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"My Mummy Has a Hole in Her Face": Living with Facial Eye Disfigurement

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Abstract

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Keywords

Facial Eye Disfigurement, visible difference, post-cancer, facial disfigurement, cancer survivor, social media, active intentional decision making, social exclusion, Interpretative Phenomenological Analysis (IPA)

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People living with facial eye disfigurements (LwFED) are often shunned by a society that makes spontaneous judgements based on appearance. This article is a case study of the lived experience of Toni, a 27-year-old woman LwFED, the result of her treatment for ocular cancer. Semi-structured interviews facilitated the exploration of her experiences. We present the findings chronologically but interwoven with themes such as: being strong for others; responding to her partner's abuse; dealing with strangers; and reinventing her sense of identity and supporting others. We identified institutional perspectives of work, hospital, and family within the prevailing UK that impacted Toni's experiences of LwFED and argue that institutional perspectives need to be educated about the ordinary person's daily grind of LwFED to address unrecognised bias and assumption. Only when identified and addressed can the reframing of social, institutional, organisational, and medical understandings and responses facilitate and support the lives of those LwFED.

Keywords: Facial Eye Disfigurement, visible difference, post-cancer, facial disfigurement, cancer survivor, social media, active intentional decision making, social exclusion, Interpretative Phenomenological Analysis (IPA)

Introduction

What is perceived to be beautiful, ugly, or disfigured is culturally proscribed, with beauty aligned with good and trustworthy (Sofer et al., 2017) and disfigured as bad (Garrisi et al., 2018b; Hartung et al., 2019; Holden & Pheasant-Kelly, 2016; Moran, 2020; O'Dea, 2018). People make spontaneous judgements within as little as 33 milliseconds of exposure to a face (Klapper et al., 2016; Todorov et al., 2009). Approximately 60% of our social judgements of a person occur from "reading" faces (Oosterhof & Todorov, 2008). People living with facial eye disfigurements (LwFED) have higher incidences of Post-Traumatic Stress Disorder, alcoholism, post-trauma increased incarceration, unemployment, binge drinking, and marital problems (Garrisi et al., 2018c; Levine et al., 2005). People living with facial disfigurement are seen to be less attractive, less employable, less intelligent, and have higher psychological issues such as anxiety and post-traumatic stress (O'Dea, 2018; Stone & Wright, 2013). Disfigurement can be the result of trauma, congenital issues, or surgery. Between 31-51% of affected people experience social and emotional issues (Rumsey, 2008). To explore these issues, we have undertaken a case study of one person, Toni, using interpretative phenomenological analysis (IPA).

Literature Review

Historically, considerable attention had been given to "psychological and social problems of the physically handicapped and disabled, [but] for the most part, strikingly devoid of reference to the facially deformed" (Macgregor et al., 1953, p. 4). Despite early work by Rumsey (1983), Facial Disfigurement (FD) remains the "last bastion of discrimination" (McGrouther, 1997, p. 991). People LwFD face staring, bullying, and avoidance; have fewer friends; are less like to be employed, married, and have children; and are frequently dismissed by medical staff who see FD as cosmetic (Changing Faces, 2017; Coats et al., 2000; Gagnon, 2016; Halioua et al., 2011; Mujeeb & Kamal, 2018). Clarke et al. (2003) conclude that "Visible disfigurement is associated with a range of psychosocial difficulties; however, the problems encountered by patients with eye conditions are under-researched" (p. 35). There are secondary traumas to overcome for those battling facial cancer (Al Bdour & Mohamed, 2018) and burns (Partridge, 1990; Van Loey, 2020). The most severe form of facial disfigurement is with the eyes and ears (Clarke, 1999). O'Dea (2018) and O'Dea and Southcott (2023) are the first to discuss the lived experience of those LwFED and their family members.

This article addresses the lived experiences of one person LwFED named Toni. When interviewed, she was 27 years old and receiving treatment for ocular cancer, which caused her FED. The question that drove this IPA study was, how did Toni understand her lived experiences concerning FED?

Methodology

Given our question of inquiry and our intention to attempt to understand how Toni understood her lived experience concerning LwFED, we selected Interpretative Phenomenological Analysis (IPA) as the most appropriate methodological approach. IPA case studies are founded on the principle that the most effective way to engage with a participant's experiences and understandings is to "invite participants to offer a rich, detailed, first-person account of their experiences" (Smith et al., 2009, p. 56). A basic tenet of IPA is its idiographic emphasis which generates small sample size (Eatough & Smith, 2008), including a single subject as the participant (Smith & Fieldsend, 2021). In accordance with the most common data collection strategy used in IPA (Smith et al., 2009), we decided that semi-structured interviews would be the most appropriate manner in which to obtain a rich data set from someone who lives with FED. Semi-structured interviews facilitated the exploration of individual experiences (Patton, 2002), involving "actively seeking negotiation of meaning … achieving intersubjectivity between the researcher and interviewee" (Hviid, 2008, p. 136). Semi-structured interviews afford "the interchange of thoughts and feelings, both conscious and unconscious, between two persons or 'subjects,' as facilitated by empathy" (Cooper-White, 2014, p. 17).

We sought participants for our study who self-identified as LwFED. Toni is one of a number of case studies in a wider study; each written up as either individuals or in small family units in accordance with the principles of IPA (Smith et al., 2009). We initially advertised on social media platforms and encouraged others to pass the information on. Word-of-mouth snowballing resulted in many volunteers from around the world coming forward. We have undertaken many case studies, including this one. Toni responded to the online platform invitation and volunteered her time and expertise as she self-identified as currently LwFED, thus fitting our agreed criteria. Zali and Toni spoke repeatedly via an online chat program building rapport. Toni was formally interviewed on one occasion. This interview lasted for over two hours. The interview was professionally transcribed, and returned to Toni to alter if she wished (Smith et al., 2009). After this interview, Toni's health deteriorated so although Zali and Toni continued to be in contact, a second formal interview was not undertaken.

Researcher Positionality

First author Zali was the interviewer. As an educator and counsellor, she works with people LwFD/FED, their family, and other professionals. She has FED, thus holding both emic and etic roles. First author Zali lives with FED, this is viewed as an asset as an interviewer because an insider can build quick rapport with the participant to develop a rich data set. Adriansen and Madsen (2009) state, “being an insider in relation to one's interviewees gives the advantage of having a shared history and a close knowledge of the context, and these benefits outnumber the disadvantages.” She interviewed the participant in which she employed traditional forms of bracketing entailing “setting aside their pre-understanding and acting non-judgementally (Sorsa et al., 2015, p. 8). By revisiting the data and new evolving comprehension stemming from the data, including member checking and working with colleagues, Zali was able to suspend her lived experience of FED to authenticate the participant’s lived experience (Birt et al., 2016; Fischer, 2009).

The second author, Jane offered independent etic data interpretations. Jane does not live with FED but has long been on this research journey with Zali and has gained deep insight into her lived experience. Jane brings this understanding to offer a separate lens on Zali’s interpretation of her findings.

Trustworthiness

We have addressed trustworthiness within the way we analysed and wrote the article by conducting member checks; confirming the interview transcript and our interpretation with the participant; having robust discussions and consensus between authors; ensured our analysis is grounded within the data; quoted the participant’s voice verbatim, and the data presented is plausible, meaning makes sense and is authentic to the reader (Anney, 2015; Elo et al., 2014; Lincoln & Guba, 1986; Rolfe, 2004). Our careful processes provide the article with a credible (use of insider interviewer) and dependable (use of participant’s quotes) stance. The research conducted had ethical approval from Monash University Human Research Ethics Committee, we recruited Toni (name used at participant’s preference).

Limitations

A limitation of this article is that this is a case study of one participant’s experience, and therefore no generalisations can be made (Patton, 2002). Our intention is to begin to bring a voice and story to those who live in the FED community, heralding this as an opportunity to look introspectively and individually as to how we view and interact with people LwFED within the community at large because of the stories shared within this article. Instead of generalisation, we prefer to think of our work being transferable, meaning that “the findings from one case to another is possible” (Schwandt, 2007, p. 127). Further research is required to ascertain whether this is a “once off” or consistent experience of those who LwFED. We are aware that our analysis remains “interpretative (and thus subjective) so the results are not given the status of facts; [but rather are] transparent (grounded in example from the data) and plausible (to participants, co-analysts, supervisors, and general readers)” (Reid et al., 2005, p. 20).

The Participant: Toni

Toni responded to the invitation via “Lost Eye” (https://losteye.com/support.php), a Facebook page dedicated to helping and sharing the lived experiences of people with one eye.

At the time of interview, Toni was 27 years old and living in Kent, England. She was a carer for the elderly, working in a nursing home. Toni was the eldest of three girls, her family of origin consisting of her parents and two younger sisters. She had been in a serious relationship with her partner for 10 years with two children aged two and four. At the time of interview, she had left her abusive partner and stopped working as monocular vision was deemed problematic by her workplace. She was single parenting, looking for public housing, and considered her life stressful. Then Toni's support system was her mother, her best friend and her two younger sisters. Toni maintained a social media and media presence as an advocate for people coming out of domestic violence, cancer and to a lesser degree LwFED.

Toni agreed to be named, and the interview occurred via Skype. The interview questions afforded a platform to "bounce off" and was adapted to suit the participant's lived experiences. This approach enabled the researcher to develop ideas and press for more information on a certain stream of consciousness accounts in real time. Zali used her skills of active listening and personal storytelling to build rapport with the participant, quickly developing trust by sharing stories with a fellow insider. This enabled the participant to relax and feel understood. The questions included: What happened to your eye? How did/do you feel? How has it affected your life? What has been the most difficult time in your life caused by your eye? How has affected your self-perception and how society views you? What could you do to change your society for yourself or for people like us?

Analysis

Toni affirmed the interview transcript. In analysis, Zali bridled her preconceptions (Vagle, 2018), containing her own lived experience of LwFED. We use the term "bridling" as espoused by Dahlberg et al. (2008) as an expansion on the phenomenological notion of bracketing. Bridling is more than just the suspension of one's assumptions and biases, it always recognises the presence of the researcher in the research but uses the metaphor of the bridle to capture notions of restraint Dahlberg et al. (2008). We felt it essential that Toni's authentic voice be present, thus we included verbatim quotations and employed inclusive person first practice (Crocker & Smith, 2019). Zali and Jane each brought their own prior experiences, assumptions, and preconceptions to the sense-making process (Fade, 2004; Mjøsund et al., 2016). We each analysed the transcripts independently before we deliberated and offered individual perspectives. This way, we reached a shared agreement about how we understood and interpreted the gathered data. Reading and re-reading with wide margins to note themes and sub-themes to gain an insight of the participant's world was performed and robust discussion between colleagues resulted in the agreed themes and sub themes presented (Reid et al., 2005; Smith et al., 2009). Noting body language, facial expression, and tone of voice, marginal codings allowed identification of emergent themes, and development of overarching themes (Braun & Clarke, 2006; Smith et al., 2009). This iterative and careful process afforded us the opportunity to increase trustworthiness and reach a consensus (Rodham et al., 2015). Once we reached consensus, we built a table of initial coding, emergent themes, and overarching themes (see Table 1).

Table 1
Presenting IPA Methodological Decision Making from Initial Coding to Overarching Themes

Initial coding	Emergent themes	Overarching themes
Life before FED • Living in an abusive relationship with two Children • The unthinkable (loss of an eye) **Life LwFED** • Being strong for children and extended family • Managing other's feelings • Responding to partner's abuse • Dealing with strangers • New life skills • Reinventing identity • Supporting others	**Lived experience (self)** • Bullying • Discrimination • Survival • Loss of income • Isolation **Response to Lived experience** • Active Intentional Decision Making _AID • Reinventing self-identity • Acceptance • Belonging • Resilience **Responding to others (positive and negative)** • Family (children, partners, extended) • Friends • Strangers **Becoming pro-active** • Being strong for others (including online) • Family support • Creating community	**Managing LwFED** • Hope • Active Intentional Decisions • Resilience • Identity formation • Helping • Advocacy • Resilience

This table demonstrates the methodical process we undertook in building the themes under which we present the data. A brief illustration of this is where we were able to follow links from the initial coding of being strong for children and extended family through emergent themes (responding to others) to the overarching theme of the foundational blocks of Active Intentional Decisions (AIDs), resilience and the ability to reinvent identity to match up with Toni's values (O'Dea, 2018).

Findings

We offer Toni's stories under two, time-related headings: Life before FED and Living with FED. We include verbatim quotations from our data to allow space for Toni's voice to be heard. Weaving through this chronological ordering are several recurring topics, such as: being strong for her children and family of origin; responding to her partner's abuse; dealing with strangers; reinventing her sense of identity and supporting others. Ultimately, we weave a tapestry of Toni's lived experiences of LwFED and surviving cancer.

Life before FED

When interviewed, Toni had recently left an abusive 10-year relationship with the father of her two young children. Trying to please her partner, Toni had deferred her dreams of becoming an Occupational Therapist. Before she had cancer, she felt unable to say no to him. She reminisced:

> I don't feel that I really did anything that I wanted to do. It was all about keeping him happy, keeping the house tidy. I didn't feel like I was really living, and everyday trying to do everything that he wanted me to do. I didn't really see my friends and family. It was very sad.

Remembering her life before cancer, Toni could not fathom going through life losing an eye:

> I have friends and things and they all know I couldn't have that done but it's not a cosmetic procedure [laugh] ... it's life or death ... you just get it done, and I'm sure if they were in the same situation, then they would do the same.

In Toni's remembrances, the onset of her cancer was a clear demarcation. She Toni described what happened:

> My eyes ... started swelling and there was a lot of pain, I went to the optician, and they said the back of my eye was actually striped, and they sent me off for an MRI scan, which showed that there was the tumour, and then … the biopsy.

She was told that it was chemotherapy and radiotherapy resistant. Toni continued:

> I was referred to the oncologist [who] said the best choice is to just get rid of all of it, and that was hard. I took a few days to say yes, but it was the best chance of survival, especially with children.

Throughout the ordeal of cancer, Toni tried to manage other people's feelings and support those around her. Her mum and family were "very upset to begin with." Her sisters were "really supportive. My middle sister … was very upset but then when they saw how I just dealt with it, I think that made them feel better." Toni minimised her own feelings and focused on managing the feelings of others, particularly her children and family. But beneath that, Toni:

> Was really scared, but mainly for the children. I don't to leave them behind ... I was only 27 and I went through a lot of feelings of I want to do more with my life, I don't feel I've done enough to leave right now [laugh] ... whatever you have to do … get rid of it because I'm not worried about the consequences, I'm worried about the cancer.

Battling cancer, Toni continued to managed others' feelings. She spoke lovingly of the mutual support with her friend:

> She had something bad happen in her life at the same time, so we supported each other a lot to help us both get through a difficult time ... I would have found this past year a lot more difficult without her.

After surgery to remove the cancer and her eye, Toni received good news that they had "they tested all the margins … and they got it all, I didn't need any follow-up treatment, they just got it all in surgery." This was a huge relief, but then the reality of LwFED began to surface.

Living with FED

Toni found that LwFED involved often confronting changes, accommodations and negotiations. Although separated under sub-headings, Toni's life was often tangled and overlapping. We begin with Toni's immediate family, then discuss her reappraisal of her relationship with her ex-partner and his mother. Then we present Toni's data under the headings of dealing with strangers, reinventing her sense of identity, and supporting others (face-to-face and via social media).

Being Strong for her Children and Family of Origin

Threaded through Toni's interview was her belief that she needed to be strong for everyone else, her family, strangers, other cancer survivors and people via social media. On the day of her surgery, Toni consoled her family, explaining that "when they saw how I just dealt with it, I think that made them feel better." She was strong for her young children, thinking of ways to make them understand through making a picture book which included:

> Photos of before I had my eye removed and when it was poorly and it's got all the pictures all the way through [and] at the end with my prosthetic eye, and it tells the story of why I've had it removed. They love it, … they read it together and they look at the pictures. It's got all the pictures of all the surgery. This is me before I got unwell and my swollen eye. I went to hospital, and I had a biopsy which is a test to find out what was wrong. I found out it was cancer so I had my eye taken away so it couldn't spread around my body and make me very ill. I don't have my right eye anymore. When I was feeling better the doctor put metal on my implants ready for the magnets to hold my new eye … And then [making] my prosthetics ... they removed all the poison and I'm all better now. That's the end. And they love that. They sit and they read through it, and I think it's a nice little reminder for them of what happened and why I am like I am.

Responding to her Partner's Abuse LwFED

Toni found the most difficult time was coming to terms with her partner's reactions to how she looked LwFED after surviving cancer, she explained:

> My now ex-partner's reaction to everything was horrible. It helped me see him then in a much different light. He wasn't the supportive partner that I thought he was. He made nasty jokes about how I looked, but then again that's helped me because we don't have him around anymore, and as a result the whole family are better off ... I think before that there had always been an excuse as to why he was like he was. Then when he was using <u>my</u> looks and <u>my</u> illness as his

> excuse, it really ... it showed me that it's just an excuse and we're better off without him. It was very difficult. We were together for ten years, but over the months that we've not been together, it's just me and the children are a lot better. So, it's just time is the healer, isn't it? ... It will take me a long time I think before I properly get over it all, but I feel much more confident, much more independent ... and have those moments in life where you just appreciate where you are and what you've done and that you're still here.

Toni found resilience within herself in dealing with her ex-partner describing that the last time her children spent time with their father was why she ceased contact with him:

> My son came home, walked through the front door, pointed at my face and just went "ugly wide mummy," and I just said, that's it, I'm not having the insults come from the children because that's worse than having them come from him. So, I spoke to people, and I just stopped it [visitations with Dad], and since then they have been much better. They told me that their dad told them to say it. They were just copying his behaviour.

Toni's decision to leave her abusive partner was the catalyst of being able to create a new identity. Further, Toni was able to talk about the loss of her eye with her son's classmates. She recalled:

> One of the girls, aged six said "oh, if you didn't have it taken away, what would have happened?" And I said to her "well I would have got very, very poorly because it would have all spread and I would be very poorly," and she said, "well would you have died?" And I said, "I could have done yes." And she said, "well I'd rather have one eye than be dead." I just went "yes, so would we!"

Toni's new sense of self involved reconnecting regularly with family and friends and the adopting an independent "can do" attitude. Toni explained:

> I can do the things that I couldn't do … I have a better outlook on life because life is too short for drama, for stress, for arguing. I've completely changed from the person I was a year ago to the person that I am now. I've just evolved I think [laugh].

Dealing with Strangers

Toni found that LwFED often involved confronting exchanges and negotiations:

> When I first got it, I was really worried about ... the first time I went out … I had a big white medical patch, and then all the strangers would stop you in the street and ask you what you've done and what's happened to your eye, and why do you look like that. Sometimes you're just trying to pop around the shop.

Throughout the interview, the interviewer and interviewee shared and laughed about shared experiences of LwFED. This sharing normalised Toni's experiences from the daily intrusions of strangers' comments, the staring and avoidance of others, and different reactions between men, women and children. Toni explained what most annoyed her:

> What have you been up to? … like it's my own fault [laugh]. People deferring and asking about the issue to the nearest person in front of the FED/FD person is a consistent issue. And I remember somebody actually asking my son, I had a black patch on, and somebody asked [him] ... there's no need to put my son into this, it's hard enough for them to have to deal with mummy looking like she does when they've got strangers making jokes about it ... that made me quite cross when they started making jokes. They asked my son why is mummy was dressed like a pirate? [Zali asked if her son had a response] Oh yes, he said because my Mummy's got a hole in her face [laugh]. I gave him a little high five afterwards like good child, well done [laugh].

New skills of the use of deflection and humour to combat intrusive interjections of strangers needed to be mastered. Toni described an incident when she was wearing her prosthesis, "A child at the summer fair actually said, 'oooh look at your eye, it's creepy.'" Staring and the avoidance of others is well-researched (Gagnon, 2016; Halioua et al., 2011; Rumsey et al., 1982), Toni's lived experience extends this to people LwFED.

During the interview, Toni stated repeatedly that she did not feel comfortable going out in public without either her eyepatch or prothesis. She stated:

> I wear a lot more make-up now. I do tend to sort of make the rest of my face look nicer maybe to compensate … I do still get looks ... I don't actually go out without my eye-patch on or without my eye ... I wouldn't go outside without my eye.

Toni recalled one time she did something different:

> I was with a friend a few months ago, and it was a really hot day, and I was wearing my prosthetic eye and I said, "it's so hot, I can feel that it's hot behind there and it's not very nice," and she said, "oh well just take it off," and I said to her "I can't do that" [laugh]. "What would people say if they saw me walking down the street without it covered?" And she was quite surprised because I'm very open about it on social media and things, I'm very open about it … But I don't feel like I could just walk down the street, I guess. When I open the door ... it's quite amusing when you open the door to delivery drivers [laugh] without your eye in [laugh] … people tend to be quicker ... "there's your parcel, see you later" [laugh].

Reinventing Her Sense of Self

Toni felt that she has created a new sense of self for herself. No longer a victim of abuse or cancer, Toni reinvented herself realigning her life to accommodate changed realities. Toni found herself unemployable so focused on her giving, entrepreneurial spirit. She re-connected with family and friends, received counselling, and began to advocate for herself/children, and people living with cancer/FED. Toni explained:

> It's made me a stronger person because I feel like I have a very good reason for why I look like I do. I think that makes it a lot easier for me because there wasn't any other choice. I had to get rid of it. So, I feel like if people were to really judge me for that, then that shows bad character on their side.

Part of Toni's new sense of self is as a single, jobless mother because she no longer had a partner to mind her children whilst she worked. She was no longer able to work in her previous job:

> I can't really work in the nursing home now … there's been a few times where I've worked with maybe some aggressive patients, so it might not be a good idea to have that blind side around somebody who could use it to their advantage.

Toni remained positive, stating that "I'm sure I'll find something else or … better." She began a small business manufacturing custom made eyepatches.

In re-inventing herself, Toni sought assistance to reach decisions and accept LwFED:

> After the cancer and the removal of the eye, I did have counselling, I went onto antidepressants, but all that made me realise was that it was making me depressed. I don't think it was the change in me, I think it was the reaction from him [her partner]. … So now I feel much better … it helped a lot ... it helped me come to the decision that I came to. It helped me realise that if I can do it on my own, even if I do not have one of my eyes, I can still do everything that other people can do.

Supporting Others (Face-to-face and via Social Media)

Toni spoke about helping others in different ways. She spoke about how she would like to educate strangers about asking a person LwFED about their face. Toni explained that she would prefer that people just ask a polite direct question. Ultimately, she thought that people should be more open and unashamed, which would generate greater acceptance in others. Toni uses humour and tries to teach others:

> In education, … humour does help me get through. I think it's fantastic to get a laugh out of things, there's no point in being miserable. I was very lucky to have a disfigurement that can be covered … people shouldn't judge you on how you look because it doesn't change how intelligent you are, and it doesn't change what's inside just from having what's on the outside altered, you're still the same person. If anything, I'm now more accepting because I can see how easy it is to go from a normal [laugh] looking person to being disfigured ... I obviously am disfigured, but I don't feel like it changes me. I'm still the same person I just look different.

Since LwFED she has become pro-active in helping people like her:

> I'm making the eye-patches now. I love making the eyepatches and send them around to people ... I've got more friends on social media in the same situation. There's the Lost Eyes and there's a few cancer people that I speak to, and it's very nice to have that feeling of community with people all around the world. We all have similar experiences ... they understand ... it's a very difficult thing to understand until you go through it.

Toni has built a very vocal and open online presence about her lived experience with LwFED and cancer. She was quite articulate when it came to clarifying the difference between

LwFED and beating cancer and how social media has been a positive element in the development of who she has become. She explained that it is nice to talk to people who are living with cancer because they understand the cancer journey, and to speak to people LwFED is also good because they understand the day-to-day changes and challenges such as “how you look and how your look changes a lot.” Toni added that:

> I think the general public, when they hear of a cancer patient it tends to be a chemotherapy patient or something like that. I don’t think you tend to think of facial disfigurement from cancer as much until you’ve gone through it.

Finding her voice, Toni was able to receive and give support to others. She recalled social media comments received:

> Mostly they’re really supportive, but when people know all the background why my face is like it is, I do get a lot of support, and it’s really helped I think to have that support of people because I think in a way if it’s people that don’t know me who support me, then I should appreciate the people in real life that do support me as well [laugh]. I’ve had support from so many people … today, somebody sent a thank you for sharing my story because it helped him feel better about what he’s having to deal with in life, and it’s little moments like that that make me really appreciate that I can do that for people, or I can help them live their lives better … if you use your traumas to heal others, then that can help ... use your hardships to help other people and then that helps you.

Ultimately, it is here after the cancer battle had been won, where Toni reassessed her life, figuring out that life is short and realigning her life to fit her values of family and having fun. It is in this moment where Toni emerged from a victim of cancer and domestic violence to being victorious, outgoing and vocal using social media to find her voice and being able to speak out about what life is like living with cancer and FED.

Discussion

The tapestry of life is full of interwoven experiences. Toni, is no different, her ability to travel through the arduous decisions of becoming disfigured (diagnoses of cancer and removal of eye); noticing other’s responses as well as her own termed silencing disfigurement (removing herself and her children from an abusive relationship to consoling and choosing to be strong for her loved ones); being a disfigured person (reinventing herself); making active intentional decisions (O’Dea, 2018) to live and re-establish her life; and learning how to break the silence and become a person LwFED (Konradsen et al., 2012). We keep her voice and story in the foremost of our minds and see her as a multifaceted person, not just as a series of labels.

More broadly, Toni’s life in England is framed by law in which “the rights of people with disfigurements are protected in law by the Equality Act 2010” (Saunders, 2020). Annually more than five hundred thousand people in the UK acquire some form of disfigurement from diverse reasons such as cancer and cancer surgery. There are different societal factors that impinge on the lives of those LwFED, such as the medical professions, social services, education, and the wider community. These form Toni’s culture. People in the UK LwFD “can suffer twice, firstly from the cause or condition and secondly from appearance related prejudice and discrimination, often on a daily basis” (Garrisi et al., 2018a, p. 6). In this societal context, Toni described numerous challenges to her rights. For example, Toni finds it difficult to walk down the street without stares, avoidance of others, obtrusive comments and must come up with novel ways of handling the misperceptions of herself by her society (Halioua et al., 2011; Jamrozik et al., 2017; Rumsey, 1983; Rumsey et al., 1982; Rumsey et al., 1986; Rumsey & Gahagan, 1986; Stone, 2021).

In the UK, tabloids and popular media regularly depict people living with disfigurement as bad, criminals or requiring surgery (Garrisi et al., 2018a). Specifically, people LwFD/FED within society are "systematically misrepresented in the media" (Garrisi et al., 2018a, p. 9) and have become a common trope in film as evil and crazy (Wardle et al., 2009). Because of this widely understood misinterpretation, public behaviours such as staring (Halioua et al., 2011) and avoidance with the general public, often affording people LwFD/FED double the distance they normally would (Rumsey et al., 1982). In a world that espouses to be more inclusive, the inclusivity of ordinary people LwFED is not seen as something to be sensationalised or looked up to as the "ordinary everyday disfigurement issues particularly prejudice and stigma are neglected and less visible" (Wardle et al., 2009, p. 5). This pervasive failure to represent the breadth of facial disfigurement is marked by underrepresentation or misrepresentation and a tendency to sensationalise or frame it in tragedy (Saunders, 2020; Wardle et al., 2009).

Overcoming cancer is seen to be viewed more favourably by society because the media portrays people who overcome cancer as someone who has won a battle, often sensationalising and using words such as war/battle/survivor to possibly weaponise their outcomes thus creating heroes of those who defeat one of the most feared diseases of modern times (Cherian et al., 2020; Clarke & Everest, 2006). Cherian et al. (2020) found that social media posts relating to cancer survivorship celebrated milestones; honoured survivors; expressed identity; chronicled social support, and renewal. Such posts seem to be rarely written by the cancer survivor. Although social media can assist individuals to recreate their identity as survivor and hero of their own story. To some degree, this was the case with Toni who easily identified as a cancer survivor but found her LwFED harder to accommodate and own. Toni did not deny that her FED was there and was a biproduct of surviving cancer, she just did not see herself as disfigured, until she was confronted by stepping out the door into society whereby, she was seen to be lesser and something to be feared.

In a society that does not address the everyday issues relating to disfigurement, a tension exists between Toni being able to clearly wear the applauded label of "heroic cancer survivor" and when she identifies as LwFED she encounters silence and discomfort both within society at large, and within herself and ability to identity as LwFED. Toni complies with societal demands, which sensationalises her as a cancer survivor. It seems that others find it more palatable to hear her story of how she got her FED than to look at her. Once people know that her FED is a "battle scar" of surviving cancer, they seem to find her FED less confronting.

There is a wealth of resources to help fund cancer research and support those living with cancer. The psychological and psychosocial aspects of living with cancer are accommodated through being able to tap into various counselling programs (Lleras de Frutos et al., 2020; Ochoa et al., 2017). Toni did receive counselling for cancer but *not* the day-to-day issues of LwFED. For this study, Toni's journey began with the reality of having cancer, experiences in hospital and with medical professionals, eye removal followed by the reality of what she looked like after the lifesaving surgery leaving her with FED. Toni entered the hospital with two eyes and cancer, and left in bandages minus an eye, later being informed that she was cancer free. This was where she then travelled through the physical healing of her body and obtaining a prosthesis which she wore mostly whilst out in public. After this, Toni was left to navigate the effects of surviving cancer LwFED almost by herself, with the institution of hospital offering no assistance, no referrals to any specialised organisations. Toni was in the unique position of living in the UK where Changing Faces offers specialised counselling for people LwFD/FED. Toni was left to her own devices to be able to find help LwFED. She reached out to various support social media pages, and Lost Eye on Facebook was where Zali initially came to know and interview Toni as she came forward offering to tell her story.

Role of Social Media – Toni's Cancer Narrative

Toni has also shared her story on British media. She described receiving very positive responses to sharing her story and explained that the extended community she has found via social media had afforded her the ability to overcome and journey with LwFED in a healthy manner. Toni presents as someone who did not succumb to the prevalent disgust and other negative emotions associated society views people LwFD/FED, resisting anxiety depression and social reclusively which LwFD/FED can bring about (Islam et al., 2010; Stock et al., 2015; Stone, 2021; Stone & Potton, 2014). Toni offered the public a positive story of resilience and determination.

The BBC was interested in Toni as a young mother surviving cancer for the sake of her children and helping others in her position with her surgeon encouraging her to make a business out of making eye patches (https://www.bbc.com/news/av/health-41365427). Toni made British headlines in 2020, her cancer narrative was accentuated, this time because she was being denied possible life prolonging cancer treatment due to the pandemic lockdowns in England at the time (Cleary, 2020). Perhaps this a political statement being made by the media outlet, the question remains as to whom benefitted by the telling of this story using *this* narrative. Society got to know Toni as a cancer survivor and now, a possible COVID statistic. Nowhere in this media charade was the story of Toni LwFED told. The seemingly eye-catching, bigger, grander narrative of battling/surviving/denial of medical treatment in the wake of the cancer returning was the narrative that the British media chose. This example exemplifies the sensationalising of the cancer survivor narrative at the expense of the daily living experiences that could have also been told concurrently with the cancer narrative corroborating with Wardle et al. (2009) and Garrisi et al. (2018a).

There is a growing body of research around the use of social media and the role the medical institutions play in facilitating the dissemination of appropriate information and what they need to make their patients aware of upon their journey to survivorship of cancer (Cherian et al., 2020; Jiang, 2017; Walton et al., 2017). The role of social media whilst LwFD/FED appears to be missing in this conversation, as does the presence of support from medical institutions entering this space to help support. Again, there seems to be a difference between them (cancer survivors) and us (LwFD/FED), but Toni lived as a person LwFED and a cancer survivor.

Family and Work

The way in which the public society interacted with Toni whether it be the people at the picnic with her mum, to the postman delivering letters, out in public with her children and having her children must speak for her, the examples here are just a few. The identified institutions of work and family were impacted by LwFED. Toni lost her income and her job as a carer due to LwFED. She repeatedly lost her assumptive worlds (Beder, 2005; Kauffman, 2002; Liechty, 2002) but built new imagined worlds to replace them. She was deemed no longer "fit for work" when her workplace decided she was a risk to herself, possibly the clients she would be working with as well as the workplace itself, with maybe a potential Workcover claim increasing their insurances. Toni is not alone in this experience of losing a job and finding it difficult to gain meaningful employment (Brewington et al., 2004; Coats et al., 2000; Mojon-Azzi & Mojon, 2007; Monjon-Azzi & Mojon, 2009; Spirito Dalgin & Bellini, 2008; Stone & Wright, 2013).

There is a need to redefine work when it comes to surviving cancer, looking at work in a broad context (Pritlove et al., 2019). With this concept in mind, Toni was doing a lot of work. To combat the loss and inability to gain meaningful paid employment in the society, which says it does not judge and is inclusive of all people, Toni began her own business in creating individual stylised eye patches, which she sold through her online platform on Facebook to customers around the world. Children growing up as children of a mother LwFED were impacted personally and socially. The illustration here is where Toni was on a school excursion before LwFED, before cancer, her appearance would have been a non-issue. Research has been done on parents and their FD teens (Prior & O'Dell, 2009) and the quality of life in mothers of children diagnosed with FD (Barnett et al., 2006; Habersaat et al., 2013). There is nowhere where the effects of parents living with FD affects their children. The *Disfigurement in the UK* report (Changing Faces, 2017) found people LwFD tended not to have children not because of infertility issues but because of the social and emotional issues attached to LwFD/FED upon the children. Zali concurs. She recognises that her child has less friends and is the brunt of what she calls "second generation discrimination" implying the looks of her mother can have a negative impact on her child.

Zali's seminal work on her own lived experience with FED depicts a framework in which to look at Toni's experiences through (O'Dea, 2018). She identifies four major foundation blocks, which are: "active intentional decision making (AID) (the decision to be positive, persist, press on, prove wrong, educate); Hope (People's attitudes can change, or be affected by my reactions to their actions); Resilience (based upon sense of self-autonomy); Personal belief system (spiritual awareness and connectedness with someone outside time and space)" (O'Dea, 2018, p. 2329).

In this qualitative case study using IPA, we report that Toni evidenced three of these – Active intentional decisions (AID), hope and resilience. The former through her ability to reflect upon and realign her life with her values, looking introspectively through the lens of mortality and "seeing" the abuse she had endured within her former partner. Toni chose not to continue her relationship and leave with her children. LwFD is difficult and potential loss of partner can be very real (Changing Faces, 2017; Eroglu & Ersanli, 2018). She chose to make AIDs throughout her cancer journey, from intentionally saying yes to removing the cancer/eye, through to intentionally choosing to obtain a prosthesis and wearing it in public.

Toni's resilience and AID to choose life enabled her to withstand the issues she encountered in public with her prothesis. Her resilience is evident through her ability to adapt to life LwFED, being proactive and reaching out to various self-help groups on social media, creating income from her own eye patch business after LwFED took away the career she had chosen. This leads to the foundation block hope (O'Dea, 2018). Through her AID in sharing her story she gives and receives hope; through her business in making individual stylised eyepatches, she has identified herself as FED and a survivor of cancer. People LwFD are less likely to obtain a job, the least likely candidate to be employed (Stone & Wright, 2013). We feel that there is a remarkable confluence in both Toni and Zali creating their own forms of income through their AID/hope and resilience of wanting to help others or create hope for people with similar experiences. Toni creating her own business of making eyepatches to enhance someone's self-esteem, and Zali creating an organisation Karibu Anawim (https://www.karibuanawim.com) in the hope to be able to use her abilities to help professionals, families and people LwFD/FED.

Conclusion

This research may be used for educative purposes for professionals ranging from medical and allied health practitioners, primary secondary and tertiary educators through to other professionals including but not limited to the legal field, policy makers and human resource personnel. It also adds to the growing body of knowledge of shared experiences and stories for other people LwFED around the world therefore normalising our lived experiences and hopefully alleviating the isolation of this people group from both inside and outside this portion of society. Our research is helpful in several ways. Firstly, it offers the expert advice and experience of an individual who has the lived experience of LwFED. Secondly, this research extends the knowledge of what it is like LwFED furthering Zali's seminal work within the area and affording us the transferability and new insights of the different types of lived experience (O'Dea, 2018; O'Dea & Southcott, 2023). Thirdly, by examining the lived experience of LwFED we see the need for society to be educated on their unknown negative bias towards people LwFED. Lastly, this research raises the issue of where do people LwFED turn to in order to receive support for the ongoing issues they face on a daily basis and how well known and accessible are these resources within the fields in which people LwFED would regularly attend, places for example, such as their local hospitals and doctors or within the education systems as second generation discrimination was raising its ugly head in Toni's expert experience.

LwFED permeates every aspect of self, and society. Toni's story of LwFED is as heart-warming and faith building. There is obviously more to Toni than this discussion has room for. As this article allows Toni's voice and story to be heard, it is only right for Toni to have the last word with regards to LwFED. She says:

> People [society] should just be more accepting because I prefer if people just ask. I would rather somebody just came over and said, oh, why do you have that then? … Maybe if people were more open about it. People [LwFED] don't like strangers seeing them without their prosthetics … I think if people [LwFED] were more open than people [society] would be more accepting ... but it moves around in circles because I think if people [society] were more accepting, then people [LwFED] would be more open.

We are saddened that society is still staring, avoiding and making people LwFED feel shame and invisible. What is lacking is public education to raise awareness and the telling of ordinary people's stories for the purposes of de-mystifying, alleviating fear within the general society, and normalising LwFED. These issues need to be addressed by policy makers, practitioners and financial assistance given to appropriate care organisations to support people LwFED. Specialised training of medical/allied health care practitioners as well as anyone working with the public in unmasking their unknown bias is required.

Only three known organisations tackle the diversity of those LwFD/FED born with or acquired. These are, Changing Faces (UK), About Face (Canada) and Karibu Anawim (Australia) (www.karibuanawim.com). Not all people can overcome and conquer LwFED in a healthy manner, but the difference in Toni's story is when faced with death through cancer, Toni chose to reflect and realign her life to her values and invent a new life LwFED for herself and her family.

Postscript

Toni's lost her battle with cancer in 2020, leaving her parents to raise her young children. The news devastated the writers, and Zali remains in regular contact with her family. Toni donated her body to a teaching hospital and has become a "silent teacher" for future medical practitioners (Smith, 2018). Toni wanted to help others and found a way, a legacy of giving and helping, even death could not stop her. In 2022 Toni made news again with the release of a UK documentary series called My Dead Body which aired early December. Toni's story was told showing they how they dissected her donated body to further educate medical world about how the cancer spread throughout her body. This public dissection was the first of its kind in almost two centuries, her selfless gift has helped over one thousand medical students thus far: https://www.theguardian.com/global/2022/nov/27/her-dying-wish-why-toni-crews-chose-to-let-her-dead-body-be-filmed

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