made sense of their experiences, as well as the extent to which they identified with their appearance, its control and the views of others. Also, as with the other analysis chapters, the participants’ identifications with how they looked was dynamic, not static.
Chapter Eight Analysis

**Transition and re-negotiation: identities in the aftermath of an acquired facial ‘disfigurement’**

Chapter Introduction

‘The acquisition of a permanent injury or disability will not merely disrupt the taken-for-granted functioning of the lived body. It will shift the perspective from which the person engages with the world, changing possibilities, projects and meanings’ (Edgar, 2009, p.127).

Having established that facial ‘disfigurement’ can shift the taken-for-granted functioning of the lived body and lead to ambiguous, transitional and sometimes liminal identities; I had anticipated finding a set of clear identity reintegration narratives. However, I was wrong. Participants took months, years and decades trying to achieve various strands of body-face identity restitution. Using the work of health sociologist Frank (1995, p.29) during the analysis phase it became clear that the aim of identity restitution remained an aim in some cases (Clara, Stephen). In addition, that restitution was a complex and sometimes contradictory affair, as Clara’s narratives indicated. The extent of embodied identity restitution was influenced by the context of body-facial change, and the participants’ ability to negotiate being, knowing and performing as the same sort of person in light of threats to embodied ‘control, body-relatedness, other relatedness and desire’ (Frank, 1995, p.29). I found that most narratives retained elements of liminality up to the period of the interview (2011-12) as people continued to live with: differences in somatic, visual and performance related embodiment; the ongoing threat of cancer; being episodic patients; and as a result of asking the same body-self questions about unrelated additional health conditions. Consequently, the two sections of this final analysis chapter will explore the dynamic, ongoing nature of embodied identity transition and renegotiation in the more immediate and longer-term aftermath of experiencing an acquired facial ‘disfigurement’. The first section considers three strands of continued identity transition and liminality (biomedical, cancer related and visual). The second section uses Frank’s (1995, 2010) work on illness and
identity shift to explore how the participants made sense of their narrated identities in the aftermath of their critical incident. Finally, I draw on the data and its theoretical influences to propose a new tripartite theory which explores the participants’ ability to negotiate identity restitution in the life beyond ‘disfigurement’.

Continued disruption, transition and liminality

Biomedical
In Chapter Six I used Philpin’s (2007) work to explore how biomedical professionals, cultures and environments could be viewed as ritual cleansers. Martin, Gillian, Andrew and Sylvia all had their highly polluting, ambiguous and liminal statuses removed by a host of medical professionals (Philpin, 2007, pp.52-53). Indeed, without biomedical intervention those participants would have died. Although, as well as saving lives and cleansing identities, biomedical institutions, environments and cultures can also be seen to extend ambiguous states through the episodic perpetuation of a patient status in a liminal place (Philpin, 2007), and through participants’ dissatisfaction with some treatments and their outcomes. Regarding the former point, the six participants who had a cancer diagnosis had to return for regular checkups initially to assess their remission status. Richard, William, Natasha, Sylvia and Eileen had all undergone further cancer treatment involving engaging with biomedical professionals, environments and cultures. For those who had experienced accidents, Gillian, Martin and Andrew all had multiple reconstruction operations to rebuild their body-faces in the months and years after the event.

Regarding the latter point, four participants relayed additional identity disruption and upset caused by problematic biomedical treatments or encounters long after the initial disruption. Agnes’s asymmetrical smile was the result of accidental nerve cutting during childhood surgery to remove a life-threatening ear infection. Six decades later she continued to be conscious of the difference and to avoid smiling and having her photograph taken when possible. Likewise, Clara’s childhood injuries were not treated properly and she developed noticeable scar tissue, which became frequently commented on; she withdraw from social networks and hid behind her hair at school and became disengaged with lessons for the rest of her school career. When she had her nose reconstructed at the age of 17 the surgeon did not comply with her requests and she became even more aware of her continued facial appearance (Leder, 1990), which made her even more monadic and
dissociated (Frank, 1995). Though various biomedical tests and treatments were conducted for Stephen’s acne rosacea, they did not have the desired restorative effect. Nor did he feel that his emotional and social suffering was being taken seriously by his GP. Stephen became increasingly socially avoidant (Goffman, 1959; Bury, 1982). Finally, Jonathon’s original misdiagnosis and subsequent late cancer diagnosis had meant he had to undergo a stronger form of medical treatment. This had disrupted the control of his body, his biography and predicted future much more than the ‘disfigurement’ and left him feeling very angry.

‘Treatment absolutely stunning, the hospitals no problem, it was just the circumstances at which I arrived at that, that I am angry with... I have written it down, I have got I think 54 hospital visits in a year, 18-mile round trip and after the second one (cancer diagnosis), this one, there were 63 because they said chemo and radiotherapy phenomenal disruption to my life, there wasn’t room for anything else’ (Jonathon, 2011).

Even when body-faces had been bio-medically cleansed, bound and reconstructed these steps did not necessarily lead to identity reintegration. Some participants, for example Gillian took decades to re-associate with her body-face and two participants, Clara and Stephen remained in monadic, dissociated states at the time of the interview, approximately 50 years and 25 years respectively after the change had occurred. ‘Social life is ruined, my work life is ruined you know, there is loads of aspects of my life erm... which have been ruined you know’ (Stephen, 2011). If and when a participant did start to move towards embodied identity reintegration, it generally occurred away from biomedical professionals, cultures and environments and happened in multiple stages as Sylvia’s quote illustrates:

‘I was going through this process of rehabilitation not psychologically, but physically...’ (Sylvia, 2011).

Cancer and continued liminality

Little et al. (1998) found that living with a cancer diagnosis could result in an ongoing transitional health status, regardless of longevity. Whilst Callaghan (2004) found that patients who had undergone head and neck cancer surgery reported distress, negative self-image and loss of self-esteem in the aftermath. The narratives of some participants who had had cancer, or who were in remission at the time of the interview echoed these sentiments (Sylvia, Natasha, Jonathon). Even if the surgery and chemotherapy/radiotherapy
had been declared successful, the threat of its return with associated chaos and existential threats was omnipresent (Callaghan, 2004). Five of the six participants with cancer experiences had a further episode and treatment. As such they continued to be patients in liminal places, e.g. hospitals and clinics and to inhabit transitional identities, somewhere between health and sickness, life and death. This was a significant identifying experience; however other elements of their embodied selves came through during the narrations. William had had three more facial cancer episodes. However, through regular monitoring and early treatment he was able to continue managing and performing his identity (Goffman, 1959; Butler, 2004) as an astute problem solver, thus linking his past, present and future. Natasha was in remission with advanced (stage four) cancer, which she dealt with by ‘boxing’ up her lifeworld and identities into compartments and ‘pretending it’ wasn’t happening, or by not thinking about it. She talked about herself as a shop owner, wife and mother, ‘and you know in lots of ways my life is as easy as it conceivably could be if you could just not think about the health side of it’ (Natasha, 2011).

Though Jonathon’s lifeworld had been significantly disrupted through a cancer diagnosis and subsequent treatments, he was still able to continue performing (Butler, 2004) aspects of his identity i.e. community involvement, learning and control of others. As a member of a cancer support group he had been able to invite oncologists to speak about treatment developments. And though Jonathon had been cancer-free for a few years prior to the interview its spectre remained on the horizon, as it did with Sylvia (Jackson, 2005; Philpin, 2007). Even when she had been given the all clear by health professionals after the first cancer episode she did not believe them. This illustrated the critically inquiring and ‘confident’ aspect of her identity, which was still present though much diminished in the early aftermath of the treatment:

‘... and she looked at me and she said, you will be pleased to know that it is working and it’s shrinking. And do you know, I just didn’t believe her... Had I been in any other situation I would have just jumped up and kissed her, but I just knew she was lying...’ (Sylvia, 2011).

Reflecting on reflections: some visual implications of acquired facial ‘disfigurement’

During the last chapter, I explored how the experience of acquiring a facial ‘disfigurement’ could lead to visual identity disruption, transition and liminality. I do not wish to repeat myself here, but to offer some more academic explanations as to why visual liminality may
continue for months, years and decades after the original ‘disfigurement’ occurred, as with Clara and Stephen.

Looking at a reflection in the mirror in the aftermath of facial ‘disfigurement’ is a reminder that the face is always on show to self and others and always vulnerable (Levinas, 1969, p.251) to the physical, verbal and non-verbal actions of others. Sylvia, Clara, Stephen, Gillian, Marie and Agnes’s altered appearances and voices were commented on by unknown others in ways that made them uncomfortable and upset. Clara was called Miss Piggy by school children, Marie had an uncomfortable work phone call with someone who thought she was chewing a sweet; she was still coming to terms with her ‘alien’ sounding voice. Gillian was ridiculed in a bar by an unknown and rude ophthalmologist who commented on her missing eye. Gillian then felt obliged to recount the whole story upsetting her and ‘ruining’ her night out in the process. Stephen’s boss knew he was sensitive about his acne rosacea, though he still brought the subject up in work meetings, thereby making it worse and leaving Stephen silent, upset and angry. In this quote, Sylvia articulates the distress of having an ever-present facial injury, disability or health problem compared to one that is hidden from view:

‘When you see somebody with a facial disfigurement you take a step back and think oh my God... the initial (silence) it’s shock, because with our faces we can’t cover up the damage that is done’ (Sylvia, 2011).

When looking in the mirror people are also reminded that their facial capabilities may have diminished, for example the ability to see, to communicate, to smell, eat and drink, which in turn disrupts and alters perception, sense making and people’s ability to take part in habitual socially orientated activities, such as eating in restaurants. In spite of being less concerned about her visual appearance Doreen was disappointed that she could no longer eat out with her sister and friends, as she had to blend her food first and felt conscious in front of others. Whilst for those with cancer, looking in the mirror could be a visual reminder of the threat of existential curtailment. However, for some participants, the marks left on the body by the removal of disease were a positive reminder that they had lived to tell the tale. These sentiments were expressed by Sylvia, Natasha, Jonathon and William.
When some participants looked in the mirror they were reminded of disruptions to the spoken and physical performance of their previous body-face. In the period before the car crash Martin strongly identified with himself and his abilities in a visual capacity. In the aftermath, he was devastated as he could not recognise himself, or his former abilities, though he became interested in what could be done and some years later became visually re-associated, as he learned new performances with his body, such as playing golf. This was also true for Gillian. When she looked in the mirror for the first time the full emotional trauma of the accident hit her. At the time of the interview over two decades later Gillian had reconstructed her identity and appearance and was happy with both, though she still carried a performance prop (Goffman, 1959) in the form of a hat, in case of unwanted comments from strangers.

In other respects the act of looking in the mirror or at a photograph after an acquired facial ‘disfigurement’ reminded people that they were not autonomous, bounded individuals (Shildrick, 2008). Instead, through engagements with biomedical cultures, practices and institutions involving the removal and reconstruction of facial matter, the participants were reminded of their intercorporeal condition (Csordas, 1994) and the suffering of others (Frank, 1995). This recognition (Frank, 1995), lead all bar one of the participants to give their time and energy to charities to help people with similar conditions and experiences. It gave William a sense of existential perspective. The remaining one, Stephen was considering starting a Facebook page for people with acne rosacea.

‘You can always find someone much, much worse than yourself, doesn’t matter whatever, if you fall out of an aeroplane and smash yourself to bits you will find that somebody is even worse off. So, it doesn’t trouble me anymore. Go and sit in the waiting room of the oncology clinic, you look around think hey I am one of the lucky ones’ (William, 2011).

Renegotiating embodied identities in the aftermath of an acquired facial ‘disfigurement’

Theoretical overview
This is the second and more significant section of the chapter. It contains a number of elements which are key to answering the second research objective (to explore the relationship between acquired facial ‘disfigurement’ and embodied identity shift using a
narrative methodology). Drawing on a range of phenomenological (Merleau-Ponty, 1962; Leder, 1990) and embodiment (Grosz, 1994; Csordas, 1997) authors, I have argued consistently that embodied experiences are key to understanding the world, and consequently to identity making and remaking. I will be drawing on some of these authors to help explain the research findings, in particular the work of health sociologist Frank (1995) who explores what happens to individuals when their storied identities are disrupted. Apart from this overview, the section is divided into three further sub-sections Ripples, Waves, and Tsunamis, which assesses how far the participants were able to re-negotiate their previous embodied identities in the light of body-facial disruption, a shifting and multifaceted process I will refer to as contested negotiation. I thought long and hard about how to name the three sub-sections and how to ensure that they accurately reflected the participants’ experiences. I decided to apply the metaphor of life being like trying to navigate an ocean in a small boat, with the advent of facial ‘disfigurement’ being one event that the participants’ had to navigate. I chose this metaphor because like sailing on an ocean, the life course is dynamic; influenced by a number of currents, environmental factors, and habitual and unhabitual disruptions will always occur.

Starting with the first category, experiences always cause disruptions in embodied lives and therefore always influence identities (Csordas, 1997). Consequently, acquiring a facial ‘disfigurement’ created ripples in the embodied identities of all the participants’ lives. Some participants were able to navigate, or negotiate the challenges, leaving ripples in embodied identities, shifting them but leaving them largely intact. Whereas for others, the body-facial disruptions caused greater disturbances, or metaphorical waves in their lives, which threatened their perceived life map and compass. For people in this group, the renegotiation of previous identities was harder to achieve. Finally, for some participants’ the body-facial event was engulfing. Like a tsunami, it crashed through their life map and identity compass, leaving chaos in its wake, requiring the reformulation of embodied identities. As with Frank’s (1995) explanations, these three categories (Ripples, Waves and Tsunamis) are offered as a guide to exploring the relationship between experiencing an acquired facial ‘disfigurement’ and identity shift. Each sub-section will start with a summary of group characteristics then move onto an analysis of participant’s narrated stories. I want to be clear that the participants did not progress through these categories in a linear fashion. Nor are they to be read as static, unchanging responses; they describe how the participants’ made sense of their experiences in the aftermath of corporeal and biographical disruption and in their life beyond. I also want to be clear that the degree of
body-facial change did not necessarily relate to the perception of identity change in the participant’s life. This finding concurs with earlier facial ‘disfigurement’ conducted by Rumsey et al. (2004).

**Bodies, loss of control and ‘narrative wreckage’**

Before expanding on the three categories of identity re-negotiation I want to describe and evaluate the theoretical work I have used to develop them. In *The Wounded Storyteller* Frank (1995, pp.2-3) argues that serious illness, in which I am including body-facial ‘disfigurement’ disrupts the past and anticipated futures through the magnification of pre-existing problems of embodiment. Problems such as bodily control, body-relatedness, other relatedness and desire (Frank, 1995) which if not resolved can lead to ‘narrative wreckage’, necessitating the creation of new or revised identity stories. Starting with control, Frank (1995) asserts that there are two key control-related questions: the degree to which a person can ‘reliably predict’ how the body will function and the degree to which they can control its functioning. Contingency (unforeseen events) occur when bodies are exposed to forces they cannot control. Overall, control depends on the physiological possibilities, the degree of predictability and contingency and the person’s reaction to this. Frank (1995) argues that the second issue of embodiment, body-relatedness, concerns the extent to which people associate, or connect with their body-selves, or dissociate (disconnect) from them, or their parts. Thirdly, other-relatedness concerns the individual’s relationship with other bodies, including the quality of empathic engagement and the sharing of transformative experiences, such as a cancer diagnosis and treatment. Frank describes two ends of the relatedness spectrum. The dyadic relation is one where an individual recognises that they share the world and are in relations with others. For example, with illness, the pain is individual but the suffering is shared with others who have had the same or similar experiences. Whereas, monadic bodies understand themselves as ‘existentially separate and alone’ (Frank, 1995, p.36), in which view people are encouraged by bio-medicine, through the segregated design of medical spaces which encourages clinician and patient, rather than patient and patient interaction. Finally, the body’s problem with desire is knowing what the body wants and expressing it through and with the body. Desire is expressed at a corporeal level and is related to wanting more or less of something, for example, a person’s appetite for life in the midst of illness. Though the body may lack desire, the person may desire to engage with activities following a return to health.
If body-facial control and activity cannot be restored then narrative restitution is under threat and chaos may set in, temporarily at least (Frank, 1995). Frank (1995) argues that people can respond to these threats through becoming one of four types of body-self: the disciplined body; the mirroring body; the dominating body and the communicative body. I will outline what they are before going on to explore them in relation to my findings. The disciplined body defines itself through ‘self-regimentation’ actions. Its most significant problem is negotiating loss of control. The response is to reassert predictability through therapeutic regimes, for example becoming knowledgeable about types of cancer and chemotherapy. However, the desire of restitution can lead to dissociation as the body-self shifts into becoming something ‘to be treated’ (1995, p.41). The disciplined body is unlikely to tell stories about itself, unless they involve treatment stories. In this sense, this body type is likely to comply with medical treatment making them a ‘good patient’ (Frank, 1995, p.42). Frank (1995) argues that the mirroring body is both instrument and object of consumption as its aim is to recreate itself in the image of other more stylish and healthier bodies. To this end, the body is used to consume and enhance itself through clothing, feeding, grooming and curing, through the consumption of medical services. The mirroring body also prefers predictability, and fears contingency, though for different reasons to disciplined body types. Disciplined bodies fear disruptions to routines unlike mirroring bodies as Frank illustrates in this quote:

‘The mirroring body fears disfigurement, which some disciplined bodies might regard as signs of battles well-fought... The disciplined body seeks predictability of performance; the mirroring body seeks predictability of appearance’ (Frank, 1995, p.44).

The mirroring body does produce desires but they are monadic, the want is for the self, not to be associated with others. Frank’s (1995) third body type is called dominating, which defines itself through force. This body type knows the contingency of disease (and I would add facial ‘disfigurement’) but never accepts it. The fear of contingency is displaced and enacted towards other people through rage. Consequently, dominating bodies are dyadic, but dissociated and lacking in desire like disciplined bodies. Finally, the communicative body is an ideal and an idealised type, providing an ethical framework for being. Communicative bodies accept contingency as part of life, as human bodies are vulnerable and break down. As such, contingency should be expected and accepted. The associations between body and experience produce dyadic, desirous bodies, which acknowledge our
interdependence with other bodies. Such experiences lead people who have suffered to see the suffering in others and to commune with them to alleviate it.

Having described Frank’s ideas I now want to critically evaluate aspects of *The Wounded Storyteller* (1995) and state my reasons for using it as an analytical aid. Segal (1999) states that the text is written in an accessible way, which facilitates the exchange of ideas between social and cultural theorists and clinical practitioners. I see this interdisciplinarity and clarity as a great strength. As a qualitative social scientist I have been frustrated by the unnecessary wordiness and complexity of some sociological and anthropological journal articles. If we make it too hard to comprehend what we do, how we do it and what we find why should we expect academics from other disciplines or epistemologies to engage with our material?

Unfortunately a weakness of Frank’s (1995) accessibility is a lack of theoretical depth (Segal, 1999; Stoddard-Holmes, 2015). This seems to be related to the cross-over function of the book, from academic to general readership; and by Frank’s autobiographical illness narratives which are woven into the account (Stoddard-Holmes, 2015). The book would indeed benefit from more academic depth and connection between chapters. Nevertheless, *The Wounded Storyteller* (1995) still achieves what it set out to do. Through Frank’s (1995) deconstruction of the problems of bodily control and the associated threats to narrated identities his work enriches our understanding of individual illness experiences. Frank (1995) offers his body-self types (disciplined, mirroring, dominating, communicative) and types of stories (chaos, quest, restitution) as guides to enhance understanding, not as exhaustive, autonomous or unchanging categories. I found this approach creative rather than limiting because I was able to move fluidly between participant accounts to explain the co-existence of seemingly contradictory typologies as my analysis developed.

When creating theory from individual experiences there is a danger of creating reductionist or limited typologies. Thomas-Maclean (2004) argues that the concept of the quest narrative, where people search for meaning after illness by reaching out to others with similar experiences is ‘too clean’, with not enough focus on ‘transformation’. Perhaps Frank is guilty as charged? However, his job as author is not to think through every possible real world permutation, nor in my opinion does this criticism weaken the validity of his argument. Through the accessibility of the typologies in *The Wounded Storyteller* (1995) I have been able to account for individual sense-making; and to develop some wider theories.
about the relationship between acquired facial ‘disfigurement’ and identity shift, including reasons for widespread and continued identity transition. In the same spirit as Frank, I offer the following three categories as a guide to understanding identity restoration in the months, years and decades following an acquired facial ‘disfigurement’.

**Ripples**

I placed Barney, Doreen and Agnes in this category. Barney had been scarred down one side of his face and had an indent in his skull as a result of a plane crash. In the process of removing cancer Doreen had had her jaw broken and part of her tongue removed leaving her unable to eat solid food and with a slight facial scar. As a result of an accident during surgery to remove an ear infection during childhood Agnes’s facial muscle had been cut and was no longer under her control. It had left her with an asymmetrical smile and a lifelong fear of anaesthetic. In summary, though there had been physiological changes, experiences of pain (Scarry, 1985) and existential threats (Barney, Doreen), the self had not been unmade by pain (Scarry, 1985) in these instances, nor had there been any loss of life map or destination (Frank, 1995) stemming from body-facial change. Rather, the participants in this group were able to achieve a high degree of identity restitution, much sooner than other ones. Though their appearance had changed, mirroring other faces was not a dominant concern in these participants’ lives. All were other-related and dyadic in their approach to life and illness. All recognised their bodily vulnerability and there was evidence of an unsentimental pragmatism expressed in their narratives. All three had a strong desire to continue communicating with and acting in the world and were able to return to revised activities and identities in the aftermath, though in Barney’s case it took a year. Relatedly, all were involved with charities, which aimed to reduce the suffering of others. For example, Doreen was involved with a local cancer support organisation and visited her sister, and people in an older persons’ care home every day. Barney had set up a branch of the British Legion and remained a key player in the Guinea Pig Club, a support group for ex-servicemen who had been operated on by facial reconstruction surgeon Archibald McIndoe, thus continuing his military identifications. Whilst Agnes had previously been chair of the local cochlea implant group.

In spite of the liminality associated with cancer (Little et al., 1998), Doreen’s diagnosis, subsequent treatment and remission status (Frank, 1995) were narrated matter-of-factly. Unlike Gillian, there was no expectation of a future career and husband and children to negotiate in the aftermath. Doreen had married several decades ago, was retired when she
received a cancer diagnosis, did not have children and had lost her husband suddenly during the treatment. A thoughtful quiet woman, Doreen had busied herself making the tea when I first arrived at the cancer support group’s Christmas party. She was dyadic and active and continued to identify herself through helping others after she had recovered from surgery and completed her speech and physiotherapy exercises. Doreen impressed upon newcomers the importance of medical compliance to reduce suffering and as a way to continue communicating with the world. She was also clear about the lack of significance of a person’s outer appearance.

Though he spent a year out of military action during WW2 Barney’s hospital period was only mentioned in a sentence before going on to talk about resuming control of his body through returning to duty, thus confirming his hegemonic male identity as an active man in control of his own body and that of others. As Goffman (1959, p.42) argues, aspects of stories which do not convey the identity that the person wants to present may be left out

‘I enjoyed it, I loved flying. And then when I eventually finished in hospital in about March 1942, I was posted straight back from hospital back to flying, doing exactly what I had been doing before...’ (Barney, 2011).

He did not say, but it is likely that Barney spent this time in a military hospital, so though he was injured, he was probably surrounded by other military men with war injuries. This was in contrast to Gillian, Martin, Clara and Agnes who had been in bad accidents and had no contextual explanation for their alteration. In addition, though seriously wounded his scars could be seen as markers of his professional identity and something gained in the pursuit of a war considered worth fighting. Barney had mentioned an unknown woman looking at him in the street, then kissing and thanking him for his efforts during WW2. If anything they seemed to enhance his identity as an action hero, not detract from it. The injuries were not serious enough to retire him from the RAF and so his military identity and highly structured lifestyle continued in the aftermath. Barney was also an active member of the Guinea Pig Club and had been for decades. (An organisation set up to conduct research and to perfect facial reconstruction techniques using WW2 RAF pilots, run by Archibald McIndoe, a pioneering facial surgeon). During McIndoe’s lifetime Barney was subject to periodic facial reconstruction. He would have been in contact with other men with similar experiences and injuries. Consequently, there was another opening to others, an additional aspect of his dyadicism, which meant he was possibly not feeling as isolated as a private civilian in hospital might. Aged 91 at the time of the interview he had kept himself slim, cognisant,
and active in the world. He kept a pair of trousers from the 1930s as a marker of potential weight gain; he did not allow himself to grow out of them. So, like Andrew his military career and bodily control was central to his identity. However, unlike Andrew, Barney’s body was not permanently physiologically damaged to the same extent, nor did his military career end after the facial event.

Though she continued to be concerned by having an asymmetrical smile Agnes’s lifeworld was more influenced through the process of becoming severely hearing impaired, though even this did not significantly disrupt her identitied stories. From an early age Agnes, unlike Clara had been dyadic, open to the world with many friends and in spite of her altered smile and loss of hearing, this orientation did not change throughout her life. With the help of a hearing aid, her own quiet determination and a supportive family and teachers, she engaged and communicated with the world achieving a chemistry degree, a research career, and fulfilling gender ideals/expectations for women of her era by marrying and having two children. In the following quote, Agnes illustrates her orientation towards the world:

‘A lot of the time I wasn’t conscious about it (her asymmetrical smile) because I am interested in people you know you get interested in people and in fact when you meet somebody who has some kind of erm, disablement or something like that. Or they look different and you think at first, it strikes you and then you get interested in the person and you forget about it’ (Agnes, 2011).

**Waves**

The desire to return to a revised ‘normality’ was strong in participants in this group (Marie, Natasha, William and Jonathon). They shared some similarities with those in the *Ripples* category. All were other-related, doing voluntary work to ease the suffering of people with similar experiences. However, they appeared to find it more difficult to negotiate a revised identitied embodiment. Participants’ stories in this group all contained transitional identities, these related to some or all of the following: emotional difficulties; existential threats; reduced bodily control and capabilities; and the recognition of bodily weakness and vulnerability (Frank, 1995). The cause of facial change was common to all in this group- a cancer diagnosis and treatment involving surgery to remove tumourous growths and to reconstruct the face. In addition, all had experienced recurring episodes in the aftermath
and all were in remission at the time of the interview (2011-12). The identities of the people in this group, as with those in the ripples group were more threatened by the disturbances to their daily lives, activities and relationships than they were by visual appearance alteration, even if they did not recognise the shift as Marie illustrates in this quote:

‘You are still the same person inside. I mean somebody probably said that to me, but at the time I would never have believed it but you are. Your face might have changed, or your appearance might have changed but you as a person haven’t. You are still the same person and if you look through aren’t you, there is no difference in you is there?’ (Marie, 2012).

In spite of the overall similarities, there were some differences between accounts. Marie’s need to impose control on her diagnosis of mouth cancer and its capacity for bodily and identity chaos was expressed through her desire to return as quickly as possible to ‘normal’ life, something she had stressed in the period before the change. She was aided in the return to normality narrative by her husband, who was present for some of the interview. Virtually a week passed between Marie’s discharge from hospital and their attendance at their son’s wedding, but her husband remembered events as taking place on consecutive days. They did not stay for the reception because Marie was not feeling well enough after the surgery, though this remained unspoken until later in the interview. The fact that they were able to attend and that the chaos of cancer had been beaten was what was articulated early on.

‘The day you came out, the day after you came out, was it- when did we go to John’s (their son) wedding was that, we didn’t go... We went to the ceremony (Marie’s husband)

Yes, I came out on the Monday and he got married on the Saturday yes I went to the service didn’t I, so that it didn’t stop me doing anything’ (Marie, 2012).

Though she had clearly experienced anxiety, shock and identity shift through the cancer diagnosis, treatment and move to long-term remission status, it was not something Marie was keen to discuss. In the ensuing 18 years, she had seemingly come to terms with the restrictions in her dietary habits, her altered voice and temporarily altered facial appearance, though there was evidence of unresolved emotional distress communicated through staring at the floor, unfinished sentences and short, clipped responses to
questions. In some respects, these narrative traits were similar to Natasha’s responses, though she was in remission with very advanced cancer and Marie had been cancer-free for 18 years. The cause may lie in unresolved emotional turmoil stemming from this period.

William defined himself throughout the narrative as an active and pragmatic problem solver who had relied on his body to complete tasks, to think through problems and to defend himself from taller men who had picked on him when he was younger. The subsequent diagnosis and removal of mouth cancer during the early years of his retirement had left both life map and embodied identities disrupted, as he could no longer rely on his body. However, there was no allowance of emotional chaos in William’s account and he talked of time being ‘taken out of normal progress’, like he was trying to side-step, or mitigate the full disruptions of the cancerous episode and its effect on embodied identities. He reported developing severe claustrophobia in the aftermath of surgery and losing confidence in his ability to continue driving abroad. However, the two strands were not connected within his narrative and it may be that he has become emotionally dissociated from his body, like Marie. Again, like Marie he has become more dyadic as time has passed, and the suffering has become an opening to others, leading to his active role as a volunteer for a mouth cancer charity. However, it was a very different other-related opening to Sylvia, who worked with facial cancer patients some years later. Her orientation was to listen and to help reintegrate the whole person. He helped people with cancer and their families to know what to expect and how to get the best from professionals, another way of chemical and technological problem solving, thus maintaining aspects of his previous identity:

‘They removed 55 lymph cells, 12 hours in theatre, 36 hours in intensive care and two weeks in hospital. Six months, doing very little and another six months to regain some form, some semblance of normality...I have had three more tumours since then, which were all detected very quickly... That is the difference between delay and non-delay. I have always got to tell people about this’ (William, 2011).

Unlike William, Jonathon’s emotional response to the threats presented by cancer and its treatment was directly narrated. He had lost an eye, suffered from a recurring ear infection which affected his hearing and balance. The radiotherapy to his head left him unable to concentrate for prolonged periods and along with unrelated health conditions meant that he had had to retire early, live off a much reduced income and to significantly cut down on his much loved charity work. Jonathon had had to recognise his bodily vulnerability (Shildrick, 1997; Perpich, 2010), though he found it hard to accept. To negotiate the
disruption Jonathon shifted his energies to an area he could control, his finances. He could not control contingency, but he could plan for it and make sure that his wife was left provided for, thus maintaining elements of Jonathon’s hegemonic masculine identity as a husband, provider and financially independent person (Connell, 2005, p.77) as the following quote illustrates

‘... So all of a sudden your lifestyle which was slotted away for this is cashed in, and this is slotted in and it takes you a while to realise that, you are actually running out of what you have been saving up for years. So you have to completely reconfigure your life financially and erm... and that’s why I think it’s taken me three years really from moving to realise where I am now. I am not a control freak but I do go into online banking every day’ (Jonathon, 2011).

Natasha’s body was constantly in the foreground, or in a state of appearance (Leder, 1990). At the time of the interview she was in remission with advanced cancer and had much experience of losing control through ill health, for example, having a serious head infection and undergoing a mastectomy for breast cancer. As with all of the participants up to this point, Natasha’s identities, for example, mother, wife, book shop owner, were more disrupted by the illness itself, e.g. the iatrogenesis associated with cancer treatments and existential threats than by her facial alteration. That is not to say she was unaffected by the change in her appearance, but it was always contextualised. Natasha had acknowledged her bodily vulnerability and developed a communicative disposition with others. Her daughter and her friends knew of her facial and cancer condition and Natasha continued to support those with a cancer diagnosis through an online cancer chat room. Her desire for life remained productive and evident. She had married her long-term partner during the year of the interview and they had just bought a puppy. However, the unspoken threat of a terminal diagnosis was more difficult to negotiate and she had dissociated by separating her life into boxes, e.g. wife, mother, sibling, cancer sufferer. The future was not spoken of in detail and there were many unfinished sentences. In this quote we see Natasha’s conflicted identity negotiations told through her body, via her wanting to follow appearance norms, but not being fully able to, whilst at the same time recognising their superficiality compared with her more significant health problems stemming from cancer and a genetic condition. In spite of these conflicts, her orientation remained worldly focused:
‘... I watch other people where they mind about their hair or they mind about, I am not sort of erm... I am not downplaying that, they mind about that, but obviously having a bad hair day isn’t the same as losing all your hair, and you know a big nose isn’t the same as erm, no facial nerves...’ (Natasha, 2011).

Tsunamis

Overall people in this grouping found the negotiation of embodied identities in the aftermath of an acquired facial ‘disfigurement’ the most challenging (performativity and visually). The name of the sub-heading reflects the seriousness of the disruption, as tsunamis engulf, they have the power to demolish previous habitualities, i.e. homes, lives and livelihoods. Unlike ripples or waves tsunamis cannot be managed, stepped over or side-stepped as William refers to doing. Instead they overpower, leaving exposed bodily vulnerabilities and chaos in their wake. In such cases, the original life map is no longer possible (Frank, 1995). A new road or landscape destination must be created once the disruptions, chaos and ritually polluted waters have subsided and been ritually cleansed.

For Stephen, Gillian, Clara, Andrew, Sylvia and Martin the facially altering event and/or its consequences had been so traumatic, that it had engulfed them for years after the event.

Four of these participants (Gillian, Andrew, Sylvia, Martin) had nearly died, their bodily capabilities were diminished and their appearances significantly altered. However, another two participants (Clara, Stephen) had what could be termed mild facial ‘disfigurements’ (scarring with a slight nasal alteration, and acne rosacea). They had not experienced existential threats nor reduced bodily capabilities yet they had two of the strongest negative reactions to the changes and continued to remain in a dissociated, monadic state.

This finding concurs with earlier research conducted by Rumsey et al. (2004), that degree of ‘disfigurement’ is not directly related to the degree of suffering the person may experience, or the degree to which they will cope with their altered appearance in the aftermath. Consequently, I will explore this set of participant reactions in two groups: those who nearly died, and those who did not face an existential crisis but found the body-facial alteration very difficult to adjust to.

Gillian, Martin, Andrew and Sylvia had different reasons for their ‘disfigurement’ though all had similar reactions. Gillian and Martin had been in unrelated car crashes, she had crush injuries to her skull, facial tissue and had lost an eye, he was burned on his face, torso, hands and legs, losing some fingers in the process. Andrew had been burned all over in an
explosion whilst fighting a war and Sylvia had experienced two episodes of sinus cancer in the process losing an eye and half of one side of her face, which was hidden by a prosthesis. Their injuries and associated emotional distress stemming from the cause or ongoing treatments, for example, skin grafts, chemotherapy, were so great that they did not have the option to return to previously known embodiment. In addition, three of the four had to change their career plans (Gillian, Martin, Andrew).

In the pre-change period Gillian had identified as slim, young, attractive, active and career-orientated. In the aftermath of the car accident as tsunami experience everything was washed away without warning, leaving chaos in its wake (Frank, 1995). Unlike Andrew or Barney, there was no noble military cause behind her injuries or positive public reaction. For the first few weeks of the aftermath Gillian remained in a liminal state between life and death, health and illness and ability and disability. When she came out of hospital Gillian’s transitional state continued as she had to live with the repercussions of her injuries and appearance change including a shaved head, losing an eye, recovering from a broken back and having to learn to walk again. In addition, facial reconstruction surgery could only start a year after the event occurred. Gillian had to rely on others to physically and metaphorically help carry her body through life during that period, though they are largely missing from her account. The sense of shock, unfairness (an avoidable accident from which the driver walked away) and dissociation remained with her for years. However, during the same period Gillian also developed an outlet for the determined, proactive aspect of herself that she narrated in the pre-event career strand of her story. Her determination and resilience became increasingly significant:

‘...when I was let out of hospital two months later, I literally fell over, couldn’t walk, had to be carried around and then it was a case of real resilience, determination, and this will not, this will not get me, I am right on top of it...’ (Gillian, 2011).

In the weeks, months and years after the crash Gillian tried to manage her emotional chaos, which included trying to express and control her own competing emotions such as shock, loss, isolation, anger and to manage her family’s reluctance to discuss ‘the accident’ for fear of upsetting her, which only prolonged Gillian’s dissociation. During the first ten to 15 years after the crash this was compounded by the lack of anticipated career or romantic success, despite her efforts on both counts, such as going on dates or applying for numerous jobs:
‘Now bearing in mind, no counselling, no counselling whatsoever! Nobody coming and saying … you have lost an eye, you have lost your face, you are 20 years old, you are going to have problems walking, you are going to have relationship problems, you are going to have identity problems, all of the above. Nothing!… Nobody wanted to talk about it, including my family, it was all brushed under the carpet. Oh don’t mention the car accident you know... Oh she is trying to get over it, how the hell do you get over that?’ (Gillian, 2011)

From the period of the immediate aftermath onwards, the negotiation of ‘normality’ became a fight and Gillian became a ‘fighter’, in the process regaining control over much, but not all of her body. Over the next two decades, she continued to mirror other bodies and to consume products and services in the pursuit of a facial reconstruction ‘fix’. And, though she eventually became happy with her reconstructed appearance, her satisfaction with life and communicative stance seemed to be more related to her embodied and emotional association, which started when she began to receive support from a facial disfigurement organisation and was able to share her experiences, suffering and isolation. Gillian became a volunteer for the organisation, helped others to mitigate their own suffering, in the process becoming emotionally associated and dyadic. As Frank argues, once the storyteller hears a story which is also theirs, ‘The illusion of being lost is overcome’ (1995, p.183). In addition, a few years before the interview she had got married and they had set up their own business, based on the rewards of her previous business career as an estate agent. They were also going through the process of adopting children at the time of the interview. And, though Gillian ‘fixed’ her face to appear ‘normal’ and kept a hat in the car ‘just in case’, she was more concerned with trying to negotiate the identities she desired before the accident - successful career woman, wife and mother. Through attaining those goals and becoming emotionally associated, Gillian narrated expressions of embodied identity restitution, even if she did have a plaster covering her eye:

‘Once you have actually got your head round the fact that you are different than you were before and you grieve and it’s a weird thing you actually have to grieve for the person you have lost... Emotionally, once you have sort of kind of got your head round that and said right this is me, I can only go forward with what I have left, you are actually on a winner. Because then it’s about enhancing the person both physically and mentally that you have become… I don’t really feel that different from anybody else now apart from the fact that I have got a plaster on my eye’ (Gillian, 2011).
Martin described a five-year identity transition in the aftermath of the car crash. During this period, he went to university and spent the holidays receiving reconstructive surgery, thus enhancing his periodically polluted and liminal status (Philpin, 2007, p.52). Though his pre-existing academic identity was strengthened, the body he had put his faith in to win at sports, to attract women, to gain friends at school was initially beyond his control and he lost confidence in his sense of ‘physicality’. Feelings of anger, depression and isolation followed, Martin’s desire for life diminished and he became monadic (Frank, 1995, p.36). Physical restitution took place in stages with varying degrees of success. Some capacities had been diminished temporarily, for example, he had to learn how to walk, thus gaining some bodily control and greater independence. However, other aspects of embodied restitution were not possible, for example the loss of fingers on both hands and the limitations of facial reconstructive surgery, which added to feelings of isolation, loss and dissociation. Martin’s emotional restitution took longer than his physical reconstruction and though he did not talk of it explicitly, he alluded to monadism, lacking desire for life (Frank, 1995, p.36), depression and suicidal thoughts:

‘I think there was a period in the middle here where I had a very, very fuzzy sense of identity I wasn’t really sure who I was and what I was... there were a lot of down places, doubting places’ (Martin, 2011).

To reflect his shifting embodied status he changed his name, from something he had been known at school by, to another of his forenames. Martin told me of the parallels between himself and an American man, Donald Cowart, who had been burned, had an altered body-facial appearance and painful medical treatments against his will. Cowart had changed his name to Dax in the aftermath, to reflect his altered state and appearance, and what sounds like his experiences of great suffering10. Towards the end of Martin’s own five-year transitional period, he talked about a seminal year, his ‘gap year’, during which he spent ten months in hospital for reconstructive work. During this year his desire to reengage with the world increased, initially through extensive reading of everything from classic literature to trashy novels. There was also a recognition of contingency, a willingness to embrace his as yet unknown future and a desire to return to an active form of embodiment in association with others (Frank, 1995).

---

10 Please Let Me Die, a documentary made about and with Dax Cowart detailing his life pre- and post-burns. http://litmed.med.nyu.edu/Annotation?action=view&annid=10105
‘I think there was a period when I went back to university, I was I think establishing- (name withheld) as my name again. And I was kind of leaving an old person, an ex-persona there and starting to say ok, I am going to face this world, God knows how, but I am going to have a go at it…’ (Martin, 2011).

‘…that’s five years on from my accident really (shows me a photo)... I look at myself and think are you sorted, and I think that was taken actually more or less the same day, might have been the day, when I said to my surgeon I really, I have got to break this. I have got to go and be a citizen. I cannot keep coming back here, I have got to have a go at it’ (Martin, 2011).

Martin began to perform (Goffman, 1959, Butler, 2004) his revised embodied identities with new types of sports, in the process regaining lost confidence and his previously strong sense of physicality. During this period, he professed to moving from a state of dissociation to one of self and other association. The opening to others through his wounds (Frank, 1995, p.183) continued in the decades that followed through his career choices. Martin became a teacher, lecturer and more latterly a chief executive officer, managing a charitable equalities organisation. In addition, seven years after the car crash at the age of 25 years he met his wife to be and mother of his children. The chaos, pollution and liminality of the tsunami had subsided and like Gillian, he had successfully negotiated pre-change future goals that he had once thought unlikely.

‘So, I am a very, very happy content character, with a life that would be nothing like the one that I had anticipated, absolutely nothing like... oh come on, no way! But (pause) but, it’s turned out well’ (Martin, 2011).

Andrew was also burned and his embodied identity negotiation shares some similarities with Martin’s, though there were also differences. In his capacity as a private citizen Martin was able to continue with his academic and student identities, thus supporting his career aspirations and fulfilling his parents’, his school’s and his own expectations. Andrew’s injuries ended his beloved career and lifeworld as a soldier in the British military along with his identity as a proficient rugby player. The months following the bombing were succinctly described as ‘a very (physically) painful period’, which he had no problem narrating. Andrew hinted at emotional pain, and though it was not articulated as clearly it was present in the
silences, long distant looks and lowered pitch compared to when he was previously very happy. Relatedly, the first few years after the bombing were not talked about in any depth. Andrew’s relationship with his fiancée broke down, no explanation was given. His body, which had previously been disciplined and predictable (Frank, 1995, p.30) in his capacity as a soldier, became a consumptive device. Though he did not raise the topic, I knew that Andrew had started to drink alcohol heavily during this period through a book that he had written and published about the period. The consumption of alcohol was a continuing aspect of his previous military identity, though he no longer had the structured daily life of being a soldier to contextualise or moderate his intake.

Andrew may have been experiencing emotional and lifeworld chaos in the early post-bombing years though he came to view his ‘injuries’ and his life in a dyadic, associated way. The bombing of his ship had attracted media attention, which continued some years after. Andrew was portrayed as a war hero and like Barney, members of the public supported him though in much larger numbers. This profile and the support helped him to negotiate the return to a revised embodiment in three respects. Firstly, he was portrayed as an ex-soldier with injuries, not disabilities, identifications which remained important to him up to the time of the interview. Secondly, in the years after the event, he began to perform some revised aspects of his former self (Butler, 2004) he worked hard to get fit to compete in sports races and physical challenges. For example, he skydived for charity. This helped him to regain control over his body and to draw on some of his previously known and enacted military skills and motivations. It also helped him to recover a sense of physicality like Martin. Thirdly, people wrote to him sharing their own stories of suffering. It had a positive effect and he became much more ‘other-related’ (Frank, 1995). Andrew began to see his own ‘injuries’ and suffering as having a purpose, to help ease the suffering of others, which included inspiring a mother not to take her own life and the lives of her three children.

‘It became a different world...there was a relevance to my injuries because it was helping others (silence) and it was affecting others positively you know... There are three little girls who are still walking this planet, certainly as far as I am aware. Because the mother wrote to me and said after seeing my documentary, she wasn’t going to take her life and her daughters’ you know so (breathes out) that, you know if nothing else those three little girls who are now fully grown women I hope’ (Andrew, 2011).
A revised embodied identity was in place, not the one he envisaged, but one in which he had achieved many aspirations of his pre-facial change life. During the years and decades that followed, Andrew had developed a varied successful business portfolio (partly as a result of his media work), married and had three children. He continued to be a ‘proud Welshman’, associated with the military ‘by some sort of metaphorical umbilical cord’ and he continued to campaign to improve the conditions of soldiers. He also continued to follow rugby as a fan. Decades later the early self-doubts and lack of confidence had been replaced with a recognition of his bodily limitations and vulnerability (Perpich, 2010), confidence in his capabilities, e.g. intellectual, and a continued dyadicism enacted through charitable works and equalities campaigns. At the time of the interview, Andrew felt that his facial ‘disfigurement’ had enriched his life and presented new opportunities and successes in business. Just like Martin and the other participants, his face did not define him though it did identify him visually.

‘… my face has been my fortune you know. It’s stood me out in a crowd where others have to adorn themselves with body art, piercings, or outrageous, outlandish hairdos you know, so you have a look at all of those issues and I have never had to do any of that…’ (Andrew, 2011).

The final participant in this first sub-section is Sylvia. Having been bodily associated in her pre-facial disfigurement life she became dissociated even before the first of her two sinus cancer episodes had been fully diagnosed. In the wake of the chaos stemming from the existential threat the previously ‘powerful’ Sylvia had been replaced by someone much weaker that she did not physically relate to. This was compounded when she came to look in the mirror for the first time after surgery to remove part of one side of her face. Sylvia became monadic (Frank, 1995), shutting her emotions off from herself and others for several years. Her desire to engage with the world diminished, though not her desire to be and to perform the role of loving and attentive mother.

‘I just wanted to run and hide and just get away from it... I really shut myself off from society. I did go to the children’s open evenings at school because to me that was very important, I had to show them that I was ok. But that was a nightmare...I was absolutely flat as if my emotions and everything had just been put in a box and shut away. I had the key erm... but I didn’t want to open it, I didn’t want to be angry’ (Sylvia, 2011).
Her partial return to desire, and interaction with the world was told through two experiences with her children (the central protagonists of her story) involving journeys and bodily movement with her children and then husband. In the aftermath of the surgery she was told not to swim by her surgeon. She defied him in an act of embodied agency and took the children swimming, then swam on holiday later that year: ‘...and I can remember just going into the sea for the first time and actually swimming out to the horizon and thinking I am alive, I am alive, I am alive’ (Sylvia, 2011). In the second bodily performed experience, she spoke of being ‘dragged up these hills by the children’ whilst on holiday in Wales. These two experiences marked the start of her physical ‘rehabilitation’. The comment was both symbolic and prophetic. Her life in the aftermath of the cancer diagnosis and treatment was metaphorically an uphill struggle or ‘tough fight’ for survival and the return of her previous lifeworld, that she could not side-step as other participants had professed to do, e.g. William.

In spite of her physical ‘rehabilitation’ which included learning to use her face again, i.e. speaking, eating and communicating, Sylvia’s emotional and appearance related dissociation lasted for several years until she engaged with others and shared her experiences and suffering - by making television programmes, setting up a charity and receiving a funded place on a seminal overseas study trip on facial reconstruction. In the process, she became a much more confident and associated person, moving to a communicative, dyadic stance (Frank, 1995). Through these experiences Sylvia recognised the wound as a half-opening to others and the contingency of life (Frank, 1995): ‘... and that was the actual recovery stage for me, to actually share with other people...’ (Sylvia 2011). Control was not only restored but intensified as Sylvia’s attention shifted from the domestic sphere and her previous role as a nursery nurse to time devoted to travel, and developing a charity to support facially different people across Britain. In the process, her marriage broke down as the traditional gender roles of husband and wife shifted and she became more confident and agentic. As Butler (2004, p.21) argues, when people lose some aspect of life control traditional gender roles are found to be unstable and become undone.

Some decades later at the time of the interview, Sylvia presented as an associated, emotionally articulate, confident person who had managed to negotiate a return to a revised and ‘enriched’ restitution in the aftermath of a cancer causing facial ‘disfigurement’. As the head of a charity, she continued to lead an active professional life with much travel and her family, now grown up, remained significant. However, there remained traces of
liminality, through being an episodic patient and through never really coming to terms emotionally with her embodied experiences.

‘I will never ever, as long as I live come to terms with this, what I will do is learn to accept who I am now. And, that was the challenge to actually reach that stage’ (Sylvia, 2011).

‘I found a different Sylvia, I found a number three Sylvia that I didn’t even know existed. The skills that I had, and the ability to be able to make people laugh despite the awful, awful story. There was that sense of humour that was always there and will always be there which was the original Sylvia and light-hearted… but what I have seen is, is me growing in a different way from the children’s nurse and a mother and the woman at home.’ (Sylvia, 2012)

This final part of the tsunami sub-section will consider the experiences of two participants who also experienced engulfing chaos in the wake of facial ‘disfigurement’. Unlike Sylvia, Martin, Andrew and Gillian, Clara and Stephen found it difficult to move beyond states of dissociation and monadism in the longer-term. In summary, both were bodily focused, mirroring the activities of others around them. Both had diminished desire to engage with the world, though not uniformly. There did not seem to be a recognition of contingency and there was an ongoing sense of liminality enhanced by the holding of conflicting ideas concerning appearance and emotions. In addition, neither had experienced an existential crisis in relation to their facial ‘disfigurement’.

Unlike Andrew or Barney, there was no noble cause or public adulation arising from Clara’s facial change and unlike Gillian or Martin, there was no sense of the loss of a life on the cusp of career or romantic fulfilment. Nor was there an underlying existentially threatening cause such as cancer, leaving her feeling lucky to be alive as with Sylvia or Natasha. There was a clear division between Clara’s previously ‘happy childhood’, and the one she experienced after the two accidents, which had ‘blighted’ her life. One had left her with scar tissue on her lips, the other had left her with a broken and squashed nose which could only be reconstructed in her later teenage years. When Clara had the surgery, the surgeon did not comply with her reshaping requests and she remained deeply unhappy with her resulting nose, leaving her face and body in a perpetual state of appearance (Leder, 1990). Clara was left with strong convictions of her ‘ugliness’ which were undiminished at the time of the interview, some four decades later. Although she had been considering other
influences on her life during the weeks before the interview, such as her upbringing. Even
with more recent insight, Clara found it difficult to negotiate a number of competing
tensions in her life, such as the relationship between appearance and morality and
presented herself as a ‘mass of (unresolved) contradictions’.

‘I have been quite extrovert... but I am introverted in other ways because of my nose. Or is it
my nose or was it just the upbringing?’ (Clara, 2012).

After the accidents Clara became partially monadic (Frank, 1995, p.36), becoming
withdrawn at school and at her beloved horse riding lessons to avoid unwanted attention.
When her parents moved house to a new area where she knew no one and had no friends
Clara became increasingly monadic and her desire to be in the world diminished.

‘... and I went very introverted, very quiet because my nose, as I said I used to sit on
the back, on the back row if I could in class or I would sit on the front and have my hair here,
I slept most of my way through school, hated it, absolutely hated it I had no friends,
overweight and ugly. This has made me feel so ugly all my life...’ (Clara, 2012).

Though hers had disappointed her, Clara continued to put her faith in the body. She wore
heavy makeup from an early age, to hide her face and to fit in. Her activities in this respect
mirrored known (1960s fashion model Twiggy) and unknown female contemporaries as she
tried to consume solutions to her resolve appearance-related conflicts (Frank, 1995). It did
not work. The lack of social interaction growing up, her low self-esteem and faith in the
value of good looks led her to partake in some very unhappy heterosexual relationships
with attractive men. Referring to the deeply upsetting consequences of one failed
relationship Clara conjectured ‘... and I think if I had had a normal early teen years and I had
been prettier that wouldn’t have happened to me. Then again, who knows?’ (Clara, 2012).
In this quote we see an inaccurate equation of outer beauty with moral character, a societal
trope recognised and identified by Synnott (1993). Now that Clara’s body was aging, it was
getting harder to make it conform which upset her greatly. However, she continued to
exert some control of her facial appearance through the ritualistic application of makeup,
which took an hour and a half every day owing to another health condition, and included
seven coats of various mascaras.
The other health condition was debilitating with potential future existential implications. Clara had had to retire earlier than planned, her husband helped her to dress and she used a mobility scooter to go shopping. She was also part of a mobility scooter committee, to ensure issues of accessibility were noted and addressed by the local council. In this respect, Clara expressed a desire for positive change, she was connected to others and got a chance to illustrate her intelligence, something she prided herself on. However, in another example of her ‘contradictory’ nature, she was more concerned by her appearance than by her ‘disability’, nor did she express any desire to promote issues of appearance equality.

‘I have not asked what happens then because I don’t think anything can happen there is no treatment, there is no cure you just put up with it. And hope, touch wood, fingers crossed it doesn’t get worse and you know you think I have got this to cope with, but that (her facial appearance) bothers me more’ (Clara, 2012).

Clara’s facial appearance did play a large part in how she had perceived her life developing. It had influenced her life and facilitated in the development of a series of conflicted, unresolved identities and beliefs such as feeling confident, ‘ugly’ and introverted; valuing good looks over personality and serious health conditions, and being married yet keeping people distant. However, her position had begun to shift, Clara conjectured that her reaction to the accidents and her subsequent choices and identifications had also been influenced by: being an only child; her parents’ segregatory practices; her religion and by moving house.

‘I think it’s a combination of all things being an only child and having a very sort of sheltered upbringing and that I wasn’t allowed to do anything, see they didn’t want me to mix because I was Jewish and go out to these Christian things and that, and yet, I wasn’t brought up in a Jewish environment so I was sort of in no-man’s land’ (Clara, 2012).

Stephen, the final participant in this sub-section, could not negotiate a revised restitution after decades of living with worsening acne rosacea. Stephen had placed his faith in his body and his ability to previously control it and others, such as fighting to stop a child being hit. However, a decade after his acne rosacea had first appeared Stephen was no longer able to control his body’s response leaving him in chaos. Insensitive or curious comments were asked several times a day and he soon became anxious around people, which made an attack more likely. Stephen dissociated from his face and became increasingly monadic.
over the ensuing decades. At one point the chaos became so difficult to live with that he had considered suicide, though would not ‘do it’ to his children. Stephen had also considered cutting his face with a knife to have a permanent facial disfigurement that others could identify with, instead of the transient condition by which he was judged by and not taken seriously.

At the time of the interview, Stephen had been on sick leave with an unrelated injury which he had managed to manipulate, to allow him to remain away from the office with its varied temperatures and unwanted facial inquiries. He wanted to work, but could not envisage a future with that firm or any other with acne rosacea. His desired aim of a successful career with promotion prospects and financial rewards was in tatters. Stephen reportedly rarely left the house; when he did leave, he preferred to leave at night so no one could see him, also the temperature was cooler, or else he remained in the car where he could control the temperature. Overall, Stephen’s identity narrative focused on his facial appearance and his inability to control and the life he had lost, including career and socialising opportunities. Though he was married with a wife and four children, two of which were present in the background while the interview was being conducted they rarely featured in his story. He alluded that his condition had interfered with his marriage, though he did not elaborate. He did say that the children were not to mention his face, nor would he take part in family photos unless necessary; even then he manipulated the image to reduce the redness, or else he changed the colour to shades of black and white. In spite of his lacking desire, monadic and dissociated position Stephen contacted me to be interviewed because he wanted the wound to be a ‘half-opening’ (Frank, 1995, p.169) to others, not in person but through my research and virtually through the Internet, he was considering setting up an acne rosacea support page on Facebook\textsuperscript{11}. Unlike Gillian, Martin, Sylvia, Doreen or Andrew, there was no recognition of contingency or revised restitution of confidence in his body-face and its dynamic place in the world.

‘I have told you bits of it, because it’s a story of 25 years. If it can help to stop one person saying something to somebody who has got a facial disfigurement then it’s worth it...’ (Stephen, 2011).

\textsuperscript{11} A web-based social media organisation.
Chapter Summary

This chapter took me significantly longer to write than I had anticipated. It became evident that the relationship between embodied identity shift and acquired facial ‘disfigurement’ was complex and not wholly explainable by the severity or size of the ‘disfigurement’. I started by exploring the participants’ experiences of ongoing transition and liminality through continued biomedical engagement, cancer and a disrupted sense of visual recognition. Identity restitution (Frank, 1995) did not occur for all participants after ‘disfigurement’. When it did happen, it was through a process of contested negotiation, which could take years and occur in strands, e.g. physical, emotional, visual, which did not necessarily happen at the same time.

The extent to which participants were able to renegotiate identitied embodiment was influenced by: the cause and context of the ‘disfigurement’; the degree of investment placed in bodies and appearances; the extent to which participants were able to return to previously known visual and enacted identities; their ability to move to a more communicative position which recognised vulnerability and contingency (Frank, 1995); the support they received from professionals, allied support groups and loved ones, and comments from others - known and unknown. Based on their ability to negotiate these influences on their identity, participants were placed into one of three groups. Experiencing an acquired facial ‘disfigurement’ had caused ripples, or shift to occur in the lives of all participants, though the shift could be incorporated more easily into existing identities. However, most found that the experience caused more than ripples in their pasts, presents and futures (Frank, 1995). Some had to navigate metaphorical waves through the spectrum of cancer and its existential threats, which remained on the horizon for participants in this group. While some were engulfed by a tsunami-like experience, and left to negotiate temporary or longer-term chaos. Most of those I interviewed in this category were able to negotiate a revised restitution in the months, years and decades after their facial event. Though, two who had not experienced an existential threat remained deeply monadic, dissociated and distressed by their altered appearance and the perception of its influence on their lives. These participants were more focused on their outer appearance and their inability to control it. They had invested more of their idea of themselves in their body-face, and its appearance and how it looked to others unlike the participants in the ripples group who had not invested as much energy in their facial appearance, or its change.
A life lived: experiencing facial ‘disfigurement’ and identity shift

Chapter Nine Conclusion

Findings, implications, reflexions and next steps

Chapter outline
This concise concluding chapter contains three sections. Having used a narrative methodology I have decided to present the first section, research summaries and their implications, as a set of three evolving stories. During the second section I will reflect reflexively on the PhD project, both in terms of its place within wider academic knowledge structures and more subjectively, through my experiences. I will be describing reflexivity here as a series of overlapping questions about the ethics, politics, methodology and location of the research (May and Perry, 2011). The final section will conclude with some thoughts about what I intend to do with the findings and how I intend to build on the work with further research plans.

Findings and implications

Beyond Descartes and ‘Disfigurement’: a call for complex, contextual research
As far as I am aware, few published accounts have synthesized pre-existing biomedical; psychological; social science and humanities research and biographies on the social significance of faces, life with a facial ‘disfigurement’ and the relationship between facial transplantation and identity shift before. Though it has been challenging to accomplish, the endeavour has been quite revealing. Through reading health related social science material I have learned that the development of Western medical professions, research and treatments has been strongly influenced by Cartesian ideas (Grosz, 1994, p.6). This influence is evident within academic facial ‘disfigurement’ and transplantation journals through the conceptualisation of persons and identity, the choice of research methods and through the values associated with ‘disfigurement’. Firstly; persons have been largely identified in a single role, that of medical patients (Kirmayer, 1988, p.59, cited in Lock and Gordon, 1988), thus stripping them of complexity and agency. In addition, faces have been metaphorically severed from bodies and persons, and from their socio-cultural, political
and economic contexts, from the passing of time and associated identities. For example, several biomedical authors of facial transplant papers have conjectured that identity is located corporeally within the face (Swindell, 2007) which is capable of being ‘*transferred*’ from donor to recipient (Swindell, 2007) or ‘*split*’ during the transplant (Carolessa and Pradeu, 2006). This is problematic not least because it reduces complex issues of identity to appearance recognition and people to the role of biological dupes. Furthermore, it takes no account of previous lives, identified experiences, or the causes, contexts and consequences of body-facial and biographical disruption (Bury, 1982; Leder, 1990; Frank, 1995).

Secondly; many facial ‘disfigurement’ studies start from the premise that people with damaged/differently looking faces will have a poorer quality of life and poorer mental health (Vickery et al., 2003; Cash et al., 2004; Lawrence, Fauerbach and Thombs, 2006). To rectify this situation physiological and/or psychological repair is required to enable their return to ‘normality’ in a world challenged by difference (Shildrick, 2010). The processes and procedures of facial transplantation take this premise one stage further. Whilst I am not disputing the benefits that therapy and reconstructive treatments can bring, the medical focus on mind and body repair is only one of a number of issues that make up peoples lifeworlds and embodied identities. Joseph Merrick may well have been Victorian Britain’s most well-known person with neurofibromatosis. He appeared to suffer socially, emotionally and physically through his condition and public reactions to it (Goffman, 1986) though he was also articulate, well-travelled and financially solvent until he was robbed (Howell and Ford, 2009). Lucy Grealy dissociated from her body-face after an episode of childhood cancer and died of a drugs overdose in adulthood, though she also went to university, became a writer, published an acclaimed book about her experiences and travelled widely across America and Europe (Grealy, 2004; Patchett, 2004).

Finally, many facial ‘disfigurement’ studies have been designed using positivist methodologies such as quantitative measurements and rating scales. As Thompson and Kent (2001) and Bessell and Moss (2007) have illustrated a number of these studies have had low participation rates, sometimes using unvalidated methods, which may not be relevant enough to address the issue of facial disruption and ‘disfigurement’. One piece of research illustrating a dualist, positivist understanding of the relationship between facial ‘disfigurement’, transplantation and identity was written about by Modgil (2011). Modgil argued that identity was located within the face and that it was possible to ‘*objectively*’ ‘*quantify and predict*’ the extent of a person’s identity shift after facial transplantation using a model of his devising which involved taking a series of facial measurements (2011,
Taking these three issues into consideration it has become evident that we need to find new ways to research and discuss the situated, complex and dynamic phenomena of facial ‘disfigurement’ and all of the disruptions associated with it such as biographical and identity disruption.

I want to be clear that the focus of my argument does not lie with individuals. Decades of ‘disfigurement’ research findings have illustrated that people can experience heightened anxiety and depression and be more likely to isolate themselves as a result of unwanted intrusive stares and comments due to their facial appearance (Newell and Marks, 2000; Rumsey and Harcourt, 2004; Halioua et al., 2011). However, the aim of this PhD research has been to go beyond conjectural identity discussions and dissociated quantitative findings and the application of a phenomenological epistemology, embodiment theory and a narrative methodology has been hugely rewarding. Experiences of the lived body produce embodied identities which are selectively created and reproduced through the sharing and revising of life stories. As Frank argues ‘The self is being formed in what is told’ (1995, p.55) which can shift over time in light of new experiences (I am using the terms self and identity interchangeably.) Consequently, the relationship between acquired facial ‘disfigurement’ and embodied identity disruption and shift cannot be researched or understood using Cartesian dualist ideas or a positivist methodology. Consequently identities cannot be transplanted between persons during facial transplant surgery (Carolessa and Pradeu, 2006 and Swindell, 2007) nor can the extent of identity shift be measured afterwards (Modgil, 2011). But where does this rejection of Cartesian ideas leave us? Whilst I strongly believe in the virtues of theoretically informed qualitative research I do not want to propose the replacement of one set of values with another. My thesis has only begun to scratch the surface of the complex, multifaceted relationship between body-faces, facial appearance, ‘disfigurement’, transplantation and society. I would like to use this opportunity to call for interdisciplinary academic discussion about how to research these issues in ways which take account of corporeality; temporality; historical associations; societal and medical power structures; cultural tropes and values; healthcare systems; psychological-emotional processes; corporeal shifts in capacity; biographical storytelling and performativity; disruptions and transitions; and human complexity and creativity. Phenomena such as felt and visual identities, transition and liminality, confidence, sociability, competing emotional states and suffering have been identified by the participants at various stages of their corporeal and biographical journey. Social scientists, psychologists, ethicists and others are well placed to explore these complex states using a variety of theoretically informed methodologies in
ways that move beyond current disciplinary boundaries (myself included) to really enhance our understanding of what it is like to live with facial ‘disfigurement’ and transplantation over time and in differing cultural contexts.

**Socio-culturally embedded body-faces**

The first objective arose as the result of an identified research gap in many facial ‘disfigurement’ and transplant papers. Clinical and ethical authors alike have prefaced their arguments by noting the socio-cultural significance of faces and/or the hypothesized relationship between the face and a persons’ identity (Carolessa and Pradeu, 2006; Swindell, 2007; Carty et al., 2012). However, very few have utilised philosophical, theoretical or empirical findings to contextualise their work or add social resonance to their findings. The findings presented in Chapter Four not only bring together overlapping but distinct bodies of research rarely found elsewhere, they also illustrate that body-faces play integral, diverse and dynamic roles in human socio-cultural life and its reproduction. I make three points.

Firstly, though some ‘disfigurement’ and transplant authors refer to ‘the face’ (Lantieri, 2012, p.250) there is no single or ubiquitous definition of the term (Levinas, cited in Critchley et al., 2002), nor are there any intrinsic or universal values attached to faces (Perpich, 2010, p.185). Definitions of face incorporate notions of facade; personhood; agency; interaction and cognisance (Perpich, 2010), which thereby involve identification; appearance; self and other; activity and constraint. Consequently, faces are complex, situated, dynamic and varied so it is inaccurate to simply refer to ‘the’ or ‘a’ face in abstract, generic terms.

Secondly, it is clear that faces, unlike other body parts have played diverse and important roles in social reproduction for thousands of years. Faces and heads can be either hidden from view to denote an altered status, for example during a funeral or a ritual of transition or, faces can be read in an attempt to know more about an individual and place them within a framework of meaning, for example phrenology or physiognomy. In both respects the face is recognised as a site which is linked to the individual and social identity of the wearer, which could explain the strong association in facial transplantation papers. As part of the process of social reproduction, the faces of some populations have been valued or devalued. Drawing on Deleuze and Guattari’s concept of faciality (1987, p.168) it is possible to see how powerful elite groups have used facial and bodily appearances to legitimate and
perpetuate social, economic and legal inequalities (Dudley, 2002; Benson, 2008). However, faces can also be used to promote positive socio-political change, for example the use of faces on flags to galvanise solidarity around a cause, as with Nelson Mandela in South Africa to promote the end of apartheid and equality for all South Africans. It has become evident that faces are invested with a host of powerful and dynamic socio-cultural meanings, which have potential economic and equalities ramifications. These investments need to be acknowledged and examined more closely by academics working within the fields of facial ‘disfigurement’ and transplantation research.

Finally, the outdated and inaccurate trope that a person’s moral worth can be gleaned from an examination of their facial appearance continues to have some influence within Western societies. Given continued Western interest in the visualisation of Regency and Victorian fiction, e.g. Austen, the Brontë sisters, and the print and visual media industry’s fascination with the pursuit of bodily attractiveness (Carter and Steiner, 2004) it is little wonder that several participants reported receiving unwarranted negative comments about their faces from social others. Thankfully, national facial equality organisations like Let’s Face It and Changing Faces are working hard to expose this inaccurate and damaging association, to build resilience in people and to challenge national myths and stereotypes. Based on the findings of this research I would like to see the 2010 UK Equality Act being extended to include facial prejudice and discrimination and implemented, with prosecutions if necessary. At the same time, state and other relevant institutions, i.e. media, should fund ongoing initiatives, which challenge the association between facial damage and moral damage at all levels. We identify each other using our faces, but they do not define us as we move through life, nor should they be allowed to.

Disrupted and dynamic identities
As parts of persons faces are diverse, dynamic and always in a state of change. What makes faces different to other body parts is that they are always on show, play a significant role in our perception and sense-making of the world and they help us to recognise ourselves and each other. However, facial recognition is not the same as identity. The use of a phenomenologically located, narrative methodology has lead me to conclude that the relationship between acquired facial ‘disfigurement’ and embodied identity shift is a complex one which cannot easily be predicted according to the degree of body-facial alteration. Disruption occurs not just corporeally to body-faces but to lives; biographies;
relationships; careers; identified performances and perceived pasts, presents and futures (Goffman, 1959; Grosz, 1994; Frank, 1995; Butler, 2004). Consequently, embodied identities are not located within faces, but within cognisant, conscious, sensory and agentic body-faces which means that they cannot be transplanted between individuals during surgery.

The predominance of quantitative methods in facial ‘disfigurement’ research has meant that it has been difficult to get an in-depth understanding of how individuals make sense of corporeal and biographical disruption at the time of the facial event and in the years to come. My research has indicated that disrupted, transitional and liminal aspects of embodied identities can last months, years and decades after the event or events has occurred. One of the hardest aspects of the analysis was to make sense of the chaos in peoples lives, to understand how those with similar conditions could react so differently. And inversely, why people with seemingly minor facial differences could react so strongly when those who had nearly died did not always have such dissociative, socially avoidant reactions in the longer term. I have concluded that this complex, significant and ongoing transitional identity phase has not been fully researched or represented within the academic research community and this gap needs to be addressed.

The extent to which the participants were able to successfully negotiate revised embodied identities was influenced by the cause and context of the ‘disfigurement’, the extent of corporeal and biographical disruption and the extent to which the person was able to recognise their body-self, somatically, visually and performatively during and in the continued aftermath of the phenomena. To express this complexity I formulated the identity disruption categories of ripples, waves and tsunamis. Though most participants were eventually able to negotiate revised identities, for a few the integration of experiences, previous identifications and performances disrupted futures, emotions and relationships remained a work in progress (Frank, 1995, p.97). Even those who had become associated expressed traces of liminality decades afterwards. In conclusion, I am proposing a new theory, that the relationship between embodied identity shift and acquired facial ‘disfigurement’ is one of ongoing and contested negotiation between wider socio-cultural facial values, transitional/liminal identity states during and after the event(s) with the aim
of previous identity restoration. Figure 3\textsuperscript{12} summarises this dynamic relationship, which incorporates self, other, and social factors.

Figure 3 Acquired facial ‘disfigurement’ and embodied identity shift: a summary of influences

\textsuperscript{12} Inspired by Csordas (1999, p.19) figure on the relationship between ritual healing and identity politics.
Reflexive reflections: macro and micro considerations

Overview
Thankfully, the researcher-centred reflexivity debates of the 1990s have matured into a series of wider research-focused discussions such as the circumstances of knowledge construction and the scrutinisation of methodological choices. At their core, these reflections challenge the assumption that there is an unproblematic relationship between the social sciences and the production of a valid and reliable representation of the ‘real’ world (May and Perry, 2011, p.15). During this section I will critically reflect on some macro and micro factors influencing the production of this thesis, specifically: the knowledge economy (May and Perry, 2011); using a narrative interview method; the ethnographic extent of the research; how I represented myself to participants, and I will finish with an exploration of my own PhD journey.

The knowledge economy
May and Perry (2011) take a critical approach to the study of reflexivity. Influenced by Foucault, they seek to widen the focus from isolated individual researcher accounts, to include meso and macro power structures and associated socio-political processes, as these influence the contexts and consequences of research. They argue that particular values are increasingly being associated with universities, in their role as knowledge producers and in their relationships with governments, businesses and society in general. Research, which can prove its value as ‘robust’, ‘relevant’, and transferable becomes prioritised, particularly during a period of economic recession (May and Perry, 2011, p.201). In turn, this perpetuates modernist and realist cultures of academic working centred on the production and exchange of knowledge. The authors report that knowledge production in universities is generally centred on autonomous individuals, working within ‘isolated’ environments, whose ‘expertise’ cannot be challenged, making it difficult to foster a space and a place for the practice of research reflexivity.

Reflecting critically on May and Perry’s (2011) work on academic knowledge production and exchange in relation to this PhD has been revelatory. My initial area of interest was in embodied identity shift in people who were going to have or who had already undergone facial transplantation surgery. I met separately with three facial transplant surgeons. In spite of their hectic surgical and other senior academic duties, all gave time to speak to me, one was even happy for me to interview her whole team. However, when I tried to gain
access to interview prospective facial transplant ‘patients’ on the British transplant waiting list I was denied access. Interpreting May and Perry’s (2011) argument, it is possible to view my lack of access to facially ‘disfigured’ people as the result of the un-reflexive structures of scientific positivism, acting through the control of powerful academic experts. In this act of denial, the medical experts as knowledge producers perpetuate biomedical models of disability and sustain a ‘knowledge’ of facially disfigured people as vulnerable ‘patients’, not persons (May and Perry, 2011, p.84). However, research is rarely simple and my request may have been denied for other reasons. Significant attention has been given to the psychological support of people prior to the transplant (Brill et al., 2006; Clarke and Butler, 2009; Coffman and Siemionow; 2013). I am not a clinical psychologist. If people on the transplant waiting list had shared stories of extreme suffering with me, I might not have had enough training to manage impact of the disclosure. I was surprised by the depth and variety of suffering that had been revealed when I had asked people about their faces, and I would not want to cause additional distress. Having acknowledged this I hope to use my present research experience to develop post-doctoral research with people who are waiting to or who have undergone facial transplantations. With the right planning, support and communication in place between all stakeholders, issues of access should not be insurmountable.

**Evaluating narrative interview methods**

In this section I draw on my PhD student experiences to reflect on the advantages and limitations associated with using narrative interviews. I have found that using an open biographical first question allows the teller to situate events and experiences within their own lifeworlds. This allows for the organic evolution of ideas and identities, as people change and overlay their experiences with revised meanings over time (Riessman, 2008). For example, the participants started their narratives from a variety of identified locations, which reflected what they wanted to prioritise. Andrew started by saying that he was born into the military, something he strongly identified with even after he had left the British Army. Gillian and Martin started by identifying themselves as young, attractive intelligent career-orientated individuals with family, friends and romantic attachments, before the sudden car crashes which would alter their lives and identified embodiments. This person-centred, life course approach is missing from many of the quantitatively informed facial ‘disfigurement’ studies, which can present people in a partial light. Whilst I do not wish to
challenge these findings, I want to widen the possibilities for research methodologies and for human understanding in this area.

In other respects, I have found that through their design, narrative interviews are open to moments of spontaneity. People can recall events as they remember, sometimes halfway through a story, which adds additional context to an experience (Bauer, 1996). Consequently, the order in which experiences are relayed does not matter. As part of the analysis, I went through each interview and placed the events in the participants’ own timeframe, as advocated by Doucet and Mauthner (2008, pp.405-406), which enabled me to develop an understanding of starting points, seminal moments, gaps in the telling of an event, and points of reference. Also, through the practice of active listening, I have been able to identify early similarities and themes arising between cases, for example the emotional significance of looking in the mirror in the aftermath of the facial event. It was something I had picked up from reading the biographical accounts for the interview review and it was raised during my first interview, which I was using as a pilot exercise, so I added it to the question list. The addition yielded dividends; it became clear the participants identified with their lifeworld and embodied identity and not just with their face when they looked in the mirror.

Finally, through the process of active listening I have been able to gather information about critical incidents and sensitive topics in a non-threatening way, one which has revealed what I would not have thought of asking about or felt comfortable doing so. Participants revealed existential and emotional threats caused by blood loss, cancer, being burned or nearly drowning; thoughts of self-harm and staying off work unnecessarily just to avoid people; divorce and one account of abuse within a relationship (which was addressed at the time). All of these were significant aspects of participants’ life stories and relevant to embodied identities, not all of which focused on their faces, illustrating that identities are not bound up in the physicality of faces, as hypothesised by Carolessa and Pradeu (2006), Swindell (2007) and Carty et al. (2012), but embodied experiences throughout the life course.

There are, however, some limitations associated with narrative interviewing and with interviews more generally. Although the aim is to gain the experiences of the participant with little interference from the interviewer, this is by no means a detached or neutral process (Atkinson and Delamont, 2006; Gubrium and Holstein, 2009; Atkinson, 2010). Firstly, people may have preconceived notions of what you are trying to find out, which may influence which experiences they chose to recount (Huberman and Miles, 2002). During the
first four interviews I conducted, all tellers stopped at some point and said, ‘is that the sort of thing you are looking for?’ (William, 2011). I explained that it was their experiences I was interested in, and that I did not have any preconceived ideas. During the course of the interview, participants may have responded to my cues, deliberate or otherwise, leading them to alter their story. One participant decided to show me pictures of his face prior to change, then at regular intervals after being burned in a car fire through to successive reconstructive procedures. Martin prefaced the photos by saying that he had ‘traded on his looks’ at aged 18 to get women, then proceeded to show me a picture and hesitantly look for my agreement. Mirroring his reactions to the before pictures was easy enough. I was not sure what to do when he showed me the next few photos of Martin’s freshly burned face and upper torso. I felt shocked and distressed on his behalf, but outwardly looked empathetically neutral, as narrative guidance strongly suggests the avoidance of personal opinions, which may influence the narrative (Wengraf, 2004; Reissman, 2008). This moment so early on could have been a turning point. If Martin interpreted my lack of mirroring his own ‘horror’ at his freshly burned appearance as indifference, it could have shifted his perception of me and altered his narrative, perhaps leading to a less rich account. I do not think this was the case, but I will never know.

‘Through our presence and by listening and questioning in particular ways, we critically shape the stories participants chose to tell us’ (Riessman, 2008, p.78).

Riessman (2008) argues that power shifts from the researcher to the teller during a narrative interview and that this encourages greater equality in the conversation. I find this problematic on two counts. Firstly, the aim of narrative interviewing is for the participant to take control through what they choose to share, or keep hidden, which aspect of the life course they chose to start at, how and where they end it and who features in-between. Secondly, conversation usually involves the swapping of stories between individuals. Verbal interaction during a narrative interview is unbalanced. Comments from the interviewer are very limited and focused; they are expected to give nothing away other than a nod, a smile or a concerned look, while the other is expected to reveal all by disclosing suffering, intimate events and emotions. This highly structured approach might work with people who are used to telling their story, but it does not work with all participants. Some may talk just to fill the space; others may need a compromise position with some semi-structured questions (Wengraf, 2004). Also I used the photographs to enhance my familiarity with the participants so that they would disclose more. Some participants, particularly the ones in their seventies and older did indeed need more prompting as they were unused to talking at
length about themselves to a stranger, especially regarding sensitive life events. The use of their photographs aided this process. I make no apologies for this; the main objective of the social scientist is to gain high quality research data within ethical parameters. I would like to argue that I have achieved this (Chapter Three, Ethical frameworks and the protection of facially ‘disfigured’ people).

Enhancing the ethnographic snapshot

The field in this project has been participants’ homes, places of work, or in two cases, on the end of a telephone. The interviews themselves, particularly those conducted at home offer an ethnographic ‘snapshot’ of lifeworlds and embodied identities. To move beyond snapshots I could have developed my understanding by volunteering at a relevant organisation over a period of time. However, there were a few challenges associated with this idea. Firstly, Changing Faces and Let’s Face It were based in London and Kent respectively, and I was based in Liverpool, hundreds of miles away. I did not have the funds to travel regularly. As it was, I followed developments on their websites during the research period. I could have volunteered at a group for a specific health-related condition closer to home, i.e. cancer, burns. However, recruiting participants with only one health condition might have given me a partial understanding of the relationship between facial change and embodied identity shift. The final mix of facial change causes (cancer, accidents, acne rosacea) served to enhance my understanding of the complexities of this issue.

Representation and matching

Hallowell, Lawton and Gregory (2005) argue that on a basic level, social science research is based on a degree of trust and reciprocity between researchers and participants and that the self that is put forward in such encounters seeks to facilitate this. However, this may take many forms. Lippman (2005) states that we may decide to ‘match’ ourselves to our participants to help develop rapport and ultimately enhance the disclosure of thoughts and experiences. One way this can be achieved is through a consideration of clothing choices, as these can contain gender, social status and other social messages (Lippman, 2005, pp.42-50). In Lippman’s case she chose to wear a simple wool coat, rather than her mother’s proposed gift of a fur coat during a cold Canadian winter, to relate to the working-class women she was interviewing.
I was very aware of what I did not want to wear. If I had been wearing a suit, participants could have mistakenly interpreted me for a medical professional, especially as I was asking about their experiences of ‘disfigurement’. However, this was not how I wanted to be identified. Firstly, I did not want the interview to feel like a formal encounter as people may have not opened up which would have diminished the quality of the data. Secondly, the fieldwork was an attempt to get away from medical professional-led patient health encounters, which can cut across life story narratives (Chase, cited in Josselson and Lieblich, 1995). Thirdly, a perceived power difference could have inhibited the flow and extent of participant narrative sharing, as professional knowledge and speech is privileged during a medical encounter (Wendell, 1996). Therefore, I made a conscious effort to appear less ‘expertly knowledgeable’ (May and Perry, 2011) than medical professionals.

I wished to appear relaxed, interested and approachable. To achieve this aim I selected a head shot of me taken on holiday for the publicity material, it shows me smiling with windswept hair. To reflect this informal, approachable manner I chose to wear smart casual clothing, but not denim, to let my interviewees know I was relaxed, but taking their accounts seriously. To successive participant queries ‘is this what you are looking for?’ I responded I am here to listen to your story, you are the expert here. What I did unconsciously match, were snippets of incidental personal and cultural experience in the spaces between the beginning, middle, and end of the interview, as these helped to develop rapport. In this except, the participant and I swapped pleasant rugby league stories over coffee. Apart from facilitating rapport and disclosure, this aspect of our encounter helped to establish his previous identity as an active young man in control of his body, which included playing rugby:

‘... My dad is a big rugby fan, we are, we are league people, my parents are from St Helens so I go to the odd Saints\(^{13}\) match (A-M)

\textit{Ok, I have a great fondness for Wigan}^{14}\ (Andrew)

Oooohh (pronounced in a negative jokey way, as the two teams are archrivals) (A-M)

\textit{Exactly erm, because it was the first rugby league match I ever went to...’} (Andrew).

Hallowell (2005) suggests that another way to ‘match’ the participant is to ‘wear’ their condition. This was not possible, though I did have traces of understanding. I had had acne

\(^{13}\) Saints is the nickname for St Helens Rugby League Club.

\(^{14}\) Wigan Rugby League Club.
in my twenties and my Uncle had recently died from head and neck cancer. Whilst these are poor substitutes for the experiences of my participants, traces of their stories did feel familiar, for example, feeling self-conscious of facial appearance and being aware of the suffering of others with cancer or their families (Frank, 1995, pp.169-171).

I do believe that my relaxed, informal appearance and manner worked. People told me things I had not been expecting, and went into details about sensitive experiences that I would never have asked about, for example divorce, thoughts of self-harm, and an instance of abuse within a relationship (which had been addressed at the time). As with the use of photographs to enhance familiarity, I make no apologies. Everything the participants told me was relevant to identified embodiment, but not necessarily directly related to the facial change event. This high level of disclosure helped me to reach the conclusion, along with phenomenologists (Merleau-Ponty, 1962) and advocates of embodiment theory (Leder, 1990; Csordas, 1994; Grosz, 1994; Frank, 1995), that identity is not carried within the face but within embodied experiences. Therefore, even though the face is significant in self and other recognition, it is the experiences of the whole person or in this case the body-face that counts more when forming identity.

Next steps
So far (2009-2014) I have presented the research (as it has progressed) at academic conferences across Britain, published a podcast on my research experiences and a blog article for a European anthropology website on identity and facial transplantation. I have further presentations and papers planned on identity disruption, facial ‘disfigurement’ and facial transplantation during 2015. I am considering writing a book, though this would need to be a salaried endeavour. In terms of my own next steps, I am in the process of building networks to gain post-doctoral funding to conduct research with people who are on a facial transplant waiting list, or who have already had one. The idea is to build on the findings of the thesis and to explore prospective or post-transplant embodied identity shift.
A life lived: experiencing facial 'disfigurement' and identity shift

References


Anglia Ruskin University, 2013. Guide to the Harvard Style of Referencing.[pdf]


Appendices

Appendix One: Ethical approval letter

School of Law & Social Justice Ethics Committee
Eleanor Rathbone Building
Bedford Street South
Liverpool, L69 (536,210),(652,225) 72A
England
UK

Telephone: 0151 794 3579

10/05/2011

Dear Anne-Marie,

Research title: A Face Lived: Experiencing facial Difference

Thank you for your revised application for ethical review. I have now received comments from members of the SLSJEC.

Ethical opinion
The reviewers from the SLSJEC gave a favourable ethical opinion of the above project on the basis described in the application form.

With the Committee’s best wishes for the success of your project.

Yours sincerely

Louise

Louise Ackers
Chair of SSSPREC
Email: louise.ackers@liverpool.ac.uk
Appendix Two: Participant information sheet

Participant Information sheet: adults with an acquired facial ‘disfigurement’

Invitation
You are being invited to take part in a PhD research project. Before you make a decision it is important for you to understand why the research is being done, to know what is involved and to decide whether you feel up to taking part.

What is the purpose of the study?
The study aims to understand how an acquired facial difference disrupts or impacts on an adult’s sense of identity (ability to act free from social constraints).

Who are you looking to recruit?
Adults with an acquired facial ‘disfigurement’, (which occurred at least two years ago), who will not be unduly upset by discussing their experiences.

Do I have to take part?
It is up to you whether to take part or not. If you do decide to take part and fit the criteria you will keep this information sheet and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?
The researcher will contact you to arrange a convenient time and location for you and you will be asked to complete a consent form prior to the research interview taking place.

You still have the opportunity to opt out, or to complete the research at a later date, without explanation.

On the day the researcher (Anne-Marie), will want to spend between one to two and a half hours with you, to interview you, to find out about your life before you became facially different, your life during this period and about your life today.

To explain something about your life or experiences, please feel free to bring photographs or possessions to the interview.

To maintain accuracy the researcher would like to record the interview with a small digital voice recorder, you can opt out of this.
If you feel uncomfortable with the discussion you have the right to ask for a comfort break, and/or to opt out without explanation at any point. All findings will be anonymized and kept confidentially.

You are welcome to have someone with you during the interview if it would help you.

What are the possible benefits of taking part?
I hope that you will enjoy the opportunity to share your thoughts and experiences.

Very little academic knowledge currently exists exploring how facially different people view their own faces, life chances or ability to act free from social constraint.

The information will be used to provide more insight into the lives of facially different adults, to increase knowledge and to reduce social ignorance in this area.

What are the possible side effects of the research?
This research will not be suitable for everyone.

It is possible that some people could feel upset due to the sensitive nature of some of the questions. You can choose not to answer them, have someone present with you or chose not to answer them.

As part of the research pack you will be given supportive information written for and by people with a facial difference.

This includes information taken from the organisation Changing Faces website, which contains details of their services, free counselling and regional groups.

If you have a diagnosed mental health condition and are receiving treatment this research may not be beneficial for you right now, so I would ask that you do not put yourself forward.

If you have a moderate to severe mental health illness, please do not put yourself forward.

If you are in any doubt please contact your GP first and discuss your fitness to take part.

Will my taking part in this study be kept confidential?
All information which is collected about you during the course of the research will be anonymized and kept strictly confidential.

What will happen to the results of the research study?
The results will be written up into a thesis (report), which will be used to gain a PhD, or doctoral degree by research. The findings will be summarised and presented at both conferences and published in health, disability and social science journals, so that a range of professionals and researchers can learn more.

At the end of the study you will be provided with a short copy of the findings, if you would like one. You will not be identified or identifiable in any report or publication!

Who has reviewed the study?
The study has been reviewed by Dr. Pamela Fisher and by the University of Liverpool Research Ethics Committee, who have given it ethical approval.

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study please contact Dr. Pamela Fisher at
Appendix three: Interview guidance for participants

For all the questions in part 1

- Include all the events and experiences which are important for you.
- Start wherever you like.
- Please take the time you need.
- I won’t interrupt.
- Please bring your personal possession into the conversation whenever you want to, as I can’t ask you about it.

Timeline of experiences to mention

Please include experiences from:

- the period before the accident
- the period immediately after facial change
- afterwards
- the present day
Appendix Four: Draft narrative interview schedule

Checklist table

<table>
<thead>
<tr>
<th>check understanding from information sheet</th>
<th>informed consent and both parties to sign</th>
<th>anonymised and the data will be stored securely</th>
</tr>
</thead>
<tbody>
<tr>
<td>right not to answer questions, right to withdraw, or to take a break</td>
<td>check recording equipment is working and on, if people consent</td>
<td>thank for taking part</td>
</tr>
</tbody>
</table>

**OBJECT REMINDER**

debrief at the end.

Background data

First name sex age

area live in current job highest qualification

------------------------------------------------------------------------------------------------------------------

INTERVIEW PART 1 - Themes

5) Could you tell me about your life from the period before your face changed up to the present day?

- period before accident
- period immediately after facial change
- after this
- the present day
6) Could you tell me what makes up your sense of identity and how this has changed or remained the same in the period before the accident to today?

7) Could you tell me about your experiences of looking in the mirror, from the period before the accident right up to the present day?

8) Starting with the period before the accident and finishing now, to what extent have you felt able to experience the type of life you wanted to live?

COMFORT BREAK

INTERVIEW PART 2 - to consolidate and clarify key findings arising from PART 1 ONLY:

describe the experience of ------------------ as being important for you, could you tell me a little more...?

INTERVIEW PART 3 - focused semi-structured questions

What do your experiences of life tell you about attitudes towards facial normality and difference?

Have any of these experiences ever motivated or inhibited you to think or act differently?

THANK-YOU FOR YOUR TIME AND INPUT