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Competing Narratives in Framing Disability in the UK Media: A Comparative Analysis of Journalistic Representations of Facial Disfigurement Versus Practices of Self-representations Online

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Abstract

By using discourse analysis, this paper compares and contrasts the journalistic coverage of the story of a beauty blogger with facial disfigurement with her blog. On the one hand, we will show the extent to which a self-representational account may align with the journalistic coverage, reinforcing rather than contesting mainstream representations of disability. On the other, we will demonstrate how a person with a disfigurement can use blogging to reclaim her own identity and challenge the medical objectification of her body perpetuated by mainstream media. This research found that rather than being mutually exclusive, journalism and blogging can play a complementary role in shaping the society's understanding of the complexities and contradictions surrounding disfigurement.

Contributors' Notes

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Introduction

With its wealth of publishing possibilities, the emergence of the Internet poses the question of whether the function of long-established forms of media as conveyors of public discourse must be redefined (Coleman and Blumler 2009; Dahlgren 2009; Holt and Karlsson 2015). This study aims to explore the logic of the Web in the context of disability-related issues. Online platforms can offer new and sometimes more positive ways to depict disability (Cole et al. 2011; Gonzalez-Polledo and Tarr 2016; Thoreau 2006). However, the question of whether the forms of self-representation offered by the virtual world are creating a new paradigm to re-interpret disability deserves more critical analysis.

By focusing on a case study, this article seeks to discuss how the interrelation between the journalistic media coverage of disfigurement and self-representation on a personal blog may create an exemplary site for the study of the dynamics of the construction of disfigurement. In particular, this contribution aims to examine the extent to which the personal blog of a person with an appearance impairment can provide an alternative narrative to the journalistic account of the same in mainstream media. On a more general level, this work adds up to the current discussion on the function of blogging as a means to empower self-expression for under-represented or misrepresented people. We argue that although self-representation online enables people to craft their own stories, journalism still plays an important role in shaping a public understanding and social awareness of what it means to live with a disfigurement by fulfilling both an

epistemological and a campaigning function.

Disfigurement generally refers to one's appearance being affected by a congenital or acquired medical condition. At least 1.3 million people in the UK are estimated to have a significant disfigurement. 569,000 people have facial disfigurements (Changing Faces 2017). Severe facial disfigurement is considered a disability under the Equality Act 2010. Defining disfigurement as a disability is complicated by the disagreement over what counts as a disability and by the fact that disability can take many forms (Couser 1997b, 178). Rosemarie Garland-Thomson (2005) wrote:

Bodily forms deemed to be ugly, deformed, fat, grotesque, ambiguous, disproportionate, or marked by scarring or so-called birthmarks constitute what can be called appearance impairments that qualify as severe social disabilities. (1579)

As Heather Talley (2014, 15–17) notes, the term disfigurement is subject to interpretation by individuals with disfigurements themselves but also by health professionals, judges, journalists, teachers and other members of the public.

While facial disfigurement may be more commonly referred to as a bodily condition or an altered bodily appearance and not as a disability as such, there may be some common denominators of facial disfigurement and disabilities, such as, for example, a visual impairment or paralysis. Also, both visible or invisible physical impairments face social stigma, discrimination, prejudice,

and exclusion in public life. Disfigurement has traditionally been underrepresented in the mainstream media (Changing Faces 2017). Yet, there are numerous personal blogs and social media accounts owned by people who have a disfiguring condition who are claiming their space back.

This article is based on a case study of a beauty blogger who has a congenital facial condition called cystic hygroma. She has been running her blog, mainly publishing reviews of cosmetics, since 2013. Both the provincial and national press have regularly covered her story for almost two decades, since 2000.

Literature review

Means of mass communication contribute significantly to shaping the cultural discourse and popular imagination around pathological conditions affecting physical appearance (Wardle and Boyce 2009; Shakespeare 1994). The mainstream media often create and exacerbate pressures on those distraught by their appearance (McGrouther 1997; Rumsey 1997). This is because people with disabilities are misrepresented in the mass media as well as in the literature (Couser 2000; Riley 2005). For example, Wardle and Boyce (2009) found that recurrent patterns occur in the British television coverage of disfigurement such as an association with evil, reclusiveness, and bitterness. Similarly, in Western cinema, classic Hollywood movies villains are statistically more likely to show a skin condition affecting their appearance: in this case disfigurement is used to emphasise the dichotomy of good versus evil (Croley, Vail and Wagner 2017). These misrepresentations are also reflected in

the wider coverage of disability and bodily impairments in the UK media, which are often 'clichéd, stereotyped and archetypical' (Darke 2014, 100).

The development of the practice of keeping a blog or sharing personal stories online through different formats, such as social media, makes it necessary to reassess the function of the autobiography versus the mainstream representation of disfigurement in the light of evolving communication technologies. Blogging is now a widespread form of writing that often replaces the traditional print article, as it can quickly and cheaply reach a wide and potentially international audience (Danesi 2013, 67). Blogs can be defined as periodically updated websites consisting of postings arranged in reverse chronological order so that the newest postings are displayed first (Dart 2009; Fuchs 2014; Herring and Paolillo 2004). Online personal accounts may provide a public platform for views traditionally ignored by the mainstream press (Antunovic and Hardin 2013; Mitra 2001; Nardi et al. 2004; Somolu 2007). Virtual environments made up of online communities are redesigning the traditional ways of constructing identity as something static and permanent (Bowker and Tuffin 2002, 329). The relationship between blogging and journalism has been widely discussed (Lowrey 2006; Lowrey and Mackay 2008; Messner and Distaso 2008). However, the role played by this relationship in constructing one's identity, especially with regard to disability-related issues, has received little attention.

A study on the self-representation of disability on *Ouch!*, a BBC-owned website produced mainly by disabled people, was found to be significantly different from

the mainstream media in that it was more entertaining and positive (Thoreau 2006). According to Cole et al (2011, 1175), the ability to decide how to present themselves online may allow women with disabilities to surpass the myths of 'normativity', thus crafting their own identity by distancing themselves from conventional narratives of medicalisation or rehabilitation. A blog can also function as a means of self-reflection and a way to experiment with different identities (Arsel and Zhao 2013). Furthermore, digital forms of pain expression can challenge and transform the traditional models of illness narratives (Gonzalez-Polledo and Tarr 2016). A number of studies have focused on social media, self-representation and skin conditions (Karimkhani, Gamble and Dellavalle 2014; Whitsitt et al. 2015; Gagnon and Duchemin 2016; Tembeck 2016). In particular, skin cancer, as one of the most common types of cancer in the world which causes severe disfigurement, has led to studies on its media coverage focused on a prevention campaign (Cokkinides et al. 2009; Hay 2009). However, a systematic comparison with the mainstream coverage has not been conducted. A comparative analysis permits seeing how the relationship between traditional media and blogging also reflects two binary oppositions. On the one hand, the comparison is between narratives of representation and narratives of self-representation. On the other, the opposition is expressed in terms of a medical model of disability versus a social model.

The medical model of disability holds that disability is the dysfunction of a particular body that must be fixed by a health professional (Clogston 1990; Couser 2011). The social pathology

model sees disabled people as a disadvantaged category of persons that must seek help in society (Clogston 1990). Historically, the medical paradigm played a role in 'demystify and naturalize somatic anomaly, stripping away any supernatural or moral significance and characterizing physical variation solely as a matter that science may investigate or attempt to remedy' (Couser 2011, 3). The social model of disability implies that disability should be comprehended as a sociological concept rather than as a biological flaw within an individual (Mallett and Runswick-Cole 2014, 5). However, the field of Critical Disability Studies suggests moving away from the binary proposition, the social versus the medical model (Meekosha and Shuttleworth 2009, 50) and seeing the social model of disability as not the only but one of the possible frameworks of analysis (Mallett and Runswick-Cole 2014, 16). The relationship between journalism and blogging is complicated by the fact that journalism has an epistemological function, as it seeks to inform as well as entertain. Therefore, a medical model seems fit for the purpose of shaping medical knowledge around disabling conditions. On the other hand, blogging can be seen as a tool to withdraw the body of a person with disabilities from the medical gaze and restore its humanity and individuality. The relationship between representation and self-representation and how this reflects the binary opposition between the medical model and the social model was widely discussed before the advent of digital media and some of the key ideas still hold.

According to Arthur Frank, the postmodern experience of illness is characterised by the impulse of patients to reclaim their bodies from medical

discourse (1995, 10). Mark Mossman (2001) traced the disabled autobiography as a postmodern, postcolonial attempt at self-definition that opposes stereotyped and reclaims ownership of the body and the way the body is understood. Mossman wrote:

Writing disability becomes an empowering act of control, a deconstructive critical strategy that attempts to break down oppressive and imprisoning cultural construction. By writing disability, the performance and general representation of disability are re-centred, re-focused on the disabled subject itself, which deflects and displaces the powerful gaze of the 'norm'.

According to Couser (1997a, 292), self-representation narratives are perhaps distinctively suited to validating the experience of individuals with disabilities and to counter-attacking stereotypical and patronizing '(mis)representation'. These illness narratives reflect various motives: an impulse for self-exploration and a will to provide care for those sharing the same condition (15). However, these should be considered in a critical way as being biased. In fact, Jones et al. (1984, 211) argue that in self-presentational strategies the limitations are emphasised by self-promotion and exemplification in order to impress others with their moral worthiness. Nonetheless, as Couser points out, these are common autobiographical strategies and not peculiar to narratives of disability (Couser 1997b, 215).

However, the assumption that autobiographies of people with a disability can counteract the misleading representation occurring in the media or in social attitudes has been questioned.

Putting an impairment into a narrative might lead to sentimentalising it and to connecting it to the 'bourgeois sensibility of individualism and the drama of an individual story' (Davis 1995, 3–4). Personal narratives cannot provide paradigmatic means of interpretation to revise the cultural understanding of disability; this is because they can be overshadowed by the emotions of empathy or pity evoked by the reader's identification with the narrator's personal drama (Mitchell and Snyder 1997, 11).

There are a growing number of websites that address the personal stories of people with a condition that affects their appearance. Despite this, the direct accounts published online of individuals with a congenital or acquired disfigurement and the extent to which they contribute to the public debate about the treatment of people with a disfigurement in an appearance-obsessed society has so far received little academic attention. This article seeks to fill this gap by exploring how the journalistic representational medical narrative of disability compares and contrasts with its self-representational counterpart and how the two may contribute to understanding how disfigurement can affect one's life.

Methodology

This article is a qualitative comparative case study of representation and self-representation of disfigurement in the UK. A case study highlights the characteristics peculiar to the subject under scrutiny (Altheide and Johnson 1994). It presents the opportunity to produce an in-depth examination of a particular phenomenon but it does not produce generalisations. However, Bent

Flyvbjerg (2006) observed: 'The advantage of large samples is breadth, whereas their problem is one of depth. For the case study, the situation is the reverse. Both approaches are necessary for a sound development of social science' (241). This study uses discourse analysis to explore the UK media coverage of a young woman affected by cystic hygroma. Cystic hygroma is a collection of fluid-filled sacs known as cysts that result from a malformation in the lymphatic system (GOSH). The semantic field theory holds that the lexicon of a language is organised into areas or fields within which words interdepend and define each other in various modes (Crystal 2008). The semantic fields upon which this contribution focuses are body image, activism, and medicine. This contribution seeks to address the following questions: How does the journalistic version of disfigurement compare to its online first-hand account? Which sequence of events is used in each story? What kind of tropes can be identified in both stories? Are there any stereotypical images being employed in both versions? Which account draws more extensively on medical imagery?

The story has been selected on the basis that the person in question, Katie Meehan, whose story was reported by the national and regional press, had also shared her version of the facts on her personal blog which was developed in two stages. Before opening her current blog katiemeehan.co.uk/ in January 2013 through the open-source content management system Wordpress, Katie Meehan created a previous version with Tumblr. The blog, katiemeehanofficial-blog.tumblr.com, was established in 2012 and abandoned shortly afterward. The passage from one blog to the other signalled a significant shift in the way

Katie portrayed herself online and, therefore, how she used online tools to re-negotiate the construction of her identity.

In 2015, the new blog recorded over 20,000 views (Nightingale 2015). Additional criteria for choosing the story of Katie Meehan were that she has been regularly updating her blog since its creation. She rose to prominence at a national level in April 2017 when BBC Three made a short film about her story as part of the series *Skin Deep*. Her blog has been ranked #37 by the UK LifeStyle blogs directory HIBS100 in the top 100 lifestyle blogs in Britain (July 2017). katiemeehan.co.uk/ falls into the category of digital platforms aimed at documenting personal consumption experiences (Arsel and Zhao 2010; Zhao and Belk 2007). Katie's story has received extensive media coverage from both national and local press since she was four years old.

For this study, a total of 37 articles were examined which were extracted from *The Shields Gazette*, *The Northern Echo*, *The Journal*, Newcastle, *The News of the World*, *The Daily Express*, *The Times*, bbc.co.uk and *The Daily Mail*. The articles were retrieved from the database Factiva and Google search by using the key word 'Katie Meehan'. Eventually, the sample was narrowed down to a qualitative content analysis of the *Shields Gazette* which devoted 22 articles to the story of Katie Meehan from 2000 to 2015. A long-term coverage devoted to the story by the *Shields Gazette* allowed us to observe the story in its chronological evolution. The *Shields Gazette* shows a clear media trajectory which begins with a representation of Katie Meehan as an infant. This then continues into her teenage years, gradually integrating her

direct quotes into the press coverage. It concludes with the development of Katie's entrepreneurial self with the creation of a lifestyle blog. Both the news articles and the blog entries are analysed in terms of how disfigurement is framed, the use of sources, the style of writing, the sequence of events and the lexicon adopted. As Bolcher and Riggs (2014, 202) noted, when conducting narrative inquiry, it is important to consider that stories are social performances and should not be treated as 'maps' or 'mirrors' of the experience they represent.

This article is part of a larger project aimed at deepening our understanding of the possibilities and limitations of online self-representations of disfigurement versus mainstream media coverage.

Results

News coverage of disfigurement: the role of the provincial press

The media coverage of the story of Katie Meehan extends over almost two decades from January 2000 to 2017. It was covered by the *News of the World*, *The Northern Echo*, *The Huffington Post*, *The Daily Mail*, *BBC News* online and *The Times*. However, the very first newspaper to take an interest in her story and consistently cover its developments was *The Shields Gazette*. This is the oldest evening provincial newspaper in the UK. It was founded in 1849 and is currently published by Johnston Press plc (Shields Daily Gazette 2017) with an average circulation of 5,584 (Ponsford 2017). The newspaper covers the area of South Tyneside, North East England, where Katie Meehan was born in 1995.

The vicissitudes of Katie Meehan are journalistically appealing, especially for the provincial and tabloid press, because they provide the key ingredients for a human interest story that is able to provoke strong emotional reactions among the newspaper's audience. Katie Meehan was four years old when *The Shields Gazette* decided to start recounting her story. Since the very first article, which was published under the headline 'Little Katie Meehan dreads getting a cold' (2000), the story showed a good combination of some of the determinant criteria theorised by Johan Galtung and Mari Holmboe Ruge (1965) and then updated by Tony Harcup and Deirdre O'Neill (2001, 2016) that make a story newsworthy. Katie's story matched the news values of 'proximity', as she belongs to the community the newspaper targets, 'unexpectedness', as cystic hygroma is a relatively rare lesion (Kumar et al. 2010), 'audio-visual' due to the ample use of imagery displayed to document the progress of her condition, 'negativity', as this condition was described as a potential threat to her health, 'composition', as people with a disfigurement are an underrepresented category in the news (Chancing Faces 2017) and above all 'continuity' due to its lending itself to regular updates. In fact, from the very beginning of the story, it was apparent that the child needed to undergo a series of surgical operations over an extended period of time.

When *The Shields Gazette* published its first article on Katie, who was then four years old, it explained that she had 'a rare condition' that caused her face to be constantly swollen, adding that 'she suffers playground taunts about her appearance' (Little Katie Meehan dreads 2000). Additional expressions used in this and subsequent articles included:

'the four-year-old's face and tongue swell up alarmingly and cause her great pain'; 'deformed face'; 'enlarged tongue'; 'facial disfigurement'; 'disfigured face'; 'great pain'; 'facial problems' and 'misshapen face'. When Katie was seven, she was quoted indirectly. Her mum told a journalist: 'she talks about "her fat face" but she just gets on with life' (Katie's new op 2002). As Katie grew older, the coverage emphasised how the achievements of surgery were reflected on her face, making reference to Katie's 'stunning smile' to say 'a massive thank you to the *Gazette* readers who made this possible' (Isn't she lovely 2004).

Campaigns initiated by newspapers can be powerful marketing devices, as they may function as a form of self-promotion and agenda focus (Conboy 2002, 145). The *Gazette* launched a campaign to raise money to fund Katie's operations in 2000, when it first covered the story. Updating the story every time Katie went through an operation also implied reminding the readers of the role the newspaper had in giving publicity to Katie's cause and in gathering money. A few months after launching the campaign, the *Gazette* made it public that the newspaper had raised nearly £40,000. The article opened with this sentence: 'Brave Katie Meehan has been admitted to hospital ready for her big operation tomorrow and it's all thanks to *Gazette* readers' (Katie gets set for operation 2000). On the occasion of her third operation, the journal printed: 'She has endured years of corrective surgery – much of it paid for by a *Gazette* appeal which raised £60,000' (2002). Appealing to a newspaper's audience, as it is a tight and compact community, is a common feature in popular journalism (Conboy 2006). In the coverage of the fundraising campaign to aid Katie Meehan, this idea

is reinforced by specific references to those that actively participated in the fundraising campaign: supermarket shoppers; the local school; the ex-boxer association; local pubs; a fruit vendor; as well as friends and family.

The *Gazette's* news coverage of Katie Meehan is mainly framed within a medical narrative where the surgeries are key points of development. It all started with the idea of raising funds to pay for Katie to have her very first operation back in 2000 by plastic surgeon Ian Jackson. Thus, keeping the focus on the operations also means keeping the focus on how The *Gazette* has helped to raise money to fund them. The time in-between the operations is articulated through news articles about how much money has been raised and by whom. Headlines include: 'Cash adds up for our Katie' (2000); 'Katie Fund Hits £5,000 mark' (2000) and 'We've done it!' (2000). These are alternated with updates about Katie's preparations before surgery; the actual surgery; and complications and recovery. In March 2000 a journalist travelled with Katie and her mum to give a full report on the operation aimed at restoring the position of Katie's tongue so that it could lie properly in her mouth (Katie gets set for operation 2000). These operations are described with both emotive and medical terminology. In an article published in December 2001, the atmosphere of Christmas is presented in contrast to 'another heartbreaking health setback' that Katie had to endure. In September 2002, the article 'Katie's New Op Anguish' recounts how she was preparing for 'another bout of major surgery in a bid to rebuild her disfigured face' (2002). In 2004, another article celebrating Katie's medical achievements concluded by saying that her next step

was to go through dental work, as 'her gums don't meet together and her teeth need to be restructured' (Isn't she lovely 2004). In 2012, Katie was a teenager and the *Shields Gazette* reported on her school leavers' prom; Katie is described as 'brave'; and the 'Belle of the ball' 'after a lifetime of gruelling operations' (Brave Katie's the belle of the ball 2012).

Evolution of a blog: from facial disfigurement to 'all things beauty'

If we compare the two 'About' sections in each of Katie Meehan's blogs, the former and the new one created in 2013, we can see that they differ in their content and purpose. In the old blog, Katie stated that her aim was to tell her story 'about growing up with my facial condition'; to spread awareness of Cystic Hygroma and highlight the importance of the surgery she has had (Meehan 2012). She explained what the condition entails from a medical point of view. She stated, 'fluid forms in a mass' and 'it left me with an enlarged tongue and cheek'. She referred to the long series of operations she had gone through, and she specified that these were possible thanks to the financial support of 'kind strangers' and the publicity created by the *Shields Gazette*. She expressed gratitude to the surgeon, saying 'I owe my life' and, finally, she wrote: 'Growing up with this condition was never easy. It was painful, stressful and very scary at times'.

Although this narrative looks like a form of self-expression, since she is speaking in the first person in a blog she created, it carries much of the imprint left by almost two decades of press coverage. However, at the bottom of her biographical section, she adds in between asterisks: 'This about section

shall be updated regularly'. She seems to be conscious that, in contrast to the press coverage she received, blogging allows for more fluidity as information can be digitally amended.

In fact, in the 'About' section of the new and current blogs, she has crafted another story. She starts by saluting her readers in an informal way ('Hi!') and addressing the questions 'who' ('I am Katie') and 'where' ('from the North East of England'). She introduces herself as a 'make-up addict' and states that her intention is to use her website to 'chat about products' about beauty, fashion, and food. In the second paragraph, we learn that she was previously a Business Management student and also an Equality and Diversity officer. It is only in the third paragraph that she explains that she was born with a rare facial condition called Cystic Hygroma about which she simply says that it is a lymphatic malformation and then posts a picture of herself showing what the swelling on her left cheek was like when she was a baby. By letting the picture speak for itself, she also reinforces the storytelling principle upon which her blog is based: communicating with photographs. She then mentions the fact that she has had many operations and says, 'although I have had them, I'll always have Cystic Hygroma ... which isn't so bad!' (Meehan 2013). Most allusions to the idea of struggle or pain have been erased in the new self-representational narrative. The references to the stress caused by the many surgical operations, the medical details about her congenital lesion, the function played by the press and its fundraising campaign in aiding her cause and the role played by the surgeon have been eliminated in the new 'About' section. The whole issue around her

medical history has been cut down to a paragraph of 64 words, in contrast to the introductory section of her old blog which contained over 300 words exclusively focused on her 'facial condition', as she calls it.

The purpose of the blog, as she states, is also different: the former blog was about disfigurement, while the current blog is about reviewing beauty products and life-style related issues, accompanied by photographs taken by herself. The former blog focused on her medical condition, while the latter uses and makes a display of her skills as an entrepreneur, journalist, and photographer, ultimately as a now widespread online figure, the beauty blogger. The difference is between a story about a woman who has a facial medical condition and a story of a businesswoman with a passion for photography who also happens to have cystic hygroma.

The press coverage of Katie's blog and Katie herself, when she is interviewed, shows a journalistic struggle in coming to terms with this dual account and, therefore, breaks with the traditional format which for twenty years was mainly based on Katie's surgical operations. 'Teenager who spent young years having surgery aims to inspire others with facial disfigurements' is the leading sentence of the latest article in the *Shields Gazette* devoted to Katie Meehan, written in 2015. Katie herself, quoted directly in the article, says that she hopes through her blog to reach out other people who have gone through a similar situation, show that everyone is beautiful and create a support network (Nightingale 2015). This inspirational purpose, emphasised by the *Gazette* in the headline, is an underlying motive in the new blog but it is not its declared

intent. In other words, it is not part of the self-representational narrative shaped by Katie, unlike in the previous blog, where her manifest aim was 'to spread awareness of my condition'. In the new blog, her primary purpose is to 'chat about products I love' and this is what she competently does managing to transform a passion into revenue. Half way through the article, the journalist correctly specifies that her blog centres on beauty and make-up as well as her love for photography. Throughout the new blog, the references to the fact that she lives with Cystic Hygroma are scant: out of a total of about 50 posts published between 2013 and April 2017, she mentions it only in four of them. Only in three out of these four, does she refer to the fact that she has a 'facial disfigurement'.

Emphasising that the blog is actually about make-up rather than disfigurement is informatively more accurate, not only because quantitatively the blog centres on beauty products but also because make-up has a symbolic role for Katie's self-representation. In her blog, there is little reference to the stigma surrounding people who have a visible difference, but she mentions the stigma surrounding the use of make-up:

Make-up isn't usually the first thing you'd expect someone with a facial disfigurement to love, I don't know why but there seems to be this weird stigma about it. Using makeup lets [sic] me reclaim ownership over my face, something I feel in the past I haven't really had much say in. I can express myself and you know what? I just love it so much. It's the one thing that can relax me and that makes me feel so creative. (Meehan *It's here* 2017)

This post suggests an analogy between make-up and self-representation on a blog. To some extent, both practices allow a person to reclaim their self-image and construct this image according to their will and purpose. Make-up is a means to regain control over her face, which for years has been largely defined and presented to the public through surgical operations and the lens of a medical perspective, which is recurrent in the media coverage.

The blog allows Katie to creatively shape and re-shape her own biography through various perspectives, whereas the journalistic account is more rigid and tends to stick to one particular story format. This story format portrays the vicissitudes of Katie as both a personal and a community struggle. This struggle is articulated through two main narratives: the fundraising campaign initiated by *The Shields Gazette* to finance Katie's operations and the operations themselves.

In her original blog, Katie specified that it was thanks to the generosity of 'kind strangers' and the 'publicity' raised by *The Shields Gazette* that she could have her operations (Meehan 2012). In the new blog, in a review about a local bar, she wrote: 'Growing up in South Shields and feeling such a warmth of the community there, I accepted the lovely invitation and quickly got very excited' (Cue The Cocktails! 2015). In particular, on the occasion of the publication of a BBC 3 documentary about her life, 'Skin Deep', she explicitly addressed the *Gazette* in a thank you letter: 'Without you and the amazing people from the *Shields Gazette*, I'd never be living the life I am now. It's all thanks to you' (A letter to 2017).

Katie's blog mostly agrees with this depiction with the exception of one post entitled 'How well do you know your neighbours?' She writes: 'It would be a really nice atmosphere if this was to happen (socialising between neighbours) and it just connects people together and brings a sense of warmth and community to our street' (2017). This post is sponsored, as she states at the bottom of the article. In this case, it is likely that the topic was elicited by Rattan Direct, an online retailer of furniture, embedded in a hyperlink in the post. The contradiction here is dictated by the opposing commercial interests of the newspaper and Katie's blog. It is appealing to the target audience, as a community is a recognised feature of popular newspapers. She re-confirms this in most of her posts but when this contradicts her own aims of promoting a particular lifestyle, the idea of a tight community seems to vanish in order to promote consumerism upon which her blog is mainly based. These contradictions are connected to two aspects: identity and commercial revenue which, in the context of brand management, depend upon each other. This contradiction is a reminder that Katie's blog should not be treated as a form of self-expression free of consumerist values. Ultimately, it is this that makes her blog comparable to a profit-based organisation such as a newspaper.

In her blog, Katie very seldom makes verbal references to the way cystic hygroma has affected her appearance, yet the whole blog is devoted to the care of one's appearance. For example, in March 2013 (Get some glow) Katie wrote:



It's almost springtime and that means goodbye to the old dry, flaky skin and hello to smooth, happy and glowing skin. Of course, that also means that you may need a little helping hand with getting the right products to create a good look. Beauty starts from within and this often means starting a good diet, and the best way to create that soft supple skin is by eating well. Having good healthy skin makes you feel happier and more confident!

She acknowledges being born different (A letter to 2017) and the fact that the operations have changed her appearance for the better. She refers on three occasions to her condition as a 'facial disfigurement' but never does so in a self-pitying way. In her blog, there are no explicit references to episodes of bullying. However, bullying is mentioned twice in the news coverage. In the first article, we read: 'she suffers playground taunts about her appearance' (Little Katie Meehan dreads 2000). In an interview, she told the journalist that she had received nasty comments (Brave Katie's Facing a Bright Future 2011).

At one point in her blog, she states: 'I am beautiful' (I need to stop body shaming 2016). In this post, she addresses the personal and social problem of her lack of self-confidence around her body image, not specifically related to her face. The fact that she rarely puts into words the way her appearance is affected does not mean she is negating it: her blog together with her Instagram account feature plenty of images displaying her face and thus show how cystic hygroma looks. What is negated is centring the narrative on her facial condition.

2012 marked the year in which Katie made her first attempt to gain some control over her story by inaugurating her first blog. But, as we said earlier, it is in the second blog that the medical framing is contested and replaced by language that revolves around cosmetics and beauty. In the blog, make-up replaces surgery, and the surgeon's knife and syringes are substituted with make-up brushes and lipsticks. The hospital bed is now a spa bed, as, for example, in a post about her first bikini wax (Meehan 2017).

In June 2015, on the occasion of the documentary broadcast by BBC 3 about her, Katie says, 'I definitely want to talk more about my experiences growing up with a facial disfigurement and being different from other people. Writing about myself and the media is something I can't wait to share with you all'. But she doesn't. One could argue that the reference to disfigurement here is dependent upon the BBC 3 documentary and therefore the topic of disfigurement serves the purpose of keeping the feedback loop between mainstream media and her own blog active. She does not deny the press the opportunity to cover her disfigurement, but in her blog the story is different. And it is probably this differentiation that keeps the blog alive because she does not simply repeat what people can read in the press.

Conclusions

This case study has shown how Katie Meehan has used her lifestyle blog to reclaim her own right to self-portray herself in the eyes of the public. She has created a new narrative that mainly



contests the pre-existing and ongoing journalistic accounts. It contests the main narrative because she has turned the plot from a story of disfigurement to a story of enterprise. With her blog, she has reaffirmed the right to media attention not as a person affected by a rare medical condition but as a digital influencer and a businesswoman who happens to have a rare congenital condition.

This case study has shown that representation and self-representation of disfigurement may differ mainly in the medical framing. The news coverage gives more detail about the consequences of living with cystic hygroma, and how it can affect speech, eating, and health in general. The journalistic coverage has tended to arrange the material to give prominence to key dates in Katie's recovery from operations.

Katie's blog is arranged by categorising different beauty products, and any issues concerning disfigurement, apart from the section 'About me' where she addresses it directly, must be extracted through the other posts. Thus, journalists tend to focus on disfigurement, while Katie's blog is focused on the life of a person with a disfigurement. She basically decentralises her disfigurement as not being the defining feature of her life.

In order to give some insights into the regular daily life of a person with a disability a regularly updated blog can be very useful. This is because daily news focuses on the extraordinary and the exceptional but we do not get to know about the ordinary life of 'exceptional people'. Although the provincial press has a tendency to sensationalise by turning the story of the protagonist into

either a compassionate or a heroic story of bravery, its actions can be crucial to elicit an emotional response in the audience that can be turned into capital and therefore help to raise money.

The two ways of recounting disfigurement as a newspaper story and in a personal blog are complementary rather than mutually exclusive in that the former furnishes medical information, while the latter normalises the story by drawing attention to common concerns, such as the daily care of one's complexion. The two stories combined together form a more rounded image of the person whose story is being recounted.

However, both formats, press coverage and blogs, are tied to a revenue purpose and any evaluation of the narratives must take into account the underlying commercial motives that might dictate how the material for the stories and posts have been selected and structured into a story. The press must focus on disfigurement in order to promote its mission to save Katie, and therefore justify the role of journalism. Conversely, Katie focuses on herself and her business in order to justify her presence online.

Both need to meet the interests of their target readers; this means that self-representation does not necessarily imply creating a narrative that brings a better understanding of disability. The problem is, to what extent does the combination of narratives in old media and new media contribute to increasing our understanding of disfigurement? They do because, with their contradictory narratives, they show the fluid status of the concept of disfigurement.

Disfigurement is not a static condition but a possibility of being. Therefore, it is not the digital tool that necessarily empowers the person in control of it; it is the tension with the traditional media

that highlights the contradictions in meanings associated with disfigurement and therefore shows that disfigurement is a social construct shaped by the context in which it is being narrated.

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