



# “I’m his Mum and it is My Job to Keep him Safe”: Mothering a Child Living with Facial Eye Disfigurement

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## Abstract

Mothering a child who lives with a disability, or a congenital facial condition can impact quality of life. This appertains to relationships, isolation, and feelings exclusion, can result in ongoing vigilance, grief, and may be addressed via faith and future hope. In this IPA study we explore the lived experience of a non-facially disfigured mother mothering her child Living with Facial Eye Disfigurement (LwFED). Semi-structured interviews were used to collect rich data which were analysed to reveal emergent and overarching themes. We found that our participant is constantly vigilant in response to her son’s blindness and disfigurement. This impacts his schooling and her relationships. Isolation impacts all facets of the quality of life of our participant including seeking respite, exhaustion, and relationships. She acknowledges grief and chronic sorrow. As a mother, she encounters comments and stares from strangers in social situations. Our participant uses her strong faith to attempt to find balance in her life and to envisage a future for her son. We offer the narrative of one mother with a child LwFED. We do not draw generalisations but suggest resonances with the lived experiences of others. We recommend further research, advocacy and professional support for families and society to change culture.

**Keywords** Mothering · Facial eye disfigurement · Visible difference · Grief · Chronic sorrow · Vigilance · Relationships · Faith · Interpretative Phenomenological Analysis

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## Introduction

A mother is the first voice a child hears, the first person on which they depend as they enter the new world after birth. A mother's bond is said to be often one of the strongest bonds a child ever has and if, for any reason it is not a strong and stable one, an array of issues arise that often extend into adulthood (Becker-Stoll et al., 2001, 2008; Carlo et al., 2010; Eisenberg et al., 1998; Valiente et al., 2004). Mothering is challenging, increasingly so when things do not go according to plan. Becoming a mother is often a time fraught with mixed emotions, all the fears and excitement of bringing a child into the world. Giving birth to a child whose face does not appear as you perceive it ought to offer an added challenge, particularly in relation to ongoing quality of life (QoL). Further, the eyes "are unique in the process of communication and perception, and sight is important in the maintenance of self-esteem and the confidence to live an independent life" (Watkinson & Williamson, 2023, p. 3.). We point out that it is recognised that psychosocial care of those living with "often gets less attention from health professionals" (Watkinson & Williamson, 2023, p. 6.). Further, social and professional support can significantly impact "subjective quality of life of a family" (Whitehead, 2017, p. 645). We seek to address the lacuna. This Interpretative Phenomenological Analysis (IPA) paper addresses the question, what is the lived experience of a mother who is non-facially disfigured, mothering a child living with facial eye disfigurement (LwFED).

## Literature Review

The QoL of a mother/parent whose child lives with a disability or a congenital facial condition can be impacted (Ahmadizadeh et al., 2018; Alkan et al., 2017; Eiser et al., 2005; Glinac et al., 2017; Habersaat et al., 2013a, b; Karande & Kulkarni, 2009; Miskam et al., 2017; Navab et al., 2018; Ones et al., 2005; Pisula & Porębowicz-Dörsmann, 2017; Wang et al., 2020; Weigl et al., 2005; Yamada et al., 2012). Some studies investigated the mothering/parenting of children with different craniofacial issues (Berger & Dalton, 2011; Habersaat et al., 2013a, b; Pileggi, 2017; Scheller et al., 2020; Weigl et al., 2005). Issues including high levels of anxiety, depression and stigmatisation can affect parenting including those living with a child with disability and FD (Ahmadizadeh et al., 2018; Habersaat et al., 2013a, b; Jovanova & Radovichikj, 2013; Karande & Kulkarni, 2009; Ones et al., 2005; Thwala et al., 2015; Wang et al., 2020). Parents of children with FED has briefly been mentioned in relation to assisting the parents help and support their child to "regain sufficient self-esteem and confidence to progress toward an acceptable body representation as a basis for achieving quality of life" (Williamson et al., 2023, pp. 50–51). This was in relation to achieving this new body image with appropriate medical and surgical intervention, not in relation to the ongoing lived experiences of parenting and what parents themselves experience daily living with a child LwFED. LwFED is "extremely distressing for the patient, family and friends [as the individual LwFED experiences] body image disturbances, experience physical and psychosocial challenges ... cause considerable anguish as well as affect individuals' confidence, mental health, and

quality of life" (Williamson et al., 2023, pp. 42 & 45.) Only one autoethnographic study reports the lived experienced of FED, identifying overarching themes of discrimination, isolation, and hope (O'Dea, 2018). No located studies considered the experiences of a mother without a facial disfigurement (FD) raising a child LwFED.

An individual's understanding of QoL is made up of several influences (Cella, 1994; Flanagan, 1978; Southcott & Nethsinghe, 2018; van Leeuwen et al., 2019). Physical health and socioeconomic status are mentioned briefly in this paper however the individual's subjective control over their attitude to physical and emotional endurance, ability to accomplish daily activities, persistence and life satisfaction are all contributing factors related to QoL (Bandelli et al., 2021; Carr et al., 2001; Marinelli & Plummer, 1999; Oleson, 1990). QoL is defined by the World Health Organization (WHO) as "an individual's perception of the position in life in the context of the culture and value systems in which individual lives and in relation to his goals, expectations, standards, and concerns" (WHO, 1997). Immediate cultural context involves maintaining a sense of social community through relationships with family, friends and acquaintances is paramount to psychosocial and psychological wellbeing (Cella, 1994). Wissing et al. (2021) assert that "relationships and relatedness/interconnectedness in general figure strongly in the experiences of meaning in life, important life goals, and quality of life" (p. 598).

Due to the enormity and diversity of this dimension, social wellbeing appears to be the most challenging aspect of life quality to define (Veenhoven, 2000). QoL also includes self-esteem (Farquhar, 1995) and the ability to make decisions about life path (Flanagan, 1978; Southcott & Nethsinghe, 2018).

QoL has been linked with the notion of grief when speaking about parents' experiences of raising children. We speak of grief in terms of chronic sorrow as relating to the merciless sadness which seeps into every aspect of life and persists throughout life (Burke et al., 1999; Hainsworth et al., 1994; Harris & Winokuer, 2019; Lindgren et al., 1992; Olshansky, 1962). Chronic sorrow impacts the QoL of parents who have a child with disabilities (Burke et al., 1999; Hobdell, 2004; Liedstrom et al., 2008; Lindgren et al., 1992; Masterson, 2010; Northington, 2000; Olshansky, 1962). We discuss grief in relation to chronic sorrow and how this impacts the QoL pertaining to a mother whose child LwFED. It is understood that QoL is subjective, founded and developed within the understanding and knowledge of the individual (Gabriel & Bowling, 2004; Leung & Lee, 2005; Liedstrom et al., 2008) which is fluid, often changing over time.

## Methodology

This Interpretative Phenomenological Analysis (IPA) study explores the lived experience of a non-facially disfigured mother mothering her child LwFED. IPA uses a small sample of participants because what matters is the richness of the data not whether findings can be generalisable as there is a "general misconception that generalisability is the definitive objective of any good research" (Rajasinghe, 2020, p. 183). IPA is an inductive, data-driven research approach (Smith, 2017). IPA is phenomenological and idiographic, allowing the voice, understanding, and experience to be robustly

analysed, via themes and sub-themes (Eatough & Smith, 2006; Pietkiewicz & Smith, 2014; Smith, 1996; Smith et al., 2009). IPA facilitates deeper analytical and contextual thought concerning a given phenomenon by diligently engaging with the human experience. IPA accommodates researchers' roles within the analysis (Wagstaff et al., 2014). Methodologically IPA researchers place the person as the expert of phenomena being analysed – their lived experience (Reid et al., 2005; Smith et al., 2009). We used semi-structured interviews to elicit rich data (Galletta & Cross, 2013). With ethical approval, we advertised on Facebook and Mandy (a pseudonym) responded. Zali interviewed Mandy twice, three years apart.

IPA analysis is an inductive, bottom-up approach whereby the raw data (in this case transcribed interviews) are read and re-read with wide margins for note-taking during the coding process. Wide margins and double spacing of the professionally transcribed script facilitated initial coding, seeking patterns, contentions, and tensions, and locating 'gems' (Smith, 2011). Themes and sub-themes were identified and presented in a systematic way that makes sense of the lived experience. While IPA is not prescriptive, a table of themes and overarching themes is often produced to demonstrate the analysis process (see Table 1).

Zali, a counsellor and teacher, holds both emic and etic stances, having lived experience as an individual and mothering LwFED. Within this article she bridles her experiences (Vagle, 2009). Jane holds an etic position, as an experienced educator, researcher who brought a different lens to the analysis and interpretation, enhancing

**Table 1** Mandy's Overarching and Emerging IPA themes

Overarching themes	Emerging themes	Coding
Vigilance	Blindness	Impacts of blindness
		Safety Watchfulness Playgrounds and other settings
	Schooling	Feeding tube Blind school
		Threat of institutionalization
Isolation	Fear for her son's future	Baby-sitting
	Gaining respite	Feeding (tube; sippy cup) and mealtimes
	Challenges	Small town, resourcing, accessible schooling, home-schooling
		Tiredness and exhaustion
Facing society as Mother	Relationships	Husband; friends
	Grief and chronic sorrow	Self-care; ongoing; struggle; imagined
	Stares and different kinds of talk	Pity, reaction, stares, gasps, avoidance, comments
	Surprise at Declan as an individual	Intelligence; humour
Faith	Inner vow	Protection; self-imposed
	Rewriting the narrative	Story, sharing, advocacy
	Christ follower (Christian)	Prayer, belief
	Grief with Jesus and Biblical scriptures	Bible, promises, keeping steady

trustworthiness and consensus (Rodham et al., 2015). We include verbatim quotations to give voice to Mandy (Smith et al., 2009).

Quality and rigour in IPA studies is imperative and address whether the research is trustworthy and fair (Smith & Flowers, 2009). In this study, trustworthiness is located within Zali's expertise, qualifications, and experience. Trustworthiness is built within the data by member checking in which the participant read the interview transcript and confirmed accuracy and interpretation. To enhance trustworthiness, we posed suitable open-ended questions and remained open for nuance and additional data. We undertook triangulation through frequent debriefing, peer scrutiny of the research, member checks and use of thick description (Shenton, 2004). Fairness was addressed by the ability to present a "balanced view that presents all constructions and values that undergird them" (Lincoln & Guba, 1986, p. 79).

## Findings

### The Participant

Mandy is a mother of two children, one of whom (Declan) lives with FED. His younger brother says Declan's eyes are "like pepperonis." Even though the participants were willing to be named, we believe for the purposes of this article, we have given them pseudonyms and speak in general about where they live in the world as in the future, the boys may not wish to be talked about. We call the mother Mandy and the son LwFED Declan and his younger brother Abel. They live in a small rural town in the USA.

### Themes

We found four overarching themes: Vigilance; Isolation; Facing society as Mother; and Faith (see Table 1). These themes have sub-headings and flow in a sequential order, taking the reader into the world of the expert lived experience of mothering a child LwFED.

Although we present the findings under the overarching themes, we acknowledge that there is overlap and connection between these themes as experiences are interwoven into the fabric of a person.

### Vigilance

Mandy speaks about being on high alert everywhere, regardless of whether in the house, outside in the backyard, shopping and even out at a friend's house. She perceives he is not safe when other people guide him either. Within this thread there are sub-themes of Blindness; Schooling; Relationships and Fear for her son's future life. Everywhere, Mandy is extra vigilant, keeping her son safe, she states: "Every step is dangerous."

## Blindness

Declan is blind which permeates Mandy's experience as his mother. She explained:

if he steps a single foot outside of the house, he has to be guided everywhere he goes. Every step is dangerous ... he doesn't know if he's about to walk off a cliff, he doesn't know if he's about to walk into the road, and there are cues sure, but he's six and he misses those cues a lot. We can't trust a six year old to catch those cues, and so it's difficult to never be able to let go of his hand ... my younger son now being four, whenever we go somewhere, I get him out of the car, I set him on the ground, he walks next to me all the way to where we're going, and he can walk next to me the whole time, and that's just not the case for Declan.

Mandy spoke about how this affects her,

Guiding him has become sort of second nature for me, but when I let other people walk him, I notice that they forget and let go of his hand and will walk away, and you can't do that. So I'm always having to have this extra vigilance about me to make sure that he stays safe, just because the world's not a safe place when you can't see.

Declan's blindness contributes to Mandy's understandable need to be extra vigilant to keep him safe whilst out and about.

Everyday experiences emphasise to Mandy Declan's lack of safety. Mandy discussed her need to be "extra vigilant" in social situations:

we went to the park with our home school group, and all the mums gathered under the pavilion to chitchat while their kids played, and I can't do that. I couldn't gather with them, I had to stay next to Declan on the playground.

Mandy explained how difficult this made visiting with friends:

one of my best friends just got a new home and it has a 17 stair ... flight of stairs in it ... it's so stressful for me because ... I cannot take my eyes off Declan long enough to spend time with my friends because if he gets up that staircase ... he can get up it very easily, but getting back down it is another story, and if he fell down ....

Declan's blindness means that Mandy must be ever watchful for his physical safety. This vigilance is not unreasonable, but as he gets older, Mandy seems to have fallen into a pattern of being extra vigilant ... extra vigilant when walking, at the playground, at friends' houses, this is the pattern of extra vigilance Mandy speaks of and it continues into schooling.

At the time of the second interview when Declan was older (9 years old), Mandy seemed to be able to have a little "respite" or "down time" as Declan can do some things independently at the playground. Mandy explains:

I still have to help him navigate the playground as far as safety goes, so I'm always close by. If he wants to climb things or do something ... he just usually requires my help. If it's swinging or something like that he can do that by himself. So I can put him in a swing and sit and relax, but otherwise if he wants to be walking around or climbing things or going up into the little playsets, I have to be with him just for safety reasons really. So independence is a big issue that I just have to constantly ... know where he's at all the time and just keep an eye on [him].

Declan's growing independence does not negate Mandy's need to be vigilant.

### **Schooling**

Declan is fed through a tube which adds another layer to Mandy's need to be constantly on guard. This has also impacted Declan's schooling. In the past they drove Declan to a blind school which was "two hours each way ... the only blind school in our state ... the drive was horrendous and exhausting and expensive." This was to give Declan "what he needs a school dedicated to blind kids". Declan left that school due to his feeding tube as it was

about having somebody there to feed him ... it got to the point where I couldn't bring him to school some days because there would be nobody there to feed him, and it just became a big mess to the point where Declan didn't want to go to school, and Declan was so excited about school at one point ... he loved it, he wanted to go, he was ready to go even though I wasn't really ready to let him and it just ended up being ... just a disaster ... blind school was my guess [emphasised] of what was best, and it ended up not being great ... it's difficult.

Declan needs assistance and protection, but Mandy acknowledges her lack of readiness to let Declan take risks.

### **Fear for her Son's Future Life**

When Declan was born there was an option to place him in an institution. Mandy was not offered this at the time of his birth, but she could have very easily said she did not want him and because of the State laws at the time, no one would have fluttered an eye and arranged for Declan to be institutionalised. She reminisced:

It was terrifying to know the kind of world he was going to have to grow up in, and it's not the same world anymore. And don't get me wrong, there's still plenty of things to work on and fix, but it's improving ... at least in that area, people with disabilities are being seen as human beings. And I mean I can just

say that we don't get stared at the way we used to. We don't get approached the way we used to.

Mandy acknowledges that things are changing but not necessarily quickly enough to allay her fears about Declan's future.

## Isolation

Mandy experiences isolation in several ways. Some of these are immediate to Declan, gaining respite which includes issues of baby-sitting and feeding, and the accompanying financial stress. Others are concerned with living in a small rural town community. In addition, Lacy experiences, physical burn out, tiredness and exhaustion, which make it difficult for her to maintain quality time within relationships. Mandy experiences grief and is aware that all these factors contribute to her isolation.

## Gaining Respite

Declan's physical needs are seemingly never-ending. For example, she has difficulties in gaining babysitters because Declan needs to be tube fed every four hours. She explained,

Our biggest challenge in letting other people care for him ... his vision impairment is not a huge issue because he knows our home, and we've made it safe for him ... we can find people who would come to our home and watch him and ... we could feel safe, but because he's got the feeding tube, that adds another layer because people who don't have experience with a feeding tube, they don't feel comfortable with it, and I don't blame them.

Mandy admits that she was initially uncomfortable with the feeding tube and recognises that it can make "people very standoffish and apprehensive to care for him". For the past few years, her solution has been to feed Declan and then she can have four hours' respite and go out somewhere but often "it just kind of comes to the point where it's not even worth it." Mandy seems to hope that Declan becomes less dependent.

## Challenges: Small Town, Schooling and Finance

Although a small town would appear to be of psychological and psychosocial benefit, once Declan is known and accepted it has financial drawbacks when attempting to have Declan fully supported within the public school system. Mandy explains:

It's actually a small town. We have very little here, which means that we have very little money, which means that my child who needs very expensive things and very special things ... it's really difficult to get them for him because the money just not there.



Declan would have been the only blind child LwFED within the entire local school system. Mandy explained that she needed to “think realistically – is he going to get what he needs?”. Mandy knew the school and his teachers would “do everything that they could because they really did care, but their hands are tied ... they can’t just make money here.”

Mandy explains there were options for schooling Declan like the blind school mentioned above that was her idea of “what was best, and it ended up not being great ... it’s difficult.” Due to Declan’s additional needs and no funding to draw upon, Mandy decided to home-school Declan. He is:

in a home school co-op with other children, and none of them are blind. There are several who have disabilities, so it’s a very open subject there and we’re allowed to talk about it. It’s a very comfortable place to talk about it, the family is welcome you know to talk about it, and so we just talk about it, and it’s given us a forum to talk about it, and it’s given him the ability to realise that he’s different, and also the ability to sort of like respond when people ask.

Mandy has found a small social group within which she feels less isolated.

### **Tiredness and Exhaustion**

Mandy finds it exhausting because she is constantly on guard, with little opportunity to relax. On the rare occasions she does get the opportunity Mandy finds herself in uncharted territory. She explained:

It’s tiring to constantly have to be [on guard] ... I have a hard time with relaxing ... some of my friends tell me I need to just take some time and relax. I honestly don’t even know that I know how ... it’s just I don’t do it, I don’t really get to do it very often, so it’s hard ... when I do have a chance, it’s hard to actually release and chill out.

Mandy imagines “times where I just wish I could just sit down and watch him play ... or just have him walk next to me into the store.” She feels that this impossible and explains,

“we’ve adjusted ... it’s not like a begrudging thing because I mean I’m his mum and it’s my job to keep him safe, and if that’s what it takes, then that’s what it takes”. She speaks of the emotional and physical toll this has upon her stating “it is tiring and ... and I mean emotionally tiring as well as physically”.

Being constantly ‘on guard’ and keeping watch over her child causing extra vigilance often keeps her body and mind on alert. She is so used to being on such a high state of ‘alert’ physically, emotionally and mentally, when she has time to “release and chill” she finds it a difficult task to accomplish.

## Relationships

Raising Declan LwFED and his additional needs takes a toll on Mandy's relationships with her husband. She explains, "we just don't have a lot of time together ... for each other, ... right now the focus is on raising our kids and taking care of them, and that takes up so much energy and so much time." She alludes to the physical and emotional impact of raising Declan that has a toll on their marital intimacy, "at the end of the day when it's bedtime, you know we're passing out ... I mean it makes it hard to really have relational time, like to spend time together." She would like to spend more time with her husband and regrets the ability to have a "date night" but considers it "one of those things ... it's just what Declan needs, it's just a season, it won't last forever."

Mandy's relationships with friends takes a back seat due to the stress and difficulty in either finding a competent babysitter or her friends places are not "Declan friendly". Mandy explains that it is "really hard to have relational time" because she needs to feel Declan is safe in a "perfect set-up." This means that she misses spending time with friends, explaining that "I hardly ever get to see any of them." Ultimately, "it just doesn't normally pan out that way, so we just don't get to spend a lot of quality time with many people." This extends to her husband, as she adds "including each other."

Mandy feels restricted in her ability to maintain friendships and make new friends for herself and Declan. She illustrates herself isolation from other mums in the playground.

I couldn't gather with them, I had to stay next to Declan on the playground. And so, at times it's a little isolating because people don't understand it, like those mums weren't doing anything you know wrong or bad at all ... they weren't excluding me, I'm just naturally excluded from that because you know I have to be because his safety is more important than me you know getting to sit back and relax and chat with my friends.

Even Mandy's friends do not incorporate or may leeway for Mandy's level of vigilance or need to be with her child, none try and include her by walking around with her whilst holding their conversation, rather, they chose to relax and chat leaving Mandy feeling isolated.

## Grief and Chronic Sorrow

Grief is a major factor in isolation and is generally thought about in relation to the death of a loved one, however mothering a child LwFED, Mandy speaks of being in a constant phase of grief, "I mean I think the biggest thing about grief is you can't stop it and fighting against it just makes it worse." She recognises a need to self-care which is easier now that her children are older. She explained,

I usually get up early before they do and go for a run and listen to podcasts or audiobooks. I have a little garden, a little vegetable garden in the backyard and

I work in that. I read a lot of books, that's my me time, that's the things I do for me.

Mandy understands the need to give herself "me time, that's the things I do for me" in order to combat the grief or allow for the expressions of grief to be.

For Mandy grief cohabits with mothering a child LwFED: "Grief is an ongoing companion, sometimes taking the best seat at a full table, other times off in the distance." Mandy shares her struggles as a mum and shares her grief. She wishes that she could have a "traditional family meal", but her family does not get to do that because Declan still eats.

via a tube rather than us sitting down to a family meal ... It's not a traditional family meal, but it's our family meal. I'm giving my nine-year-old baby food and a sippy cup because that's what he uses to drink still ... I'm still feeding him every bite of food as if he was an infant in that respect.

Mandy images "a family meal with all the food out on the table and everybody's serving each other and they're all eating" but her reality is

I don't even get to eat until after I've fed Declan ... and then I can eat and we can try to converse. But then Declan is done so there's this constant tug of war of sit at the table and eat with us, sit at the table and talk to us, here try this, you know smell this food, taste this food, try a bite of this food. So it's very therapised.

Grief is not static, it does never leaves Mandy mothering a child with LwFED. Such grief is called chronic sorrow. She imagines a future where Declan eats by mouth, but

I will still have missed out on how ever many years of ... he's never had a slice of his birthday cake. If I bake cookies he doesn't get to enjoy those. We sit down for a family movie and we have popcorn and he doesn't eat, and so it's just all these things that he can't participate in and enjoy.

Even if it is different in the future, Mandy still grieves, "because I missed out on all those years and I didn't get those things with him, because I still grieve I never got to breastfeed him, and I'll never get that time [again]."

Mandy explains that grief cannot be stopped "and you just have to acknowledge it and give yourself what your body, what your mind, what your heart is telling you what you need during the grieving process." She does not feel guilty if she needs "to not be around people for a while [or] if I need to go out with girlfriends and have coffee." She focuses on "caring for myself so I can care for my family. But I try to really listen to myself and what I need and give that to me too and remember that I'm deserving of it."

## Facing Society as Mother

As a mother, Mandy has had many different responses to Declan's FED from others. This is where we gain rich, grinding, and ongoing insight of what it is like to be a mother with a child LwFED. We discuss these under the headings of Stares and different kinds of talk; and Surprise at Declan as an individual.

### Stares and Different Kinds of 'Talk'

Within the first interview Mandy gives examples of stares, gasps, insinuations/rude comments, whispers and avoidance by others. She explained how other people use pity often saying 'Oh I'm so sorry' as well as the well-wishers who think that because Mandy parents a child LwFED she deserves a badge of honour.

Mandy talks about the looks she lives through mothering a child LwFED:

"when Declan was a baby it was just constant like ogling ... just people being really not tactful when they would speak to me about him." This has continued,

We get a lot of looks, we get a lot of people noticing, and the noticing is very consistent, but after that, it seems like there's a lot of different things that people can do, and I guess it just depends on people's personality type and their life experiences. Sometimes we'll have people notice and they'll go on as if you know nothing at all. Sometimes we'll have people notice and they'll stare way too long. Sometimes we'll have people notice and they'll come up to us and talk, talk nicely. We've had a few people who've come up to us and say things that were rude.

She gave examples,

They would say stuff like what's wrong with him? Why does his face look like that? And these are adults [and] that's not okay for an adult. Now kids, I have some leeway for, but adults used to say stuff ... I had an adult one time who jumped back away from my shopping cart and gasped when he saw Declan ... and it was just exhausting.

Societal expressions of disgust and implied criticism are shared by Mandy:

When Declan was a baby, I had a guy walk up and [makes gasping sound], and I just wanted to stop him ... or we'll have people who insinuate things like – oh when are you going to have his eyes fixed? Like it's not an appropriate question to ask. Like you don't ask things like that. That's not okay you know, like he deserves the same respect everybody else deserves.

Mandy speaks about "people whispering behind your back, you would know they were talking about you." The miracle of parting of the red sea is still readily available for mothers whose child LwFED. Mandy described "standing in line somewhere and people would like get out of line because they didn't want to be near us." Mandy

speaks about the apologetic narrative she receives, other people pitying her: "I just get so often, oh I'm so sorry, and I tell people for what? You know I'm happy to be his mum, I'm happy that he is my child, like I don't want somebody else to be his mum."

Mandy explains how people may be sincere in their words do not know how very wrong their expressions of their perceptions of what mothering a child LwFED is. She recounted,

We had a guy come up to us just recently ... I think he meant this as a compliment, you could just see it on his face how sincere he was. He literally like knocked on our window at a gas station and [my husband] rolled down the window and we were kind of like what's up? And we thought he was going to ask us for money, and he just went on and on and on ... I don't know how you guys do it ... my heart just breaks for you guys ... y'all are great parents for doing what you do ... I couldn't do it. You know kind of insinuating that we're doing something special by raising our child, ... and he meant it as a compliment and I get that, but on another level ... would you walk up to somebody with a typical child and just say, I couldn't do it, I don't know how you raised that kid?

There are many different ways in Mandy and Declan encounter staring and avoidance. The last example was an eye opener for Mandy as this stranger went above and beyond insisting them to wind their window down to speak about their child he had seen whilst at the petrol station. Mandy felt this to be an invasion of their privacy and totally inappropriate.

### **Surprise at Declan Being an Individual**

Often people LwFED are seen of less intelligence. Mandy shares her view as a mother:

He's a character, I mean he's got this sense of humour that's hilarious and people are kind of surprised I guess by it. Declan's really smart too, and ... people find it very hilarious to see how smart he is, and it is really funny. You know when your kid, like your toddler does something that's like above their level, and you're like how did they figure that out? And you're like surprised and entertained by it, and it's kind of like that with Declan because it is more difficult for him to figure things out.

Other examples are when a child says "eww gross" and when people are surprised at how intelligent Declan is when they expect him to be "retarded" meaning mentally delayed which "has become a derogatory term, and so people with intellectual disabilities didn't want that word associated with them anymore. So as a society we've shifted, and we've made that change." Ultimately, Mandy thinks this "has to do with being respectful of people with intellectual disabilities." In the second interview Mandy shares how people in her small town receive nine-year-old Declan LwFED:

people treat Declan like a kid ... They'll speak to him; they don't mention his facial difference they'll just be like hey how are you. And Declan's a really friendly kid too, so sometimes he'll speak first and ... they'll speak back, and he'll say hi and they'll say well hey, how are you? And he's good, my name's Declan and they'll have a little conversation.

For Mandy this is the ideal situation, Declan being able to go about his business without the stares and avoidance that has previously been discussed. Within his hometown of 2500 people, Declan is being treated as a kid regardless of his FD. They are seeing him first rather than the FD. This is ultimately what Mandy wants to have happen anywhere he goes.

## Faith

Mandy's love for her child stems from her faith, which underpins her mothering. Mandy recalled a past event that became a catalyst for change. She recalls:

We were out trick or treating one year at Halloween, and this little girl started pointing and laughing at Declan ... and this was the only time this has ever happened, it was so odd ... [the little girl's] dad turned around and realised what she was doing, he started pointing and laughing with her. And I was so mad that I just took Declan and I left. I didn't say a word to them, I just left, and I walked away and I was so mad at myself. Declan was way too little to know, like way too little to understand, but I was so mad at myself for not defending him, and not letting them know that it wasn't okay you know in that moment. And after that I was like no, I'm never letting that chance pass by again to do that.

## Inner Vow

Mandy felt shame for not standing up for her son and made an inner vow that all interactions with society should not be harmful to Declan. This vow connects her faith and parenting.

She explains:

My biggest goal ... with any interaction we have ... is to make sure that Declan always feels valued and that any interaction we have is not hurtful to him. And so if we have an interaction with a kid who's saying something that's a little bit inappropriate, I immediately ask them to stop because I want Declan to know that he's allowed to stand up for himself and he doesn't have to be a doormat and let people say things about him, he's allowed to say that's not okay. And so that's usually the first thing I'll say – okay, that's not nice, you know he can hear you and those aren't kind things to say. If you want to know why his face looks different, I'm happy to tell you, but I'd like for you to be kind.

Mandy has developed further strategies if this first attempt is unsuccessful: "I've just got more insistent and I've said I'm going to ask you stop one more time or we're going to find your mum you know ... and generally that makes them stop." When asked if Declan was aware of the stares and avoidance of others, she answered that he does not realise the comments are about him as "there's just a bunch of kids around talking and ... they're not saying his name ... he usually doesn't catch on immediately unless it's just really persistent. And then he'll say hi I'm Declan." Mandy thinks that Declan does not understand but as he gets older, her denial will not be possible.

### Rewriting the Narrative

Mandy has taken onboard the need to rewrite the narrative of disability. She explains that in the past she had been "guilty of thinking" that "disability is bad, that people with disabilities are less than, and disability is tragic, to be pitied, linked with poverty ... unintelligence, not a mental disability, not a mental impairment but unintelligent." Mandy expands on her argument, "there are plenty of people with mental impairments who are not unintelligent, and ... and I call it a stigma, and ... my theory is that the stigma exists because only one side of the story has been told." Having made this decision, Mandy became an advocate, using social media "to tell the story and to set the records straight about what disability is." She states that she is not an expert but then acknowledges that "I'm kind of an expert on this topic, so listen to me, ... I have firsthand experience ... here's our life and here's how it's beautiful and here's how it's difficult." She believes that telling her story can show others that "disabilities can happen ... and highlight that disability is not to be pitied."

Taking a position of advocacy on social media has drawn criticism, I'm had people tell me how dare I post pictures of Declan on Facebook because he has a disability. You would never say that to me about Abel ... when it's Abel I'm a proud mum posting pictures of my child. When it's Declan I'm exploiting him.

Mandy refuses to keep Declan hidden and persists:

I keep sharing and I keep sharing and I don't care if there are people who don't agree because for everyone person who disagrees, there's a hundred more who get it, and I see them getting it, and people send me messages letting me know they finally get it, and before they didn't, and it's just pretty amazing

Mandy expects "backlash but ... I know the truth, and the fact that some people don't agree with that truth doesn't mean I'm going to stop telling the truth." Mandy links standing up for the truth to her faith.

### **Christ Follower (Christian)**

Underpinning her motherly choices is her faith. She explains, “my family practices Christianity. We are Christ followers.” Her faith in Jesus is “the source of my strength.” Any choices she makes, such as the decision to home-school is “talked about with my husband a lot and [I] did a lot of research and prayed about it a lot.” She attributes her strength as a strong mother to her faith:

people say oh I can't believe how strong you are, you're so strong to do what you do, ... and it's been the leadership of God and the sovereignty of God that has just guided me through. [Faith] sort of takes the pressure off me ... I don't have to be a perfect parent, I don't have to have all the answers, and ... there is immense pressure with Declan, but... it's not the pressure that he's got to be socially where all the other kids are, or socially he's got to be accepted. Like it's not a popularity contest because he's a child of God no matter what, and that's the most important thing, and sort of where we focus and where we centre, and having our faith keeps us in that centre.

This belief system drives Mandy to share Christ's unconditional love towards Declan:

I'm happy to be his mum, I'm happy that he is my child, like I don't want somebody else to be his mum. I wouldn't give him up for the world. I wouldn't give him up for ten healthy children you know. I want him, I want who he is, and I take him fully and unconditionally, and that's what ... love really is ... it's unconditional.

### **Grief with Jesus and Biblical Scriptures**

She takes her grief to Jesus finding comfort in her relationship with Him and His word, finding solace in the Bible, her constant companion. Jesus's words soothe and offer her hope:

“I read a lot of scripture and repeat the promises ... believing and holding onto those.” She offers an example, when Declan was just first born,

Psalm 139 says “For you created my innermost being, you knit me together in my mother's womb ... I am fearfully and wonderfully made” and I repeated that over and over and over to myself in my head about Declan to remind me that God wasn't making a mistake, that this didn't take him by surprise and that he knew what he was doing and ... because there was a time when I was just angry and thought God did something wrong or ... he missed what was going on in my life, that I'd somehow missed his radar.

Mandy would “hang onto those kind of promises” and when he was born:



I just repeated a scripture in Isaiah over and over that talked about when you go through the deep waters 'I will be with you and they will not overtake you' ... that promise over and over and over ... in the moments where I felt like I was being overtaken I would remind myself of that, that God said that I will not be overtaken. And even when I didn't believe it, I would still remember it.

More recently Mandy found a:

verse in Romans that talks about Abraham and the father of many nations and how his faith is what is counted to him as righteousness because he didn't have Jesus at that time, and there's a verse in Romans that says Abraham hoped against unbelief and that just kind of shook me because even Abraham had some unbelief, but even in his unbelief he hoped ... and that ... I think that's what I've always done without realising that's what I was doing ... it didn't look it, it didn't feel like it, it didn't seem like it and I didn't really believe it, but I hoped against hope that God's promises were true and that's what I've held onto.

Relying on her relationship helps Mandy keep steady within the undulating waves of grief or chronic sorrow as they rise and fall whilst mothering Declan LwFED.

## Discussion

The overarching themes of: vigilance; isolation; facing society as mother, and faith (see Table 1) interweave, warping and wefting, creating Mandy's lived experience as a mother whose child LwFED. Her QoL is clearly affected by having a child LwFED. All of these themes are a constant hum in the background of her life, sometimes one takes precedence. For example, isolation emerges when she goes to the playground or has sparse time with her friends and husband. Going to the playground or going into new territory such as her girlfriend's new house with 17 stairs requires extra vigilance which swallows precious time with her friends creating a daily cycle of isolation, loneliness, and grief. Grief occurs especially around family mealtimes when Mandy longs for a more 'traditional' meal with everyone eating and drinking (not out of sippy cups). Mandy ascribes how she deals with such isolation/loneliness, being extra vigilant and grief chiefly to her faith in Jesus Christ.

## Vigilance

Vigilance is best described as a state of constant watchfulness or alertness or caution (Zeleny, 1992). Vigilance has been investigated in an array of mothers with children with various issues (Butner et al., 2011; In-Albon et al., 2010; Mandalayala et al., 2014; Meakins et al., 2015; Medhurst, 2002; Sullivan-Bolyai et al., 2002), Mandy's extra vigilance is apparent as she describes the ongoing difficulties of Declan's FD, blindness and feeding. She struggles to leave him on playgrounds, cannot rest at

friend's places, and has had to re-think schooling which has caused further financial stress.

Sullivan-Bolyai et al. (2002) suggest that constant vigilance can be clustered into three areas such as “ongoing monitoring of illness-related care, ... identifying appropriate and safe resources that could meet the child's needs and ... ‘juggling’: illness related care with the developmental needs of the child” (p. 24). Mandy exhibits all three kinds of constant vigilance and sometimes she slips into exaggerated vigilant parenting. Meakins et al. (2015) found collective influences that culminate in vigilant and exaggerated vigilant parenting. Typical parenting involves things like family beliefs, parenting styles and child temperament. Vigilant parenting includes these and adds child vulnerability, complex care and monitoring requirements, insufficient or unreliable support. Exaggerated vigilant parenting includes the previous two categories plus persistent uncertainty, elongated stresses on parent and parental isolation.

Being vigilant comes with mothering but being extra vigilant is exhausting and requires a lot of effort. Continuing being as vigilant or as Mandy calls “extra vigilant” may become stifling to Declan as he gets older, exacerbated by not allowing him to ‘flex his independence’ in age-appropriate ways. Mandy anticipates future problems, for example if Declan were to be hospitalised and seen as ‘different’, without her vigilance he might be institutionalised or somehow treated as less than or disrespected. She is trying to create a new narrative in which Declan's life matters.

## Isolation

Isolation is prevalent in literature regarding the lived experience of people LwFD either congenitally or acquired for example through cancer (Askins & Buck, 2014; Bowers, 2008; Hearst, 2007; Newell & Marks, 2000; Person et al., 2008; Rumsey & Harcourt, 2007; Stacey & Edwards, 2013) O'Dea (2018) identifies isolation as one of her constant battles she daily faces eye to eye LwFED.

Existing research addresses mothers who have a child who have a physical or mental disability telling of the isolation and loneliness of parents that reduces QoL (Ahmadizadeh et al., 2018; Alkan et al., 2017; Miskam et al., 2017; Navab et al., 2018; Ones et al., 2005; Person et al., 2008; Pileggi, 2017; Pileggi et al., 2018; Pisula & Porębowicz-Dörsmann, 2017; Scheller et al., 2020). Pileggi et al. (2018) state:

Caring for a child with a [facial] difference or disability further complicates discourses around mothering ... the fact that mothers share in the stigma and marginalization of their children with [their mental or facial] differences [mothers] have their own sense of self-worth and competence as a parent eroded as they come up against negative societal views. (p. 250)

Our exploration of the lived experiences of Mandy a mother whose child LwFED offers ground-breaking engagement with her voice. In accord with the tenets of IPA, we view Mandy as the expert of her own experience. In our study, isolation extends towards the main care giver, Mandy in her mothering of Declan LwFED. Erosion of QoL and isolation is evident within Mandy's descriptions of the difference of sharing

pictures of her son Abel as opposed to the negative societal views of sharing pictures of Declan.

### **Facing Society as a Mother**

Facing society as mother, the third theme is presented within this discussion relating to grief. Grief over being isolated from her friends and family, but this runs deeper as grief is prevalent in Mandy's story. Freud began the journey into grief and loss with many other theorists following (Field & Horowitz, 1998; Freud, 1957; Gilbert, 1998; Love, 2007; Neimeyer, 2000, 2001; Neimeyer et al., 2010; The, 2012; Witney, 2012; Worden, 2014, 2018). In a rare study linking grief with FD related to head and neck cancer, Callahan (2005) theorises five steps in recovery including confronting the loss, confronting possible denial, reframing the experience and integration of the experience. None have investigated the grief attached to mothering a child LwFED. Worden developed a sequence of tasks which the mourner can visit and rework over time. His four tasks are: Task 1 – to accept the reality of the loss; Task 2 – To process the pain of the loss; Task 3 – To adjust to an environment where the deceased is missing and Task 4 – To emotionally relocate and memorialise the dead person in a way that one can move on with life (Worden, 2014, 2018).

### **Grief**

Most grief theories focus on the death of a person, but Mandy is living with grief as the mother of a child LwFED. Her grief is evident throughout the interviews and is woven into daily routine. An example of grief in Mandy's experience is their unique family meal setup wherein one family member does not partake in the food lovingly prepared by Mandy.

In a dual process model (DPM) of grief, Strobe uses the word oscillate, listing two alternating stressors associated with loss: (1) those related to the loss and (2) those related to restoration (Strobe & Schut, 2005, 2010), implying people whose loved one has passed oscillate between "grief itself and reengagement with a world transformed by their loss" (Worden, 2014, p. 96). Mandy can be found oscillating in many ways: between what she thought her newborn would look like and what is; what she imagined family mealtimes would be like, and what is; how she would like to develop and maintain relationships with friends and husband, and what is. She can be seen accepting the loss of what she thought Declan would look like as a baby as seen in Worden's theory and is able to process the pain of loss and adapt to an environment of what is instead of what 'should have been', however she oscillates or has to spend more time on the tasks of processing pain of loss and adjusting to an environment of what is or what Strobe calls stressors, those related to the loss and those related to restoration continually.

This is an ongoing process which Declan and Mandy will experience in many life milestones yet to be achieved, such as finishing primary school, finishing secondary, and getting a job. All these milestones will be filled with some grief over what could have been as opposed to what is. This type of grief can be viewed as chronic sorrow whereby there is a pervasive feeling of sadness which can intensify at different life

milestones and is persistent throughout life (Liedstrom et al., 2008; Lindgren et al., 1992; Masterson, 2010; Northington, 2000; Olshansky, 1962).

## Faith

What is unique is the way in which Mandy processes the grief attached to mothering Declan LwFED. It is her faith in Christ to help accept the reality, process the pain and adjust to an environment of what is, through prayer and recounting scripture regardless of whether she harbours the occasional doubt. This resonates with Callahan's notion of integrated experience (Callahan, 2005), however LwFED is alive and active requiring many more reframing of new experiences related to the original and integration of that experience, oscillating Wardens and Callahan's tasks and Strobe's stressors.

Faith enables Mandy to rise and advocate for herself as well as her child, positively affecting her QoL. Mandy's faith in Christ adds a level of protection, it enables her not to settle with the way things are, but accept them, meaning she cannot change what transpired within her womb, but she can journey through life with the assistance of her personal relationship with Jesus and reading the Bible. O'Dea (2018) agrees with Mandy, having a personal belief system of faith in God as being one of the major reasons leading to her resilience and why she can live in a world which is unsavoury towards her LwFED. Acceptance does not mean what is happened/happening is fair, right or just, rather, it is a vehicle in which we can learn to heal and engage with the world as it is. There is limited relevant literature written regarding Christian faith and grieving (Borland Jr, 2017; Hall, 2018; Slater, 2014).

## Limitations

General limitations of this study are that this research highlights one case study of a participant's lived experience being a non-FED mother mothering a male child LwFED, as of such there is no generalisability being able to be made. Rather this research extrapolates and widens the scant literature available on the lived experience of mothers with children with disabilities. There is no known literature that approaches the lived experience of mothering a child living with FED. Pileggi (2017) and Pileggi et al. (2018) write specifically about mother-daughter relationships whereby the daughters identify as living with FD. There is no identified literature found specifically focusing on a non-FED mother mothering her male child LwFED. This study is ground-breaking research in relation to the FD/FED communities.

## Conclusion

Ultimately, grief and chronic sorrow impacts every facet of Mandy's QoL. Mandy provided her rich expert experience of what it is to mother a child LwFED. Within the two lengthy interviews given three years apart, we see the hum of the overarching themes of vigilance, isolation, facing society as mother, grief and faith. Each one of these ascribed themes constantly trudging alongside her mothering. This paper pro-

vides a voice to one mother with a child LwFED. It does not assume to draw generalisations as this is an IPA case study although there are resonances with how other's lived experiences of mothering may be impacted by grief and chronic sorrow which in turn impact QoL. In this one unique case, we discuss the complexity and interweaving of challenges and chronic grief that challenge a mother living with a child LwFED. We do not suggest answers, rather we highlight the importance of looking deeply into the life of individuals in difficult circumstances whose QoL is poor due to the conflicting demands of self-expectation, the challenges of societal behaviours, the shortcomings of professionals and institutions, and the over-riding sense of isolation. We suggest further research is required, focusing on advocacy and professional help for families, and educating society to change the culture of stares and avoidance into one of acceptance. There are organisations such as Karibu Anawim in Australia that seek, resource and nurtures individuals, their families, and provide community education. This paper is intended to open dialogue and offers an insightful and telling narrative of a non-FD mother, mothering a child LwFED and the impact this has on the QoL of her, her son, her family, and others.

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## References

- Ahmadzadeh, Z., Kamran, F., Kasbi, F., Nourouzi, R., & Makhlesin, M. (2018). Quality of life and its related factors in Iranian mothers' with a mentally retarded child [Research]. *Koomesh journal*, 20(4), 719–724. <http://koomeshjournal.semums.ac.ir/article-1-3669-en.html>.
- Alkan, F., Sertcelik, T., Sapmaz, Y., Eser, S., E., & Coskun, S. (2017). Responses of mothers of children with CHD: Quality of life, anxiety and depression, parental attitudes, family functionality. *Cardiology in the Young*, 27(9), 1748–1754. <https://doi.org/10.1017/S1047951117001184>.
- Askins, M. A., & Buck, E. (2014). Preparing children for a parent's cancer surgery. *Psycho-Oncology*, 23, 65. <https://doi.org/10.1002/pon.3478>. <https://onlinelibrary.wiley.com/doi/epdf/>.
- Bandelli, G., De Santi, M., De Felice, F., & Brandi, G. (2021). Physical activity interventions to improve the quality of life of older adults living in residential care facilities: A systematic review. *Geriatric Nursing*, 42(4), 806–815. <https://doi.org/10.1016/j.gerinurse.2021.04.011>.

- Becker-Stoll, F., Delius, A., & Scheitenberger, S. (2001). Adolescents' nonverbal emotional expressions during negotiation of a disagreement with their mothers: An attachment approach. *International Journal of Behavioral Development*, 25(4), 344–353. <https://doi.org/10.1080/01650250143000102>.
- Becker-Stoll, F., Fremmer-Bombik, E., Wartner, U., Zimmermann, P., & Grossmann, K. E. (2008). Is attachment at ages 1, 6 and 16 related to autonomy and relatedness behavior of adolescents in interaction towards their mothers? *International Journal of Behavioral Development*, 32(5), 372–380. <https://doi.org/10.1177/0165025408093654>.
- Berger, Z. E., & Dalton, L. J. (2011). Coping with a cleft II: Factors associated with psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *The Cleft Palate-Craniofacial Journal*, 48(1), 82–90. <https://doi.org/10.1597/08-094>.
- Borland, K. W. Jr. (2017). Designing and implementing the humane crisis organizing framework for resilience with grief, stress, and faith stakeholders. *Journal of Contingencies and Crisis Management*, 25(3), 199–193. <https://doi.org/10.1111/1468-5973.12184n>.
- Bowers, B. (2008). Providing effective support for patients facing disfiguring surgery [Review]. *British Journal of Nursing*, 17(2), 94–98. <https://doi.org/10.12968/bjon.2008.17.2.28135>.
- Burke, M. L., Eakes, G. G., & Hainsworth, M. A. (1999). Milestones of chronic sorrow: Perspectives of chronically ill and bereaved persons and family caregivers. *Journal of family nursing*, 5(4), 374–387. <https://doi.org/10.1177/107484079900500402>.
- Butner, J., Story, N., Berg, C. A., & Weibe, D. J. (2011). Fractals, vigilance and adolescent diabetes management: A case when regulation may be difficult to measure with current medical standards. *Multivariate Behavioral Research*, 46(1), 33–57. <https://doi.org/10.1080/00273171.2011.543029>.
- Callahan, C. (2005). Facial disfigurement and sense of self in head and neck cancer. *Social Work in Health Care*, 40(2), 73–87. [https://doi.org/10.1300/J010v40n02\\_05](https://doi.org/10.1300/J010v40n02_05).
- Carlo, G., Mestre, M. V., Samper, P., Tur, A., & Armenta, B. E. (2010). Feelings or cognitions? Moral cognitions and emotions as longitudinal predictors of prosocial and aggressive behaviors. *Personality and Individual Differences*, 48(8), 872–877. <https://doi.org/10.1016/j.paid.2010.02.010>.
- Carr, A. J., Gibson, B., & Robinson, P. G. (2001). Is quality of life determined by expectations or experience? *British Medical Journal*, 322, 1240–1243. <https://doi.org/10.1136/bmj.322.7296.1240>.
- Cella, D. F. (1994). Quality of life: Concepts and definition. *Journal of Pain and Symptom Management*, 9(3), 186–192. [https://doi.org/10.1016/0885-3924\(94\)90129-5](https://doi.org/10.1016/0885-3924(94)90129-5).
- Eatough, V., & Smith, J. (2006). I was like a wild wild person': Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology*, 97, 483–498. <https://doi.org/10.1348/000712606X97831>.
- Eisenberg, N., Cumberland, A., & Spinrad, T. L. (1998). Parental socialization of emotion. *Psychological inquiry*, 9(4), 241–273. [https://doi.org/10.1207/s15327965pli0904\\_1](https://doi.org/10.1207/s15327965pli0904_1).
- Eiser, C., Eiser, J. R., & Stride, C. B. (2005). Quality of life in children newly diagnosed with cancer and their mothers. *Health and Quality of Life Outcomes*, 3(1), 29. <https://doi.org/10.1186/1477-7525-3-29>.
- Farquhar, M. (1995). Elderly people's definitions of quality of life. *Social Science and Medicine*, 41(10), 1439–1446. [https://doi.org/10.1016/0277-9536\(95\)00117-p](https://doi.org/10.1016/0277-9536(95)00117-p).
- Field, N. P., & Horowitz, M. J. (1998). Applying an empty-chair monologue paradigm to examine unresolved grief. *Psychiatry*, 61(4), 279–287. <https://doi.org/10.1080/00332747.1998.11024840>.
- Flanagan, J. C. (1978). A research approach to improving our quality of life. *American Psychologist*, 33(2), 138–147. <https://doi.org/10.1037/0003-066X.33.2.138>.
- Freud, S. (1957). Mourning and melancholia. In J. Strachey (Ed.), *The standard edition of the complete psychological works of Sigmund Freud* (14 vol., pp. 237–260). Basic Books.
- Gabriel, Z., & Bowling, A. (2004). Quality of life from the perspectives of older people. *Ageing and Society*, 24(5), 675–691. <https://doi.org/10.1017/S0144686X03001582>.
- Galletta, A., & Cross, W. E. (2013). *Mastering the semi-structured interview and beyond: From research design to analysis and publication*. NYU Press.
- Gilbert, R. B. (1998). Living beyond your losses: The healing journey through grief. *Journal of Palliative Care*, 14(2), 59–60. <https://doi.org/10.1177/082585979801400216>.
- Glinac, A., Matović, L., Delalić, A., & i., M. (2017). Quality of life in mothers of children with cerebral palsy. *Acta clinica Croatica*, 56(2), 299–307. <https://doi.org/10.20471/acc.2017.56.02.14>.
- Habersaat, S., Monnier, M., Peter, C., Bolomey, L., Borghini, A., Despars, J., Pierrehumbert, B., Müller-Nix, C., Ansermet, F., & Hohlfeld, J. (2013a). Early Mother-Child Interaction and later quality of attachment in infants with an Orofacial Cleft compared to Infants without Cleft. *The Cleft Palate - Craniofacial Journal*, 50(6), 704–712. <https://doi.org/10.1597/12-094.1>.

- Habersaat, S., Monnier, M., Peter, C., Bolomey, L., Borghini, A., Despars, J., Pierrehumbert, B., Müller-Nix, C., Ansermet, F., & Hohlfeld, J. (2013b). Early mother-child interaction and later quality of attachment in infants with an orofacial cleft compared to infants without cleft. *The Cleft Palate - Craniofacial Journal*, 50(6), 704–712. <https://doi.org/10.1597/12-094.1>.
- Hainsworth, M. A., Eakes, G. G., & Burke, M. L. (1994). Coping with chronic sorrow. *Issues in Mental Health Nursing*, 15(1), 59–66. <https://doi.org/10.3109/01612849409074934>.
- Hall, M. T. S. (2018). *The effects of Christianity on adult resiliency when overcoming grief*. [Master of Science, ACU]. Digital Commons.
- Harris, D. L., & Winokuer, H. R. (2019). Living losses: Nonfinite loss, ambiguous loss, and chronic sorrow. In D. L. Harris & H. R. Winokuer (Eds.), *Principles and practice of grief counselling* (pp. 121–137). Springer. <https://doi.org/10.1891/9780826173331.0008>.
- Hearst, D. (2007). Can't they like me as I am? Psychological interventions for children and young people with congenital visible disfigurement. *Developmental Neurorehabilitation*, 10(2), 105–112. <https://doi.org/10.1080/17518420701263146>.
- Hobdell, E. (2004). Chronic sorrow and depression in parents of children with neural tube defects. *Journal of Neuroscience Nursing*, 36(2), 82–88. <https://doi.org/10.1097/01376517-200404000-00005>.
- In-Albon, T., Kossowsky, J., & Schneider, S. (2010). Vigilance and avoidance of threat in the eye movements of children with separation anxiety disorder. *Journal of abnormal child psychology*, 38(2), 225–235. <https://doi.org/10.1007/s10802-009-9359-4>.
- Jovanova, N. C., & Radojichikj, D. D. (2013). Parents of children with developmental disabilities: Stress and support. *The Journal of Special Education and Rehabilitation*, 14(1/2), 7–19. [https://oadd.org/wp-content/uploads/2011/01/41010\\_JoDD\\_17-2\\_21-34\\_Ritzema\\_Slaveczeck.pdf](https://oadd.org/wp-content/uploads/2011/01/41010_JoDD_17-2_21-34_Ritzema_Slaveczeck.pdf).
- Karande, S., & Kulkarni, S. (2009). Quality of life of parents of children with newly diagnosed specific learning disability. *Journal of Postgraduate Medicine*, 55(2), 97–103. <https://doi.org/10.4103/0022-3859.52839>.
- Leung, L., & Lee, P. S. N. (2005). Multiple determinants of life quality: the roles of Internet activities, use of new media, social support, and leisure activities. *Telematics and Informatics*, 22(2005), 161–180. <https://doi.org/10.1016/j.tele.2004.04.003>.
- Liedstrom, E., Isaksson, A.-K., & Ahlstrom, G. (2008). Chronic sorrow in next of kin of patients with multiple sclerosis. *Journal of Neuroscience Nursing*, 40(5), 304. <https://link.gale.com/apps/doc/A186991740/AONE?u=monash&sid=bookmark-AONE&xid=31262519>.
- Lindgren, C., Burke, L., Hainsworth, M. L., M., A.&, & Eakes, G., G (1992). Chronic sorrow: A lifespan concept. *Scholarly Inquiry for Nursing Practice*, 6(1), 27. <https://pubmed.ncbi.nlm.nih.gov/1585085/>.
- Love, A. W. (2007). Progress in understanding grief, complicated grief, and caring for the bereaved. *Contemporary Nurse*, 27(1), 73–83. <https://doi.org/10.5555/conu.2007.27.1.73>.
- Mandalayala, T. M., Parker, K. J., & Maestripieri, D. (2014). Early experience affects the strength of vigilance for threat in Rhesus monkey infants. *Psychological Science*, 25(10), 18–93. <https://doi.org/10.1177/0956797614544175>. -1902.
- Marinelli, R. D., & Plummer, O. K. (1999). Healthy aging: Beyond exercise. *Activities Adaptation & Aging*, 23(4), 1–11. [https://doi.org/10.1300/J016v23n04\\_01](https://doi.org/10.1300/J016v23n04_01).
- Masterson, M. K. (2010). *Chronic sorrow in mothers of adult children with cerebral palsy: An exploratory study* [Doctoral Dissertation, Kansas State University]. ProQuest Dissertations Publishing.
- Meakins, L., Ray, L., Hegadoren, K., Rogers, L. G., & Rempel, G. R. (2015). Parental vigilance in caring for their children with hypoplastic Left Heart Syndrome. *Pediatric Nursing*, 41(1), 31–41. <https://go.gale.com/ps/i.do?p=AONE&u=monash&id=GALE%7CA403916301&v=2.1&it=r&aty=sso%3A+shibboleth>.
- Medhurst, A. (2002). *Vigilant coping: Understanding the behaviour of three mothers in the neonatal unit* [Doctoral Dissertation, Monash University].
- Miskam, H. M., Juhari, R., & Yaacob, S. N. (2017). Stress and quality of life among mothers with thalassaemic children in Malaysia. *International Journal for Studies on Children, Women, Elderly and Disabled*, 1, 176–183. <https://www.semantic-scholar.org/paper/ Stress-and-quality-of-life-among-mothers-with-in-Miskam-Juhari/c19dfe52fb5a2d8260eed024a7ecb16f233c6fcc>.
- Navab, M., Dehghani, A., & Salehi, M. (2018). The effectiveness of compassion-focused group therapy on quality of life and change in the goals and priorities of mothers of children with attention deficit / hyperactivity disorder. *Quarterly Journal of Child Mental Health*, 5(1), 127–137. <http://childmentalhealth.ir/article-1-285-en.html>.

- Neimeyer, R. A. (2000). Grief therapy and research as essential tensions: Prescriptions for a progressive partnership. *Death Studies*, 24(7), 603–610. <https://doi.org/10.1080/07481180050132802>.
- Neimeyer, R. A. (2001). Reauthoring life narratives: Grief therapy as meaning reconstruction. *The Israel Journal of Psychiatry and Related Sciences*, 38(3/4), 171–183. <https://pubmed.ncbi.nlm.nih.gov/11725416/>.
- Neimeyer, R. A., Burke, L. A., Mackay, M. M., & van Stringer, D., J. G (2010). Grief therapy and the reconstruction of meaning: From principles to practice. *Journal of Contemporary Psychotherapy*, 40(2), 73–83. <https://doi.org/10.1007/s10879-009-9135-3>.
- Newell, R., & Marks, I. (2000). Phobic nature of social difficulty in facially disfigured people. *British Journal of Psychiatry*, 176, 177–181. <https://doi.org/10.1192/bjp.176.2.177>.
- Northington, L. (2000). Chronic sorrow in caregivers of school age children with sickle cell disease: A grounded theory approach. *Issues in Comprehensive Pediatric Nursing*, 23(3), 141–154. <https://doi.org/10.1080/01460860050174693>.
- O'Dea, Z. (2018). The Ayes have it!. *The Qualitative Report*, 23(10), 2313–2336. <https://nsuworks.nova.edu/tqr/vol23/iss10/6>.
- Oleson, M. (1990). Subjectively perceived quality of life. *Image - The Journal of Nursing Scholarship*, 22(3), 187–190. <https://doi.org/10.1111/j.1547-5069.1990.tb00205.x>.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43(4), 190–193. <https://doi.org/10.1177/104438946204300404>.
- Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair*, 19(3), 232–237. <https://doi.org/10.1177/1545968305278857>.
- Person, B., Addiss, D., Bartholomew, L. K., Meijer, C., Pou, V., Gonzalez, G., & Borne, B. V. (2008). Can it be that god does not remember me?: A qualitative study on the psychological distress, suffering, and coping of Dominican women with chronic filarial lymphedema and elephantiasis of the leg. *Health Care for Women International*, 29(4), 349–365. <https://doi.org/10.1080/07399330701876406>.
- Pietkiewicz, I., & Smith, J. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Czasopismo Psychologiczne - Psychological Journal*, 20(1), 7–14. <https://doi.org/10.14691/CPPJ.20.1.7>.
- Pileggi, V. (2017). *A summary of research on the mother-daughter relationship and the influence of facial difference*. About Face. <https://www.aboutface.ca/wp-content/uploads/2017/01/AF-Research-Summary.pdf>.
- Pileggi, V., Rice, C., Stead, S., & Atkinson, K. (2018). Resistance in Relationship: Mothers' Armoring of Their Adolescent Daughters Living with Facial Difference. In S. Pashang, N. Khanlou, & J. Clarke (Eds.), *Today's Youth and Mental Health: Hope, Power, and Resilience* (pp. 247–263). Springer International Publishing. [https://doi.org/10.1007/978-3-319-64838-5\\_14](https://doi.org/10.1007/978-3-319-64838-5_14).
- Pisula, E., & Porebowicz-Dörsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of polish children with high functioning autism or Asperger syndrome. *PLoS One*, 12(10), <https://doi.org/10.1371/journal.pone.0186536>.
- Rajasinghe, D. (2020). Interpretative phenomenological analysis (IPA) as a coaching research methodology. *Coaching: An International Journal of Theory Research and Practice*, 13(2), 176–190. <https://doi.org/10.1080/17521882.2019.1694554>.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20–23. <https://thepsychologist.bps.org.uk/volume-18/edition-1/exploring-lived-experience>.
- Rodham, K., Fox, F., & Doran, D. (2015). Exploring analytical trustworthiness and the process of reaching consensus in interpretative phenomenological analysis: Lost in transcription. *International Journal of Social Research Methodology*, 18(1), 59–71. <https://doi.org/10.1080/13645579.2013.852368>.
- Rumsey, N., & Harcourt, D. (2007). Visible difference amongst children and adolescents: Issues and interventions. *Developmental neurorehabilitation*, 10(2), 113–123. <https://doi.org/10.1080/13638490701217396>.
- Scheller, K., Ulrich, J., Scheller, C., & Watzke, S. (2020). Psychosocial and socioeconomically aspects of mothers having a child with cleft lip and/or palate (CL/P): A pilot-study during the first year of life. *Journal of Clinical and Experimental Dentistry*, 12(9), 864–869. <https://doi.org/10.4317/jced.56288>.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information IOS Press*, 22, 63–75.
- Slater, J. P. (2014). Faith unravels: A rabbi's struggle with grief and God. *Conservative Judaism*, 64(4), <https://doi.org/10.1353/coj.2013.0034>.



- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11*(2), 261–271. <https://doi.org/10.1080/08870449608400256>.
- Smith, J. A. (2011). View for the top. 'We could be diving for pearls': The value of the gem in experiential qualitative psychology. *The British Psychological Society, 12*, 6–13. <https://doi.org/10.53841/bpsqmp.2011.1.12.6>.
- Smith, J. A. (2017). Interpretative phenomenological analysis: Getting at lived experience. *The Journal of Positive Psychology, 12*(3), 303–304. <https://doi.org/10.1080/17439760.2016.1262622>.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage Publications.
- Southcott, J., & Nethsinghe, R. (2018). Resilient Senior Russian-Australian Voices: "We live to sing and sing to live. *Applied Research in Quality of Life, 14*(1), 39–58. <https://doi.org/10.1007/s11482-017-9580-1>.
- Stacey, J., & Edwards, A. (2013). Resisting loneliness' dark pit: A narrative therapy approach. *Tizard Learning Disability Review, 18*(1), 20–27. <https://doi.org/10.1108/13595471311295978>.
- Strobe, M., & Schut, H. (2005). To continue or relinquish bonds: A review of consequences for the bereaved. *Death studies, 29*(6), 477–494. <https://doi.org/10.1080/07481180590962659>.
- Strobe, M., & Schut, H. (2010). The dual model of coping with bereavement: A decade on. *Omega, 61*(4), 273–289. <https://doi.org/10.2190/OM.61.4.b>.
- Sullivan-Bolyai, S., Deatrck, J. A., Gruppuso, P., Tamborlane, W., & Grey, W. (2002). Constant vigilance: Mothers' work parenting young children with type 1 diabetes. *Journal of Pediatric Nursing, 18*(1), 21–29. <https://doi.org/10.1053/jpdn.2003.4>.
- The, L. (2012). Living with grief. *The Lancet, 379*(9816), 589. [https://doi.org/10.1016/S0140-6736\(12\)60248-7](https://doi.org/10.1016/S0140-6736(12)60248-7). <https://doi.org/http://dx.doi>
- Thwala, S. K., Ntinda, K., & Hlanze, B. (2015). Lived experiences of parents of children with disabilities in Swaziland. *Journal of Education and Training Studies, 3*(4), 206–215. <https://files.eric.ed.gov/fulltext/EJ1067249.pdf>.
- Vagle, D. (2009). Validity as intended: 'bursting forth toward' bridling in phenomenological research. *International Journal of Qualitative Studies in Education, 22*(5), 585–605. <https://doi.org/10.1080/09518390903048784>.
- Valiente, C., Eisenberg, N., Shepard, S. A., Fabes, R. A., Cumberland, A. J., Losoya, S. H., & Spinrad, T. L. (2004). The relations of mothers' negative expressivity to children's experience and expression of negative emotion. *Journal of Applied Developmental Psychology, 25*(2), 215–235. <https://doi.org/10.1016/j.appdev.2004.02.006>.
- van Leeuwen, K. M., van Loon, M. S., van Nes, F. A., Bosmans, J. E., de Vet, H. C. W., Ket, J. C. F., et al. (2019). What does quality of life mean to older adults? A thematic synthesis. *Plos One, 14*(3), e0213263. <https://doi.org/10.1371/journal.pone.0213263>.
- Veenhoven, R. (2000). The four qualities of life: ordering concepts and measures of the good life. *Journal of Happiness Studies, 1*(1–39). [https://doi.org/10.1007/978-94-007-5702-8\\_11](https://doi.org/10.1007/978-94-007-5702-8_11).
- Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., & Holland, F. (2014). The accordion and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology. *The Quantitative Report, 19*(47), 1–15. <https://doi.org/10.46743/2160-3715/2014.1216>.
- Wang, H., Hu, X., & Han, Z. R. (2020). Parental stress, involvement, and family quality of life in mothers and fathers of children with autism spectrum disorder in mainland China: A dyadic analysis. *Research in Developmental Disabilities, 107*, 103791. <https://doi.org/10.1016/j.ridd.2020.103791>.
- Watkinson, S., & Williamson, S. N. (2023). Introduction. In S. Watkinson, & S. N. Williamson (Eds.), *Ocular disease and sight loss: Meeting psychosocial needs* (pp. 1–14). Springer. [https://doi.org/10.1007/978-3-031-21728-9\\_1](https://doi.org/10.1007/978-3-031-21728-9_1).
- Weigl, V., Rudolph, M., Eysholdt, U., & Rosanowski, F. (2005). Anxiety, depression, and quality of life in mothers of children with cleft lip/palate. *Folia Phoniatrica et Logopaedica, 57*(1), 20–27. <https://doi.org/10.1159/000081958>.
- Whitehead, A. L. (2017). Neighborhoods, Family Functioning, and mothers' Mental Health for families with a child with an Autism Spectrum Disorder. *Applied Research in Quality of Life, 12*, 633–651. <https://doi.org/10.1007/s11482-016-9480-9>.
- Williamson, S. N., Seewoodhary, R., & Watkinson, S. (2023). The psychosocial impact of ocular disease on body image. In S. Watkinson, & S. N. Williamson (Eds.), *Ocular disease and sight loss: Meeting psychosocial needs* (pp. 35–56). Springer. [https://doi.org/10.1007/978-3-031-21728-9\\_3](https://doi.org/10.1007/978-3-031-21728-9_3).

- Wissing, M. P., Schutte, L., Liversage, C., Entwistle, B., Gericke, M., & Keyes, C. (2021). Important goals, meanings, and Relationships in Flourishing and Languishing States: Towards Patters of Well-being. *Applied Research in Quality of Life*, *16*, 573–609. <https://doi.org/10.1007/s11482-019-09771-8>.
- Witney, M. N. (2012). Using metaphor and narrative ideas in trauma and family therapy. *Hervormde Teologiese Studies*, *68*(2), 1–5. <https://journals.co.za/doi/abs/10.10520/EJC125606>.
- Worden, J. (2014). Theoretical perspectives on loss and grief. In J. Stillion, & T. Attig (Eds.), *Death, dying, and bereavement: Contemporary perspectives, institutions, and practices* (pp. 91–103). Springer Publishing Company.
- Worden, J. W. (2018). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (5th ed.). Springer Publishing Company.
- World Health Organization (1997). WHOQOL: measuring quality of life. <https://apps.who.int/iris/handle/10665/63482>.
- Yamada, A., Kato, M., Suzuki, M., Suzuki, M., Watanabe, N., Akechi, T., & Furukawa, T. A. (2012). Quality of life of parents raising children with pervasive developmental disorders. *Bmc Psychiatry*, *12*, 119. <https://doi.org/10.1111/j.1601-6343.2007.00383.x>.
- Zeleny, R. O. (Ed.). (1992). *The world book dictionary volume two: L-Z* (24 vol.). World Book.

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