MANUSCRIPT

Title

Disrupted faces, disrupted identities? Embodiment, life stories and acquired facial 'disfigurement'

Martindale AM and Fisher PL

Abstract 197 words

Questions about the relationship between faces, 'disfigurement' and identity intensified following the first facial transplant (2005). Over a decade later, empirical research exploring the influence of acquired facial 'disfigurement' on embodied identity disruption and re-formation remains limited. A common strand of thinking assumes identities are contained within faces. Commentators have suggested that identities can be diminished through 'disfigurement' and restored or replaced through reconstruction or transplantation. The authors question this claim and provide a conceptually-informed, empirical alternative drawing on the results of a phenomenologically located, narrative study exploring identity shift in British adults following acquired 'disfigurement'. Findings suggest that faces are important to humans, and that identities can be disrupted in the aftermath of facial 'disfigurement'. Though, the relationship is not simple and cannot be predicted by the degree of corporeal change. Disrupted, liminal and contradictory strands of identity emerged; pre-existing identities were strengthened, and new ones emerged, other non-related experiences were also influential. Nuanced, relationality was at the heart of participant sense making. Consequently, the authors reject the idea that identities are contained within faces and call for the development of a wider social and relational facial phenomenology to more comprehensively explore this fascinating, multi-faceted relationship.

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MAIN TEXT

Disrupted faces, disrupted identities? Embodiment, life stories and acquired facial 'disfigurement'

Introduction

Context

Since the announcement of the first facial transplant (France, November 2005) discussions about the relationship between faces, 'disfigurement' and identity have heightened (Bluhm and Clendenin 2009, Pearl 2017, Yaron et al. 2017). Changing Faces (CF 2017), a national UK appearance equality and support organisation report, state that 569,000 children, young people and adults in the UK live with a facial 'disfigurement'[1]. However, 14 years after the first facial transplant empirically informed social science research into the relationship between faces, 'disfigurement' and identity remains limited in output.

Taking bio-medically influenced commentaries on facial transplantation as its contextual point of departure, the purpose of this paper is to provide a phenomenologically (Merleau-Ponty 1962) influenced understanding of the relationship between faces, 'disfigurement' and identity. The study explored the lived experiences of 13 British people using a narrative methodology and participant photographs (Martindale 2015). The study and the paper illuminate how acquired 'disfigurement' can disrupt everyday lives, activities and taken-for-

granted assumptions (Yaron et al. 2017) in the months and years following the facial event(s). Underpinning the research is an understanding of persons as embodied beings, simultaneously corporeal, cognisant and conscious, existing within a specific time and space (Toombs 1993) and social and physical environments (Carel 2011).

In addition, the authors offer a timely contribution to contemporary debates about facial transplantation. Facial transplants are associated with a high risk of mortality and raise ethical questions (Bound 2017, Coffman and Siemionow 2014, Sonn et al. 2010). Equally, facial transplants raise broader questions about society and the human condition, in particular the widespread tendency to equate facial appearance with 'personal' identity (Bluhm and Clendenin 2009, Pearl 2017, Perpich 2010).

The paper is relevant to the sociology of health and illness for a number of reasons: firstly; the participants spent extensive time at hospitals, outpatient clinics and primary care centres following unanticipated changes to facial appearance; secondly 'facial disfigurement' is often constructed as an individualised, periodic medical problem rather than as an embodied, socio-culturally embedded phenomena. Finally, we wanted to interrogate the accuracy of medically-informed reductionist approaches which equate appearance directly with identity (Bluhm and Clendenin 2009, Bound 2017, Pearl 2017). In the remainder of this introduction we outline how 'disfigurement' and identity have been discussed in facial transplant commentaries and explore how sociological literature can inform such discussions.

Identity and facial transplant commentaries

Since the perceived link between faces, 'disfigurement' and identity is a developing area of sociological and anthropological study, one way of exploring current thought is to draw on transplant discourses. Certain clinical, bioethical and media commentators have suggested that faces play a substantive corporeal role in identity formation. The suggestion is that the face is '*…the bearer of personal identity*' (Perpich 2010 175), which can be damaged or weakened through 'disfigurement' and restored or replaced through facial reconstruction or transplantation (Pearl 2017, Perpich 2010). For example, bio-ethicist Swindell has remarked that with '*facial allograft transplantation, the person is gaining an identity, whereas in the case of severe facial disfigurement, the person is losing an identity*' (2007 451). When discussing the case of a Spanish man who had undergone an extensive transplant British newspaper The Mail on Sunday asked '*Can the world's first full face transplant patient live with his new identity?*' (Reid 2010). Emphasizing the importance of outer appearance in identity formation Carolessa and Pradeu (2006) stated, '*The transplantation of visible organs provokes more serious questions for the recipient. Visible organs are components of an individual's identity...*' (183). Continuing this theme Carty et al. (2012) have suggested that blind facial transplant recipients may adjust more easily after surgery, since they cannot see the results and the identity transfer, which is assumed to have taken place. In 2017 a paper entitled '*Bioengineering a Human Face Graft: The Matrix of Identity*' (Duisit et al. 2017) was published exploring developments in facial tissue engineering and transplantation. The implicit link between faces and identity was not discussed. Prior and Orly (2011) found members of the British public and medical professionals thought faces played an important role in identity formation, even if participants did not always know why.

These sources suggest that faces reveal essential information about a person's identity (Perpich 2010) and, in doing so, position facial reconstruction and transplant teams as powerful, agentic restorers of identity to passive, disembodied persons. Faces play important roles in self and other recognition, communication, identity (re-)creation and symbolic sociality. Here we question whether identities reside within faces and whether facial transplant and/or surgery can restore previously lost identities (Black 2011, Perpich 2010). As Perpich (2010) argues:

'*…bioethics will do better, both phenomenologically and ethically, by moving away from the idea of the face as a non-fungible marker of personal identity (and thus as somehow qualitatively different from other organs or parts of the body) and toward an understanding of human embodiment as plastic in form and plural in meaning'* (177-178).

Pearl (2017) concurs, '*…we already knew that appearance does not correlate directly with and inherently with behaviour and character*' (164), attributing the idea that identities are contained within faces as a form of contemporary physiognomy. The final part of the introduction will expand on the contribution social science literature can make to our understanding of the relationship between faces and identities.

Social science research on faces, 'disfigurement' and identity

Substantive work over recent decades has illustrated that embodied identities are shaped and re-shaped by people's relationships with their bodies and others over the life course (Csordas 1994, 1997, Merleau-Ponty 1962, Leder 1990). Both faces, or 'body-faces' (the acknowledgement that faces are parts of embodied, embedded persons) and identities are dynamic and nuanced phenomena involving selves, others and wider considerations. As Butler (2003 cited in Magnus 2006 50-

53) argues, the subject is not free to tell their own story since '…*every "I" begins in and through others*'.

Goffman's *Stigma, notes on the management of spoiled identity* (1963) illustrates that facial 'disfigurement', acquired stigma and identity disruption are related, being co-produced by selves, others and wider society. People with a facial 'disfigurement' can be visibly discredited and cease to be accorded the respect they had previously taken for granted on the basis of their social identity (comprised of multiple dimensions such as professional status, age, gender and appearance). '*The general identity- values of a society may be fully entrenched nowhere and yet they can cast some kind of shadow on the encounters encountered everywhere in daily life*' (Goffman 1963 153).

Frances Cooke Macgregor also concluded that self, other perceptions and wider social values about appearance were key to understanding sense-making about facial 'disfigurement'. In 1967 Macgregor found variations in participant sense-making following her study into motivations for plastic surgery of the nose. Whilst one group was keen to hide discredited ethnic identities, individuals in a second group were motivated to have surgery based on the perceived relationship between an unaesthetic facial feature and personality traits. Similar to Goffman (1963), Macgregor (1967 132) found that participants personalities were influenced by negative reactions and stereotypes within social encounters '*Because I look like a clown, people expect me to act like one*.'

Both of these early studies highlight the importance of context and others in perceptions and sense making; and these point to the usefulness of participant-centred research and methodologies. Leder's (1990) concept of bodily

'appearance' has proved a useful tool to study the relationship between acquired facial 'disfigurement' and identity disruption as it takes into account the role of self and of others in on-going sense making and starts from an embodied, phenomenological perspective. Leder (1990 13) has argued that unanticipated illness or injury has the capacity to disrupt taken for granted or 'absent' embodiment. Experiences associated with acquired 'disfigurement' such as pain, bodily trauma and existential anxiety have the potential to shift faces from their background status, to one of heightened awareness or 'appearance'. Appearance can be external and internal, and result from self-awareness and/or attention from others. Unhabitual changes in appearance can threaten everyday life, activities and associated sense-making (Leder 1990 108). The authors draw on Leder's (1990) concept of unanticipated body-facial appearance to explore its potential influence on participant lives and embodied, relational identities.

An innovative field of social science research is emerging to explore the relationship between faces, 'disfigurement' and identity (Black 2011, Bound 2017, Le Breton 2014, Pearl 2017, Perpich 2010, Yaron et al. 2017). Contributions so far have been largely but not exclusively of a philosophical, conceptual and historical nature with a range of illustrative examples. Drawing on the work of philosopher Levinas, Perpich (2010) has demonstrated the multiplicity of meanings evoked by the word 'face, including façade; personhood; agency; and interaction and cognisance, which are qualities of embodiment. For Black (2011) these variations are indicative of the pluralistic roles and activities associated with faces such as recognition, perception and relationality. Black argues that a face is a '*shifting, multiplex, distributed and layered phenomenon*' (2011 1) which can only be understood in association with others, '*The face is brought into being by communication and communication can only exist in the relationship between*

bodies' (Black 2011 21-22). Similarly, Pearl (2017) rejects the claim that identities are located within faces, reminding us that judgments are made about the faces and identities of non-'disfigured' persons. '…*we judge the hell out of people for how they look, for how they present themselves, for the colour of their skin, the performance of their gender*…' (2017 165). This is nothing new: social science commenters (Benson 2008 Giddens 1991, Popovic 2007, Synnott 1993) have indicated that facial appearance has been used to judge people's moral and economic worth, intelligence and character since antiquity As Benson (2008) states:

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

Le Breton (2014) calls for the development of a '*social phenomenology*' so as to better understand the relationship between faces, disfigurement and identity. In a conceptual piece which draws on empirical examples he also seems to be proposing a stronger, more direct relationship:

'*Any alteration to the face puts at stake the sense of identity. Disfigurement destroys the sense of identity of an individual who can no longer recognize himself or be recognized by others*' (Le Breton 2014: 1).

Le Breton does not appear to be implying that identities are located in faces, but that individuality, sociality, relationships and symbolic participation become threatened when 'disfigurement' occurs. Finally Yaron et al. (2017), drawing on Leder's phenomenological and embedded perspective, conclude that people living with a facial prosthesis (mostly through cancer) experience facial 'disfigurement' as a disruption that requires them to work to varying degrees to develop a revised

sense of embodiment, engagement with themselves and others and with the material world around them.

Drawing on social science literature, the authors recognise that the relationship between acquired facial 'disfigurement' and identity is likely to be influenced by socio-cultural considerations; disrupted embodiment; dynamic relations with others; and subject to on-going sense making (Black 2011, Pearl 2017, Yaron et al. 2017). This paper adds to knowledge through generating nuanced, relational, empirical insights into the influence of acquired facial 'disfigurement's on embodied identities over the life course. It has been achieved through the use of a bespoke narrative, visual methodology which has resulted in a unique dataset. The next section outlines the study and its methodology in more depth.

The Study

As the aim was to explore identified experiences over the life course a narrative methodology was selected. Over recent decades the narrative turn within the social sciences has helped to illuminate '*profoundly social influences*' on story telling (Gubrium and Holstein 2009 22) and illustrate the complexities of identity formation, disruption and renegotiation (Gilligan et al. 2003, Doucet and Mauthner 2008, Gubrium and Holstein 2009, Riessman 1993, 2008). Narrative scholars have illustrated that (life) stories are crafted from selected lived-experiences which shift in meaning and significance as bodies change and new experiences occur (Doucet and Mauthner 2008, Gilligan et al. 2003, Gubrium and Holstein 2009, Riessman 1993, 2008). As Williams (2000) has argued, '*If stories express being-in-the-world, narrative reconstructs not only an individual's biography but their relationship to their place and history*' (139).

To achieve the study aims, narrative interviews were designed (Table 2) and conducted by the first author with 13 adults living in Britain. University of Liverpool ethical approval was gained (2011) and good ethical practice was adhered to throughout (BSA 2011, ASA 2011). University approved publicity materials were sent to more than 60 groups including: British facial support organizations; facially-related-single-issue health groups and newspapers in England. This broad approach ensured the inclusion of participants and sense making beyond a single cause, condition and geographical region.

In keeping with a phenomenological orientation there were no prior classifications of 'disfigurement'. Instead, people '*living with an acquired facial 'disfigurement'* (Information Sheet) were invited to contact the first author if they were interested in being interviewed. Through self-selection, the aim was to gain an in-depth understanding of participant descriptions and perceptions of 'disfigurement'.

Prior to fieldwork the first author attended a 'disfigurement' sensitizing workshop, to hear Changing Faces' (CF's) perspective on how to interact sensitively with 'disfigured' people. Potential participants were provided with details of CF's specialist therapeutic services e.g. appearance related counselling, in case they became distressed. CF aims to '*provide advice, support and psychosocial services to children, young people and adults…challenge discrimination and…campaign for Face Equality*' (CF website 2018). The authors share an ethical concern with CF however, CF played no role in influencing the research process or findings.

Eleven interviews were conducted on a face-to-face basis, while the remaining interviews took place on the phone. The interviews lasted between 40 minutes and three hours in length. All participants identified as white British and

heterosexual, six were men, seven were women and they were aged between 39-91 (Table 1).

Table 1 Participant facial 'disfigurement' cause and time of occurrence

Participants were asked to bring everyday objects, for example, photographs to help tell their life stories. This request served several purposes: to facilitate dialogue; add contextual and multi-sensory richness to life histories (Larkin et al. 2006, Tinkler 2009); explore representations and meanings beyond the image; and, to enhance data quality. These aims were achieved when nine participants provided photographs and two more spoke about them during phone interviews. They included images of faces before and after but, for the most part, photographs of everyday life involving selves and others, for example, at weddings, parties, work and on holiday. One quiet, older man used a photo album of his military and civilian achievements to help illustrate stories characterised by themes of hegemonic masculinity. Other female participants drew on images on display in the home involving selves and others as a particular narrative unfolded.

In keeping with a narrative method, there were three phases to each interview (Table 2). Phase one focused on exploring participants' lives before, during and after 'disfigurement' using a few open questions (Table 2). For example, can you tell me about your life before your face changed? The task of the interviewer was to listen and not interrupt, other than gentle prompting to encourage elucidation (Wengraf 2004). Phase two involved a closer questioning of emotive topics, seminal moments, silences and contradictions in chronological order using participant phrasing. The aim was to encourage participant reflection to gain additional context, depth of data and interviewer understanding of the narratives and their significance (Reissman 2008, Wengraf 2004). During phase three semi-

structured questions were asked about identity, identity disruption and facial 'disfigurement' (Table 2), to cover areas that participants might not have addressed. A full complement of 39 sets of data was achieved. All participants received a transcript and were invited to comment or withdraw content: none withdrew, three added additional comments. The resulting dataset (field notes, audio-recordings, transcripts and post-interview participant comments) were securely stored, anonymised and subjected to extensive analysis.

Table 2 The (post-pilot) interview topic guide

To elicit a descriptive, analytical and critical understanding of the relationship between acquired facial 'disfigurement' and embodied identity disruption the first author constructed a bespoke listening guide containing 14 techniques under five headings (Table 3). The works of narrative practitioners Gilligan et al. (2003), Doucet and Mauthner (2008) and Gubrium and Holstein (2009) were selected as they reject simple associations between narrative and identity; identify the limits of narrative research; and, allow for multiple, reflexive readings that open up the data and allow for multiple interpretations. As Gubrium and Holstein argue:

'*Concern with the production and reception of stories in society requires that we step outside of narrative texts and consider questions such as who produces particular kinds of stories, where are they likely to be encountered, what are their purposes and consequences, who are the listeners…?*' (2009 23).

These concerns were reflected in the construction of the listening guide (Table 3). Though the study focused on perceptions of 'individual' identity disruption, the aim was to understand how self-other relations, context and environment influenced sense-making over the life course. For example, through focusing on the '*active I*' and the role of significant others Doucet and Mauthner (2008) and

Gilligan et al's (2003) work helped to illuminate differences in post 'disfigurement' lives, activities, relationships and self-perceptions. Gubrium and Holstein's (2009) deconstruction of stories as resources at hand, environments, experiences, story-telling and audiences helps to illuminate how nuanced accounts are constructed, how these phenomena may influence sense-making, and why this may vary between individuals. In addition, these authors encourage analysts to look for gaps, inconsistencies and contradictions to generate layered and dynamic understandings of identity construction. Tinkler's (2009) work on the use of photographs during interviews enhanced descriptive and critical understanding of visual aspects of identity. Rich description often followed the sharing of a seemingly simple photograph. For example, Clara's retrieval of old photo albums led to unanticipated narratives that were explored during phase two:

'*I don't like seeing myself in photos, I just thought I would show you that how nice I was when I was younger though and I didn't realise it because of the perception of this* (points to her nose). *But I had a cracking figure really and had all the dirty old men after me, really did. But you know looking back I was probably ok looking, apart from the nose, but this nose I always feel it's there*…'.

Once all individual accounts had been subjected to the guide (Table 3) a further comparative analysis was completed to explore sense making between participants with similar and different facial experiences before, during and after 'disfigurement'. The next section, empirical findings explores experiences of becoming 'disfigured', in particular two areas that could influence participant sense making: the cause and context of 'disfigurement' and perceptions of visual change.

Table 3 Narrative analysis techniques applied to each account

Empirical findings: Body-facial appearance and identity disruption

Introduction

Acquired facial 'disfigurement' occurred thorough cancer (six participants), accidents (six participants) and acne rosacea, a worsening skin condition (one participant). See Table 1. Consequently, there where variations in the type and extent of body-facial disruption and the time-scales and contexts in which it occurred. Analysis indicated that these phenomena influenced participant sense making and that the relationship between acquired facial 'disfigurement' and identity disruption was not simple, as Clara's interview illustrated:

'*I am mass of contradictions….I feel like I am three people, there is one that is really silly, ditzy blonde, there is one that is a very cool business woman…I have been quite extrovert in things like that, but I am introverted in other ways because of my nose. Or is it my nose, or was it just the upbringing?*'(Clara).

To illuminate the relationship between body-face, acquired 'disfigurement' and identity disruption two emergent areas of participant focus are explored here: the causes and contexts of 'disfigurement', and perceptions of visual change. The causes and contexts of 'disfigurement' were selected as they built on the understanding of embodiment used in this paper and because they influenced participant sense-making at the time of the event(s) and in the years to come. Perceptions of visual change were included because looking in the mirror/and or being in photos after the facial event(s) emerged as a seminal experience and a more immediate marker of disruption. Exploring perceptions of visual change has

also enabled the authors to take Leder's (1990) bodily appearance work in a new direction.

Sense making about identity (disruption)

Causes and contexts: accidents and cancer

Martin experienced an accident in his late teens. Prior to this, he identified positively with himself in relation to his peers:

'*I was quite a successful child…I was always in the top-ish group in the class, and I was able to play sport and I was able to be quite a sociable lad about the place*…' (Martin).

Martin lost control of his car and it caught fire. His face, arms, upper body and legs were badly burned, he nearly died, had to have fingers amputated and he spent months in hospital:

'...*I was completely, completely swamped…I was sort of aware of people's reactions to my face, but actually rather the physical pain, enduring the endless operations, the unbelievable discomfort…I suppose you have got two processes going on and I certainly was conscious of them. One was managing other people's reactions to me, you know I really needed my mother not to, and my family not to think that I was going to go down into the pits because she was so supportive and damn it this is my fault...the other process was this ghastly grinding of all the emotions of loss and anger and self-blame and self-pity…and it was hard not to feel revolted, frankly. I felt tarnished, I felt damaged beyond repair*…' (Martin).

Alien and alienating sensations including pain, emotional conflict, managing close relationships and the severity of his injuries threatened not only Martin's existence, but his present and future identifications of success (career, romantic

and sporting), based on his '*good looks*', intellect, and physical abilities. Though his face was involved, it was the experiences of the whole person that led to Martin's early perceptions of a '*damaged*' or spoiled identity (Goffman 1963) and ritually polluted, liminal state caused through bodily matter being '*out of place*' (Douglas 1969). Turner defined liminal entities as '*neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial*' (Turner 1969 95). Martin inhabited a '*blurred*', liminal status for several years following his accident as he lived between health and illness, between ability and disability, between hospital and everyday life. '*There is a transition process…it sounds as if it was a nice easy process, no way, no. Between 19xx and 19xx there were a lot of down places, doubting places…*' (Martin).

Barney also experienced a sudden, life-threatening event, though his response was different. He had been a young pilot in the British Royal Air Force during World War Two. Barney's planed crashed into the sea during a military operation with the loss of his crew. He was rescued and spent a year in hospital being treated by pioneering plastic surgeon Archibald Mc Indoe:

> '*I enjoyed it; I loved flying, and then when I eventually finished in hospital in about March 1942, I was posted straight back from hospital back to flying doing exactly what I had been doing before…'* (Barney).

Barney's injuries necessitated a 12 month hospital stay involving extensive reconstruction work. He was left with an indent in his head and a long vertical scar the length of his face. However, this aspect of his story received little attention. Unlike Martin, there was a wider physical and moral context for Barney's injuries and they could be anticipated:

'*…I think it's all in the mind. As far as I was concerned, I had this crash and if you are flying airplanes it's what you expect to have really and erm… you just get on with it.*' (Barney).

In addition, the experience appeared to enhance, rather than disrupt his sense of self given that Barney was able to return to what he had previously identified with e.g. being a military man, a pilot, and a leader of men fighting in a positively regarded war. In this context his facial scar and treatment by a pioneering surgeon could be seen in a positive light:

'*…we were in the middle of a war… I was in standing outside the post office in Kent like this and some woman came up to me and grasped me and said how wonderful I was…Service to the country*' (Barney).

Participants with cancer (Natasha, Doreen, Jonathon, Sylvia, Marie, William) did not have this positive public value, or career based anticipation of disruption to draw on. In addition, cancer related body-facial appearance (Leder 1990) carried the potential to cast an on-going disruptive shadow on perceptions of self and future life. Prior to facial cancer Jonathon identified as a successful, family man in control of his life, his career, his finances and his future. A late diagnosis and two courses of cancer treatment tore through his perceptions of control:

'*it was hard at 53 you know to* (pause) *you are in your swing* (pause) *there you are really going, both kids had left home, both two nice incomes coming in, two cars and all of a sudden you are on £68.90…I think I was on three months sick pay, but after then it was what can you do*...?' (Jonathon).

In the context of existential uncertainty and treatment related disabilities Jonathon sought to maintain control of his life and of others through more

assertive financial management and taking up voluntary work when paid work was no longer an option:

'*I am one of those people who my wife of many, many years will say I can't do anything by halves and if I join a football team I have to be the captain, club secretary, erm... and the same thing has applied most of my life*' (Jonathon).

Throughout the interview Jonathon appeared to be much more concerned with the on-going impact of cancer on his health, life and relationships rather than by alterations to his facial appearance. This finding was also echoed in Natasha's account. Natasha was in her late thirties and living with cancer resulting from an underlying genetic condition. '*I have always tended to kind of walk across a, walk along a precipice really when it comes to the health and that has always been a bigger issue to me than the face*' (Natasha). Living between health and illness Natasha compartmentalized her life to avoid an uncertain future '*I don't think about that much now because I tend to put things in boxes*…' (Natasha).

William (75) identified as active, married with grown up children, and a retired industrial chemist '*If people had trouble with their plant and couldn't make it work properly people like me would go along, sort the problem out…*'. William's former career continued to play a role in sense-making even though he had experienced four cancerous episodes and treatments since becoming retired. Cancer had become a problem to be quantified, treated and solved:

'*12 hours in theatre, 36 hours in intensive care and two weeks in hospital, six months doing very little and another six months to regain some form, some semblance of normality….I have had three more tumours since then, which were all detected very quickly, one hour in theatre, home the next day, pottering in the garden at the end of the week*' (William).

Though suffering from claustrophobia since his first cancer treatment William was keen to focus on his new hobbies. Digital photography and computer literacy had restored confidence and led to a strengthening of his problem solving identity:

'*I have done about 500 postings on the website* (a cancer support web forum) *where people write in say hey I have got a problem, what do I do about it?*' (William).

These examples illustrate that the causes and contexts of facial 'disfigurement' could influence sense-making. Identity disruption, transition and liminality could occur as perceptions about selves, abilities, pasts and future lives were disrupted, though not in all cases.

Perceptions of visual change: mirrors and photographs

Whilst beyond the scope of this paper, understandings of gender are clearly embedded in the data. Gillian, like other participants (Martin, Andrew, Sylvia) spoke of looking in the mirror for the first time after 'disfigurement' as a traumatic experience partly due to the loss of her good looks and their role in her anticipated future life. Aged 20, her ex-boyfriend had crashed his car into a wall at high speed. He had walked away while she suffered significant injuries e.g. broken spine, underwent emergency surgery, nearly died and lost an eye. Three weeks later Gillian saw her reflection for the first time:

'*…I asked one of the male nurses to give me a mirror. Oh my God…scarring all over my face from the lacerations and I am just looking at it thinking the elephant man has arrived in my mirror, it's not me. And then it really hit home, then it was inconsolable tears. …and then all of these emotions just come flooding through about how am I going to deal with it? I can't look at anybody looking like this. How am I going to live my life at 20 years old? Who is going to love me? Who is going to want to speak to me?...I think the*

fight just clicked in and I just thought right well as is me, how do I fix it? What is the solution?... suddenly you suffer this huge loss and then it's a case of building back up what you have got left' (Gillian).

Like Martin, Gillian was experiencing shock, pain and multiple competing emotional states, including anger at the driver (which later fuelled her identity as a fighter), shock, grief, and being happy to be alive. Similar to William she was trying to find a '*solution*' to a chaotic situation. Gillian did not recognize her body-face, and feared that she would not find a husband or be able to have children, based on how she looked. She felt that she had lost a promising job in public relations because of her altered appearance. For over a decade after the accident Gillian became disembodied and lived in an emotionally conflicted, liminal state; simultaneously a '*fighter*' and a seeker of emotional and identity re-negotiation based on facial reconstruction, though it didn't fulfil expectations:

'*Then it is years of looking in the mirror going oh, it's still not right. Have another operation, it's still not right. Have another operation. Oh God, well that was really painful it's still not right and that just went on for years…*' (Gillian).

Sylvia expressed similar early sentiments. Prior to her two diagnoses and series of treatments for sinus cancer, she identified as having '*an idyllic life'*, being '*blissfully happy*' and '*marginally attractive*' and '*very slim*' with '*really good hair'*. Significant weight loss, exhaustion, sickness and the loss of a cheek, bone and teeth resulting from the treatment, together with its existential implications led to a lack of self and life-world recognition when Sylvia looked in the mirror:

'*I went to the mirror in the bathroom…and I had to take out this obturator because I had lost my teeth…without it I can't speak…I just was in total despair thinking how can I live the rest of my life with this?... And then I heard the children coming up and we had a bathroom with a loo in it…the door was never locked, but from then on I started locking*

the door. I was aware that that image that I saw of myself wasn't one that I was familiar with…and just eating to try and build my strength up which I found really, really difficult, and I wouldn't speak on the telephone because I didn't sound the same….The whole Sylvia had changed and gradually that half of Sylvia had slowly disappeared and for weeks, the character this other person who I didn't recognize, because I was so withdrawn from everybody and everything…' (Sylvia).

Locking the bathroom door became a metaphor for distancing Sylvia and her much loved family from the trauma she was experiencing. Sylvia continued to fill and perform the roles of wife and mother, though she only '*pretended*' to be '*ok*' for her family and entered a state of emotional liminality which was to last for '*seven years*':

'*I was absolutely flat as if my emotions and everything had just been put in a box and shut away. I had the key erm… but I didn't want to open it*' (Sylvia).

In contrast, Stephen had developed acne rosacea in his twenties. He had not experienced severe body-facial injuries nor an existential threat. However, in the context of worsening symptoms; intrusive and negative comments; no reported cure and diminishing control over his appearance Stephen began to avoid people and looking in the mirror:

'*…you can wake up you know Saturday morning, you could feel good, and then you look in the mirror and it's like oh God, my face is red and you just feel it's self-esteem, your confidence, you haven't got any…*' (Stephen).

He also avoided being in photographs:

'*…there was no photographs of me and the kids, because I had always avoided it. And any photographs of me and the kids or me and anybody else, I would change the colour through some Photoshop I had made them either black and white or I had made them grey scale, because I looked better*' (Stephen).

Stephen had managed to exert some limited control, though it was only a partial victory. Seeing his reflection reminded him of the continued, negative impact of rosacea on everyday life and sociality, Stephen became socially avoidant:

'*when I say it has ruined my life it has ruined my life. Yes, it's affected friendships, relationships, erm… prospects, work, everything you know down to like, erm… I don't go to a gym anymore*…' (Stephen).

In contrast, Barney and Doreen were less concerned about visual changes to their outward appearance. Barney, for reasons already stated. Doreen was a retired woman whose perception of self-worth was more related to her moral world than her body-facial appearance:

'*I'm still me, I just have a different appearance' well, if you take the apple, if its bruised you peel the skin off and the core is fine, people need to accept others for what's inside*' (Doreen).

The findings illustrate that contexts, causes and changes in visual appearance could influence sense making following acquired 'disfigurement'. Bio-medically 'fixed' body-faces did not necessarily reassert a sense of lost control or lead to 'fixed' identities; in fact, it could lead to further identity disruption and liminality as Gillian', Martin's and Sylvia's account illustrate.

Discussion

Reflecting on key findings

In the aftermath of the first partial facial transplant (2005) commentaries have suggested that faces are important as they house essential identities (Carolessa

and Pradeu 2006, Carty et al. 2012, Duisit et al. 2017, Swindell 2007). We agree that faces have a role to play in on-going identity creation, and that identities can be disrupted following acquired facial 'disfigurement'. However, we reject claims that identities are facially based, that they can be restored to (passive) recipients via medical interventions or transplanted between persons. The use of a phenomenological, narrative, visual methodology has illustrated that layers of identity are created and re-interpreted across the life course, in association with others and wider social influences. Acquired facial 'disfigurement' can be one of those influences.

The causes and contexts of 'disfigurement' could disrupt lives and embodied identities as could perceptions of visual change. Both these aspects illuminated the importance of others and wider socio-cultural influences in sense-making, which concurs with findings by Goffman (1963), Macgregor (1967) and Yaron et al. (2017). Associated existential threats and their treatments e.g. for cancer had the potential to disrupt perceived selves and futures far more than an altered appearance. Participants who also experienced related damage to other body parts e.g. a broken spine, the loss of fingers or an eye stated that these injuries could disrupt performative aspects of everyday life and identity such as being active, independent or sporty. These combined experiences could lead to on-going liminal states (Turner 1969) as participants lived between: life and death; health and illness; corporeal wholeness and damage; ability and disability; anticipated perceptions and realities, and with competing emotional states. However, not all identities were disrupted, some were strengthened, e.g. war hero or problem solver and new related and unrelated experiences such as becoming a spouse or parent also influenced perceptions of self. Taking these findings into consideration we do not support Le Breton's assertion that facial '*Disfigurement destroys the*

sense of identity' (2014 1) as this reifies faces and does not take into account other influencers of identity, individual agency and sense-making.

Though the data is rich, the sample size of 13 is small and draws only on the experiences of 'white', heterosexual British participants in a single-interview encounter. More diverse, deeper insights could be gained by focusing future research on specific social groups, and through the use of multiple-encounter interviewing (Wengraff 2004). In addition, stories are continually being overlaid with the meanings of newer experiences over time. Consequently, what a narrative methodology can offer is a meaningful description and analysis of a participant's life and experiences depending on what they chose to disclose during interview and how it is analysed and reported (Doucet and Mauthner 2008, Larkin et al. 2006). Nevertheless, this novel methodology and unique dataset has led to the production of new empirical knowledge about the relationship between faces, acquired 'disfigurement' and identity, and suggestions about how it might be more comprehensively explored in the future.

Towards a facial phenomenology

We agree with Yaron et al. (2017) that phenomenology '*offers important clues into how a person's being-in-the-world is affected by their embodied internalization of the other's gaze*' (289) and concur with Le Breton's (2014) call for a more nuanced, social phenomenology, albeit with caveats. Taking the significance and plurality (Black 2011) of the body-face as a point of departure we propose the development of a facial phenomenology. One which incorporates the roles of embodied self, other and wider social processes as a more comprehensive

way to understand the multi-layered relationship between persons, facial 'disfigurement' and identity.

Perpich (2010) has suggested that there is a need for bioethics to move away from the idea that faces are '*somehow qualitatively different from other organs or parts of the body*' (177-178). Corporeally faces are parts of bodies, however, they are also different. Unlike other body parts faces are meaningful sites of interactive matter (Benson 2008), simultaneously engaged in the making of self, other and relationships through perception, communication and sense making; and they have been embedded in the processes, practices and performances of social reproduction for over two millennia (Pearl 2017, Synnott 1993).

Leder's (1990) useful ideas on bodily appearance would benefit from revision to include the exploration of wider social processes over the life course starting before the facial event. Prior to any accident, illness or injury body-faces are in perpetual states of corporeal and socio-cultural appearance and are subject to habitual change, and on-going sense-making (Benson 2008, Black 2011, Martindale 2015, Synnott 1993). Incorporating both perpetual and unanticipated body-facial appearance in future research designs could enrich what we know about the relationship between faces, sociality and social reproduction. As could the use of a narrative methodology, which helps to make sense of '*an individual's biography*' and '*their relationship to their place and history*' (Williams 2000 139).

Conclusion: facing outwards

The original contribution of this paper is that it draws on a growing body of social science work and a unique dataset to demonstrate the complex, socially contingent, evolving relationship between identity creation and facial

appearance/'disfigurement'. The authors have illustrated how identities can be disrupted and influenced post facial injury/condition over the life course; as shaped by facial circumstances, age, sexuality, gender, ethnicity, family, place, social context and other phenomena. Consequently, we have concurred with Le Breton's (2014) call for a social phenomenology and advanced the field; in the process illustrating the need for empirically informed research. Longitudinal work of this kind and its wider dissemination is critical for informing the development of appropriate health and social supports for people experiencing on-going identity disruption, conflicting emotional states and facial discrimination. Equally, it is needed to help refute constructions of identity as static, individual, and facially located phenomena.

Footnotes

1 The first author started the research using the term facial difference, though facial 'disfigurement' was used widely by participants, so it was adopted instead. However, the term can carry negative value judgements so 'disfigurement' has been placed in inverted commas.

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