The Use of Storytelling to Make Sense of Painful Life Events:

Implications for Clinical Practice in

Counselling Psychology

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THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION/CONFIDENTIALITY REASONS:

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PART A: PREFACE

This portfolio consists of three pieces of academic work that I have completed as part of my training in counselling psychology. The first piece consists of a qualitative research project investigating how individuals with facial disfigurement psychologically reconstruct themselves following a traumatic accident or illness, adopting a narrative analysis. The second piece consists of a critical literature review that examines the benefits of storytelling in cancer survivors, along with implications for the practice of counselling psychology. The final piece consists of a combined client study and process report that explores how a young woman, following an abrupt break-up with her boyfriend, psychologically reconstructs herself towards love and acceptance using a person-centred approach. Although each piece of work is distinct in its own way, one common theme that runs through all three pieces of work is the crucial role that storytelling plays in the lives of individuals who have experienced some form of life-threatening or transitional event. I will now discuss each chapter in further depth and provide the reader with a summary of the thematic connections of this portfolio.

Part B: The Research

In this section, I present a qualitative research study that explores how individuals who have acquired a facial disfigurement psychologically reconstruct themselves following a traumatic accident or illness. Semi-structured interviews were used with a heterogeneous sample of seven individuals who had acquired diverse range of FD. Narrative analysis was adopted because storytelling has been documented by various narrative writers to be relevant for the study of disruptive life events (Crossley, 2000; Frank, 1998). Narrative scholars assert that when one's life narrative is disrupted by illness or trauma, the role of storytelling becomes highly crucial, because it allows the person to put their emotional pain into words and give it meaning (Murray, 2003). Subsequently, three distinct genres emerged in this study: *'the outsider'*, *'the helpless prisoner',* and *'the wounded survivor'.* I have contextualised the findings of this study within wider psychological literature, and clinical implications for the practice of counselling psychology are outlined and discussed.

Part C: Critical Literature Review

This chapter critically reviews and evaluates the benefits of storytelling in cancer survivors. According to Carlick and Biley (2004) when an individual is affected by cancer, their whole internal world may fall apart. Their once healthy lifestyle is replaced with fear, threat, and anxiety, and the need to make sense of life becomes highly important (Carlick & Biley, 2004). This paper further demonstrates that during such difficult times, storytelling becomes an important tool for communicating meaning to individuals by helping them to make sense of their illness. I have drawn upon previous work that has explored the benefits of storytelling in cancer clients, addressed their strength and weaknesses, and made clinical suggestions for the practice of counselling psychology. Three important areas are covered within this paper: the role of meaning-making and its relationship to positive adjustment in cancer survivors; online storytelling in the form of web-logging and its positive benefits in cancer patients; and the role of expressive writing and its promising effect in helping this specific population to deal with difficult feelings and come to terms with their cancer experience. What this review essentially highlights is that storytelling functions as an empowering, validating, and affirming experience for individuals affected by cancer.

Part D: Combined Client Study and Process Report

This piece of work, written in my third year, reflects my clinical competence as a counselling psychologist and highlights my work utilising a person-centred approach. It documents my therapeutic work with a young woman who went through an unexpected separation with her boyfriend and who, as a consequence, was grieving due to a sense of loss. This chapter includes biographical details of my client, a comprehensive formulation based on the person-centred approach, development of our therapeutic work together, and difficulties in my work with the client, along with an evaluation of my therapeutic work. Also included in this piece is a ten-minute segment of transcript from one of our therapy sessions. Throughout this excerpt, the reader may recognise how I facilitate a space using Rogers's six core conditions, in which the client can feel safe enough to make sense of her loss and be

more open and expressive of her feelings. Throughout this combined client study and process report, I have also made continuous reflections on my therapeutic interventions and therapeutic process.

The Portfolio Theme

One common theme that connects all three pieces of work is the role of storytelling in the life of individuals who have experienced some form of life-threatening and transitional event. In essence, this portfolio documents how the role of storytelling is relevant for the study of disruptive life events. It could be argued that person-centred therapy is a form of storytelling, in the sense that it is concerned with the stories that individuals bring into therapy. After all, McLeod (1997) viewed psychotherapy as a storytelling process, evident when he stated that "whatever you are doing, or think you are doing, as therapist or client can be understood in terms of telling and re-telling stories" (p. 5). Therefore, this portfolio demonstrates how individuals create stories about their experiences of loss and emotional pain in order to make sense of them and to provide their lives with a sense of harmony and coherence (Adler, 2011).

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Part B: The Research

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How do individuals with an acquired facial disfigurement psychologically reconstruct themselves following a traumatic accident or illness? A narrative analysis

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Abstract

The aim of this study is to explore how individuals with an acquired facial disfigurement (FD), following a traumatic accident or illness, psychologically reconstruct themselves using a narrative analysis. Whilst previous studies on visible difference have employed both quantitative and qualitative based methodologies, there is only a handful of research in the psychological literature that specifically explores the subjective experience of people with *facial cancer* and *facial trauma*. In particular, there is a lack of attention on how this population *reconstruct their internal world* and make sense of their FD. Narrative analysis was used as a way of gaining an insight into the ways that these individuals reconstruct themselves and make meaning of their disfigurement. Thus, a sample size of seven individuals who had acquired a disfigurement either as a result of an accident or facial/oral cancer took part. Participants were interviewed using semi-structured interviews. Findings revealed the following narrative genres: ***'the outsider'***, ***'the helpless prisoner'***, and ***'the wounded survivor'***. In the genre of *'the outsider'*, participants presented themselves as vulnerable and submissive protagonists who were humiliated, persecuted, and ostracised from the rest of society. The genre of *'the outsider'* demonstrates how the consequences of living with a FD and of being a constant victim of social disgrace can leave a profound impact upon one's sense of self and identity. In the genre of *'the helpless prisoner'* protagonists shared their stories of living a restricted life and their stories were characterised by stagnation, helplessness, and a sense of isolation. Finally, in the genre of '*the wounded survivor'*, protagonists portrayed their lives as a series of challenges that provided them with an opportunity for growth, acceptance, and compassion. The findings of this study are put in the context of counselling psychology and clinical implications are discussed.

Chapter 1: Introduction

1.1   Outline of Chapter

This chapter will provide the reader with an overview of appearance-related literature, focusing specifically on facial disfigurement (FD). Importantly, given that counselling psychologists at some point in their professional work will encounter individuals with visible differences; this chapter will contextualise the literature within the field of counselling psychology. A clear definition and description made regarding counselling psychology and its philosophy will therefore be included at the beginning of this chapter. Thereafter, I will detail a conceptual definition of FD. I will then provide an overview of the significance and functions of the human face, followed by a discussion of the advantages of facial beauty, in order to shed some light on the difficulties that people with FD experience as a consequence of living with a face that deviates from the 'norm'. The justification for choosing *acquired* disfigurement over *congenital* will be further explored. Following this, current literature on FD will be examined and critiqued, and the importance and benefits of storytelling in relation to this population will be explored. Finally, this chapter will end with a rationale for the current study, along with the researcher's own story (personal reflexivity).

1.1.1 *A Note on Language*

It would be important to make explicit my position with regard to the actual word 'disfigurement'. I am aware that this word carries with it powerful negative connotations, because it is considered devaluing and stigmatising to the individual. In accordance, a number of writers and researchers in the field, such as Partridge (1999) and Rumsey and Harcourt (2004), suggested using a terminology that is less negatively framed, such as 'visible difference'. For this reason, I felt that it would be an appropriate decision to use both words interchangeably, given that the word 'disfigurement' is widely used in the literature, by the wider public and charities like Changing Faces. When referring to the word disfigurement, like Changing Faces, I

have used the word as a noun rather than as an adjective. For example, instead of writing 'a disfigured face', I have referred to it as a 'face with a disfigurement'.

1.2   Counselling Psychology: Definition and Philosophy

As defined by the British Psychological Society's Division of Counselling Psychology: Professional Practice Guidelines (BPS, 2006):

> "Counselling psychology is a branch of professional psychological practice influenced by the human science research and psychotherapeutic traditions. Counselling psychology draws upon and seeks to develop phenomenological models of practice and enquiry in addition to that of traditional scientific psychology" (p. 1).

Counselling psychology places the *therapeutic relationship* and *therapeutic process* at the forefront of its discipline (James, 2013). Thus, the root philosophy of counselling psychology takes a humanistic valuing base, focusing on subjective and inter-subjectivity, values, beliefs, and meanings (BPS, 2006; James, 2013). Furthermore, Cooper (2009) mentioned that counselling psychology is not only restricted to a set of values, but also the application of these values. These essential values are identified as six principles:

1. Prioritisation of the client's subjective and inter-subjective experiencing.
2. Main focus on the client's growth and actualising tendency.
3. A dedication towards empowering the client.
4. An equal and democratic relationship between therapist and client.
5. An appreciation of the client as unique.
6. An understanding of the client as a socially and relationally embedded being.

Unlike the medical model, which places an emphasis on categorisation, diagnosis and pathology, counselling psychology takes a non-pathological and relational stance towards clients (James, 2013). Traditionally, FD has been a topic of interest and the province of health psychologists and social psychologists. Based on the literature reviewed so far, the researcher noticed a relative absence of FD research in the

counselling psychology literature. One possible explanation could be that counselling psychology, when compared to the other professions, is a relatively novel discipline, which was officially recognised by the British Psychological Society in 1994 (Corrie & Callahan, 2000). Since then, research conducted in the area of counselling psychology has focused on relational and process-oriented aspects, not taking into consideration topics associated with the 'clinical' or 'medical' field. In fact, Martin (2011) noted that most articles in the counselling psychology research appeared to be small-scale exploration studies of trainee or therapist experiences, discussion or theoretical topics. Undoubtedly, FD is a topic that has much relevance to the field of counselling psychology. People who live with a visible difference are most likely to experience psychological (depression, anxiety, PTSD, low self-esteem, grief), intra-personal and interpersonal difficulties. Moreover, given that counselling psychology places a high value on the therapeutic relationship, deals with a wide range of mental health problems, and works with the subjectivity and inter-subjectivity of individuals, it is legitimate to state that it has important and valuable contributions to make to the field.

1.3   Definition of Facial Disfigurement

Changing Faces, the charity, defines disfigurement as constituting "aesthetic effects of a facial mark, rash, scar or skin graft on a person's skin, lack of symmetry or paralysis to their face or body". It is, however, important to note that not everybody with these descriptions would consider themselves as having a disfigurement (Henry, 2007). Harcourt and Rumsey (2005) defined disfigurement as "difference from a culturally defined norm which is visible to others" (p. 88). In this paper, I shall focus on individuals with *acquired* FD whose appearances have traumatically and suddenly changed. This type of disfigurement is caused as a result of trauma, such as burn injuries, violent attacks, road and traffic injuries, the aftermath of a cosmetic surgery, or the result of an illness diagnosis, for example, cancer or skin diseases.

1.3.1 'Severity' of Facial Disfigurement

A number of scholars in the field (Rumsey & Harcourt, 2005; Bradbury, 1996; Millstone, 2008; Robinson, Rumsey, & Partridge, 1996) have found that there is no direct relationship between size or severity of disfigurement and psychological distress. Interestingly, a cross-sectional survey by Rumsey, Clarke, White, Wyn-Williams and Garlick (2004) revealed that those with the least visible disfigurement displayed higher levels of anxiety, and those with 'minor' injuries displayed higher levels of depression and social anxiety. Tebble, Adams, Thomas, and Price (2006), found that patients with facial lacerations (deep cut) experienced significant levels of self-consciousness and anxiety. Therefore, there appears to be no empirical evidence to support the fact that individuals with a 'severe' disfigurement suffer higher levels of psychological distress compared to those with 'minor' visible difference (Robinson, 1997 as cited in Rumsey et al., 2004). For the purpose of this study, the author will not employ words such as 'minor' or 'severe' when referring to participants' disfigurement. It is considered that this form of language denies the subjective and emotional impact the disfigurement may have on the individual (Henry, 2007), because what might be perceived as a 'severe' disfigurement to one person may not be perceived as such by another (Rumsey & Harcourt, 2008).

1.3.2 Significance of the Human Face

The human face is the most noticeable body part. It is the place of recognition and communication, which conveys emotions and expressions to the world around us (De Sousa, 2008). Callahan (2004, p. 75) explained that the face is distinctive from the rest of our body because "it is our presentation to the world". After all, it is through the face that beauty and attractiveness are perceived (Furness, Garrud, Faulder, & Swift, 2006), and it is connected to our sense of identity and relationship with others (Callahan, 2004; Rumsey & Harcourt, 2004). Each part of the human body holds a 'literal' and 'symbolic' significance and function, according to Bard and Sutherland (1955) and Sutherland (1959, as cited in Callahan, 2004, p. 74-75). They stated that the arm signifies strength and capability, the hand suggests creativity, expression and the ability to provide, and our legs stand for speed, vitality, and ability. Our

"reproductive organs signify not only pleasure and intimacy but also ability to procreate, nourish and pass on a legacy through one's progeny". For the same reason, we may see that each aspect of our face has a function in itself (Callahan, 2004). The eyes communicate insight and understanding, and through which we are able to establish interpersonal relationships. The mouth signifies a wide range of emotions, and our voice functions as a tool for verbal communication. With reference to self and ego, the face communicates ideas, self-awareness, perception, and emotions. The face also reflects self-esteem and self-concept (Callahan, 2004). Therefore, acquiring a disfigurement to the face may result in a profound adjustment to self and identity.

1.3.3 Advantages of beauty

We live in a society that places an enormous focus on beauty and attractiveness (Masnari et al., 2012). In fact, this preoccupation is so profound that people with no facial deficits use cosmetic and plastic surgery to enhance their beauty. Everywhere we go, we are reminded of and exposed to the importance of beauty, which is communicated in magazines, billboard ads, and television screens that are filled with attractive male and female faces. Interestingly, Bates and Cleese (2001 as cited in Rumsey & Harcourt, 2005) found that various disciplines, including Greek philosophy, evolutionary biology, and mathematical proportions, suggested that there is a tendency for an inherent pleasure towards symmetrical faces, also referred to as *the golden mean*, which constitute delicate or baby-like features (small nose, large lips and eyes). Darwin's theory of evolution has pointed out that nature only accepts the best, the fittest, and the most beautiful (Johnstone & Oliver-Rodriguez, 1997). Other scholars, such as Armstrong (2004), argued that beauty cannot simply be explained by such theories or mathematical concepts; rather, they argued that standards of beauty and attractiveness are socially constructed; in other words, humans come to learn what is attractive and what is not through culturally presented ideas, and this has led to a belief that different cultures view beauty and attractiveness differently (Little, Jones, & De Bruine, 2011). Meanwhile, others have found that what constitutes beauty is a combination of several factors, such as averageness, symmetry, sexual dimorphism, delicate grooming, and youthfulness, as

well as a pleasant expression (Rhodes & Zhebrowitz, 2002; Thornhill & Gangestad, 1999).

Regardless of these arguments, throughout history, humans have always gravitated towards that which is beautiful and attractive, and they have associated beauty with positive qualities for centuries, dating back to the ancient Greeks (Van Leeuwen & Macrae, 2004). To mention, a great number of scholars (Dion, Berscheid, & Walter, 1972; Langlois, Roggman, & Rieser-Danner, 1990; Langlois et al. 2000; Eagly, Ashmore, Makhijani, & Longo, 1991) have found that physical attractiveness results in positive social consequences, supporting the hypothesis that "what is beautiful is good". For example, Dion et al. (1972) found that physically attractive people are perceived by others to possess desirable personal characteristics, such as being more successful, happy, wealthy, and intelligent. Langlois et al. (1990) showed that even infants display both visual and behavioural preferences for attractive faces. Other researchers (Eagly et al., 1991) found that people with unattractive faces were perceived as lacking in social skills and perceived to be less intelligent and emotionally unstable. Attractive people are also more successful at mock interviews and more likely to be hired than unattractive people (Cash & Kilcullen, 1985). In addition, it has been found that people in general avoid sitting next to people with a FD when travelling on trams (Houston & Bull, 1994). These findings are altogether consistent with the idea that facially unattractive people are discriminated against and perceived in a negative light by the wider public. Millstone (2008), who further expanded on the myths of ugliness and evil, stated that people commonly equate FD with a damaged personality. She noted how the media, including the film industry and fairy tales, depict the 'bad' characters with disfigurement. For example, Simba's uncle Scar in *The Lion King* was depicted as the main antagonist and had a scar next to his eye. Frankenstein's monster was equally depicted as an evil character based on his overall appearance and FD, and despite his gentle and kind nature, he was a constant source of hatred, disgust, and rejection. One may conclude that the exposure of negative images by the media inadvertently influences the way people with a FD are viewed (Millstone, 2008).

1.3.4 Incidence and Prevalence of Facial Disfigurement in the UK

Julian and Partridge (2007), on behalf of Changing Faces, carried out a thorough search in the form of existing studies, data, and websites in order to establish an accurate estimate of the prevalence and incidents of FD. Their search showed that, currently, there are over one million people (1,350,000) in the UK who suffer a disfigurement to their face or body. Out of these, 542,000 people, that is, one in 111, suffer a disfigurement to their face. Their survey showed that roughly 415,500 people are expected to acquire FD; some of these will remain temporary, whilst some are life threatening. However, a more recent estimate of these numbers is needed as this survey was conducted roughly 8 years ago. Also, there appears to be no mention of what year's consensus population these estimates were based on, and it is therefore difficult to know what the exact figures are.

The increasing need for qualified counselling psychologists with unique training in FD in various burn/cancer units/dermatology clinics are of vital importance. Moore, Chamberlain, and Khuri (2004) demonstrated that head and neck cancer (HNC) participants in their study reported that they had "nowhere to go" and "no one who could understand" their existential concerns and suffering. Similarly, Williams, Davey, and Clock-Powell (2003) reported that burn survivors in their study had never, prior to the research interview, been offered the opportunity to share their stories in that much 'depth'.

1.3.5 Why not include *congenital* Facial Disfigurement?

The decision to exclude congenital disfigurement in this paper was based on the knowledge that those individuals whose appearances had been changed as a result of a trauma or illness underwent a different psychological process as opposed to those who were born with a visible difference. It has, however, been suggested that those who acquire a FD, such as facial cancer, have more difficulty in processing the shock and adjusting to their self-image compared to someone who was born with a FD and has come to regard this as part of their self (Koster & Bergsma, 1990; David & Barrit, 1979). Bradbury (2012) asserted that individuals who live with a congenital

disfigurement have grown up with a different face and, as a result, may have to cope with a fundamental sense of flaw or difference. Also, those who were born with a congenital FD are from very early on subjected to constant bullying and isolation, and as infants are more prone to encounter negative stares from adults (Bradbury & Hewson, 1994). As a consequence, they are likely to experience a sense of shame and lack of a robust ego development early on in life. In contrast, individuals with acquired FD experience a normal early development, but they are later faced with a loss of sense of self and identity, along with the stigma of looking different (Versnel, Duivenvoorden, Passchier, & Mathijssen, 2010). For this reason, because the latter group had experienced a normal development, it was the psychological reconstruction process of this particular population that was of main interest to the researcher.

1.3.6 Acquired Facial Disfigurement

Individuals who acquire a disfigurement to their face as a result of an accident or illness are confronted with a number of social and emotional problems (Thompson & Kent, 2001). Namely, they have to cope with feelings of loss and grief towards their former appearance (Harcourt & Rumsey, 2008), as well as having to adjust to a new appearance (Rumsey & Harcourt, 2004). In addition, some of these individuals may experience a profound disturbance to their self-concept and identity (Harcourt & Rumsey, 2008; Threader & McCormack, 2015; Gullick, Taggart, Johnston & Ko, 2014). Research that has looked at previously healthy individuals who have acquired a disfigurement to their face, caused by facial lacerations or fractured facial bones, found that when compared with a control population, the affected group displayed significantly lower life satisfaction, higher rates of depression, alcoholism and higher frequency of posttraumatic stress symptoms, and body image problems (Levine, Degutis, Pruzinsky, Shin & Persing, 2005). In addition, participants reported greater marital and occupational problems and more frequent contact with the legal authorities. Rybarczyk and Behel (2002) stated that many patients who acquired a FD caused by trauma, exhibited greater levels of hostility since they perceived their disfigurement to be arbitrary. These feelings in turn resulted in blame or anger, either

towards the self or others, and patients were more prone to idealise their physical appearance to how it was prior to the accident. Whilst the above-mentioned articles highlight some interesting findings with respect to the psychological effects of people with acquired FD, they mainly focus upon psychiatric conditions and adopt quantitative based methodologies. Thus, they fail to offer an insight into the subjective experiences of these individuals.

Gullick et al. (2014) found that people with facial burns, indeed, experienced the highest degree of emotional trauma. For example, Partridge and Robinson (1995) noted that burn injury survivors often exhibited intense psychological reactions, which ranged from shock, anxiety, fear, confusion, and depression to euphoria, poor self-image and a loss of independency and autonomy. McLean et al. (2015) discovered that survivors of facial burns, who were inpatients at a hospital in Australia experienced problems with respect to their self-image and developed a troubling relationship with their bodies. However, this perceived relationship with their bodies differed slightly between genders. While female participants explained feeling distraught about an altered face, male participants experienced a heightened consciousness with regards to their bodies in general.

Whilst this study offered useful psychological insight into the subjective experiences of people with FD, the study included 4 males and 2 females. The lack of an even gender distribution restricted additional insight into female experiences. Also, the fact that participants were inpatients should be questioned. Williams and Griffiths (1991) asserted that psychological problems develop years after a burn injury, so this may have restricted insight into other potential psychological problems. In addition, the sample of inpatients may have limited insight into other groups of facial burns. Besides, the focus of this study was on the 'lived experience of people with facial burns, and the patient-body relationship'; this study did not explore the psychological reconstruction process of people with FD.

In line with such findings, in their book, Lansdown, Rumsey, Bradbury, Carr and Partridge (1997) presented an account of a male burn survivor who explained how, following his facial burns, he had to rebuild a new self. He described his pre-burn self as carefree, confident and cheerful, but following the accident, he transformed

into an insecure, sad and vulnerable person whose life was suffused with challenges and emotional pain.

The concept of identity change was presented by Threader and McCormack (2015), as they explored the lived experience of nine people with head and neck cancer. They found that, due to a change in facial appearance following a surgery, participants had difficulty in adjusting to a new 'self'. This theme was identified as *'identity struggle'*. Participants found this process rather traumatic given that they were no longer identifiable from their former 'self'. Participants compared changes in their appearance with changes to their personality, and this process prompted them to reassess their identities. As a result, participants became withdrawn and embarrassed to engage with others, thereby isolating themselves from the outside world. On top of this, the negative reaction they received from others proved challenging, and many respondents were confronted with grief and loss due to a changed appearance. Another interesting theme that emerged was the *'change to self: a need to belong'*. As participants reassessed their identities, a new self emerged, and this new self expressed a desire to belong and connect with other stigmatised groups, predominantly, because participants felt they were able to understand and empathise with one another.

Whilst this study provided valuable insights into the internal world of people with HNC, exploring how people with HNC construct their identities was not the main focus of the research. Rather, it explored more broadly the psychological experience of HNC. For example, the research examined questions such as the experience of HNC diagnosis and the role of surgery. Besides, the majority of respondents were males, with the exception of one female respondent.

Patrick et al. (2007) showed that youths who suffered from acquired FD, compared to youths with congenital FD, reported markedly poorer QoL (quality of life) on self-image and negative consequences domain. Lansdown et al.'s (1997) book provided an insight into this phenomenon by sharing the stories of three survivors who acquired a FD in either childhood or teenage years. The first narrator, when reflecting on his teenage years, explained how his joyful, social and outgoing persona changed into a reserved and self-conscious person. As he recalled, the experience of being bullied and teased at school further reinforced in him a sense of

inadequacy. He believed that his inability to excel at school and find a 'high rank' job was due to his feelings of worthlessness and inferiority. In fact, he was incapable of sustaining a healthy and steady relationship with women, which he believed, was partly due to how this accident had shaped his personality. Another narrator, who suffered facial acne in teenage years, wrote how the experience of her face had made her feel unworthy as an adult. She felt ugly and repulsive. Though she was not bullied at school, the few revolting comments she received from acquaintances were enough to negatively affect her sense of self. Consequently, perceptions of her unattractiveness hindered her ability to be intimate with men.

Whilst the aforementioned accounts offer us rich and valuable insight into the lived experiences of people with FD, they are based on anecdotal accounts and thus lack empirical evidence.

It has been reported that negative self-perception in people with facial acne negatively affects their peer acceptance and perceived sexual attractiveness (Magin, Heading, Adam & Pond, 2010). Additionally, O'Brian, Roe, Low, Deryn and Rogers (2012) found that individuals who lived with a romantic partner, and who had acquired a FD caused by cancer, experienced a disruption with reference to their intimate lives. This was mainly due to the changes that were brought upon their personalities. For some, this change was expressed in terms of loss of independence and personal esteem, while for others an altered appearance resulted in a lack of confidence and low self–esteem. A number of scholars in the field of FD have postulated that repeated harmful reaction and remarks directed at people with FD resulted in damaged self-confidence, self-esteem and self-image (Macgregor, 1990; Robinson et al., 1996). To illustrate, the final narrator in Lansdown et al. who had suffered a facial palsy as a child, recalled how the experience of being bullied and teased at school had a detrimental effect on her confidence. The aftermath of these painful experiences left her socially anxious and self-conscious.

Turpin, Dallos, Owen and Thomas (2009) conducted a striking qualitative study, which explored the personal meaning and impact of head and neck cancer survivors. Of specific interest was how it impacted on the self. Ten individuals who had acquired a FD following a surgery were recruited. Interpretative phenomenological analysis was used in conjunction with repertory grid analysis. Repertory grid analysis

involved giving respondents the task to use a set of 'professional constructs' to help them comprehend the way in which they construed or interpreted their world. The five theoretically derived constructs were identified as self-conscious –comfortable, ashamed-proud, attractive-unattractive, valued-worthless and healthy-ill. The grids were analysed using the GRIDCOR.

Four superordinate themes were identified and these were labelled as *'destruction of self'*, *'altered relations with the body'*, *'disenfranchised self'* and *'conservation of self'*. In the first theme, *'destruction of self'*, participants perceived the HNC as an attack on their 'fundamental sense of self' (p. 31). They struggled in coming to terms with a loss of their previous facial appearance and, for the majority of participants, the loss of self moved beyond physical losses, to losses of valued roles. Especially for male participants, the loss of employment had a powerful negative effect on their sense of self and identity. For instance, some male participants described themselves as 'lazy' and 'defunct'. Participants generally viewed themselves as flawed and defected, and their reactions to loss ranged from anger, sadness to suicidal thoughts. The second theme, *'altered relationship with the body'*, reflected changes in ways that participants perceived their bodies, and the negative impact that this had on their self-perception. For example, one participant viewed her distorted appearance so disturbing that she perceived herself as being ugly. In the theme of *'disenfranchised self'*, participants reported being scrutinised by others, which left them with a sense of being exposed. There was a sense that other people's views about them had changed. This transformation eventually made participants feel as if they were imprisoned in a body that was not congruent with their 'true' sense of self. Considering the lack of meaningful social relationships, participants felt that they were insignificant to others. Thus, they were left with a sense of being disenfranchised and not valued by others. Finally, the fourth theme was described as *'conservation of self'*. In this theme, participants attempted to maintain a positive sense of self, for instance, by "constructing valued identities of themselves as survivors" (p.38). However, respondents' narratives reflected a 'pragmatic' sense of acceptance rather than a state of 'acceptance' (p.38) since respondents were "engaged in a process of emotional and cognitive avoidance" (p. 38).

Although the above study produced some very interesting and meaningful themes by combining Interpretative Phenomenological Analysis (IPA) with repertory grid analysis, this study explored the *personal meaning* of HNC for respondents, focusing predominantly on respondents' sense of self. It did not, however, explore changes in how the participants reconstructed their perception of self. This means that the aforementioned study was heavily focused on an 'insider view', whilst at the same time, neglecting to take structural and social factors into account (Willig, 2008). Lastly, this study was limited to a homogenous group of HNC patients and did not include other forms of facial injuries (Turpin et al., 2009).

1.4 Psychosocial impacts of acquired Facial Disfigurement

According to Cash (1990), when people are faced with a disfigurement to their face or body, not only do they have to cope with their own reaction to an altered appearance, but equally other people's reaction to it. Cash explained this process from two overlapping perspectives: 'the view from the inside', focusing on the psychological aspects, such as an individual's self-concept, emotional wellbeing, and quality of life, and 'the view from the outside', concerned with how appearance affects social interactions and interpersonal relationships. Given that counselling psychologists deal with both interpersonal and intrapersonal relationships, it could be argued that they are well placed to work with this population group (BPS, 2011). In the section that follows, a further exploration of each of these perspectives will be examined in order to gain some insight into and understanding of these two strands.

1.4.1 Social impacts of acquired Facial Disfigurement

Research into facial disfigurement has documented the ubiquitous existence of social distress in this particular population group (Rumsey & Harcourt, 2008). An extensive number of studies have confirmed that individuals who live with a disfigurement experience difficulties in social interactions (Jowett & Ryan, 1985; Lanigan & Cotterill, 1989; Porter, Boeuf, Lerner & Northund, 1986, 1987, 1990). One of the most common problems includes feeling stigmatised, being confronted

with aggressive and negative behaviour, rejection, and feelings of exclusion. These reactions altogether are likely to leave the individual in a place of psychological distress and isolation (Clarke, 1999; Vardy et al., 2002; Tebble, Thomas, & Price 2004). To date, society has always judged people with visible differences negatively, and this can be found in a great number of sources, for example, myths, folklore, legends, and history (Valente, 2004).

In order to understand the views and perceptions of the wider public towards FD, researchers used actors and altered their appearances so that they looked visibly different; findings showed that people stood further away from people with a visible difference and offered them less help, and generally viewed them as less desirable (Bull & Stevens, 1981; Rumsey, Bull & Gahagan, 1982). To find out more about the social consequences of FD, Koster and Bergsma (1990) showed that cancer patients, following an alteration to their face, encountered the greatest problem in the interpersonal sphere, specifically in reference to intimate relationships and superficial encounters with strangers. Similarly, Timms (2013) concluded that moderate visible acne could very well prevent people from establishing social relationships, not as a result of social anxiety, but as a consequence of the stigma and prejudice that are directed towards them. As Papadopoulos, Bor, and Legg (1999; Papadopoulos, Bor, Walker, Flaxman & Legg, 2002; Thompson, Clarke, Newell, & Gawkrodger, 2010) further pointed out, people who suffer from skin-related conditions, such as vitiligo, are equally confronted with the stigma of looking different, thus affecting their interpersonal relationships and social behaviour.

Further evidence has demonstrated that burn survivors experience interpersonal difficulties as a result of looking visibly different. Rahzani, Taleghani, and Nikbakht-Nasrabadi (2009) carried out a qualitative research using grounded theory in order to examine the psychosocial aspects of burn survivors with FD. Participants reported being confronted with negative reaction, avoidance, reproach, and disgust, which often resulted in isolation and avoidance of social contact. Van den Elzen et al. (2012) further stated that although avoidance behaviour in people with FD led to a decrease in stress levels, it also resulted in restricted social behaviour and less interpersonal contact with others. In fact, a recurrent theme apparent amongst patients with FD caused by oral cancer, as shown in Röing, Hirsch and Holmström

(2007) study, was the expressed fear of how they would *'exist in the eyes of the other'*. Similarly, Bonnano and Esmaeli (2012) found that participants with FD caused by cancer perceived their interactions with acquaintances as well as strangers stigmatising. This was expressed in the form of intrusion, sympathy, or benign neglect from either acquaintances or strangers. It was found that benign neglect was the preferred pattern of interaction, where strangers and acquaintances did not pay particular attention to the person's FD. In contrast, sympathy and intrusion appeared to be the most stigmatising patterns of interactions, whilst benign neglect was not considered as such.

Although both studies (Rahzani et al., 2009; Bonnano & Esmaeli, 2012) provide us with an insight into the social processes of people with FD, they do not specifically address what it means for these individuals to live with a FD. Willig (2008) noted that a particular limitation of grounded theory is its focus on social processes, thus neglecting the phenomenology of the research. For the second study (Bonnano & Esmaeli, 2012), it was decided that interviews would be conducted via telephone. However, given that this study was qualitative, it should have preferably been conducted face-to-face in order to retain non-verbal communication, adding richness and value to the data. Thus, it could therefore be said that the study lacked 'ecological validity' (Willig, 2008).

Given that counselling psychologists, regardless of their therapeutic orientation, place a great importance and focus upon the therapeutic relationship, focusing on relational problems (Woolfe, Dryden & Strawbridge, 2003), it would be pertinent that when presented with this client group, they focus on facilitating a trusting, authentic, and non-judgmental atmosphere in which their clients come to feel accepted and valued at all times (Rogers, 1957; Henry, 2007).

1.4.2 Psychological impacts of acquired Facial Disfigurement

The face is the most visible body part through which we express our emotions and personality; it is also the seat where our identities can be confirmed and recognised (Jaspal, 2012; Callahan, 2004). Because of this, individuals who acquire a

disfigurement to their face are prone to developing profound psychological problems (Rumsey & Harcourt; 2004; Rumsey, Clarke & White, 2003; Robinson et al, 1996; Tebble et al., 2006; Callahan, 2004). Adsett (1963) stated that individuals who acquire a FD are faced with a loss of physical parts and cherished life activities. He believed that these losses contribute to depressive reactions and, at times, even denial associated with bravado behaviour. According to the author, depressive reactions could therefore be described as self-directed, inward-turning anger. That is, individuals who have suffered disfigurement may begrudge their body for a perceived failure of the body to maintain its integrity, upset that the body has forsaken them (Adsett, 1963).

Magin, Adams, Heading, Pond and Smith (2006) found that psychological problems affecting people with acne were clearly linked to their self-image and self-esteem. The researchers found that impairment in self-image contributed to low self-esteem and lack of confidence. For example, one particular respondent expressed how acne had come to define her, and another respondent described that living with acne had made him feel 'unworthy' and 'unacceptable' as a human being. In addition, respondents expressed embarrassment and self-consciousness. These feelings were closely related to their self-image and self-esteem. In addition, some participants expressed that acne had negatively and permanently affected their personalities. These were manifested in avoidant behaviour and social phobia.

In his book, Pattison (2013) discussed the role of shame in the context of FD. He stated that a sense of shame originates out of a relational dynamic, based on the way in which the affected internalises the gaze of the other. Considering that it is through the face that we express our sense of self and identity, the role of shame then becomes a significant factor (Pattison, 2013). To expand on the concept of shame, the author shared a case study of a young woman, named Lucy, who from early childhood acquired cancer of the jaw, Ewing's sarcoma. For Lucy, a sense of shame dominated most of her life. From the earliest of days, until adulthood, she felt persecuted by the stigma and negative reactions of others, which evoked in her a terrible sense of shame. Lucy grew up thinking that she was unworthy of love and attention, and thus began to internalise the negative responses of others. Moreover, Lucy felt so ashamed of herself that she believed other people were within their

rights to tease and bully her. These events led Lucy to engage in an 'attack self' mode, in order to protect herself from getting hurt. Pattison (2013) believed that this form of coping mechanism was adopted by the victim as a way of exerting control of his or her own abuse. Lucy adopted religion as an alternative coping strategy. Praying, she hoped to forgive those who had wronged her. Through the process of prayer she disassociated herself from a painful reality (Pattison, 2013).

Callahan (2004) stated that patients with HNC are confronted with an overwhelming sense of loss because they experience a threat to self. This threat appears to be inevitable, as the individual, over their entire lifetime, has familiarised themselves with and come to know their face as it was (Callahan, 2004; Jaspal, 2012). In a recent article, Jaspal (2012) argued that individuals who do not receive appropriate levels of self-esteem, distinctiveness, continuity, self-efficacy, meaning, belonging, and coherence are prone to experience a threat to identity, which is often the case in individuals with FD (Jaspal, 2012). Other researchers have found that some of the most common psychological problems found amongst patients with various types of skin conditions included social anxiety, low self-esteem, depression, suicide, shame, and embarrassment (Benrud-Larson et al., 2003; Koster & Bergsma, 1990). Furthermore, Koster and Bergsma (1990), when studying individuals with facial cancer, found that the negative reactions of others to FD, along with the person's own ideas of their appearance, caused a violation to both their self-image and sense of security.

Murray and Rhodes (2005) explored the experiences, concerns, and perspectives of individuals with visible acne. Semi-structured interviews were conducted with 11 adults who lived with visible acne. Interpretative Phenomenological Analysis (IPA) was used as a method of choice in order to best access the feelings and internal worlds of the participants. Their analysis produced the following emergent themes: powerlessness with regard to their facial acne; comparisons, self-image, and identity. It was found that the theme of powerlessness was related to participants' inability to control their acne condition, thus preventing them from improving their situation. In terms of participants' self-image and identity, analysis showed that respondents' general outlook and behaviour was dependent upon how severe and progressive their acne appeared to be. In fact, Bull and Rumsey (1988) asserted that people who live

with a FD are faced with a sense of powerlessness and helplessness due to lack of a sense of control over their environment. Participants expressed a tendency to compare themselves with others, and with themselves, to how they looked before the acne. It is believed that such process of personal and social comparisons allowed respondents to evaluate their state of happiness and self-worth. Generally, respondents perceived themselves as less worthy when comparing themselves to others. Furthermore, acne contributed to negative psychological reactions in respondents, such as, depression, anger, frustration, and suicidal thoughts. The analysis revealed that participants' lack of self-esteem, confidence, and self-worth made them feel undeserving of love and attention. Due to such an internal sense of insecurity, participants experienced problems in their sexual and romantic relationships and, in many instances, acne led to relationship breakdown, and the prevention of forming new relationships.

Although Murray and Rhodes's (2005) study seemed promising, it is bound by limitations. Firstly, the interviews were conducted via email, in which there was an exchange of two emails over a period of six to eight weeks. It is therefore likely that each participant's response (psychic reality) did not reflect the 'here and now' experience; rather, they may have been dependent upon the progression of their acne condition or other negative life events affecting them at that time. Secondly, this style of interviewing led to a loss of valuable non-verbal communication, thus leaving out some rich and nuanced data that could have otherwise been useful to acknowledge if carried out face-to-face (Selwyn & Robson, 1998). Significantly, this study did not explore the ways these individuals make sense of and reconstruct their internal world.

Newell (2000) found that individuals with FD (either congenital or acquired) were at an increased risk of developing psychological distress, especially anxiety and depression. It has been established that the negative evaluation of the wider public puts this group at an increased risk of psychological morbidity, particularly social phobia (Newell & Marks, 2000). Newell and Marks (2000) showed that participants with FD displayed the same degree of social phobia as patients diagnosed with social phobia, but were less agoraphobic and more socially phobic than patients with agoraphobia. In fact, participants in Rahzani et al.'s (2009) study whose family

members and friends avoided them due to their FD, suffered a range of psychological problems such as sorrow, shame, fear of being rejected, hatred, and hopelessness.

The degree between body location and visibility of facial acne in relation to psychological distress was discussed by Papadopoulos, Walker, Aitken, and Bor (2000). Researchers assigned participants to three different experiential groups consisting of 107 participants with facial acne, 25 who had truncal acne and 65 who had a combination of facial/truncal acne. Participants were then asked to complete the adult version of the Coopersmith Self-Esteem Inventory (SEI), along with the Situation Inventory of Body Image Dysphoria Questionnaire (SIBID). Results indicated that those individuals who lived with acne vulgaris reported significantly poorer self-esteem and body image than the control group. In turn, it was also found that participants with facial acne reported poorer self-esteem and body image than individuals in the truncal acne group. Thus, this study informs us of how delicate and important the face is, because, as Callahan (2004) wrote, the face is simply "our presentation to the world" (p. 75).

Nevertheless, it is difficult to state exactly whether participants' low self-esteem was due to their facial acne or other factors as there was no indication of psychological screening prior to the start of this study in order to weed out those participants who had personal experience of mental illness. Importantly, this study did not explore the subjective accounts and experiences of participants. This is extremely important, because a deeper and more insightful appreciation of the psychological process of this population may allow counselling psychologists to provide appropriate methods of therapeutic intervention and support (Harcourt & Rumsey, 2008).

1.5   Positive adjustment to visible difference

Research focusing on the negative experiences of visible difference has been widely recognised, but little focus has been placed upon positive adjustment and coping (Egan, Harcourt, & Rumsey, 2011; Eiserman, 2001). This is an important point because a holistic understanding, as opposed to a focus on distress and suffering, may provide us with a greater understanding of the wide range of emotional responses which may have previously gone unrecognised (Eiserman, 2001). Given

that counselling psychology is unique in its focus on the wellbeing, subjectivity, and personal development (Woolfe et al., 2003), positive outcomes of FD can enable counselling psychologists to learn new skills and coping strategies from their clients and, as such, implement them in their therapeutic work. For this to happen, a shift towards resilience, as opposed to 'defect', is needed (Partridge, 1999; Eiserman, 2001).

Egan et al. (2011), three health psychologists, found that not everybody who has a disfigurement experiences psychological distress. Individual and group interviews were carried out with a wide range of visible differences in order to explore the experiences of people who reported having adjusted positively following a visible difference. Participants reported becoming more resilient and understanding towards others and life; the emotional support and input from their families enabled them to hold a more positive and accepting attitude towards themselves, which gave them the strength to move on. Interestingly, Eiserman (2001) conducted a pilot study on the positive outcomes of facial difference. He found that a considerable number of participants reported that they would not remove their facial difference if they were given a chance to do so, since this would mean losing aspects of themselves, which they found positive.

Studies concerning burn injuries have mostly focused upon clinical features of the injured, such as etiological and epidemiological management (Lau & Van Niekerk, 2011; Van Loey & Van Son, 2003). One danger to this, according to Bendelow (2006), is that when such medicalised discourses are used, they prevent any possibility for the subjective and emotional experiences of individuals to be expressed. In order to acknowledge the subjective and emotional experiences of people with burn injuries, Lau and Van Niekerk (2011) adopted a narrative analysis as a way of exploring how young burn survivors' experiences of injuries led to a reconstruction of self and a shift in their thinking about others and the world (for more, see Hunter et al., 2013).

Although participants' stories revealed the need for acceptance, heightened self-awareness, and an increased need for recognition, their accounts also reflected counter-narratives of expressed positive emotional and psycho-spiritual growth and rebirth of the self, thus reflecting a positive, transformative, and resilient aspect of

their healing process. Williams et al. (2003) explored the narratives of recovery, adaptation, and resiliency amongst burn survivors and they found that although respondents' accounts contained themes of loss, anger, and depression, some of the participants expressed that their faith and belief in religion helped them to cope and gain further strength, whilst others had experienced a spiritual awakening following their burn injury. In addition, participants believed that helping others and giving back was an important facet in their healing process. Interestingly, in comparison to their male counterparts, women reported that they were able to perceive the adversity as something valuable. For example, many of them reported how their burn injuries led to personal growth, such as insight, self-esteem, gratitude, and identity. Threader and McCormack's (2015) study showed that as participants, due to their HNC, struggled in understanding their new self, they developed a greater sense of compassion and understanding for other people.

Gilboa (2001) noted that in terms of positive adjustment to visible difference, it is not so much size or the severity of the disfigurement that determines whether someone adjusts positively; rather, it is the individual's personality that governs their adjustment and coping. This finding was demonstrated by Gilboa, Bisk, Montag and Tsur (1999), who found that positive adjustment and coping was related to an extrovert personality trait, along with attitudes such as hope, optimism, and self-control (self-efficacy) (Hagedorn & Molleman, 2006), whereas those with a neuroticism trait, low self-esteem, and social anxiety coped negatively in relation to their adjustment. There has also been evidence to suggest that resiliency can foster posttraumatic growth, because resilient people tend to be optimistic, open to new experiences, curious, and show a high level of positive emotions, such as humour and relaxation (Askay & Magyar-Russell, 2009).

Nonetheless, it should be noted that Lau and Van Nierkerk's (2011) were not explicit about what areas of participants' bodies were affected, as a disfigurement to the face as opposed to the hand may impact the individual's sense of self and identity differently (Koster & Bergsma, 1990). For example, Papadopoulos et al. (2000) showed that people with facial acne reported poorer self-esteem and negative body image than people with truncal acne. Moreover, it should be noted that Lau and Niekerk's (2011) study mainly focused on younger adults, ranging from age 14-20,

with the eldest being 24. Despite some of these limitations addressed in the above studies, nevertheless, they show that some people cope and adjust remarkably well.

1.6   Gender and visible difference

It is generally believed that women who acquire a facial difference exhibit greater psychological distress, because they place higher value on facial beauty and attractiveness (Katz, Irish, Devins, Rodin & Gullane, 2003). This, in part, is due to the enormous pressure that society directs at women to look 'beautiful' and flawless (Katz et al., 2003). Yet, other researchers have found that this is not necessarily the case. Bradbury (1996 as cited in Bradbury, 2012) noted that clinical practice has, in fact, shown that boys and young men are deeply affected by their disfigurement, reporting being more prone to bullying, feeling different from others, physically weaker, and appearing less attractive to girls. However, when studying the relationship between disfigurement, gender, and social and psychosocial adjustment in patients with HNC patients, Katz et al. (2003) found that, although there was generally a high level of satisfaction and adjustment amongst all participants, women were more likely to report higher depressive symptoms and lower life happiness than their male counterparts. Moreover, women were also more likely than men to benefit from social support, whereas this was not the case for men.

Borimnejad, Parsa-Yekta, Nikbakht-Nasrabadi, & Firooz (2006) compared gender differences between male and female patients living with vitiligo in Iran. Their sample size consisted of 53 females and 24 males, and results indicated that female participants showed a greater degree of impairment in quality of life compared to their male counterparts. Generally, women reported less satisfaction in interpersonal relationships, social interactions, and sexual activity than did the male participants. Nevertheless, the findings of this study need to be treated with caution, considering that the male sample size was notably lower than that of the females. Perhaps an even distribution of the genders may have produced different results (Borimnejad et al., 2006). This study was restricted to a Muslim country with a different set of cultural values and beliefs, and attitudes towards visible difference may therefore vary (Borimnejad et al., 2006). Moreover, in evaluating the impact of social

interaction skills for individuals with FD, Robinson et al. found that women displayed significant higher depression scores than men but similar levels of anxiety, social avoidance, and distress.

Additionally, it has been found that men are less likely than women to use camouflage in order to cover their FD (Lanigan & Cotterill, 1989). One explanation for this, according to Robinson et al. is that men are able to adopt more effective coping strategies, which allows them to adjust more positively. Another explanation could be that although men are affected by their appearances, they suppress these very feelings in order to avoid appearing 'weak' (Robinson et al., 1996). It could be suggested that these men may equally feel ashamed for caring or worrying about their appearance. Mahalik, Good, and Carlson (2003) wrote that showing a lack of emotion is indeed part of the 'strong-and-silent' and 'tough-guy' masculine script, which depicts men as fearless, domineering, in control of emotions, and stoic. Thus, this may have implications for the counselling psychologist, in that they need to remain aware of the fact that men may not seek therapy for their FD, based on the belief that they would appear 'weak'.

Altogether, currently, there seems to be a paucity of research to support these clinical findings, and research specifically exploring FD in relation to gender appears to be scarce, especially with regard to qualitative-based methodologies. Further research in this area is therefore warranted, as this would allow counselling psychologists a greater appreciation and awareness of the ways that different genders cope and make sense of their FD.

1.7   Cultural views and visible difference

Considering that most appearance-related literature has been carried out in the Western world, there is currently a lack of research investigating the perception of various cultural and ethnic groups towards people with visible difference (Hughes et al., 2009; Mattoo, Handa, Kaur, Gupta & Malhotra, 2001). According to Hughes et al. (2009), the issue of disfigurement, stigma, and shame may be closely associated with cultural expectations of beauty. It is believed that religion may have a powerful

impact upon personal beliefs, attitudes, and perceptions related to healthcare (Hughes et al., 2009). In order to find out more about this phenomenon, Hughes et al. explored the attitudes and views of British South Asian communities in the UK towards people with disfigurement. A total of 63 participants were recruited from various community settings, coming from Bangladeshi, Indian, and Pakistani backgrounds, with different religious beliefs, such as Muslim, Sikh, and Hindu.

Participants gave various descriptions and definitions relating to disfigurement. Some participants referred to disfigurement as 'ugly' and perceived disfigurement to involve minor 'deformity' in shape, colour, or features of the person's face. Respondents spoke of how within their culture, flawless fair skin, a small nose, and big, beautiful eyes are highly valued. Some respondents associated disfigurement with mental illness and a bad character. Respondents explained that the origins of disfigurement stemmed from cultural myths and religious beliefs. For example, some respondents considered disfigurement as being the result of a sin, whilst others accepted it as the creation of God. Cultural beliefs were reflective in respondents' accounts, for example, the belief that sexual encounters during pregnancy resulted in a disfigurement, or that disfigurement could be the consequence of bad deeds. Furthermore, participants spoke of how disfigurement resulted in families feeling ashamed of the person affected and how efforts were made to hide the person. Girls were perceived to be less fortunate when affected by a disfigurement since this impacted their future prospect of getting married, whereas, for boys, there was much more tolerance and acceptance. In terms of social and emotional reactions, some respondents reported that they would be shocked and frightened when approached by someone with a disfigurement, whilst others reported a sense of sympathy and pity. Social exposure of people with disfigurement remained limited as families attempted to protect them as well as escaping feelings of shame. It was also believed that disfigurement hindered the person from applying for jobs due to discrimination. The only place in which visibly different individuals were accepted was within religious ceremonies and gatherings.

Although Hughes et al.'s study generated some very interesting results, it has limitations. The interviews were conducted in a language other than English and, therefore, it is likely that the interpretation of the actual discussions and notes may

have not accurately reflected the experiences of the respondents when translated into English (Hughes et al., 2009). In addition, facilitators did not tape-record the interviews as they viewed this approach as culturally sensitive. Such an approach may have very well contributed to a lack of rigour (Hughes et al., 2009). Importantly, this study did not include people who had personal experiences of visible difference; such an approach may have inevitably produced a richer insight into participants' subjective worlds.

Papadopoulos et al. (2002), a team of health and counselling psychologists reported that the Indian and Pakistani group who suffered from vitiligo, compared to the Caucasian and Afro-Caribbean with vitiligo, appeared more negative about their skin condition and reported a greater degree of dissatisfaction in quality of life. Participants similarly reported that 'other people' believed that suffering from vitiligo was a response to 'karmic punishment'.

1.8   Adaptive and maladaptive coping strategies

Living with a visible difference may pose a great psychological challenge to many people, and in order to protect the self, and maintain self-esteem (Kent & Keohane, 2001), one may engage in various types of coping strategies. It has been found that some of the most common coping strategies adopted by people with visible difference include avoidance and withdrawal (Newell & Marks, 2000; Kondo & Yamazaki, 2005).

Newell (2000) presented a model based on the hypothesis that psychological difficulties in people with FD originate out of a fear of the changed body and the reaction of others. Part of this fear, he suggested, was related to the sociocultural norms associated with body image, which, in turn, exacerbated negative feelings about one's disfigurement. In essence, what perpetuates psychological difficulties in people with FD is the fear of how they will be perceived, as opposed to their actual appearance. Newell (2000) proposed that individuals who manage to adapt positively to their disfigurement and reintegrate into society are people who can deal with a series of confrontations of their disfiguring part into society and, as such, are able to

develop more adaptive coping strategies. He believed that confrontation led to social integration, whereas fear resulted in social isolation. It has, however, been suggested that these forms of coping strategies are maladaptive and leave a negative effect on the psychological wellbeing of those affected (Kondo & Yamazaki, 2005), and likely to inhibit the development of more positive coping strategies (Kent, 2000).

Literature has found that acceptance coping is an important element in the development of PTG (posttraumatic growth) (Askay & Magyar-Russell, 2009). It is generally believed that that those who can accept that the traumatic accident occurred or, in this case, their disfigurement, and that it cannot be changed, are able to shift their energy towards aspects of the situations that they instead can control (Askay & Magyar-Russell, 2009). Interestingly, Magin et al. (2006), when conducting a study on individuals with acne vulgaris, found that a sense of internal locus of control and self-efficacy diminished psychological difficulties in respondents. For example, support from friends and family along with self-control measures, such as camouflaging, dietary manipulation, exposure to sun, the use of salt water and face washing, all had positive impact on participants, for the reason that these self-help measures were within participants' control (Magin et al., 2006).

Coping is a term that describes various strategies a person can adopt in order to manage stressors, which constitute cognitive, behavioural, and emotional aspects (Krishna, 2009). The current most widely accepted model to explain the way humans cope with stressors is known as Lazarus Transactional Theory (Lazarus & Folkman, 1984 as cited in Krishna, 2009). This model constitutes a 'problem-focused strategy', 'emotion-focused strategy', and 'appraisal-focused strategy'. In the problem-focused strategy, the person may go as far as to confront those who ridicule and stare at them. For example, in a study by Moss, Byron-Daniel, and Walsh (2011), it was found that those participants who were less well-adjusted displayed greater sensitivity to the verbal or behavioural attacks of others and were therefore more likely to respond in a hostile and aggressive manner. Though most health professionals would consider aggression and confrontation as maladaptive and unhelpful, this seemed not to be the case for some participants in Thompson and Broom's (2009) study, who reported that such a coping style enabled them to regain their social status since this allowed them to deal with the humiliating behaviours of

others. Furthermore, participants in Thompson, Kent, and Smith (2002) engaged in a variety of maladaptive behavioural coping strategies, such as avoidance and escape. Some participants even described using camouflage in order to disguise their disfigurement. The emotion-focused strategy includes activities such as distracting oneself. Egan et al. found that, in their study, participants who reported adjusting positively to visible differences adopted various coping strategies such as distraction (going for a run), watching a movie, and focusing on other aspects of their body rather than just their disfigurement. The appraisal-focused strategy occurs when the person employs defence mechanisms such as denial or detachment (Krishna, 2009). However, this may not benefit the individual in the long term as it prevents the individual from confronting their FD and processing what has been lost, thus delaying the healing process (Krishna, 2009).

Robinson et al. argued that focusing on maladaptive coping strategies is ineffective; instead, they advocated for an emphasis on more adaptive strategies. For instance, participants in the Egan et al. study reported that they were able to cope positively because they had learnt to 'confront and embrace' the difficulties presented to them whilst, for others, finding faith and spirituality helped them cope more effectively. Another positive coping strategy used was 'cognitive reframing', where participants described trying to 'see the bigger picture' as opposed to spending time focusing on their disfigurement. Other strategies included humour, positivity, determination, and dealing with things one day at a time. Finally, the use of downward social comparison had a positive effect on participants' self-esteem since this enabled them to compare themselves with others who were 'worse off' (Egan et al., 2011; Thompson & Broom, 2009).

Participants in McLean et al.'s (2015) study who suffered from facial burns expressed that they managed to cope positively following changes to their appearance. This was managed by remaining hopeful about their recovery, resiliency, and positively rationalize about their situation, as well as engaging in purposeful reflection about their lives. Making meaning of their current state was another form of adaptive coping strategy. Importantly, a number of studies (Egan et al., 2011; Thompson & Broom, 2009) reported that the use of social support, such as

talking to others who had experienced similar issues, had been an important factor in their recovery process.

Nevertheless, the findings of these studies raise important implications for the practice of counselling psychology. Given that counselling psychology is distinctive in its focus on "facilitating personal growth and actualization of potential" (Cooper, 2009, p. 120), counselling psychologists would be well placed to work with these issues. Hence, an appreciation of positive adaptive strategies may enable therapists to implement these skills in their therapeutic work and help those who are yet struggling.

1.9   Visible difference and the benefits of storytelling

Storytelling has long been documented by various narrative writers to be relevant for the study of disruptive life events (Crossley, 2000; Riessman, 2000; Frank, 1998). Crossley (2000) talked about the significant value of storytelling on the experience of trauma and illness. A great number of narrative scholars have equally examined the role of storytelling in the context of illness, disruptive life events, and trauma (Carless & Douglas, 2008; Frank, 1995; Papathomas & Lavallee, 2012; Shohet, 2007; Thornhill, Clare, & May, 2004; Thorne & McLean, 2003). One of the main functions of narrative, according to Murray (2003), is that it 'brings order to disorder', and helps the narrator to organise the disorganised and to give it meaning. Murray (2003) wrote that stories "not only bring meaning and order to our lives but also, reflexively, provide structure to our very sense of selfhood" (p. 115). When this sense of selfhood is disrupted in the form of a deep illness or trauma, the value of stories becomes significant because they allow the narrator to engage in a process of 'narrative reconfiguration', creating a sense of order, meaningfulness, and coherent identity (Crossley, 2000). Central to the idea of narrative psychology is the importance of time and temporality, relationships, and connections, and when we are faced with a life-threatening situation or illness, this 'lived' sense of time and identity becomes disordered (Crossley, 2000). The function of narrative is therefore to bring a coherence and meaning to this sense of disruption through the use of storytelling (Murray, 2003). Carless and Douglas (2008) maintained that mental

illness threatens one's sense of self and identity, when one's dominant storyline remains that of illness. In the same way, narratives and storytelling can be beneficial and valuable when working with individuals who have acquired a FD. Surely, acquiring a disfigurement to the face disrupts not only one's 'lived' sense of time but also threatens one's sense of self and identity. As a result, narratives can therefore offer this population an opportunity to create a sense of coherence, order, and connection, also referred to as an "ontological security" (Crossley, 2000).

1.10   Aims and Justification for the Current Study

The literature reviewed so far provides us with an insight and understanding of people who live with various types of FD. Additionally, the articles presented here reviewed both quantitative and qualitative research papers on FD. Presently, there is only a handful of research in the psychological literature that specifically explores the subjective experience of people with *facial cancer* and *facial trauma*. These articles are usually limited to a homogenous sample of FD, for example, including FD caused by cancer only or survivors of burn injury only. In addition, for instances where qualitative studies were identified and explored, they did so at the expense of specifically looking at how people with a diverse range of acquired FD *construct meaning* or make sense of their FD. Importantly, none of these articles were retrieved from counselling psychology journals; rather, they were either carried out by health psychologists or medical professionals. This study will be the first to identify and explore this phenomenon from a counselling psychology perspective.

Thus, it is hoped that this study can provide a more in-depth understanding of the accounts of individuals who have acquired FD adopting a narrative analysis. Of particular interest is how these individuals psychologically reconstruct themselves following a FD. What psychological processes do they experience as a result? Above all, the findings of this study are intended to contribute knowledge and insight to the practice of counselling psychology so that practitioners can increase their knowledge, and improve their clinical work when approached by this clientele.

1.11   The Researcher's Story: Personal Reflexivity

In qualitative research, the investigator is perceived as an important 'instrument' throughout the process, and is therefore required to reflect on how their agenda and internal processes impact upon the research (Haverkamp, 2005; Morrow, 2005). Willig (2008) wrote that researchers need to make explicit their personal experience, or lack of personal experience, in relation to the topic of inquiry, as this will inevitably shape the phenomenon under investigation.

My interest in FD grew as I came into contact with a young man who, several years ago, had been involved in a severe fire accident. Later, he came to be one of my friends, and I got to know him better on a personal level. He would often share his story with me and explain what it felt like to live with an appearance that deviated so much from the norm. In 1998, the city of Gothenburg in Sweden was struck by a catastrophic fire accident that shocked the whole nation and the rest of the world. Sixty-three young people lost their lives in a discotheque fire, and roughly 250 were severely burnt. My friend was one of them. He suffered 90% burns, leaving him with massive disfigurement to the face and body. He underwent hundreds of plastic reconstructive surgeries, and looks as best as he can today. Obviously, this accident changed his life forever, and the psychological consequences of this trauma were immense. In my interactions with him, I often felt very moved by his story and wondered what it must feel like to live with a FD in a society that can be so judgmental and discriminatory towards people with a visible difference. Having embarked on the professional doctorate, I decided to choose FD as my object of inquiry as I felt that the field of counselling psychology has much to learn, and much to contribute to this population.

As evident by now, the reader will recognise that I have no personal experience of FD. Murray (2003) stated that "although the narrator tells the story, the character of the story will depend upon to whom the story is being told; the relationship between the narrator and the audience and the broader social and cultural context" (p. 116). I have carefully considered the fact that I am a young, white Middle Eastern female in my early thirties, who, in the eyes of many, may be considered to have a 'pretty' and symmetrical face. This obviously has implications on the research process in the sense that some of my participants may have been uncomfortable with it at first. I

was particularly aware of this when interviewing young women whom I thought might be vulnerable to these issues, and inevitably be affected by my presence. I wondered whether this could possibly lead to the development of a negative transference, in the form of comparison, envy, and anger. Moreover, I had also reflected upon the fact that I was an academic researcher completing my doctorate, and I considered what this might mean in my encounters with the participants. Undoubtedly, there was an imbalance between the participants and myself: my respondents were in the subordinate position and I was in the position of power. The way in which I managed this was to create a working alliance with my respondents. I aimed to facilitate a space of warmth and acceptance, making my respondents comfortable and safe in sharing their stories with me. I made use of my counselling psychology skills by applying Roger's core conditions in which empathy, unconditional positive regard, and congruence (Rogers, 1961) were expressed at all times throughout the interview process. As a result, the majority of the respondents reported how helpful this process had been in allowing them to talk and make sense of their experiences.

Furthermore, the interviews produced rich and nuanced data of respondents' narratives. As Andrews, Squire, and Tamboukou (2008) noted, research interviews are a relational process between the interviewer and interviewee, whereby the two actively shape the interview process. I acknowledge that the narratives produced in this research are also a product of my own existence, taking into account my personal background, lack of experience with, and knowledge of FD (Riessman, 2008). Having had no previous experience of FD was positive in the sense that I walked into this process with no predetermined knowledge of what it must feel like to live with a visible difference. Instead, I approached my participants with an open mind and unbiased attitude. However, at the same time, I also feel that my personal assumptions about visible difference impacted the research in their own way. Prior to embarking on this object of inquiry, I recall feeling an immense sympathy for this group of people; perhaps we can call it pity, in that I perceived them as helpless victims of their fate. I quickly became aware of these thoughts and managed to bracket them as best as I could by writing them down in my reflective notes. Nevertheless, these presumptions may have unconsciously impacted the research

process, for example, in the manner I probed respondents along with any non-verbal behaviour that I displayed.

After all, carrying this research project, at times, evoked strong feelings in me, such as anger, helplessness, and despair, along with a deep sense of injustice. Upon reflection, I recognise that these feelings were part of a counter-transference process, in which I owned the emotions of my participants. Because of this, I was also aware not to overstep my boundaries in terms of offering my participants therapy. Rather, I allowed them a space in which they could feel 'safe enough' in sharing their stories with me. I hoped that this in itself would provide them with a 'therapeutic' experience. Importantly, the way in which I contained my emotions was to write them down in my reflective diary as well as addressing them in personal therapy. Finally, I would like to mention that the research process, although tedious and difficult at times, was equally rewarding and incredibly insightful. I feel very privileged to have co-constructed these accounts alongside my participants, and my hope is that this research study provides counselling psychologists with a better insight into and knowledge of living with a facial difference. In particular, I hope that this research is able to improve the lives of those who live with a visible difference.

Chapter 2: Methodology

2.1   Introduction

In this chapter, I will address the methodological aspects of this research project, detailing the design of the study, as well as the philosophical and theoretical perspectives that underpin it. I will begin this chapter by discussing the rationale for using a qualitative research paradigm. After this, I will justify the reason for choosing a narrative analysis, and simultaneously discuss the possibilities for alternative qualitative approaches considered at the time. I will then move on to outline my epistemological standpoint and reflexivity, along with the ethical aspects of this study. Finally, I will end this chapter with a thorough explanation of my analytic steps.

The aim of this study is interpretative and explorative, and in order to remain within this frame of reference, a qualitative paradigm was considered so that a small sample size could be selected and analysed in greater depth. I felt that a narrative analysis would allow me to gain a deeper appreciation of the ways individuals construct meaning and make sense of their experiences. Bell (2002) explained that the act of storytelling provides a window of understanding into people's beliefs and experiences. At the same time, it is intended that this research should provide counselling psychologists with an insight and understanding of the common themes and experiences expressed by this client group and, as such, inform the practice of counselling psychology. Furthermore, given the lack of knowledge and research in this area, especially with regard to the use qualitative research, I felt that adopting a narrative study would be a worthwhile contribution.

Throughout the interview procedures, I wanted to offer my participants the opportunity to talk about their experiences in a non-judgmental environment. I felt that sharing their stories with me, and being given a chance to have their voices heard in a contained environment, would hopefully provide a therapeutic experience. This was especially kept in mind as I was dealing with a delicate topic and my aim was therefore to deliver a positive benefit for my participants and act in their best interest (Willig, 2008).

2.2 Justification for Adopting a Qualitative Research Paradigm

Willig (2008) stated that qualitative research is more concerned with the meaning of human experience and seeks to explore how individuals make sense of their world and experience different events. Questions such as 'what' it means to live with a certain condition, or 'how' people cope with different situations, appears to be a central theme. In contrast, quantitative research seeks to acquire knowledge through a formulation of specific questions or hypotheses and then systematically aims to answer those questions; it seeks to identify cause-effect relationships (Willig, 2008; Gravetter & Forzano, 2006). Further to this, the aim of qualitative research is to describe and explain human experiences and events, not to predict outcomes, which quantitative research focuses upon (Willig, 2008). Silverman (2005) asserted that "if we are concerned with exploring people's life histories or everyday behaviour, then qualitative methods may be favoured" (p. 6).

The articles presented in Chapter 1, reviewed both quantitative and qualitative research papers on FD. However, there was a lack of attention on how people with acquired FD *reconstructed* themselves psychologically. Given that the focus of this study was to understand how individuals construct meaning and make sense of their FD, it was decided that a qualitative study would be most appropriate as it aimed to capture the subjective experiences of the phenomenon. I therefore decided that a qualitative (narrative) research would enable me to capture a 'richer' and more subjective data of my chosen topic. Additionally, it has been suggested that qualitative research can give voice to disadvantaged groups whose accounts have been neglected and silenced, and it is my hope that this research can allow the voices of these stigmatised individuals to be heard, and, in turn, offer them a sense of empowerment. In line with this, considering the emotional, sensitive, and personal nature of this topic, I felt that a qualitative methodology would do the participants' stories more justice since this would allow participants to communicate their accounts more meaningfully (Thorpe, 2013).

2.3 Compatibility of Qualitative Research with Counselling Psychology

Given the setting, qualitative researchers are keen to conduct interviews in the presence of their participants, whereupon the interactional processes of both the interviewer and the interviewee will be of interest to the research and its findings, something which quantitative research does not consider (Willig, 2008). There is a common acknowledgement amongst qualitative researchers that the method of data collection and analytic processes underpins subjectivity and reflexivity, both of which are common and crucial aspects within the field of counselling psychology (Morrow, 2005). Personally, as a trainee-counselling psychologist, I recognise that my work in clinical practice involves listening to my clients' narratives and acknowledging and respecting their subjective experiencing through the establishment of a strong therapeutic relationship. For these reasons, I felt that a qualitative methodology would be more congruent with my role as a counselling psychologist as, ultimately, it is concerned with a search for meaning, understanding, and unique individual subjectivity (Woolfe et al., 2003; Rafalin, 2010). The compatibility of qualitative research with counselling psychology has been identified by a number of scholars (Rafalin, 2010; Rennie, 1994; Ponterotto, 2005). Importantly, given that the topic of this research deals with clinical health and illness, I hope that a qualitative research methodology can help to 'bridge the gap' between research and clinical practice (Rennie, 1994).

2.4 Definition and Justification for Narrative Research

The definition of narrative can vary depending on which theoretical orientation the researcher adopts (Riessman, 2005; Overcash, 2003). For example, Riessman (2005) explained that in social history and anthropology, a narrative could be defined as an entire life story, gathered from observation, interviews, and documents. In the socio-linguistic tradition, the definition of narrative is limited to specific stories and used to answer a single interview question. However, within the discipline of sociology

and psychology, the concept of narrative can be perceived as "encompassing long sections of talk – extended accounts of lives in contexts that develop over the course of single or multiple interviews" (Riessman, 2005, p. 1).

In this paper, I shall provide a common definition of narrative in the context of my research project. As Murray (2008) asserted, narratives are constructed and can be defined as "an organized interpretation of a sequence of events. This involves attributing agency to the characters in the narrative and inferring causal links between the events" (p. 113). Overcash (2003) explained that the concept of narrative is not only restricted to stories or accounts explained by the participant, but it is also the evaluation and analysis of those accounts that are part of what constitutes a narrative, requiring the researcher to identify themes and details in the data. Narrative methods are therefore not limited to storytelling per se but are perceived as a scientific tool that can produce data for analysis (Overcash, 2003).

According to Crossley (2000), narrative psychology is based on the idea that human beings understand themselves through stories, language, and writing, and it is through this process that individuals come to create themselves. Narrative psychology was developed in dealing with issues related to the psychology of trauma by gaining an appreciation of how individuals adapt and respond to traumatic situations (Crossley, 2000). In line with this, Willig (2008) explained that telling a story gives people a sense of coherence and meaning in what may seem to be a disorganised and puzzling series of events. Murray (2008) elaborated that the function of narrative is to "bring an order to disorder" (p. 114).

I felt that my research methodology would allow my participants the opportunity to construct meaning through the use of language and stories, and through this process be able to give a coherent and meaningful expression of their experiences. Elliott (2005) argued that narrative research seeks to empower participants and allow them to contribute and make decisions. Narrative research has also been referred to as collaborative, meaning that there is an equal power distribution between the researcher and the interviewee (Overcash, 2003). Subsequently, I felt that a narrative psychology would bode very well with my research as it involves the process of 'construction' of self and my topic is specifically looking at how such a population group re-constructs themselves psychologically (Lyons & Coyle, 2007). Hoshmand

(2005) wrote that narrative research, with its emphasis on meaning-making and the nature of storytelling, could be particularly relevant to the counselling psychology profession, especially when dealing with life transitions and life experiences. Given that my research focused on acquired FD resulting from an accident or illness, I felt that life transition would be a relevant concept experienced by my participants.

2.5   Key studies on Narrative Research

As outlined in Chapter 1, scholars have argued that narratives have a significant role in constructing and, at times, transforming the lives of individuals affected with terminal illness, trauma, sexual abuse or mental health issues (Crossley, 2000; Frank, 1995).

Papathomas and Lavallee (2012) conducted a study on the 'Narrative Constructions of Anorexia and Abuse: An Athlete's Search for Meaning in Trauma'. In this study, Papathomas and Lavellee (2012) aimed to interpret the life history stories of one former elite tennis player, Beth, who suffered from anorexia nervosa. Throughout the interview with Beth, it became evident that she had been a victim of sexual abuse by a former tennis coach at the age of 13. Thus, this aspect became an integral part of her story, as did her problems with anorexia nervosa. Researchers were therefore particularly interested in how Beth made meaning of her eating disorder experiences, and the sexual abuse she encountered. Furthermore, attention was paid to the role of narrative processes in constructing these meanings, and the implications that these constructed meanings had on the person's identity, experience, and action (Papathomas & Lavallee, 2012).

It is believed that individuals with mental health difficulties, particularly schizophrenia, are at a great risk of being stigmatized and silenced (Thornhill et al., 2004). Thornhill, et al. (2004) carried out a narrative analysis identified as 'Escape, Enlightenment and Endurance: Narratives of Recovery from Psychosis'. This study involved 15 individuals who had either recovered or were recovering from psychosis. The authors argued that, "because the breakdown of shared meanings in part, defined psychotic experience" (p.181), and given that such narratives contained

elements of chaos, disruption and incoherence, narrative analysis was deemed as an appropriate choice of method, since it allowed for a space in which respondents could reconstruct meaning and coherence to their psychotic experiences, as well as enabling a space in which their silenced voices could be heard (Thornhill et al., 2004).

Another main function of narrative is its role in the maintenance and construction of self-identity (Crossley, 2000). Recent studies on narrative identity have emphasized upon the process of psychological adaptation and development (McAdams & McLean, 2013). An example of this is a study carried out by Lau and Niekerk (2011), who explored the subjective meaning-making process of six individuals who had acquired burn injuries in South Africa. More specifically, researchers were interested in how these individuals reconstructed their self as well as their social reality. The use of narrative framework enabled participants to acknowledge their deficits, but also create counter-narratives, which emphasized positive, transformative and resilient aspects of their healing process.

For the purpose of this research, narrative analysis was selected because it was concerned with the construction of meaning and sense-making processes. The aim of this study was to examine ways, that individuals with FD psychologically reconstruct their selves and make sense of their FD. Simultaneously, narrative analysis has been recognised as a suitable methodology when dealing with trauma and health-related issues, an area that is salient for this particular research. Given that narrative analysis fosters human empowerment (Hiles & Cermak, 2008) it was important to allow the silenced voices of a stigmatised group to be heard. At the same time, narrative analysis has been concerned with psychological adaptation and development (McAdams & McLean, 2013), and it was intended that such method was crucial in helping respondents to create counter-narratives about their selves, while at the same time acknowledging their stories of pain and suffering.

2.6   Methodological Considerations

The two research methods I considered as alternative options were Interpretative Phenomenological Analysis (IPA) and Discourse Analysis. Narrative psychology, similar to IPA, is concerned with the subjectivity and experience of human beings. It is interested in how individuals think and feel and how they reflect upon themselves and about what is happening to them (Lyons & Coyle, 2007). Smith and Osborne (2003) concluded that IPA, similar to narrative analysis, is concerned with the lived experience of the individual and explores the individuals' real subjective experience from his/her perspective. However, Crossley (2000) argued that phenomenological approaches are limited in the sense that they are too focused with an 'insider view' and heavily emphasise the experience of the individual, thereby not taking structural and social factors into account. Secondly, the nature of IPA is to focus on 'texture' of experience and therefore aims to answer questions such as 'what it is like' to live in a particular moment or situation (Willig, 2008). More commonly, IPA seeks to explore the experience of people being in a relationship with something. For example, had I been interested in exploring the experience of therapy for people who have had a FD, or the experience of a therapist working with facial disfigurement, then IPA would have been an appropriate choice. However, my intent was to focus on the ways individuals re-construct themselves, taking into consideration their subjectivity as well as structural and social factors.

Another methodology that was considered at the time was discourse analysis. Discourse analysis, like narrative analysis, shares a social constructionist paradigm and includes the study of languages, examining how individuals construct meaning through the use of discourse (Willig, 2008). I did not feel that a discourse analysis would be appropriate only because of its limitation to language. By contrast, as Lyons and Coyle (2007) asserted, discourse analysis rejects the idea of using an individual's underlying subjective experience, something which narrative analysis does. My aim was therefore to focus on the subjectivity and experience of participants. As Crossley (2007) explained, although narrative analysis is similar to discourse analysis in the sense that it emphasises the importance of language, the two approaches differ in terms of the emphasis they put on subjectivity and experience. Consequently, Crossley (2007) communicated that narrative psychology,

unlike discourse analysis, focuses heavily on the content of the narrative. More precisely, "a narrative analysis will be an analysis of something, of some specific event or trauma that features significantly in a person's life and is the driving force for them having produced their narrative" (Crossley, 2007, p. 136). Usually, narrative researchers deal with issues of identity and self-construction (Crossley, 2007). For these reasons, I felt that a narrative analysis would be an appropriate choice of methodology for my chosen topic.

2.7 History and Function of Narrative Research

Recent attention to narrative studies developed in the 1980s as part of an increased interest in languages (Murray, 2003). Since then, narrative research has developed and become part of qualitative methodologies that challenge the more traditional positivistic philosophies. According to Hiles and Cermak (2008), narrative psychology has existed with its own identity for more than two decades as a field of study. Although narrative inquiries have been used within a wide range of other human and social sciences, it is only within recent years that an interest in narrative has grown in the field of psychology. A particular interest in stories has always existed in psychology, and these can be found in life-span development studies, personality studies, biographies, and case studies (Hiles & Cermak, 2008). The notion of narrative has also played a significant role within the psychodynamic tradition. For example, Freud perceived his clients' narratives in therapy as a window to their unconsciousness, unravelling the depth of their personalities. Alfred Adler talked about the notion of life scripts and life scenarios, and Carl Jung made use of narratives in the form of symbol and myth (Hiles & Cermak, 2008).

Murray (2008) explained that the function of narrative is to bring "an order to disorder" (p. 114). When the narrator is telling a story, he or she is trying to "organize the disorganized and give it meaning". The act of telling a story helps people organise the events of their life and give them meaning. Murray (2008) further elaborated that when we experience a sense of chaos or crisis in our life, such disruption encourages us to restore some sense of order. Crossley (2007) stated that

it is, in fact, through the telling of stories that we come to establish our identities and sense of self.

In addition, stories also have a capability to encourage human empowerment and challenge oppression and suffering (Crossley, 2000; Hiles & Cermak, 2008). Importantly, narratives are not merely accounts of experience told by individuals, but rather performative in the sense that they encourage human action. Importantly, "narrative is not simply a literary genre, or merely a form of human discourse, but is a basic property of the human mind" (Hiles & Cermak, 2008, p.148). Finally, stories equip the individual with pragmatic and convincing responses to cope with life's events (Hiles & Cermak, 2008).

2.8   Limitations of Methodological Approach

In this section, I aim to outline the limitations of qualitative research as a whole and then provide common criticisms that are relevant to narrative analysis. As with quantitative approaches, a stance of objectivity and neutrality is assumed on the researcher's part, where material is being analysed and interpreted independently from the researcher. However, contrary to quantitative methodologies, a qualitative approach requires the researcher to take an active role and engage with the material; therefore, it is deeply influenced by the researcher (Lyons & Coyle, 2007). Qualitative research can often be criticised for its very small sample size, as it requires the researcher to engage with a more in-depth data analysis. However, one could argue that a small sample size enables the researcher to acquire a richer data and take into account and respect people's subjective experiencing. Issues of reproducibility and generalizability are also of concern in qualitative research. Qualitative research does not assume that the sample, which constitutes their data and analysis, is typical of a certain population; rather, it aims to produce a rich and detailed insight into a particular experience or account (Lyons & Coyle, 2007). Silverman (2005) stated that qualitative research has also been criticised for lacking in science and therefore being subject to bias. Further criticism on qualitative research is its heavy focus on the subjective experience of individuals, thereby neglecting the social and environmental factors (Silverman, 2005).

Like qualitative research, there are a few common criticisms that exist amongst the narrative community. Bell (2002) noted that narrative could be criticised for its lack of suitability for all studies. For example, a narrative analysis would be useful when we want to analyse something, of a specific event or trauma or exploring issues related to identity and self-construction (Crossley, 2007). Similarly, with narrative research, the material used in the analysis will be greatly influenced by the researcher as the researcher's own background and personal beliefs may impact upon the way they interact during the interview process as well as the data (Lyons & Coyle, 2007). Furthermore, because of its collaborative nature between the researcher and participant, it is important to recognise that the constructed narrative and analysis illuminates both the researcher as well as the participant (Bell, 2002). The author further argues that the nature of truth and subjectivity of the researcher is constructed, just in the way that narratives are ambiguous and multilayered. Finally, ownership of participants' narratives appears to be a serious ethical concern in narrative research as it means that the researcher is 'imposing' meaning on participants' lived experiences[1] (Bell, 2002).

2.9   Advantages of Narrative Research for Participants

Overcash (2003) conveyed that narrative research not only provides insight and knowledge to clinical research, but it benefits the research participants as well. Before moving on to explain the benefits of narrative research, I will briefly discuss the similarities that narrative research hold in relation to therapy. It could be explained that from a person-centred perspective, when we are just 'being' in the room with a client and listening non-judgmentally to their narratives, by communicating our empathy and humanity, we may provide our clients with a therapeutic experience (Rogers, 1980). Similarly, in narrative research, participants are encouraged to talk about their stories, and the act of telling their stories could be therapeutic, provided that it is done in a containing environment. Willig (2008) wrote that telling stories about what has happened to us gives us a sense of meaning and coherence. It has also been suggested that the act of telling stories about the

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[1] Will explain further in Ethics section.

experience of illness could be therapeutic for research participants (Overcash, 2003); nevertheless, telling stories about our life whilst experiencing an illness could be therapeutic, a term which Frank (1995) referred to as "interview as therapy". However, due to the very sensitive nature of my topic, I recognise that there may be a risk that, for some of my participants, the interview may not serve a therapeutic purpose and, in contrast, evoke negative feelings in them. I will further elaborate this discussion and planned back-up procedures in my Ethics section, should this occur.

2.10   Epistemological Standpoint

Willig (2012) explained that the term 'epistemology' is related to a branch of philosophy that concerns itself with the theory of knowledge, constituting assumptions that we make about knowledge and knowing. Lyons and Coyle (2007) pointed out that an epistemological position is crucial as it will inform the researcher of what kind of knowledge his/her study aims to produce. In this research study, my epistemological position will be influenced by three schools of thoughts: 'social constructionism', 'critical realism' and 'contextual constructionism'. Starting with social constructionism, Burr (2003) explained that a social constructionist perspective adopts a critical stance to the assumption that the way we interpret the world reflects a 'real' or 'objective' entity. In contrast, a social constructionist approach believes that the ways we understand the world and ourselves are based upon social processes, especially through language as a verbal medium. This therefore draws attention to the fact that human experience and perception are products of a historical, cultural, and linguistic context (Willig, 2008; Crossley 2007). Furthermore, Willig (2008) asserted that language is a crucial aspect of socially constructed knowledge. For this reason, I decided that a social constructionist perspective would fit well with a narrative analysis as narrative involves storytelling through a verbal medium.

As a researcher, I recognise that by using a narrative analysis, my participants will convey their stories through the use of language; however, I acknowledge the fact that the language they use to convey their FD is a construction of a wider historical, social, and cultural context (i.e. influence from their families, media, culture, etc.).

Therefore, I feel that a social constructionist approach in my epistemology would be useful. Willig (2012) stated that a social constructionist position "invokes a reality which pre-exists and indeed shapes the ways in which individuals construct meaning within particular contexts" (p.30). This means that social constructionism is closely connected with a critical realist position (Willig, 2012). A critical realist position states that whilst there is a reality, we need to remain critical of it. Madill, Jordan and Shirley (2000) explained that a critical realist position recognises the existence of an underlying reality independently from human understanding. Whilst I believe that my participants hold a subjective reality, the meanings that they attach to their experiences and their stories will be unique, as they all experience different parts of a 'reality' (Willig, 2012). It could be said that this 'reality' is influenced by the wider sociocultural as well as historical context in which they live. Therefore, a critical realist and social constructionist both believe in the knowledge and understanding of human reality as socially constructed (Willig, 2012; Crossley, 2007).

As a researcher, I simultaneously recognise that the reality my participants are conveying through their stories is a certain reality to them, and that, for me, that reality may be perceived differently based upon my own assumptions and prejudices. I therefore need to remain aware that my perception of reality will influence what I am hearing and what I am interpreting through their narrative. Therefore, the knowledge produced in this study will be constructed, and, as such, subjective and context-specific.

Finally, the contextual constructionism approach is also closely interlinked with both a social constructionist approach as well as critical realist position in the sense that it assumes that we make sense of influences that are around us and in our environment, and that we understand things within a specific context. Such a position argues that knowledge is situational and that one's research findings are dependent upon its data collection and analysis (Madill et al., 2000). Furthermore, Willig (2012) explained that a contextual constructionist suggests that different perspectives can give different insights into the same phenomenon. For example, it is very likely that the stories my participants convey could be explained differently with a different researcher in a different context. I suspect that my participants may relate their stories differently depending on with whom they are interacting. I also do not think

that I am neutral in this process, but recognise that my own personal experiences, biases, and perceptions will impact upon the way I interact with my participants throughout the research process[2].

2.11   Epistemological Reflexivity

Elaborating upon the work of Paul Ricoeur, the French philosopher, made a distinction between two types of hermeneutics (Josselson, 2004, p.1). The first one is referred to as the *hermeneutics of restoration* and the other as the *hermeneutic of demystification*.   The former aims to "restore meaning to the text" (capture the subjective experiencing and meaning-making of the individual), whilst the latter is concerned with "decoding meanings that are disguised" (making an interpretation of hidden meanings in the text). Considering that I was dealing with a marginalised and oppressed group of individuals, every attempt was made to do my participants' stories justice by allowing them to have their voices heard (Josselson, 2004). However, I did not feel as if a mere restoration of meaning was enough; rather, I wanted to offer my respondents' stories with some type of psychological insight and deeper meaning. I felt that such an approach would allow me, the researcher, to gain an insight into respondents' psychological worlds. As such, I think that my background as a counselling psychologist enabled me the opportunity to explore respondents' narratives in further depth. In fact, Josselson (2004) agreed that "creative narrative research requires integrating these shifting stances and images-both unearthing the intended meanings and viewing them from another perspective in which such meanings point to other meanings, and thus enlarge our vision of some aspect of human life" (p. 24). Following the advice of Josselson (2004), I remained mindful in presenting the manifest content first (restoring participants' meanings) before moving on to decoding their latent meanings. After all, we must firstly acknowledge what the respondent means before we can move on to analyse the hidden meanings (Josselson, 2004).

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[2] I have reflected on my personal reflexivity throughout in the Introduction (Chapter 1) as well as in the Synthesis (Chapter 4).

2.12   Methodological Procedures

2.12.1   Procedure and Sampling

A purposeful sample of seven participants took part in the study, five women and two men. Narrative research does make use of a small sample size as it aims to capture a rich data of individuals' subjective experiences. I therefore felt that a small sample size would give me the opportunity to devote more time towards analysing the data in more depth as opposed to choosing a larger sample size. The inclusion criteria for taking part in this research project included males or females above the age of 18 who acquired FD as a result of a traumatic accident or illness. Given that the recruitment process proved challenging, I did not have the option to select an even number of men and women, hence, the unequal gender distribution.

The decision to recruit a heterogeneous sample was based on the idea of a 'maximum variation sampling' (Sandelowski, 1995). This means that people with a diverse range of acquired FD was selected. This decision was made in order to provide a range of varied experiences of the phenomenon (Sandelowski, 1995), with the intention to help generate useful insights of the phenomenon under investigation (Rubin & Babbie, 2009). For example, a homogenous sample consisting of FD caused by cancer would have restricted insight and knowledge into other forms of acquired FD. In addition, given that the recruitment process proved to be difficult, I did not have the privilege to be selective about participants. Thus, the decision was made to include people with a diverse range of FD.

I also considered exclusion criteria, which took into account the length of time the individual had lived with their FD. The Changing Faces charity suggested that a period of at least six months would be appropriate. They argued that this might depend on the person's ongoing treatment. For example, people who have been involved in a road traffic accident or a recent fire accident may not be psychologically prepared to talk about their experiences, at least for a few years. Moreover, at the early stages of my research, I contemplated whether individuals with congenital FD could be included; however, I chose not to include this sample

group as the experiences of these individuals may differ to some extent from the experiences of those who have acquired their FD.

In what follows, I have presented a table of participants' background, which includes their age, gender, ways that FD was acquired, and the stage of life which disfigurement was acquired. This is then be followed by a short illustration of each participant's 'story'.

Table 1.   A table of participants' backgrounds.

Participants *Pseudonym	Age	Gender	Way of acquiring disfigurement	Stage of life disfigurement was acquired
Helen	55	F	Attacked by a dog	Young childhood
Olivia	20	F	Attacked by a dog	Young childhood
Anne	52	F	Severely beaten by her ex-partner /domestic violence	Adulthood
Tasneem	30	F	Kerosene oil accidentally splashed on her face	Young childhood
Thomas	57	M	Oral Cancer	Adulthood
Wendy	65	F	Facial Cancer	Late adulthood
William	69	M	Oral Cancer	Late adulthood

2.13 Participants' 'story'

<u>Helen</u>

Helen was a middle-aged female in her fifties. She acquired her FD as a young child. At the time of the accident, Helen was visiting a family friend when a dog attacked her, "tore a big hole" in her face, and ripped her ear off. Helen stated that she did not have any vivid memories of the accident, possibly because the experience was too painful to bear. However, she described her childhood years as particularly difficult, given that she was subjected to repeated bullying and teasing. Helen felt that having acquired a disfigurement in childhood had a negative impact on her identity and sense of self. This was evident when she said "when you're very young, when you're still developing your sense of who you are, I think it really impacts that". Helen also believed that having lived with a "visible reminder" most of her life contributed to a fundamental sense of being flawed and "different".

<u>Olivia</u>

Olivia was a young female in her early twenties. Olivia was also attacked by a dog, and did not, like Helen, recall the actual incident. The attack left Olivia with a visible scar on her face. Olivia explained that it was not until she grew older that she realized she looked different from others. Similar to Helen, she encountered a great deal of teasing and bullying from others and the consequences of growing up with a visible difference left it scars on Olivia. For example, her narrative revealed that she had come to develop "perfectionist" tendencies as a child, and thus wanted to excel at school because she "did not want to be the child that was always cared for". In her romantic relationship, Olivia aimed to be portrayed as the "stronger" person as she feared being perceived as "weak".

<u>Anne</u>

Anne was a middle-aged female in her early fifties. She was severely and brutally beaten by her ex-partner to the point that she lost one eye and was left with a big

hole in her face. When Anne realized that she had lost her vision she felt so distraught that she attempted suicide. Throughout her account, Anne expressed a great deal of self-loathing, which was expressed by words, such as, "ugly" and "worthless", and this had led her to refuse using mirrors in the house. On top of this, she was subjected to nasty comments and inappropriate stares, which led her to lash out and grow increasingly angry. Anne's account revealed that she had developed obsessive-compulsive behaviour, such as, washing herself several times a day, and counting how many times she washed herself. Anne explained that her love for her granddaughter kept her alive. However, she could not accept her appearance and mostly isolated herself from the outside world.

Tasneem

Tasneem was a young Pakistani female in her early thirties. At the time of the interview she resided in Pakistan. She was born and raised in rural poverty. Tasneem acquired her disfigurement in childhood and recalled how one day, when she helped her mother wash clothes, her mother became so angry that she kicked the stove, which contained kerosene oil. Unfortunately, the stove broke and the place caught fire, as did Tasneem. At school, children ridiculed her, and as an adult her husband's family rejected her. Her own brother called her "monkey" and "ugly". Tasneem explained that she had nowhere to go and nobody who could understand her concerns. Tasneem was the subject of repeated social disgrace due to her unusual appearance.

Thomas

Thomas was a male in his late fifties who had been diagnosed with oral cancer. The cancer involved removing three inch of his jaw, teeth and part of his tongue. This procedure left Thomas with a visible scar on his face. Thomas felt a great deal of pain, both physically and psychologically. He described it as a "breakdown" and not being able "to get away from it". He usually kept himself inside the house and would only socialize with people he knew well. Thomas felt a strong sense of injustice for

what had happened to him, and though he struggled to accept his face, he hoped he could one-day love and accept himself.

Wendy

Wendy was a female in her late sixties who had been diagnosed with facial cancer, a few years prior to the interview. She was informed by the doctors that the bones inside her face had to be removed, which included her cheek bone, right jaw bone, palate and nose bone. This meant that she also lost her one eye. Wendy was so shocked that she described "shaking from head to toe". The period prior to her surgery and after was marked by episodes of "euphoria". Sometime later, Wendy described falling into a state of despair whereby she could no longer take care of herself. After a few months, however, Wendy gradually gained an inner strength to move on with her life, and accept her face. She also reported that the experience of her face had made her more compassionate and equipped her with an inner strength.

William

William was a man in his early seventies who had been diagnosed with oral cancer, and doctors eventually had to remove his jaw and tongue. William felt so distraught by the news of his cancer and altered appearance that he attempted suicide. However, the support he received from his family proved invaluable and gave him the strength to "fight" for his life. William explained that, at times, he was overcome with feelings of despair but he aimed to always look at the bright side of life. Similar to Wendy, so did William find meaning in his suffering. He reported that he had developed more empathy towards other people and believed that the experience of his face had made him a "stronger" person.

2.14 Recruitment

Participants were recruited from various locations. The first participant was a contact acquired through a lecturer at City University who had expressed an interest to take part when hearing about my research. The remaining six respondents were recruited

via 'Katie Piper Foundation' 'Changing Faces' and 'Let's Face It: For Facial Disfigurement and Cancer'. I managed to establish contact with the above-mentioned charities, all of which deal specifically with disfigurement, in particular FD. The Katie Piper Foundation and Let's Face It granted me permission to put my advertisement flier on their website. Changing Faces agreed to put my advertisement on their website subject to some amendments. Interested participants were then able to contact the researcher and further information was provided with regard to the purpose of the study, the consent form, and methods of data collection. I made certain that recruited participants received the abovementioned information by email prior to the interview, were offered a hard copy at the time of the interview, and between recruitment and the day of the interview, participants were invited to ask any questions that they had in relation to the research.

My recruitment process started in January 2011 and posed a great challenge. In conversation with my research supervisor, we came to the conclusion that this may have been due to the way I presented the research study and myself in my advertisement flier; the descriptions I used might have seemed very cold and neutral, depicting me as a scientist who was only interested in carrying out an investigation about FD. I suspected this may have put people off when reading my advertisement. I therefore decided to change the style of my writing and become a bit more 'human' in my communication. I thought that it would be a good idea to firstly introduce myself and also talk a bit about my reasons for wanting to conduct this research. I considered asking my friend (who acquired a FD) for his suggestions on what would be good to include in the advertisements, as he would probably have a better understanding of this population group. After a discussion with my research supervisor, I recognised the importance of presenting the study and myself in a way that would highlight the importance of what I could offer participants as a counselling psychologist. Although I was not offering them therapy, it would be important to communicate that giving the participants a voice to talk about their stories and experiences in a non-judgmental environment would hopefully enable them to have a therapeutic experience. Furthermore, it was important to highlight that the purpose of this research was to help people like myself, who have not gone through such experiences, to gain insight and an understanding of the experiences and common themes expressed by this population group. As a result, I updated my

advertisements in order to better communicate to potential participants that their contribution would provide positive knowledge for therapists who are working with FD. I also highlighted the fact that individuals who have not had such experiences are more likely to make assumptions about FD, and that an increased awareness about this topic would diminish such assumptions. Fortunately, these changes led to a more progressive recruitment and I managed to receive more emails from respondents who appeared interested in taking part.

2.14.1   The Research Interview

Interviews were conducted at well-established locations at a date and time convenient to the participants. For health and safety reasons, it was decided with the research supervisor that interviews should take place at well-recognised institutions, such as universities, GP surgeries, or therapy centres that offered private rooms. Given that some participants lived outside of London and travelling posed a difficulty, I made plans to travel to a more convenient destination for them. In fact, two respondents expressed discomfort travelling because of their appearance, and therefore the decision was made to travel to their location. Three interviews were conducted at City University, another interview took place at Birmingham University, in a private room, and two interviews took place at therapeutic clinics outside of London. My final interview was with a young female who lived in Pakistan. Given that it was impossible to conduct a face-to-face interview with her, the decision was made, together with my research supervisor, to conduct an interview with her via Skype. Both of us had access to webcam, and so this eased up the process. Although I am aware that this style of interviewing is not the same as interviewing someone face-to-face, nevertheless, the respondent appeared highly eager to take part and I felt that this would not only allow the respondent to share her story with me, but through her participation, she could add further richness and depth by providing a different cultural insight of FD to this study. Also, I offered to reimburse any tickets that my participants bought if they travelled from outside of London. One participant travelled from Wales and I reimbursed his ticket for coming to London. At the time of the interview, all participants were given an information

sheet explaining the purpose of the research and data collection, along with the consent form. Participants were all offered an opportunity to ask me any questions prior to the interview. Most importantly, I reassured respondents that any information shared would remain strictly confidential and that they reserved the right to withdraw from the study at any time.

Essentially, as I was aware that I was dealing with a delicate group of individuals who had been traumatised as a result of either an accident or illness, I wanted to ensure that I created an environment where respondents felt safe and contained to share their stories with me. Through the act of storytelling, they were being given a chance to have their voices heard, and, hopefully, they would find both the process and the experience therapeutic. Therefore, in order to comply with the above descriptions, as a trainee-counselling psychologist, I made use of my basic counselling skills (empathy, listening, reflecting, and summarising) and monitored my participants' emotional responses by tuning in to the process of the interview and asking respondents how they were feeling throughout the sessions. A few of the respondents remained emotional and I ensured they were allowed adequate time to recompose. I also conveyed to participants that if they felt overwhelmed by sharing their stories with me, at any point throughout the interview, they had the option to opt out and, in such a case, the researcher would sensitively deal with the participant's emotional state. However, although some of the respondents felt emotional, none of them were distressed by the interviews [3]. Semi-structured interviews were conducted, and even though the nature of these interviews were predefined questions, the interviews were open and emergent so that participants could freely discuss and add anything that they felt was important to them (Hunter et al., 2013). Similar to Hunter et al. (2013), I allowed for the research interview to 'flow naturally'. At first, I wanted to make use of McAdams' interview protocol, as I thought that would serve as a good guide, but I soon realised that McAdams' interview guidelines were mainly taken in the form of a life-story biography and that was not particularly helpful for my study. The aim was to ask specific questions that would be the most relevant for my research topic. Thus, I decided to ask more specific focused questions that I created in the hope that it would produce the narrative data relevant to my study. Riessman (2008) explained that using specific

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[3] Will further elaborate in the Ethics section

probes can be created by the interviewee in the moment as it would allow the researcher to follow the narrator's path. Thus, I decided to use probes during my interviews in order to best facilitate the narrative data I hoped to gain:

1. Can you tell me of the event leading up to how you acquired your FD? What happened on that day? How did you acquire your disfigurement/injuries?

2. How did you feel when you found out about your face?

3. What does it mean for you to live with a FD? In what ways do you see yourself, now that you have acquired a FD?

4. What was your initial reaction when first finding out about your face?

5. Do you feel that this experience has changed you in anyway? If so, in what ways?

6. What are some positive and negative impacts of facial disfigurement?

The first interview I conducted took approximately two hours. In hindsight, I realise that being a novice researcher, and having no prior experience with narrative analysis, I was anxious that I would not be able to elicit the right narratives from my participant, whilst simultaneously remaining aware that I needed to find a balance in terms of posing questions appropriately and avoiding intrusion on or suppressing my interviewee's story. The majority of participants reported that they felt pleased about having taken part in the study, and being given an opportunity to have their voice heard. Most of them conveyed that this would be a good opportunity for others (lay people as well as professionals) to acknowledge what people with FD go through, and that by taking part in this study, they could hopefully help others who were going through a similar experience. Riessman (1993) explained that usually in narrative research, interviewees provide their stories irrespective of the researcher's encouragements or set of structured interviews, which especially applies to in-depth narrative interviews. For a semi-structured narrative interview, it is recommended that the researcher asks the interviewee simple questions that have a clear connection to the interviewee's life experiences (Elliott, 2005). In general, for a semi-structured narrative interview, Riessman (1993) asserted that, normally, the length of time lasts

anywhere between 90-120 minutes. Most of my interviews ranged from 60-90 minutes.

2.14.2 Procedural Reflexivity

As a counselling psychology researcher, I am aware that the nature of my research is very delicate and sensitive. My interviews involve people who have experienced severe trauma and who possibly continue experiencing trauma as a result of other people's reactions and discrimination towards them due to their FD. On reflection, I recognise that an important factor I needed to take into serious consideration was the way that, as a researcher, I presented my study and myself to my participants. When I first presented my research study on the Katie Piper Foundation website, I struggled to find participants. Having reflected on this issue carefully and discussed it with my research supervisor, I recognised that it might have possibly had to do with the way that I came across to my audience. Not only had I as a researcher applied neutrality throughout my advertisement, but I had also used language that most likely made my participants feel as 'subjects of interest' to my study, being predominantly interested in their facial disfigurement. In some ways, I was unintentionally communicating that I was merely interested in them because of their facial disfigurement – their difference. I had to change this style of communication and realised that it would be important to reiterate to participants that as a counselling psychologist in training, I wanted to offer my participants an opportunity to voice their concerns in a safe environment and hopefully through talking about their experiences, and sharing their stories with me, enable them to have a therapeutic experience. I also hoped that this research interview would provide my participants with a sense of empowerment by telling their stories, and, equally, give them a space to make sense of their experiences. Having said this, I am aware that although I am not offering my participants therapy, I needed to offer my participants an experience that was therapeutic. Moreover, I also remained aware of the potential language used throughout the interviews. For example, 'facial disfigurement' and 'disfigured' are powerfully loaded words that may indicate to an individual that they are 'not as everyone else', they are 'abnormal'. I therefore remained conscious of the

implications of using such language throughout the interview when facing my participants. I am not certain whether there is a 'specific' way of verbalising myself and that perhaps if I attempted to be politically correct about the issue, this could be even more insulting to my participants. One way I dealt with this matter was to ask my participants what they preferred to be called and explored their thoughts around this issue. Participants in this study did not suggest alternatives for FD and felt that the word 'disfigurement' could be used within this context.

2.14.3 Pilot Study

Before deciding on the research question, a pilot study was carried out to explore the possibilities of themes that might come up in the interviews and these would help the researcher to formulate their research question as well as choosing an appropriate methodology approach. Three respondents willingly took part: two males and one female, all of whom were disfigured as a result of a fire accident. The respondents were recruited in Sweden and one of the respondents was an acquaintance of the researcher. The remaining two participants were introduced to the topic through the researcher's friend and expressed an interest in taking part. The participants were then asked to freely explain their stories of living with this condition, and prompt questions were asked throughout the interviews. There was a clear difference in the way the male respondents spoke about their condition as opposed to the female. For the female participant, the main concern surrounded beauty and her process of coming to terms with a new face, whereas for the male participants, the main focus was on rebuilding their identities and the sense of injustice and anger it had brought them. The following themes were generated as a result of the interview:

1. Participants expressed feelings of loneliness, helplessness, anger, and sadness.

2. Participants discussed suffering from low self-esteem and sense of self, hating oneself for looking like a "monster".

3. Participants brought up a sense of longing and need to relate to others who were in the same situation as themselves, as they all felt incredibly lonely and in pain.

4. Participants conveyed a need for mental self-preparation before going out, "people's reactions remind me of what I look like".

5. Participants reported experiencing recurrent flashbacks, posttraumatic stress symptoms, and depression. Two of the three respondents were on antidepressant medication. They all suffered from panic attacks and anxiety.

6. Participants expressed a desire for normalcy: "I just want to be normal; a big part of my adolescent years was gone because I had to grow up and accept things".

7. Participants expressed feeling unfairly treated by society: "Do I not deserve more? Why can I not get a job? At times I think about suicide".

8. Participants expressed a lack of identity. "I do not feel like I have an identity because of what happened to my face, people cannot see where I come from. I feel like I have been reborn into a different life".

9. Participants expressed their struggle in possible self-acceptance. "I am not sure whether I can ever come to accept my looks"; "I have learnt how to live with it".

10. Participants expressed that this experience has made them feel more positive and negative about themselves, at times feeling irritable, aggressive, insecure, and unstable. However, they had also learnt how to manage difficult situations. As one respondent conveyed: "This experience has definitely made me more humble, understanding, and sensitive to others."

2.15   Transcribing in Narrative Research

When transcribing a narrative interview, it is generally not recommended to put a great deal of emphasis on fine details, such as intonation or pauses, since this may simply hamper the reading process (Crossley, 2000). Therefore, as suggested by the author, micro-details of discourse were not of main interest to the researcher, but rather a full description of the content of the narrative, which included the researcher's questions and interviewees' answers.

2.16 Narrative Analytic Strategy

There is no standard or correct way of analysing narrative data due to the overwhelming and wide mixture of narrative methods and procedures that exist. Approaches to narrative analysis differ depending on the investigator and the research question (Riessman, 2008; Crossley, 2000). I therefore decided to adopt an approach to analysis that was congruent with my chosen topic. The analytic procedure of this study drew upon the work of several writers (Murray, 2003; Lieblich, Tuval-Mashiach & Zilber, 1998; Gergen & Gergen, 1983; Mishler, 1986; Crossley, 2000). I started the analysis by listening to the tapes several times before transcribing them verbatim, mainly so that I could get a feel of the interview process and familiarise myself with respondents' stories. After all, as Murray (2003) asserted, the aim of re-reading the accounts is to familiarise oneself with both the content and structure of the narratives. I then re-read the transcripts several times and made relevant notes, as well as monitoring my emotional reaction in relation to the data. For the purpose of this study, analysis consisted of three aspects, namely, the analysis of 'narrative genre', 'narrative tone', and 'core narrative'.

2.16.1 Narrative genre

The first part of my analysis consisted of the analysis of narrative genre. This type of analysis, according to Thornhill et al. (2004), is suitable when studying 'illness narratives' (Frank, 1995). As I read through the transcripts, the main question asked was 'What kind of a story is this?' In order to answer this question, aspects such as plot development, structure, and use of language was taken into consideration. The analysis of narrative structure was informed by the work of Gergen and Gergen (1983). They suggested that these structures fall into three different categories: progressive, regressive, and stable narratives. Caution was made not to use them in a schematic way, but rather apply it appropriately so that I could capture the essential shifts of the narrative accounts (Murray, 2003). For example, stories that reflect advancement, success, and achievement reflect a progressive structure, whereas

decline or deterioration reflect a regressive structure, and a stable narrative reflects neither progression nor decline (Mishler, 1986). Gradually, as each text was analysed, a story type began to surface. These stories were then categorised according to the genres identified and were named based on concepts or language emerging from the text (Thornhill et al., 2004). Once these various parts were identified in the text, I began to look for subplots that had emerged following the dominant plotlines. The reason for this was that I wanted the stories to unfold naturally as opposed to fragmenting them into different parts. During the second part of the analysis, which could be referred to as the interpretation stage, I made use of genres found in literature, such as comedy, romance, tragedy, and satire, and connected them to the dominant plotline found at the initial stage of the analysis.

2.16.2   Narrative tone

Narrative tone is one of the most central aspects of narrative analysis, as indicated by Crossley (2000). Narrative tone is concerned with the overall emotional tone of the accounts (Murray, 2008). Throughout the analysis process, I kept track of whether participants' accounts reflected an optimistic or pessimistic tone, along with a range of other emotions that were written down in the text, such as anger, excitement, despair, devastation, and empathy. Each text was read and re-read several times before the most dominant emotional tones could be identified (Crossley, 2000; Murray, 2008). Emotional tones could be found both in the content of their accounts as well as the manner in which they were told. Importantly, my own subjective response to the stories was also taken into consideration when analysing the emotional tones (Thornhill et al., 2004).

2.16.3   Core narrative

The analysis of core narrative was informed by the work of Mishler (1986). The way I identified core narratives was similar to that of the analysis of narrative genre. That is, I looked for language, plot development, and structure in the texts. Each story was

then summarised in a few words (e.g. "I march the beat to a slightly different drum"). As Thornhill et al. (2004) asserted, the identification of the core narrative has been used to characterise key features of narratives as a whole.

Throughout the analysis, I was advised by my supervisor to ask "What is the function of this story? Why are respondents saying what they are saying?" Such questioning allowed me to gain a deeper psychological insight into respondents' accounts. This approach is specifically important to psychologists, because they are interested in how people make meaning of their lives (Schiff, 2012). Therefore, for the purpose of this study, a functional approach to narrative was adopted. For example, in the narrative of *'the trapped'*, it emerged that the function of their stories was to communicate the damage and trauma that had been brought upon respondents' lives.

2.17   Validity in Qualitative (Narrative Research)

Polkinghorne (1988, p. 175) stated that in order for narrative research to be valid, it needs to be "well grounded" and "supportable". This requires the researcher to provide a coherent and consistent interpretation of their existing data so that it presents itself as comprehensible to both colleagues and participants (Lyons & Coyle, 2007). In order to ensure the trustworthiness and credibility of this study, I have provided a thorough explanation of the steps followed, which can be found in Chapter 4.

2.18   Ethics

This research study has been granted full ethical approval by the Department of Psychology at City University. I have throughout the whole project abided by the British Psychological Society (2004) code of ethics. I have ensured to "protect my participants from any harm or loss, and aimed to preserve their psychological wellbeing and dignity at all times" (Willig, 2008, p. 19). The following procedures were taken in order to ensure the safety and protection of my participants:

2.18.1   Informed consent

Informed consent was given to all participants who took part in this research study. A full description about the research study, the aim of this research, and why they had been selected to take part were provided.

2.18.2   Confidentiality

Confidentiality of all participants was respected and they were reassured that any information disclosed would remain strictly anonymous, including any potentially identifiable information. Throughout the study, audio recordings and transcripts were kept securely (locked cupboard), or on a computer as password-protected files, to be destroyed once the examination board has approved the study. However, as the nature of my study focused on individual narratives, and since it is through narratives that we identify ourselves, protecting my participants' narratives became a serious ethical matter. Therefore, in order to protect participants' details, full transcripts would not be provided in the appendices, but only a sample transcript for the purposes of the examination board. However, should it be the case that the examination board requires the full interview transcripts; these will be provided but will be requested to be withdrawn before the thesis is published in the library. I have also omitted any identifiable information, such as places where the event occurred, number of siblings, occupation, etc. Nevertheless, it is recognised that if too much information was omitted, then the narrative may lose its content and richness.

2.18.3   Right to Withdraw

Participants were informed from the beginning that they had the right to withdraw from the study at any point and that all research material would be destroyed should

they make such a decision. Participants were also notified of their right not to answer questions that made them uncomfortable during the interview.

2.18.4   No Deception

I have been fully transparent and answered any questions that were posed to me.

2.18.5   Debrief

After the interview, participants were given space to talk about their experiences and how they felt about the interview procedure. I treated my respondents sensitively and empathically and was open to answering any questions posed by them. Due to the very sensitive nature of this research, some of the respondents felt upset as painful feelings were evoked in them, as a result of visiting their past. For the sake of safety and protection of my participants, throughout the interview I monitored their emotional state through the use of basic counselling skills (empathy, listening, summarising) and tuned in to the process of the interview by asking them how they were feeling. At various points, I asked whether I was going too far and if they possibly felt overwhelmed by the questions posed. Participants were informed that they had the right to terminate the study at any stage.

Furthermore, should it be the case that any one of my participants felt distressed or vulnerable after the interview, I discussed with them that arrangements could be made to refer them to one of my colleagues (a trainee counselling psychologist) for a few sessions of therapy. If participants lived outside of London, I would organise for them to see a therapist in their local area. After the interview, the researcher made a follow-up telephone call the next day and attempted to confirm participants' feelings. As part of the researcher's standard practice, participants were provided with an aftercare pack at the end of the interview, to include information about the research and a list of psychological organisations that they could keep for future reference.

2.18.6   Ethics and the use of Online Skype Interview

Due to geographical dispersion, one of the interviews was conducted via Skype with a participant who resided in Pakistan. I therefore ensured, to the best of my ability, that appropriate measures were taken to meet ethical standards. A few days prior to the interview, I sent the respondent an information sheet, consent form and de-brief sheet as email attachments, and she then scanned the signed consent form and returned it by email. To build a rapport with the respondent prior to the interview day, I conversed with her via Skype and introduced myself, and gave her the opportunity to ask any questions she had in relation to the research. Bertrand and Bourdeau (2010) discussed that physical presence is important when conducting interviews in order to build trust. However, because physical presence was not an option in our relationship, in order to maintain good rapport and a trusting relationship, during the interview process, I delicately tuned in to check with the respondent that she was doing fine and, where appropriate, made use of my counselling psychology skills. Although the use of webcam was suitable, this style of interviewing still differed in contrast to the more traditional face-to-face interviews. Interviewing a participant via Skype can also pose technical difficulties, such as poor connection, voice hacking, and screen freezing. Fortunately, this was not an issue in our interview session. After the interview, the respondent was debriefed over Skype and the researcher contacted the respondent the following day to ensure that she was emotionally and psychologically contained.

2.18.7   Ethical Reflexivity

A particular ethical concern in narrative research relates to its interpretative nature. Narrative research requires the researcher to make their own interpretations and meanings for participants' narratives, which may differ extensively from the participants' own accounts. Although the interpretative text belongs both to the participant and researcher, these interpretations are merely owned by the researcher (Bell, 2002). I have therefore presented my participants' stories as accurately and as honestly as possible, by providing a detailed excerpt from transcripts highlighting my analysis.

Chapter 3: Analysis

3.1   Introduction

This chapter attempts to explore the in-depth narrative accounts of participants who live with an acquired FD, through the use of a narrative analysis. I therefore hope to provide the reader with useful insights into the ways that these individuals psychologically re-construct themselves and, as such, make meaning of their experiences, through the act of storytelling. As previously mentioned, a narrative approach was deemed appropriate as it allows for a focus on the construction of meaning. In doing so, participants' stories were categorised according to recognised genre, core narrative, and emotional tone. Three distinct genres emerged as a result of the analysis. These genres were named as the following: *'the outsider'*, *'the helpless prisoner,* and the *'the wounded survivor'*. Each genre has a number of subplots, which yield different nuances of meaning. For example, within the genre of *'the outsider'*, a number of subplots emerged, which were identified as 'a sense of being different', 'desire for acceptance and belonging' and 'empathic and understanding attitude towards life'. The subplots for the genre of *'the helpless prisoner'* were identified as 'shame', 'a sense of injustice' and 'despair'. Finally, the subplots that emerged for the genre of *'the wounded survivor'* were 'loss and grief' and 'resilience and growth'. With regard to the identification of emotional tones, decision was made to include the most dominant tones of each narrative and, for this reason; three emotional tones were identified in each individual narrative.

For the sake of clarity, it is appropriate to point out that participant' stories, and indeed genres, were not mutually exclusive. Although each genre contained its own character and uniqueness, there were some overlap and amalgamation between and within them. The reader may notice that in Chapter 4, at various points, narrative tone was discussed as a subplot within some of the genres. Kleres (2010) argued that, in narrative analysis, emotions are manifested in different ways. One such way, he argued was that emotions could be described as "complex, episodic, and structured" (p.185). Indeed, "an emotion is structured in that it constitutes part of a narrative –roughly, an unfolding sequence of actions and events, thoughts and feelings- in which the emotion itself is embedded" (Goldie, 2000 as cited in Kleres, 2010, p. 185). For this reason, emotional tone of shame was used as a subplot in the

genre of *'the helpless prisoner'* because shame was 'essentially emotionally structured' (Kleres, 2010, p.188) throughout. However, in the genre of *'the outsider'*, shame was not constituted narratively in such a way; rather it was expressed in a discrete manner.

Moreover, in the narratives I analysed, and with specific regard to the dominant storyline genre, certain events that were considered significant and relevant to the topic in question were selected so that they fitted in with the dominant plot of the story at that time. This way, these events were privileged over events that did not fit in with the dominant plot. Namely, during the analysis stage, participants' stories not only contained stories about how they re-constructed themselves psychologically, but their stories also seemed to be nested within stories (Morgan, 2000). For example, one of my participants talked about the deep sense of guilt she felt over her parent's separation shortly after her face was demolished by a dog. Though this part could be considered as the subplot of her story, nevertheless, it seemed to have little relevance to the dominant plot, and the decision was therefore made to exclude this part of her narrative. Thus, the stories presented in this study have all been analysed and interpreted to the dominant plot relevant at that time.

Each participant's quote has been highlighted in *italics.* Pseudonyms have been used throughout and, where appropriate, I have omitted and changed any details that may run the risk of revealing participants' identity. I have referred to participants' quotations using their pseudonym, page, and line number throughout. Pauses and silences are indicated by... and any non-verbal cues are indicated by a bracket [ ] with the appropriate word inserted into it. Participants' quotes have been left unedited so that it may stay as close as possible to their narratives, thereby reflecting their exact language and expression. At various points, I have aimed to keep participants' excerpts in full, in order to retain the holism of their accounts, as it may otherwise run the risk of losing the core of the point.

Furthermore, throughout the analysis, I have made use of theoretical frameworks with reference to narrative theory as well as to existing literature on FD. Also, at various instances, I have, where necessary, provided clinical implications for counselling psychologists. The reader will also notice that throughout the excerpts, I have highlighted certain words or sentences in bold text. I felt this would be helpful

in showing how these words refer to and connect with the genre, tones, and metaphors and allusions of each participant's narrative. Each participant excerpt presented in this chapter will follow in temporal order, thus allowing for a construction of a coherent narrative. Also, rather than fragmenting the texts into themes, which is a common strategy in other methodological approaches, such as IPA and discourse analysis, my attempt in this chapter was to present the narratives as a whole. I will now present each genre in further detail and, where appropriate, provide illustrative quotes in order to support my findings.

A table of my findings can be seen below, covering the genre, core narrative and the emotional tone.

Table 2.   Findings of Participants' genre, core narrative, emotional tone.

3.2   Genre of 'the outsider'

Participant	Genre	Core narrative	Emotional tone
William	*'The wounded survivor'*	*'I am going to fight it'*	Empathy Despair Grief
Tasneem	*'The helpless prisoner'*	*'My background is such that I had to live life which I am living now'.*	Empathy Shame Despair
Thomas	*'The helpless prisoner'*	*'You can't get away from it'*	Shame Anger Despair
Helen	*'The outsider'*	*'I march the beat to a slightly different drum'*	Shame Empathy Anger
Anne	*'The outsider'*	*'I see myself as nothing'*	Shame Anger Despair
Olivia	*'The outsider'*	*'I am different'*	Empathy Sadness Shame
Wendy	*'The wounded survivor'*	*' I can cope and I can help others cope'*	Empathy Euphoria Despair

Ubiquitous research has established that individuals with FD encounter a great deal of social stigma. This research, however, brings a novel understanding to the concept of FD and social stigma, as it provides an insight into the storied world of these individuals by demonstrating how the consequences of living with a FD and of being a constant victim of social disgrace, can leave a profound impact upon one's sense of self and identity. Hence, this study has brought about interesting individual variations in this common theme. As the stories of each narrator was unpacked, it became evident, for example, how Helen as a result of being a victim of social stigma developed a 'pleasing' character, and never perceived herself as 'good enough'. For Olivia, this was manifested in an attempt to portray a 'strong' persona to the world. She also developed 'perfectionist' tendencies, thereby, inhibiting the expression of her true self. For Anne, the consequences of being *'the outsider'* resulted in feelings of hostility and self-loathing. This genre has therefore highlighted a range of psychological processes associated with being *'the outsider'*. It could therefore be suggested that participants' stories reflected the mythic archetype of tragedy. Participants presented themselves as submissive, emotional, and fragile protagonists who felt that the world had treated them unkindly. The overall dominant tones of their narratives were that of empathy, shame, and anger. In short, their stories could be perceived as pessimistic in tone and regressive in structure. The primary function of their narratives was to allow participants to make sense of the challenges that involved in being *'the outsider'*.

All three participants willingly and generously shared their stories with me. Despite this, the interview remained an emotional experience for the women. I appreciate that this research has been an emotional experience for my participants, possibly due to its very sensitive nature. But, nevertheless, I have sensitively and accordingly followed the BPS ethical guidelines all the way throughout the research process[4]. In line with this, none of my participants were distressed by the research, and even though they may have found it emotional to some extent, I was left with a sense that this experience had been liberating and insightful for them. Olivia and Helen were the only two participants who decided to engage in psychological therapy after the interview, with the intention of working through their feelings of grief and loss.

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[4] Please refer to Ethics section

Helen

Helen elaborates on being *'different'* and never feeling as if she was *'as good as'* the rest:

> *I think a lot of the messages you get from the world, covert and overt, probably mostly covert are that **you are not as good**, kind of. I think it's probably, friends who's black and we talk about this sometimes, you know, that the experience is to some degree, certainly the public experience aren't necessarily that different you know, name calling, staring, pointing…and that kind of judgment.*

> *Cause it's just not, it feels like, again it's I'm probably generalizing cause it's not everybody, but it feels like, I suppose again it's akin to racism in a sense of **you're judged not just as different, but as not as good as, you know** (Helen: 2, 45-53)*

Helen's account conveys her feelings of inadequacy, which can be found when she gives voice to her feelings in the form of an analogy; by comparing her feelings to those of minority groups, i.e. black people who experience racism in society. In particular, this sense of inadequacy can be reflected in her choice of language: *'not as good as'*. The words *'judged'* and being *'different'* suggests that she does not feel part of the crowd. Helen's sense of self has been affected in a way that she regards herself very poorly. Thus, Helen's portrayal of herself being *'not as good as'*, *'judged'* and *'different'* would fit in with the broader genre of *'the outsider'*.

Harcourt and Rumsey (2004) recognised the profound psychological effect that FD can have on people, such as low self-esteem and sense of self. This population is therefore frequently subject to negative and intrusive stares in the form of aggression, pity and disgust (Rumsey & Harcourt, 2004; Clarke, 1999; Vardy et al., 2002; Tebble et al., 2004). The sense of being 'different' was echoed by participants in Thompson et al. (2002) research, as they found that women experiencing vitiligo developed a sense of being '*different'* from others.

As Bamberg and McCabe (1998) noted, personal narratives serve many rhetorical functions – to remember, argue, convince, engage or entertain the audience. From a

narrative perspective, the rhetorical functions of Helen's excerpt aims to persuade the audience (me). There is a sense that she wants to convince the audience of how stigmatised and discriminated she has felt by society, and how these prejudiced treatments, as a result, has come to make her feel inadequate and isolated from the rest.

Henry (2011) described that people who are visibly different may have never experienced a truly warm, authentic and healing relationship with others. In fact, she noted that their desire for human contact has repeatedly been rejected. Therefore, counselling psychologists who work with this population group need to be aware of these issues. For example, building a therapeutic alliance based on congruence, warmth and acceptance would be pertinent here (Rogers, 1961).

Moreover, the notion of feeling like an *'outsider'* is further reiterated in Helen's narrative, when she looks back at her childhood and teenage years:

> *When I was a child it was horrible. Because loads and loads of stories like, you know, a little girl at school that I wanted to be friends with. And her mom went up to the headmistress's office and said I frightened her daughter and loads of stuff like that. And **getting teased and bullied and, I'm terribly sociably anxious, and I think that's from being bullied**.*

> *And ...as a teenager, where you're really concerned about your looks, feeling like, you know, you know where the blokes the nice one and the ugly one, **and even the ugly one doesn't even want to dance with you**...and all, all those kind of formative years, it's really...**but...I think you always feel different**...and perhaps you, **I suppose, I have perhaps chosen to choose to be different in many ways, you know live a slightly alternative lifestyle** and things. Erm, people say I, you know**, I march the beat to a slightly different drum and I think some of that is rooted in feeling like an outcast for a long time** (Helen: 11, 351-364)*

In the above excerpt, Helen revisits her past and recalls memories of when she was bullied and rejected both as a child and adolescent, which is obvious from her

description from line 351 onwards. These years appear to have posed a great difficulty and challenge for her, evident when she reports *"I'm terribly sociably anxious, and I think that's from being bullied"*. This expression suggests that the bullying and sense of exclusion left Helen psychologically wounded, leading her to develop social phobia.

Newell and Marks (2000) found that people with FD experienced the same degree of social phobia, as did patients who were diagnosed with social phobia. Furthermore, Harcourt and Rumsey (2005) found that adolescents with FD experienced social isolation and decreased popularity at school, a finding that corresponds well with Helen's experience as an adolescent. When reflecting on her life in the present, Helen believes that the negative experiences of her past, i.e. being bullied and rejected, led her to choose a *'slightly alternative lifestyle'*, which was expressed by Helen in the form of a metaphor: *'I march the beat to a slightly different drum'*. This metaphor implies that Helen never felt part of a crowd, thus communicating her feelings of exclusion and separateness.

Helen's character is presented as a fragile and submissive protagonist who was the victim of repeated stigma and rejection, both as a child and adolescent. One may conclude that the villains depicted in her story were the children who repeatedly bullied and rejected Helen. These characters were perceived as powerful in the sense that their behaviour and reactions left a great impact on Helen's mental health, leading her to develop social anxiety. Helen's above account can be classified with reference to the genre of tragedy. According to McAdams (1988, pp. 55), characteristics of the tragic story include dying Gods, heroes, violent death, sacrifice and isolation. Therefore, in the classic genre of tragedy, the protagonist, or "hero finds himself separated in some fundamental way from the natural order of things".

Helen's capacity for insight and self-reflection is evident. Even though she possesses the "psychological mindedness" (Davanloo, 2001) into how the wounds of her childhood have affected her adulthood, the use of psychodynamic therapy could be helpful in order to create a space in which the expression of her past experiences and affects could be *felt* and worked through in therapy (Shedler, 2010). Such process could help the development of 'an emotional insight', which functions at a deeper level and eventually leads to change (Shedler, 2010). At the same time, attending to

the therapeutic relationship, through the use of transference, could help counselling psychologists to detect how the client's childhood wounds further have impacted upon on their relationship with others (Shedler, 2010).

As Helen's plot unfolds, her desire for acceptance and belonging becomes more apparent:

> *I think it's more about **being acceptable just as a person,** you know, just that you feel, perhaps there's always that anxiety, **am I going to be accepted by this person**, which I suppose to some degree is normal, but I think when you're facially disfigured, it feels like there's an extra level of that, you know (Helen: 20-21, 666-670)*

Helen's expressed anxiety could be understood as her fear of being singled out and rejected, evident by her comment, "*am I going to be accepted by this person?*". Thus, we may conclude that Helen's account reflects a desire to be accepted and validated. Previous research on visible difference has, in fact, shown that people are confronted with a great deal of social stigma, which prevents them from gaining social acceptance (Timms, 2013; Papadopoulos et al., 1999; Papadopoulos et al., 2002; Thompson et al., 2010). Besides, Helen's comment leaves me wondering whether she has ever come to accept herself. In person-centred terms, Helen is experiencing a lack of what Rogers (1961) coined as "unconditional positive regard".

Therapeutically speaking, by approaching the client with a prizing, warm and respectful attitude (Rogers, 1961) where the "therapist's thoroughgoing conviction of the dignity and capability" of each client is communicated would be a crucial part of therapy in order to help clients feel recognised and accepted as worthy individuals (Richert, 2003, p. 196).

Although Helen's story takes a negative and pessimistic stance in general, her story also contains positive elements, such as her ability to feel empathy and concern for others:

> *Erm, some people reckon I'm not bad with people; I do like kind of work, I mean I trained as a counsellor (Helen: 16, 514-515)*

> *The positives are, as I said, it gives you more empathy for other people, who suffered, and I think particularly for groups of people who are stigmatized or outcast (Helen: 19, 617-618)*

> *When I watched that documentary, I can't remember that guy's name, you know, and he's never had a girlfriend, and I'm like 'you poor soul' (Helen: 20, 659-661)*

The empathic tone in Helen's narrative was conveyed both in the content and in the manner in which it was told. Helen's choice of becoming a counsellor could be understood as her ability to connect with and understand others. The fact that Helen mentions *"I am not bad with people"* indicates her ability to establish a bond with others. It seems that the wounds of Helen's past led her to not only develop an inner empathy and sensitivity towards other characters, but also choosing a career path that enabled her to work with vulnerable individuals like herself. In the final excerpt, Helen relates to a young boy who has never had a girlfriend and then says *"you poor soul"*. Helen's character could therefore be perceived as affectionate, sensitive and understanding towards others.

McAdams (2006) would identify Helen's ability to empathise and care for others by a term he called the *redemptive self*. He explained that protagonists of such character behave in a pro-social manner, aspiring to improve the lives of others and leave a positive legacy of the self.

Helen's narrative was dominated by an overall tone of shame when she described covering her face with make-up as an adolescent:

> *And I think it was the psychological help it gave me and then I don't, then I just gradually, it was **I would not go out of the house without this make up on** and then it gradually, I just, but it really served a need for me at that time, you know. I needed it then (Helen: 13, 409-412)*

Helen's childhood character is portrayed as one who felt haunted by the reaction and behaviour of the children who bullied her. These reactions altogether caused her to develop feelings of shame, so that, as a consequence, she would *"not go out of the house"*. Even though Helen thinks the incident of her face has not made her ugly, her

sentence *"but I think sometimes I feel ugly"* is an indication that her narrative is dominated by a tone of shame. In addition, we may also hypothesise that Helen's self-perception of being *'ugly'* is likely to be connected to the genre of *'the outsider'* as the years of bullying and rejection evoked in her all kinds of negative affect.

Given that individuals with FD are likely to be victims of social exclusion and bullying, they are prone to develop shame and self-criticism. Counselling psychologists could use compassionate focused therapy in order to help and teach their clients to think more kind and compassionate thoughts about themselves (Gilbert, 2009; Gilbert & Procter, 2006). Counselling psychologists need to create an atmosphere, which is de-shaming, safe and compassionate (Gilbert, 2009). This requires the therapist to adopt attributes of compassion and self-kindness, as well as, expressing them to their client (Gilbert, 2009).

> *Erm, I don't think, would I say, I don't think it's made me ugly as an adult, but I think sometimes I feel ugly (Helen: 12, 392-393)*

As we may notice, more specifically, Helen's feeling of ugliness has come to define her. In fact, literature has shown that people who suffer from a visible difference report poor self-image and self-consciousness (Harcourt & Rumsey, 2008; Magin et al., 2006)

Thorne and Mc Lean's (2003) study found that students whose narratives contained traumatic events positioned themselves in either of the following ways: as courageous and brave, caring and concerned or weak and vulnerable. Helen's narrative suggests that her feelings of shame and insecurity positioned her as a weak and vulnerable protagonist.

Furthermore, the consequences of being victimised and rejected left its scars on Helen:

> *Because I hate, **because of being bullied and left out**, just **desperately, desperately wanting to be liked**, which I still do at ...whereas most people seem to grow out of it, **I just want to be liked so much** [crying](Helen: 12, 371-373).*

Helen's above narrative communicates her feelings of loneliness and separateness when she says *"bullied and left out"*. Her use of *"desperately, desperately"* signifies a tone of helplessness, by emphasising it twice. Her emotional crying communicates the sense of sadness and distress with which she is overwhelmed. We may conclude that as a result of the negative encounters, Helen developed a pleasing character, evident by her comment *"I just wanted to be liked so much"*, thus reflecting her need to be recognised and accepted.

Furthermore, this sentence validates the genre of Helen's story since, ultimately, her fear lies in becoming an *'outsider'*. The way in which Helen positions herself in relation to other characters continues to be submissive and desperate (Bamberg, 1997). This is evident by the way in which she hands over the power to others to decide whether or not she should be liked.

Helen's need to be liked and accepted has clinical implications for counselling psychologists, since it is likely that this type of behaviour will be re-enacted in the therapeutic relationship. Counselling psychologists therefore need to remain aware of issues such as transference, and identify and explore these wishes and drives in vivo with their clients (Shedler, 2010). These explorations can lead to "greater flexibility in interpersonal relationships and an enhanced capacity to meet interpersonal needs" (Shedler, p. 99).

When Helen was given the opportunity to reflect on how she believed that the experience of her face had changed her as a person, she replied:

> **I generally see myself as a bad person** [cry]. But I also see myself as somebody who tries to be a good person, but fails miserably a lot of the time. Erm [deep breath]…[deep breath].

> What else am I like? **I am a bit perfectionist**. I try, I find life quite hard work, and I try really hard and that like, I like to keep all my, not everything but there are some areas, like keeping the paperwork all in order. And I think it's my attempt to create order in me. To fight off, to keep the distance of the kind of chaotic and random, scary nature of life, you know, cause anything could happen at any minute, sort of thing (Helen: 16, 500-510)

Helen's character above is described in a negative tone when she conveys being a *"bad person"*. In a way, Helen has come to construct a narrative of herself as *'bad'* based on how others have treated her (Morgan, 2000). Morgan (2000) wrote that the way in which we construct a narrative is based on how the other characters in our story view us. Additionally, Harter (1999) outlined that individuals come to internalise social interactions into their self-perception.

Furthermore, Helen's reference to *"fails miserably"* as a person reveals her poor self-perception and self-criticism. It is possible that her feelings of *'failure'* are connected to being rejected and singled out by others. This notion is supported by Rumsey and Harcourt (2005), who asserted that appearance plays a fundamental and important role on our self-concept. The authors believe that others' negative evaluation or judgment of our appearances can have a huge impact on our self-esteem.

Helen's story of being 'bad' could be altered within the therapeutic relationship (Richert, 2003). For example, by applying narrative concepts to therapy, the therapists can help clients adopt a more worthy personal story (McLeod, 1997).

Helen's narrative also communicates her *'perfectionist'* tendencies. It seems that Helen has developed an obsession about keeping things in order. As she insightfully reports, it is her way of creating order in her psyche, distancing herself from a dangerous and chaotic world. We can see from Helen's tragic narrative that not only has she found life challenging, but equally dangerous, as evident by her expression *"scary nature of life"*. Gradually, as Helen's story progresses, she experiences a moment of enlightenment with regard to her feelings of self-loathing. This turning point in Helen's narrative is similar to what Murray (2003) would describe as a moment of epiphany:

> *That's something that just struck me actually, cause I just said about my face, what I remember more is other people's reactions and perhaps **that's why I hate myself**, because perhaps I look for the mirror in them too much. You know, if someone is critical of me, I always go away and think perhaps they're right, you know, instead of*

*thinking, **oh piss off or something** [laugh]. I'll think perhaps they're*
right. Perhaps I am terrible person (Helen: 24, 782-787)

Helen believes her feelings of self-hatred originate from the internalisation of the
negative judgment of others, which is conveyed by her in the form of a metaphor: *"I*
look for the mirror in them too much" (Rumsey & Harcourt, 2005). This expression
also reveals Helen's low self-esteem in that she defines her beauty based on the
judgment of others. A further example of this can be found when she says *"when*
someone is critical of me, I always go and think perhaps they're right".

Gilbert (2009) wrote that when working with self-critical clients it is worth looking
at their childhood memories in therapy. It would be vital that counselling
psychologists, through a safe, warm and compassionate relationship, demonstrate to
their clients how traumatic childhood experiences (i.e. teasing, bullying), further
contributed to such self-attacking thoughts (i.e. self-hate). Gilbert (2009) wrote that
compassion also develops as a result of the formulation the therapist shares with
their client regarding early memories in childhood. Essentially, this type of
demonstration teaches clients to have compassion and understanding for their
background.

Helen's hysterical laugh could be perceived as a defence against her anger, which is
revealed by her *"piss off"* comment.

Helen's is gradually able to put the pieces of her life together. Murray (2003, p. 114)
stated that the function of narrative is to "bring order to disorder", and Helen's
narrative fulfils this function. In summary, this process has enabled Helen to re-
establish a sense of meaning, coherence and connection, thus bringing an
"ontological security" to her life (Crossley, 2000; Davies, 1997).

And I think that's, this is really interesting, cause I don't think I've ever
thought this out as this clearly before but, I think that who I was
supposed to be, I think kind of died that day and I suppose the rest of it
*has been partly about **survival** and part of survival is about being liked*
isn't it?

*I think particularly as a child, because of course as a small child you could literally die if the clan **completely excommunicates you**, can't you. You know if they **completely reject you**, you could die. **So I think I try and be nice to people too much,** which is silly really isn't it, it actually doesn't make them like you (Helen: 28, 920-926).*

The dénouement of Helen's story is clearly stated in the above two extracts. Helen's sentence *"I think that who I was supposed to be, I think kind of died that day"* confirms what Henry (2011) would refer to as mourning the existential loss of one's identity. Her life and, in particular, childhood seem to have been suffused with a series of challenges, evident by her discourse *"survival"*. The word survival implies her attempt to endure moments of psychic challenge and part of this challenge included being *'rejected'* and *'excommunicated'*.

In narrative terms, Helen had come to develop what Riessman (2000) referred to as the performed characteristic of a *'pleaser'*. One may further speculate that Helen's niceness could be interpreted as a defence against her inner feelings of anger.

In brief, Helen's narrative can be recognised as a tragedy in which the protagonist suffers adversity (Murray, 2003). In Helen's case, this constitutes the traumatic incident of her face, loss of a happy childhood, and experience of being ostracised and isolated, along with a range of other psychological difficulties that developed as a result of these events. Helen's relationship with other characters in her story remained submissive and weak.

From a psychodynamic perspective, Helen's 'pleasing' character could be defined as a "passive defence against anger" (Malan, 1979). Counselling psychologists could, therefore, through a strong therapeutic alliance, sensitively help uncovering these unconscious defences with their clients, and allow for their feelings of rage and anger to be worked in therapy.

The dominant plotline of Helen's narrative as *'the outsider'* could fit in with Frank's (1998) "quest narrative", in which a sense of purpose and enlightenment is often discovered through the storytelling process. In Helen's case, her character was portrayed as a reflective and insightful protagonist who felt a great deal of compassion and empathy for others. For instance, her choice of becoming a

counsellor reflects her willingness to repair and help, if not herself, others who were either marginalised or in similar situations as herself (Frank, 1998).

Olivia

Olivia's past is negatively recalled:

> **I went through a lot of like bullying**, and just people completely unaware of how I feel about it, so I guess that **I sort of swept it under the carpet** and didn't talk about anything anymore (Olivia: 4, 107-110).

Olivia's narrative portrays her as a vulnerable and lonely protagonist who is the subject of much bullying. Her sentence "*I went through a lot of like bullying*" refers to the main genre of being singled out and rejected.

Bamberg (1997, p. 339) wrote that storytellers usually adopt a particular social position vis-à-vis their audience. Olivia's sentence above positions 'the other', i.e. the bullies in her story "as highly individuated and unjust agents, whose actions are wilfully targeted at the 'I', construing the relationship between the two characters as one of perpetrator and victim".

Kish and Lansdown (2000) asserted that children with visible scars and disfigurements are subject to harmful and negative social perceptions, and are often at risk of being socially rejected. This notion supports Olivia's struggles in being accepted and isolated based on her looks. Furthermore, her use of metaphor "*I sort of swept it under the carpet*" refers to the emotional tone of her narrative, and highlights her unprocessed feelings and sadness in relation to her face. Thus, Olivia has repressed painful feelings in relation to her experiences of being bullied.

In therapy, counselling psychologists can help their clients to come to terms with these painful memories and feelings. One such way, McLeod (1997) suggested, is to help their clients to tell emotion-bound stories in therapy, such as: whispering, shouting, writing a letter, telling in the first person, third person or telling into space.

The consequences of being bullied left Olivia with a sense of insecurity and inadequacy:

Yeah, I think probably just even now looking at myself now, I still pick,
I mean not all the time but still pick things that I could change, and that
I, I've actually been to the hospital and they're just saying, you know,
you're the best it's going to be, so forget about it and move on from
that [cry] which is quite difficult to be told [short laugh] ...[short
laugh] I'm sorry for crying (Olivia: 4, 120-126)

Not only does Olivia appear unhappy about her appearance, but there is also an overall sense of not being *'good enough'*, and inadequate, evident when she says: *"but still pick things that I could change"*. O'Dea (2006) asserted that adolescence is a time of heightened vulnerability to issues such as body image and peer relationships. Mc Lean et al. (2015) discovered that individuals who suffered from facial burns experienced poor self-image and troubling relationships with their bodies. Furthermore, Olivia's submissive and fragile character is revealed when she makes an apology for crying. I felt that Olivia's laughter was a defence against her feelings of shame.

Similar to Helen, Olivia's account emphasises her capacity to feel empathy and concern for others:

I am definitely able to understand other people's point of view, you
know, and I mean, I know you're not suppose to say never, but I do
never criticize other people's appearances or, or, **I'm able to sort of**
step out of how, you know, you direct judgment and see how they
must be feeling *(Olivia: 5, 158-161).*

But I'd want to be able to help other people in that same way. *Maybe*
to come to terms with it, rather than hide it (Olivia: 9, 284-286)

Maybe the fact that I can look at other people in a different way, *I*
guess that's the only positive thing I can see (Olivia: 10, 310-311)

The emotional tone of empathy was obvious throughout Olivia's account, expressed by her in different forms. The fact that Olivia mentions *"I'm able to sort of step out of how, you know, you direct judgment"* and *"see how they must be feeling"* appears

to be a clear indication of empathy, since she is communicating how she is able to put herself into others' shoes.

Olivia expresses the emotional tone of empathy by stating *"But I'd want to be able to help other people in that same way"*. This sentence demonstrates that Olivia feels a special connection and concern for people who have been through similar experiences. Egan et al. (2011), in their qualitative study on people who had adjusted positively to facial disfigurement, identified two main themes: personal growth and relationship with others. Participants reported an improved understanding as well as expressing a desire to reach out and help others. These findings bode well with Olivia's narrative.

In addition to feelings of empathy, we can see that in line 286, there is a sense of shame included in her story when Olivia mentions *"rather than hide it"*. This reflects how ashamed Olivia felt about her own face and, thus, felt the need to hide herself. Olivia's feeling of shame is completely justified, since she was always the subject of other people's ridicule, disgust and rejection (Timms, 2013; Papadopoulos et al., 1999; Papadopoulos et al., 2002; Thompson et al., 2010). In the final excerpt, Olivia reports that she is able to *"look at other people in a different way"*. This sentence suggests that she is able to feel more concern and understanding towards others.

McAdams (2006) showed how stories of redemption begin with themes of suffering to an enhanced status or state. That is, in personal stories the protagonist at first experiences a negative emotional state such as fear, despair, shame and guilt. But as the story progresses, the negative scene is salvaged and redeemed into a positive, in which the protagonist reports positive emotional growth, i.e. more resilience and understanding towards others and life.

Similarly, Olivia describes that living with a disfigurement makes her feel *'different'*:

> *In the way that I want to see it, is like **I'm different** so, you know, that's something that makes me stand out from everybody else, **but I think deep down I don't want to be different to everybody else** (Olivia: 7, 228-230).*

Even though Olivia's narrative carries a positive connotation when she says *"stand out"*, nevertheless, her sentence *"I don't want to be different to everybody else"* communicates a desire to belong. Olivia's wish for not wanting to be different has a close connection with the dominant plot of her story, *'the outsider'*.

A number of scholars in the field of appearance have noted that people with a FD are extremely sensitive to stigma, prejudice and rejection, and therefore are likely to feel lonely and isolated (Clarke, 1999; Vardy et al., 2002; Tebble et al., 2004). The notion of being different has equally been echoed in Thompson et al.'s (2002) research, as they found that women experiencing vitiligo developed a sense of being *'different'* from others.

Olivia further expands on the notion of being different and not fitting in:

> *And I just have a memory of being in and out of hospital or, always the child that had to be cared for because I had like constant nosebleeds because of the scar running down my nose. And so I was always the one everyone was trying to look after, but I felt like I didn't need looking after, **I just wanted to fit in with everyone else**.*

> *Then I think I tried to turn it around in the next school, and that's when I became absolutely obsessed with just doing well and proving that I can be something, rather than the person who needs help. Cause, I don't like being the person that needs help [short laugh] (Olivia: 17, 537-545).*

Olivia's description of past experiences depicts a challenging and painful childhood where her desire to belong was evident. This can be found when Olivia says, *"I just wanted to fit in with everyone else"*, suggesting that she never felt part of the crowd.

Furthermore, in an attempt to fit in, Olivia explains that she became *"absolutely obsessed"* with doing well in school in order to prove that she is *"something"*. The word *'something'* implies that Olivia felt inadequate and *'not good enough'* in comparison to others. As a result, the consequences of feeling *'different'* led Olivia to construct an identity that had to be *'perfect'*, *'strong'* and *'obsessive'*.

Kerr, Crowe and Oades (2013) asserted that a narrative approach to mental health recognises that a person is a collection of multiple selves living within multiple realities. They argued that it highlights the multiple, fragmented nature of personal identity and emphasizes that people's stories are complex. "The self is multidimensional whereby identity does not cohere around a core self, but is an integration of different selves telling different stories in a dialogical, dynamic interplay between themselves, others, and environment" (p. 109). Thus, Olivia's 'obsessive', 'strong' and 'perfect' selves constitute part of her identity.

The consequences of wanting to remain a strong person led Olivia to take on the role of the supporter in her family:

> *A lot of stuff has happened in the past five years that, in like our family* ***I've taken the role of the supporter maybe, rather than being supported****, which is…I don't know, I felt at the time, and now I can't deal with… (Olivia: 12, 394-397)*

Instead of being supported, Olivia became the supporter. In narrative terms, the concept of the word 'hero' means someone who is a defender or protector (Goethals & Allison, 2012), and even though Olivia struggled with issues of her own, she was still able to attend to her family's needs. Furthermore, the fact that Olivia mentions *"now I can't deal with"* suggests that she is finding life as a supporter rather difficult.

Olivia also reported that the pressure of wanting to remain strong as a child *"took away, like the fun from childhood, I became grown up too quickly" (Olivia: 17, 547-548)*. The above sentence communicates a loss of a childhood that Olivia experienced as a result. Her discourse *"took away,"* suggests that it was outside of her control, and that she was robbed of an innocent childhood. Thus, it suggests that Olivia was never able to mourn the loss of her childhood.

With this in mind, counselling psychologists need to provide a space of 'holding' (Winnicott, 1965) to enable their clients who acquired a FD in childhood to grieve the loss of a childhood they never had.

Olivia's narrative is followed by a series of tragic life events. The tragic tale belongs to the mythic archetype of sunset, autumn and death phases. They include stories of death, isolation and sacrifice; usually, the tragic hero encounters defeat and is perceived as a victim of his own fate (McAdams, 1988).

The attempt to present a strong persona to the world was further conveyed by Olivia:

> *I think in our relationship, if you look at us as an outsider, I'd come across as the stronger character, and the more confident person. Yet, he knows it's the complete opposite way round. But I don't want it to be… I don't like crying [laugh] (Olivia: 21, 675-679).*

For example, Olivia expressed that she avoided talking about her feelings to her boyfriend because she did not want to portray herself as *"not being able to deal with it, which it does feel like" (Olivia: 11, 338-339).* Ultimately, she fears that if she mentions something about herself, it *"scares people away, doesn't it" (Olivia: 11, 368-369).* O'Brian et al. (2012) found that individuals who lived with a romantic partner, and who had acquired a FD caused by cancer, experienced a disruption with reference to their intimate lives. This was mainly due to the changes that were brought upon their personalities.

Olivia has thus far been able to produce a coherent and stable narrative. Ochs and Capps (2001) suggested that stable narratives are coherent and usually characterised by an orderly, linear sequence of causal events, allowing the narrator to make sense of past experiences, and providing a resolution of the experience. Throughout my encounter with Olivia, I was left with a sense that this interview offered her a space in which she was able to not only grieve the loss of her past life, but also allowed her to voice her pain and make sense of a disordered life (Murray, 2003).

Finally, Olivia recognised that she needed to do something about her emotions. However, part of her was reluctant, as she did not want to appear weak:

> *But just recently, it's just dealing with the emotion, I need, I need to do. I haven't been able to admit that I need to… (Olivia: 25, 808-810).*

> *I don't know how to, I don't want people to know I need help. No, it's*
> *that ...admitting weakness thing. So it's hard to know whether this is*
> *just my personality, whether this is how I'm meant to be or whether this*
> *is a result of other things (Olivia: 29, 946-950)*

The dénouement of Olivia's narrative ends with her coming to an insight that letting others know about her vulnerabilities puts her in a position of weakness. In spite of this, she expresses a desire to do something about it when she says *"I need to do. I haven't been able to admit"*. We may conclude that Olivia's narrative reflects Frank's (1995) 'restitution' storyline, because, despite her ambivalence, Olivia's story signals a willingness to seek help and restoration.

Therapeutically speaking, counselling psychologists could explore with their clients what being 'weak' personally means to them. As Penn and Frankfurt (1994) suggested, allowing clients to counterbalance self-defeating monologues (you are weak) to exploration of helpful voices that are positive and confident may enable clients to construct soothing and more compassionate stories about themselves. This can, for example, take the form of journal writing, letters or poetry.

Anne

For Anne, feelings of being an outsider are similarly described:

> *I don't know, it's horrible. I mean you go in a shop and people just*
> *stare at you. You know, kids they're pointing and laughing, and it's*
> *horrible (Anne: 3, 88-89).*

Anne perceives the reaction of others towards her as negative and embarrassing. This is evident when she explains how children *'point'* and *'laugh'* at her, which makes her feel humiliated. These reactions all together have left Anne with feelings of being an outsider. Bonnano and Esmaeli (2012) found that participants in their study, who had acquired FD as a result of cancer, frequently reported being subjected to stigma, inappropriate staring and negative comments.

You know with people who are so nasty, I mean you wouldn't believe it, but you know, I mean look at her. I mean even then, you know like, when you, if on the rare occasions that I've gone out, I've no, I haven't got the confidence I used to have, and when you go out, I mean you get really, really nasty remarks. You know, sometimes I just ignore it, but other times I really rip at 'em. You know, I can't, I can't stop myself from saying something really nasty back (Anne: 4, 117-123).

Anne's narrative reflects the emotional pain of being humiliated and ridiculed by others. This, in turn, has most likely initiated Anne's lack of confidence and kept her in isolation. A strong strand of angry protest further accompanies her account when she uses quotes such as *"rip at 'em"* and *"saying something really nasty back"*. Moss et al. (2011) found that those participants who were less well adjusted to their appearance were much more sensitive to the behaviours of others and more likely to express hostility.

In narrative terms, Anne is portrayed as a protagonist who is completely helpless with regard to how she is being treated by others. As Bamberg (1997) suggested, when narrators tell a story, they tend to position characters in space and time, and give order to and make sense of what has happened. The above account provides Anne with the opportunity to make sense of how she was left feeling humiliated by others.

Partridge (1998), founder of Changing Faces, suggested cognitive behavioural therapy as an appropriate intervention for people who live with visible difference. This involves teaching clients about their own thoughts, feelings and behaviours, as well as the cognitive, behavioural and emotional reactions of others. The second component involves social skills training.

Counselling psychologists could therefore, through a collaborative relationship with their clients, help them to understand their cognitive, behavioural and emotional reactions when meeting people in public. For instance, clients can be taught that when they are in crowds or public places, they may feel anxious, self-conscious or embarrassed. These feelings can, in turn, bring about aggressive or defensive behaviour (Fauerbach, Spence & Patterson, 2006). Equally, clients need to

understand the thoughts, feelings and behaviours of other people. It is helpful to learn that some people may initially be shocked or confused when encountering a person with FD. These thoughts may further lead them to act rudely or clumsily, for example (Fauerbach et al., 2006). An enhanced understanding of these reactions may help clients to develop a new set of cognitive and social skills and, in turn, increase their confidence in socially challenging situations (Patterson, Ptacek, Cromes, Fauerbach & Engrav, 2000).

The second component, Partridge (1998) recommended, was the use of social skills training in therapy, which counselling psychologists can implement. This form of training is meant to provide clients with a range of skills and techniques when out in the public, such as role-playing and modelling (Partridge, 1998).

The emotional tone of anger continues to pervade Anne's story as she recalls situations in which she was teased and humiliated:

> *Or like, if, if on the rare occasion I do go out and I go out in a pub, I mean if a bloke does say look, you know, and I'll say well, if you know, if you've lived with somebody, well actually I use to say to **them I lived with a bastard and he did this to me**. I'll say, **you know, how good do you feel now?!** You know, it's alright, you and your mates laughing, I'll say, **but because of a bastard, I said, I look like this. And it usually, you know shuts them up** and like I say, it's not all the time that I'm like that, a lot of the time I just ignore it, well I try to. And then I go home and have a good cry… (Anne: 7,226-233)*

Anne's reaction towards others indicates her feelings of anger. For example, the tone of anger can be perceived when she says *"bastard...I look like this"* or when she uses words such as "shuts *them up"*. Anne's emotional state of having a *"good cry"* further reflects her feelings of helplessness and anger. Furthermore, Moss et al. (2011) also found that a person's level of hostility and aggression serves to protect them from perceived social ranking when it is under threat.

The difficulties and struggles of Anne's past drove her to the point of suicide, which is elaborated in the below account:

I tried to commit suicide a few times. I mean, it's not nice admitting it,

but I did try to commit suicide (Anne: 8, 240-242)

In the above excerpt, Anne presents herself as feeling miserable and completely distraught, and one can sense a deep feeling of hopelessness and despair in her narrative when she says *"I tried to commit suicide"*. It appears that following her facial disfigurement, Anne lost faith in God because she believed that life was just not fair. But equally, she started isolating herself and was badly victimised. The consequences of these experiences altogether left her in a terrible mental condition, thus leading her to become suicidal. Anne's narrative can be compared to that of a tragic tale in which the protagonist encounters defeat, isolation and death, and is perceived as the victim her fate (McAdams, 1988).

Moreover, Anne's suicidal tendencies can be understood in the context of wider literature, which suggests that those who suffer from a FD are more vulnerable to suicidal tendencies (Koster & Bergsma, 1990). The authors concluded that relational factors are related to individuals who experience such despondency. In the same way, Anne's despondency and suicidal ideation can be connected to a lack of an emotional relationship with others.

Given that individuals with FD may present with suicidal ideation, it is important that counselling psychologists inquire about them. As suggested by Partridge (1998), counselling psychologists should also ask their clients about the quantity and quality of interpersonal contact they receive. This information may give clues as to how vulnerable and alone the client may be.

However, the birth of her grandchild was a turning point for Anne as she no longer expressed a wish to die, and this was evident when she said: *"she's what's keep me going" (Anne: 8, 256)* and *"If anything happened to her, I think I'd just die. You know, but it has stopped me from thinking about suicide" (Anne: 9, 275-276).* The love and connection Anne developed for her grandchild gave her a sense of purpose. In other words, a life without her grandchild is empty and meaningless. In narrative terms, we may suggest that her grandchild has come to play the active role of the hero for the reason that she saved Anne's life, giving her hope and a sense of meaning (Frank, 1998a).

Similar to Helen, Anne's narrative was pervaded with feelings of self-loathing and shame:

> *I mean sometimes, you know I don't look at myself in the mirror. I mean it's never ever look at myself in the mirror without my patch. I always have my patch on if I'm; I mean it's very rare that I wear mascara. So I don't have to look at myself. In fact, I think I've only got one mirror in the whole house (Anne: 11, 337-342)*

Anne's excerpt above confirms her feelings of self-loathing. This can be found when Anne mentions *"I don't look at myself in the mirror without my patch"*, followed by *"I always have my patch on"*. These sentences suggest that Anne finds herself ugly and repulsive, hence why she cannot stand looking at herself in the mirror. Furthermore, the eye patch allows Anne to hide herself behind it as a way of covering the 'ugly' side of herself, thus protecting her from feelings of shame.

Harcourt and Rumsey (2004) reported that individuals with a visible difference experience a devastating effect in terms of self-evaluations, self-perception and self-esteem. Turpin et al. (2009) identified a theme called *"altered relationship with the body"*, which reflected changes in ways that participants perceived their bodies, and the negative impact that this had on their self-perception. Anne's low self-esteem was expressed along with a general sense of worthlessness: *"I don't consider myself pretty. Don't know, I just hide away really…" (Anne: 13, 409)*, followed by *"I see myself as nothing" (Anne: 13, 418).* This sentence echoes what Williams et al. (2003) found in the narratives of burn survivors: the loss of a sense of self and the loss of one's self-worth.

Given that self-criticism and self-attacking cognitive processing is apparent in people who experience shame, the recognition and addressing of this problem would be essential (Clarke, Thompson, Jenkinson, Rumsey & Newell, 2014). Compassion-focused therapy could be an effective and useful form of intervention that counselling psychologists can utilize with this group of people. Through a compassionate, validating and safe relationship, counselling psychologists can teach their clients to empathize with their own distress, whilst, at the same, being sensitive and responsive to the compassion from others (Gilbert, 2009; Gilbert, 2010).

The difficulties of being an outsider and living an isolating life obviously left its scars on Anne:

> *I mean, I've been on antidepressants now for twenty odd years now*
> *(Anne: 13, 438-439)*

The tone of despair can be further detected in Anne's narrative when she mentions being on *"anti-depressants"*. This sentence reveals the fact that Anne has struggled and suffered mentally for many years. A great number of scholars have confirmed that people who acquire a disfigurement to their face also experience profound psychological problems (Rumsey & Harcourt, 2004; Robinson et al., 1996; Tebble et al., 2006; Callahan, 2004; Newell, 2000).

Overall, Anne's narrative takes a regressive shift with a pessimistic tone throughout (Murray, 2008). The possibility of overcoming challenges was never an option for Anne; rather, they seemed to be endless. This is evident when she says *"I mean, I'm never going to get my eye back, am I?"* and *"No, I'm not going to get better…"*

Following the accident, Anne developed a compulsive behaviour whereby she washed herself several times a day, because it made her feel dirty:

> *I know it sounds stupid, but I used to spend nearly all day in the bath*
> *because… I felt dirty, and then I, I stopped doing that. Have to have a*
> *bath five times a day, and then I've cut that down. I mean it's taken me*
> *twenty years to; I've cut down to two or three showers a day (Anne: 25,*
> *829-833)*

We may hypothesise that Anne's feelings of being dirty originated from her inner feelings of self-hate. One may assume that Anne's compulsive behaviour functioned as a form of punishment against herself.

Anne also reported counting how many times she washed herself:

> *If I'm washing I've got to wash above my arms so many times and my*
> *legs so many times. And if I don't do it so many times, the days going to*

be an absolute mess, you know it's not going to turn out a good day. So
I've got to count how many times I've, I rinse my hair and how many
times I, you know, like scrub my head, you know like shampoo it (Anne:
28, 918-923)

As Shohet (2007, p. 360) would describe, Anne's narrative "locates the protagonist's problem not just in internal, faulty psychological mechanisms but also in the inter-subjective space of interaction with socializing others". Anne's compulsive behaviour could further be interpreted as an attempt to control a chaotic and scary life that dominated her world for so long.

Finally, as the interview came to an end, Anne said that the first thing she would do is to "*go home and have a bath or a shower*", and when the interviewer inquired whether telling her story made her feel dirty, she replied: *"I never thought of it that way, maybe that is why I have so many" (Anne: 27, 908).*

Anne's reply *"I never thought of it that way"* suggests that she was partially able to make sense of her behaviour. Murray (2003, p. 114) wrote that the primary function of narrative is that it "brings order to disorder", and although Anne's story for the most part remains chaotic, I was left with a sense that she was able to give voice to the unjust and painful part of her life. Taking a closer look at Anne's narrative, it fits with what Ochs and Capps (2001) referred to as the 'authentic' narrative. This type of narrative lacks coherence and stability and remains, for the most part, questioning and ambiguous in its nature. In response to the interviewer's final question of whether Anne could see any positive and negative impacts of FD, she replied:

I can't really think of …

Negative, I look ugly.

Just no positives at all (Anne: 29, 971-974)

The dénouement of Anne's story ends with a negative and pessimistic tone. In narrative terms, Anne felt defeated by her disfigurement and her life was suffused with tragic events and challenges. Anne's narrative is reflective of what Frank (1995, p. 97) would posit as the 'chaos' or, more precisely, 'wreckage' narrative. This type

of story portrays life as 'never getting better', and 'reveals vulnerability futility and impotence'.

Clinically, in such instances, counselling psychologists can, from a narrative model, help their clients to discover different ways of telling their story. One such way is to help them create alternative stories. For example, if Anne perceives everything about herself as negative, the therapist's task would be to help her reconstruct a more positive and healthy story about herself (White & Epston, 1990).

3.2.1 Summary of the genre of 'the outsider'

Protagonists in the genre of *'the outsider'* all reported an experience of being humiliated, persecuted and ostracised from the rest of society. Their characters were mainly portrayed as vulnerable and submissive both in relation to other characters (i.e. villains) and the audience (researcher). The reader may recognize that as the stories of each narrator were unpacked it became evident how, for example, Helen, as a result of being a victim of social stigma developed a 'pleasing' and submissive character, and never perceived herself as 'good enough'. For Olivia, this was manifested in an attempt to portray a 'strong' persona to the world; she also developed 'perfectionist' tendencies, thereby, inhibiting the expression of her true self. For Anne, the consequences of being *'the outsider'* resulted in feelings of hostility and self-loathing. However, despite this, participants (Helen, Olivia) reported that the experience of their FD had lead to positive emotional growth in the sense that it enabled them to feel empathy for other people's suffering. The dominant emotional tones shared across the narratives included: empathy, shame, and anger. Thus, the mythic archetype of their stories reflected that of tragedy.

3.3 Genre of 'the helpless prisoner'

Narratives of *'the helpless prisoner'* shared a focus upon the restricted life of participants. Their narratives were therefore characterised by stagnation, hopelessness and negative emotional experiences. As a consequence, they reported

living a life in complete isolation, with limited contact with the outside world. Participants presented themselves as helpless and miserable protagonists who felt imprisoned by their disfigurement. However, whereas Thomas expressed feeling imprisoned by his face, for Tasneem, the sense of being imprisoned was not only restricted to her face, but also to her social standing as a woman with a disfigurement in Pakistan. The dominant tones of their narrative included that of anger, despair, and shame. The primary function of this narrative was to make known the psychological damage and trauma that the disfigurement had brought upon participants. This narrative reflected the mythic archetype of tragedy, evident by the themes reflected in their accounts.

Tasneem begins her story by explaining the difficulties she had to withstand being a woman whose facial appearance deviated from the norm.

> *It's not about the tradition of Pakistani woman because many women are living their life according to their desire, but still, my background is such **that I had to live life, which I am living now**. So sometimes, **it is very depressing, er, to do nothing and just staying at home** (Tasneem: 1, 18-24).*

The theme of being imprisoned can be found in Tasneem's story when in line 23 she conveys that she *"had"* to live life a particular way. The word *'had'* implies that Tasneem's life was imposed upon her, and that she was not allowed to live life according to her own *"desire"*. Further, Tasneem mentions how depressing it can be *"to do nothing and just staying at home"*. This sentence suggests that living a restricted life led her to become depressed.

The sense of being imprisoned is further evident in the below account:

> *It's really isolated, it's so frustrating, in the morning. This morning I was not really feeling well, cause when you have no job, you are well educated and then you can do many things, you have courage, you are strong, but when you are not doing anything and you are still isolated so, and because of my face of course, so it is very complicated life, it is not easy.*

I cannot go to parties or things, because somewhere I feel that people will make an issue of my face and they will start talking about my face, and I, I have interesting looks, but still I want to be er, to be treated like a normal woman (Tasneem: 5, 187-194)

Tasneem finds her own situation as *"frustrating"* and the theme of imprisonment is found in the manner in which she talks about her life. For instance, she talks about feeling unwell because she has to stay at home, despite the fact that she is '*well educated, strong and courageous'*. She is not able to use her skills, because of how she looks, evident when she says "*because of my face of course, so it is very complicated life"*.

Tasneem's experience is consistent with the findings of Papadopoulos et al. (2002), who examined the beliefs of vitiligo patients, and found that when participants of Indian or Pakistani origin were compared to Caucasian or Afro-Caribbean participants, they experienced a greater impairment in quality of life. Her social life was equally affected as she talks about not being able to join social gatherings or parties because of her appearance. Similarly, participants in Hughes et al. (2009) study reported that females in the South Asian culture were more unfortunate than males. It was found that participants faced employment discrimination, thus leaving them to feel restricted and isolated. Thus, Tasneem felt that she was devalued and disenfranchised by others (Turpin et al., 2009).

These restrictions altogether left Tasneem in a *"miserable"* state. The regressive shift and pessimistic tone of her narrative is reflected below (Murray, 2003):

But here it is a miserable life. It is really a miserable life (Tasneem: 5, 212-213).

Tasneem is very despondent about her life in Pakistan. The fact that she emphasises *"miserable"* twice indicates how strongly she feels about it.

However, despite the sense of misery, Tasneem has yet a grain of hope that one day she can clear the way for her daughter:

But then I think I have a daughter now, so the things which I couldn't
achieve or in the restricted way in which I am living maybe because of
my face or because of my gender, I think I can clear the ways for my
daughter. So this is the only hope with which I'm ok with living this
isolated life because I have this one hope, it's ok I have this problem,
but then my kids will be alright (Tasneem: 5, 214-218)

The above account indicates that Tasneem was not able to *'achieve'* and live an enriching life because of the restrictions she had to withstand as a consequence of her appearance and gender, expressed in line 214-215. But, despite this, Tasneem remains hopeful and accepting that one day she will be able to improve the lives of her children. In narrative terms, Tasneem features as the main hero in this part of her story, aiming to rescue her children at the expense of sacrificing her own life (Goethals & Allison, 2012).

Furthermore, her next sentence *"where will I go"* implies that Tasneem is imprisoned in a situation over which she has no control or power:

*But now I'm in this situation, **I cannot go anywhere, I cannot go back***
to my family, and, and our government, is also not like they will
***support me** or and is also very, very difficult for, I think almost*
impossible for a lone woman to live in this area at last (Tasneem: 7,
279-280)

The notion of imprisonment can be further found in Tasneem's helpless tone, and also in the content of her text, when she says *"I am in this situation, I cannot go anywhere, I cannot go back to my family"*. This sentence implies that she feels shackled, and the actual word *"cannot"* suggests that she has no alternative but to stay.

Tasneem's social positioning is rather passive and victimised. As Riessman (2000) stated, narrators use particular grammatical resources to create their identities. For example, they use grammatical forms in order to intensify their vulnerability (Ochs & Capps, 1996).

Clinically, the dominant discourse of being 'imprisoned' can be worked through collaboratively between therapist and client. Counselling psychologists can help clients to uncover social forces that define and maintain their problems. This form of intervention, which is referred to as *second order externalizing,* moves the client away from the "individual with the problem" to a "group member constrained by social forces" (Vodde & Galan, 2002, p.445).

Thus, the task of the counselling psychologist is to help "facilitate a connection to others who resist oppression" (p.445). White and Epston (1990) suggested that it would be crucial to help clients to connect with the experiences of other survivors. They proposed that this could be done either through letters, narrative compilation or real life contact with others. For example, by connecting Tasneem to the stories of others who similarly felt imprisoned, restricted and helpless by their disfigurement would enable her to identify with the pain of other sufferers and thus, bring her out of this state of isolation. In addition, by establishing a connection to the stories of other survivors, the creation of a 'counterforce' in opposition to the voices a 'helpless prisoner' is facilitated (Vodde & Galan, 2002, p. 445). This form of intervention, they believed, would generate a sense of empowerment since it encouraged survivors to collectively confront the forces of oppression (Vodde & Galan, 2002).

Part of the reason for why Tasneem rather kept herself inside the house, away from others, is explained in the below excerpt:

> *Most of the times people also laugh at my looks. Especially males, they, they really erm, because now I'm eight months pregnant, so I have a swollen belly, and when I go out, so this is a ridiculous thing for them to see my face like this, and then my belly, maybe they are thinking, how can she be pregnant? Because here, maybe in every society, but here if a woman has one spot on her face then she is nothing, she is useless (Tasneem: 10, 421-427)*

Tasneem shares with us a particularly humiliating situation in which she was ridiculed and laughed at because of her face and pregnant belly. According to Tasneem, *"here if a woman has one spot on her face, then she is nothing, she is*

useless". This sentence indicates that FD is not an accepted phenomenon in her country.

As Hughes et al. (2009) were able to point out; stigma towards people with a visible disfigurement is very common in the South Asian community. Rahzani et al. (2009) found, that the perceptions and behaviours of people approaching a person with disfigurement included the following reactions: reproach, avoidance, negative thoughts and beliefs, stigmatisation and pity.

Moreover, we may hypothesise that Tasneem has internalised the negative behaviour and reactions of others into her very sense of self and identity:

> *At that time, I thought that I'm like trash. I have no identity, I am*
> *nothing, I am waste like garbage or something (Tasneem: 16, 690-691)*

Using expressions such as *"I'm like trash"* or *"I am waste like garbage"* reflects an extreme negative perception, which she holds of herself, containing no human value whatsoever. Harcourt and Rumsey (2008) wrote that it is very common in people with visible difference to express negative self-image and self-perception.

As Ochs and Capps (1996) expressed, narratives have the potential to generate a *"multiplicity of partial selves"*. In this case, Tasneem's narrative portrays a protagonist self who is completely worthless and invaluable. Carless and Douglas (2008) pointed out that stories that are dominated by an illness narrative focusing on deficit and dysfunction threaten the individual's sense of self and identity. In the same way, Tasneem's miserable and tragic story can affect her sense of self and identity.

Following Gilbert's (2010) model of compassion-focused therapy, counselling psychologists can help clients who present with similar self-defeating and self-critical thoughts like Tasneem to develop attributes of self-compassion and self-acceptance. One such way is to show clients how to be kind and empathic towards themselves (Gilbert, 2010).

The notion of being imprisoned is further elaborated by Tasneem:

> *For me it is very hard to fight for my rights because first of all I'm a woman, and second I have this er, disfigurement (Tasneem: 22, 959-960).*

The word *'fight'* in this context implies that she is to contend against a battle *of being imprisoned.* However, this battle appears to be *'very hard'* because of the inevitable difficulty in being a woman and living with a disfigurement. Also, the word *'fight'* further confirms the notion of imprisonment in the sense that she has limited freedom in terms of her basic rights. To fight also means to break free from the challenges and oppression with which she is faced. However, we may conclude that Tasneem's use of the discourse *'fight'* expresses a desire to defeat her enemy, which in this case represents cultural and societal norms.

The emotional tone of shame was equally found in Tasneem's narrative:

> *But I don't feel so much confident and then I try to hide myself, but at that time then my husband pushes me like a normal woman, 'okay go and bring your food, just go, go, cheer up and go'. At that time it's very hard to explain that I have been surrounded by all these feelings and I need some protection, I need shelter, I don't want to face people right now (Tasneem: 10, 401-407).*

In the above account, Tasneem mentions *"I try to hide myself",* followed by *"I need some protection, I need shelter"*. These expressions suggest that Tasneem does not want to be visible to others. Tasneem mentions of words like *'hiding'*, *'protection'* and *'shelter'* reveals her feelings of being flawed and defected:

> *And then at the age of like nine, I would be nine, nine and a half …and then I had to, I had to cover my face. I had to cover my face like er, like all other er, er, older women of our society. So at the age of nine, or nine and a half I was like a mature woman, and then I was using a burqa (Tasneem: 15, 631-634).*

The notion of *'hiding'* reappears in Tasneem's account when she says *"I had to cover my face"* using a burqa. This expression confirms the sense of shame that overwhelmed her at a young age. Tasneem's feelings of shame are consistent with

literature, which suggests that visible difference brings with it all kinds of psychological problems, including shame and embarrassment (Pattison, 2013).

Similarly, Tasneem's story expresses empathy and concern for others:

> I, I have this accident which has **made me much sensitive about the issues of life, about people, about the relationship**. *Like for them, it is erm, I think it is difficult to understand the delicacy of a relationship. But I think erm, I know about life much more than them (Tasneem: 20, 858-861)*

One of the positive elements of living with a disfigurement appears to be that Tasneem has become *"much sensitive"* about issues of life. According to her, she developed a more *'delicate'* and understanding attitude towards relationships and people in general. Askay and Magyar-Russell (2009) found that participants in their study of post-burn recovery reported experiencing positive emotions and emotional growth following their trauma. Some of these included warmer and more intimate relationships with others. Tasneem's story is also reflective of what McAdams (2006) referred to as the 'redemptive self'. In other words, the negative scene in Tasneem's story is transformed into a positive emotional experience and growth.

The consequences of being shackled and isolated, along with the experience of humiliation, obviously left its scars on Tasneem:

> I was using pills also. The CBT was not very good, but whenever I, I felt depressed, I would just go and have this Xanax tablets or anything which I like to just get right off er the sad feelings. And I also er, think that this disfigurement has er caused a sort of instability in my personality. It is very hard to feel happiness and it is very easy to feel erm, any sad moment.

> It is my favourite er, hobby, you can say, to stay depressed. Sometimes when I realise that I am so much happy or normal, or relaxed, I don't enjoy it at all. I think why there is no erm grief today, why I'm so happy. And my husband also realises it, and I feel more happy when

> *I'm depressed. And I know this is because of this accident. Because of*
> *this accident and then the injustice (Tasneem: 17, 720-732)*

Tasneem's story reflects a sense of misery and despair when she talks about using *'pills'* and having tried CBT as a way of dealing with her depression. Tasneem's way of coping with her feelings of despair was to numb them with Xanax tablets. Tasneem's communicates how despair dominated her life. This is evident when she states that the majority of her time was spent in emotional pain and agony, which can be further confirmed by Tasneem comment *"It's my favourite er hobby, you can say, to stay depressed"*. We may conclude that Tasneem's state of despair is a response to her feelings of anger, associated with a sense of being imprisoned, helpless and victimized.

Davenport (1991) highlighted the importance of helping victimized clients to acknowledge, experience and benefit from their anger. She wrote that this process would be crucial in order to help them to "move away from shame and helplessness to self-affirmation and empowerment" (p.144). Following the advice of Davenport (1991), counselling psychologists can work with both aspects of the client's ego, meaning that they can engage with the client's fearful and helpless part, as well as the angry and hateful part. Eventually, such process would "encourage and support further empowerment" (p.144). Importantly, counselling psychologists need to facilitate a "holding environment" (Winnicott, 1965) whereby compassion and validation is expressed, in order to make possible for both parts of the client's ego-state to be safely explored (Davenport, 1991).

Despite the struggles and challenges, Tasneem still thought of herself as a strong and capable fighter:

> *And the good thing is that er, still I am like, I feel I am a strong person,*
> *and **I'm still fighting** with the family and everyone (Tasneem: 24,*
> *1038-1039)*

Tasneem's character is depicted as a strong and resilient protagonist. For instance, the word *'strong'* implies that Tasneem felt resilient and powerful, despite the fact that she was continuously oppressed and victimised. Equally, the mention of *'I'm still fighting'* suggests that Tasneem is a survivor who is determined to continue to

fight for her own rights, without letting others degrade her. In a psychological sense, Tasneem's ability to 'fight' can be perceived as a coping strategy. Such findings have also been replicated by participants in Egan et al.'s (2011) study, in which, in order to adapt positively to their situation, they used inner strength as a coping strategy.

Goethals and Allison (2012) wrote that the element of struggle is a theme pervading throughout the hero's narrative, because in order to become heroes, they must overcome difficulties and obstacles. Tasneem's ability to withstand adversity and 'fight' for herself without ceasing to give up is an example of a heroic character. Applying the concept of narrative type (Frank, 1995), Tasneem's story would be reflective of the 'quest' narrative. Characters in the quest story come to learn something from their illness/pain. More clearly, Frank (1995) wrote that in the quest story, the characters form some meaning to their pain and suffering.

For Thomas, the sense of being imprisoned was felt in relation to his face:

> *And then again I look in the mirror, and I can see it quite plainly everything, cause I have to look at it all the time, **I have to deal with it twenty four hours a day**. You know, I get up in the morning, look in the mirror and there it is**, it's not going to go away. It's going to be with me forever** (Thomas 3-4, 97-101)*

Thomas's account indicates that the scars on his face are inevitable; he cannot escape or avoid them. Thomas's face is depicted as an enemy over which he feels helpless. For example, he states *'I have to deal with it twenty-four hours a day',* followed by *'it's going to be with me forever'*. Researchers have pointed out that FD differs from other types of disfigurements to the body because it cannot be disguised and is directly connected to a person's sense of identity and relationship with others (Callahan, 2004; Rumsey & Harcourt, 2004).

Counselling psychologists can help clients to create alternative thoughts about their disfigurement. For example, Clarke et al. (2014) suggested that instead of viewing their scars/disfigurement as a sign of weakness and 'disease', counselling psychologists can help their clients to create a more healthy relationship with their scar/disfigurement and thus, view it as a symbol of survivorship, strength and

resilience (Clarke, et al., 2014). According to the authors, this form of intervention will eventually empower the client and lead to an enhanced confidence.

Not only does Thomas feel devastated about his face, but, also, along with it, there is an experienced sense of loss:

> *It's [sigh] I mean, I'm ---years with a face that I got used to, and now, all of a sudden, it's completely different, it's changed, you know. (Thomas: 4, 107-109)*

The theme of loss is expressed by Thomas in the way that he reflects on his previous life, talking about a face that he was accustomed to as compared to now, when it's *'completely changed'*.

Thomas is experiencing what Henry (2011) referred to as the loss of one's existential identity. Röing, Hirsch, Holmström and Schuster (2009, p. 1083) found in their study of oral cancer patients that their participants experienced moods of "existential anguish", that is "a changed understanding of their place in the world, loss of language or loss of a body part".

Crossley (2003) wrote that serious illnesses potentially pose a direct threat to one's sense of ontological security; "when a person receives a terminal diagnosis they are immediately shocked out of the complacency of the assumed futurity of their existence and their whole conception of themselves, their life and their world is likely to undergo radical changes" (p. 440). The way in which Thomas relates to his body, and the sense of loss that he has experienced, has brought a disruption and disturbance to this experienced sense of 'lived time' (Crossley, 2003, p. 440).

Here, Thomas talks about being reminded of his scars, both physically and mentally, and for Thomas, this is analogous to *'torture'*. The word torture in this context refers to suffering:

> *It's just a reminder, reminds you all the time that it's there, so it's not just the physical, it's the mental reminder. It's like a torture, and it does hurt, you know, in there [pointing at his head] and physically (Thomas: 5, 137-139)*

Thomas's narrative reflects closely the experiences that oral cancer patients showed in Röing et al.'s (2007) study. Like Thomas, participants reported a sense of not being able to escape from their wounded mouths. Findings suggested that participants were, in fact, feeling both physically and emotionally vulnerable, even during a time when their treatment was progressing. In narrative terms, the antagonist in Thomas's story is his wounded mouth, from which he cannot escape, being a constant source of agony and 'torture'.

The notion of *'hurting'* mentally is described by Thomas in the following excerpt:

> *Physical pain you can numb with morphine, but psychological pain you can't, can you, you can't numb that really. No, apart from taking mind-altering drugs, morphine's bad enough… (Thomas: 6, 168-170)*

The psychological distress following Thomas's surgery is yet evident here when he refers to not being able to numb the psychological pain. Rumsey and Harcourt (2004) stated that some of the common problems experienced by this population group include depression, isolation and social anxiety. Frank (1995) wrote that stories of illness enable the individual to repair the physical and mental damage that illness has brought to their body. In telling his story of pain, Thomas may gradually begin to repair this sense of damage.

The emotional tone of shame is apparent. It is clear that Thomas felt embarrassed and troubled by his face, as he talked about not being able to *'hide'* it, and the mention of *'mask'* signifies his wish to be invisible.

> *You can't hide it, unless you wear a mask. (Thomas: 10, 331)*

> *I don't want them to look up at me; I don't want to be noticed. I just want to be a face in the crowd (Thomas: 12, 382-383)*

> *You know, if somebody looks at me, I look away cause I don't know them. You know. Cause I don't want to draw attention to myself. Cause somebody sees you looking at them; they're going to look ain't they? When you look away, they ain't going to be looking at ya, so its human nature [laugh] you know (Thomas: 18, 580-588)*

The tone of shame is further expanded as Thomas conveys not wanting people to *'look up at me'*, and not wanting to be *'noticed'*. This quote suggests that Thomas feels worried and embarrassed about his appearance. Thomas's fear of being noticed by others is expressed in the above account when he says *'if somebody looks at me, I look away'*, revealing his feelings of shame and embarrassment. Threader and McCormack (2015) found that participants with FD became withdrawn and embarrassed to engage with others, thereby, isolating themselves from the outside world.

In fact, some of the most common problems experienced by people with FD constitute self-consciousness, detrimental self-evaluation and low self-esteem (Harcourt & Rumsey, 2008).

As previously mentioned, because self-criticism and self-attacking cognitive processing is linked with shame, in therapy it would be vital that counselling psychologists acknowledge and address this processing style with their clients (Clarke et al., 2014). The use of compassion-focused therapy could be helpful in teaching clients how to empathize with their own distress and be kind towards themselves (Gilbert, 2009; Gilbert, 2010). This, of course, requires the therapist to express compassion within the relationship and create an atmosphere which is de-shaming and safe for the client (Gilbert, 2010).

Consequently, this sense of shame apparently had a restrictive impact on Thomas's life. Below, we can see how Thomas's life changed to the extent that he did not feel confident enough to go out by himself:

> *So, it's good, so I can go and have a couple of pints, and you know I get a taxi driver that I know, and I know most of them, they come and get me, and take me home, after I've finished. That's the only time I socialise, but I don't go out of my way to meet new people or anything like that, I wouldn't go up and start a conversation with somebody I didn't know (Thomas: 18, 580-584).*

A perceived sense of shame is obvious here, when Thomas states that he cannot go out alone, but rather *'they come and get me, and take me home, after I've finished'*. This quote suggests that Thomas feels vulnerable and embarrassed in exposing

himself to others, possibly out of the fear of being judged and rejected. In line with this, Newell and Marks (2000) confirmed that what may restrict people with FD is their phobic anxiety specific to social interactions. Thomas phobic anxiety could therefore be related to his feelings of shame.

Clarke et al. (2014) stated that the underlying core belief in people with a visible difference is that they are 'abnormal' and disgusting. As a result, they are likely to share thoughts that others view the self as disgusting and flawed (external shame), hence making them rejectable and defenceless against the attacks from others (Gilbert & Procter, 2006). So, in order to prevent negative reactions from others they engage in a range of safety behaviours (Clarke et al., 2014). For Thomas, the safety behaviour he adopted was avoiding social gatherings with people he did not know.

Counselling psychologists can, through a collaborative and empathic relationship, help their clients who display safety behaviours by exposing them to situations that they fear. Importantly, helping clients to develop coping tools in order to face the feared situation would be crucial (Clarke et al., 2014). An example could be that counselling psychologists, through role-playing, help clients to develop ways to answer embarrassing or awkward questions. This form of intervention as indicated by Clarke et al. (2014) can foster confidence, self-efficacy and perceived control over the situation.

In narrative terms, Thomas's story of shame can be perceived as a dominant cultural narrative, which he has come to construct as a result of society's view on FD (stigma, discrimination, looking ugly, etc.). Therefore, this type of story can only be viewed as oppressive and dominant (Kirkpatrick, 2008).

Thomas's attempt to make known his feelings of suffering in relation to his face is described in the form of a metaphor:

> *I call it breaking down. Where you just want to stop and think, oh God,*
> *no! I don't know how to describe it, it's what I call, you know, when*
> ***you just break down and just want to stop it. Yeah you want to stop***
> ***the bus and get off, but you can't, cause you're on that ride for good****.*
> *You know? [short laugh](Thomas: 26, 870-872).*

Thomas's disintegration of emotion is apparent when using words like *'breaking down'*. His comment *'oh God no'* reflects a sense of disbelief and shock. Likewise, his metaphor **'***Yeah, you want to stop the bus and get off, but you can't, cause you're on that ride for good'* gives voice to a hopeless protagonist who feels trapped by his scars and who cannot find a way out. Thomas's laughter seems to be a defence against an internal anger.

Narratively speaking, Thomas's above account allows him to 'bring order to disorder' and to give it meaning (Murray, 2008, p. 114), given that the above narrative illustrates his state of disintegration, when using words such as *'breaking down'*. Sarbin (1990, p. 58) further stated that "the intergenerational continuity of sacred stories reflects the habits of socialized human beings to assign truth value to remote events which have been rendered in metaphor".

The sense of imprisonment is further evident in Thomas's account:

> **No one's going to take it away. It can't be taken away**. *God's not going to take it away. Nor is your best mate or any of your family, or a loving woman,* **nobody's going to take it away, it's going to be there all the time** *(Thomas: 27, 873-875)*

There is a complete lack of hope in Thomas's narrative and despair that not even God, nor anybody else for that matter, is capable of removing his scars, which is obvious when he states *'No one's going to take it away'*. Furthermore, his mention of *'it's going to be there all the time'* communicates a sense of eternity.

Bamberg and McCabe (1998) wrote that personal narratives serve many rhetorical functions: to remember, argue, convince, engage or entertain the audience. From a narrative perspective, the rhetorical functions of Thomas's excerpt aims to convince the audience that no one is capable of rescuing him. Thomas is therefore overcome as the central character in his tale, and his story remains regressive in structure and pessimistic in tone (Murray, 2003).

Furthermore, Frank (2000) emphasised the need to be heard, for those who tell their stories of illness, and Thomas's manner of speech and repeated use of *'it cannot be*

taken away' suggests that he was given an opportunity to share his feelings of powerlessness and trappedness in relation to his face.

The emotional tone of anger can be found in Thomas's narrative:

> *I didn't ask for it, I'd done nothing wrong, oh. While there are dictators and mass murderers walking about the place, you know, nothing wrong with them, and I got this. Where is justice? Human justice. God's justice? (Thomas: 27, 884-887)*

Life has just not been fair to Thomas. The sense of anger and despair is obvious as Thomas feels unjustly treated when comparing his own life to that of *'mass murderers'* and says *'and I got this'* and *'where is justice'?* Thomas does not believe that he has done anything bad to be worthy of this kind of life. His anger and sense of despair can therefore be connected to his feelings of grief and loss. Callahan (2004) noted that HNC patients are confronted with an overwhelming sense of loss, because they experience a threat to self. According to the author, this threat is inevitable since the person, throughout their lifetime has come to know their face as it was.

Combs and Freedman (2012) wrote that when people are put in situations when they feel that they have done nothing wrong to incur injustice or harm, or when they are helpless in any way to act, it can lead them to negative conclusions about their identities. Despite this, narrative writers believe that people do respond, even in the most limiting and abusive situations. According to narrative therapists, no matter how small people's responses are, there are still openings for preferred stories (Combs & Freedman, 2012). Therefore, counselling psychologists can help their clients to look for stories of personal agency in disempowering situations (Combs & Freedman, 2012).

Although Thomas's narrative, for the most part, remains negative and miserable, the end of his account reflects a grain of hope. Thomas explains that following his surgery, he bought himself a cat (although he was never fond of cats) to see whether he could get over his dislike of cats and, if so, then perhaps he could start accepting and loving himself:

> *So I got over my dislike of cats, through catharsis yeah. Can I do that in this way, but put myself through the worst thing imaginable, once you've done that, I might be able to bring myself out of this crap (Thomas: 28, 935-938)*

Thomas's comment *'bring myself out of this crap'* suggests that he feels unhappy and stuck. He bought an animal that he disliked in order to develop tender feelings towards it, and it is possible that he held similar feelings towards himself. The dénouement of Thomas's narrative includes a wish to leave this state of misery and reach a level of self-acceptance. Frank (1995) called this type of a storyline the 'restitution' narrative where the storyteller expresses a desire to return to a time when life was 'normal'.

Finally, Thomas's account ends as he talks about the negative aspects of living with a facial scar. According to him, he still has not found "*the bright side of life yet*":

> *Everything [laugh] everything about it is negative, isn't it? You can't really eh, you can say look on the bright side, well I haven't found the bright side yet. I might do through what I was telling you about, I might do (Thomas: 33: 1104-1106)*

As it stands at the moment, Thomas feels unhappy and miserable for living a life with facial scars. His laughter functions as a defence against the frustration he feels. But, despite his negative outlook, Thomas still remains hopeful that one day he will overcome this sense of negativity, when he says *'I might do'*. Focusing on Thomas's plot development, at the end of his story, we can notice that it remains both regressive and stable in structure. By using Gergen and Gergen's (1983) initial formulation for narrative structure, Lieblich et al. (1998) stated that the regressive narrative involves a decline and deterioration, whilst in the stable narrative; there is no progression or decline, something that is reflective of Thomas's account.

Clarke et al. (2014) perceive optimism as a protective factor to psychosocial distress in people with disfigurement. Counselling psychologists can therefore help their clients to promote attributions, such as optimism, by collaboratively identifying clients' negative automatic thoughts, and challenge negative unhelpful thoughts and assumptions.

3.3.1 Summary of 'The helpless prisoner'

In the narratives of 'the helpless prisoner', protagonists' stories were characterised by stagnation, hopelessness and negative emotional experiences, such as anger, despair and shame. They presented themselves as helpless and miserable protagonists who felt imprisoned by their disfigurement. However, whereas Thomas expressed feeling shackled by his face, for Tasneem, the sense of being shackled was not only restricted to her face, but also to her social standing as a woman with a disfigurement in Pakistan. The classic tale of tragedy was yet present within this genre, for the reason that participants felt defeated by their disfigurement and lived a life in complete isolation. Nevertheless, although Tasneem felt that her disfigurement had caused many disruptions to her life, equally she felt that her experience had made her more resilient, understanding and empathic towards others. For Thomas, however, living with a disfigurement was an ongoing battle with which he yet had to come to terms.

3.4 Genre of 'The wounded survivor'

In the narrative of 'the wounded survivor', life was portrayed as a series of challenges that provided an opportunity for self-growth and acceptance. Although protagonists' accounts show tragic features of loss, despair, disintegration and a wish for self-destruction, these individuals manage to find a way of overcoming their life crisis. One protagonist described feeling euphoric and empowered in the initial process of recovery, since this meant that she was in complete control of her life, whilst another gained his inner strength from the encouragement of his family and friends. Protagonists also presented themselves as active agents of change in their stories. Both these participants reported that their experience of FD had equipped them with a greater empathy and understanding towards others. With this in mind, their narratives reflected participants' struggles, as well as their positive achievements.

Wendy

Wendy reports the devastating state in which she found herself when surgeons informed her of her cancer. At the same time, she was informed that the bones inside her face, along with one eye had to be removed:

> *And in that time, those few minutes I mean, I couldn't really take it in, I had no feelings really, except **shock** because I thought they were going to tell me 'oh yes you've got a bad infection there, erm, if you take these antibiotics they will repair it and help you'. I really thought, I was so naïve, and when they said you're going to have scans and operation in this next two weeks, and then when it started to sink in to me that **I just started a big shaking attack in the chair. And I was shaking from head to toe; I couldn't control myself** (Wendy: 3, 105-113)*

The theme of disintegration is illustrated in the above narrative as Wendy talks about her initial reaction when finding out about her diagnosis, and what would come to happen to her face as a result. Her description of a *"big shaking attack"* and the fact that she was completely out of her depth, not being able to *"control myself"*, confirms this sense of disbelief and shock. Scholars in the field of visible difference have established that when an individual is faced with a serious illness, in this case, facial cancer, they are confronted with a threat to self and Wendy's reaction above reflects this (Callahan, 2004; Turpin et al., 2009). Crossley (2000) explained that serious physical illness could shatter a person's 'ontological' assumptions by rupturing the person's sense of time and future.

Following the news of her operation, Wendy was able to emotionally distance herself as a way of coping with the shock of her cancer and operation:

> *And that fortnight I became a whirlwind of getting things prepared because my life was going to change, and erm, although it hit me I didn't feel sad. I felt I've got a job to do here (Wendy: 5, 171-173)*

Wendy explains that she became a *'whirlwind'* of getting things prepared and although it *'hit'* her, she *'didn't feel sad'*. According to Adsett (1963), individuals

who acquire FD may employ a range of defensive mechanisms, such as denial with bravado-type behaviour. Thus, such a defence mechanism protected Wendy from painful and unbearable feelings.

The emotional tone of euphoria is illustrated in the manner in which she talks:

> *It was very funny and I set about, that night, until six o'clock the next morning, cleaning out my kitchen cupboard. I ended up with about bin of bags of rubbish that could be thrown out, paper, dishes I didn't want, and I cleaned all the cupboards out, and then I got the stepladder out, I suddenly thought that on top of the wardrobes and the cupboards there was a lot of dust, cause I never get up there and clean them. I can't let anyone else, if I die, I can't let anyone else come in and see how dirty I was [short laugh] (Wendy: 5, 192-198)*

This particular account suggests that Wendy encountered unbearable anxieties, which manifested itself in the form of a manic defence. Furthermore, Wendy's laughter in this instance also signifies her defence against the pain and anxiety she felt. As Ochs and Capps (1996, p. 22) noted, every storytelling provides the narrator and audience with a fragmented self-understanding: "Each telling of a narrative situated in time and space engages only facets of a narrator's or listener's selfhood in that it evokes only certain memories, concerns and expectations." In a sense, narratives are understood by partial selves. Wendy is sharing with the audience aspects of her euphoric self.

Adsett (1963) suggest that if a client presents with bravado-type denial in relation to their loss, and if this denial serves as a positive function for the client, the therapist should accept and respect the client's denial. However, if the denial results in maladaptive functioning, fostering feelings of worthlessness and inferiority, then, perhaps counselling psychologists could in a gentle and supportive way question the client's defences (Adsett, 1963).

Shortly, after the surgery, Wendy's feelings of mania gradually decreased and she fell into a state of despair:

> *And I went down, thinking I can't go out like this, thinking **I can't live my life.** And yet before I thought, right, let's get through that. Get through the operation, trust the surgeon keeps you alive, and I was absolutely a star patient. Everyone thought I was marvellous at the hospital.*
>
> *And then when I went suddenly, **I hit the brick wall**, and I realised, a full realisation, it was when I saw the whole thing, without the dressings on later on. And it hit me all of a sudden that **I can't cope with this; I can't go out and live a life like this, what's going to happen to me**. Then that **sent me down**. And I had that **long period in the woods**, you know, where I was down, so there are different stages to this (Wendy: 9, 318-327)*

Wendy's account depicts a fragile and hopeless protagonist. For example, her use of the metaphor *'I hit the brick wall'* reflects her inability to make progress and move on with her life. Wendy's feelings of hopelessness and despair can also be found when she says *'I can't cope with this, I can't go out and live life like this'.* Furthermore, as a result of these feelings, Wendy describes spending a *'long period in the woods'*, a metaphor for describing her feelings of despair.

According to Koster and Bergsma (1990), previous research has also confirmed this finding: facial cancer, and its treatment, ruptures a person's emotional balance. This ranges from depressive symptoms to fear and anger, and patients may experience feelings of helplessness and depression.

Ochs and Capps (1996) noted that personal stories of the past are always told from the temporal perspective of the present. The ability to use present tense in order to describe past events (*'I hit the brick wall, 'I can't cope with this', 'what's going to happen to me'*) may indicate a continuing preoccupation in the narrator's mind, meaning that the events of the past are not contained but, instead, continue to haunt the narrator's state of consciousness (Ochs & Capps, 1996).

As time went on, Wendy still found herself in a state of despair, and during this time she paid regular visits to her psychiatrist:

> *Whenever I went to see him I was miserable. I didn't have any clothes much, and my hair was falling out still. I looked dreadful. And erm, at that time, I didn't even wash myself properly because I was so down. I used to get taken into a taxi to the hospital to see him (Wendy: 10, 384-387)*

This comment suggests how dejected and hopeless Wendy felt. This is evident when she describes feeling *'miserable'* and not being able to manage her personal hygiene. The fact that she was *'taken into a taxi'* suggests that she felt so depressed that she was even unable to function.

On the way home that day, when terminating weekly therapy with her psychiatrist, Wendy was overcome with a sense of empowerment:

> *I started feeling this excitement within me that, yeah, **my life is up to me, this is my life, it's nobody else's, it's down to me whether I cope or not**. It was like a sudden, that erm, I'm like this, nothing is going to change my face, I 'm disfigured, I don't care, I'm going to get on with life, it was amazing to me, because again I didn't know that was going to happen to me (Wendy: 10, 400-404)*

The theme of empowerment was found in Wendy's account when in line 401 she reports, *"This is my life, it's nobody else's, it's down to me whether I cope or not"*. Notwithstanding this, Wendy's reaction could be perceived as manic, both in the manner and content in which her account is conveyed. For example, her mention of *'I started feeling this excitement within me'* is an indication of her state of euphoria. We may hypothesise that when Wendy terminated the contract with her psychiatrist, she was left with a sense of hopelessness and despondency about her life. Research has, in fact, shown that people who suffer from a visible difference are prone to developing profound psychological problems (Rumsey & Harcourt, 2004; Robinson et al., 1996; Tebble et al., 2006; Callahan, 2004; Newell, 2000; Rumsey et al., 2004). At the same time, the theme of acceptance can be found when Wendy says *"I'm like this, nothing is going to change my face, I'm disfigured, I don't care"*.

A further example of the theme of acceptance can be found in Wendy's account when she says:

*But overall of that thing my life is saved. And it means such a lot to me to go on and living as I can. Erm, my life is precious, you know, and I think about that more. I don't take it for granted, you know, I think about my life an awful a lot, and what I must get done and what I must do. **I don't even have to cope with my disfigurement, erm, it's nothing, it's my way of life and this is me. It doesn't worry me at all** (Wendy: 13, 494-499)*

Wendy's comment *'my life is saved'* as well as *'my life is precious'* reflects a positive and optimistic feeling that she holds in relation to life. Also, the fact that Wendy mentions that she no longer has to *'cope'* with her disfigurement and that *'it's my way of life'*, along with *'it doesn't worry me at all'*, suggests that not only has she reached a level of acceptance with regard to her face, but, equally, she has become more resilient. In a study by Egan et al. (2011), participants who identified themselves as having adjusted positively to a visible difference also reported becoming more resilient and resourceful.

Apart from reaching a stage of acceptance, Wendy describes having developed a strength, which she previously was not aware of:

*It's made me realise that I have the sense of character that I may have not realised before. **I'm a very strong person**. And erm, these, I mean **I realised, yes I can do it**, you know erm, what's wrong with me, nothing's wrong with me. **I can cope with anything that comes along** (Wendy: 16, 615-618)*

*This experience of my face probably **gave me the strength**, I mean, I wonder what I would be like if I got cancer in my leg bone and they said right we've got to take your leg off, up to your knee. Would I cope as well, I don't think I would. But who knows. You know, I'd probably think oh golly, you know, this wretched disease, it looks as if it's going to get me in the end. **But I'll jolly well fight it** (Wendy: 16, 641-646)*

A clear illustration of a sense of endurance in Wendy's account is expressed when she says *'I'm a very strong person',* and *'yes, I can do it and I can cope with anything that comes along'*. The use of discourse in these expressions reflects

Wendy's belief and confidence that she is capable of overcoming these obstacles. In the next account, Wendy's narrative suggests how the experience of her cancer and face gave her the strength and resilience to continue to 'fight' any challenges that come her way. Askay and Magyar-Russell (2009) observed that where positive emotions and growth in participants who had encountered trauma was present, these included a greater sense of personal strength.

However, despite the positive and strong attitude that Wendy held in relation to herself, the bouts of despair and hopelessness re-visited her:

> *Nowadays, some years on, I have come to realise that my fundamental characteristics are all still there. The bouts of depression when life's problems from the past, now unsolvable, sit heavily upon me. The feelings of inadequacy where I know I am not as good as others. My failures in life where my failures in life where everything I've done seems wrong. I often cannot recall anything I've achieved or, although I guess I have, must have done so; In fact I know I have (Wendy: 18, 689-695)*

The tone of despair is once again revealed in her story when she talks about the *'bouts of depression'*, feelings of *'inadequacy'* and her *'failures in life'*. A possible explanation for Wendy's fragile mental state could be that she never fully allowed herself to process the traumatic event that took place in her life. Instead, her coping strategy was to become manic and repress these very painful feelings by becoming overly *'excited'*.

Counselling psychology draws upon a relational framework, focusing on the ways individuals relate to self, others and the world around them (Milton, 2010), and with this is an emphasis on meaning-making and subjective experiencing. Individuals who acquire a disfigurement caused by cancer are confronted with the loss of their previous self, loss of body parts, physical attractiveness and threat to life itself (Callahan, 2004; Clarke et al., 2014). Brief psychodynamic therapy may offer a useful way to work with this clientele. Using a therapeutic relationship based on trust and empathy, counselling psychologists can uncover ways in which individuals attach meaning to their trauma, with regards to how they view themselves, others,

and the world around them (Krupnick, 2002). In this context, the expression of intense emotions such as sadness and anger in relation to the loss can be worked through (Krupnick, 2002). The therapeutic process can help clients make connections between childhood experiences and the present by exposing the relationship between them and demonstrating the ways in which these early conflicts made the client more vulnerable to their current trauma (Krupnick, 2002). More specifically, clients should be encouraged to express and process their loss in relation to self, body parts and physical attractiveness, as well as the loss of opportunity, in terms of relationships (Clarke et al., 2014). Part of this process requires therapists to identify and address how clients repress painful and threatening thoughts, feelings and impulses from consciousness (Krupnick, 2002).

Similarly, Wendy explained that the experience of her FD has enabled her to feel a sense of concern and empathy for others:

> *And that's so true of me, that erm, whatever happens to someone, If I'm there for them, **I understand I'm there for them**. I've still got that ability even if I was very depressed. That probably would carry me out of my own depression because, I wouldn't be thinking inwards. **I'd be thinking I've got a lot of empathy for someone else**. You know, I can walk in other's shoes (Wendy: 21, 833-839)*

> *But erm, **it's about putting someone else before yourself isn't it?** What's life if you go about in your own selfish little box isn't it? (Wendy: 21-22, 850-852)*

> ***But you're there for people, aren't you**? I mean you need to give some time. **I am much more aware of charities and their needs now**. And that's one I've done, I've given an awful a lot to charities [short laugh] in money. You know, I never did very much before, except the odd pound in the odd box (Wendy: 22, 865-868)*

Wendy's compassionate and empathic character is clearly demonstrated in the above excerpts. It seems that the experience of her face and cancer enabled Wendy to identify with the pain of others in a much more sensitive way. For example, she conveys *'I'm there for them'*, followed by *'putting someone else before yourself isn't*

it?' Also, the fact that she contributes money to charities shows her willingness and compassion to help people in need. In fact, giving back to others was a common theme amongst participants who had survived a burn injury in Williams et al.'s (2008, p. 69) study.

Wendy's act of kindness and compassion can, in narrative terms, be referred to as a story of redemption (McAdams, 2006). In such stories, negative scenes are salvaged and redeemed by positive events. Redemptive sequences usually begin with the protagonist experiencing some level of emotional pain; however, the negative scene then gives way to the experience of growth and other positive emotional states. We may therefore observe that Wendy's plot is moving forwards and as the story's protagonist she continues to grow (McAdams, 2006).

At the end of her story, like Helen, Wendy reached a moment of epiphany when she came to the realisation that her *'bouts of depression'* could be seen as part of her recovery process, and not necessarily as something negative, from which she previously escaped:

> *'**It's mad, it's mad, so I'm my real self again** and I can say to someone, why can't I say to someone argh, they can say to me, they can tell by my voice, they say are you ok. I say well not really. They say well I can tell by the way you are and that is okay now. Cause, I like other people will say to me, I'm not feeling okay today (Wendy: 27, 1076-1080)*

This excerpt illustrates a rather significant moment for Wendy. She has come to the realisation that it is acceptable for her to embrace vulnerability, and that these feelings constitute a part of her '*self*', evident by her comment *'it's mad, it's mad, I'm my real self again'*. This expression confirms the notion that her euphoric self was only a defence that she used as a way of coping.

Riessman (2000) asserted that storytellers do not reveal an 'essential self' as much as they perform a 'preferred self'. These are selected from a multiplicity of personas or selves that individuals switch between as they move through life. In Wendy's case, we may hypothesise that her euphoric self was a reflection of her 'preferred self',

whereas her depressive self can now be perceived as the 'essential' or 'authentic self'.

In therapy, rather than trying to help individuals to stay 'true to themselves', counselling psychologists can focus on different facets and experiences of self and "help people choose the relationships, contexts, and commitments that support their preferred ways of being or help them bring other aspects of themselves into problematic contexts in ways that will change their experience" (Combs & Freedman, 2012, p. 1043).

Using the concept of Frank's (1995) narrative type, Wendy's story is reflective of the 'quest narrative' in which her illness is viewed as a challenge and used as an impetus for change (Frank, 1995). Not only did Wendy gain an inner strength, but this experience also led her to develop an increased understanding and empathy for others. Thus, we may suggest that Wendy's character became a hero throughout the course of this story.

William's narrative was equally fraught with anxiety and shock when finding out about his cancer diagnosis, along with the news that he would, as a result, lose his jaw and tongue. His initial reaction was as such:

> *...Shock, disbelief...why me? What do I do? ...I took an overdose (William: 6, 252-258)*

William found himself in a complete state of disintegration, fear and hopelessness when diagnosed with cancer, evident by his comment: '*Shock, disbelief, why me?*' He felt so distraught that he decided to end his life. Röing et al. (2007) noted that the mouth is the centre for speech, taste and swallowing. According to the authors, the mouth is particularly important to our sense of identity, ability for self-expression and the way in which we experience the physical world. One may hypothesise that for William, it meant that he would lose both the physical and emotional part of himself, which, at the time, felt unbearable and incomprehensible and William did not, at the time, seem to have the resources to deal adequately with such a life stressor, thus leading him to the brink of suicide (Callahan, 2004).

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In narrative terms, the above extract reflects the plotline of tragedy as it is both pessimistic in tone and associated with psychopathology (McAdams, 1993). The author noted that in the tragic tale, the protagonist is "separated in some fundamental way from the natural order of things" (p. 51). Additionally, William's suicide attempt mirrors this sense of self-fragmentation and despair.

Following his suicide attempt, William explains that he received a great deal of support and encouragement from his family, and this kept him motivated to move on and *'fight'* for his life, which further instilled in him a sense of hope and reason to live:

> *They had a row, argued. And they said that I was being selfish, because they did not want me in their memory. And that's when I thought right I'll fight it…it was a struggle (William: 6, 267-270)*

The word *'fight'* was also mentioned in William's account. In this context, *'fight'* refers to an ongoing battle that William found himself in, with regard to his face and cancer. Islam et al. (2010) found in their study of acquired facial trauma patients, that one of the predictors that influenced psychological adjustment amongst their patients was the level of social support that they received.

Part of William's *'struggle'* involved feelings of despair that seemed to re-visit him, and for this, he sought professional help:

> *I see a psychiatrist every three months, because I still get very …as I said, bad days. Sometimes I am up, sometimes I am down. Even now, especially if I…am with other people (William: 6, 276-278)*

> *It's so many different things. Things I used to love. I used to love walking, I used to love dancing, I used to love karaoke. I can't do those things now. And if I see something on television that depresses me, then I sink very low (William 7, 309-311)*

William's feelings of despair are reflected in his account when he talks about his mood swings, and how they are exacerbated when he is around others. Equally, the theme of loss is expressed in William's account when he talks about losing

everything he once loved and enjoyed. The loss of these meaningful activities further contributed William *'to sink very low'* and become *'depressed'*.

Rumsey and Harcourt (2004) stated that some of the most common negative emotional responses reported by people with visible difference are difficulties with social interaction and negative self-perception. Similarly, Newell (2000) found that individuals with a FD are at an increased risk of developing anxiety and depression.

The theme of loss continued to pervade William's life, as he was no longer able care for himself physically, and felt that his 'personal freedom' had been taken away:

> *It has taken away a lot of my freedom… and I have to rely on somebody*
> *…for those personal things like washing and shaving …that is it. But*
> *otherwise, I have to live with it (William: 10, 462-464)*

William's experience echoed what Röing et al.'s (2007) participants had reported, namely, their life world had changed in the sense that they became dependent upon others to take care of them.

Thomas's depressive reactions could be described as self-directed, inward-turning anger (Adsett, 1963). Individuals who have suffered disfigurement may begrudge their body for a perceived failure of the body to maintain its integrity, upset that the body has forsaken them (Adsett, 1963). According to the author, this sense of loss includes a loss of physical parts and loss of precious life activities/roles.

It is vital that counselling psychologists facilitate a space of 'holding' (Winnicott, 1965) so that clients' feelings of despair and loss, as well as rage and anger can be worked through in therapy (Leiper & Maltby, 2004). Emotional development is reached once the client is able to confront and process their emotional and psychological pain (Leiper & Maltby, 2004).

Apart from the experience of loss and despair, William was also haunted by the negative reactions of others:

> *Another thing that makes me feel bad is if I have people stare at*
> *me…and I have been told on the bus…that I, I'm a freak (William: 7,*
> *329-330)*

> *They say that if I was a dog or a cat, I would be put down and that's*
> *how it should be (William: 8, 344)*

It is evident that William was subject to humiliation and hatred by others. These reactions altogether made him miserable, causing him to *'feel bad'*. Ryan, Oaten, Stevenson and Case (2012) found that participants with FD were both subject to behavioural avoidance as well as emotional disgust. The authors concluded that their participants' disfigurement was treated like an 'infectious disease'. Literature concerning facial disfigurement has documented that individuals with visible differences are frequently subjects of social disgrace (Bonnano & Esmaeli, 2012). According to the authors, some of the most common negative reactions from the public include intrusive questioning, negative or avoidant behaviour, staring and teasing. William's experience confirms these findings.

Below, William questioned whether he had done something bad in order to *'deserve'* this type of life:

> *What have I done to deserve this, have I done something bad?*
> *(William: 11, 505)*

> *Have I hurt somebody? (William: 11, 510)*

William conveys this type of questioning with a tone of guilt, as he believes his FD could be a form of punishment for something that he had previously done. Thus, William's search for meaning as a reaction to his sense of loss and grief is evident. In fact, Riessman (2008) wrote that making sense of disruptive and traumatic life events helps the storyteller to contain emotions and create order, thus allowing them to search for meaning.

Following his cancer and FD, William continued to live life as a single man. Here, he provides us with a dialogue that he had with his psychiatrist:

> *Dr Wiseman, that's my psychiatrist… he's asked me many times if I*
> *think I will meet somebody else. I said no…nobody, now, if I hadn't got*
> *this done then perhaps I would have met somebody, but… that's life, I*
> *can't change it …The only person who can change it is God above. I*

send a lot of prayers. Ask for help. Ask for guidance (William: 12, 558-563).

William's response above illustrates a more negative and pessimistic account of his narrative, as he remains dejected about meeting a potential partner, based on his appearance. This is evident by his comment in line 559, when he says *'If I hadn't got this then perhaps I would have met somebody'*. William's response is consistent with the findings of Koster and Bergsma (1990), who reported that cancer patients who lost aspects of their faces encountered the greatest problems in the interpersonal sphere, specifically with regard to intimate relationships and superficial encounters with others. William's response has been that of shying away and convincing himself that he is unworthy of the attention of others, thus preventing him from finding a partner.

Similarly, William's account reflects his willingness to help others in need, along with his ability to feel concern and empathy for other people's suffering:

I try to help other people (William: 13, 580)

And if you help… somebody's who's facing it, I found if you talk to somebody face to face…you can bond, like I said you can bond with a person. You tell her your experiences and she will tell me hers, and that's, and we work our way round. I hope that after she's spoken to me, she's going away (pause) a bit brighter, happier, and that a load has been lifted off her shoulders…in that way we can help somebody. You help somebody with, to get their confidence back (William: 14,638-644)

Yeah. In any way I can, even if it's just to sit there and listen, that didn't happen to me, I had nothing (William: 14, 648-649)

William's capacity for compassion and empathy is evident when in line 642 he says, *'I hope that after she's spoken to me, she's going away …a bit brighter, happier, and that a load has been lifted off her shoulders.'*

Even though William's life was portrayed as a series of challenges, paradoxically, these challenges provided him with an opportunity for growth and advancement (Murray, 2003). William's account contains what McAdams (2006) would refer to as "sequences of redemption" where the protagonist who at first experiences a negative emotional state is able to transform these into positive emotions, such as emotional growth, empathy, joy and happiness. In William's case, his redemptive self meant becoming more understanding and empathic towards others. Williams et al. (2003) showed that their participants, similar to William, reported a greater sensitivity to the suffering of others, which appeared to be an important aspect of their healing process.

Frank (1998) emphasised the importance of listening to ill people's stories, not in such a way as to offer them a 'quick' fix by doing something 'therapeutic', but rather as clinicians, we ought to honour clients' suffering, helping our clients hear exactly what story he or she is telling. In fact, it is "only through reflection that story- telling and life become truly ethical" (Frank, 1998, p. 209).

In spite of all the challenges, William remained positive and believed in the importance of meeting and socialising with others:

> *Er…I still go to Karaoke (William: 7, 321)*

> *I'm out and about as best as I can (William: 12, 531-532)*

> *As much as I can, I mix with people (William: 12, 540)*

William's account shows his willingness and resilience to fight for his life by taking part in meaningful activities and interacting with others. Furthermore, as previous research has shown (Williams et al., 2003; Egan, et al., 2011), individuals who have acquired a disfigurement were able to reframe their adversities in the context of other positive experiences such as personal growth, meaning-making, a moment of epiphany, or insight. William's narrative is reflective of his attempt to strive to regain self, as well as striving for a regained freedom (Moi & Gjengedal, 2008).

Reaching the end of his story, William was given a chance to reflect on the positive and negative aspects of living with a visible difference:

The positive is…I suppose, having this it's, it's I suppose made me stronger (William: 17, 789)

When I first came out I was, what's the word, erm…I couldn't face the world, I couldn't face other people but now I can, yeah that's a positive. Negative, I don't think about it (William: 17, 794-796)

I have to be positive, and I am being positive, if I didn't feel that way, I wouldn't be sitting here today… (William: 17, 806-807)

William's persistence in keeping a positive mindset, and ignoring the negative, possibly enables him to cope and move on. William's response was similar to that of participants in Egan et al.'s (2011) study, who equally reported that the experience of their visible difference had equipped them with an inner strength and positive outlook. Participants reported that they were able to embrace and accept the difficulties presented to them, as they could no longer change their appearance. In fact, one participant responded similarly to William: "just get out there and enjoy your life, and be positive" (Egan et al., 2011, p. 744). Thus, the process of living with a FD increased William's awareness of identity, leaving him with a new self-image (Konradsen, Kirkevold, McCallin, Caye-Thomassen & Zoffman, 2012) as he equally learnt to adjust to an altered sense of self (Callahan, 2004). Furness et al. (2006), in their study of facial surgery, referred to this process of adaptation as *'coming to terms'*.

In keeping with Frank's (1995) concept of narrative types, we may suggest that William's story is reflective of a 'quest narrative'. This type of narrative demonstrates how illness can be transformed into something meaningful. Quest stories are told when the storyteller comes to new insights about themselves (Frank, 1995).

3.4.1 Summary of 'the wounded survivor'

In the narrative of the wounded survivor, life was portrayed as a series of challenges that provided an opportunity for self-growth and acceptance. Although, protagonists' accounts show tragic features of loss, despair, disintegration and a wish for self-destruction, these individuals manage to find a way of overcoming their life crisis.

One protagonist described the initial process of recovery as feeling euphoric and empowering since this meant that she was in complete control of her life; while the other gained his inner strength from the encouragement of his family and friends. Both participants reported that the experience of their FD had equipped them with a greater empathy and understanding towards others. The overall mythic archetype of this narrative reflected that of a 'comedy'. In this type of tale, themes of resurrection and defeat of the powers of darkness are present (McAdams, 1988). Participants' regressive narratives were transformed into a progressive, and the "narrators were able to redefine their values and realise the positive features of the changed life" (Murray, 2008, p. 121).

Chapter 4: Discussion

4.1 Outline of chapter

This chapter will comprise a summary of the findings drawn from the analysis section, with the intention of presenting each narrative genre in the context of wider literature. As demonstrated in the analysis chapter, three distinct genres had emerged and these were identified as: *'the outsider', 'the helpless prisoner'* and *'the wounded survivor'*. The aim of this research is to look at the ways in which individuals with FD psychologically reconstruct themselves following a traumatic accident or illness. At the same time, it is intended that the findings of this research provide counselling psychologists with an understanding of and insight into the dominant themes expressed by this population, and, as such, inform the practice of counselling psychology. I will, therefore, for each genre that I present include further implications for clinical practice. The end of this chapter will be followed by a critique of the study and suggestions for future research.

4.2 Introduction

As pointed out earlier, participants' stories – and, indeed, genres – were not mutually exclusive; rather, there was some overlap and amalgamation between and within them. Narrative genres were explored by attending to dominant themes, language, plot development and structure of the narratives. There was a relationship between emotional tones and narrative genre in my study. For example, shame, anger and despair were found in the genre of *'the outsider'*; shame, empathy and despair in the genre of *'the helpless prisoner;* and empathy, euphoria and despair in the narrative of *'the wounded survivor'*. There was, however, a slight difference between the emotional tones in each genre, for instance, in the genre of *'the wounded survivor'*, although despair and empathy were found in both narrators' scripts, the third emotional tone differed as one of them felt euphoric, and the other felt grief. This only confirms the fact that narrators, at various points, processed their feelings differently. The core narratives were also reflective of the genre and emotional tones

of the narratives. For example, in the genre of **'the helpless prisoner'**, Thomas's core narrative was identified as *'you can't get away from it',* and his emotional tone reflected shame, anger and despair. Wendy's genre was **'the wounded survivor'**, her core narrative identified as *'I can cope and I can help others cope'*, and the emotional tone identified as empathy, euphoria and despair. For Helen, the core narrative was termed *'I march the beat to a slightly different drum'*, the emotional tones as empathy, shame and anger, and her genre as **'the outsider'**. Moreover, the reader will notice that as each **genre/dominant plot** is explored in further depth, the **subplots** within that specific genre is equally brought to light, this way allowing for the story to unpack itself.

According to Morgan (2000), the dominant stories that we create will not only affect our present life, but also have further implications for our future actions. For instance, in the narrative of **'the outsider'**, the dominant stories participants created involved that of being ostracised and rejected. As a result, the effect of being ostracised had further implications for how protagonists acted, felt and behaved in the future, which, in this case, for example, led to the creation of **subplots** about themselves as being *'different'*. Importantly, there was a variation in participants' subplots. To illustrate, in the subplot of *'belonging and acceptance',* the ways in which participants coped was described differently. For Helen, this meant that she became a *'pleaser'* in order to be accepted and liked by others, whereas for Olivia, this was manifested in an attempt to portray a *'strong'* persona to the world in order to *'fit in'* and be like everyone else. It could be argued that these variations are indeed part of our human diversities and thus, reflect the variability of narrative processes. Smith and Sparkes (2006, p. 170) wrote that stories "shape our identity, guide action and constitute our mode of being". It is my hope to be able to illuminate how the challenges of, for example, being *'the outsider'* impacted participants' sense of self, shaped their identity, and influenced their lives emotionally and psychologically.

4.2.1 Genre of 'the outsider'

Participants in the genre of *'the outsider'* shared their experiences of being ostracised, humiliated and rejected based on their appearance. The mythic archetype of this genre was reflective of the classic tragedy. McAdams (1988) noted that in the tragic story, "the hero finds himself separated in some fundamental way from the natural order of things" (p. 55). Essentially, the genre introduced a novel concept to the notion of social stigma and FD by expanding upon existing knowledge. That people with FD are subject to stigma and rejection, for instance, was already an explored theme. This genre, however introduced the way in which individuals living with an acquired FD perceive themselves as outsiders, and consequently reconstruct the self. This discovery was made possible as each individual narrative unpacked itself, thus providing me with an access and insight into how respondents' processed their psychological world.

Helen and Olivia were both attacked by a dog in their childhood, and because of this, they had from very early on been introduced to a face that deviated from the norm. What emerged from their stories was that these young women were frequently bullied and victimised due to their unusual appearance. For instance, Helen's recollections of being persecuted and ostracised had serious ramifications on her life, evident by her comment *'I'm terribly sociably anxious, and I think that's from being bullied'*. Similarly, Olivia's childhood was negatively recalled when she said *'I went through a lot of like bullying'* and the consequences of these negative events elicited further feelings of insecurity and inadequacy, which manifested in her attempt to seek plastic reconstructive surgery. These findings support literature, which suggests that stigmatized children are more deficient in relation to their peers, and also at a greater risk of developing negative self-image and psychological difficulties (Rumsey & Harcourt, 2007; Magin et al., 2008).

It could be argued that this study has further added an insight into how childhood experiences of visible difference can impact upon an individual's later life, emotionally and psychologically. One source that has shed light on this process is a book by Lansdown et al. (1997). For example, one male narrator who had been involved in a car accident as a young child, and who consequently suffered facial injury explained how the experience of being a victim of bullying further reinforced

feelings of inadequacy. The consequences of his facial injury led to a lack of confidence, feelings of inferiority and worthlessness. Another female narrator, who suffered from facial palsy as a child, recalled how the experience of being bullied and teased at school had a detrimental effect on her confidence. Thus, the aftermath of these events left her socially anxious and self-conscious. The final narrator, who had acquired severe facial acne, explained how the experience of her face made her feel unworthy as an adult, she felt ugly and repulsive. Though she was not bullied at school, the few revolting comments she encountered from friends and adults in general were enough to negatively affect her sense of self. Thus, the aforementioned accounts complement the findings of the existing study by providing valuable insight into how FD in childhood can have a detrimental impact upon the individual's later sense of self and identity.

Nevertheless, for Anne, being a constant victim of stigmatisation was so disturbing that, at times, she would '*rip*' at people, acting in a very aggressive and hostile manner. Anne's reaction resonated closely with Moss et al. (2011) study, who found that participants that were less well-adjusted in relation to their visible difference displayed greater sensitivity to the verbal or behavioural attacks of others, and were therefore more likely to respond in a hostile and aggressive manner. Thompson and Broom (2009) noted that this type of hostile behaviour was an adaptive strategy in order to deal with the excruciating pain of being excluded. Perhaps, as is suggested by Thompson and Broom (2009), Anne's aggressive and hostile behaviour could be understood as a form of coping mechanism adopted to protect herself from the pain of being excluded. Whilst Anne acted in a hostile and aggressive manner, this was not the case for Olivia and Helen. One explanation for this difference could be that Helen and Olivia both grew up with faces that were fundamentally distinctive and flawed from a very young age, so they may have been exposed to the judgmental and cruel reaction of others from very early on in life. For Anne, however, this was a sudden process, and may have, as a result, been too overwhelming for her to deal with.

Jaspal's (2012) article may shed some light on the discrepancy in respondents' reactions. Namely, Jaspal (2012) stated that individuals who acquire a disfigurement later in life are more vulnerable to experience threats to the continuity principle,

predominantly because they must learn to assimilate within their self-concept "an undesirable and, in many cases, unanticipated sense of change" (p. 333). This usually requires the individual to adapt to changes in interpersonal relationships and physical appearance (Jaspal, 2012). In line with this, Versnel et al. (2010) argued that those who acquire a disfigurement later in life experience a normal early development, but are then confronted with a loss of self, along with sudden changes in social status and social response. Thus, it could be argued that these assertions provide a framework for understanding the variations in participants' reactions.

4.2.1.1 A sense of being different

As participants' narratives unfolded, they reported that the experience of their FD, along with the negative and stigmatising reaction of others had left them with a sense of being *'different'*. Helen's core narrative, reflected in the form of a metaphor, communicated this sense of 'difference' when she said *'I march the beat to a slightly different drum'*. For Olivia, this sense of difference was evident when she said *'but I think deep down I don't want to be different to everybody else'*. However, for Anne, a felt sense of *'difference'* was experienced in relation to ways people belittled her. The findings of this study complement the work of Thompson et al. (2002) as they found that women who suffered from vitiligo developed a sense of being 'different' from others as their disfigurement gradually progressed, and these feelings were further exacerbated by the stigmatisation, negative remarks and humiliation they were subjected to. Participants in Thompson et al. (2002) study further reported that the idea that they were different from others had a negative emotional and social impact upon their lives. This finding was consistent with the experiences of participants in my study. For example, Helen's feelings of inferiority were evident when she stated *'you are not as good as'*. Olivia used a similar comment when she said *'proving that I can be something'* and for Anne this was expressed as *'I just hide away really'* along with, *'I see myself as nothing'*. These expressions were all indications that respondents suffered from a lack of confidence, low self-esteem and sense of self. It could be argued that these findings were consistent with Magin et al. (2006) as well as Murray and Rhodes' (2005) qualitative studies. They found that people who suffered from acne vulgaris experienced a range of adverse

psychological problems, including that of low self-esteem, poor self-image, embarrassment and self-consciousness.

Furthermore, both Helen and Anne expressed a subjective sense of self-hatred and unworthiness, which was evident at several instances throughout their narratives. For Anne this was manifested in perceiving herself as *'ugly'* and repulsive, thus avoiding looking at herself in the mirror. Her feelings of self-loathing were further evident in the manifestation of her obsessive and compulsive behaviour, acting as a form of self-punishment. These findings support Koster and Bergsma's (1990) assertion that acquiring a FD causes a violation to one's self-image. Turpin et al. (2009) found that participants who had acquired a FD developed a troubling relationship with their bodies, perceiving their bodies negatively. Such negative perception in turn had a devastating impact upon how they perceived the self. These findings were consistent with Anne's account. The emotional and psychological effect that FD had brought on Anne's life was rather powerful. Following her FD, Anne felt so dejected and hopeless that she made a suicide attempt; evident by her comment *'I tried to commit suicide a few times'*. These findings support previous literature, which suggest that people who live with various types of visible differences develop negative self-perceptions, maladaptive thought processes (Rumsey & Harcourt, 2004), and suicidal tendencies (Koster & Bergsma, 1990). Murray and Rhodes (2005) who explored the experiences of individuals with severe visible acne found that the presence of acne not only made respondents feel inadequate and less worthy, but respondents also suffered from anger, despair, and at times even suicidal thoughts. In addition, the authors noted that participant's lack of confidence, low self-esteem and self-worth made them undeserving of love and attention. Due to such an internal sense of insecurity, Murray and Rhodes (2005) discovered that these psychological constructs eventually led to problems in sexual and romantic relationships, and in the establishment of new relationships. This finding, particularly, reflected closely the experience of Anne. For example, due to a lack of confidence and low self-esteem, including feelings of shame, Anne refused to socialize with others, let alone meeting a potential romantic partner.

4.2.1.2 Desire for acceptance and belonging

A subplot that emerged across all three narratives was a desire for belonging and acceptance. Each narrator communicated this differently. For example, Helen developed a *'pleasing'* and submissive character in order to be liked and accepted by others. For Olivia, this meant adopting a '*strong'* persona in order to show others that she was not any different from the rest, because she *'just wanted to fit in with everyone'* and thus be accepted. Anne's desire for affiliation with others was revealed when she very fondly talked about her grandchild, explaining that she was the only person in the world who completely loved and accepted her unconditionally; everyone else devalued and vilified her. Threader and McCormack (2015) as they explored the lived experience of people with HNC found that participants in their study, due to being repeatedly excluded and ostracised, expressed a desire to be connected and affiliated with other stigmatised groups. It was believed that they could better relate to people who were in a similar situation. In my study, participants equally expressed a desire for connection and belonging with others due to repeatedly being stigmatised and excluded. However, while respondents (Helen and Olivia) in my study communicated their desire for belonging and acceptance through the construction of various types of personalities, this was not the case for participants in Threader and Mc Cormack's (2015) study. Future research could explore further, how, specifically, a lack of belonging connected to FD impacts upon ones sense of self and identity.

The socio-psychological theory of identity threat and identity process theory suggests that individuals need to receive sufficient levels of belonging, as a lack of it may result in identity threat (Jaspal, 2012). Participants' narratives confirmed this theory by showing how the lack of belonging caused a strong sense of alienation and internal threat. For Anne, however, her desire for acceptance and belonging did not manifest itself in this way. Bradbury and Hewison (1994) professed that children with congenital FD, because of being isolated and rejected early in life, experienced a lack of robust ego development. Although Olivia and Helen did not suffer from congenital FD per se, they acquired their disfigurement fairly early on in life, so this may have had a detrimental impact upon their ego development. This research seems to confirm the notion that those who acquire a disfigurement in younger years may

be prone to developing a fragile sense of self and identity, which in this case, manifested itself in a 'strong' persona and a 'pleasing' character.

Moreover, all three participants in this study made use of negative coping strategies in order to deal with the negative reaction of others, such as avoidance, social withdrawal, aggression and use of plastic and reconstructive surgeries. These findings were consistent with previous literature which showed that those who cope less well use negative coping strategies in the form of social avoidance, withdrawal and aggression (MacGregor, 1974; Kondo & Yamazaki, 2005; Newell & Marks, 2000; Moss et al., 2011; Thompson et al., 2002). Gilboa et al. (1999) found that individuals who adjusted less positively to their FD displayed neurotic and introverted personality traits, in contrast to those who adjusted well. Although it is difficult to precisely state the reasons for why some cope better than others, it is likely that for participants in this genre, a combination of a lack of self-efficacy, negative coping strategies, along with a neurotic and introverted personality, may have contributed to their inability to cope more effectively. Further research exploring the role of personality traits in people with visible difference is therefore warranted.

4.2.1.3 Empathy for others

Participants' narratives also contained positive elements, such as their ability to feel empathy and concern for other people. Helen and Olivia both expressed that the experience of their FD enabled them to better understand the pain of others, and both expressed a desire to help those in need. Helen had, in fact, trained as a counsellor, which could be understood as her ability to connect with and understand others. Similarly, Olivia spoke of wanting to become a therapist and help people like herself. Indeed, participants' desire to help others can be perceived as a form of coping mechanism, whereby the act of helping functioned as an affirmative and positive experience for them. The ability to feel empathy and compassion for others were equally reported by participants in Williams et al. (2003), as well as Egan et al. (2011) studies. Participants in both studies reported that the experience of their disfigurement had not only made them more resilient, but they had, as a result of this process, managed to develop a humbling and understanding approach to life. In addition, Threader and McCormack's (2015) study showed that as participants, due

to their HNC, struggled in understanding their new self, they developed a greater sense of compassion and understanding for other people. In other words, this reflected ways in which participants redefined their self. These findings were congruent with the experiences of both Helen and Olivia.

4.2.2 Clinical implication for Counselling Psychology

4.2.2.1 *Support groups or group therapy*

What really stood out for participants in this genre was the subjective sense of being excluded, which then resulted in a range of social and psychological difficulties. The desire for belonging and acceptance proved to be a significant factor for participants in the present study. I suggest that it would be important to facilitate support groups, or, alternatively, group therapy for these individuals so that they can be given an opportunity to relate and connect with others that are in similar situations. This would need to be facilitated in a non-judgmental, accepting and warm environment using Rogers's (1961) core conditions of empathy, congruence and unconditional positive regard. It has been suggested that social support groups have a function of alleviating threats to one's sense of belonging (Jaspal, 2012). On top of this, according to Jaspal (2012), these groups allow the individual to develop and increase their self-esteem in a safe and non-judgmental and non-stigmatising environment. The establishment of support groups may equally increase the person's self-efficacy by being exposed to other participants' narratives of success (Jaspal, 2012).

Lansdown et al. (1997) outlined a number of benefits that support groups can have for people with FD. Amongst others, they suggested that support groups can be a suitable forum where people with similar backgrounds meet and share their stories. Participation in such groups can lead to the development of nurturing, supportive and lasting friendships with other members. Another benefit is that support groups conducted in a safe and nurturing space can help those affected to develop healthier social and coping skills (Lansdown et al., 1997).

4.2.2.2 *Adopting a relational and compassionate focused CBT to work with self-critical and self-defeating thoughts*

What emerged from this study was that the experience of being *'the outsider'* had significant emotional and psychological consequences for respondents. Particularly, for Helen and Olivia, growing up with unusual faces in early childhood had a profound impact upon their ego development, leading to a fragile sense of self and identity.

As counselling psychologists it is therefore vital that we develop an awareness and understanding of these processes. In this section, I embrace a relational approach to CBT in order to show how we can effectively work with these issues by placing the therapeutic relationship at the centre of our therapeutic work (Safran & Segal, 1996). This is significant because in counselling psychology, the therapeutic relationship is perceived as a crucial tool for change and healing (Woolfe et al., 2003). Gilbert (2009) wrote that people who are subjected to early experiences of abuse, bullying, rejection and neglect can "become highly sensitive to threats of rejection or self-criticism from the outside world and can quickly become self-attacking: they experience both their internal and external world as turning hostile" (p. 199). For Helen and Olivia, early experiences of being excluded and rejected by peers and others contributed to feelings of inferiority, worthlessness and shame. In other words, as a result of these painful encounters, participants developed negative styles of thinking, beliefs, feelings (i.e. 'I'm worthless', 'I am inferior') and ways of coping (Gilbert, 2007) (portrayed a *'strong'* persona and developed a submissive and *'pleasing'* character). In such instances, Gilbert (2007) asserted that it would be important to re-frame meanings of past events and grieve past losses and traumas in therapy. I therefore suggest, in line with Gilbert (2007), that it would be important that counselling psychologists through a warm, caring, attentive and empathic relationship help their clients to recognise how early traumatic relationships with peers and others (i.e. being rejected, excluded and bullied) contributed to their feelings of inferiority, worthlessness and shame, and how these interactions, as a result, further shaped their adult styles of relating (Gilbert, 2007). For example, Helen developed a *'pleasing'* and submissive character, whereas Olivia portrayed herself as *'strong'* in order to fit in and be accepted. Gilbert (2009) stated that

sharing of such information with clients could essentially help them to develop compassion and understanding for their background.

Secondly, from a relational perspective, Helen's pleasing character or Olivia's attempt to portray herself as *'strong'* has clinical implications for counselling psychology, because essentially these styles of relating, which could be regarded as a way of coping, are likely to be re-enacted in the therapeutic relationship. Parpottas (2012) suggested that an attention to the transference in therapy is vital because it could potentially help counselling psychologists to gain an understanding of the client's phenomenology and problems. Counselling psychologists therefore need to create and maintain a strong and secure bond where both therapist and client can observe and accept what is happening between them (Parpottas, 2012). Such an exploration can eventually help clients become aware of the process and understand how it is connected to their difficulties. In conjunction with the use of transference, counselling psychologists can adopt cognitive behavioural techniques by challenging client's negative automatic thoughts (NAT), core beliefs, assumptions and maladaptive behaviours (Parpottas, 2012).

Nonetheless, given that all three participants more or less suffered from self-defeating thoughts such as being ugly, worthless and inferior, particularly Helen and Anne, who exhibited intense feelings of self-loathing and shame, I suggest that compassionate focused therapy could be a necessary form of intervention. Gilbert (2009) noted that individuals who exhibit high levels of shame and self-criticism often struggle in being kind, compassionate and caring towards themselves and others. In compassionate focused therapy, the task of the therapist is therefore to work compassionately with clients, by sharing qualities of warmth, tenderness and empathy, whilst at the same time, helping clients to develop kind and compassionate thoughts towards themselves; in doing so, clients will be more accepting and tolerant of their own distress, and essentially, learn to empathize with their pain (Gilbert, 2009).

4.3   Genre of 'the helpless prisoner'

Participants in the narrative of **'the helpless prisoner'** reported living a life in complete isolation, with limited access to the outside world. Their narratives were characterised by stagnation, hopelessness, isolation and negative emotional experiences, such as anger, despair, and shame. Overall, it could be said that their narratives were pessimistic in tone and stable/regressive in structure (Gergen, 1998). These narratives portray life as 'being a litany of woes' and the mythic archetype of their narratives could be characterised as one of 'tragedy' (Murray, 2003, p. 124). Furthermore, McAdams (1988) explained that tragic stories predominantly involve tales of violent death, isolation, sacrifice and heroism, and it was found that the majority of these tales were present in both Tasneem's and Thomas's accounts.

Participants presented themselves as helpless and miserable protagonists who felt imprisoned by their disfigurement. Whilst Thomas expressed being imprisoned by his face, for Tasneem, the sense of being imprisoned was not only limited to her face, but also to her social standing as a woman living with a FD in Pakistan. The primary function of their narratives was to make known the psychological damage and trauma their disfigurement had brought upon their lives. To my mind, the genre of **'the helpless prisoner'** has not been identified previously in any literature relating to FD. This could be because the focus of other studies has not precisely been on exploring the psychological reconstruction process of people with FD.

Tasneem's story of trappedness was communicated as *'My background is such that I had to live life which I am living* now'. Throughout her account, Tasneem talked about the difficulty of living with a FD in Pakistan, where she described her life as *'difficult'* and *'isolating'* because she was restricted to staying at home all day. Tasneem was unable to find a job due to discrimination, and socialising with others was avoided due to the negative and unwelcoming reaction she perceived from others. Although Tasneem was married, her husband had cheated on her, and despite this, she was incapable of asserting her rights. Feeling incapable of such contributed to her feeling trapped and powerless. A prevalent theme that emerged from Turpin et al.'s (2009) study was the *'disenfranchised self'*. The authors found that participants who had acquired a FD due to HNC struggled in establishing meaningful social relationships with others. This was predominantly because participants experienced their encounters with others as demeaning and devaluing, which in turn contributed

to feelings of helplessness and powerlessness. The way in which Tanseem's husband treated her was not only demeaning but also devaluing, leaving her in a helpless and vulnerable position.

Tasneem had also at various points communicated that it was *'hard'* for her to *'fight'* for her rights as a woman living with a FD in Pakistan. In accordance with this, Papadopoulos et al. (2002) found that the Indian and Pakistani groups who lived with the skin condition vitiligo, when compared to the Afro-Caribbean and Caucasian groups, reported a greater impairment in quality of life. Based on these results, the authors concluded that there might be a cultural explanation for these differences (e.g. karmic punishment, being cursed). It has also been suggested that the level of stigmatisation amongst the Indian and Pakistani groups negatively impacts the interpersonal and romantic relationship of the sufferer (Papadopoulos et al., 2002; Matto et al., 2002). Nevertheless, these findings confirm Tasneem's account, which suggests that being a woman and living with a FD in Pakistan can be particularly debilitating and 'restrictive', predominantly based on the culture's views and perceptions about visible difference.

Thomas's story of imprisonment was felt in relation to his FD, which prevented him from living a fulfilling life. His narrative depicted his face as an enemy over which he felt helpless and, very much like Tasneem, the majority of his time was spent in isolation. Thomas referred to the notion of trappedness, as *'you can't get away from it'*, which was discernible throughout his account. For Thomas, living with a FD was described as a *'torture'*, which caused him a great deal of physical and psychological pain. The theme of imprisonment was briefly expressed by participants in Röing et al.'s (2007) study, who, following an oral cancer treatment, described feeling incapable of escaping from their wounded mouths. The fundamental nature of their experiences was described as embodiment in a mouth that has become 'unreal' or 'uncanny'; in other words, escaping from a malfunctioning body was impossible. Like Thomas, participants reported being physically and emotionally vulnerable; however, whilst Thomas's story of imprisonment was mostly dominated by psychological pain, participants in Röing et al. (2007) study referred to their pain as mostly physical, hampering their ability to eat, swallow and drink.

The finding of this present study can therefore be seen to offer a distinctive way of understanding the experiences of people with oral cancer from a psychological perspective and, as such, adds further depth and richness to the experiences of those who live with a FD.

4.3.1 Shame

A common finding in this study was that participants' feelings of shame prevented them from socialising with others. For example, Tasneem avoided going to parties because of other people's reactions. Her mention of words such as *'hiding'*, needing *'protection'* and *'shelter'* confirms these very feelings of being flawed and defected. As a child, she was constantly the subject of other people's scrutiny and unwelcoming attention, which led her to using a burqa in order to hide herself behind it. Similarly, Thomas's feeling of shame was apparent when he communicated how difficult it was when people looked at him, and how impossible he found it to *'hide'* his face, unless it was covered by a mask. The only times Thomas would consider leaving his house was when he was surrounded by people with whom he felt comfortable, and his mention of being *'ugly'* further confirmed his feelings of shame. Threader and McCormack's (2015) study may shed some light on the findings of this study. Following a HNC, participants in their study expressed difficulties in adjusting to a 'new self'. Thus, what happened was that their altered appearance was compared with changes to their personality. This initially led participants to re-describe and re-assess their identity, which resulted in feelings of shame and embarrassment, and participants were reluctant in exposing themselves to others. Similarly, it could be argued that participants in my study, coping with changes in their own appearances constructed new identities of shame and embarrassment.

Pattison's (2013) book shared the story of a woman who from an early stage had acquired cancer of the jaw. Her story resembled closely the experiences of respondents in my study. It was revealed that, from early childhood, Lucy felt persecuted by the stigma and negative reactions of others, which evoked in her a terrible sense of shame. Lucy eventually grew up living 'less than a human life',

predominantly because she internalised the negative reactions of others. Her story highlights a person who, humiliated by her FD, sought refuge in hiding herself from the gaze of others, and the psychological turmoil associated with being seen. Subsequently, these encounters had a debilitating effect on her self-esteem, confidence and self-worth. Thus, Lucy grew up thinking that she was unworthy of love and attention. Such finding was consistent with the experiences of my participants. For example, Tasneem's story showed how the persecution of others, from an early stage of life, eventually resulted in feelings of shame (i.e. wearing a burqa, isolating herself, hiding). For Thomas, a sense of shame had a crippling impact on his life; evident by the way he avoided interaction with other people and mostly kept himself isolated from the outside world. Following his surgery, Thomas no longer pursued a romantic relationship with women, perhaps because, similar to Lucy, he no longer believed that he was worthy of any kind of love or attention.

Furthermore, the findings of this study confirm literature, which suggests that people who live with FD report difficulties in social interactions, and negative behaviour patterns such as avoidance (Rumsey & Harcourt, 2004; Van den Elzen et al., 2012; Papadopoulos et al., 2002; Thompson et al., 2010). Avoidance has been identified as a maladaptive coping strategy, which, at worst, will exacerbate psychological distress (Thompson et al., 2002). Therefore, it is likely that participants' avoidance strategy, which involved withdrawing themselves from social gatherings, further contributed to the development of social anxiety. In fact, Magin et al.'s (2006) study, which explored the psychological effects of acne vulgaris in adults living in Australia, discovered that a number of participants stated that the presence of their acne had contributed to a negative and permanent change in their personalities. Namely, they had developed an avoidant personality, as well as social phobia. These findings were consistent with the experiences of Tasneem and Thomas who rather kept themselves inside and did not engage in public spheres.

Newell's fear avoidance model may offer us a way of understanding the experiences of participants in the context of this research. Newell (2000) presented a model based on the hypothesis that psychological difficulties in people with FD originate out of a fear of the changed body and the reaction of others. Part of this fear, he suggested, was related to the sociocultural norms associated with body image,

which, in turn, exacerbated negative feelings about one's disfigurement. In essence, what perpetuates psychological difficulties in people with FD is the fear of how they will be perceived, as opposed to their actual appearance. Newell proposed that individuals who manage to adapt positively to their disfigurement and reintegrate into society are people who can deal with a series of confrontations of their disfiguring part into society and, as such, are able to develop more adaptive coping strategies. He believed that confrontation led to social integration, whereas fear resulted in social isolation. In this study, participants' fear of how they would appear in the eyes of others led them to withdraw socially and become isolated. To expand further on this concept, Newell and Marks (2000) found in their study that participants with FD displayed the same degree of social phobia as participants who solely suffered from social anxiety and agoraphobia. Participants' accounts therefore resonate closely with the findings of Newell and Marks's (2000) study, suggesting that their avoidance strategy was most likely adopted as a way of escaping feelings of social anxiety.

4.3.2 A sense of injustice

A prominent finding deriving from this study was the shared discourse of injustice echoed in participants' accounts. For Tasneem, a sense of injustice was felt in connection to her face and social standing as a woman, and her account conveyed this when she expressed a need to *'fight'* for her rights in order to break free from the strains of injustice, which oppressed her as a woman and denied her of her very basic rights. An example of this is demonstrated when she says: *'for me, it's very hard to fight for my rights because first of all I am a woman and second I have this disfigurement'*. Tasneem's narrative depicted her as a victim of scrutiny and oppression. She felt persecuted in her encounters with family members and the broader society, which were destructive to her self-image, which, in turn, had led her to adopt a position of **submissiveness** and **inferiority.** Thus, Tasneem lacked any control or power to change her situation.

For Thomas, however, the sense of injustice was accompanied with an emotional tone of anger, communicated in the following way: *'I didn't ask for it, I've done*

nothing wrong', followed by *'where is justice?'* The dominating tone of anger in Thomas's account at various points referred to the unfair life he was subjected to. In general, living with a disfigurement proved to be distressing and challenging, because he was suffering physically and mentally. Thomas had lost his long-time partner and could no longer foresee having a new romantic relationship, and he was no longer able to engage in activities he once enjoyed. The fear of how others would perceive him should he expose himself restricted his life. In summary, life was just not fair. It could be argued that these negative and unjust situations led Thomas to construct an image of himself as **helpless** and **powerless.** Subsequently, Thomas felt he lacked a sense of control over his life.

These findings are consistent with Bull and Rumsey's (1988) assertions that people who live with a FD are faced with a sense of powerlessness and helplessness as they lack a sense of control over their environment. To date, the theme of injustice has not been identified in any psychological literature relating to FD. Future research should therefore continue to explore the underdeveloped theme of injustice felt by individuals with FD. This is an important point because as Combs and Freedman (2012) noted, people who are victims of injustice could potentially construct faulty conclusions about their identity.

Furthermore, Hughes et al.'s (2009) study can shed some light on the findings of this study. The authors explored the attitudes and views on British South Asian communities in the UK towards people with visible difference. A number of themes were found which are relevant in the context of my research. Firstly, participants in their study seemed to hold a great deal of stigma and negative perception towards people with a visible difference, to the point that they associated disfigurement with a bad character or mental illness. Participants also reported that families of those who lived with a disfigurement felt a great deal of shame, and thus wanted to hide the person. It was also revealed that being a woman with a disfigurement in Pakistan, India or Bangladesh was much more difficult than being a man. Participants also reported that disfigurement limited the person to apply for jobs due to discrimination. Thus, Hughes et al. (2009) seem to offer an understanding that being a woman and living with a FD in Pakistan can bring with it many challenges and human suffering.

Borimnejad et al.'s (2006) study compared male and female experiences of living with vitiligo in Iran, and indicated that females more so than men showed a greater degree of impairment in quality of life and social interactions. Thomas's experience seems to suggest that even for men the experience of disfigurement can be a debilitating experience.

4.3.3 Despair

Originating throughout participants' narratives was a shared expression of despair. Tasneem's story of despair was evident when she spoke of using Xanax tablets in order to diminish her feelings of sadness, and explained that it was particularly *'hard'* for her to feel happiness, followed by *'it's very easy to feel erm, any sad moment'*. This quote suggests that Tasneem's story of despair had come to dominate a big part of her life. For Thomas, feelings of despair emerged as he talked about feeling *'psychological pain'* alongside a series of hopeless thoughts such as *'no one's going to take it away. It can't be taken away'*. What also emerged from their narratives was that participants had not received the appropriate and professional treatment they so needed. Although Tasneem had a brief experience of Cognitive Behavioural Therapy, she did not find it particularly useful. Thomas also felt troubled by the absence of any support when he stated *'if I had the right type of counselling'*, showing how a lack of professional support meant that he had to cope on his own. Although previous quantitative studies (Koster and Bergsma, 1990; Rumsey & Harcourt, 2004; Rumsey et al., 2003; Islam et al., 2012; Lawrence et al., 2006; Bundy & Sadiq, 2011; Newell, 2000; Tebble et al., 2006; Callahan, 2004) have provided valuable insights into the relationship between despair and FD, qualitative work by Murray and Rhodes (2005) succeeded in highlighting the sense of hopelessness and despair, by giving voice to participants' subjective experiences. For instance, one particular respondent in their study used discourses such as *'violently depressed'* and *'psychological torment'*, which resonated closely with the experience of Thomas who used words such as *'torture'* and *'psychological pain'*. It could be argued that a qualitative study offers a deeper understanding to psychological problems associated with FD. The findings of this present study

further complement the phenomenology of a burn survivor in Lansdown et al.'s (1997) book. This particular survivor explained that, following his facial burns, he rebuilt a new self. This new self reflected an insecure, sad and vulnerable person whose life was suffused with challenges and emotional pain. His story reflected closely the experience of Tasneem and Thomas.

In addition, Murray and Rhodes (2005) showed that participants often felt helpless and powerless due to a lack of control over their acne condition. As their acne condition worsened, it prevented respondents from living a healthy, stable and fulfilling life, restricting their ability to plan ahead. This sense of instability caused participants to feel helpless and restricted, leading to feelings of despair. The sense of helplessness and powerlessness with regards to FD was similarly expressed in this present study. Central to this research was that participant' stories of imprisonment further contributed to their feelings of despair. In an attempt to escape the negative reactions and unwanted attention of people, participants engaged in a process whereby they isolated themselves and avoided any contact with the outside world. In Tasneem's case, the cultural beliefs and practices in Pakistan with respect to FD was so extreme and powerful that it negatively influenced her life, emotionally and psychologically. For Thomas, his FD evoked feelings of shame and embarrassment to the extent that it restricted his ability to live a healthy and fulfilling life. Therefore, this study highlights that fear regarding one's appearance can induce negative feelings in an individual. The negative feelings expressed in this study restricted the lives of the participants, thus leaving them to feel imprisoned. This sense of imprisonment diminished both their sense of personal agency as well as their sense of control over their lives, which, in turn, caused the participants to feel helpless and depressed. In other words, it was the fear of what one's appearance could produce which brought about the participants' distress and not the disfigurement in and of itself.

4.4   Clinical implications for Counselling Psychology

4.4.1 *Personal agency in Narrative Therapy*

A salient finding that emerged from this study was the expressed sense of injustice. Combs and Freedman (2012) noted that people who are victims of injustice often

feel that they have done nothing wrong to stand unfairness and thus feel helpless to act or change their situation. According to Combs and Freedman (2012), this can potentially result in a construction of faulty conclusion about one's identity. Given that participants in this study perceived their situation to be unjust, and consequently felt helpless and powerless to act, I would recommend narrative therapy as a useful approach in which counselling psychologists, at times of disempowering situations, can help exploring stories of personal agency with their clients who suffer from visible difference (Combs & Freedman, 2012). This is important because it allows clients not to define themselves based on unjust situations (Combs & Freedman, 2012). In addition to this, it is also believed that people who stand against injustice often respond in their own little ways, but this usually goes unnoticed. Therefore, the task of counselling psychologists is to bring this forth and make it known in therapy (Combs & Freedman, 2012). In the context of this research, Tasneem's response to injustice was reflected in her account as an attempt to *'fight'* for her rights. In therapy, counselling psychologists can help Tasneem to recognise that her ability to 'fight' could be perceived as a 'heroic form of resistance' (Hutchinson & Lema, 2009), which meant that she actually responded to the situation and was not a helpless victim of her fate. Combs and Freedman (2012) mentioned that even though people's responses may be small, they create opportunities for *preferred stories* to be told, and at the same time, allow the person to separate from the problem. Narrative scholars believe that because illness and oppression have the capacity to silence a person's voice, the role of storytelling in therapy becomes crucial because it allows for the voice of the person to be heard, and, as such, helps to facilitate a sense of empowerment (Rappaport, 1995). In short, narrative therapy can assist clients to develop counter-narratives about their lives, instead of dominant and master narratives that are oppressive (Kirkpatrick, 2008).

4.4.2 *Compassion Focused Therapy and shame*

Emanating from the genre of *'the helpless prisoner'* was an intense sense of shame. Clarke et al. (2014) described that individuals who live with a visible difference are prone to experience shame. This, according to the authors, is because shame is

usually linked to early experiences of being rejected and ostracised; especially so, when the affected has internalized the judgmental and critical reactions of others. Clarke et al. (2014) further noted that body shame consists of two general types; externally-focused fears and internally-focused evaluations. Externally-focused fears are based on anxiety over being rejected due to one's appearance. Internally-focused evaluations occur when an individual holds destructive relationship with their self. They may perceive the self as 'ugly' and 'flawed' (Clarke et al., 2014). Participants in my study experienced both internal and external shame. For example, it could be argued that Thomas's expressed shame originated out of a fear of being rejected based upon his appearance. This was evident when he avoided social gatherings and was uncomfortable in exposing himself to others. Thomas equally experienced internal shame when he used the word *'ugly'*. Tasneem's account, reflected self-critical and self-attacking thoughts when she said: *'I am like trash'* or *'I am waste like garbage'*. Similarly, Tasneem avoided social gatherings out of the fear of being reproached and bullied.

Clarke et al. (2014) professed that because self-criticism and self-attacking thoughts are closely linked to feelings of shame, they need to be acknowledged and focused upon in therapy. One way in which counselling psychologists can work with the issue of shame is through the use of compassion-focused therapy (CFT). This model, developed by Gilbert, gleaned aspects from CBT to tackle shame-related issues through a compassion-based approach (Gilbert, 2009). In line with Clarke et al.'s (2014) advice, I propose that counselling psychologists should firstly begin to identify the power and function of their clients' self-critical thoughts. An attention to and exploration of underlying beliefs are vital, otherwise it may prevent the possibility for self-critical thoughts to be challenged (Clarke et al., 2014). Once these self-critical and destructive thoughts have been identified and acknowledged, counselling psychologists can integrate them into their formulation, engage in cognitive restructuring, and apply a compassionate-based approach to help their clients to develop empathy and kindness towards themselves (Clarke et al., 2014). Adopting self-compassion attributes in psychological therapy can be used to help the client shift away from self-destructive thoughts and move towards more self-nurturing psychological processes (Gilbert, 2009). This involves helping clients to develop feelings of compassion for themselves, for others and from others (Gilbert,

2010). Simultaneously, counselling psychologists ought to create an atmosphere that is de-shaming, compassionate and safe (Gilbert, 2010). Compassionate feelings can also be created through *compassionate –imagery*, which aims to develop compassionate feelings in the client through the use of imagery (Gilbert, 2009). For example, Clarke et al. (2014) suggested that clients should be encouraged with the help of their therapist to imagine what it would feel like if they possessed qualities of compassion, kindness and warmth.

4.5   Genre of 'The wounded survivor'

The genre of *'The wounded survivor'* portrayed life as a series of challenges that provided an opportunity for self-growth and acceptance. Although protagonists' accounts show tragic features of loss, despair, disintegration and a wish for self-destruction, these individuals manage to find a way of overcoming their life crisis. As such, participants reported that the experience of their FD had equipped them with greater strength and empathy. The overall mythic archetype of this genre reflects that of a 'comedy'. McAdams (1988) referred to the archetype of comedy as "dawn, spring and the birth phase, involving stories of the hero's birth, of revival and resurrection, of creation and of the defeat of the powers of darkness, winter and death" (p. 54). In this genre, participants' regressive narratives were transformed into the progressive, and "narrators were able to redefine their values and realise the positive features of the changed life" (Murray, 2003, p. 121).

Turpin et al. (2009) when exploring the meaning and impact of HNC participants, discovered a theme, which they identified as *'destruction of self'*. This theme related to the shock and devastation participants experienced upon receiving an HNC diagnosis. The diagnosis was accompanied by the emotionally overwhelming news that participants were at risk of losing parts of their face. Respondents' emotional reactions to loss of self ranged from despair, anger, sadness and suicidal thoughts. Such findings were consistent with the experiences of participants in my study. For example, Wendy said: *"I just started a big shaking attack in the chair. And I was shaking from head to toe; I couldn't control myself"*. Following this, Wendy had a period where she fell into a state of euphoria. This was her way of coping with the

painful news of her cancer and change of appearance, and shortly after, Wendy described having *"a long period in the woods"*. For William, the news of his cancer and its potential consequences on his appearance was so devastating and profound that he could no longer bear to contain these violent feelings, and thus attempted suicide. William explained visiting his psychiatrist because he still had periods of despondency and experienced a fluctuation in his mood.

David and Barrit (1979) concluded that facial cancer that occurs in later years causes a 'violent mental shock', and the person afflicted has more difficulties in adjusting to their self-image compared to someone who was born with a congenital FD. This is because the person has familiarised themselves with that old image for so long. The accounts of my respondents confirmed these 'violent' emotional reactions, thus confirming the assertion that acquiring FD at an advanced age can be particularly devastating and shocking. The diagnosis of HNC was thus seen as an "attack on their fundamental sense of self" (Turpin et al., 2009, p.31). The findings of this study further support the notion that individuals who acquire FD are faced with a threat to their self-concept and sense of security (Koster & Bergsma, 1990).

4.5.1 Grief and loss

Adsett (1963), a psychiatrist, presented an insightful psychodynamic article on the emotional reactions of individuals with facial cancer. Adsett stated that emotional reactions, which he referred to as depressive reactions and denial (accompanied with bravado-type behaviour), are manifested in individuals who acquire a facial cancer. Depressive reactions are common and connected to a sense of loss that individuals experience following a facial mutilation (Adsett, 1963). Adsett (1963) argued that depressive reactions could be described as self-directed, inward-turning anger. Individuals who have suffered disfigurement may begrudge their body for a perceived failure of the body to maintain its integrity, upset that the body has forsaken them (Adsett, 1963). According to the author, this sense of loss includes a loss of physical parts and loss of valued life activities/roles. A subplot that emerged in the genre of *'The wounded survivor'* was that of loss. Participants in my study experienced two types of losses; a physical loss and an existential loss of identity.

Loss for Wendy meant a loss of her past life, which was communicated by her as *'bereavement for your past life'*. Wendy had not only lost her facial features, such as an eye and half of her facial skeletal bones, but she had also lost part of her existential identity. For William, a sense of loss meant a combination of tangible and intangible losses. William lost his jaw and tongue, but as a consequence he had also lost his ability to eat and taste. The intangible losses in William's account contained loss of autonomy, independency and the loss of a potential future romantic relationship. For example, both of my participants lived isolated lives, which confirmed the prospect that they suffered from social losses. Perhaps, as suggested by Adsett (1963), respondents in my study felt so begrudged and betrayed by their bodies that they turned this anger against themselves, thus being a source of their depressive reactions. It could be argued that this depressive state was a process whereby respondents grieved and mourned the lost body part.

Williams et al. (2003) explored the stories of "recovery, adaptation and resiliency in burn survivors". It was found that the theme of loss was a significant part of participants' post-burn reality. These losses included the loss of physical ability, job career, body image and interpersonal relationships. Psychological losses included the loss of self-worth, sense of self, independency and autonomy. Such findings resonated closely with the experiences of participants in my study. The findings of this present study further support Harcourt and Rumsey's (2008) assertion that people who acquire a FD eventually have to cope with feelings of loss and grief towards their former appearance. Also, the findings of this present study complement literature that suggests people who acquire a disfigurement are likely to undergo a process whereby they mourn the existential part of their identity, in other words, mourning the loss of *"not being who I was"* (Henry, 2007, p. 281).

Wendy's reaction to loss was a rather tumultuous process. Her account reflected the difficulty in coming to terms with a sense of loss by adopting a stance of *'euphoria'*. Such finding confirmed Adsett's (1963) assertions that individuals who suffer from facial cancer engage in a process of denial accompanied with bravado-type behaviour. It is further argued that such a coping strategy may not be helpful in the long term because individuals who express positive or defensive symptoms during early stages of loss are likely to delay their healing process (Krishna, 2009). Such a depiction resonated closely with Wendy's reaction to loss, which could be

understood as her way of coping with unbearable and overwhelming emotions. Having said this, what this study simultaneously showed was that although Wendy engaged in a process whereby she defensively denied what had happened to her, this defensive stance indeed allowed her to cope effectively and move on with her life. However, what was revealed in this study was that although emotional dissociation helped Wendy to cope effectively, as time went on, this manifested itself in a delayed grief response, whereby she fell into depression, despite the fact that she had acquired her disfigurement years earlier, evident by her comment '*bouts of depression*'. Such a reaction has been termed amongst bereavement theorists as *'absent grief'*, which involves an absence of prolonged distress following a traumatic and life-altering situation (Krishna, 2009).

In summary, whilst Wendy coped with her feelings of loss by adopting intrapsychic processes such as defensive denial, for William, this was manifested in his attempt to take his own life followed by feelings of despair. As William's account unravelled, his ability to cope was processed more naturally than Wendy, predominantly because he was able to feel pain along with negative emotions such as despair.

4.5.2 Resilience and growth

Wendy's core narrative was described as *"I can cope and I can help others cope"*, which suggested that the experience of her FD had equipped her with an inner strength and ability to feel warmth and compassion for other people. Part of this strength involved her capacity to accept her appearance and appreciate that her life had been saved from cancer. A similar experience was echoed in William's account when he explained that the incident of his FD had made him *'stronger'*, and his core narrative was identified as *'I am going to fight it'*, which reflected an acknowledgement to contend with ongoing struggles. It could be argued that participants in my study constructed identities of themselves as survivors. The findings of this study complement the works of previous scholars who explored the experiences of people having adjusted positively to their visible difference (Egan et al., 2011; Williams et al., 2003). These studies showed how participants were able to perceive the adversity they endured as a positive experience. These positive benefits

were identified as personal growth, insight, self-esteem, gratefulness and identity. Whilst Wendy's account reflected her ability to gain personal strength, growth and gratitude; for Thomas, the two integral aspects of his account involved personal growth (empathy) and resilience.

Participants in the aforementioned studies (Egan et al., 2011; Williams et al., 2008; McLean et al., 2015), similar to respondents in my research, expressed a desire to give back to their communities and help others. This altruistic act of kindness referred to the theme of personal growth. Participants' altruistic behaviour, similar to respondents in the narrative of *'the outsider'*, could be understood as a form of adaptive coping strategy, in the sense that the mere act of giving back to others brings about pleasurable feelings in the giver. On top of this, it is possible that participants' willingness to help others was an important facet in their emotional healing process and this was evident when, for example, Wendy explained that helping others made her feel better about herself. Such findings resonated closely with participants in Williams et al. (2003), who discovered that the act of helping others was an important facet in their healing process. For example, participants in Egan et al.'s study stated that their visible difference led to the improvement of interpersonal relationships and understanding of other people. This finding was consistent with the accounts of my participants. To illustrate, Wendy's connection and sense of concern for other people was communicated in the following way: *'whatever happens to someone, I am there for them'* and for William, the experience of his FD meant that he became more understanding and empathic towards others. These findings confirm Threader and McCormack (2015) study, who discovered that as HNC participants struggled to come to terms with a new 'self' they developed a greater sense of compassion and kindness towards other people. Similarly, participants in my study redefined a new self that was more compassionate, empathic and understanding.

Egan et al. (2011) revealed that participants had adopted various coping strategies that contributed to their positive adjustment. Some of these coping strategies were identified as 'inner strength', 'positive outlook', 'cognitive reframing', spirituality and social support. Some of these themes overlapped with the findings of my study. For example, in the case of William, the level of social and moral support that he

received from his family was a crucial aspect of his recovery. One way in which William was able to adjust positively was through the persistence of a positive attitude and acceptance. For example, despite the challenges he had encountered, he still believed in the importance of integrating himself into society, by socializing with others, in order to avoid falling back into a depressed state and becoming isolated. These findings complement the work of Moi and Gjengedal (2008) who found that participants with burn injuries made an effort to "regain freedom", striving for a life that resembled their past. Acceptance coping was likewise present in Wendy's account when she said *'I am disfigured, I do not care'*. In addition, Wendy's previous comment *'my life is precious' and 'my life is saved* conveyed her optimistic and positive attitude towards life. These findings complement Askey and Magyar-Russell (2009) assertion that acceptance coping is an important element in the development of PTG (posttraumatic growth). It is generally believed that individuals who can accept the traumatic incident, in this case, their FD and that it cannot be changed, are better able to cope and shift their energy towards aspect of situations that they instead can control (Askey & Magyar-Russell, 2009).

Gilboa (2001) noted that a contributing factor to positive adjustment is the personality of the individual that governs their coping and adjustment. The author further noted that attitudes such as optimism, hope and self-efficacy are contributing factors to positive adjustment. Participants in my study held a positive and optimistic attitude in the face of challenging life events. It could also be the case that participants in my study displayed a more extraverted personality trait compared to those who coped less well. Therefore, further research is needed in order to investigate the role of personality trait in people who report adjusting positively to a visible difference. Nevertheless, this study showed that although emotional dissociation may have later health costs, it can enhance resilience and allow for adversarial growth in the individual, and that, equally, cognitive engagement with the traumatic loss can lead to resilience and adversarial growth.

4.6   Clinical implications for Counselling Psychology

4.6.1 *Working with loss in Narrative therapy*

Counselling psychologists who work with this specific clientele need to remain aware of the painful sense of loss that many of their clients may present in therapy. People who have acquired a disfigurement to their face are not only confronted with a loss of physical damage and mutilation but also grapple with a loss of their existential identity (Henry, 2007), their independency and autonomy. Frank (1998) advocated the importance of listening to the stories of those who live in "deep illness". Frank claimed that stories need a listener, be it in the presence of somebody or alone; the mere act of telling a story is a relational process (Frank, 1995). Individuals who live in deep illness have therefore a desire to be heard and understood, and counselling psychologists can make this possible by attending to their clients' stories. Frank (1995) suggested that the mere act of "bearing witness" to the ill person's story could assist them through a process of pain and suffering. The use of storytelling in narrative therapy may therefore enable clients to bring a sense of coherence and meaning to what otherwise may seem a disruptive and chaotic life plot. In the case of Wendy, for example, the incident of her face appeared so traumatic that it led her to engage in a process of emotional dissociation, whereby she excluded painful aspects of the event out of her memory and the narration of her experience in a social context (Neimeyer, Herrero & Botella, 2006). Narrative theorists refer to this activity as *narrative dissociation* (Neimeyer et al., 2006), which then, according to the authors, will promote the development of a "silent story". Stories of this kind resist reintegration into the person's self-narrative. Therapists could help the client to construct a coherent narrative of the actual event, which facilitates an integration of the loss into the person's self-narrative (i.e. loss of their previous self) (Neimeyer et al., 2009), in other words, helping the person to mourn their old self before they can reconstruct a new self (Williams et al, 2008). I will suggest a number of narrative 'techniques' based on the work of Neimeyer et al. (2009) that I think will be valuable when working with individuals who have acquired a FD and who, as a result, are struggling to come to terms with their loss.

One way to meaningfully integrate the experience of loss in therapy is to allow for the process of *narrative retelling* to occur. This can provide an atmosphere of social validation for the narrator's account, and restore the empathic failure or silence that the bereaved person has encountered (Neimeyer et al., 2009). Throughout the process of *re-telling,* therapists need to focus on the most difficult parts by staying with them in sessions until the associated images and meanings are experienced as less painful. This process allows the individuals to regain mastery of difficult material and counteract maladaptive coping strategies such as avoidance. In addition, the use of *therapeutic writing* has also been widely used amongst narrative practitioners. This approach may be valuable for those clients who are unable to adequately verbally express their thoughts. As such, clients would be invited to write about themselves in relation to the loss from the perspective of a compassionate other, or even use meaning reconstruction interviews. Neimeyer et al. (2009) believed that meaning reconstruction allows the client to re-access the vivid image of their loss and to seek a fresh narrative from those images.

4.6.2 *Focus groups*

What emerged from this study was that despite the sense of loss and negative emotions that participants encountered as a result of their face, nevertheless, they managed to cope remarkably well, and were able to move on with their lives. Based on these findings, perhaps it would be worthwhile if counselling psychologists created focus groups for individuals who have acquired a disfigurement by inviting those who have coped positively to meet those who are yet struggling. Individuals who have coped positively could then share their stories with the rest of the group and allow others an insight into their world by showing how they managed to overcome these difficulties. This could be a powerful experience for those who are still struggling emotionally, as this shared group experience may allow them a realisation that there is *hope* and possibility for recovery.

4.7   Critique and Evaluation of Present Study

Although this study has generated some rich and valuable findings, it is nevertheless bound by some limitations. The stories that participants shared in this study took place at a particular time and particular context. As human beings, we are always evolving and in a constant state of flux; as such, the stories that we share with one another are likely to change as time moves on. Therefore, the findings of this study can only be representative of this population at this particular time in their lives. Secondly, this study consisted of a small sample of mainly white British respondents, with the exception of one participant, who was of South Asian origin. The findings of this study cannot therefore be generalised to all people who live with an acquired FD. Having said this, the small sample size allowed me as a researcher to engage in an in-depth analysis of the data. In addition, given the sensitive nature of this study and the stigma attached to people with FD, many people with FD may have felt vulnerable and ashamed of their appearances, and therefore were reluctant to take part. Thus, stories of those individuals who felt most vulnerable and ashamed were not included in this study. Importantly, as with any qualitative research, it should be acknowledged that the construction of this study was based on a mutual relationship between the participants and myself. The findings of this study would have been entirely different had it been conducted in a different context by a different researcher. In other words, the interview process, analytical stage and genres of each story would have differed had another researcher carried out this study. Inevitably, the researcher's background, prejudices and preconceptions have all shaped and impacted upon the findings of this research (please see Chapter 1). Given that my topic focused on how people with FD reconstruct themselves psychologically, careful attention was paid not to focus entirely upon negative experiences or challenges relating to FD when interviewing respondents; rather, I aimed to find a balance between both challenges and positive experiences. Choosing a heterogeneous sample could be regarded as a particular strength of this study, because such an approach helped to produce useful insights and knowledge into other forms of FD (Rubin & Babbi, 2009).

In order to ensure that my research was of good quality, I followed Yardley's (2000) four essential criteria necessary for good qualitative research. Yardley outlined them

as follows: 'sensitivity to context', **'commitment and rigour'**, 'transparency and coherence' and 'impact and importance'. Sensitivity to context comprises the context of theory, sociocultural setting and the social context of the relationship between researcher and respondents. Sensitivity to context has been demonstrated in this study by providing a thorough review of the relevant theoretical and empirical literature in the Introduction chapter, as well as positioning current findings in the context of existing psychological literature throughout the Analysis chapter. In terms of sociocultural context, participants' stories, and the findings produced in this study were understood and analysed as part of their social and cultural backgrounds. For example, some of my respondents described themselves as 'ugly', 'worthless' and 'not good enough'; such accounts were all understood as being reflective of negative social encounters, which participants had internalised. As such, reflective of my epistemological standpoint, respondents' stories were all analysed in the context of their social and cultural background. I showed sensitivity to social context by ensuring that I had established a collaborative, warm and trusting relationship with all my participants. I believe that my background as a trainee-counselling psychologist enabled me to facilitate a space where participants felt safe and contained enough to share their stories with me, which consisted of rich and delicate material. I regard this as a particular strength of the present study. In addition to this, although I knew that this research was towards the completion of a doctorate degree, I wanted to ensure that my participants, by taking part in this research, equally felt that they gained something valuable from it.

My commitment to the research topic can be demonstrated throughout the past four years in which I have been engaged with this project and been in continuous contact with my research supervisor by keeping him up-to-date on my progress. A rigorous approach was taken by carefully reading up on narrative analysis in order to ensure that my analysis was adopting a conservative narrative approach. I have also, at various points, sent a sample of my interview extracts along with my analysis to my research supervisor so that he could give me appropriate feedback for cross-validation purposes, and to confirm that the account presented was plausible.

Transparency and coherence was demonstrated by giving a thorough and detailed description of the data collection and analytic procedures. I have included extracts of

participants' narratives and remained reflexive throughout this research study. An example of analytic procedures can be found in the appendices so that the reader can grasp how I have gone about analysing the transcripts. In order to further ensure transparency, I kept a reflexive diary whereby I documented my internal feelings along with how my preconceptions and biases had possibly impacted upon the study and how hearing the stories of my participants had impacted me in return.

Finally, Yardley (2000) stated that a research produced needs to be judged by its impact and importance. It is therefore not sufficient if a research produces a thorough, plausible and sensitive analysis and yet cannot be of clinical and theoretical relevance (Yardley, 2000). In accordance with the author, I hope that my research has drawn upon empirical literature in order to present a novel perspective by having contributed knowledge and understanding to the area of FD. Its clinical importance, although not yet implemented in clinical practice, I hope will be of benefit to this specific population, as well informing the practice of those clinicians who work with this clientele.

4.8   Implications for Future Research

This exploratory study has highlighted several areas for future research. As was apparent, the majority of respondents in this study were females; only two participants were representative of the male sample. Future research should include a balanced sample of the sexes in order to gain a better understanding of, and insight into, the male narratives. Prior to embarking upon this research, my presumption about FD was that women are more likely to suffer than men. However, this research has proven that this is not necessarily the case. Further insight and awareness as to how men psychologically reconstruct their self is needed so that counselling psychologists can tailor their therapeutic skills when working with this population. For example, a more balanced sample of the sexes may allow counselling psychologists to observe any differences between the ways male and females process their disfigurement.

Given that the stories participants shared in this study were context-specific, and bound by a single moment in time, an important area for future investigation would be to conduct a longitudinal study, with the aim to explore how this population reconstruct themselves psychologically over a long period of time. Doing so may allow counselling psychologists an insight into the ways that these individuals cope over time or track any changes that occur over time. In line with this, research should also explore the psychological processes of individuals who have acquired a disfigurement in childhood, and track their developmental changes into adulthood, in order to explore how childhood experiences of FD impacts upon the individual's later sense of self and identity. Such findings may allow counselling psychologists to develop better insight into the experiences of both children and adolescents and, as such, enable them to tailor their therapeutic approach to fit the needs of this vulnerable population.

Although the majority of participants in this study were of white British descent, one participant was of Pakistani origin. The present study was able to show that cultural factors do influence psychological wellbeing, which has been replicated in others studies (Thompson et al., 2010; Papadopoulos et al., 2002). For this reason, I would suggest that future research in the field of FD should focus on cultural differences. Such discovery could enable counselling psychologists to gain more awareness and knowledge of how individuals from various cultures and ethnic backgrounds psychologically process their disfigurement. Such discovery may enable counselling psychologists to provide the appropriate level of therapeutic support.

What further stood out from this research was that the theme of injustice had previously not been explored in any literature linked to FD. Future qualitative research should explore the psychological impacts a sense of injustice can have on individuals affected by FD. Given that discussion regarding the role of personality trait and visible difference remains uncertain, I would be very keen to conduct a similar study, using a combination of quantitative and qualitative (mixed method) studies whereby personality measure traits in combination with research interviews would be carried out. This would allow the researcher to determine whether personality traits play a key role in the adjustment process of visible difference or

not. If this is not the case, counselling psychologists can identify other factors that may contribute to a person's inability to adjust.

4.9 Reflexivity on Research Process

The findings of this study were a joint process between participants (tellers) and myself (listener) in which both parties actively shaped and formed this research, rather than conducting a research based on 'answers' and 'responses'. This interview could mostly be referred to as a 'circular process', with my respondents and I attempting to make sense of what was brought up in the interviews (Hyden, 2013). Although semi-structured interviews were assigned to all my interviews, I did not stay with them in a rigid and robotic way; rather, I remained flexible in order to allow respondents to freely share their stories with me and, where necessary, give them sufficient time to recompose and ensure that they were emotionally and psychologically contained. I felt that this approach was highly salient to my research, predominantly because I was researching a very sensitive topic. I remained aware of the fact that as participants disclosed such personal and sensitive material about themselves, there was a potential risk of re-traumatisation. I adopted a humanistic attitude throughout all my interviews by facilitating a space of warmth, acceptance, empathy and trust so that respondents could feel safe enough in relation to me. Secondly, given that this was a population whose voices had never been heard, I felt that it would be important to facilitate a space for their 'untold stories' to be told (Hyden, 2013). Although none of the participants in this research were re-traumatised, two respondents felt that the research process had provided them with material (feelings of loss), which they wished to explore in therapy. In fact, I felt that the mere act of sharing their stories with me had been a liberating, validating and insightful process for them. Simultaneously, being exposed to the pain and suffering of my participants affected me emotionally, whereby I felt very sad and protective of them. As a result, at times, I felt a need to offer my respondents a therapeutic 'intervention'; however, acknowledging my role as a therapeutic researcher, I remained mindful of the boundaries between research providing a therapeutic experience and therapy, and, as such, refrained from falling into a 'therapy trap'. I

must add that I was appalled and shocked to hear of the inhumane and cruel treatments that my respondents were subjected to as a result of looking visibly different. In all, I feel that conducting this research, although immensely challenging at times, has enhanced my understanding of FD. Being able to listen to and analyse participants' accounts has provided me with invaluable insight into, and understanding of, their psyche. The use of narrative methodology and narrative therapy has simultaneously helped me to appreciate the important role that storytelling can have in the lives of those who have experienced disruptive life events. I feel very passionate now about the use of storytelling in therapy and I look forward adopting such an approach when working with my future clients. Although I am aware that the insights I have gained from this research is reflective of a small sample size and cannot be generalised to all people who live with FD, I trust that it will be a good foundation in which I can further my knowledge and practice when working with this population. Nevertheless, it appeared that the majority of respondents in this study found this research experience to be a helpful and insightful process for them.

4.10 Conclusion

The aim of this study was to investigate how individuals who have acquired a FD psychologically reconstruct themselves, following a traumatic accident or illness. The narratives shared in this study revealed that all of the participants had, more or less, suffered psychologically as a consequence of such life-altering event. Their stories were suffused with emotional pain, agony and a sense of disintegration. However, at the same time, a number of the participants expressed that the experience of their face had enabled them with an inner strength, and an ability to understand and connect with others who were less fortunate.

This study is the first to adopt a narrative analysis in order to explore how survivors with a diverse range of acquired FD psychologically reconstruct themselves. Significantly, this research has brought a novel understanding to the concept of FD and social stigma. That people with FD are subject to stigma and rejection, for instance, was already an explored theme in the wider literature relating to FD.

However, this research provides an insight into the storied world of these individuals by demonstrating how the consequences of living with a FD and of being a constant victim of social disgrace, can leave a profound impact upon one's sense of self and identity. As we are aware, the early years of a child's life are extremely important in the formation of their later sense of self and identity. This study has also shed some light on this process, by showing how visible difference acquired in childhood can have further psychological and emotional consequences in adulthood.

What further emerged from this study was the genre of *'the helpless prisoner'*. To date, this genre has not been acknowledged and identified in any previous literature linked to FD. Thus, it could be argued that this study succeeded in highlighting how participants with FD were depicted as miserable and helpless protagonists who felt imprisoned by their disfigurement. Consequently, this genre emphasised how their stories were suffused with emotional pain, helplessness, a sense of injustice and stagnation.

At the same time, the use of a narrative analysis, showed how, despite a sense of loss, disintegration and mental pain, participants with an acquired FD, *constructed* identities of themselves as *survivors*. Their stories revealed how protagonists redefined a new self that was compassionate, tolerant and understanding.

Hence, this study offers new and important insight into this phenomenon and will hopefully inform the practice of counselling psychology.

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Appendix A

CITY UNIVERSITY LONDON

Consent Form

Project

This research project is part of my doctoral thesis in counselling psychology at City University, London

The psychology department at City University has granted ethical approval for this study.

Purpose of this research

The aim of this research is to look at how individuals with facial disfigurement reconstruct themselves psychologically, after a traumatic accident or illness. It is intended that this research bring an insight into how counselling psychologist's can support individuals with facial disfigurement and in turn increase their knowledge and understanding around this topic. .

Equally, I hope that this interview will give you an opportunity to have your voice heard and talk about your experiences in a non-judgemental and confidential environment. Hopefully this interview will provide you with an insight and a space to reflect and make sense of your experience!

Procedure

As part of this research project you will be asked to take part in a semi-structured interview, which will allow you to share your story with me. The interview will be audio –taped, and any information you disclose will remain STRICTLY CONFIDENTIAL.

Due to the sensitive nature of this topic, you may find that painful images, memories or feelings may arise in you as you talk about this subject, I will therefore give you adequate time to recover during the interview but should you find this upsetting ,you can choose stop the interview at any point you feel is appropriate.

You have the right to not answer questions that you do not feel comfortable with and the right to withdraw from the study at any point. Regardless of your choice, your decision will be respected and remain confidential at all times.

I understand that the results of this research will be published and that my personal details will in no way be identified.

The researcher will at all times abide by the British Psychological Society (BPS) code of ethics and protect the confidentiality of all participants.

I would like to thank you for taking part in my study!

I have read and understood the above consent form.

Date ....

Participant's name...............................

Participant's signature............................

Date ....

Researcher's name...................................

Researcher's signature ....

Appendix B

Information Sheet

Dear…

Thank you for taking your time to take part in my research study!

My name is Paniz Samsami and I am a counselling psychologist in training.

As part of my doctoral studies in counselling psychology at City University, I aim to carry out a research project that looks at how individuals with facial disfigurement reconstruct themselves psychologically, following a traumatic accident or illness.

I am mainly interested in hearing your story of living with facial disfigurement.

If you feel that the above description resonates with you, please do let me know. I would be happy to assist you and answer any questions that you may have.

Throughout this research interview, I hope to be able to offer you with a safe space where you can feel comfortable to share your story with me. You may realize that by being given a voice to talk about your experiences and share your story in a safe environment will enable you to have a positive and therapeutic experience.

It is also hoped that this research will help people like myself to gain an understanding of the experiences and common themes that people with facial disfigurement experience in their daily life. Psychologists who have not gone through such experiences would likely not possess the insight and understanding on this matter. Your contribution could therefore provide positive knowledge for counselling psychologists who work in this area.

This research study is supervised by Dr. Don Rawson, a qualified counselling psychologist and has prior to commencement been approved by the ethics board of this institution.

As part of this research project you will be asked to take part in a semi-structured interview. The interview will be audio –taped, and any information you disclose will remain STRICTLY CONFIDENTIAL. The interview will last approximately between 90-120 minutes. All recordings will be kept in a safe locked cupboard or in a password protected file and destroyed once the study has terminated. Your recordings will not in any way be used for any other purposes than this research.

Due to the sensitive nature of this topic, you may find that painful images, memories or feelings may arise in you as you talk about this subject, I will therefore give you adequate time to recover during the interview but should you find this upsetting ,you can choose to stop the interview at any point you feel is appropriate.

For further details and questions please contact either myself or my supervisor on the below contact information.

Researcher: Paniz Samsami

Email: ██████████████

Phone: ██████████

Research Supervisor: Dr. Don Rawson: ██████████████████

Appendix C

Would you like to share your story with me?

Are you currently living with facially visible scars, or know someone that does?

My name is Paniz Samsami and I am counselling psychologist in training. As part of my doctoral studies in counselling psychology, I am carrying out a research project that specifically looks at how individuals who have acquired a facial disfigurement, as a result of an accident or illness, psychologically reconstruct themselves.

I am mainly interested to hear your story of living with facial disfigurement.

Perhaps before I move on to describe the details of this research study, I can tell you a bit about what got me interested in this field?

Many years ago, a very close friend of mine was involved in a fire accident which left him facially and bodily disfigured with 90 degree burns. This accident changed his life forever and the physical and psychological consequences of this trauma were immense. Having witnessed what my friend had to go through; I felt it would be important that as a trainee-counselling psychologist I could somehow contribute to this field and help individuals who have experienced similar events as my friend.

As a counselling psychology trainee, I hope that I can offer you a safe space where you can feel comfortable to share your story with me. You may realize that by being given a voice to talk about your experiences and share your story in a safe environment will enable you to have a positive and therapeutic experience.

Therefore, as part of this project you will be asked to take part in an informal interview that will be audio-recorded. Your participation will of course remain STRICTLY CONFIDENTIAL and all identifiable information will be destroyed, you also reserve the right to withdraw from the study at any point.

It is also hoped that this research will help people like myself to gain an understanding of the experiences and common themes that people with facial disfigurement experience in their daily life. Psychologists who have not gone through such experiences would likely not possess the insight and understanding on this matter. Your contribution could therefore provide positive knowledge for counselling psychologists who work in this area.

This research project is supervised by Dr. Don Rawson, a qualified counselling psychologist at City University, London.

If this topic sounds like something you can identify with, and would be interested in finding more about, please do get in contact with me and I would be very happy to provide you with more information!

I look forward hearing from you and thank you for considering taking part in this research study.

Researcher : Paniz Samsami

Email : █████████████████

Phone : ██████████

Research Supervisor : Dr. Don Rawson

Email: ████████████████████

Appendix D

I have provided you with a list of organizations that offer psychological support, should you ever be interested in contacting them and finding more information for future reference!

British Psychological Society
St Andrews House
48 Princess Road East,
Leicester, LE1 7DR
+44 (0)116 254 9568
+44 (0)116 227 1314
enquiries@bps.org.uk
www.bps.org.uk

British Association of Counsellors and Psychotherapists
BACP House,
15 St John's Business Park
Lutterworth
Leicestershire
LE17 4HB
01455 883300
bacp@bacp.co.uk
www.bacp.co.uk

NHS Direct   0845 46 47
www.nhsdirect.nhs.uk

Samaritans
08457 90 90 90
jo@samaritans.org

SANE 1st Floor Cityside House,
40 Adler Street
London, E1 1EE
Tel. 020 7375 1002
sanemail@sane.org.uk

Changing Faces
The Squire Centre, 33-37 University Street,
London,
WC1E 6JN.
0207 391 9270

Katie Piper Foundation
Building 3, Chiswick Park,
566 Chiswick High Road,
Chiswick,
London W4 5YA, United Kingdom

The Healing Foundation
At the Royal College of Surgeons of England
35-43 Lincoln's Inn Fields
 London, WC2A 3PE
0207 8696920

Appendix E

CONFIDENTIALITY AGREEMENT ON THE USE OF AUDIOTAPES

This agreement is written to confirm the confidentiality procedures for the use of audio taping by Paniz Samsami for the purpose of psychological research.

The participant gives Paniz Samsami the permission to audio tape based on the following conditions:

1. The participant reserves the right to withdraw their consent from the study at any stage.

2. The tapes are only used for the purpose of this research study.

3. The tapes will only be used by Paniz Samsami unless requested by the examination board; these are also professionals who are bound by the British Psychological society code of ethics.

4. The tapes will be stored safely in a locked cupboard or on a password-protected file. All audio-recordings will be destroyed once the study has finished.

5.This agreement is subject to the current Code of Conduct and Ethical Principals of the British Psychological Society and adherence to the law of the land in every respect.

I have read and understood the above conditions and agree to their implementation.

Participant Signature --

Participant Name: --

Psychologist Name --

Part C: A Critical Literature Review

The benefits of storytelling in cancer survivors: Implications for the practice of counselling psychology

Chapter 5: A Critical Literature Review

The benefits of storytelling in cancer survivors: Implications for the practice of counselling psychology

5.1   Introduction

Whilst the benefits of storytelling have been extensively acknowledged in the literature, the promising effects of storytelling, particularly in connection to oncology samples, remains limited (Merz, Fox & Malcarne, 2014). Within recent years, however, there has been a growing understanding that narrative can be a useful approach in helping individuals to cope with their cancer (Carlick & Biley, 2004). Although it has been postulated that storytelling can help individuals with cancer to separate themselves from their problems in order to gain perspective, establish meaning and to develop a greater self-awareness and decrease emotional distress (Carlick & Biley, 2004), there appears to be very little empirical research that supports these depictions. Those studies that have examined these issues suffer from methodological limitations, approach used (e.g. cognitive behavioural and existential approach) and variability in measures (Kreuter et al., 2007). In this review, I will, therefore, outline and critically evaluate what has been established to date with regard to storytelling and its positive effect on this specific population.

Storytelling has been used to help and guide individuals in need (Swatton & O'Callaghan, 1999). Bettelheim (1976) believed that fairy tales could help to enhance and enrich a child's development. Undeniably, throughout human history, the concept of myths, fairy tales, self-help books, autobiographies and stories of Biblical origin have all functioned as a means of communicating meaning to individuals (Swatton & O'Callaghan, 1999; Carlick & Biley, 2004). In addition, storytelling has been perceived as relevant for the study of disruptive life events (Crossley, 2000; Frank, 1998a). It has been suggested that when one's life narrative is disrupted by illness or trauma, storytelling allows the person to engage in an act of narrative reconstruction, in terms of rebuilding a sense of coherence, finding meaning and adapting to the trauma or illness (Crossley, 2000). In fact, a myriad of research has documented that people who are faced with trauma are compelled to

make sense of the traumatic event or find some sort of meaning in their experience (Davis & Novoa, 2013; Currier, Holland & Neimeyer, 2006; Neimeyer, 2006; Papathomas & Lavallee, 2012). Narrative scholars advocate that creating and telling stories of one's life fosters the development and maintenance of a coherent identity and sense of self (Murray, 2003; Crossley, 2000). Murray (2003) wrote that the function of stories is that it "brings order to disorder" and gives it meaning. It is important to note, however, that meaning and coherence are not innate aspects of narratives; rather, they are created in the act of storytelling (Carless & Douglas, 2008). Consequently, it has been suggested that storytelling can transform the negative experiences of trauma into something positive and constructive, fostering growth and awareness (Fuertes, 2012; Hutchinson & Lema, 2009). Interestingly, Neimeyer (2006) perceived posttraumatic growth (PTG) as a form of meaning reconstruction, and meant that, because storytelling has a function of attributing meaning to our lives, a narrative framework can provide a useful means to understand and foster life-enhancing processes (Neimeyer, 2006).

5.2   Implications for the practice of counselling psychology

Woolfe, Dryden and Strawbridge, (2003) explained that the theory and practice of counselling psychology differs from the other medical models, such as psychiatry and clinical psychology, in the sense that it aims to facilitate wellbeing and empowerment as opposed to a focus on sickness and pathology. Given that counselling psychology places an enormous value on the therapeutic relationship, meaning, subjective and inter-subjective experiencing of the client (Kasket, 2012), storytelling could be a powerful means of intervention used by counselling psychologists when working with clients who are suffering from a life-threatening illness, such as cancer. Indeed, stories are not only relational in nature (Frank, 1995) but they foster a sense of growth, meaning and empowerment in the individual (Hutchinson & Lema, 2009). Given that the mental health field has focused on identifying symptoms, emotional concern, behavioural problems and other deficits (Tedeschi & Kilmer, 2005), the implementation of storytelling when working with cancer clients may enable counselling psychologists to move away from problem-

saturated stories, which hinder the development of meaning construction, to stories that foster growth, resilience and competence (Hutchinson & Lema, 2009). Importantly, whilst much of the literature on storytelling and cancer has been featured in health psychology and medical publications, very little research has explored how storytelling can benefit cancer survivors from a counselling psychology perspective. In this chapter, it is therefore my intent to review, evaluate and critique available literature, which explores the role of storytelling and its benefit for people suffering from cancer from a counselling psychology perspective. Before reviewing the available literature, I will begin by clarifying some common terminologies and definition with regard to the topic in question.

5.3 *Use of language*

Whilst Frank (2000) wrote that people prefer to tell stories rather than narratives, Polkinghorne (1988) stated that narrative constructs events into a story form, which consists of a beginning, middle and an end. Conversely, Wiltshire (1995) perceived stories as more informal and subjective accounts of personal experiences, while narratives as formal and structured. However, for the purpose of this review, given that both terms, 'story' and 'narrative', are used interchangeably in the literature (Riessman & Quinny, 2005), I will also make reference to both terms synonymously throughout this review.

5.4 Psychological definition of narrative

Narrative or storytelling can be defined as: "an organized interpretation of a sequence of events, which involves attributing agency to the characters in the narrative and inferring causal links between the events" (Murray, 2003, p. 113). Wigren (1994) noted that although stories can vary individually and culturally, "any story that divides experience episodically, connects events causally, elicits and makes sense of affect and considers the consequence of events for characters, may be considered a complete narrative" (p. 416).

5.5 The concept agency in cancer survivors

The diagnosis of cancer can be a debilitating experience for most people involved. Cancer survivors are confronted with their own mortality, fear and existential angst; and inevitably, they have to live with the uncertainties of life. Therefore, a cancer diagnosis causes a disruption to patients' physical and psychological world (Midtgaard, Stelter, Rorth & Adamsen, 2007). It has been recognised, for example, that patients experience a loss of control throughout their illness; predominantly due to the alteration of their prognosis and diagnosis (Bulsera, Ward & Josek 2004). More specifically, given that other medical professionals decide upon their treatments, patients often experience a loss of control over themselves and their bodies (Bulsera et al., 2004).

Cheng, Chen and Chou (2000), explored the experience of hospitalized adolescent cancer patients. They discovered that a common theme throughout adolescent accounts was "confinement of body, time and space". That is, participants felt 'captive' in the limited space of hospital whilst having to withstand physical suffering. One way in which participants retained this sense of agency was managed by three factors, and these were identified as 'keeping balance of life', 'completion of developmental task' and 'holding life esteem'. Taylor, Richardson and Cowley (2010) discovered that the transition process into hospital care could mark a period of change in a person's identity. The feelings of incapacity or inadequacy associated with being a subject of medical treatment can bolster a person's sense of not being in control, rendering their lack of control salient to their new identity. The person seeking care relinquishes control of their body to others and their sense of control in the process (Taylor et al., 2010). The subsequent side effects of cancer treatment can cause many patients to experience a loss of strength, fatigue and nausea. The physical impairment that accompanies these side effects can result in a loss of independency and autonomy, preventing patients to live ordinary lives (Adler & Page, 2008). For example, a study concerning women with ovarian cancer confirmed that the lives of these patients were deeply affected by their cancer (Howell, Fitch & Deane, 2003). This was evident by patients' loss of daily functioning, incapacity to work, financial problems and sexual dysfunction (Howell

et al., 2003). In addition, numerous women expressed worries over potential recurrence of their cancer. Thus, it could be argued that these complications, in turn, can disrupt a patient's ability to be an influential and active agent of their life.

5.6 The Role of Meaning-Making in Cancer Survivors

When an individual is affected by cancer, their once healthy lifestyle is replaced with fear, threat and anxiety, and the need to make sense of life becomes highly important (Carlick & Biley, 2004). Romanoff and Thompson (2006) wrote that individuals make sense of their world through a process of meaning construction. Given that narrative provides us with a means of constructing meaning (Romanoff & Thompson, 2006), in this review, I will include a few articles on meaning-making and meaning construction. Furthermore, the need for meaning-making amongst cancer patients is highlighted by Lee, Cohen, Edgar, Laizner and Gagnon (2006), who suggested that following a cancer diagnosis, many patients experience a loss of meaning in life. Thus, the need to make meaning becomes integral to one's survival, and in coping with the illness (Lethborg, Aranda & Kissane, 2008). In fact, it has been suggested that meaning in life is positively associated with psychological wellbeing (Lethborg et al., 2008).

Park, Edmondson, Fenster and O'Blank (2008) conducted a one-year longitudinal study in order to investigate whether cancer survivors' meaning-making ability would result in survivors making positive meaning from their cancer experiences, such as posttraumatic growth, meaningfulness and a restored core belief (the world is predictable and fair). In addition, it was hypothesised that the meanings made would result in psychological adjustment. 250 middle-aged cancer survivors were recruited via the Hartford Hospital Cancer Registry in the first year, consisting of 172 women (69%) and 78 men (31%). One year later, participants received a follow-up questionnaire with a response rate of 172 participants, with the majority consisting of a Caucasian population suffering from various types of cancer. All participants had completed their cancer treatment two years prior to this research study. A number of measures were utilised, such as the Positive Reframing Subscale from the BRIEF COPE, in order to measure meaning-making. Posttraumatic growth was measured

with the Perceived Benefits Scale and life meaningfulness was assessed with the Perceived Personal Meaning Scale. The psychological adjustment outcomes included repetitive thoughts and wellbeing. Repetitive thoughts were measured with one question: "How often do you think about your diagnosis of cancer in relation to living your life on a day to day basis?" Finally, wellbeing was measured with the Mental Component Score (MCS), a short survey form.

Results confirmed that meaning-making was related to growth and meaningfulness, but did not directly correlate with restoration of a just world belief. With regard to the relationship between meaning-making and psychological adjustment, all three areas (posttraumatic growth, meaningfulness and belief in a just world) were positively related to psychological adjustment. The results also appeared consistent across the year as meaning-making influenced meanings made, and meanings made correlated with psychological adjustment and wellbeing. Scholars in the field have stated that even though meaning-making is an important factor in the adjustment of life-threatening illnesses or situations (Gillies & Neimeyer, 2006), unless the process of meaning-making leads to meanings made, only then can the individual adjust positively to the stressful events (Segerström, Stanton, Alden & Shortridge, 2003).

Nevertheless, this study is bound by some limitations. There appears to be no clarification with regard to the reliability and validity of some of these measures, except for the Perceived Personal Meaning Scale, which had a good predictive validity. Also, due to a lack of existing measure of meaning-making, researchers adopted a different measure, which may have not adequately assessed the phenomenon of meaning- making. Secondly, the sample size of participants was small, and cannot therefore be generalised to the wider population. Finally, despite its longitudinal nature, this study did not go beyond one year to examine the meaning-making processes of cancer survivors (Park et al., 2008). The authors meant that the timeframe of meaning-making in cancer survivors might well extend beyond several years. In fact, Bowman, Deimling, Smerglia, Sage and Kahana (2003) showed that posttraumatic growth was reported by cancer patients to extend 10 years and beyond their diagnosis. Importantly, given that the aim of this study was to understand the ways in which individuals make meaning of their experiences, it would have been more useful had the authors taken into account participants'

subjective experiences. Such an approach would have allowed for a richer and more in-depth account of participants' meaning-making experiences.

However, results concerning meaning-making and its relation to positive adjustment have yielded mixed findings. For example, Tomich and Helgesson (2002) found that searching for meaning was associated with negative emotions and poorer quality of life in women with breast cancer. Likewise, in a study of women with breast cancer, Kernan and Lepore (2009) found that participants who were engaged in an ongoing search for meaning reported a significantly poorer negative affect compared to women who were never or very rarely engaged in a search for meaning. They also found that a significant number of women's search for meaning did not result in meanings made. The authors concluded that a search for meaning might be both ineffective and distressing to the patient. As Bonanno, Wortman and Nesse (2004) and Davis, Wortman, Lehman and Silver (2000) pointed out; patients who persistently attempt to make sense of their illness without finding meaning may experience poorer health outcomes, particularly cancer survivors who have moved beyond the early stages of their cancer diagnosis into a stage of survivorship. Also, those individuals who lack a sense of purpose and meaning in other areas of their lives might be more prone to experience a delay in their search for meaning as opposed to those who exhibit a "stronger, well-preserved sense of purpose and commitment in other spheres' of their lives" (Sherman, Simonton, Latif & Bracy, 2010, p. 365).

Contrary to the above findings, Evans, Shaw and Sharp (2012) reported that cancer patients who were able to share their stories of illness to a healthcare professional at an initial consultation, a 'holistic assessment' as opposed to a reductionist approach, showed a greater insight into their emotional experiences. Such an assessment allowed patients to vent their emotional pain, "to integrate and express their vulnerable self" (p. 11). Thus, the authors concluded that being able to make meaning of one's illness could lead to the development of positive adjustment in cancer survivors.

In addition, Lee et al. (2006) carried out a study to investigate whether the use of a meaning-making intervention (MMI) in cancer patients with breast or colorectal (colon) cancer would result in high self-esteem, optimism and self-efficacy. Eighty-

two cancer patients from four different university hospitals in Canada were recruited using a randomised control design in order to ensure a fair distribution between breast and colorectal cancer patients. Following this, participants were assigned to either a control group who did not receive psychological support per se, but were allowed to participate in various hospital and community-based support groups, or an experiential group that consisted of patients who received four sessions of meaning-making intervention. The MMI group allowed participants to reflect on their emotional responses and cognitive appraisals of their cancer experiences using a narrative storytelling approach. After this, participants in both groups were asked to complete pre and post measures for self-esteem (the Rosenberg Self-Esteem Scale), self-efficacy (the Generalized Self-Efficacy Scale) and optimism (the Life Orientation Test-Revised). Results of their study indicated that individuals in the MMI group, compared to the control group who received regular care, reported significantly greater levels of self-esteem, optimism and self-efficacy. Similar findings were replicated by Henry et al. (2010), who found that meaning-making intervention (MMI) appeared to be a promising and effective intervention amongst a group of ovarian cancer patients. In addition, theoretical perspectives on meaning-making asserts that when individuals make meaning, they engage in a process whereby they attempt to reduce the discrepancy between appraised[5] and global meaning[6], and "restore a sense of the world as meaningful and their lives as worthwhile" (Park, 2010, p. 258).

A particular strength of this study was that all measures used to assess for self-esteem, self-efficacy and optimism had a good internal consistency and predictive validity. Another strength was that the MMI had been empirically tested, and was specifically designed to examine whether a meaning-making intervention would result in positive psychological adjustment amongst breast cancer and colorectal cancer survivors. However, the use of self-reported measures may have led individuals to engage in self-deception and socially desirable behaviour (Holtgraves, 2004).

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[5] Appraised meaning refers to the degree in which an event is threatening or controllable, and in which individuals attempt to explain the causes of such an event or situation (Park, 2010).
[6] Global meaning refer to one's beliefs, feelings and goals (Dittman-Kohli & Westerhof, 1999 as cited in Park, 2010). Such belief is further made up of views regarding justice, predictability, self-views, control and coherence (Koltko-Rivera, 2004).

Rafalin (2010) stated that one of the fundamental philosophies of counselling psychology is its emphasis on individual subjective experiencing. In addition to this, counselling psychology aims to facilitate a space for meaning exploration and interpretation (Chen, 2001). It could be suggested that counselling psychologists are well placed to work with and help their clients to make meaning of their cancer experiences through the act of storytelling.

5.7 Online Storytelling Amongst Cancer Survivors

In recent years, the popularity of private and public forums on the Internet, whereby individuals tell their stories of illness, such as cancer, in order to find healing and recovery, has become widely prevalent (Thompson, 2012).

De Boer & Slatman (2014) conducted a qualitative study to see how women make sense of their breast cancer experience, whilst narrating their story on a personal weblog. For this, a narrative approach was adopted, since its aim was to focus on the construction of meaning and subjective experiencing. The authors collected a total of five weblogs on breast cancer, which they followed monthly for one year. What emerged from their analysis was that web loggers communicated their self-narration in four different ways: 'Estranged Cancer Patient', 'Transient', 'Heroic Survivor' and 'Disfigured Woman/Girl'. The authors found that storytelling through the medium of web logging facilitated several positive benefits.

Firstly, the reversible nature of blogging offered these women a therapeutic experience by continuously writing and re-rewriting their stories. Secondly, web logging allowed the cancer survivors to spontaneously, and sporadically post stories about their cancer experience, which resulted in progressive and surprising narratives about the self. Lastly, documenting their stories online allowed the women to connect with and support other cancer survivors who were going through a similar process. As Orgad (2004) noted, when people share their stories online with other sufferers, they also share their experiences with one another. Such processes enabled them to seek reassurance, validation and legitimisation that their stories had been correctly constructed (Orgad, 2004). In fact, it has been suggested that the mere act

of telling a traumatic story to another elicits a sense of validation and affirmation in the teller, which facilitates healing and growth (Neimeyer, 2006).

Although one strength of this study was its choice of methodology (narrative analysis), which fitted well with the phenomenon under investigation, the authors were not clear about the severity or stage of the women's cancer experience, as this may have impacted their sense-making process.

Similar to the above-mentioned study, Hoybye, Johansen and Tjornhoj-Thomsen (2005), a team of Danish researchers showed how storytelling may act as a powerful source of social and emotional transformation amongst a group of breast cancer survivors who participated in an online support group. An ethnographic case study was used with semi-structured interviews and participant observation. Fifteen women with breast cancer who spoke Danish, Swedish or Norwegian agreed to partake in the study. All of the women had been diagnosed with stage I-IV cancer, with a mean age of 41 years, and they had all undergone breast surgery and received chemotherapy. Ethical considerations were taken into account, and researchers ensured to ask participants for permission in order to participate in their online conversations, as well as using quotations from their discussions. This was important because, as King (1996) noted, the Internet raises issues of privacy and informed consent.

Findings revealed that the use of storytelling empowered the women by instilling in them a sense of control as they were introduced to various resources. Consequently, this also led the women to feel as if they were able to regain some sense of control over their bodies in terms of diagnosis, possibilities and risks. At the same time, the act of sharing stories was not only perceived as altruistic, but as an opportunity for the storyteller to deal with their own experiences of cancer and make it meaningful, thus leading to increased self-esteem. Moreover, the support forum was empowering because it gave the women the opportunity to act in situations they had previously felt helpless in. In addition, some of the online group members shared survivor stories of breast cancer, and this appeared to help the audience to feel encouraged and hopeful about their own situation. The forum appeared to facilitate a space in which women shared tragic stories (exhaustion, loneliness, fear, surgery and sexual difficulties) as well as comic stories. The women believed that the use of humour

and laughter functioned as a form of relief, both to the author and audience. Finally, sharing stories with one another led to the formation of a strong bond between the women.

Similarly, participants in Pelusi and Krebs' (2005) study reported that being able to tell their stories was an integral part of their healing process. Participants indicated that sharing their stories helped them to acknowledge their own journeys, as well as helping others who were in a similar situation. In line with the above findings, Hoffman (2004) asserted that storytelling fosters the establishment of a strong relationship. Indeed, Frank (1995) acknowledged and valued the significance of storytelling amongst people who were seriously ill, stating "those with a critical illness need to become storytellers in order to recover the voices that illness and treatments often take away" (p. 7). In addition, Varre, Slettebø and Ruland (2011) found that sharing one's story of cancer with other patients in online support groups functioned as an important coping strategy, making the patient's life more "comprehensible, manageable and meaningful". According to the authors, online storytelling provides the patient's life with a sense of coherence, which can result in positive adjustment and wellbeing.

Given the positive and transformative effects of narration, this study suggests that storytelling has significant implications for the practice of counselling psychology. Counselling psychologists who work within oncology settings should, for example, facilitate offline support groups for cancer survivors, in which storytelling can be used as a means for therapeutic intervention. Such interventions may prove to be empowering and validating experiences for all those who take part.

Writing about one's illness has been acknowledged to decrease stress and enhance physical and mental wellbeing (Frank, 1995). Chiu and Hsieh's (2012) study explored what it meant to cancer patients to write about their illness on the Internet, and how reading other fellow patients' stories impacted upon their illness experience. The sample consisted of a total of 34 cancer patients, who were interviewed in seven focus groups, using a grounded and inductive approach, predominantly college graduate females with an average age of 40 years. Most participants had been diagnosed with respiratory or circulation cancer or female reproduction cancer, and all women in the study reported having a stable condition.

Findings revealed the following themes: 'To be remembered after their death', 'writing for relief and gaining strength' and 'finding survivors'. In the first theme, respondents reported that writing about cancer stories on the Internet allowed them the opportunity to be known and remembered. Some of the women even spoke of wanting to leave a legacy of self after their death, for their families and children. Others reported that sharing their stories with cancer survivors provided them with an opportunity to contribute even after their death. Interestingly, two patients reported that writing about their cancer online allowed them to confront their own death, and move on with their lives. In the second theme, participants believed that writing on the blog enabled them to express negative emotions, such as anger, fear, pain, helplessness and despair. In doing so, participants felt that it equipped them with an inner strength to survive. Finally, in the third theme, reading stories of other cancer survivors helped patients to gain strength and confidence to fight their own cancer. In other words, those patients who had survived and lived a healthy life acted as good role models for the readers. Moreover, patients also talked about being able to form social contacts and bonds with other cancer survivors, which helped them to fight the cancer. These findings echo Leseho and Block's (2005) assertion that healing from traumatic or painful experiences can begin when our stories and voices have been listened to.

Given that the majority of participants in this study were college graduate females over the age of 40, the results cannot be generalised to other populations (Chiu & Hsieh, 2012). It is also possible that participants who decided to take part in this study were those who felt positive and safe about sharing their stories online, in comparison to those who may not have felt comfortable in doing so. As the authors acknowledged, the findings of this study cannot be generalised to those individuals with limited access to the Internet, such as people from lower socioeconomic status and the elderly. Despite these limitations, considering the empowering and healing aspects of writing, this study shows that counselling psychologists could suggest to their clients with cancer to write about their illness experiences either online (creating a blog) or offline (personal diary).

5.8   Expressive Writing and Cancer

Expressive writing was initially developed by Pennbaker and colleagues as an intervention to help people express difficult traumatic experiences (Merz et al., 2014). It has been suggested that expressive writing functions as a cathartic experience, as it allows the author/writer to express and release their emotions (Pennbaker & Chung, 2007 as cited in Merz et al., 2014). Although writing about one's illness may result in distress, the positive benefits of expressive writing enable the writer to reflect, process and reframe their experience. Such a process disconnects the event from the emotional reaction to it and further assimilates it into the person's self-schema (Low, Stanton & Danoff-Burg, 2006). Further to this, expressive writing has also been linked to the development of self-mastery and self-regulation in cancer survivors (Creswell et al., 2007). Other writers have postulated that expressive writing may enable the individual to recognise how well they have coped with their cancer experience and, as a result, increase their confidence to cope with stressors and regulate their thoughts, feelings and behaviours in relation to their cancer experience (Merz et al., 2014). Importantly, given that individuals who suffer from a serious illness often experience a diminished sense of control, expressive writing may help them to regain this sense of lost control (Anderson & Conley, 2008). In her article, Willig (2009) wrote how the need to "take a stand and tell a story" was an important part in dealing with her skin cancer experience. She stated: "Writing (in my case, a personal diary) provided the opportunity to create (and maintain) a reflective space that allowed me to develop a stance towards the situation I found myself in" (p. 183).

In order to test the efficacy of expressive writing amongst a group of males with testicular cancer (TC), in their study, Pauley, Morman and Floyd (2011) hypothesised that expressive writing may lead to increased mental wellbeing, general quality of life and improved sexual health. Investigators divided participants into three different groups: one group was assigned to write about positive experiences with TC; another group wrote about negative experiences of cancer; and the final group wrote about innocuous subjects. Their study showed that participants who were assigned to write about positive experiences of their TC showed significant improvement in their general mental health in comparison to the other two groups.

Additionally, it was found that participants in the negative expression group did not show any significant improvements in their mental health, and participants who were invited to write about innocuous subjects, in fact, showed a slight decrease in their mental health. In line with such findings, it was also discovered that cancer patients, when presented with stories of other cancer survivors, preferred to read more positive stories as opposed to negative stories about their cancer experience, as they found this to be more helpful (Reardon, Taylor, Aspinwall, Giuliano & Dakof, 1993). Other researchers, such as Craft, Davis and Paulson (2013), found that breast cancer survivors who used EW to write about their breast cancer experience, breast cancer trauma and facts about breast cancer reported a significant improvement in quality of life. Crossley (2003) wrote that when individuals are confronted with a serious illness, they are faced with a threat to their "ontological security" by "throwing into doubt assumptions about time and the future" (p. 439). One way in which individuals can adjust to such threat is through the use of narrative, which can be done either consciously or unconsciously.

However, expressive writing about one's illness does not always result in a positive experience. Jensen-Johansen et al. (2013) examined the effects of an expressive writing intervention (EWI) on cancer-related distress, depressive symptoms and mood amongst female breast cancer survivors in Denmark. In a randomised controlled trial, 507 Danish women who were diagnosed with stage I-II breast cancer were allocated to three home-based writing exercises that lasted for approximately twenty minutes once a week. Participants in the experiential group were asked to write about any traumatic or distressing experience they had encountered and to explore their feelings and emotions in relation to these events. Participants in the control group were asked to write objectively about their daily activities in an emotionally neutral manner. Subsequently, researchers hypothesised that participants in the EWI would report lower levels of distress in comparison to the control group. The following measures were used to assess for cancer-related distress and assessed at three months and nine months after the study: Impact of Event Scale IES, depressive symptoms (Beck Depression Inventory BDI-SF) and mood (Profile of Moods State POMS and Passive Positive Mood Scale PPMS). Findings revealed that women in the EWI group did not report a decrease in distress compared to the control group.

Although a strength of this study was the large random sample used (Jensen-Johansen et al., 2013), participants in the experiential group were not directly asked to write about their cancer experiences per se; instead, they were instructed to write about any traumatic or distressing event. Participants may have therefore not included feelings and emotions associated with their breast cancer experience. Also, the investigators varied the instructions slightly between sessions in order to 'avoid uniformity'. This may have threatened the consistency, and, as a result, the internal validity of the study (Merz et al., 2014). Furthermore, as the authors acknowledged, the writing topics were not analysed using qualitative analysis of the letters, capturing the subjective experiences of the individuals; rather, they were categorised according to self-reports.

A similar finding was replicated by Low, Stanton, Bower and Gyllenhammer (2010), who hypothesised that women who were assigned to write about their emotions related to cancer would show a decrease in intrusive thoughts related to cancer and depressive symptoms, compared to women who were assigned to write about their cancer diagnosis and treatment (for similar results, see Mosher et al., 2012). However, contrary to their hypothesis, results indicated that writing about cancer-related emotions did not result in a decrease in psychological distress. Thus, the above studies did not confirm Heiney's (1993) conceptual framework, which suggests that storytelling amongst oncology patients promotes hope and a sense of emotional catharsis.

To elaborate further on Heiney's framework (1993), Heiney asserted that storytelling has the ability to affect four aspects of our lives, which constitute the cognitive, affective, interpersonal and personal. In the cognitive area, storytelling has a positive function of promoting knowledge and assisting-problem solving. In the affective area, storytelling has a cathartic effect and can inspire hope. In the interpersonal sphere, there is an opportunity for a sense of connection and belonging with others who are going through a similar situation. Furthermore, in the personal sphere, the patient acquires insight through the identification of oneself in the storyteller's narrative. In line with this, Heiney's framework was reflected in a focused programme evaluation conducted by Chelf, Deshler, Hillman and Ramon (2000) with the intention of exploring attitudes and beliefs about storytelling as a method

for coping with cancer amongst a group of people who had attended a workshop related to cancer and storytelling. Participants consisted of cancer patients, their relatives and regular people. Following the workshop, participants were asked to complete a questionnaire, which was designed to examine the extent to which participants believed that Heiney's four domains elicited therapeutic effect as a result of attending the workshop.

Results showed that 97% of participants believed that storytelling was a positive and effective strategy for dealing with cancer. 82% of the people found that storytelling was an effective method for promoting knowledge (cognitive domain) and 89% believed that storytelling was an effective strategy for inspiring hope (affective domain). Furthermore, 58% of participants reported that storytelling was an effective method for establishing a bond and connection with others (interpersonal domain) but only 53% of the respondents believed that storytelling resulted in increased insight (personal domain). Similarly, other researchers have found positive benefits in storytelling. For example, McQueen, Kreuter, Kalesan and Alcaraz (2011) examined the effects of personal storytelling about breast cancer and mammography amongst African American women. Participants were randomised to watch a narrative video, which contained stories of African American women having survived breast cancer, or a regular informational video. Findings showed that those women who were exposed to the narrative video expressed more positive and negative emotions, were more engaged with the video and were able to identify with the characters in the stories. Cohen's (1994) phenomenological study, in which he examined the use of bibliotherapy, asked his participants "how reading may have been helpful in a difficult life situation". Participants reported that they were able to identify themselves with the characters in the stories. Thus, the process of identification led participants to feel affirmed, validated and more hopeful. What the above study suggests is that counselling psychologists should, where possible, encourage their clients to read stories of other cancer survivors, or even more crucial, provide support groups for cancer survivors to meet and share their stories with other cancer survivors.

5.9 Clinical Implications for the Practice of Counselling Psychology

Counselling psychologists will inevitably, at some point throughout their professional career, encounter clients who have been diagnosed with cancer, and it is therefore important to know how to therapeutically work with such a client group. Given that counselling psychology places an enormous focus upon the therapeutic relationship, subjective experience, and a search for meaning and understanding (Woolfe et al., 2003), it could be suggested that they are well placed to work with cancer clients who attempt to search for meaning and to make sense of their illness. This review has indeed demonstrated that the need to search for meaning and telling one's story is pivotal to cancer patients.

In his book, *The Wounded Storyteller,* Frank (1995) wrote that people who are ill "need to become storytellers, in order to recover the voices that illness and its treatment often take away" (p. 7). Frank (1998a) perceived storytelling as a relational process, arguing "a story needs a listener. I needed their gift of listening in order to make my suffering a relationship between *us*, instead of an iron cage around *me*" (p. 199). It is therefore pertinent that counselling psychologists, through the use of a strong and collaborative therapeutic alliance, genuinely and wholeheartedly *listen* to their clients' stories. By allowing their clients' stories to be heard and understood, they create a climate in which clients can come to feel validated, affirmed and empowered. Thus, such a relational encounter can help clients to construct a new map for their recovery or journey (Frank, 1995).

5.9.1 *Narrative therapy*

Narrative therapy is one model counselling psychologists can adopt to help clients who suffer from cancer. This approach is very valuable because it encourages cancer clients, in disempowering and life-threatening situations, to create stories of agency (Hedtke, 2014). Instead of focusing on stories of loss and despair, narrative therapy focuses on stories of strength, which further creates hope in the individual (Hedtke, 2014). Such a process, according to the author, involves asking questions that separate the person from the problem. Narrative therapies do not mean that the

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therapists ignore the despair and emotional pain of their client; rather, the therapists create enough room for both feelings to be expressed simultaneously (Hedtke, 2014). In fact, allowing the client to develop a response to their despair will help them gradually to "restore a semblance of agency" (p. 14). Narrative has also been utilised by oncology doctors to instil and maintain hope in their cancer patients by providing a plot structure to their stories (Crossley, 2003). This method, discovered by Del Vecchio Good et al. (1994), was referred to as "therapeutic emplotment". Through the use of 'therapeutic emplotment', oncology doctors encourage their patients to focus on the 'here and now' and to entrust in the efficacy of the treatment they receive. At the same time, patients are encouraged by their doctors to explore their feelings of anxiety, fear and threat to self within this wider plot (Crossley, 2003). In support of such claims, narrative therapy allows the cancer client to move away from problem-saturated narratives to stories that foster resilience, growth and empowerment (McAdams, 2008).

5.9.2 *Online web-logging*

This review also found that online web-logging was an important factor in cancer survivors' adjustment and emotional wellbeing. These individuals felt more affirmed and empowered by hearing the stories of other survivors, as well as sharing their own stories of cancer. Counselling psychologists should, therefore encourage and introduce their clients to various online support groups where they can seek affiliation with other survivors. According to Kreuter et al. (2007), online web-logging functions as a form of 'parasocial' relationship. This definition is based on the notion that when we engage ourselves in reading stories, literature or newspapers, we are establishing a connection with the characters in the stories, even if they are fictional (Kreuter et al., 2007). The authors mean that social forums, through the use of storytelling, can offer cancer survivors a 'parasocial' relationship, which may produce similar health benefits to face-to-face social supports.

5.9.3 *Support groups*

More importantly, the use of support groups can be another very useful intervention for cancer survivors. As shown in this review, given that many individuals benefited from the experience of sharing their stories in online forums, the use of support groups can have a similar effect. Counselling psychologists can run a weekly support group in which cancer clients are invited to take part and share their stories with other group members. Undeniably, in stressful and life-threatening events, such as cancer, clients have a psychological need for belonging and connection (Lethborg et al, 2008). The effectiveness of support groups was shown by Björneklett et al. (2011), who carried out a long-term follow-up of a randomised study of support group intervention with women who suffered from breast cancer. For this study, 382 women with breast cancer were randomised to either an intervention group (n=181) or control group (n=181). Their study showed that those women who took part in the intervention group reported significant improvement in mental (anxiety and depression) and physical health, total fatigue, cognitive function and body image in comparison to those women in the control group. These results suggest that counselling psychologists should arrange support groups and encourage their clients to take part so that clients can feel safe to share their pain and suffering with other members, feel connected and process their experience of cancer with other survivors (Lethborg et al., 2008).

5.10 Summary and Suggestions for Future Research

In summary, this review illustrates the potential of storytelling in individuals who have encountered a life-threatening illness such as cancer. Most of the studies presented here showed that storytelling functioned as a validating, affirming and empowering experience for cancer survivors. Importantly, sharing one's story with others created an opportunity for social connection and a sense of belonging. Thus, the evidence reported in this review suggests that storytelling is positively associated with psychological adjustment and wellbeing. Nevertheless, it should be noted that a

number of studies presented in this review suffered limitations due to lack of validity and reliability of some measures used, whilst others (quantitative studies) used small sample sizes and were mainly restricted to female samples only. Also, most of the studies in this review were conducted in Scandinavian countries or North America. Two of the studies that aimed to investigate the meaning-making process in cancer survivors adopted a quantitative approach; however, the use of a qualitative study would have added more richness and depth to participants' meaning-making process. Thus, such an approach lacks methodological sensitivity to capture the actual sense-making process of these individuals. A greater consideration of these areas in future research could enable more generalisations.

Despite the above-mentioned limitations, these findings suggest that counselling psychologists should, where possible, use narrative therapy and storytelling as a therapeutic intervention with this population. Counselling psychologists could also, when carrying out research with cancer survivors, make use of a narrative analysis in order to offer their participants a hope-inspiring and empowering experience throughout the research interview. Future research should include more heterogeneous samples from various ethnic and cultural backgrounds, along with an inclusion of more male samples. It could be the case that males are more reluctant to share their stories of pain and suffering. Most of the studies presented here were quantitative; thus, more qualitative research is needed to add more richness and depth to the subjective experiences and processes of these individuals. Future research could investigate how the use of storytelling, in the form of diary or weblog, impacts the cancer survivor's sense of self and identity, based on a narrative analysis.

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Part D: Combined Case Study and Process Report

A client's reconstruction of self- towards love and acceptance: A person-centred approach