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“Everything Seems to Be the Right Eye in Our Family”: Intergenerational Family Living with Facial Eye Disfigurement: An Interpretative Phenomenological Analysis

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Abstract

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Keywords

Facial Eye Disfigurement, visible difference, facial disfigurement, facial difference, lived experience, intergenerational trauma, intergenerational eye health, eye health, eye issues, Duanes syndrome, Interpretative Phenomenological Research (IPA)

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“Everything Seems to Be the Right Eye in Our Family”: Intergenerational Family Living with Facial Eye Disfigurement: An Interpretative Phenomenological Analysis

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This paper presents the lived experience of an intergenerational family, spanning three generations living with Facial Eye Disfigurement (FED). Living with vision loss and FED is estimated to affect nearly 8 billion people worldwide. Inadequate attention is paid to the impact of Living with FED (LwFED) on the lives of individuals. This research offers a deep dive into the lived experiences of one family LwFED. This family comprises a grandfather (deceased), son, wife, and child, all of whom have lived or live with FED. In this Interpretive Phenomenological Analysis (IPA) study three interviewees are deemed the experts. Data were collected using in-depth semi-structured interviews conducted by Zali who lives with FED. Our findings speak of childhood and subsequent issues living with FED (LwFED), family experiences of living with family members with FED while simultaneously LwFED themselves, shared stories and role modelling. We discuss LwFED healthily through the creation of a safe family space through acceptance, belonging, and support. We introduce and discuss the role of the eyelid, functioning versus non-functioning. We offer insights and understandings of an intergenerational family living with LwFED to advance research and inform practice within diverse fields.

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Introduction

Globally it is estimated that 7.9 billion people live with vision loss and concomitant Facial Eye Disfigurement (FED) with that set to increase to 9.7 billion by 2050 (Watkinson & Williamson, 2023). A common outcome of FED and vision loss is that many people live with monocular vision (sight in only one eye). The severity and impact of these conditions are grossly overlooked which “greatly underestimates the magnitude of eye conditions and service needs” in the lives of people (Burton et al., 2021, p. 506). Facial disfigurement (FD) affects significant numbers of people, for example, in the UK 569,000 or one in 111 people are living with such conditions (Changing Faces, 2017). FD affects every aspect of people’s lives including social media presence, dining out, selecting a career path, marrying, or having children (Changing Faces, 2017; Stevenage & McKay, 1999). Living with FD means people speak to you less, have less interaction with you, and fear “catching” it (Oaten et al., 2011; Park et al., 2003; Ryan et al., 2012; Stevenage & Furness, 2008). For about twenty percent of patients living with facial trauma, their vision is also threatened (Soparkar & Patrinely, 2007). People who experience sudden monocular vision adapt more slowly than those with gradual

vision loss, and those who lose an eye in “early” childhood tend not recall a specific period of adapting to being monocular (Coday et al., 2002). Society has an intrinsically negative bias towards people living with facial disfigurement (Hartung et al., 2019). This paper looks at three generations of one family, all living with facial eye disfigurement (LwFED) and living with people LwFED. This inductive research addresses the question, how does a family of acquired and birthed people LwFED understand themselves, each other, and society? Exploring in depth one family, offers evidence to challenge assumptions, engage reader attention, inculcate empathy, and ultimately change attitudes and behaviours (van Manen, 2017).

When viewing faces, appearance matters. The face perceived to be attractive activates reward areas in our brains, when we view a face which is stigmatised, such as FD/FED, it fails to activate regions of our brain associated with empathy and social cognition and self-reports feel disgust in response to viewing stigmatised groups, judgements about them are made extremely quickly (Aharon et al., 2001; Hartung et al., 2019; Todorov et al., 2009; Tsukiura & Cabeza, 2011; Wang et al., 2015).

The eyes are a major area of focus during social interactions (Coday et al., 2002) and subsequently people LwFED seem to elicit avoidance or staring within social interactions raising implicit negative bias towards people LwFD (Boutsen et al., 2021; Gagnon, 2016; Halioua et al., 2011; Hartung et al., 2019; Oaten et al., 2011; Pell, 2019; Ryan et al., 2012). Few papers have addressed the lived experience of those LwFED (O’Dea, 2015, 2018; O’Dea & Southcott, 2023a, 2023b).

Methodology

The phenomena explored is the lived experience of one family: (A) personally LwFED as well as (B) being a family member living besides a person with the lived experience, sharing space. This is a unique study as each interviewed family member has experienced LwFED at some point in their lives whilst simultaneously living with other family members LwFED. This intergenerational study spans three generations. We examine this phenomenon via Interpretative Phenomenological Analysis (IPA) which uses an inductive approach to the data, meaning the data is not viewed through a particular filter, rather, the data speaks for itself (Smith, 2017). IPA examines phenomena, is specific, interested in understanding lived experience, permits personal expression, knowledge, and experience (Eatough & Smith, 2006; Pietkiewicz & Smith, 2014; Smith, 1996, 2017; Smith et al., 2009).

In accord with IPA, we both analysed the data independently and then combined interpretations to create a shared analysis (Wagstaff et al., 2014). IPA researchers also acknowledge that the person is the living expert within the area being studied rather than the researcher being the “expert” (Reid et al., 2005; Smith et al., 2009). In IPA studies data is read and re-read. Emergent themes are generated, sub-themes developed, and overarching themes identified. The themes are then interpreted giving space for the expert’s voice which in turn is analysed and discussed, in this case the phenomenon is the lived experience of Ian, Mary and Sheree (real names used with permission). A professional transcriber was used to transcribe the interviews verbatim, double spacing and wide left hand side margins was used to begin coding, searching for patterns, contentions, and tensions, and re-read and for the “gems” (Smith, 2011).

Authors’ Positionality

The first author Zali is an insider, living as an individual and mother LwFED, she is also a published researcher within the field. She provides professional training/consultancy and specialist counselling within the field. In this article she bridles her experiences to be able to

look at the data with a clear eye (Vagle, 2009). Vagle et al. (2009) discuss bridling, which is “a relatively new term used by Swedish researcher Karin Dahlberg ... to describe what phenomenological researchers should do with their assumptions and preunderstandings as they aim to either describe or interpret phenomena” (pp. 348-349). The second author Jane as an experienced educator and IPA researcher holds an etic position, bringing a different lens to the exploration of the transcriptions which enhances trustworthiness in reaching thematic consensus (Rodham et al., 2015). When we speak of our shared analysis and interpretation, we use the plural pronoun. When we speak of the data collection via interviews, we use the singular pronoun as Zali was the interviewer. We include lengthy quotations to allow Ian, Mary, and Sheree to speak for themselves as the experts in their own lived experience (Smith et al., 2009).

The Participants

With ethical approval, Zali asked family and friends whether they would be interested in contributing to research, Ian, Mary and Sheree eagerly agreed. They freely gave their time and expertise as they recognised their family was unique wherein the three generations all had right eye disfigurements either acquired or congenital. Semi-structured interviews, known to stimulate rich data, was used to explore the phenomena (Galletta & Cross, 2013). Ian, Mary, and Sheree were interviewed on the same day, within their home, everyone took Zali to their most comfortable space where the interview took place.

We share the lived experience of four family members within three interviews. The Grandfather Joseph (deceased) story was retold through his son Ian, daughter-in-law Mary and grandchild Sheree. Ian, Mary, and Sheree either live/lived with FED personally and live with a family member LwFED. Both Grandfather Joseph (Joe) and his son Ian acquired their FED. Mary is the wife of Ian, mother to Sheree and daughter-in-law to Joseph who herself had LwFED when she was young but grew out of it. Sheree is their daughter (and granddaughter to Joseph) who speaks about LwFED herself having Duane’s syndrome from birth, and secondly what it was like to live with father and Grandfather who LwFED. We introduce the three people LwFED and weave their stories to establish a holistic view of each person from personal insights LwFED as well as what it was like living with the others.

Findings

Our findings respond to our research question, how does a family of acquired and birthed people LwFED understand themselves, each other, and society? Our findings are derived from an in-depth exploration of the experiences of four people (three interviewed and one remembered by the participants). We first introduce Joseph (Joe, the grandfather) whose story is retold through his son (Ian), daughter-in-law (Mary), and grandchild (Sheree). Next Ian who tells his own story coupled with stories about him from his wife and child, followed by Sheree who shares her own story. Lastly, we offer Mary’s story as told by herself and her daughter Sheree. In turn, the LwFED experience of each is recounted, and then the perspectives of each family member added. We have also addressed the stories of Ian and Sheree under sub-headings. For Ian these are bullying and parental support; growing up monocular; loss of dream job; staring; eye protection and safety consciousness; humour and storytelling; use of derogatory speak, and role models. For Sheree the sub-headings are self-conscious/laughed at/bullied, poor school record, employment and studying, isolation, and role models.

Joseph's Story

Joseph passed away at the age of 87. At the age of fifty, Joe lost his right eye whilst pouring molten aluminium. Ian (his son) explained when pouring a metal mould, they push “what they call pop holes through the top of the mould so the air can go out while the metal’s rushing into the mould.” Ian continues, “Dad had a pair of safety glasses on, only the left side had lens. The right side didn’t have a lens in it.” He explains that the metal came up the pop hole and “hit him in his right eye. And when he did, he instinctively closed his eye, and the metal burnt his eye and the insides of his eyelids.”

Ian and his wife Mary visited Joe that night in hospital and Ian reminisced “I just took one look at him, and I said, ‘you’re a bloody copycat Dad.’” I said, “why did you go and do something silly like that for?” Ian explains his father always “was very, very self-conscious of the fact that his eye was badly deformed because it was burnt. They took the eye out straightaway, but his eyelids were very badly deformed.” He shared that, Joe was “was going on fifty when it happened ... his first fifty years of double vision and then all of a sudden bang! He’s only got part [vision], and it affected him a bit.” To cope with this Joe escaped and semi-retired interstate. Joseph was self-conscious and camouflaged his eye by wearing extra dark glasses. According to Ian, Joseph wore glasses all the time apart from when he was at home and at night-time when “it didn’t worry him. He was alright. But he had to take his artificial eye out of a night-time and just put it in a little bottle of water, and I don’t have to.”

Ian, Mary’s, and Sheree’s Recollection of Joe

The story with Joseph is captured through three people’s memories of him. Ian had had several years of experience with a protheses, but he recalls “I had to try and help console him a bit.” Ian did this by: “I just told him, you’ve just got to get used to it and make sure you watch out for people on your right and stuff like that.” Mary (Joseph’s daughter-in-law) added she could not recall an incident or an event she had been at with Joseph where she felt other people were uncomfortable because of his FED. She explained that she was not worried by Joseph’s FED, as it was “just the same as with Ian” except that Joseph used “darker glasses.” Sheree had little to say about her grandfather except she was familiar with the way both her father and Grandfather looked saying, “I grew up with my grandfather like that as well as my father, and it was just part of who they were.”

Ian’s Story

Ian at the time of interview was 73 years of age, “I was an iron moulder for 32 years” living in Victoria, Australia. His family of origin was made up of mother, father, sister, and brother. Ian is the first born in the family. He reports that his family of origin were “shattered” about the incidences which lead him to have his eye ultimately removed. Ian lost his eye in a few traumatic episodes spanning from the age of 6 through to 19 years old. The first incident happened:

I got shot in the eye with a slug gun or air gun now they call it. I was having a bit of an argument with the neighbour next door and there was a bunch of kids with me, I stuck me head around the corner, and I got shot in the eye. I was six and a half years old so it would have happened in 1950.

Ian’s first operation tried to stabilise his remaining left eye. He was in hospital for about two months. At the age of 14 Ian started seeing bright colours out of his “bad eye” whilst his

Mum was knitting him a jumper. She tested his eyesight herself and then they went to a specialist in Melbourne who suggested surgery.

Ian had another operation “to try to get the colour to come back.” After the operation “I could see a lot better in colours.” Four weeks post-surgery Ian was playing with his younger brother who accidentally kicked him in the eye which “set everything back.” He underwent another two operations “to try to ease the pressure in it.” Then, around 19 Ian got an ulcer in the eye which:

got really bad ... it ulcerated and went milky ... I went to see me specialist about it, and he said, “Well I’ve got some bad news,” and I said, “Are you going to have to take it out?” And I said that’s the best news because I said the pain used to be excruciating, and no pain killers or anything would help.

Ian’s eye was removed “I was quite happy. I just had to get a prosthetic and I’ve had that since then and I’ve just lived with it.” He was “just glad to have the pain gone and I didn’t have any pain after that, so it was just one of those things.”

Ian’s Childhood and Subsequent Issues LwFED

Ian’s experiences are discussed under the sub-headings of bullying and parental support; growing up monocular; loss of dream job; staring; eye protection and safety consciousness; humour and storytelling; use of derogatory speak and role models.

Bullying and Parental Support for Ian

Ian was bullied during primary school because “I only had the one eye ... they would just bully me because I couldn’t play sports and things like that because I was always conscious of doing damage to me good eye.” He recalls an incident where his best friend’s mate “whacked me on the head with a hammer.” Ian “picked up one of the old little half shovels, a metal one, and swung it at him and sliced his nose open.” They did not pick on him so much after this incident at primary school.

During secondary school Ian remembers, “there used to be about four of them and they used to chase me around and they’d bloody try and catch me and give me a bit of a belting.” Ian finally had enough of this and “halfway up the second flight of stairs and I just had a go at them, I said the first one comes up, I said I’ll kick his bloody head off.” Ian was serious “and they realised I wasn’t going to muck around, so they started to leave me alone a little bit then. But it wasn’t that long after that I gave away school.”

Constant bullying resulted in Ian falling behind academically, he retells, “it’s in the fourth year which was, it did affect me then because I was starting ... I fell a long way behind in the maths.” The headmaster told his mother the school would help but Ian recalls most of the teachers were not available to help. Ian found a few “teachers would be there to help me, but a couple of them wouldn’t.” He recalls teachers said, “you fell behind, you’ve got to learn to catch up yourself. And mum went in and had a go at them, I can tell you that.” Ian says his mother “was only little, but by crikey could she go off! But no, I fell behind, so I knew I’d fail in the mid-year exams, and I knew that I couldn’t catch up, so I left and went to work.” After leaving school in fourth grade due to falling academically behind because of being monocular visioned and the level of bullying endured, Ian did a few small jobs and then the family moved to Melbourne where “I got an apprenticeship in a foundry as an iron moulder.”

Growing up Monocular

Growing up monocular according to Ian meant: "I've always got to be wary of my right-hand side. As I said, my vision's very wide, but my poor old nose blocks it a bit ... on my right-hand side." He explains, "when people come up and I know they're coming, I've got to turn my head slightly to be able to pick them up." Another strategy Ian uses is: "if I'm doing something and when I go to turn around, I've got to double check to make sure there's no-one there because if I don't, I'll just walk straight into someone."

Loss of Dream Job

Ian "wanted to look like being an architect or building drawing. Had to have the maths and things like that. As far as the skill for drawing, I had that." He states he required mathematics and with no support from the teachers: "I dropped away badly there [as there was no support] not with teachers and stuff like that."

Staring

Ian recalls not much staring happening to him as he grew up or even into his later age. He states, "now and again you see someone would look at you." If he is looking somewhere and his "good eye moves and your right eye doesn't move that much, somebody would look at you and say what's going on there?" He has had kids look at him whilst getting out of the car "I'd look around to say something to Mary and not move my head but move my eye, and I've had a couple of kids look as if to say what's going on here, you know what's happening?"

Eye Protection and Safety Consciousness

Ian understandably is conscious he has sight in only one eye and is self-conscious and safety conscious about this. Working as an iron moulder, Ian took safety into his own hands and used the available safety equipment at that time. Ian explains what he felt he had to do to protect himself:

I was very careful. I always wore shields. I did wear safety glasses for a while until they brought out the full-face shield ... I wore them all the time even though a lot of the others didn't bother, I did." Ian remained "very conscious of watching what I do as far as you know I've always had safety glasses for when I do things and stuff like that." Even in his older years when he has had to wear ordinary glasses "sometimes I don't put a safety glass on, but I make sure I've got my glasses on when I'm doing a bit of grinding or drilling and stuff like that." He explained he "didn't play much sport because I couldn't see to me right too much." As for ball sports, he says most of them have a hard ball "and if I get hit in the eye with it, and you know I'm going to be up the proverbial creek.

Humour and Storytelling

Ian, developed his sense of humour:

Over the years ... I always joke about sport and things like that. I always say I'm a one-eyed Collingwood supporter [Australian Rules football team] and I

can prove it. I always said ... I was going to get meself an artificial eye with a magpie [Magpie is the teams mascot bird] on it and things like that. But I never did.

A funny moment happened when Ian and his mates were:

lining up to go and get Grand Final tickets at Collingwood and I happened to just rub me eye and the next thing you know it's bouncing around the bloody footpath and me mate took off like a scalded cat [he was] embarrassed because I'd rubbed it out. Pushed it out.

Another time Ian found amusing was when he had his spare eye on because:

I had one that had got a little bit small because the socket does shrink a bit. I put it in a ring box, and Mary happened to be in the car and going through the car one day and finds this ring box. Oh! He's got a ring for me. No, no, no he's got a ring for me. So, she opens it up and here's the eye looking at her.

On another occasion, he placed his fake eye in the ashtray of the car after having given up smoking at the age of 21. Ian explains "so being a non-smoker, so I put it in there and I always said, if anyone pinches me car, I'll be able to identify them." Ian recalls another pivotal story which is retold by other family members. He states:

I was up on the Gold Coast where Mum and Dad were, they were living up there, and we went down to the beach and that and swimming and I realised oh bloody surf, I've got me eye in. I put it in me pocket in me boxer togs [bathers] I had on then and I'm swimming away and the surf must have ripped it out and then after that I was saying, oh bloody hell, I've lost me eye. And I said, well one thing about it, I've got me eye on the Gold Coast now and I can perve on all the girls.

In these stories, it is clear Ian uses humour and shared storytelling to assist with living with FED within his life.

Use of Self-Derogatory Speak

Ian explains he uses self-derogatory speak to himself and says that running himself down before anyone else has the opportunity is something he does quite a lot. He shares:

I do abuse meself quite a bit and call meself a one-eyed B Bastard. When I do something wrong meself If I do something stupid or wrong meself, I go you stupid, one-eyed idiot or something like that. But I say that meself and I've always done something like that. I'll run meself down. When I used to work, I used to run meself down especially in the pub and that when I worked in there. I'd run meself down before I had a go at anyone else.

This derogatory self-talk has worked itself into his everyday language, and has been used as a coping strategy to deflect perhaps unwanted attention he would have otherwise incurred because of LwFED.

Role Models for Ian

Most people took Ian as himself, because “that’s the sort of person I am.” Ian says his father shaped the way he is “because I am my father’s son in every way.” His mum sometimes couldn’t decipher between them having to have a “double look to see who was who.” His father was so influential because they “worked together we used to do things together” like gardening, chicken farming, and other shared projects. Even in adulthood Ian worked by his father and came to be a great support when his father lost his right eye.

Family Experiences Living with Ian

Ian’s family’s experiences are discussed under the sub-headings of: Ian marries Mary; married life with Ian; Mary parenting with Ian; growing up with Ian – Sheree and Ian’s FED effects on children and grandchildren.

Ian Marries Mary

Ian met Mary when he was a cleaner at the same job as where Mary worked. Mary used to make chips and being inquisitive Ian wanted to know how: “I wouldn’t mind seeing how they made chips, potato chips and that you know, how they cook them and stuff like.” The forewoman knew Ian and Mary, so she asked Ian “to come around one weekend, on Saturday when they worked over ... you know the extra half day. So, I went in there and I looked around and I just happened to see this nice-looking girl there.” Ian inquired about this “nice looking girl” and a little while later:

Unbeknownst to me one day at work ... she [the forewoman] come in and told me ... oh I’ve got Mary on the phone, and she wants to talk to you and she told Mary that I wanted to talk to her.

The forewoman put Ian on the phone, “and it just went from there, we went out ... I felt at ease. I really enjoyed being in her company.” Ian doesn’t remember exactly when he told Mary about his eye: “I just mentioned it, I had an artificial eye and I’ve only got the one eye, and she just didn’t seem to mind. And we just went from there and it’s 46 years now and we’re still married.” Ian “was 27 and Mary was 25 when we got married.”

Married Life with Ian – Mary’s Experience

Mary met Ian “at the chip factory, ... He came in to see how the chips were made.” Ian and Mary’s relationship started then. Ian told Mary about his eye shortly after they met. Mary was “inquisitive just to see what it was like inside without the false eye, without an eye socket without an eye.” Mary was not bothered by the disfigurement. Mary said Ian’s eye “doesn’t worry me, it doesn’t worry the kids, grandkids are even okay with it.” She admits that this is perhaps true because everyone is so accepting of his eye: “None of us, even myself have known him any other way. The children have grown up with him with the eye.” She reiterates “as I said, they’ve known nothing else.”

Mary gives an example of being at her niece’s engagement party when:

Sitting at the table with ... I think there was about six at the table ... the kids weren’t there or anything, and he just started rubbing his eye and it fell out ... I don’t know if it was under his chair or under the table. Under the table, and here

he was on the floor [laugh] trying to find his eye. Only the people at the table knew. [The table consisted of] they were my sister in-law's sister and her husband and another couple which I can't remember. I think she knew about it and probably her husband did too so. We just laughed in the end. I think we all had a laugh; it wasn't really an awkward moment ... but it was fun.

Mary cannot recall LwFED affecting Sheree, Ian or Joe whilst out in public neither did she have to defend herself or her family because of it.

Mary Parenting with Ian

Mary recalled an incident at their second daughter's kindergarten fun night. She remembers they were at a fun night; Ian had an infection in his eye, taken his eye out and wore a patch. She says, "I just had this inkling, 'cause there was kids there too, that some of the kids might have been a bit scared with the patch ... they had not seen this type of thing." Both parents and children attended, and Mary could "could just pick up and so could he [Ian] some of the kids weren't sure." This was when she suggested he leave, and she would catch a lift back home because she said, "we don't want kids being scared." Mary's strategy when she found or had an "inkling" people were upset and awkward was to ask Ian to leave. So, he did. Apart from this incidence "there was not really any other times that you know I noticed anything." Out in public Mary says "nine times out of ten he's got glasses on" which may attribute for the reason and provide some obscurity or camouflage for Ian's FED.

Mary says, "I felt a bit sorry for Ian" and suggested he leave, "because how he would have been feeling." Ian agrees saying, "I do remember the kids weren't keen. I thought it might be better, as Mary said." So, Ian left "to ease the kids' minds." Mary went to the head person for the evening and "just explained to her and she understood [as] some of the kids might have been a bit wary." This was Mary advocating for Ian in a sense that after they had discussed Ian's departure because of the children's sake, Mary advocated and spoke to the head about her husband and the reason why he departed.

Ian speaks about LwFED and parenting Sheree, suggesting how he dealt with things may have helped Sheree as his confidence may have also given her confidence to be herself.

Growing up with Ian LwFED – Sheree

Ian's daughter Sheree doesn't think that growing up with her father Ian LwFED affected her because:

It was a part of him [emphasis added] growing up ... he had his eye like that well before I was even born, so it was just second nature to me ... I just grew up with him with his eye like that. None of my friends have ever said anything that they're scared of him or anything because of it.

But she says:

I know it affected one of my sisters, it didn't affect me ... she couldn't stand the look of it when he took it out, whereas I just took it as part of him ... I know in the last couple of years, if he's had to take his eye out and ... had to put it in a glass of water, I know she's said to him, can you cover the glass because I can't look at it? She couldn't stand the sight of it.

Sheree doesn't believe that she was bullied at school because her father was LwFED, rather the bullying she experienced was because of her own FED. Whilst growing up Sheree cannot remember anyone staring or avoiding her because of his appearance.

Sheree thinks that all three of them (Sheree, Ian and Mary) having functioning eyelids may have made a difference in how people reacted. She says, "whereas when my grandfather was alive, he used to take his eye out before he went to sleep, his eyelids didn't close so you could see actually inside after he'd taken his eye out." She shares three stories her father told her repeatedly. The first was: "he's got his eye on the girls from the Gold Coast because he's lost one up in the water up." The second was: "when Mum found a ring box in the glove box, and she thought oh, he's bought me a ring and she opened it, and it was his spare eye." The third was when he was working at a cleaner at a college, "he had his car stolen early one morning and in the car was his spare eye. So, as dad always said, they would have got a shock when they found it, opened the ashtray up and found that."

Ian's FED and Effects on his Children and Grandchildren

Ian's children and grandchildren have no issues with his eye, Ian states, "my own children got on with it alright, and my grandkids ... are alright with it." He used to explain, "I've got a sore eye and things like that, that's how I put it, and there was a couple when they were younger, they didn't mind if I didn't have it in and stuff like that."

Sheree's Story

At the time of interview Sheree was aged 45. She had been a primary school teacher and resides with her parents Ian and Mary in Victoria, Australia. When she was growing up, she lived with her mother, father and two younger sisters. Sheree is the eldest child. Sheree has lived with FED all her life, as "the muscles behind the eye when they developed, mine didn't develop behind my right eye properly ... it's a condition called Duane's Syndrome." She exclaimed, "I don't know about Dad how he was, and I think mum just thought that it was something that I'd grow out of." Sheree describes Duane's syndrome as:

When the foetus is developing, the muscles don't develop properly behind the eye. When I go to turn my eye to look right, instead of turning my eye, I'll turn my whole head because my eye just stays still it doesn't move. It's a habit. I don't realise I'm turning my head ... Left eye moves, but the right eye just doesn't.

Despite having lack of movement Sheree says she can see out of it "fine." She says, "I have glasses for reading and that's it."

Childhood and Subsequent Issues LwFED

Sheree's experiences are discussed under the sub-headings of self-conscious/laughed at/bullied; poor school record; employment and studying; isolation and role models.

Self-Conscious, Laughed at, and Bullied

Sheree says:

I was self-conscious when I was younger about it because I got teased a lot when I was at primary school. They just used to call me names and ... call me cross-eyed and everything, and I was very quiet and shy when I was younger.

Sheree was “laughed at because of my eye.” She states she can only recall being called cross-eyed, and it was only verbal, never physical abuse/bullying. The bullying came from “more boys actually,” in primary school she “didn’t have a big circle of friends.”

Sheree changed primary schools frequently but was predominately bullied at one school. She continues:

I don’t remember being teased as much at secondary school ... Whether the primary kids didn’t understand about my problem with my eye as much as the secondary kids because they were older [and] I would have told them what the problem was.

Poor School Record

Sheree didn’t finish secondary school, she “failed Year 10 by one subject, but they thought I could cope so they put me up.” Sheree would have been happy to stay down a year but “four weeks into Year 11, I found I wasn’t coping, and I said right, I’m leaving ... I started looking for work. I don’t think I got any work straightaway, but then I started at a community college.”

Employment and Studying

Between 18 and 25, “I did other numerous courses, computer courses, childcare.” Sheree did find work at “the literacy enhancement programme at a primary school. I worked there for a year and a half.” Her passion for becoming a teacher began when “I did work experience ... in Year 10 at the local kindergarten near us and I loved it.” Sheree completed a double degree, Bachelor of Arts and Teaching majoring in Children’s literature and Indigenous studies. She taught school and now teaches her “nieces in the holidays.”

During her teaching years, in a couple of schools:

Some of the kids mentioned my eye, and once they were told what was, they were fine after that ... I only said something if the kids asked me. If they didn’t ask, I didn’t say anything and ... some of the kids didn’t ask me at all.

If she did have to explain, she recalls:

I’d just have then all sitting on the floor ready to begin class, and I’d tell them. But it depended on the individual class and the school. With my eye they could see that it was just the one that didn’t move properly, ... I’d just tell them that the muscles didn’t develop properly behind the eye when I was born. I mean I couldn’t go into too much detail because they wouldn’t have understood about Duane’s Syndrome.

Isolation

Sheree’s life is continually changing, and she feels it can be isolating. She explains, “I haven’t got a big circle of friends, but the few close friends I do have accept me for who I am.”

Isolation for Sheree is complex and multi-faceted. She offered several explanations before mentioning her FED. For example, during her childhood the family moved around a lot, and she attributes her loss of friends to this rather than living with FED, she states, "I've had [friends] throughout primary and secondary school ... because of moving, we just lost contact." During her schooling she confesses that she might have been isolated because of her FED, but she qualified, "but I know a lot of my thing was just being shy in the first place." Issues also contributing to her isolation were her other illnesses such as arthritis and walking with a "stick." Sheree explains, "I know some people stared at me ... partly because of my eye and partly because of my arthritis and I use a walking stick." Sheree recognised that her isolation was caused by several factors and seemed to avoid allocating it all her FED, offering several other reasons first.

Role Models for Sheree

Sheree states that her parents are the most influential people in her life because, "they've just told me I can do whatever I want. They haven't told me that because of my problems I can't do specific things." Her mother and father have been a great support and encouragement to her and continue to be. Their advice to Sheree when she was young was:

If you want to ... whatever you want to do ... like when I wanted to go to university, they said, "Well, if you can do it, you can do it." It's up to you whether you want to go and do it or not, but they didn't say, "Well no you can't."

Catalyst for Change

Sheree feels empowered to share with others her experience LwFED. She said when she could label FED, she moved from being a naturally shy woman to being able to come "out of my shell." Sheree's FED, Duane's Syndrome:

Actually had a proper name, compared to just saying, oh you've got a lazy eye that doesn't work properly, but having the name of the syndrome and being able to read up about it and find out all this information about it [was empowering].

Once Sheree found the label: "it gave the actual problem a name," and along with that came some sense of identity. Duane's syndrome is rare. Sheree recalls her last visit to the optometrist: "he had a couple of medical students with him, and he asked me if they could come in to have a look at my eye because he said it's something they don't come across very often anymore." Her optometrist explained that, "My eyelids do actually close a little bit ... So normally when I'm looking straight, my eyelids are open fully with that eye, but when I do look sideways, they do start closing a little bit."

Parenting Sheree

Mary and Ian's Experiences of Parenting Sheree

Mary says parenting Sheree was "no different from the others." When Sheree was young, Mary thought she would grow out of it. She reminisces, "I don't think they [doctors] thought that ... but I did. It's been no hassle." Ian speaks of parenting Sheree. He suggested

how he dealt with LwFED himself, role modelling living with FED confidently, may have helped Sheree to have the confidence to be herself.

Mary's Story

Mary's story about her living with FED herself is short due to her growing out of her FED experience as a young child. However, her experience of FED as a child, provided a ground for her later living with family members LwFED. Her story is woven throughout this paper documenting her experiences with dating and marrying Ian, having Joe as a father-in-law and parenting Sheree, all who LwFED. We include Mary's story here to add trustworthiness. Her life experience has meant that she doesn't have a problem with living with her family members LwFED. Mary speaks for herself and her grandchildren: "it doesn't worry me, it doesn't worry the kids, grandkids are even okay with it."

Of herself, Mary explains, "I had a turn in my eye." Mary could not recall whether it was her left or right eye. Her mother "took me to different specialists and they'd said I'd grow out of it, which I did." She recalls having "drops, I think it was only drops" to help rectify her turned eye. At the time of interview, Mary was 71 years old and remains a nervous speaker. Her daughter Sheree expanded on Mary's FED story which was confirmed by Mary and Ian. Sheree explained that Mary:

Had the same problem as me, a lazy eye, but her mother was told that it would probably correct itself, which it did [use of eye drops]. It wasn't as advanced as mine ... hers corrected itself whereas mine never did.

The Family Scare

Sheree recalls an event where her sister could have almost lost her eye. She recalls:

We were having takeaway one night, ... and mum needed a knife to cut [the food] ... she asked [middle child] to go and get a knife out of the drawer, and [she] went and got a knife, and instead of holding the knife properly like you should, she held it upwards and next thing the tip of the knife went into the white of her eye ... the tip of it just touched the white of her eye, but it actually never did anything to her eye. She was very lucky, very, very lucky. And that was her right eye too.

Ian added, "We were a bit worried, we took her to the doctors, and had her checked, but ... it didn't do any damage really. But everything seems to be the right eye in our family. I don't know why."

Discussion and Concluding Remarks

In this complex case family study, spanning three generations with four stories being told of four people's living experience both as someone LwFED and as a family member living with a person LwFED. We see the overarching themes of acceptance, belonging, support, role models for each other from both within the family, being vigilant about the eyes, and role of eyelids. This family creates a safe space to confidently be themselves. This can be seen within father/son relationship which after the FED accident to the father, the son became the role model. Ian also attributes his confidence as influencing his daughter's self-confidence. Sheree speaks of her parents being her role models, never limiting her choices due to LwFED. All four

family members have shared experiences such as societal shunning, school bullying, struggling gaining employment of choice/dream. We have presented these experiences under several sub-headings to assist the reader to follow this complex case of the experiences of four generations LwFED recounted by three interviewees who talk both about themselves and each other.

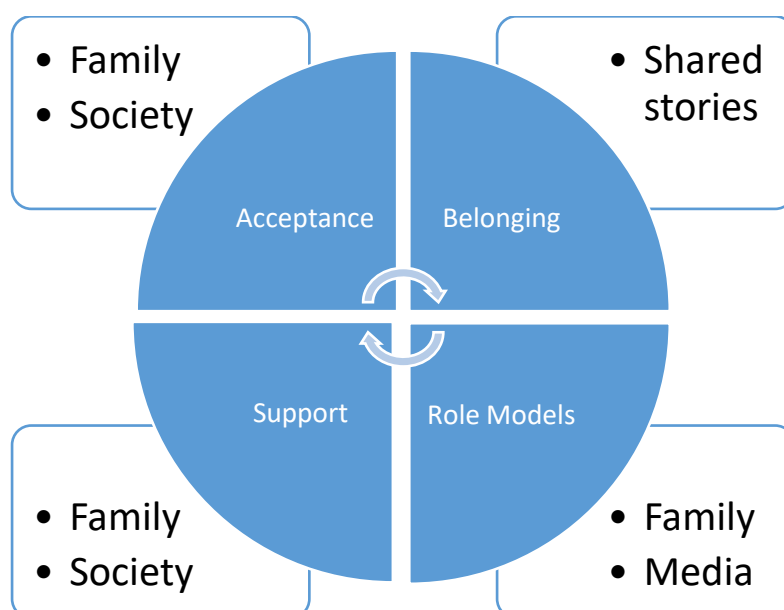
From the data we have presented and our subsequent analysis, we present our Discussion under four overarching constructed from several emergent themes. The four overarching themes are a sense of acceptance, belonging, support (role models, vigilance), and the role of eyelids.

Table 1
Overarching Themes

Overarching Theme	Emergent Themes	Initial Coding
Acceptance	Family	Father/Son
		Son/Father
		Daughter/Father
		Mother/Daughter
		Father/Daughter
		Wife/Husband
	Grandfather/Grandchild	
	Society	Limited staring avoidance of others
Belonging	Shared stories	Story: The “engagement ring” box
		Story: The missing eye at the Gold Coast
Support	Family	Parental support (Ian and Joseph) Child helping parent (Ian and Joseph)
	School	No teacher’s academic assistance re monocular visioned
Support: Role Models	Family	Whole family as role models in all possible dyads
Support: Vigilance	Family	Careful around the face/right eye/eyelids Family scare with second daughter
Role of Eyelids	Operational/Functional blinking normally	No need for camouflage
	Deformed/Not blinking properly	Need for camouflage (Joseph)

One could argue acceptance, belonging, support (role models, vigilance), and the role of eyelids, could be viewed as a whole part the package. True they interweave however what is unique is that the prevalence of all is passed down throughout the generations. For example, Ian’s mother and father happen to be his advocates and his most influential people role models, and Sheree states says her parents are the most influential people in her life. The roles were reversed later in life when Ian was supportive of his father Joseph when he lost his eye. This is a strong three-generational family bond that has flowed to the fourth generation with the grandkids unconcerned with the appearance of either their aunt or grandparent. We offer a schematic overview of the iterative process of successful familial LwFED (see Figure 1).

Figure 1
Iterative Process of Successful Family Living with FED



Literature suggests LwFD leads to a lesser quality of life (Castaneda et al., 2016; Crerand et al., 2017; Depprich et al., 2011; Glinac et al., 2017; Levine et al., 2005; Nitescu et al., 2012; Ones et al., 2005; Wang et al., 2020). Coupling LwFED with monocular vision adds to difficulties and impacts acceptance of appearance, negative psychological impact (judged more by appearance than personality, loss of self-esteem, decrease in socialising, depression), reduced ability to play sport, work, drive, and read (Coday et al., 2002). This family builds a rich foundation wherein acceptance of one's difference is the norm, taken as a part of identity but not its totality. When all four elements of the iterative process are felt to be present, they act as a buffer to external elements (for example, social and media representations). These elements may be felt experienced, forming co-morbidities such as anxiety and depression, to which family members have mentioned experiencing but for other reasons (not LwFED), for example Sheree described being depressed due to ongoing arthritic pain. Nordlicht (1979) confirms the importance of the iterative cycle wherein the family supporting influence "provides a secure base to which the patient can return, physically and emotionally, when the strain in the outside world becomes too great" (p. 1382).

A longstanding but relevant study categorised five family patterns when living with a child's FD:

1. Avoidance – trying to spare the child adversity avoiding any situation which could expose them to questioning including relatives and strangers it is a conscientious withdrawal
2. Hiding – sourcing special clothing, posturing the child to hide the disfigurement from strangers, feeling uncomfortable in the presence of strangers because of the FD
3. Denying – Minimising or denying, inability to discuss the disfigurement
4. Undoing – making the disfigurement beautiful instead of allowing the stigma to take effect. Strangers did not make them uncomfortable, however discussion about the disfigurement does.
5. Normal – Open discussion about the FD to normalise and receive advice, never attempting to hide the disfigurement. (Bryt, 1953, pp. 178-179)

This family fits into Bryt's fifth family category, "normal." For example, Mary describes treating Sheree as she would any other of her children, unless Sheree's FED was to topic of direct conversation (Bryt, 1953). Sheree was able to speak about her FED to the children in secondary school because of her emotionally secure parental encouragement and support from her parents. Bryt says that this brings "warmth and friendliness ... experienced at home, into their relationships" (Bryt, 1953, p. 187).

Belonging requires a sense of feeling "accepted, included, understood, welcomed, liked and appreciated" (Allen, 2021, p. 2). Belonging does not depend on the number of others or groups you attach yourself to but rather it is "a perception or an evaluation of how you feel [that] may relate to the quality of social connections ... satisfaction with them or even a way in which someone feels towards a place or an event" (Allen, 2021, p. 2).

This family demonstrates a very strong sense of belonging and acceptance of each other and their FED normalising it just as a part of who they are. Through shared stories they maintain a sense of belonging and the family role models of LwFED have at some point or other been the most influential person in each other's lives. Families who use their storytelling aid in healing, the more explicit and clear the language is the more beneficial it is creating a "language of family storytelling can become the language of family hope" (Kiser et al., 2010, p. 248). Conversely, if people choose to silence their experiences this can "rupture the child's ability to know his own experience" (Lijtmaer, 2017, p. 282).

The theme of being vigilant and safety conscious around the face, particularly the eyes can be seen through Ian, Sheree and Mary's shared stories about each other, and the story about the second daughter's escape from LwFED. Being concerned and safety conscious of the remaining eye is understandable and warning others about the ease of eye accidents is understandable. The acceptance, sense of belonging, familial role modelling and shared stories may have curtailed what could have been a fear of losing and being in a constant state of vigilance not allowing or not doing any activity which would jeopardise the other eye. Studies have demonstrated an increase of vigilance, poorer quality of life and withdrawal from social activities all link with LwFD (Al Bdour & Mohamed, 2018; Crerand et al., 2017; Levine et al., 2005; Meakins et al., 2015; Murray & Rhodes, 2005; Sullivan-Bolyai et al., 2002; Topolski et al., 2005).

The role of the eyelids is significant in this data pertaining to Joseph's injury later in life. Age is not a buffer to how people are psychosocially or psychologically "better equipped" to handle LwFD (Hamlet & Harcourt, 2015, 2020). Ian, Mary and Sheree have functional eyelids but, in the accident, Joseph's eye lids were severely damaged, and his eyelids no longer closed when blinking or sleeping. Joseph masked his eyes presumably to avoid stares, comments, and to address his own psychological discomfort with his disfigurement (Gagnon, 2016; Halioua et al., 2011). The impact of eyelids has received minimal recognition (Clarke et al., 2003; O'Dea, 2018). Functioning eyelids may be a contributing factor of why Ian and Sheree felt that they suffered less discrimination, staring and avoidance due to LwFD. Confirming this, the Zali's eyelid does not function normally which draws unwanted attention and the "constant need to address concerns and judgements of others" (O'Dea, 2018, p. 2319).

Ultimately, this tightknit family holds and consistently enacts all four of the necessary attributes to successfully create a safe family space: acceptance; belonging; support and role models to function as a "normal" family. This is despite the sharing of LwFED across three generations. This may be because they share such a bond through storytelling and role modelling.

This paper is unique as it presents the intergenerational stories of three generations of one family. Each generation has congenital or acquired LwFED. We advance four positive attributes to a strong healthy intergenerational family LwFED with overarching themes of familial acceptance, belonging, role modelling and support. These attributes have enabled this

family to LwFED from a personal perspective as well supporting family members living with LwFED. What we found is that when these attributes are present and enacted they create a scaffold for healthier LwFED. Corollary to this is being vigilant and safety conscious of the functioning eye rather than becoming hypervigilant and ruminating on such. This paper introduces the specific discussion of the impact of eyelids, where a non-functional eyelid cannot be hidden. We offer insights and understandings of an intergenerational family LwFED to advance research, inform practice, and scaffold effective strategies to support families LwFED within diverse fields, such as medical, allied health and education (Coday et al., 2002; Pell, 2019; Swift & Bogart, 2021).

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