

# Typologies of adaptation: parenting children with primary lymphoedema

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## Key words

Chronic illness, qualitative methods, parenting, children

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**P** rimary lymphoedema results from congenital lymphatic damage that requires lifelong management of symptoms (e.g. swelling, pain, heaviness).

Approximately 1.2 in 100,000 people under the age of 20 years live with lymphoedema (Smeltzer et al, 1985; Rockson and Rivera, 2008). Researchers have studied the impact of children's lymphoedema on parents regarding parental support (Todd, 2019; Todd et al, 2002) and nurturing child self-efficacy and self-management (Moffatt et al, 2019). Moffatt and Murray (2010) identified possible variations in parental approaches to maintaining normalcy for their children with lymphoedema.

This study, guided by family stress theory, explored possible variations in approaches to parenting among parents of children with lymphoedema. Study outcomes have implications for the development of interventions by healthcare providers, social workers, child life specialists, and family life

## Abstract

Mothers of children with primary lymphoedema may be vulnerable to experiencing feelings of helplessness, frustration, grief, and excess stress that can lead to negative moods and child behavioural problems. This study aimed to gain an in-depth understanding of the lived experiences of these mothers. Data were collected using semi-structured interviews with mothers (n=26) of children with lymphoedema from seven countries. Qualitative data were coded using a codebook. Codes were then subject to discussion by the research team who identified a pattern of parenting approaches. Approaches to parenting fell along a continuum from unguarded, relaxed, and open to overprotective, anxious, and worried. These resulting typologies of these approaches provide insight into the unique challenges these mothers face that may be used by healthcare providers, social workers, child life specialists, and family life educators to ensure that mothers, fathers, and other caregivers are receiving the support they need.

educators to support parents in adapting to parenting a child with this chronic condition.

## Literature review

Childhood chronic conditions impact the entire family system (Barlow and Ellard, 2006; Coffey, 2006; Lewandowski et al, 2010). For parents raising children with chronic conditions, this can provoke increased parental stress (Cousino and Hazen, 2013). Parents' experience of illness-related stress due to feeling inadequately equipped is correlated with their perceptions of their children's vulnerability and their desire to protect their children (Bourdeau et al, 2007; Mullins et al, 2007). To mitigate increased stress, parents of children with chronic conditions may modify their parenting approaches.

## Parenting children with chronic conditions

Maccoby and Martin's (1983) general

model of parenting styles ranges from excess permissiveness to strict discipline. Similarly, researchers have theorised that parents of children with chronic conditions employ parenting styles ranging from medical neglect to overprotectiveness. Medical neglect occurs when parents fail to engage in behaviours required for the care and safety of their chronically ill child. Limited research on parenting styles among parents of chronically ill children suggests that these parents are more inclined than parents of healthy children to engage in neglectful behaviours (Pinquart, 2013). However, concepts of safety can be ambiguous for children with chronic conditions. Overall, parental neglect of children with a chronic illness is understudied (Coller and Komatz, 2017).

Overprotection among parents of chronically ill children may stem from parental perceptions of the child's vulnerability (Mullins et al, 2007) and/or anxiety while learning how to care

for their child (Sallfors and Hallberg, 2003). Overprotection can manifest as hypervigilance (Sallfors and Hallberg, 2003), limited parent-child separation, and high levels of parental control (Bourdeau et al, 2007). These parents may simultaneously encourage dependence while maintaining high levels of control and discouraging independence (Bourdeau et al, 2007).

Parental overprotectiveness of children with chronic conditions may also be context dependent. Younger children are less likely to be attuned to their parents' overprotective behaviour than older children. Thus, overprotective parenting behaviours may have a greater effect on adolescents in the form of anxiety or uncertainty (Mullins et al, 2007). Less educated parents are more likely to view their children as vulnerable and their children are more likely to have school absences (Anthony et al, 2003). This could be due to a lack of education about the child's illness or a lower parental estimation of the child's abilities.

### Realities of caring for children with lymphoedema

Primary lymphoedema, which is congenital with most individuals developing the condition before age 35, is rare and commonly misdiagnosed (Brouillard et al, 2021; Pateva et al, 2022). Many children experience years of tests, examinations and inappropriate or ineffective treatments (Moffatt and Murray, 2010; Harding, 2012; Todd, 2019).

Once diagnosed, lymphoedema must be treated with compression garments to manage lymphatic swelling (SMaclellan and Greene, 2014; Pateva et al, 2022). This is labour-intensive, requires lifelong vigilance and often poses a significant financial burden.

Children grow quickly and garments may become damaged or wear out their elasticity through regular play (Feldman, 2004). Garments are rarely covered by health insurance providers (Weiss, 2022). Coverage by insurance depends on the country where the family lives. In places where garments are covered either fully or partially by insurance, families incur less of a financial burden annually than those for whom garments are not covered. As garments wear out and children grow, replacing garments more often is more necessary than it is for adults.

Additional management includes

infection prevention, exercise, obesity prevention, and manual lymph drainage (MLD). Lymphoedema increases risk of cellulitis in the affected regions and cellulitis worsens lymphoedema symptoms. Avoidance of disruptions to the skin barrier mitigates this risk, including routine sunblock and bug spray application, as well as clothing covering the affected skin when compression is not being used (Maclellan and Greene, 2014). Exercise encourages the natural flow of lymphatic fluid throughout the body; healthy weight management prevents more severe symptoms associated with obesity (Feldman, 2004; Mehrara and Greene, 2014; Todd, 2019). MLD is a massage technique that drains lymphatic fluid outside the affected region, (Maclellan and Greene, 2014). MLD must be performed regularly either by the patient, caregiver or a certified provider depending on the age and ability of the child (Feldman, 2004; Todd, 2019).

Children with lymphoedema may also experience psychosocial stressors around body image, self-confidence, and self-esteem (Harding, 2012; Todd, 2019) that may impact relationships with peers who are naturally curious but may also bully or isolate the child with lymphoedema (Harding, 2012; Hanson et al, 2018). Lymphoedema can also limit mobility and lead to asymmetric body size making seemingly simple activities challenging, such as finding clothing and footwear that fit and are functional (Todd et al, 2002; Harding, 2012;). Hanson et al (2018) found that children with lymphoedema felt restricted in their ability to engage in physical activities with their peers, such as sports, which reinforced their sense of difference and abnormality.

### Parenting children with primary lymphoedema

A small body of research exploring the lived experiences of parenting a child with lymphoedema has shown that managing lymphoedema can create challenges for parents and parent-child relationships. Specifically, Todd (2019) found that parents of children with lymphoedema are likely to experience depression, anxiety, and worry. Hanson et al (2018) found children's frustration with parental monitoring was a source of parent-child conflict.

Moffatt and Murray (2010) conducted one of the only studies exploring the

experiences of parents and the readiness of their children to self-manage their lymphoedema. Data was collected through parent-child case studies; children and parents were interviewed either separately or together. They found that parents experienced challenges with lymphoedema diagnosis and treatment as well as frustrations with healthcare systems. Moffatt and Murray (2010) also reported a range of parenting approaches characterised by tension between allowing certain freedoms (e.g. walking on the sand at the beach, removing compression garments/wraps) and limiting those freedoms to keep children safe (e.g. keeping children inside to avoid skinned knees, bug bites and sunburn). They concluded that parents navigated that tension with attempts to normalise life for their child and the family.

### Family Adjustment and Adaptation Response model

The Family Adjustment and Adaptation Response (FAAR) model guided our exploration of the unique experiences of parents of children with lymphoedema (Patterson, 1988). The FAAR model draws attention to how families respond to stress through creating new perspectives, approaches, and behaviors to adapt or adjust in the face of stressors.

According to the FAAR model, families will work toward maintaining or regaining a sense of homeostasis or normalcy when faced with stressors, which requires the development of new ways of coping (e.g., reducing the stressor, adding additional supports, changing the meaning associated with the stressor; Patterson and Garwick, 1994). The FAAR model has been applied to families coping with chronic conditions (Berge et al 2006; Baiocco et al 2017) including lymphoedema (Radina and Armer, 2001; 2004).

### Aims

This study aimed to extend beyond Moffatt and Murray's (2010) work and offer an in-depth exploration of potential variations in approaches to parenting children with lymphoedema. Moffatt and Murray's (2010) study included children with either primary or secondary lymphoedema. We aimed to focus narrowly on the unique experiences of parents raising children with primary lymphoedema. Specifically, we

**Table 1. Interview questions reflecting the Family Adjustment and Adaptation Response (FAAR) model.**

<b>Demands</b> Child's primary lymphoedema diagnosis	<ul style="list-style-type: none"> <li>• What unique challenges have you experienced as a parent of a child with lymphoedema?</li> <li>• How has lymphoedema affected your family financially, if at all?</li> </ul>
<b>Capabilities</b> Social support, coping behaviour, approaches to parenting	<ul style="list-style-type: none"> <li>• What solutions or strategies, if any, have you found that help to address LE-related challenges?</li> <li>• What advice would you give to another parent who experienced similar LE-related challenges?</li> <li>• What advice do you wish another parent had given you that might have helped you deal with these challenges?</li> <li>• Describe for me what you have done to advocate for your child in healthcare, school-based, and other settings. What motivated you to advocate for your child in this way?</li> <li>• How have you explained what lymphoedema is to your child and your other children, if any, who do not have lymphoedema?</li> <li>• Who has provided you personally with support as a parent of a child with lymphoedema?</li> <li>• What adjustments has your family had to make, if any, in order to cope with lymphoedema?</li> </ul>
<b>Meanings</b> Situational, family identity, world view	<ul style="list-style-type: none"> <li>• What conversations do you have as a family (household and extended) about lymphoedema?</li> <li>• How do you think your family feels about lymphoedema? What meaning does it have for you?</li> <li>• What do you feel helps to keep your family strong in the face of challenges; both related to lymphoedema and other family challenges?</li> </ul>

explore how parents negotiate the tension between permissiveness and protectiveness within the context of the parent's desire, or lack thereof, for normalcy. This study responds to Kazak's (1989) call for research on identifying unique stressors related to specific chronic illnesses and the variables influencing families' ability to adapt to stress brought on by a chronic illness.

## Methods

We used a qualitative study design with the main objectives being:

1. To gain an in-depth understanding of mothers' lived experiences of caring for a child with primary lymphoedema.
2. To identify the unique challenges that these mothers face in caring for their children.

### Participant recruitment and sampling

Participants were biological mothers of children who were under the age of 18 and diagnosed with primary lymphoedema. Participants were recruited from The National Lymphedema Network and The Lymphedema Treatment Act Advocacy Group through newsletters, listservs, and web-based interfaces. Potential participants contacted the principal investigator to be screened for study eligibility prior to data collection.

### Participants

Participants (n=26) were women, English-speaking, predominantly white (n=25), college-educated (n=18), and ranged in age from 25 to 64. Participants

primarily lived in the US (73%) with a smaller proportion living in the UK, New Zealand, Australia, South Africa, Ireland and Canada. Of their children (male [n=14], female [n=15]), two-thirds were diagnosed with lymphoedema before the age of two. All the children were diagnosed before 15 years of age. Two-thirds of the children were affected by lymphoedema in their legs and one-third were affected in their genitals, feet, hands, face, chest, and/or entire body.

### Data collection methods

The study protocol was approved by Miami University's Institutional Review Board (Protocol ID: 001182r). Participants first completed an online questionnaire with demographic data and lymphoedema specific information (e.g., age of onset, location of lymphoedema, and symptoms). Semi-structured interviews were then conducted via video or audio calls and were transcribed by trained undergraduate research assistants. All subjects gave oral informed consent and electronic copies of consent information were provided. Interview questions were open-ended and reflected the FAAR model (Table 1).

### Data analysis

A research team led by MER conducted iterative data analysis over a three-year period. First, demographic information and categorisable data from questionnaire and interview transcript data were summarised into case reports for each mother-child pair in Excel. The research

team developed a codebook in which team members first familiarised themselves with the data by reading each transcript. They then discussed potentially relevant codes and subsequently created a codebook. Examples of codes included "caring for garments," "depriving a child of feeling normal," "finding clothing," "socialising with peers," and "parent worries when the child was supervised by another adult." Two team members independently read each transcript and applied the codebook. The team reviewed the coding and made adjustment to ensure consistency.

Throughout the review process several related codes coalesced around approaches to parenting, which became the focus of the analysis. At this point, a subgroup of the research team began refining patterns operating in the data related to parenting. This subgroup consists of the Principal Investigator (MER), four former members of the research team in training for careers in healthcare (medical doctor, physician assistant; MMM, MED, KEC and LMR), and one upper-level undergraduate student studying public health and epidemiology (RK).

At this point in the analysis, we adopted a consensual qualitative research approach (Hill et al, 1997) and employed Glaser's (1965) constant comparative method. This involved continual revisiting of transcripts and semi-weekly discussions where we further clarified the differences between the three parenting approaches by comparing cases across the evolving group delimitation. MMM who was not directly

Table 2. Representative quotes from participants in each typology and subtheme.		
Participant	Subtheme	Representative quotes
<b>Naturalized Modification</b>		
Nicole (white, male child age 9, US; upper limb, lower limb, genitals and feet lymphoedema)	Adapting to a “new normal”	“The only time I really had to worry about someone else doing any of his care was... when he went to camp... he has never been to an overnight camp. One of the activities was swimming. So, I needed to talk to them about helping him get on and off his garments which he still can't do himself. Because they're tight, they're difficult. And just the precautions of what to look out for. He can do everything like everybody else but if he gets a cut or a bug bite, you do need to clean it really well.”
Lindsey (white, female child age 13, US; right and left leg LE)	Adapting to a “new normal”	“I think it has just gotten to the point where it is a part of our life, who we are. As a family...it is what it is and it is what we have to deal with. We have just gotten so used to seeing [her] walking around in her nighttime garments and daytime garments, it's just part of our normal life.”
Amber (white, female child age 3, US; left leg lymphoedema)	My child can do everything, just differently	“My husband and I both... are outdoors a lot and... she can't get a bug bite, she can't get a [scrape], she's going to get cellulitis. We were two parents of a newborn...we knew things would be different with the baby but now we can't... ever be outside. And then we...realised we can still do the things that we love to do, we just have to... take a few precautions and just kind of let her be a kid.”
Erica (white, female child age 12, US; right leg lymphoedema)	My child can do everything, just differently	“It's just about keeping it normal...does she want to go spend the night at a friend's house? Sure, she does but she needs to wear her wrap... so it's about finding ways to make her feel like she can do what everyone else does.”
<b>Flexible Safeguarding</b>		
Samantha (white, female child age 2, Ireland; both feet lymphoedema)	It is what it is – acceptance	“We give her old bandages to bandage her dollies... trying to make it normal for her. When the time comes, we'll have to explain that she just had a bit of extra fluid in her feet and it's OK as long as she lets us treat it and she's just like the rest of the people – something just doesn't work the same.”
Kimberly (white, mother, male child age 3, US; feet and trunk lymphoedema)	It is what it is – acceptance	“It's kind of a family activity because we all sit around and wrap bandages together and they kind of, it's just a way of life for our family and so we kind of do it all together and they don't seem to grumble and they just are all a part of it.”
Jamie (white, female child age 17, US; left leg lymphoedema)	Mixing approaches	“She's not limited in any way but understands what her limitations are... medically and what we need to watch out for so that's one of my main things which is why I have a 504, it's one of the reasons why I have all of these in place. I just want to make sure that everybody that's in her life understands what her situation is from her teachers to her coaches, to her friends... she can't go hiking like a normal person because she has to risk getting blisters which can cause infection.”
Sydney (white, female child age 7, US; both legs lymphoedema)	Mixing approaches	“She does not wear her garments to school. She's little and her muscle tone is not that good so if we were to put her in her garments for school she wouldn't be able to do recess. She wouldn't be able to do gym. If it's just adjusting just what people think of a regular lifestyle, like how many people just send their kids running outside in grass... bare feet? Never done that. Never going to do that. It's small things but it's things that sometimes as a mom you feel like, I am gypping my kid of her childhood because she's never slushed around in a muddy puddle? I don't know. But I'm not ready to take the risk.”
<b>Conscious Protection</b>		
Jessica (white, female child age 7, New Zealand; full body)	Accepting difference	“I don't know how much she understands because she never talks about it. She does know she's different. When she was a baby, I saw her one day looking at her hand and then looking at mine and then looking at hers again. So, she knows she's different.”
Marie (white, female child over age 18, US; nearly full body)	Accepting difference	“She is in college... and trying to do interviews and she has trouble getting appropriate footwear for... business outfits and things like that. She has trouble getting footwear for... dances that she's going to and things like that. In high school, she pretty much turned down everybody who asked her to a dance just because she wouldn't be able to wear shoes and she doesn't like to stand out. So, shoes are a huge problem. Clothing [is] a little bit less of a problem, except now she refuses to wear anything that shows her stockings. Dresses have to be long and... she wears long pants all summer, she doesn't wear shorts except to work out and things like that.”
Rebecca (white, female child age 13, US; both legs, right hand and ankles)	Parental restriction in order to protect	“She said she was going to be in the NICU at University Hospital and I said absolutely not. You can't become a nurse because you can get stuck by a needle. You're around sick people. Her immunisations, when they did them, they didn't fully take so she's not fully immunised. I said healthcare settings, probably not a great idea.”
Claire (white, female child over 18, US; both legs)	Parental restriction in order to protect	“You can't go in there... I don't care because that's a hotbed of bacteria. You cannot go in there. It's like momma's bear comes out that if she goes, this has to happen. Probably more so in the camp stuff because it was having to be really firm especially like you can't go swimming in the lake.”

involved with the initial identification of the three parenting approaches, served as an auditor (Hill et al, 1997). The audit led to the identification of characteristic sub-themes that were distinct for each parenting approach. We then clustered quotes illustrating the overarching themes and parenting approaches that reflected specific sub-themes until we reached clarity and consensus that each parent belonged in their assigned parenting approach group. As we considered these emerging parenting approaches, we turned to the FAAR model to gain clarity about how each approach balanced stressors with resources and how successful they were in facilitating families' adaptation/adjustment to their new normal with lymphoedema. The three parenting approaches we identified are Naturalised Modification, Conscious Protection and Flexible Safeguarding. No differences were found among the participants who described these three approaches regarding parents' ages or length of time caring for a child with lymphoedema.

## Results

### Three typologies of approaches to parenting a child with lymphoedema

We identified patterns operating in the data that reflected three typologies of parenting approaches that fell along a continuum: Naturalised Modification (n=12/26), Flexible Safeguarding (n=7/26), and Conscious Protection (n=7/26). Across these three typologies, we identified two sub-themes that varied among them:

1. Unique maternal approaches to normalising their child's lymphoedema.
2. Mother's distinct choices in restricting or limiting their child's behaviour.

Example quotes from the data that reflect these typologies and subthemes can be found in *Table 2*. Additional demographic information and details of the children's lymphoedema can be found in *Table 3*.

### Naturalised Modification

Mothers classified as Naturalised Modification (n=12) demonstrated a parenting approach that focused on ensuring their child's ability to lead a "normal life". These mothers were driven by the fear that lymphoedema would prevent their children from engaging in typical childhood activities, like sleepovers and dances. While these mothers did worry

about lymphoedema-related complications during daily activities, they worried more about their child's emotional well-being and identity formation outside of the lymphoedema diagnosis.

Naturalised Modification mothers described a process of accepting lymphoedema as the "new normal", followed by encouraging their children to see themselves as "normal" and empowering them to participate in a wide variety of activities. While Naturalised Modification mothers did occasionally modify an activity to prevent lymphoedema complications, their parenting decisions were rooted in the belief that their child was just like any other child. Every decision these mothers made about their child was viewed through the lens of ensuring their child's sense of normalcy.

### Subsample participant description

All Naturalised Modification mothers were white, and the majority were aged 35–54 (n=9) and lived in the US (n=11).

### Typology subthemes

*Adapting to a "new normal"*. All Naturalised Modification mothers established a new normal following the diagnosis and management of their child's lymphoedema. This new normal included acceptance of their child's lymphoedema and the extensive management the diagnosis requires. The process demanded time and was initially met with resistance and difficult emotions. Naturalised Modification mothers knew they had reached their new normal when their overwhelming emotions subsided. Additionally, once mothers integrated lymphoedema management into their daily routine, a sense of their everyday life returned. Naturalised Modification mothers found assurance that their new normal resembled that of a family with children who do not have lymphoedema. The culmination of the normalisation process for Naturalised Modification mothers was a firm belief that their child's life is and would be just like any others. This is the lens through which Naturalised Modification mothers made decisions about their child's participation in activities.

*My child can do everything, just differently*. A central component of Naturalised Modification mothers' concept of "normal" was the belief that their child could do anything that a child without

lymphoedema could do. At times, this required modifications, accommodations or precautions to ensure their child's safety. These adjustments made important family activities possible and enjoyable. Naturalised Modification mothers did not want their children to miss what they deemed as essential experiences of childhood (e.g., summer camps, overnight sleepovers). In addition to implementing modifications, the mothers ensured the other adults involved understood and could help with the modifications. Concerned that their child would suffer from low self-esteem and helplessness, Naturalised Modification mothers intentionally avoided overprotecting their child. They wanted their child to learn they are capable and are not fragile from the risks lymphoedema poses. Once Naturalised Modification mothers accepted their life with lymphoedema as the new normal, they ensured their child would lead a normal life, which they described as one where their child could do anything even if that meant taking precautions to protect from any lymphoedema-related complications.

### Flexible Safeguarding

Mothers classified Flexible Safeguarding never reported seeing lymphoedema as normal and never insisted that their child was just like any other. Rather, Flexible Safeguarding mothers accepted that lymphoedema management would be a part of their everyday life. They were not driven by fear of their child not being "normal" or of potential lymphoedema consequences. They balanced lymphoedema management carefully, approaching every decision about their child's engagement in activities by weighing the potential harms related to lymphoedema complications with the potential social or emotional benefits their child would receive by participating.

### Subsample participant description

Most Flexible Safeguarding mothers were white (n=6). All Flexible Safeguarding mothers reported some post-secondary education or higher levels of educational achievement. Most children whose mothers were categorised as Flexible Safeguarding had an early onset of lymphoedema, more specifically before 12 months (n=5).

### Typology subthemes

Flexible Safeguarding mothers worried

**Table 3. Participant description by typology.**

Demographic characteristic	Naturalized Modification (n=12)	Flexible Safeguarding (n=7)	Conscious Protection (n=7)
Mother's race	White, n=12 Other, n=0	White, n=6 Other, n=1	White, n=7 Other, n=0
Mother's age	25-34, n=1 35-44, n=5 45-54, n=4 55-54, n=2	25-34, n=3 35-44, n=3 45-54, n=1 55-54, n=0	25-34, n=2 35-44, n=3 45-54, n=2 55-54, n=0
Mother's educational background	High school graduate, n=2 Post-secondary education, n=0 2-year degree, n= 0 4-year degree, n= 2 Professional degree, n= 6 Doctorate degree, n=2	High school graduate, n=0 Post-secondary education, n=1 2-year degree, n= 1 4-year degree, n= 2 Professional degree, n= 3 Doctorate degree, n=0	High school graduate, n=0 Post-secondary education, n=0 2-year degree, n=2 4-year degree, n=1 Professional degree, n=4 Doctorate degree, n=0
Mother's country of origin	US, n=11 UK, n=1	US, n=4 Ireland, n= 1 Canada, n=1 South Africa, n=1	US, n=4 Australia, n=1 Canada, n=1 New Zealand, n=1
Mother's marital status	Married, n=8 Divorced, n=2 Unknown, n=2	Married, n=6 Divorced, n=0 Unknown, n=1	Married, n=5 Divorced, n=0 Unknown, n=2
Insurance coverage	Adequate, n=5 Inadequate, n=6 Unknown, n=1	Adequate, n=3 Inadequate, n=3 Unknown, n=1	Adequate, n=3 Inadequate, n=2 Unknown, n=2
Number of siblings	No siblings, n=2 One sibling, n=5 Two siblings, n=2 Three siblings, n=1 Four siblings, n=1 Unknown, n=1	No siblings, n=2 One sibling, n=5 Two siblings, n=0 Three siblings, n=0 Four siblings, n=0 Unknown, n=0	No siblings, n=2 One sibling, n=2 Two siblings, n=1 Three siblings, n=0 Four siblings, n=0 Unknown, n=2

about their child's activities and lymphoedema-related complications. Those with younger children expressed worry that their child might not have typical teenage experiences (e.g., attending prom, playing competitive sports). In addition, Flexible Safeguarding mothers cited concern regarding health insurance coverage for lymphoedema management. Unlike Naturalised Modification mothers, Flexible Safeguarding mothers did not establish any sense of a new normal. Rather they integrated lymphoedema management into their daily lives with an air of neutrality and adjusted their parenting approach based on any given circumstance, a notable contrast from a rigid parenting approach.

*It is what it is – acceptance.* Flexible Safeguarding mothers accepted their child's condition with the mindset it is what it is. By incorporating lymphoedema management into typical, everyday childhood

experiences, these mothers described their child's lymphoedema "as a way of life". Unlike Naturalised Modification mothers, these mothers did not extensively worry that their child was not living a "normal, healthy, happy" life. They did not search for ways to make their child's life resemble that of a child without lymphoedema; rather these mothers simply intertwined lymphoedema and their daily lives.

Flexible Safeguarding mothers incorporated lymphoedema management with daily family activities as a typical pattern of behaviour, refraining from creating a "new normal" and neither attempted to nor desired that their child live a life like children without lymphoedema. Instead, they recognised lymphoedema as an immutable fact and dealt with it as it existed. Instead of creating a new normal to provide their children with a "typical childhood experience," Flexible

Safeguarding mothers allowed decisions to be guided by the child's condition.

*Mixing approaches.* Flexible Safeguarding mothers exhibited both restrictive and adaptive parenting approaches, demonstrating flexibility in changing circumstances. Examples provided in Table 2 exemplifies how the same parent might adopt a mixed approach, with restrictive and adaptive characteristics, in response to specific circumstances. Flexible Safeguarding mothers allowed circumstance to dictate which lens, restrictive or adaptive, to employ in response to lymphoedema stressors.

**Conscious Protection**

Conscious Protection mothers followed a restrictive parenting approach aimed at preventing lymphoedema complications. For example, these mothers feared their child would have a typical childhood injury

(e.g., falling on the playground, getting a bug bite) and consequently develop cellulitis, which can develop into a life-threatening condition. Conscious Protection mothers accepted their child as different and, in turn, restricted their activities to prevent accidents that could lead to adverse health consequences.

### ***Subsample participant description***

Seven mothers used a Conscious Protection parenting approach; all were white (n=7) and majority married (n=5). Notably, the Conscious Protection group lived in a variety of countries including the United States (n=4), Australia (n=1), Canada (n=1), and New Zealand (n=1).

### ***Typology subthemes***

*Accepting difference.* Conscious Protection mothers centred their parenting style around lymphoedema-related limitations and lymphoedema management. These families accepted changes, including numerous appointments, consistent lymphoedema treatment, and complication prevention strategies, as part of their “new” lives. Although Conscious Protection mothers successfully wove their child’s lymphoedema management into their lives while also not viewing their families as normal.

A defining characteristic of Conscious Protection mothers was their choice to accept the differences between their child and children without lymphoedema in the absence of feeling a need to normalise their child. In other words, they acknowledged their child to be different from other children. The Conscious Protection mothers believed that lymphoedema-related challenges caused their children to miss opportunities. As a result, their children experienced life differently than those without lymphoedema. In addition, Conscious Protection mothers applied this perspective to the family unit by accepting changes in multiple facets of their lives. Despite the obstacles and changes that their child’s lymphoedema presented, these mothers created a new life for themselves, and their families centred around lymphoedema and its management. The mothers understood that their child was different from others and fully accepted those differences.

*Parental restriction in order to protect.* By extension of viewing their child as

“different”, the Conscious Protection Mothers insisted their child had unique needs. As a result, Conscious Protection mothers restricted their child more than they would a “normal child” to protect them from lymphoedema-related complications. Conscious Protection mothers prohibited their children from activities the mothers considered harmful. As their children aged and began considering their futures, the Conscious Protection mothers continued to set limits out of concern for their child’s safety. The Conscious Protection mothers acknowledged their child’s differences and managed their lymphoedema by restricting them from activities that they deemed risky. For these families, lymphoedema was part of their lives and the limitations that came with it had to be accepted.

## **Discussion**

The FAAR model highlights how parents, and families more generally, must continually work to regain homeostasis in response to growing or diminishing stress and developing new coping strategies accordingly (Patterson, 1988; Patterson and Garwick, 1994). The mothers in this study adopted three distinct parenting strategies to cope with their child’s lymphoedema diagnosis and management: Naturalised Modification, Flexible Safeguarding, and Conscious Protection. In so doing, they exhibited caregiving approaches that renegotiated the family’s homeostasis into something new and manageable.

While the mothers’ shared some coping strategies to regain homeostasis after receiving an undesirable and unwanted diagnosis for their child, their remaining coping strategies within the FAAR model differed by parenting typology (Patterson and Garwick, 1994). Naturalised Modification mothers changed the meaning of the stressor by undergoing an emotional “normalisation” process, concluding that their child was just as capable as a child without lymphoedema. They added supports, such as modifying activities to prevent lymphoedema complications, within the context of maintaining their child’s identity as “normal”. In sharp contrast, the Conscious Protection mothers changed the meaning of the stressor by identifying their child as “different” from other children without lymphoedema (Patterson and Garwick, 1994). Todd et al (2002) noted similar

approach as Conscious Protection mothers in their findings and concluded that parents of children with lymphoedema found this realisation to be difficult. By seeing their child as “different”, Conscious Protection mothers experienced hyper-vigilance to mitigate their child’s risk of lymphoedema complications, a strategy in line with Salfors and Hallberg’s findings (2003). When unable to monitor their child directly, Conscious Protection mothers worried that supervising adults would be unable to properly manage their child’s lymphoedema, though this anxiety was not limited to only Conscious Protection mothers (Bourdeau et al, 2007). In contrast to Naturalised Modification and Conscious Protection mothers, Flexible Safeguarding mothers did not change the meaning associated with the stressor. Rather, they adopted an “it is what it is” mindset. This is best summarised by Samantha’s description of managing lymphoedema as “just a way of life”. Their somewhat neutral perspective allowed for mixed, and sometimes even contradictory, strategies to modify or restrict their child’s opportunities in response to changing circumstances.

The three typologies of parenting approaches appear to operate along a continuum from prioritising protection and prevention (Conscious Protection) to prioritising opportunities and socialisation (Naturalised Modification). We consider these typologies to be fluid in nature and therefore acknowledge that parents experience novel stressors and will continually create new ways to cope. That is, parents could adopt a different parenting approach in response to change in lymphoedema or other factors, such as the growing maturity and independence of adolescence. This continuum of typologies still reflects the FAAR model (Patterson, 1988), in that families respond to crises (e.g., diagnosis of lymphoedema, flare up in lymphoedema symptoms, etc) by finding ways to adapt or adjust. Additionally, the Conscious Protection mothers had children with a higher average age at the time of the mother’s interview (mean=18.29, SD=14.61) compared to Naturalised Modification (mean=9.67, SD=6.76) and Flexible Safeguarding mothers (mean=8.29, SD=5.71). Conscious Protection mothers were also more likely to report that their child had experienced a serious lymphoedema-

related complication. This could suggest that as children age and accumulate adverse experiences, parents adapt to new stressors by adopting Conscious Protection parenting types.

Previous studies of parents of children with lymphoedema identified an internal tension between parents providing a “normal” life for their child and protecting their child from lymphoedema-related complications (Todd et al, 2002; Moffatt and Murray, 2010). Moffatt and Murray (2010) identified this as a singular theme for the parenting experience. Naturalised Modification mothers exemplified Moffatt and Murray’s (2010) theme that “[parents of children with lymphoedema] made every attempt to “normalise” life for the family and the affected child.” However, our analysis revealed that Moffatt and Murray’s (2010) observation did not capture a significant proportion of mothers’ experiences. In the present study, we found that these mothers resolved this tension by adopting one of three distinct parenting approaches that varied along a continuum in two dimensions, including normalisation and limitation strategies. For example, Flexible Safeguarding mothers did not undertake an extensive normalisation process; rather, they adopted the mindset of it is what it is. For Conscious Protection mothers, in contrast from Naturalised Modification mothers, accepting a “new normal” meant accepting their child as “different” and in need of protection.

There are several possible explanations for why the present study observed diverse parenting approaches in contrast to Moffatt and Murray’s (2010) singular parenting theme. Moffatt and Murray’s (2010) sample (n=20) were all from the UK, which offers national healthcare coverage. Sharing nationality, culture, and insurance coverage may explain why one specific parenting style was adopted in response to a more homogenous set of circumstances. The present study, however, includes mothers from a diverse range of countries employing a wide array of healthcare systems, including the private insurance market of the US, the US Veteran’s Health Administration and various international healthcare systems with mixed private and public components. In this study, about half of mothers identified as having adequate insurance (n=11). Differing in nationality, culture, and insurance coverage

could also contribute to a heterogeneous set of stressors resulting in a continuum of adaptive responses.

Finally, a notable portion of the participants in Moffatt and Murray’s (2010) sample (n=20) had a family history of lymphoedema (n=7). In contrast, the present study sample (n=26) had far fewer family members with lymphoedema (n=3). The diversity in parenting approaches may also be reflected by mothers’ varying familiarity with lymphoedema.

Additionally, Moffatt and Murray (2010) identified adolescence as a challenging period for parents of children with lymphoedema. Specifically, parents reported difficulty relinquishing control of their child’s lymphoedema management, fearing their adolescent would not properly manage their condition. However, in the present study a specific approach to parenting adolescents was not observed. Hanson et al (2018) found adolescence to be a challenging time for the adolescents themselves who often felt misunderstood by their parents. For example, when adolescents developed an autonomous and deliberate decision-making process to balance their lymphoedema management with a desire to conform with peers, their parents often perceived their choices as management noncompliant (Hanson et al, 2018). In this study, mothers noticed specific struggles their adolescents faced (i.e., school dances, clothing styles, shopping) and cited their child’s self-esteem as a major source of concern. However, we did not observe a pattern of conflict between mothers and adolescents regarding treatment compliance. The discrepancy between parental and adolescent perspectives among multiple studies suggests there is an importance for future research to focus on improving communication between parents and their children with lymphoedema.

Research on children’s perspectives with lymphoedema revealed diverse views in how children see themselves in relation to their lymphoedema. Some children felt different from their peers and experienced self-consciousness, low self-esteem, and fear of infection (Moffatt and Murray, 2010; Hansen et al, 2017; Todd, 2019). These children disengaged from activities they perceived to be risky and limited their career aspirations because of lymphoedema symptoms (Hansen et al, 2017). Other

children grew to accept or ignore their condition (Moffatt and Murray, 2010). Hansen et al (2017) and Todd (2019) found that children diagnosed at a young age considered lymphoedema to be normal. Some children insisted that they were as normal as any child and engaged in a wide range of activities (Hansen et al, 2017). In this study, we only considered mothers’ perspectives who intended for their perspective on lymphoedema to be adopted by their children. For example, Ashley, a Naturalised Modification parent, encouraged her son to engage in activities that risk lymphoedema complications so he could develop confidence in managing his lymphoedema. Conversely, Jessica, a Conscious Protection parent, viewed her daughter as different and perceived that her daughter also viewed herself as different from other children from a young age.

Future research could further explore how a parents’ perception of their child’s lymphoedema could influence the child’s perceived future and their belief about their own condition.

### Implications for practice

These findings revealed unique stressors faced by mothers of children with lymphoedema. The mothers’ frustrations may be related to lymphoedema’s rarity, which fosters diagnostic delays and limits available support. There is need for increased awareness and education of lymphoedema in healthcare settings broadly which could help alleviate the concerns of mothers in our study. Healthcare professionals, child life specialists, counselors, and social workers educated in lymphoedema would be well-positioned to provide specific and collaborative support to mitigate parental stressors to consider all facets of child’s life.

### Limitations

Although this study provides valuable insight on parenting children under the age of 18 with lymphoedema, several limitations exist. Participating mothers were predominantly white, English-speaking, college educated and lived in countries practicing Western medicine. A more diverse group of participants could yield additional parenting approaches in various cultural or geographical contexts. Additionally, participants were all recruited through lymphoedema advocacy groups. Qualitative differences may exist between



activist and non-activist mothers, limiting our study's generalisability. Our study was also limited by its cross-sectional design. A longitudinal study would be better positioned to observe the influence of childhood development on parenting approaches, as well as further characterising parenting approaches as a continuum.

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