



## Exploring an individual's experience of disfigurement: a narrative analysis

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**ABSTRACT**

Adopting a thematic narrative approach this study explores Katie Piper's story of acquired disfigurement and how the experience affected her sense of self and identity. The research employed dual perspective 'big' and 'small' narrative approach. The 'big' narrative demonstrated the development of Katie's sense of self, reflecting on her past experiences and comparing who she feels she is now. The ongoing 'small' narratives suggested by interactions from the documentary, enabled the negotiation of Piper's social identity, as she shared her experiences with other people with disfigurements. Both narrative forms were explored for points of continuity and change, issues of agency and ways of establishing similarity and difference to others, to understand how Katie Piper's experience of disfigurement had a positive impact on her identity. The findings present the narrative material that best illustrates the complexity of her feelings towards disfigurement in relation to; appearance, responses to other people, independence and positive experience.

KEY WORDS:	DISFIGUREMENT	NARRATIVE ANALYSIS	IDENTITY	KATIE PIPER	'BIG' AND 'SMALL STORIES
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## Introduction

The charity Changing Faces estimates that there are 1.3 million people in the U.K. who have a significant disfigurement to their face and body. An estimated 540,000 have a significant facial disfigurement (Changing Faces, 2009). Some of the many forms of disfigurement studied by psychologists include individuals that have: burn injuries (Corry, Pruzinsky and Rumsey, 2009), cleft lip and palate (Millard and Richman, 2001, cited in Rumsey, 2002) and facial disfigurements (Topolski, Edwards and Patrick, 2005, cited in Patrick et al, 2007). It is difficult to define precisely what constitutes a disfigurement (Rumsey and Harcourt, 2004). The individual who is affected may have a different perception from those that view them. These attitudes will be influenced by: personal attitudes and values, the prevailing sociocultural environment (Rumsey and Harcourt, 2004), and past experiences. Disfigurement is used to describe the “aesthetic effects of a mark, rash, scar or skin graft on the skin or an asymmetry or paralysis to the face or body” (Harcourt and Rumsey, 2008). Elks (1990) argued facial disfigurement is defined by the negative reaction it receives, without a negative reaction it is a difference not a disfigurement. This relates to Macgregor’s (1979, cited in Rumsey and Harcourt, 2004) description of facial disfigurement as a “social disability”. Other phrases to describe disfigurement may be used such as visible distinction or visible difference (Rumsey and Harcourt, 2004). This study employs the term disfigurement as it is a common word used widely in public and in British law, the Equality Act 2010. Disfigurements can result from a variety of causes: congenital conditions, acquired as the result of illness, injury or surgical interventions. This study explores an individual’s experience of acquired disfigurement.

Adjustment to disfigurement often includes many physical and psychosocial challenges. One major challenge is adapting to the changes in appearance (Patterson et al, 1993). Physical appearance is an important facet of the self and influences perceptions of and interactions with others. Evidence suggests positive assumptions are related to attractiveness (Dion, Berscheid and Walster, 1972, cited in Langlois, 2000). Langlois et al’s (2000) meta analysis suggested the preferential treatment attractive people receive is widespread, and even found in occupation settings (Hosoda, Stone-Romero, Coats, 2003). In contrast consistently negative assumptions are made for individuals with unusual appearances. Changing Faces and COG Research Ltd (2008) explored the prevalence of negative assumptions around disfigurement. Findings revealed 9 out of 10 people implicitly judged individuals with disfigurements as being less attractive, less likely to succeed, and less likely to live a happy life. This bias was present irrespective of age, gender, socio economic status, and level of education. Qualitative research using grounded theory, found people with disfigurements reported others avoiding them (Rahzani, Taleghani and Nasrabadi, 2009). Similarly narrative research suggested Taiwanese women living with leprosy experienced discrimination throughout their lives (Shieh, Wang and Lin, 2006). These findings highlight prevalent prejudices and social stigma of disfigurement. Rumsey (2002) suggested people with disfigurement also experience prejudice in employment settings, despite the fact that the Equality Act (2010) makes this form of discrimination illegal. Therefore physical appearance is more than an issue of vanity; it has an effect on how we feel we can be treated.

Body image refers to an individual's perceptions, feelings and thoughts about their body, including their face. Quantitative research has explored the role of body image in long-term adjustment (Thombs et al., 2008) and short-term adjustment in adult burn survivors (Fauerbach et al., 2000). Findings presented body image as the most important predictor of long-term psychosocial functioning (Thombs et al., 2008). Lawrence, Fauerbach and Thombs (2006, cited in Corry, Pruzinsky and Rumsey, 2009) investigated 346 people, 60% had facial burns. Findings suggested individuals that placed great importance on their appearance, were more likely to experience negative adjustment to their scars, than those that felt their physical appearance was not important. Similarly individuals suggested their coping improved when they focused on other aspects of their appearance, rather than their disfigurement (Egan et al, 2011). This study explores the narratives a female constructs to make sense of the dramatic changes in her appearance and the effect this has on her identity.

The experience of disfigurement is complex, and the psychosocial impacts are influenced by the cause, location, visibility to others, individual's developmental stage, and a variety of situational and social factors that may impact self perceptions and adjustment (Rumsey, 2002). Research to date cannot confirm that congenital or acquired disfigurements are associated with greater adjustment (Rumsey, 2002). Disfigurement from an injury may have a different impact on an individual's body image, than disfigurement caused by life saving medical procedures (Rybarczyk and Behel, 2002). Body image changes relating to accidents may be characterized by idealization of previous appearance and feelings of anger, whereas disfigurement from medical procedures may be anticipated and understood as necessary. Conversely White (2002) found body image dissatisfaction was reported after life saving breast cancer surgeries. White (2002) argued the body part that is disfigured may mediate body image dissatisfaction. Employing narrative analysis this study explores the personal meanings attached to an individual's facial disfigurement caused by acid attack.

The location of the disfigurement impacts upon an individual's body image and adjustment. The face is critical in social interactions (Cole, 1998, cited in Patrick et al, 2007) so it is unsurprising facial disfigurements are associated with higher levels of distress (Topolski et al., 2005, cited in Patrick et al, 2007), especially if the eyes and mouth are affected. This suggests distress is associated with how visible the disfigurement is to others. Distress may be moderated by concealment or camouflage; however this may create greater anxiety around eventually revealing the disfigurement (Rumsey, 2002). Conversely Thombs et al (2007) suggested distress may not be related to location as they found facial burn injuries were not associated with depression. However the sample was recruited from the same hospital in Maryland, which may suggest these findings relate to cultural or hospital specific care differences.

There is no empirical evidence to support a biomedical bias that assumes severity of disfigurement correlates to level of psychosocial distress or positive adjustment (Robinson, 1997, cited in Rumsey et al, 2004). Contrary to this biomedical bias, Lansdown et al (1977, cited in Cash and Pruzinsky, 2002) suggested mild disfigurements may cause similar or greater anxiety than severe conditions. Children with mild form of skin disorder reported more concerns about their appearance and

staring from others, than children with severe forms of same disorder (Scheppingen et al, 2008). Reasons for this are that mild disfigurements may produce a greater range of reactions from others. The inconsistency and lack of control over reactions may cause greater anxiety.

Previous research emphasizes adjustment to disfigurement is varied; many people experience difficulties that dominate their lives, while others find effective coping strategies and feel their disfigurement plays a small role in relation to their self esteem and body image (Rumsey, 2002). Some people describe their experience of disfigurement has been a good advantage as increased resilience (Meyerson, 2001, cited in Rumsey and Harcourt, 2004). Williams, Davey and Klock-Powell (2003) found that women reframed their adversity by acknowledging the unexpected gains they achieved through their burn injuries, including personal growth, insight, identity and gratitude. Experiencing disfigurement had also lead many people to choose jobs that focused on helping others, highlighting a positive outcome of the experience (Egan et al, 2011). There is no simple explanation why some people seem to adjust to more positively than others. Despite the complex factors involved there is agreement around the main difficulties experienced. These include unfavorable views of self (Rumsey, 2002), low self worth (Bradbury, 2011), anxiety and depression (Kent and Thompson, 2002, cited Rumsey et al, 2004), difficult interactions with other people (Macgregor, 1974) and the consequences related such as social avoidance (Harcourt and Rumsey, 2008). People living with disfigurement encounter social challenges; reactions from other people can include verbal abuse, staring, and unsolicited questioning about their appearance (Thompson and Kent, 2001). Macgregor (1990) describes these as visual and verbal assaults.

The anticipation of negative reactions can impact an individual's interpersonal style (Macgregor, 1974) causing avoidance of social interactions or adopting defensive interactions styles (Rumsey, 2002). Anticipating negative reactions can also affect the perception of others. Kleck and Strenta (1980, cited in Harcourt and Rumsey, 2008) found when individuals believed had a temporary scar they reported negative reactions to their disfigurement from others, despite the scar being removed prior interactions. These findings support Macgregor's (1974) suggestion that interactions are negatively influenced by people with disfigurements.

Rumsey, Bull and Gahagen (1986, cited in Rumsey et al, 2004) challenged this assumption related to physical appearance and highlighted the importance of good social skills to overcome negative interactions. This research promoted the development of social skills training for people with disfigurements (Robinson, Rumsey and Partridge, 1996), and this training has been found to effectively reduce social anxiety in adults with facial disfigurements. However a recent review suggests there is a lack of evidence to support the effectiveness of current psychosocial interventions, due to methodological limitations including small sample sizes, absence of controls and sporadic reports of findings (Bessell and Moss, 2007).

Qualitative research identified social inclusion and acceptance to help positively manage negative comments to disfigurement (Thompson and Broom, 2009, cited in

Egan et al, 2011). Social support from family and others with shared experiences were also important factors in an individual's positive adjustment to disfigurement. However the narratives in Tighe (2011) research showed how the impact of disfigurement through breast cancer treatment can put strain on relationships.

This study employs narrative inquiry to explore an individual's experience of disfigurement. Narratives have three key features; they are representations of temporal sequences of events or experiences. Narratives are meaningful as they provide ways for people to communicate and evaluate important aspects of their experiences. Access to this subjective information is useful for this study to gain the personal meanings Katie Piper attaches to her experience of disfigurement. Narratives are also social as stories are co-constructed between the teller and listener and they provide space to negotiate social identities (Phoenix, 2008). The plot a narrator creates is selected and organised for their audience, usually in a specific social context for a particular purpose (Gubrium, 2006). This provides understandings of connections between individuals and social contexts. An assumption underpinning narrative research is that human beings make sense of their experiences and identities by creating and telling stories. People are especially likely to create stories to make sense of difficult life experiences (Bruner, 1990, cited in Riessman, 2008). This is typical of illness narratives (Kleinman, 1988, cited in Tighe et al, 2011), where storytelling provides structure to lived experiences (Riessman, 2008). Similarly Crossley (2000) argued narratives provide a sense of coherence and meaning and act to rebuild a sense of identity. Storytelling provides a sense of who we have been (Singer and Salovey, 1993, cited in King and Courtney, 2004), who we are now (Bruner, 1990) and who we could be in the future (Markus and Nurius, 1986, cited in King and Courtney, 2004). Suggesting our sense of self is socially constructed through language and interactions.

Narrative analysis has been an appropriate method for this research. Exploring this research topic with discourse analysis is useful to identify dominant discourses around disfigurement: Cypher (2010) explored discourses around facial disfigurement specifically surrounding the first partial face plant in 2005. However this approach restricts the focus of analysis to language, failing to acknowledge human experience. In comparison, Prior and O'Dell (2009) employed interpretative phenomenological analysis to explore the experiences and perspectives of adolescences living with facial disfigurement. Unlike discourse analysis, this study focused on the adolescences' personal experiences, but lacked exploration of the sophisticated uses of language. Whereas narrative approaches appreciate the ways language shapes and constrains our identities and experiences, whilst also recognizing individual subjectivity. This study employed thematic narrative analysis (Riessman, 2008), focusing on the events and cognitions to which language refers to, exploring what the content of Katie Piper's narratives communicates about her personal experience of living with disfigurement.

Narrative approach is interested in how stories reflect the construction and expression of an individual's identity (Squire, 2008). Identity formation is often explored in relation to how dilemmas of identity are resolved or not. Bamberg (2010) highlighted three challenges of self and identity formation: maintaining a consistent sense of self

across time and change, suggesting identity formation is distributed over time and contextually linked. Identity formation also involves identifying similarities and differences between self and others; Baker (2004, cited in Bamberg, 2010) suggests this is how social relationships are produced. The third dilemma concerns issues of agency, whether an individual determines their own actions, or if society determines their actions. Bamberg (2010) suggests a dynamic relationship exists between the two positions; people use existing repertoires, but allow transformation, particularly in construction of 'small' stories.

There is debate in narrative research regarding its concern, positioning 'small' against 'big' stories (Bamberg, 2006). The 'small' narrative approach explores the naturally occurring stories people create in everyday interactions, and considers their relation to micro-social context and wider social structures. This approach is more socially orientated than 'big' narrative research, and is commonly employed by conversation and discourse researchers (Georgakopoulou, 2007, cited in Andrews, Squire and Tamboukou, 2008). Bamberg (2006) argues 'small' stories reveal how narrators portray a sense of sense and identity in interactions. Comparatively the 'big' narrative approach is concerned with an individual's past experiences and often used by life story researchers.

Ochs and Capps (2001, cited in Georgakopoulou, 2006) suggested 'big' narrative approach privileges coherence, whereas 'small' story approach finds inconsistencies more interesting (Bamberg, 2006), as present the ways narrators manage a sense of self in context of social interactions. Georgakopoulou (2006) proposed 'small' stories refer to underrepresented narratives such as ongoing, future and hypothetical events. Georgakopoulou (2006) also argued 'big' approaches present the person as whole, whereas 'small' approach present identities are fragmented. However Freeman (2010) argued identity formation requires a reflection over time that 'small' stories cannot provide in moment to moment interactions; suggesting 'small' stories are where aspects of our identities are expressed, realized and negotiated, rather than the source of self and identity.

Despite the debate positioning 'small' against 'big' stories, some researchers suggests for an integration of both perspectives (Phoenix and Sparkes, 2009). Employing both perspectives together would provide an inclusive approach to identity formation, and be useful in telling the whole story of who we are (Freeman, 2010). Both approaches tell different but interlinked aspects of experience, and failure to consider integration of the two may constrain the creativity of qualitative researchers and also fail to acknowledge the creativity of narrators. (Phoenix and Sparkes, 2009).

This study adopts a pluralistic approach to the study of self and identity by using Katie's (2011) autobiography and the ongoing 'small' narratives suggested in interactions during the documentary (2011). By exploring the 'big' and 'small' narratives Piper creates and tells, this study identifies thematic narrative connections across her experience of disfigurement, discovering the impacts on her sense of self and identity.

## Background to study

### Participant

Katie Piper was born 12<sup>th</sup> October 1983 in Hampshire, England. In March 2008, she was the victim of an acid attack that caused severe facial disfigurement. Katie underwent pioneering surgery and intensive treatments in England and France. Prior to the attack, Katie was a model and TV presenter and she is now the founder of the Katie Piper Foundation. In 2009 Katie made her first documentary 'Katie: My Beautiful Face'. The follow up series 'Katie: My Beautiful Friends' was broadcasted on Channel four on 22<sup>nd</sup> March 2011. Katie published her autobiography, 'Beautiful' on the 17th February 2011. As these sources are available in the public domain anonymity in this study was not necessary.

Using two public examples of narratives prevents my role in the research having any impact on the stories Katie Piper discussed. On reflection another advantage of using naturally occurring data is that analysis is unaffected by any relationships that may be established through the research process. Unlike other qualitative methods which may involve researchers spending long periods of time with participants, listening to and possibly sharing personal experiences. However Riesman (2008) suggested the researcher stills influence the narratives through the decisions made in the analysis process, including transcription.

I chose to explore Katie Piper's experience because she appears to have a positive experience of living with disfigurement. This contrasts with the majority of research findings that predict otherwise, as she is a female, sustained facial disfigurement and had an appearance orientated modeling career. Currently not many studies present positive aspects associated with disfigurement (Sodergren et al, 2004). Instead most research assumes pathological responses to facial disfigurement (Prior and O'Dell, 2009). Only a small number of studies present positive outcomes with disfigurement (Egan et al, 2011). This study contributes to the small, but growing area of research that presents living with disfigurement as positive, challenging previous findings that portray the experience as mostly negative. The materials used in this study present the different narratives Katie Piper constructs about her experience of living with facial disfigurement over thirty months.

### Data Collection

Ethical committee approval was obtained prior to data collection (see appendix 1). The television series material was taken from the broadcasted Channel four documentary: 'Katie: My Beautiful Friends' (2011). This consists of four one hour episodes and follows Katie Piper setting up her charity and meeting other people living with disfigurement. The documentary was recorded via Sky Plus. The written narrative is Katie Piper's (2011) autobiography 'Beautiful'; this describes her life before the attack and thirty months afterwards. The autobiography consists of twenty four chapters, and chapter



twenty one onwards coincides with the production of 'Katie: My Beautiful Friends' (2011).

The interactions Katie had with the people she met during the television series were transcribed. This decision was made as the other material featured in the television series did not relate to Katie's personal experience. Unlike the speech from the documentary the autobiography text did not require transformation. The episodes were transcribed verbatim however; rhythm of speech and gestures were not recorded. This decision was made as thematic narrative analysis (Riessman, 2008) was employed and producing a 'clean' transcript enables exclusive focus on content (Elliott, 2005). The decision to create 'clean' transcripts prevented exploring the influence an audience has on the way a story is in great detail. Therefore in employing thematic narrative analysis, rather than structural analysis, the influence of the local context on the narratives was neglected. Despite this thematic narrative analysis was more appropriate for this study to explore what the content of Katie Piper's narratives communicates about her experience of living with disfigurement.

Standing (1998, cited in Elliott, 2005) suggested the choices in transcription raise issues about power differences between participant and researcher. This also relates to a disadvantage of using the television series and autobiography as they have been edited by other sources in the publication process. However editing would be more concerning if the autobiography was the only material used as it is published to present a coherent life narrative. Whereas although the television series will also have undergone an editing process the interactions Katie engages in are not scripted.

The findings of this study are presented in a chronological biographical account exploring how Katie Piper reconstructs her experience of disfigurement over three years. This order is maintained to preserve the narrative content, as fracturing texts can de-contextualize the original account by disrupting the sequence and structure that is essential to narratives (Mishler, 1986, cited in Riessman, 2008).

## **Data Analysis**

Riessman's (2008) guidance on thematic narrative analysis was adopted. The transcripts and autobiography were analysed with reference to the narrator's experience of disfigurement and impact on her identity (see appendices 2-4). Four steps enabled the approach: defining concept of narrative, analyzing texts with attention to form and language, and determining the 'unit of analysis'. The definitions of narratives in this study are inclusive, referring to all speech and text that relates to living with disfigurement. Relating to the 'big' story approach (Bamberg, 2006) the concept of the written narrative was Katie Piper's personal life story about disfigurement. The 'small' narratives from the documentary were defined as short segments of interactions about particular experiences of disfigurement. The 'unit of analysis' was the narrator's understanding of experience and impact on identity.

The texts were read numerous times noting words and phrases that made reference to the narrator's identity and experiences of disfigurement. The content of each television episode was analysed independently, and the narrative themes identified were compared across all four episodes. The autobiography was analysed as a whole. Narrative themes, changes in narrative tone and functions of imagery were also recorded, in attempt to identify the meanings constructed within and between the 'big' and 'small' stories Katie created. The use of language was viewed as a resource; this approach aims to prevent the researcher's personal interest from influencing the themes identified. Both narrative forms were explored for dimensions of identity formation: continuity and change, similarity and difference of self in relation to others and issues of agency. The narrative material that highlights the complexity of Katie's experience in relation to the four core themes is presented.

## **Discussion of findings**

Both narrative forms were explored to reveal the ways Katie Piper made sense of her experience and constructed her sense of self and identity over the thirty months following the acid attack. The narrative themes identified in the autobiography and television series are: appearance, response to others, independence and positive experience. How these narrative themes are actively incorporated into her experience of disfigurement as positive is explored.

### **Appearance**

This section explores Katie's interpretations of her appearance before the attack and during the thirty months afterwards. The narratives describe Katie's evaluations of who she feels she is in the context of her changing appearance, illustrating her physical identity loss during her experience. An individual's physical appearance is an important aspect of the self (Grogan, 1999, cited in Cash and Pruzinsky, 2002). Physical appearance influences an individual's behaviour, self perceptions, interactions with others and psychological adjustment.

The autobiography presents Katie's reflections on her past before the attack, often referring to how appearance orientated she was previously. When reflecting on her past Katie often refers to herself in the third person rather than the first person, indicating a distance from her previous thoughts and feelings. This narrative separation is emphasized by presenting her earlier sense of self as impossible to regain and often associated with death imagery:

The songs I used to listen to just filled me with grief...That girl had been so full of hope and ambition and determination, but she was now dead and gone. (p. 96)

Describing her previous self as "that girl" displaces herself as a character in her narrative situated in past time. This distancing suggests an awareness of how her experience of disfigurement has transformed her identity. It may also imply "hope and ambition" are not emotions she feels at the time of her reflection. Referring to her previous self as "dead and gone" may reflect feelings of loss or bereavement. When disfigurement is acquired through injury people report feelings of loss towards former

appearance and this can disrupt their self concept (Harcourt and Rumsey, 2008). Similarly Partridge and Robinson (1995) described the loss of facial and body image through burn injury as a bereavement experience.

It could be suggested there is some personal continuity in that Katie could have experienced negative feelings towards her appearance prior to the attack, whilst she was working as a model in London:

If I had a spot, I refused to leave the house, and if my hair extensions weren't sitting right, I fretted all day. The more immersed I became in this world, the more my self confidence turned into vanity. I was totally self absorbed, but I was too dazzled by the promise of the bright lights, the glitz and the glamour to even realize. (p. 22)

Katie describes a great degree of investment and critical evaluation of her appearance, with any perceived imperfections eliciting negative emotions and having a disproportionate impact on her thoughts and actions. Katie suggests her appearance related concerns increased while she became "immersed" in "this world". The verb "immersed" emphasizes how completely occupied she felt she had become in the world of modeling, becoming more than a job, her way of life. Katie's reflections of herself at this time are not favorable and may represent a realization of how self absorbed she was previously. This description also implies a sense of naivety as Katie reflects on her previous ambitions of fame.

Another comparison between who she is now and her sense of self before that attack, occurs when she discusses what her former self would have done if she knew about the attack beforehand.

If I'd known what he was planning, I probably would have killed myself there and then. The old Katie never could have contemplated losing her beauty. She was so vain, so self obsessed, and her looks had been her life. (p. 210)

This highlights the extent to which Katie's appearance dominated her former sense of self. The description "old Katie" creates a distance from her former feelings enabling self-critique, and suggests an awareness of her identity transformation. Williams, Davey and Klock-Powell (2003) suggested burn survivors' impressions of their past before injury contributes to their adjustment; one participant reported life before burns as perfection and described life with burns as the opposite. This suggests the unfavorable view of Katie's pre-burn identity as "self obsessed" may aid her adjustment and successful development of her post burn identity. This description may illustrate how living with disfigurement has made her more resilient, as before the attack she could not imagine been able to cope with her experience. Research suggests living with disfigurement increases resilience (Egan et al, 2011). This also points out that the attack had a profound effect on her and took away a central feature of her identity, her appearance and modeling career. Williams, Davey and Klock-Powell (2003) found burn survivors struggled to redefine their sense of self when their injuries prevented them from their former occupation. Participants reported feeling loss and no longer been the person they were. These findings also raise issues around agency, as participants

position themselves as passive, with injuries forcing them to leave previous occupations rather than their choice.

This extract from the autobiography refers to a period of time in hospital before Katie saw her injuries. Katie recounts her disbelief when a nurse gave her some handouts relating to coping with disfigurement:

Disfigured? I wasn't disfigured! I was Katie Piper, model and TV presenter. That word had nothing to do with me. Absolutely nothing. (p. 105)

The tone suggests Katie is offended to have “disfigured” used to in relation her. She corrects this description by detailing her career, highlighting how she defined herself in terms of her job. The outrage Katie is presented to feel is illustrated by the repetition that disfigurement had “absolutely nothing” to do with her.

Several months after Katie is discharged from hospital, a negative narrative tone is used when discussing her feelings about her appearance.

I never wore anything remotely fashionable, just kid size tracksuits and high necked tops to hide the scars on my neck and chest. It was as if I'd lost the right to wear nice things. I was so ugly it was laughable to make an effort. (p. 131)

This may suggest Katie feels she is now “ugly” and nothing can improve how she feels about her appearance, not even wearing nice clothes. Egan et al's (2011) participants reported that focusing on parts of their appearance that they could control such as clothes or hair improved their coping. This suggests Katie's negative self image is maintained by focusing on her disfigurement, rather than diverting her attention to other aspects of her appearance. “The right” may relate to feeling like she does not deserve to wear nice clothes. Or it could imply her human right, this relates to instances in the autobiography where Katie describes feeling dehumanized due to her disfigurement. This supports Rumsey (2002) suggestion that disfigurement is often associated with unfavorable views of self.

During the television series Katie talks to the interviewer about one of the girls she met during the series, reflecting on her own earlier disinterest in her appearance.

“She's probably felt that she's lost the right to try, and the right to be young and trendy. And I did... I mean I was in a Primart tracksuit for the best part of a year, and that is not me.” (Episode 2)

During this interaction Katie makes sense of who she is now by comparing how she felt and acted previously. What “I” was doing is mentioned and compared with what is “not me”, highlighting her identity transformation by discussing how differently she feels and talks about herself now. This reflection also suggests Katie sees aspects of her former self in the person she is talking about, creating a sense of shared experience and understanding of their disfigurements. This connection of similarity may develop the formation of Katie's identity as someone with a disfigurement.

During the months following discharge from hospital Katie adopts a resentful narrative tone and describes devalued feelings about herself:

I was ugly, I was useless; I was a pathetic waste of space. (p.129)

This extract highlights the importance Katie placed on her appearance with the order of words used, “ugly” led to being “useless”. This could be understood in terms of her career which is dependent upon her looks, so losing those looks made her useless in modeling, leading to viewing herself as “waste of space”, as she defined herself in terms of her career. Some research suggests people with facial disfigurements often report feelings of low self worth (Bradbury, 2011).

Doubts and concerns about appearance mainly arise when Katie discusses the memory of her physical appearance before the attack:

I felt a wave of nostalgia for my old life. People used to photograph me because I was beautiful, someone to be admired. But now I was deformed, a burned thing to be pitied or reviled. ‘Don’t think that way, Katie’, I scolded myself. ‘Take it on the chin. Or on what’s left of it anyway. (p.187)

This suggests a sense of longing for her “old life”, particularly her appearance. How she feels about herself now, eight months since the attack, is a total contrast: “a burned thing”, echoing previous feelings of not being human. However these self loathing thoughts are challenged in this internal dialogue, where the narrative then adopts a satirical tone. Arguably this use of humor is a coping strategy for Katie; similarly Thompson and Broom (2009) found sarcasm as a source of resilience in individuals with disfigurements. The change in tone seems to encourage Katie not to torment herself about her previous appearance, to instead accept her current situation and try to deal with it as best she can.

In the months that follow Katie adopts a more positive approach to her appearance:

‘You’re a survivor, not a victim,’ became my mantra... Ever so slowly I was learning to come to terms with what had happened. My beauty might be gone but so what? Who said burns couldn’t be beautiful anyway? I almost convinced myself. Almost. (p.197)

Mantra is associated with creating transformations, typically spiritual, it could be suggested this internal dialogue reflects the development of an increased confidence in how she feels about her appearance. However “almost” implies she does not actually regard her burns as beautiful and perhaps recognizes an element of overconfidence or self-delusion about this statement. Defining herself as a “survivor” illustrates a developing determination to overcome the difficulties encountered through her life threatening experience, and to not appear helpless as “victim” suggests.

This increased self confidence is also challenged a year after the attack, as concerns relating to appearance emerge when Katie discusses her feelings about going on a date during the documentary:

“If I went on dates before I would go feeling like well they’re going to fancy me. But so now it’s such a new feeling... mixture of really excited on a high, then absolute dread, am I making a fool of myself, embarrassing that I’d think he’d fancy me anyway” (Episode 2)

This illustrates the abundance of self confidence Katie had before the attack when juxtaposed with the “new feeling” that includes uncertainty. A mixture of emotions is described but the majority relates to the chance of rejection, arguably this reflects how Katie feels others perceive her appearance.

Despite this concern, most of the narratives situated in present time, suggest Katie becomes to accept and even embrace her appearance:

Now I looked at my reflection and smiled. I did look damn good. Burnt and fabulous, that was me (p.285)

This extract suggests twenty-four months after the attack; Katie accepts her burns as part of her identity “that was me”. This supports Patterson et al’s (1993) findings that adjustment improves over time. Arguably Katie’s acceptance could be associated with an understanding of the achievable outcomes of surgery.

“You can’t sit in the mirror and go, oh god, my left eye is funny and this is funny. Yes it is! So what? There’s plenty of acid attack victims in the world that would love to look like me.” (Episode 4)

This illustrates a change in the importance Katie places upon her appearance, all participants in Egan et al (2011) study associated positive adjustment to disfigurement with placing little importance on their appearance and valuing other characteristics, like personality instead. This extract also implies a gratitude for the treatments she has received compared to others. Egan et al (2011) also found making down ward social comparisons helped participants positively adjust, because it put their disfigurement in context. In the ‘small’ narratives Katie presents this image of being satisfied with her appearance, this may be because she aims to support people through the series and is therefore positive in her approach. This presents her experience in “restitution” narrative (Frank, 1995, cited in Tighe, et al, 2011) form, that she has a positive end to her experience. Katie may employ this narrative form as it is dominant illness narrative in Western cultures, so recognizes others expect to hear her story told in this way. Also highlights how personal narratives can only be constructed from the limited options available to us in a given culture. This relates to the assumption our talk and understanding of our experiences are shaped by social expectations (Shotter, 1989, cited in Sparkes, 2004). Alternatively, because the series was recorded almost twenty-four months after the attack, Katie may have developed a more positive sense of self, than described in the earlier sections of the autobiography, and this change reflects in her attitude towards her appearance.

### **Responses to others**

The narratives describe how interactions with strangers and other people with disfigurements impact on Katie’s feelings towards herself. Research findings suggest

the majority of difficulties people with disfigurements experience are related to social situations (Rumsey et al, 2004).

### **“Ashamed”**

When Katie was in hospital the way she made sense of other people’s reactions towards her, generally reflected her own negative view of her appearance.

I cried so ashamed that people had seen me like that. Mum, Dad, Suzy, Paul, Kay, the hospital staff and the other people on my ward... I’d sat talking to them, with no idea that I barely looked human. They probably felt sick just looking at me. (p. 108)

This highlights how ashamed Katie was by her appearance, and how she considers her burns devalue her, echoing common descriptions of not feeling human. Self consciousness and negative self perceptions are commonly expressed by people with disfigurements (Harcourt and Rumsey, 2008). It is also implied she felt she should have considered what she looked like before speaking to people. Katie describes the disgust she thinks other people and even her family must feel when they see her, which may reflect her own feelings towards her new appearance

### **“Public property”**

In the autobiography Katie describes a reaction she received from a shop assistant, eleven months after hospital discharge:

He peered at me, at my mask and my scars, then screwed up his face in disgust. ‘Get out!’ he shouted. I burst in to tears. In that second, I didn’t want to exist anymore... It was horrible: I didn’t understand why people felt they had the right to stare or comment on my disfigurement. Did it make me public property? If I had severe acne or a missing limb, it wouldn’t cause such a stir. (p. 199)

This negative reaction may relate to the perceived cause of Katie’s burns, Jones et al (1984) suggested the degree of stigmatization increased if the person is thought to be responsible for their condition. This reflects how acid attacks are common punishments, particularly for women in some Eastern cultures. The impact this situation had on Katie’s sense of self is highlighted by her reaction; “I didn’t want to exist anymore”, suggesting at the time she felt unable to cope and manage the intrusive comment. This highlights the emotional impact caused by rejection, causing her to feel devalued. Katie presents herself as the victim in this passive narrative, positioning the shop assistant with the power to make her feel devalued. Eleven months have passed from previous descriptions of feeling devalued in hospital, yet Katie’s feelings of devaluation are continuous, despite outward change in time and space. There is a subtle change in tone from hopelessness to anger, which may reflect a change in Katie’s attitude: previously the narrative suggested Katie felt ashamed in the presence of others. Whereas here it could be argued Katie is angry that people make her feel this way about herself. She questions how people felt “they had the right to stare” which suggests how inferior she felt, and her anger as to why people seemed to think their behaviour was acceptable. Katie describes how she feels her disfigurement attracts more unwanted attention than

“severe acne or a missing limb” would, this may reinforce her feelings of being abnormal or inhuman. This point is illustrated by her motivation to record her first documentary:

Maybe if I make that documentary, then they’ll understand. I thought. ‘Maybe they’ll see I’m a normal girl underneath, with feelings like everyone else’. (p. 200)

This also links to motivations for creating her charity. Katie broadens her experience to all people with disfigurement:

“They’re not alone and someone else has gone through a situation and got out the other side... it creates a kind of unity.” (Episode 4)

This could be understood that Katie wants people living with disfigurements not to feel her previous feelings of being alone, but rather to have the solidarity that comes from surviving a shared experience. Research suggests it is common for people to want to share their experiences of disfigurement to help others, describing it as emotional healing (Williams, Davey and Klock-Powell, 2003). Similarly Roberts et al (1999, cited in Egan et al, 2011) suggested helping others can improve own well being by increasing perceived social value and competence.

### **“Instant camaraderie”**

Twenty-four months after the acid attack Katie starts meeting more people with disfigurement through her charity and creating Katie: My beautiful friends. It is suggested Katie found comfort being around other people with disfigurements as they had shared understandings of her experience:

Because we’d all been through the same thing, there was an instant camaraderie between us. We all knew what it was like to endure one operation after another, to hate your reflection in the mirror. (p.281)

This presents the difficulties Katie experienced as common features of living with disfigurement. The unity described is suggested to be reassuring particularly when compared to feelings of alienation imposed when in public. Katie and George share their experiences of negative reactions from others during the documentary:

George: “This woman and her children constantly stared and mine even noticed it ... I got to the aisle... excuse me I said would you like a photograph?...Then you can stare at that all day long.”

Katie: “yeah, like this guy... was like punching in the wrong numbers to get his ticket because he was too busy looking at me... so I just turned round and went, “it’s burns!” (Episode 4)

This suggests Katie enjoys sharing her experiences and the support gained may have aided her own adjustment to disfigurement, through developing this group identity. This relates to the dilemma of identity associated with creating an individual sense of self and seeing similarities of self in others. Through this interaction Katie negotiates these connections by drawing on her similar experiences of negative reactions from others.



This acts to establish her identity within the context of her social relationship with George and with others living with disfigurements more generally. In this active narrative Katie assumes control over the unwanted attention she received, this shift in her position contrasts to her earlier passive narrative. Thompson and Broom (2009) and Egan et al (2011) studies reported benefits of speaking to others with shared experiences, such as coping with reactions to their disfigurement. However Partridge and Robinson (1995) outlined the hazards of peer led support groups suggesting they may not be beneficial for all members. Possible hazards: people may not be able to effectively support others, instead impose their own issues. They also suggested meeting other people with burns may lead an individual to question why they are not coping as well.

During the television series Katie reflects on how she felt towards people with disfigurements before her attack:

“Before this happened to me I never thought about disfigurement, it’s a really shameful thing to say but... I remember looking at them thinking oh god that’s horrible... I just didn’t think about how I might make that person feel” (Episode 3)

The shame she feels reflecting on her previous actions suggests recognition that through her experience she has established a new self image, in a previously unimagined relation to people living with disfigurement.

### **“I have the right”**

Twenty-four months after the attack, the television series and autobiography extracts overlap. Both narrative forms suggest Katie still attracts unwanted attention from other people. Rumsey (2002) found negative responses from the general population, such as staring and comments, to be common experiences for people with disfigurements.

As for the gawping from strangers, I’d grown used to it. It still had the power to make me feel embarrassed but I wasn’t ashamed anymore. (p.274)

This suggests although Katie does not welcome the sustained gaze from members of the public, she prevents these reactions making her feel “ashamed” about her appearance. This change in attitude may reflect a sense of acceptance about the way she looks and developed confidence. This self confidence is expressed in interactions with Kayleigh in the television series:

Kayleigh: “how did you get past that [not going out in public]? Did you just wake up one day and think, right that’s it, I’ve had enough?”

Katie: “Yeah, I’m not going to please everybody, not everybody’s gunna want to look at me and not everybody’s going to be educated or understand, but actually I don’t care because, I nearly died. So I can’t live my life like I’m dead now... usually the worst that could happen is people might say unkind things... And you have to kind of grit your teeth and look past that and think, well, they’re almost the idiots for being like that.” (Episode 4)

This description is a dramatic contrast to how Katie described feeling earlier in the narratives. “I don’t care” suggests she no longer allows people’s reactions to impact how she feels about herself. Comparatively Tighe et al (2011) narrative research describes how over a time a woman began to care less about people’s opinions towards her appearance that had changed through chemotherapy. Katie’s change in attitude may reflect her realization that she “nearly died”, so recognizes the challenges she has overcome and feels a need to fulfill her life. Katie positions Kayleigh in her story and advises her to ignore people’s reactions; this creates a sense of shared experience and solidarity. It could be argued Katie makes excuses for people, positioning them as “uneducated” or “ignorant”.

However when Katie talks to the interviewer immediately afterwards, she directs more anger towards people that make negative comments:

“You just want to shake people and say, do you realize what your, you know, snide comment has done to that person... she can’t help it... because she physically cannot do those things, and I can completely understand why she can’t.” (Episode 4)

This illustrates how the content of narratives can change depending on their audience; this narrative presents Katie with a different identity than expressed with Kayleigh. This highlights how the use of ‘small’ narratives from the documentary provides contradictions to how Katie interoperates negative reactions, exploring identity formation in ways big story approach cannot (Georgakopoulou, 2006). However a benefit of using a dual ‘big’ – ‘small’ approach is that a full story of how Katie makes sense of her experiences and forms her identity can be sourced. Katie clearly relates to feeling physically unable to do things due to psychological effects of people’s comments about her disfigurement, and claims this behaviour is determined by social context rather individual agency.

Rather than ignoring unwanted attention as Katie recommends, she is confrontational at times, suggesting her approach changes between responses of dismal or anger.

“What’s wrong with your face?” a lady in the newsagents gasped one afternoon. Instead of telling her I feigned surprised. “What do you mean? Am I bleeding?” I gasped. “No” she stammered. Point made I left. (p. 274)

Arguably this challenging behaviour is reflective of Katie’s developing confidence, compared to time in hospital where Katie described a sense of sympathy for people having to look at her. Instead twenty-four months later, Katie resents being made to feel different and angry about the lack of control she has over these interactions occurring. This reaction may suggest Katie wants to shame people through anger and confrontation as they attempt to shame her. Katie may employ this confrontational behaviour as a coping strategy to deal with negative reactions. Katie describes the change in her attitude:

“I had this determination inside me that was almost a bit of anger, like, no I have the right to go out in the world” (Episode 4)

This illustrates how differently she feels about herself and her disfigurement compared to earlier stages of her experience. Before Katie described losing “the right” due to her disfigurement and now she is clear she has “the right”. This highlights her increased self-belief and develops claims of agency constituted by her own increased determination, creating a coherent sense of identity. Similarly Meyerson (2001) identified determination to increase resilience in people living with disfigurement.

### **Independence**

Katie moved back into her family home due to the physical and psychological consequences of the attack. These thirty months are associated with a perceived loss of independence. Previous research suggests people that have experienced burn injuries feel a loss of their independence, particularly during their early recovery (Williams, Davey, Klock-Powell, 2003)

Living with her parents is frequently associated with descriptions of a return to early childhood:

Looking after me was impacting their lives in so many ways. It was like I was a child again. (p.154)

Five months after the attack it could be suggested Katie felt like a burden on her family, thinking of the impact caring for her was having on their lives. Family dynamics are described to have changed:

She was my baby sister... but the roles were now reversed. She was the adult now taking care of me. (p.222)

This role reversal impacts Katie’s identity changing how she feels about her role in the family. It is suggested she no longer feels like the elder sister because she needs looking after. Physically dependency during recovery from burn injury was associated with shifts in roles and this negatively impacted participant’s perceived autonomy (Williams, Davey and Klock-Powell, 2003).

Twelve months after the attack Katie still describes perceived loss of independence:

Would I have to stay with mum and dad forever? Would I be a female Peter Pan, never able to grow up? (p. 212)

This illustrates Katie’s concern that she would never regain her previous independence. Drawing on the children’s story “Peter Pan” emphasizes these fears further as this character is known for his perpetual childhood. This questioning suggests at this time Katie was unable to envisage a future where she was not living it home.

In the television series, Katie describes her desire for independence and the frustrations she feels when her autonomy is perceived to be undermined by the need to undergo medical procedures.

“I know its looks like a complete horrible bitch... but, I’ve just spent two years of my life with my mum doing my eye drops on the hour every hour... Having them tell me when to eat, what to do. And I couldn’t leave the house because I was frightened and I’ve just come back from the operation and I’ve already got everyone’s opinion on when I should go back to London, when I should do this, what I should be doing, how I should be doing my eye drops! It’s like completely take me back to how I was before and I’ve just got away from that.” (Episode 3)

This extract highlights how dependent Katie was on her parents when she was recovering from the attack. Katie is presented to have had no control with medical treatments dictating her activities hourly, and being psychologically trapped in the house due to her fears. It is suggested Katie felt she had gained a new independence compared to this earlier period in her life, but now feels this autonomy is undermined due to her medical requirements. The eye operations means she temporarily cannot see and therefore requires help from others. Her frustrations relating to this fact are intensified by her parents discussing minute details of how her medication should be correctly administered. These periods of frustration suggest she feels things returning to how they were when she first left hospital and was totally dependent. Arguably Katie’s anger is directed towards her disfigurement, rather than her family, as it is her injuries forcing her to depend on others. Comparatively some burn survivors expressed gratitude towards the people looking after them during their recovery; however others described frustrations towards these people (Williams, Davey, Klock-Powell, 2003).

Thirty months after the attack Katie moved into her own flat. During the television series she reflects on her experience of having to live with her parents due to her disfigurement, but there is a change in the form of her comparison:

“I’ve always said going back home and being ill was like being a baby again because I was really vulnerable and scared. So now I’m like the teenager moving out again.” (Episode 3)

Describing feeling “like a baby” emphasizes how dependent Katie was immediately after the attack. The reasons for living at home are associated with feeling “vulnerable” not medical purposes, emphasizing the great psychological impact the attack had. Relating to moving out as being “the teenager” reflects dominant discourses around adulthood as leaving home is seen as major part of this transition. It also reflects cultural conventions of teenage years being typical time to leave the family home in England, this is reflected in statistics: only 13% of women in late twenties live at home (The Guardian, 2009), suggesting a social stigma associated with staying past this age.

Moving out of her family home into her new accommodation is not just a physical move but is referred to in terms of new life possibilities:

This wasn’t just a new flat; it was a new chapter of my life. It meant I was back in control... I wasn’t helpless anymore. I was an independent woman again, and it felt amazing. (p. 304)

This suggests moving out symbolizes a transition in Katie's life associated with regaining her identity of being an "independent woman". This relates to an increased strength and agency as Katie positions herself to reclaim control over her life. Referring to the future as "a new chapter" could suggest a desire to leave the past behind and move on with her life in a new direction.

### **Positive experience**

The narrative forms in which Katie articulates her changing experiences of disfigurement, suggest it has ultimately had a positive impact on her identity.

Before the attack, I had hated my own company. I was a social animal, forever on Facebook ... After the attack I couldn't bear to be left alone... But now, now I enjoyed having time to think... 'How weird', I thought with a smile. 'It's like I'm more at ease with myself than I was before'. (p.197)

Drawing on narratives Katie constructs a sense of who she has been (Singer and Salovey, 1993) and who she is now (Bruner, 1990). It could be argued this reflection shows how through her experience of disfigurement she has gained a greater understanding of herself. Becoming more "at ease" suggests a sense of relief; this could suggest Katie prefers herself now compared to how she was before. This extract also highlights how 'big' stories enable the narrator to reflect over a longer period of time than available in ongoing small narratives (Freeman, 2010). The narrative implies new insights have been gained through the experience; this is further supported by a change in Katie's definition of 'beautiful' that incorporates a deeper meaning of inner beauty, which she had not previously considered:

Had it made me a better person, deep down, underneath the scars? Had it made me more beautiful, in a way I'd never even imagined? 'Wow, I've never thought about it like that before. (p.211)

This suggests Katie feels she has changed, not only physically but psychologically. This change is perceived to be for the better, and perhaps not possible without her experience of disfigurement. Research suggests some people achieve unexpected gains such as personal growth and insight through their experience of disfigurement (Williams, Davey, Klock-Powell, 2003). It could be suggested Katie's new understanding is profound and is central to her new sense of self. Indeed, this is reinforced by her autobiography titled 'Beautiful' as are both her television series: 'Katie: My Beautiful Face' and 'Katie: My Beautiful Friends'.

Although there are some instances where the experience is presented differently:

"There is a part of me that just feels like, I wish it'd never happened to me. I wish I had that face back but, I've met some really great people through been burned and it's almost like I'm a split person" (Episode 3)

This may imply Katie would prefer not to have had her experience of disfigurement in order to regain her previous appearance. The term “split person” suggests recognition of both good and bad outcomes of the experience. It is suggested the “great people” she has met have contributed to making her experience positive, and created a sense of unity. This highlights how ‘small’ stories present inconsistencies in experiences.

Katie consciously reflects on her experience of disfigurement and it is suggested to have had a large positive impact on her identity:

“I’m proud to be disfigured... and instead of breaking me, it’s made me into everything I am and everything that makes me happy” (Episode 4)

This suggests Katie sees her disfigurement as a large proportion of her identity, defining how she feels about herself. This also reflects a transition from shame to eventual pride, which is typical of narratives of profound identity change, where rejection and disgust is experienced from others. Similarly a participant in Williams, Davey, and Klock-Powell’s (2003) research reported feelings of pride and increased self esteem through living with burn injuries. This suggests the change in Katie’s sense of self is embraced, developing a greater character, which may not otherwise have being realized. This presents her experience in quest narrative (Frank, 1995) form, as highlights the personal growth and insights gained through her experience. The desire to share these personal gains with others gives coherence and meaning to her experience. Sharing her personal insights may also suggest Katie is aware her story of disfigurement will influence public perspectives of disfigurement, understanding her individual story could increase awareness that living with disfigurement can be a positive experience. Relating to Frank’s (1995) suggestion people learn how to interpret their own illness from published illness narratives. Katie constructs her narrative of positive experience of disfigurement by connecting experiences in certain ways, giving them particular meanings, focusing on her personal gains achieved.

## **Conclusion**

In conclusion, the narratives presented reflections and evaluations of Katie Piper’s experiences and illustrated the construction and expression of her new identity. Analysis demonstrates the conflicting emotions related to adapting to changes in appearance and learning to manage unwanted attention. Overall the narratives suggest Katie Piper triumphed over adversities encountered in her experience and gained an increased sense of resilience and personal insight that may not otherwise have been achieved. The development of Katie’s positive identity was achieved over time and accompanied by regaining her independence and finding support by sharing her experiences. Similarly all participants in Egan et al’s (2011) study reported an acceptance of their disfigurement but acknowledged they had not always felt this way. This also relates to how narratives are situated in the time constructed, so the narratives Katie tells now may reflect different meanings and an alternative sense of self.

This research supports Freeman's (2010) suggestion that 'big' and 'small' stories can complement each other and provide an inclusive approach to identity research. Overall the analysis shows the lived re-telling of her experiences was more contradictory in interactions with others, than suggested by the 'big' narrative autobiography. Combining these two approaches helped to convey the details of how Katie Piper experienced the imposed transformation of her life through an acid attack, which ultimately created a positive transformation to her identity. Future studies may also explore identity research using this dual perspective approach, highlighting how 'big' and 'small' stories shape an individual's identity.

Narrative approach is case centered inquiry (Riessman, 2008) so these research findings cannot provide generic explanations of the experience of disfigurement. However this research does highlight how living with acquired disfigurement is not necessarily a negative experience, as some research suggests (Rahzani, Taleghani and Nasrabadi, 2009). Future research may explore other positive aspects associated with different types of disfigurements using samples across different ages and gender.

### **Reflexive considerations**

Reflexive method considerations were discussed in the introduction and data collection section. Riessman (2008) highlights the importance of the researcher to acknowledge own interests for conducting research. I was interested in this topic after watching Katie Piper's television series. The brief knowledge of her positive adjustment may have led me to present this bias through analysis. Although I do not feel this occurred as contradictions and negative aspects of her experience were also identified and presented. However recognizing interpretations are grounded in my own perspective, analysis may have been influenced by my emotional response to the narratives. I did find Katie's experience inspiring so the analysis may reflect these feelings. My similar social position as a young female living in England may possibly have influenced interpretations as I can relate to the importance society places on appearance however; I have no personal experience of disfigurement.

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