

# The lived experience of primary lymphoedema: a phenomenological study of personage and caregiver

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## Key words

Primary lymphoedema, Lived experience, Qualitative research

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Lymphoedema is a progressive chronic disease with variable morbidity including physical impairments, functional limitations, psychosocial disabilities and changes in health status (Bulley et al, 2013; Cemal et al, 2013; Taghian et al, 2014; Greene, 2015). Primary lymphoedema (PL) is characterised by a manifestation of protein-rich interstitial fluid due to dysplasia of the lymphatic system (Szuba and Rockson, 1998; Lee et al, 2013; Zuther and Norton, 2013). The prevalence of PL is uncertain, ranging from 1 in every 100,000 persons under the age of 20 (Smeltzer et al, 1985; Greene, 2015) to 1 in every 6,000–10,000 live births (Lee et al, 2013). The prevalence is distributed comparably between genders (Schook et al, 2011). Boys present with PL more often during infancy, while girls typically present during adolescence.

Lymphoedema framework projects have evidenced a lack of basic knowledge about lymphatic system anatomy and physiology, incognisance of the pathophysiology

## Abstract

**Background:** Paucity of interprofessional knowledge concerning primary lymphoedema (PL) heightens concerns that children with PL may receive incognisant care and that psychosocial and medical resources may be insufficient. Juxtaposing a young adult's lived experience of PL with accounts from a medically-trained parent offers a new dimension to qualitative research. **Aims:** To translate and summarise the lived experience of PL and to reframe components of the parent–child journey for lymphoedema specialists and stakeholders. **Method:** This phenomenological qualitative research used an interview process to gather textual and contextual data from participants. **Results:** Six main theoretical constructs materialised that illustrated the lived experience of PL of both the patient and caregiver. **Conclusion:** Fears and challenges are encountered by both the medically trained parent and young adult along the continuum of PL during adolescence. Interprofessional medical practitioners should consider PL in their differential diagnostics, especially in the case of significant oedema that does not resolve.

and management of lymphoedema, and uncertainty about the psychosocial burden of the disease (Morgan et al, 2005; Armer et al, 2009; Hodgson et al, 2011; Davies et al, 2012). Stanley Rockson (2017) highlighted that a deplorable lymphatic ignorance has arisen in the medical community. He states that, “health care providers are ill-equipped to provide the care and solace that they [PL patients] seek” (Rockson, 2017). With the lack of interprofessional knowledge about lymphoedema, there is a concern children with PL may be victims of incognisant care or iatrogenic morbidities. In their qualitative study, Moffat and Murray (2010) note that parents had difficulties obtaining a proper diagnosis and that information about PL was inadequate, inconsistent and confusing. They report that parents and children experienced a dearth of PL treatment.

Currently, there are few qualitative studies engaging the interprofessional medical community with the life experiences of parents and children. The

current study enabled a young adult to report on her lived experience with PL. This was juxtaposed with accounts from her mother, who was a medical professional. This study presents a new dimension in qualitative research.

## Aims

The aims of the study were to:

1. Translate the lived experience of an adult child with PL and the parent of that child
2. Summarise the lived experience of the parent and child in their journey together through evaluative and care approaches
3. Reframe the positive and negative components of the parent–child journey into valuable considerations for lymphoedema specialists and stakeholders alike.

## Methods

This phenomenological qualitative study used an interview process to gather textual and contextual data from participants. Due to the limited number of young

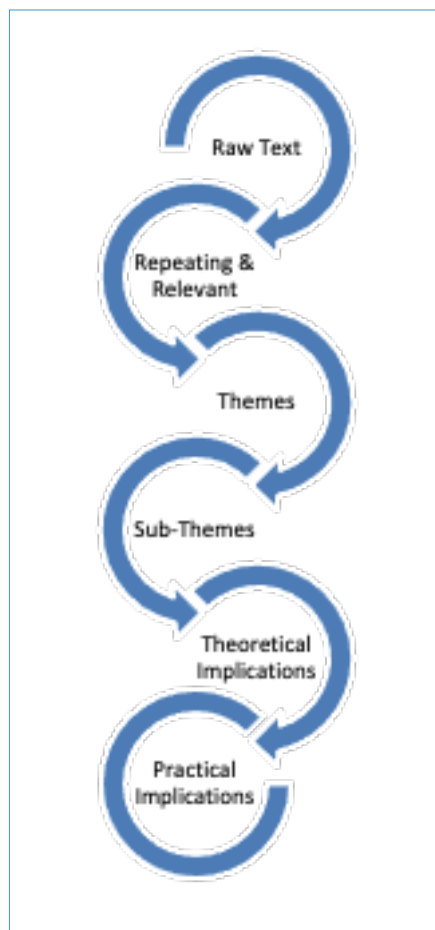


Figure 1. Methodology flow diagram.

Table 1. Themes and subthemes.

Theme	Subtheme
Disease onset	<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Diagnostics</li> </ul>
Lifestyle changes	Grieving
Medical community	
Treatment	Treatment in Germany
Support	
Future concerns	

adults with PL, purposive sampling was conducted. Young adults with PL, aged 18–25 years, with at least one parent who was present and involved during the onset and prevailing events of PL were eligible. Other medical conditions, whether physical or mental, were not exclusionary as they may have enriched the data.

Recruitment resulted in one participant with PL and her mother, a paediatrician who had practiced medicine for 15 years prior to her child developing PL.

**Box 1. Theme: disease onset.**

**Child:** “I was 15 years old and [it was] springtime. I was running during track practice, and I remember that I had not run that far. I did not twist or sprain my ankle, and I did not recall any type of pain prior to the swelling. Later that day I felt something funny, like a super-tight sensation. I looked down and my ankle was huge and I couldn’t see my bones.

“It was very startling, which led to a low-level panic. To say that it was sudden would be an understatement. Later on that day, I experienced some pain.

“My mother told me later that she had an awful feeling about it, like a sixth sense that something was wrong. I think my mom [a paediatrician] was in denial at first.”

**Parent:** “She [my daughter] was away in boarding school and she called and said that her ankle was huge and she sent me a picture. I said, ‘What did you do to it?’ She said, ‘Nothing, but it hurts!’ I knew almost immediately that what I was looking at frightened me. And being that she did nothing confirmed my fears, because you know damn well when you hurt yourself enough to cause swelling! I think that I thought that perhaps it was an overuse injury, like a stress fracture. Literally it appeared one day and never went away.”

**Box 2. Subtheme: diagnosis.**

**Child:** “I had seen as many as five different doctors and was tested for many different diagnosis. My mom launched into research to figure it out, which is good, but can be scary too.”

**Parent:** “My daughter’s diagnosis took 6 months. I think typically the journey for most primary lymphoedema patients is averaged at 10 years, especially for those when the oedema is not congenital but appears later in life. We had seen podiatry, orthopaedics, paediatricians and rheumatologists.”

Phenomenological questions were delivered by teleconferencing, which was recorded for recall accuracy. The interview was conducted in participants’ chosen environment, which allowed them to share their lived experiences with transparency. Data were transcribed within 10 days of the interview by the principal investigator.

**Qualitative analysis**

Analysis followed coding methodology as outlined by Auerbach and Silverstein (2003) and Silverstein et al (2006). The coding methodology (Figure 1) organised texts of the transcripts and progressively discovered patterns of repeating text and relevancy pertaining to the research questions and concerns.

**Results**

Six main theoretical constructs with related themes materialised from quantitative analysis (Table 1).

**Disease onset**

PL can be present at birth, but for females in particular — as in this case (Box 1) — the presentation can be suddenly revealed during adolescence (Schook et al, 2011). Parents find the onset of PL in their child

to be insidious and often resulting in emotional distress (Moffatt and Murray, 2010). Adolescents are impacted greatly by PL, as it affects peer group assimilation, body image and the clothes they can wear (Moffatt and Murray, 2010).

**Diagnosis**

People with PL are often not promptly diagnosed due their physician’s lack of knowledge of the condition (Moffatt and Murray, 2010; Harding, 2012) or the oedema being attributed to injury. The journey from symptom onset to diagnosis may take up to 12 years (Mitchell et al, 2019). This depends in part on local and knowledgeable specialists and caregiver advocacy (Moffatt and Murray, 2010; Davies et al, 2012; Watts and Davies, 2016).

With the lack of interprofessional knowledge, there is an increased risk that children with PL — whose incidence rate pales compared to secondary lymphoedema — may be victims of incognisant care or iatrogenic morbidities. The inability to access knowledgeable lymphoedema practitioners for diagnosis, treatment and continuum of care characterise the burden of PL (Stolldorf et al, 2016).

Improper diagnosis and care of children

with PL during their formative years may lead to a sense of medical abandonment and result in psychological stress for the individual and their family (Rockson, 2017; Mitchell et al, 2019). In this study, the diagnosis was made relatively quickly but did not proceed without complications, as noted by the participants (Box 2).

### Diagnosics

Timely and accurate diagnosis of PL can facilitate proper prognosis and treatment interventions. A majority of patients with PL may be diagnosed by gathering and summarising patient history and physical examination results (Greene, 2015). However, other diagnostic modalities may be required to rule in the diagnosis, rule out other etiologies, or to assess the extent of lymphatic dysfunction in PL (Greene, 2015). These modalities may include magnetic resonance lymphography, computed tomography, or ultrasonography.

### Lifestyle changes

Quality of life scales for children with chronic diseases are appropriate and beneficial but remain relatively scarce for PL (Fu et al, 2013; Kim et al, 2014). Current quality of life studies have found the dimensions of psychosocial well-being, physical and functional health, treatment and self-care to be negatively impacted by PL (Stollendorf et al, 2016). Patients have difficulties with discomfort, anxiety/depression, health perceptions,

### Box 3. Subtheme: diagnostics.

**Parent:** “My daughter had her first MRI about 5 months later [after the oedema manifested]. The MRI showed non-specific soft tissue oedema and also some boney oedema in one of the bones of the foot. They thought it was a bone bruise and contributed it to an injury. She [my daughter] ultimately had three MRIs because the fluid in the bone kept showing up. There was a lot of lab work looking for arthritic conditions. The lab work demonstrated a mildly positive ANA [antinuclear antibody], a common inflammatory marker. She had a CT of the abdomen and pelvis looking for a mass occluding venous return. She was tested for Lyme disease and HIV. So, basically, the diagnosis was made [when she was 15] clinically by ruling out other possibilities.

“My daughter had a lymphoscintigraphy, twice, and they were both normal. After she was diagnosed, she later had near infrared imaging. They were able [with this imaging] to see the dysfunction clearly – beautifully. So... she actually has bilateral primary lymphoedema. I denied the diagnosis at first. I cried all the way home when I saw it. I needed to see it, but it was hard too.

“[The Földi clinic] did some testing that was not available in the US. They did high-resolution ultrasound for dermal thickening. They diagnosed her with classic dermal thickening, which you cannot see on the outside.”

**Child:** “So, I was annoyed at first, and I was sick and tired of being poked and prodded. The lymphoscintigraphy happened after I was diagnosed. I believe the point was to survey the damage and see how bad it was. OMG! It hurt so badly! It hurt sooooo bad. And I have a high pain tolerance.”

self-confidence and participating in usual activities (Harding, 2012; Okajima et al, 2013). The desire to hide the affected extremity appears to be a concern for some (Harding, 2012). In this case study, quality of life for both the child and adult were negatively impacted by PL (Box 4). There was also a period of grieving (Box 5).

### Medical community

The burden of PL is significant physically,

psychosocially and financially (Stollendorf et al, 2016). It is unusual to have knowledgeable and readily-accessible clinics local to individuals with PL, but they can make meaningful and positive differences to patients (Watts and Davies, 2016).

While the number of hours of lymphatic education provided is not known across many disciplines, there is evidence that it is insufficient to relieve the burdens associated with lymphoedema (Logan et al, 1996;

### Box 4. Theme: Lifestyle changes.

**Child:** “After my diagnosis, I went into a pretty intense depression. At the time, the condition didn’t seem mild but was rather completely terrifying. We didn’t know at the time if the swelling was going to continue, like up my leg, into my other leg, in my torso, or in my arm. As a 15-year-old girl who is raised in a culture of extreme beauty and hyper-sexualisation, who wants to be confident, beautiful and attractive — [not] to wear an ugly, tan, bulky compression garment on my already swollen peg leg – I just wanted to be normal and for it to go away. I was deeply self-conscious about both my oedema and my compression garment. I felt like everyone was staring at me, or that they would think it was ugly. This insecurity and fear led me into a deeply unhealthy relationship when I was 16 years old that was laced with emotional abuse.

“My parents really struggled during that 2-year period of waiting to see if the other foot would drop and it would spread or get drastically worse. I believe my parents were concerned that perhaps I would be disabled. My parents were very focused on my condition.”

**Parent:** “It never occurred to me that I had a child with an underlying disability. [As a paediatrician] I understand chronic illness and how it invades every aspect of a person’s life. I understand that people’s lives can be shortened by primary lymphoedema, that it can be debilitating and have psychological impacts, especially for a 15 year old. I have seen devastating chronic problems and that reality was something I was not cut out for. I think I was able to see the arch of chronic disease and it was something that I could not fix for my daughter, which was very devastating.

“I think that [primary lymphoedema] put me in a parent–child relationship for a much longer period of time. And in some ways, we are still there. My level of involvement at the time became much more co-dependent. I actually became a certified lymphoedema therapist 2 years after her diagnosis, and continue to deliver treatment occasionally.

“It was very stressful for our marriage. We were stuck with wondering what was coming next. This terrible thing landed on our family and we had no idea where it would end. We were very stressed and very sad.”

### Box 5. Subtheme: Grieving.

**Child:** “There really is not a silver lining to this, and it is OK to admit it. It is important for people to have grief. Grief takes a while to form. My grief was that I thought, I felt, that I lost my childhood.”

**Parent:** “I think we were mourning the loss of comfortably thinking our child was OK.”

### Box 6. Theme: Medical community.

**Parent:** “My understanding is that [medical lymphatic knowledge] is getting better, but I think there is a long way to go. I hear that the number of research proposals have gone up exponentially over the last few years. However, I can tell you that I think it would be fair to say that [my lymphatic education] was well under 1 day of curriculum out of 4 years. I believe that is true. I remember learning about basic ideas and anatomy and physiology, like the thoracic duct and chylothorax. Beyond that, when it became clear that my daughter had primary lymphoma, I was 15 years out of medical school, and about what I knew was that it was bad and could not be fixed. I actually had never seen a case in my entire 15 years of medical practice. Wait a minute, I actually did see one paediatric primary lymphoma patient, but missed it. But I later took care of her [that patient] when she was 25 years old.

“After my daughter was diagnosed, and I became certified, primary lymphoma patients started coming [to my practice], and it became clear to me that primary lymphoma was more prevalent than what we thought. I have seen six local cases in the course of a few years.”

**Child:** “Looking back, [my diagnostic journey] really shows the lack of understanding in the medical community. I believe that it is getting better. But at the time it was startling, no one could figure it out.”

Davies et al, 2012). This was reflected in interviews with the parent and child (Box 6).

### Treatment

The availability of quality treatment administered by knowledgeable lymphoedema practitioners is scarce but essential for decreasing comorbid situations and facilitating proper early self-management (Watts and Davies, 2016). PL confers a financial burden that includes the cost of compression garments, accommodating clothing and lifestyle adaptation to maintain employment (Stolldorf et al, 2016). In addition to this, children and adolescents are very conscious of their physical appearance and wearing compression garments has a negative psychological impact (Stolldorf et al, 2016), see Box 4.

In this study, the participants were fortunate to receive treatment at the Földi Clinic in Germany. They attended because they heard it was the best place to go and wanted to hear what the experts had to say about the condition. The participants reported that manual therapy was administered twice a day, there was group and individual exercise, and that wearing bandages was required 23 hours a day.

Receiving the correct therapy had a big impact on the child and parent (Box 7).

### Support

Having a supportive relational space in a patient-centred specialised clinic helps individuals with lymphoedema feel both cared for and about (Watts and Davies, 2016). However, access to and the availability of local PL peer support groups is poor. Often adults access support through social media (Watts and Davies, 2016), and perhaps this is sufficient for adolescents. The Children’s Lymphoedema Special Interest Group established Lymphaletics — a multiactivity and educational event — as an opportunity for children with PL and their family members to meet and socialise with others with similar lived experiences (Todd, 2016). Children can benefit from seeing and socialising with others who have the same medical condition and parents can encourage each other, thereby reducing the feeling of isolation (Todd, 2016). In the case of the parent–child dyad, reassurance was found through meeting PL patients at the Földi Clinic. According to the parent, however, online support was felt to be more appropriate and useful as many patients at

the clinic were considerably older than the child (Box 8).

### Future concerns

As the child matures into a young adult, aspirations may be affected by chronic disease and may progress into concerns about the future, as in this case (Box 9). Coping with the disease in adulthood is one concern PL sufferers have (Moffatt and Murray, 2010). Many adolescents with PL worry that their future career options will be limited due to the condition or workforce discrimination (Hanson et al, 2018). Parents may also have concerns about their child’s future (Box 9). These tend to revolve around future sexual and nonsexual relationships (Moffatt and Murray, 2010).

### Discussion

This qualitative study reveals the lived experience of a mother and daughter dealing with PL over a period of 6 years, beginning during adolescence. The fact the mother was a paediatrician enriched the description of this lived experience and culminated in an understanding that PL is shocking, grievous, life-changing, frustrating and fear-inducing. As with most chronic diseases, the fortitude to move forward through adaptive transitions has positive outcomes and is clearly realised in these lived experiences.

In this study, there was a progressive satisfaction in the treatments the child received, as well as with the self-management of PL as the adolescent transitioned into adulthood. These positive outcomes are similar to those of other chronic diseases (Gannoni and Shute, 2010).

The unity of this lived experience for both child and adult was clearly noted in the raw text of this study, with shared themes and quotes. An interdependent alliance of support in the provision of self-care and in managing illness-related issues was apparent. Alliance is vital when managing and accepting the restrictions imposed by chronic diseases (Gannoni and Shute, 2010).

Support in a group setting appears to have additional benefits to support at home. As technology invites support through social media, new trends may emerge for children and adolescents with PL, similar to the iPeer2Peer programme

in which tailored mentorship improved self-management skills and coping efforts (Ahola Kohut et al, 2016).

The adolescents received lymphoedema care in the United States but clearly stated they received the greatest benefits at the specialist clinic in Germany, which offered a greater intensity of treatment, had knowledgeable staff members and provided the opportunity to meet others with PL. It is disconcerting that in the US, patients receiving breast cancer lymphoedema outpatient treatment are often not prescribed the recommended daily dose of complete decongestive therapy (Polo et al, 2017). This trend was noted in the current study. As the parent said: "Having been a doctor in the US and then having the experiences at the Földi Clinic, I can't tell you how far behind we are. OMG! We are so far behind! From the standpoint that if my daughter's condition worsened, I would consider leaving the country." Comparative research into the impact of inconsistent practice on clinical outcomes in the US is warranted and investigation into this trend is necessary.

### Limitations

There were only two participants in this study: a parent, who was also a paediatrician, and her daughter, who was a young adult. While this unique and small sample scenario facilitated the achievement of the aims of this research, it prevents generalisation of the findings to larger populations. Future adult-child dyad studies with parents who are not physicians are needed for comparative purposes.

The potential for researcher bias is present in the methodology and emergent manuscripts. There were limitations in the data gathering. The need to offer separate teleconferencing sessions due to distances between parties may have introduced bias. Also, teleconferencing limits the researcher from viewing a participants' body language for enhanced interpersonal communication.

Despite these limitations, this study demonstrated that both parent and child meet considerable challenges in adolescent-onset PL, and these challenges are intensified in an incognisant medical environment with a lack of lymphoedema specialists.

### Conclusion

The fears and challenges encountered as a result of PL during adolescence are

#### Box 7. Theme and subtheme: Treatment and treatment in Germany.

**Child:** "I remember that the therapy started helping right away. I went twice a week and had a physician and therapist working on me. I remember the time I asked the specialist if I needed to wear compression all the time – he said yes – I started balling!"

"What is interesting is that [prior to Földi] about 50% of my fluid had already been removed, and I thought it looked good. But there was more underlying fluid than what could be seen on the surface. They removed another 1.5 litres in 1.5 weeks. It wasn't that the treatment was different than that in the US, it was that the intensity was different."

**Parent:** "Actually the very first treatment was casting the leg, because they thought it was some kind of bone injury. Luckily, that did not make it worse."

"I pay for the garments by myself. Most people cannot do this. She probably has had 30 pairs of custom garments over the last 6 years, which are around \$300 a piece, so she probably has 10 grand in garments. But she is a teenage girl — so she needs a black, tan, pretty, etc. She has pump, which she states makes her feel better, and it is very convenient. I bought the pump with cash. Working with insurance was a choice of sanity or jail time."

#### Box 8. Theme: Support.

**Child:** "One thing about the Földi experience is that it put things back into perspective for me. I was surrounded by some of the most intense cases of lymphoedema and lipoedema. I remember thinking that these [intense cases] were going to be me in the future. I believe my parents thought the same way. [However], seeing other patients was helpful in knowing that my condition was not as bad compared to others. What was cool was that I found camaraderie in several patients who were a lot like me."

**Parent:** "These days it seems like most of them [support groups] are online on social media – like Lymphie Strong. An actual formal support group did not seem relevant for my daughter because it would have been made up of older individuals. So she sought out support online. Földi was kind of like its own support group, being around other people with lymphoedema, a camaraderie."

"The [Földi] experts did not sense that it [the lymphoedema] would progress up her leg. They do think that the contralateral side is affected and will eventually need some treatment, but that the manifestation will not travel up the leg or be seen in other areas. They also told us that women like my daughter do not have affected children."

#### Box 9. Theme: Future concerns.

**Child:** "There is always that creeping sense of doubt or fear.... "What if I hurt myself and damage the already slow lymphatics?" Or "What if it spontaneously gives out again, like when I was 15?" I was and am fearful of passing it on [childbirth], because what if I pass it on and it is worse in my kid. Fears do exist but I do not dwell on them."

**Parent:** "The first thing I worry about is an unexpected progression. This is my greatest fear. It seems to happen even in people who have been stable for years and years. Something made it [primary lymphoedema] appear overnight and we never got Jack back into the box. When we were there [at Földi Clinic], we met a woman who got primary lymphoedema in her leg at 15 years old, and much later it progressed all the way up the limb and then into the groin, and then into the abdomen, and then into the other leg. That knowledge has stayed with me. I feel like I am always waiting for the other shoe to drop, but I have calmed down quite a bit."

"She [my daughter] has never been the same... the mechanics of that ankle are not correct. Whether it is because she favours it, or because of what was going on in the bone, but she definitely has limb pain that she has to deal with."

evidenced by the participants' accounts. Interprofessional medical practitioners may do well to consider PL in their differential diagnostics, especially when there is significant oedema that does not resolve.

Medical educators should review the time given to and depth of teaching about lymphatics as part of entry-level practice to ensure patients with PL receive a proper diagnosis and prompt intervention. Lymphoedema specialists should review their use of decongestive therapy dosage and procedures and consider aligning them with evidenced-based practice. Legislative stakeholders should consider the financial, psychosocial and physical burdens of PL.

Active recruitment of lymphoedema specialists is advised, so individuals in rural and urban areas are able to access proper care, support and management. Specialised clinics offering knowledgeable care and community support for people with PL is highly recommended.

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