ILLUMINATING THE EXPERIENCES OF GROWING UP AND LIVING WITH PRIMARY LYMPHEDEMA: A LIFE HISTORY STUDY

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I was once asked why I chose to conduct qualitative research, after completing so many classes about quantitative analysis. I responded that I thought it offered me a better opportunity for personal growth. Now that I've finished this dissertation, I believe this may be the case.

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Abstract: The purpose of this qualitative research study was to collect, preserve, and understand the life histories of young adults who grew up with and are living with primary lymphedema of the lower limbs in the United States and, in doing so, illuminate the ways in which lymphedema affects their lives within their sociocultural and medico-historical contexts. Developing the life histories of four women and one man, ages 19-40, who first experienced swelling as children and adolescents offered insight into the emotional, social, and physical consequences of their condition to the trajectories of their lives. Compelled by my emic perspective as a person living with primary lymphedema, I offer substantial autobiographical reflections on my positionality.

I analyzed data using inductive thematic analysis of independent narrators' life stories and then across cases. The three major findings are: 1) Striving to Matter To and For Others and Self; 2) Complexities, Complications, and Confusions: Life Difficulties along the Journey; and 3) Lymphie Conundrums: Grappling with Normalizing/Othering. The first includes sub-themes about mattering to significant others, healthcare providers, others with primary lymphedema, and to self. The second includes subthemes about the complexities of decongestive therapy and self-management, schooling, other chronic diseases, and other priorities that push lymphedema to the background, the complications of biographical disruption and transformative brushes with cellulitis, and lingering confusions about cause and heritability. The third includes sub-themes about stigmatization, rejection, and discrimination, hiding to pass as "normal" and its costs, and straddling the lymphie conundrum with clothing.

I used the findings to answer research questions about how the narrators make sense of living with the disease and negotiate emotional, social, and physical challenges while navigating relationships, school, work, and the healthcare system. I offer practice implications for counselors, educators, healthcare providers, lymphedema therapists, and advocacy organizations. I also provide implications for theory and research. This study illuminated a wide variety of experiences within the healthcare system that correspond to the emergence of lymphedema as an important medical agenda in the United States. It also makes visible the unique aspects of living with primary lymphedema that shape lives as well as limbs.

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CHAPTER I

INTRODUCTION

My dissertation journey began during the summer of 2015, when I was surfing websites dedicated to a common but underappreciated medical condition referred to as lymphedema. *Lymphedema* is a chronic and often debilitating condition that develops due to disruption in the lymphatic circulation and subsequent impairment in lymphatic drainage. The impairment in lymphatic drainage results in swelling of a region or regions of the body that can eventually, if inadequately managed, reach striking proportions and cause unsightly changes of the skin of the affected region(s). Lymphedema may result in loss of confidence in body image and diminished self-esteem, impaired psychosocial adjustment, physical discomfort/pain, loss of function and restricted movement, and the risk of repeated, even life-threatening, infections (Rockson, 2018a). Though the condition significantly affects the quality of life (Ridner, Deng, & Rhoten, 2018), it is frequently misdiagnosed, treated too late to prevent irreversible consequences, or not treated at all (Szuba, Shin, Strauss, & Rockson, 2003). Therapy is beneficial (Szuba, Cooke, Yousuf, & Rockson, 2000), but the burden of daily self-management is onerous (Ridner et al., 2018; Armer et al., 2018). There is no cure (Rockson, 2018a).

While I was surfing, I landed on a page about an advocacy initiative hosted by the Lymphedema Education & Research Network (LE&RN) (https://www.lymphaticnetwork.org). The LE&RN page included an invitation to people with lymphedema to submit a short biography and picture of themselves that the organization would post to their website. It seemed incredible to me that people were disclosing their lymphedema on the website, as well as social media,

sometimes exposing their swollen, disfigured limbs in photographs. For most of my life, I avoided full disclosure about my lymphedema and complete exposure of my swollen ankles, feet, and toes. I felt distressed just thinking about responding to LE&RN's invitation to post my biography and a photograph.

A few months later, for a qualitative research course assignment, I analyzed a narrative written by a blogger who writes about living with primary lymphedema at *The Lymphie Life* (https://thelymphielife.com). The blogger, Alexa, developed swelling in one of her lower limbs when she was a toddler. In her narrative, "Big Milestone!" (Ercalano, A., 2014. Retrieved from https://thelymphielife.com/2014/02/17/big-milestone/), Alexa wrote about her decision regarding what to wear on a hiking trip to the desert and called it a lymphie conundrum. Her choices were shorter and cooler shorts that would expose her lymphedematous limb versus longer and warmer pants that would hide her limb and avoid stigmatizing stares and comments. Alexa's post resonated with me acutely. I am intimately familiar with the conundrums that lymphedema presents. Now, in my 60s, I look back and recognize that when I was a child, adolescent, and young woman, the decisions I made while navigating lymphie conundrums shaped my life profoundly—the social events I attended, the school and extracurricular activities in which I participated, the leisure activities I enjoyed, the occupations I pursued, and my relationships.

I understand the complexities of self-management that Alexa's hiking trip presented regarding her lymphedema. I wondered: Did she spend extra time elevating her leg during the days before the trip? What kind of shoes and socks did she wear to avoid injury to her ankle, foot, and toes? Did she remember to use insect repellant and sunscreen to protect her skin and reduce her risk of infection? Did she bring a first aid kit? I noticed that, in the photograph that she posted, her leg was bare, and I wondered if she sometimes wore a compression garment.

Finally, I wondered, how did she negotiate private space to change her socks and shoes in the hotel room that she shared with her fellow hikers?

Though Alexa and I are both familiar with the conundrums of lymphedema and the self-management complexities associated with the condition, the sociocultural and medico-historical contexts in which we grew up differ dramatically. Today, we know more about the lymphatic system and lymphedema, and treatment options are expanding. Moreover, the internet offers Alexa and me easy access to information about the condition and treatments, advice from others when feeling challenged by the complexities of self-management, and opportunities to make meaning together about the experience of living with primary lymphedema. The internet, as we know it today, did not exist during the last half of the 20th century when I was growing up and becoming a woman, pursuing a nursing career, love, and motherhood while living with lymphedema. I felt intrigued by the ways that contemporary sociocultural and medico-historical contexts shape the lives of men and women growing up with and living with primary lymphedema of the lower limbs. In what follows, I use primary LLL when I refer to primary lymphedema of the lower limbs. At other times, primary lymphedema may refer to other regions of the body, as well.

This chapter provides an overview of a life history research study I conducted with five young adults, ages 19 to 40—four women and one man—who grew up with and are *living with* primary LLL. I use the language "living with" (Lather & Smithies, 1997, p. 5) intentionally, as Lather and Smithies used the language to foreground the lives that women were living while searching to find meaning in being HIV positive amidst cultural stigmatization by those who feared the disease. In this chapter, I provide the background of the research and problem

statement, the purpose of the study, guiding research questions, an overview of the research methodology, and the organization of the study.

Background to the Research

Primary lymphedema is a visible swelling that occurs when lymphatic drainage fails due to abnormal lymphatic development resulting in an inborn, or intrinsic, fault in lymphatic vessel architecture, function, or both. The condition may be present at birth or may manifest later in life, and affect one or both lower limbs, and/or the genitalia, one or both upper limbs, and face (Mortimer, Gordon, Brice, & Mansour, 2018). Primary lymphedema is rare, affecting only 1.0 to 1.5 per 100,000 persons less than age 20 in the United States (Smeltzer, Stickler, & Schirger, 1985). In addition to the usual challenges of growth and development, children, adolescents, and young adults with the disease face emotional, social, and physical challenges, as well as practical challenges, that affect family, social, and working life and, for children and adolescents, life at school. Primary lymphedema is under-recognized and undertreated by the medical community, and people who live with the disease experience marginalization within the healthcare system (Bogan, Powell, & Dudgeon, 2007; Harding, 2012; Moffatt, Aubeeluck, Stasi, Bartoletti, et al., 2019; Moffatt & Murray, 2010; Todd, Welsh, & Moriarty, 2002; Waters, 2009). Currently, academic and medical interest in the lymphatics, lymphedema, and treatment for lymphedema is accelerating; medical and self-management options are expanding that can help people address the challenges of living with the disease.

Body Image Concerns

Scholars report that body image is a significant concern for people of all ages who live with primary lymphedema (Bogan et al., 2007; Greene, 2015; Hanson et al., 2018; Harding, 2012; Moffatt, Aubeeluck, Stasi, Mestre, et al., 2019; Moffatt & Murray, 2010, Smeltzer et al.,

1985; Todd et al., 2002; Waters, 2009; Williams, Moffatt, & Franks, 2004; Winch et al., 2016), especially for adolescents (Moffatt & Murray, 2010). Hanson et al. (2018), Harding (2012), and Moffatt and Murray (2010) report that children and adolescents hide their lymphedematous limb(s) and/or compression garments with clothing to avoid stares, intrusive questions, and stigmatization, and Waters (2009) and Winch et al. (2016) report the same about adults. Older adolescents (Hanson et al., 2018) and women (Winch et al., 2018) reported feeling self-conscious about exposing their limbs to intimate partners; young men reported sharing made-up stories about traumatic injuries causing their edema to avoid disclosing that they have a disease (Harding, 2012); and people of all ages express distress about the fashion constraints presented by the size of their lymphedematous limb(s) and/or their desire to hide their limb(s) and/or compression garments (Hanson et al., 2018; Harding, 2012; Moffatt & Murray, 2010; Todd et al., 2002; Waters, 2009; Williams et al., 2004; Winch et al., 2016).

Sadly, self-stigmatization is evident in the participant comments offered by many of the scholars reporting qualitative studies about the experience of living with primary lymphedema. Their participants used words to describe their limbs such as “ugly” (Bogan et al., 2007, p. 221; Hanson et al., 2018, p. 3; Harding, 2012, p. S4), “distorted” and “not like real legs” (Bogan et al., 2007, p. 220), “freak of nature” (Bogan et al., 2007, p. 221), “fat” (Hanson et al., 2018, p. 3), “disgusting” and “Michelin man” (Harding, 2012, p. S4) and inferred that, consequent to their appearance, “nobody will ever want to marry me” (Bogan et al., 2007, p. 218). One parent reported hearing her child say, “I wish I could chop this leg off” (Todd et al., 2002, p. 450).

Scholars report that child, adolescent, and adult research participants indicate that concerns with the appearance of their limbs affect decisions about what they do, often isolating themselves socially to avoid stigmatization (Bogan et al., 2007; Hanson et al., 2018; Harding,

2012; Waters, 2009; Williams et al., 2004, Winch et al., 2016). Newheiser and Barreto (2014) found that hiding chronic disease to avoid stigmatization may come at high emotional, social, and physical costs. Hanson et al. (2018) and Moffatt and Murray (2010) report that children and adolescents with primary lymphedema opt out of school and social activities to avoid exposure and stigmatization, and Bogan et al. (2007) and Waters (2009) report that adult participants with primary lymphedema indicated that, in their youth, they isolated themselves because of body image concerns, and that, in doing so, they may have altered the trajectories of their lives. Harding (2012), who focused on body image in her research with one woman and five men who had primary lymphedema, and Winch et al. (2018) who focused on body image and sexuality with women with primary and secondary lower limb lymphedema, recommend further research to enhance understanding of lymphedema and its effects on body image.

Self-Management Matters

Living one's daily life, according to standards for self-management published by the International Society of Lymphology (2016), is challenging and requires substantial time, energy, and financial commitment (Armer et al., 2018; Ridner et al., 2018). Schook et al. (2011) conclude that, if the condition is managed well, the age at which a child first experiences swelling will not influence progression and morbidity of primary lymphedema. Greene (2015) concurs and advises that effective self-management *matters*—dramatically contributing to maintaining the health and appearance of a 'person's lymphedematous limb(s). On the other hand, he warns, if a young person does not practice self-management effectively, their condition will progress—the limb(s) enlarging and skin changing—sending them further along the way toward a lifetime of disfigurement and disability. According to Milroy (1928), who studied a family with an inherited form of primary lymphedema, the disease does not shorten life

expectancy. With no available cure for lymphedema, self-management is an ongoing project that must go on for life—even a long one.

Scholars report that children and adolescents with primary lymphedema (Hanson et al., 2018; Moffatt, Aubeeluck, Stasi, Bartoletti, et al., 2019; Moffatt, Aubeeluck, Stasi, Mestre, et al., 2019; Moffatt & Murray, 2010), older adults with primary lymphedema (Bogan et al., 2007), and adults with breast cancer-related lymphedema of the arm (Ostby & Armer, 2015) report many challenges and barriers to self-management. These include the complexity of the treatment regimens, difficulty balancing time for treatment and life demands, lack of education and support, concurrent chronic diseases, symptom burden, and body image concerns. Parents report that their children resist self-management practices (Moffatt, Aubeeluck, Stasi, Bartoletti, et al., 2019; Moffatt & Murray, 2010; Todd et al., 2002) and the transition to adulthood seems to be a particularly vulnerable time during which adolescents with the disease struggle with adherence to self-management prescriptions while striving for independence (Hanson et al., 2018). Moffatt, Aubeeluck, Stasi, Bartoletti, et al. (2019) suggest that research priorities include developing a greater understanding of the self-beliefs that children and adolescents have about their ability to control their condition with self-management and its effects on their life. Hanson et al. (2018) suggested that prospective qualitative research studies could further examine the experiences of adolescents as they transition to adult care for their lymphedema.

Reaching adulthood does not reduce the struggle to self-manage for many people with primary lymphedema. Deng et al. (2015) report that only 68.9% of adult respondents with primary lymphedema ($N = 830$), most of whom reported lower limb lymphedema (96.7%), practiced at least one self-management modality daily, with less than half the respondents reporting that they wear compression garments (48.1%). The authors recommend exploring the

underlying reasons why some people with the disease conduct self-care, and others do not. They suggest that those who do not perform self-care may lack awareness of its importance, experience difficulty gaining access to necessary resources for self-care, experience time constraints, have limited ability to perform self-care due to other chronic conditions, and/or perceive that performing self-care in the past has not been beneficial.

Lymphedema: Paradoxically Ignored by the U.S. Healthcare System

Until the beginning of the 21st century, medical professionals knew little about primary lymphedema except for the chronic, progressive, debilitating, and disfiguring nature of the disease. In the United States, few people had an opportunity to see physicians who specialized in lymphedema or to receive treatment by therapists at dedicated lymphedema treatment centers, because so few centers existed (MacDonald, 2006). The medical treatments physicians offered were minimally effective, and self-management options were paltry. Like in the United Kingdom (Harding, 2012; Moffatt & Murray, 2010; Todd et al., 2002; Waters, 2009) young people with primary lymphedema who lived in the United States went undiagnosed for years (Bogan et al., 2007; Szuba et al., 2003). When finally diagnosed, physicians and family members encouraged people affected by the disease to "just get on with it" (Todd et al., 2002, p. 449) or directed them to "deal with it, nothing anyone can do, it's just one of those things" (Harding, 2012, p. S8). Physicians suggested that lymphedema was, simply, a cosmetic problem that did not warrant medical attention (Rockson, Granger, Skeff, & Chaite, 2004).

Researchers in the United Kingdom report that young people with primary lymphedema received inadequate treatment. Inadequate treatment led to more severe stages of the disease, rendering the visible effects irreversible, and subsequent treatment more complicated (Sitzia et al., 1998; Williams et al., 2004). No researchers have published qualitative studies about the

experience of growing up with and living with primary lymphedema in the United States. Bogan et al. (2007) conducted a related qualitative study with seven older adults with severe, debilitating noncancer-related lymphedema—three with primary lymphedema—who were undergoing intensive therapy at a U.S. hospital. However, consistent with studies about living with primary lymphedema in the United Kingdom, Ridner, Bonner, Deng, and Sinclair (2012) report that women's experiences with breast cancer-related lymphedema of the arms—the most commonly studied population of people with secondary lymphedema—reveal perceptions of marginalization from U.S. healthcare providers. The physicians, their participants claimed, are not well informed about lymphedema management, and they minimize the effects of the disease on their lives.

Authors Keeley and Moffatt (2018) suggest that lymphedema has been a neglected area of healthcare for a long time because physicians have considered lymphedema, from all causes, to be a rare condition. Moreover, they claim, many physicians fail to recognize the hidden mortality associated with complications such as cellulitis infections and sustain a nihilistic view that no effective treatment exists. Lymphedema is now recognized as a common disorder and is emerging as an important medical agenda (Rockson, 2018a). Nevertheless, paradoxically, the United States has not developed a strategic framework, or comprehensive, long-term strategy for diagnosing and managing lymphedema like the frameworks developed for other chronic diseases (e.g., diabetes mellitus, hypertension, etc.) (Stout et al., 2013). With no framework, people with lymphedema must rely entirely upon the expertise and attitudes of their physicians for diagnosis and treatment, educated in medical programs that devote thirty minutes or less to disorders of the lymphatic system (Rockson, et al., 2004). In their essay entitled *Medical Education: Deficiency or a Disgrace*, Vuong, Nguyen, and Piller (2011) write that until medical schools and/or

organizations concerned with lymphedema address this gap in knowledge and training, the lack of awareness about lymphedema will persist among healthcare providers, resulting in poor access to medical care. In the meantime, for people with lymphedema, navigating the U.S. healthcare system adds complexity to the onerous burden of self-management.

There is substantial evidence that decongestive lymphatic physiotherapy and effective use of self-management modalities, such as compression garments, can slow progression of primary lymphedema, mitigating the effect on appearance and symptom burden of lymphedematous limb(s) (Deng et al., 2015; Greene, 2015; Schook et al., 2011). Preventing deleterious effects of the disease, such as cellulitis and skin lesions, may also improve quality of life for people with primary lymphedema (Okajima et al., 2013). Despite the known benefits of treatment, the U.S. healthcare system denies access to treatments for large numbers of affected Americans, including the products designed to help manage lymphedema (Rockson, 2017). Specifically, Medicare, Medicaid, and many private insurance companies deny coverage for medically necessary compression garments (Background & History, n.d. Retrieved from https://lymphedematreatmentact.org/about-the-bill/background-information/). Paying for treatments and expensive products out-of-pocket can be a hopelessly insurmountable barrier to self-management for people with lymphedema.

People with primary lymphedema can mitigate the progression of the disease with effective self-management (Greene, 2015; Schook et al. 2011). Effective self-management can assuage body image concerns and the symptom burden of living with the disease in the present (Deng et al., 2015). Nevertheless, a substantial percentage of adults with primary lymphedema report less than optimal self-management. Investigating their self-beliefs about managing the disease and their views about the barriers and facilitators to practicing self-management may

increase understanding about the chasm that exists between self-management standards and self-management practices. Such understanding has practical implications for medical professionals, educators, counselors, and other stakeholders in the healthcare system.

Statement of the Problem

We understand little about the experience of children, adolescents, and young adults living with primary lymphedema except for concerns with body image, self-management, and marginalization within the healthcare system. The vast majority of studies about primary lymphedema are medical and/or quantitative research. What we understand about growing up and living with the disease in the United States we learned from hearing the stories of older people with disabling lymphedema (Bogan et al., 2007), who grew up well before the turn of the century, and who lived in different sociocultural and medico-historical contexts. Waters (2009) used an auto/biographical approach to illuminate the experiences of eight adults, ages 41 to 72, living with advanced and complicated lymphedema in the United Kingdom. No researchers have conducted life history studies to better understand the meaning of growing up and *living with* primary lymphedema, including the emotional, social, and physical challenges, or the challenges of self-management and navigation of the U.S. healthcare system.

There is a need to deepen, complicate, and enrich what we know about growing up and living with primary lymphedema. We need to hear the views of young adults living with the disease since their lifelong experiences with lymphedema correspond to the emergence of lymphedema as an important medical agenda in the United States. This problem needs attention because medical professionals, counselors, and educators must base their practices with children, adolescents, and young adults who have primary LLL almost entirely upon the experiences of adults with the secondary form of the disease, adults with arm lymphedema, older adults, or on

the experiences of people living with primary lymphedema in other countries with fundamentally different healthcare systems.

Purpose of the Study

The purpose of this qualitative research study was to collect, preserve, and understand the life histories of young adults who grew up with and are living with primary LLL in the United States and, in doing so, illuminate the ways in which lymphedema affects their lives within their sociocultural and medico-historical contexts. Developing the life histories of individuals who first experienced swelling as children and adolescents offered insight into the emotional, social, and physical consequences of their lymphedema to the trajectories of their lives. Developing their life histories also offered insight into their experiences with self-management and within the healthcare system as they moved through multiple stages of human development—industry vs. inferiority, identity vs. role confusion, intimacy vs. isolation—while *living with* primary LLL (Erikson, 1993).

Guiding Research Questions

Aligned with emergent flexible design in interpretivist qualitative inquiry (Patton, 2015), the overall research question that I used to serve as a navigational tool (Agee, 2009) was *How do women and men with primary LLL understand the experience of growing up and living with the disease against the backdrop of their sociocultural and medico-historical contexts?* I used the following sub-questions to direct the focus of the study:

1. What do the life histories of women and men with primary LLL reveal about how they make sense of growing up and living with the disease?

2. What do the life histories of women and men with primary LLL reveal about the challenges of navigating the U.S. healthcare system, and how those challenges shape their lives?
3. What do the life histories of women and men with primary LLL reveal about how they navigate the social and emotional challenges of growing up and living with the disease and negotiate the complexities of school, work, and relationships, and how those challenges and complexities shape their lives?
4. What do the life histories of women and men with primary LLL reveal about how they navigate the physical challenges of growing up and living with the disease and negotiate the complexities of self-management, and how those challenges and complexities shape their lives?

My personal experience as a nurse and person who lives with primary LLL, my review of the literature, and the purpose of the study drove the formation of these research questions.

Overview of Methodology

This research, analyzing the life histories of individuals who grew up with and are living with primary LLL, was informed by the theoretical perspective of interpretivism. According to Crotty (2013), the interpretivist "looks for culturally derived and historically situated interpretations of the social life-world" (p. 67). Interpretivism, grounded in social constructionism, proceeds from a set of epistemological assumptions that within a culture, people create their reality in relation to others. Life history research methodology, primarily situated within the interpretivist paradigm, enabled exploration of the lives of five young adults between the ages of 19 and 40 who grew up with and are living with primary LLL against the sociocultural and medico-historical contexts in which they live. The methodology offered a

retrospective view of the turning points, epiphanies, and transformations that changed their life courses while growing up with and living with primary LLL. Further, the methodology enabled illumination of the complexities, complications, and confusions of their day-to-day decision-making and the ultimate consequences that play out, shaping their limbs as well as their lives. In doing so, this study achieves insight into the broader collective experience (Cole & Knowles, 2001).

I solicited the participants' stories during three guided, dialogic interviews, or research conversations, typical of gathering life histories (Cole & Knowles, 2001), over five to 16 weeks. Additionally, to nuance and scaffold the retrospective life history interviews and aid in turning their life stories into life histories, I invited participants to share memorabilia such as documents, photographs, and other artifacts, related to their lives with lymphedema. These resources helped them add depth and detail to their stories. Between conversations, I offered the participants an opportunity to read and reflect on the transcripts of the conversations and adjust and expand the information contained therein. I kept a researcher self-reflexivity journal throughout the study to foreground key elements involved in being a research instrument (Patton, 2015), central to the qualitative process. Further, compelled by my emic perspective of the experience of growing up and living with primary LLL in the United States during the second half of the 20th century, I gave significant attention to exploring my positionality before beginning the research study. Throughout the recruitment, data collection, and analysis process, I took care to reflect upon my presence in the research relationship with participants. From here, I will refer to them as the "narrators" (Banister, 1999; Berger, 2015; Luttrell, 2000; Malacrida, 2007), to honor the gift of their stories to the study (Atkinson, 1995; Goodson, 2017).

Organization of the Study

This study consists of seven chapters. In Chapter I, I describe my entrance to the research topic, background to the research, purpose of the study, guiding research questions, and an overview of the methodology. Chapter II is a reflection on my positionality in relation to the research topic, providing a prelude to the literature review. In Chapter III, the Review of Literature, I provide an overview of primary lymphedema and situate the disease within a broader description of the lymphatics, lymphedema, and lymphedema treatment, with a focus on decongestive therapy and day-to-day self-management, the psychosocial consequences of the disease, and the sociocultural and medico-historical contexts of living with the disease in the United States. The chapter will serve to locate this study about primary LLL within the broader literature about the experience of living with primary lymphedema. The overview of the disease and its treatment provides a foundational understanding of the medical and personal dimensions of living with the disease for readers who are unfamiliar with the condition. I hope that by grounding the work of this study in the review of literature, implications related to these dimensions will become readily apparent in the narrators' life histories.

In Chapter IV, I describe the epistemology and theoretical perspective that undergird the research study, a description of the research methodology, and details of the methods I used to achieve an ethical, high-quality research study, with trustworthy findings. I include a reflection on my presence in the research relationship with the narrators, and acknowledge the limitations of the study. Chapter V contains the narrative portraits, or life histories, of the narrators who shared their stories, and in Chapter VI, I offer my analytical findings regarding their stories and interpretations, a collective life history. Finally, in Chapter VII, I summarize the study, answer

the research questions, offer implications from the data, and conclude with a personal reflection about my experience conducting the study.

It is my hope that this study provides glimmers of the experiences of children, adolescents, and young adults living with primary LLL in the United States. The narrators live with an incurable disease that affects their lives profoundly. They offered their life stories with humor, generous honesty, and earnest hope that their participation will improve the lives of others who grow up with and live with primary LLL.

CHAPTER II

RESEARCHER POSITIONALITY: THE STORY I FOUND

In this chapter, informed by an interpretivist approach which "looks for culturally derived and historically situated interpretations of the social life-world" (Crotty, 2013, p. 67), I represent the reflective work I conducted about my positioning in relation to the research topic *before* conducting this study. Reflecting upon my positionality in a dedicated chapter functioned for me heuristically to deepen investigation into how my positionality would shape the process and outcomes of the research (Banister, 1999). Once committed to this work, I recognized that the process of self-reflexivity is an integral part of the methodology (Finlay, 1998; Luttrell, 2010) since I am the main instrument for analysis (Patton, 2015). Moreover, regardless of the particulars of my positioning, as an analytic stance, reflexivity is a necessary strategy throughout this entire research study. Banister (1999) and Luttrell (2000) argue that one's positioning can shape assumptions about the research topic, participants, design, and orientation to the study. Therefore, from the beginning of this project, I followed the recommendations of methodologists in recording written memos about my thoughts and feelings related to each article and book chapter that I read, using them as prompts for autobiographical and/or autoethnographic reflections on my experiences of growing up and living with lymphedema. This chapter is a product of those reflective memos.

Similar to what Breen (2007) described about her experience of being the researcher "in the middle" (p. 165) while conducting her study on the experience of grief after a loss due to a vehicular accident, academic peers in my field of nursing initially challenged the credibility of

my research, implying that because I share group membership with the narrators in my study, my analysis is inherently biased. To these concerns, I respond with a reminder regarding the centrality of epistemology and theoretical perspective for governing assumptions about the process of acquiring or constructing knowledge in any study. That is, when operating from a constructivist-interpretivist paradigm, the research proceeds with the understanding that multiplicity of truths is presumed, reality is socially constructed, and relative, or "What is said to be the 'way things are' is really just 'the sense we make of them'" (Crotty, 2013, p. 64). In this vein, researchers and readers are naïve to think that not having primary LLL automatically reduces or eliminates bias. Further, from an interpretivist point of view, a researcher can never eliminate biases, and one's multidimensional positioning in the empirical world always informs the contours of a study. Nevertheless, my positionality is something with which I reckoned while conducting the recruitment, data collection, analysis, and interpretation process to achieve a trustworthy study. In Chapter IV, I discuss my strategies to mobilize feminist theory and ethics toward co-constructing meaning (Kiesinger, 1998; Kvale, 1996) with the narrators and how I addressed the concern of my positionality, including ongoing reflexivity.

Subjectivity and My Positionality

Ellis and Flaherty (1992) use the term *subjectivity* to refer to the notion of lived experience within physical, political, and historical contexts. Like Ellis and Flaherty (1992), John Gagnon (1992) connects intrapersonal aspects of subjectivity to the dynamics of social and historical forces and claims that if we are to understand lived experience, we must understand the narratives we tell about our experiences against the context created by those forces. According to Sparkes and Smith (2014), the connections between a researcher's self and the study are potent

forces that shape many aspects of conducting research and interpreting the findings. Related to subjectivity, Cole and Knowles (2001) acknowledge the autobiographical nature of all research:

> …we research who we are. We express and represent elements of ourselves in every research situation. The questions we ask, the observations we make, the emotions we feel, the impressions we form, and the hunches we follow all reflect some part of who we are as a person and researcher. (p. 89)

In life history research, as in other interpretivist approaches, researchers typically view their subjectivity as an integral aspect of being qualitative researchers that they should not only acknowledge and make explicit but view favorably (Cole & Knowles, 2001; Glesne & Peshkin, 1992) as a resource for understanding the phenomenon more intimately (Patton, 2015).

According to Cresswell (2013), all researchers bring values to a research study. In a qualitative study, the inquirers acknowledge the value-laden nature of the study and actively report their values and allegiances as well as the value-laden nature of information gathered from the field. In doing so, they position themselves in a study. According to Dwyer and Buckle (2009), a contemporary body of work and practice known as insider research "…elevates the person-hood of the researcher, including his or her membership status in relation to those participating in the research [as] an essential and ever-present aspect of the investigation" (p. 54). They forward the term, "the space between" (p. 60), to represent a concept rooted in the perspective that holding membership status in a group does not denote sameness, nor that *not* holding membership status in a group denotes complete difference. This conception supports the notion that a researcher can be both a member of and separate from the group under study.

There is overlap among many of my dynamic and fluctuating subjectivities. I am not just a woman with lymphedema, but also a woman with lymphedema who is a nurse with advanced

practice credentials, my knowledge and skills as a nurse contributing to how I manage and feel about my lymphedema and how I navigate the healthcare system. I am not just a researcher, but one who brings knowledge, skills, and ethical obligations related to my role as a nurse to the research context. My roles as researcher, nurse, and person living with lymphedema overlap partially, not completely, and do so, concomitantly. My positionality becomes even more complicated when I apply my background in educational psychology, also informed by the field of social foundations. For example, I view living with lymphedema through theoretical and social lenses such as social cognitive theory (Bandura, 1989), or feminist and critical disability theories, while daily, like the narrators in the study, I live with lymphedema amongst my own set of personal circumstances and life challenges. I acknowledge my privilege as a white American woman with social capital inherited from my parents. Equally important, I acknowledge that my education and middle class income facilitate navigation of the healthcare system to access the care I need to manage my lymphedema.

Reflexivity: Unpacking Researcher Baggage

In *Thinking Critically About "Social Justice Methods": Methods as "Contingent Foundations,"* Bailey (2019) claims, "Researchers are of course not simply efficient instruments of methodology but embodied actors in a network of intra-acting relations, materialities, contexts, and responsibilities that constitute methodological practice" (p. 95). Reflexivity, as well as the researcher's visibility and acknowledged presence in a research account, is one of the standards of "good" qualitative research that account for the embodied actor in the research role. Patton (2015) asserts that *reflexivity* means to "take the reflective process deeper and make it more systematic than is usually implied by the term *reflection"* (p.70), a process grounded in the in-depth, experiential, and interpersonal nature of the qualitative inquiry. It is through reflexivity

that researchers question and acknowledge their position, values, and pre-conceived beliefs about a particular experience (Trahar, 2009). According to Berger (2015), reflexivity:

> …means turning of the researcher lens back onto oneself to recognize and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation. As such, the idea of reflexivity challenges the view of knowledge production as independent of the researcher producing it and of knowledge as objective. (p. 220)

Like Berger (2015), my view of reflexivity aligns more with considering how we come to know and represent human beings and their experiences than as a tool for eliminating bias and improving observational accuracy that would characterize research governed by an objectivist epistemology and positivist or post-positivist theoretical perspective (Crotty, 2013).

Cole and Knowles (2001) encourage the researcher to "unpack researcher baggage" (p. 49) by writing a "personal history account of a segment of one's life for purposes of understanding oneself in relation to a broader context" (p. 49). They claim that the more detailed the account, the better it will help the researcher to gain insights into themselves as researchers. In the section that follows, I provide my personal history account, including images of me as a child and adolescent, that relates to growing up and living with lymphedema. In addition to my account, I layer "auto/biographical slices" (Bailey, 2005, para. 1) throughout the literature review to elevate information about lymphedema to the "flesh and blood of lived human experience" (de Chesnay, 2015, p. *viii*), and to represent my experiences alongside those of the narrators who participated in the study. Altogether, my narratives reveal to the reader my circumstances and pathway to this study, and how this research work interacts with and emanates from my own

experiences. This research was an intensely personal endeavor, nor did I pack lightly (Cole & Knowles, 2001).

My Lymphedema, Disclosed

In 1957, I was born, puffy-footed, but otherwise perfect to white, college-educated parents—a nurse and a Protestant minister—who intended to become missionaries in an undeveloped country. They were barely able to pay their bills but were employed, medically insured, and idealistic about the differences they could make in the world. They gave up their dreams after learning that I had lymphedema and raised me, along with my three younger siblings, in small-town, Midwestern America, with little regard to the lymphedema in my legs and feet.

I did well in school, academically and otherwise. I sang in the choir, performed in school plays, marched with the band, and played basketball. I enjoyed hiking and dipping my feet in cool mountain streams. I never really learned how to swim and never felt comfortable riding a bike. I earned my way to a Neil Diamond concert in the big city by selling print magazine subscriptions door-to-door. I loved Joni Mitchell, Bread, and *Johnathan Livingston Seagull* (Bach, 1970). I was grateful for bell-bottoms, granny dresses, and go-go boots. I liked my petite figure and the way my long silky hair glistened in the sun. Acne was hardly a concern, but I could not see without my hard, uncomfortable contacts or glasses. I struggled to understand the Viet Nam war and my favorite holiday was Earth Day. I sought refuge from the world in the keys of my piano, the strings of my guitar, and between the covers of a good book. I bossed my brothers around and antagonized my sister. I was an obnoxious thorn in my father's side and, though my parents did not agree on much, on this issue, they were united. I had a boyfriend in

high school and was devastated when he broke up with me. If asked, I would say that my childhood and adolescence were relatively normal despite my lymphedema.

After graduating high school, I attended a large university and earned my degree in business, a rebellion against the expectations of my family. Intent on re-imaging myself, as so many emerging adults hope to do when going away to college, I tucked my lymphedema into the closet and presented myself as "normal." A year after finishing my degree, I gave up my resistance to the historically gendered and socially subservient profession of nursing (Bates, 2010) that my family promoted and entered nursing school. Upon graduation, I took the Nightingale Pledge and donned the white cap with reluctance (Crow, 2017). For many years, I enjoyed practicing nursing in hospital medical-surgical and intensive care units as nursing developed into a profession that conducted interprofessional, collaborative care—and lost the cap. Often, I nursed people with chronic edema secondary to cancer treatment, injury, obesity, and other health-related problems. When hospitals switched to twelve-hour-shifts for nurses, I realized that I needed to find another way to nurse for the sake of my legs and feet. I returned to school to earn my Master's degree to practice as a cardiovascular clinical nurse specialist but then decided to teach in a nursing education program. For half my life, I enjoyed my practice as a nurse educator in an associate degree nursing program, helping non-traditional students to achieve their dreams. Overall, I have been fortunate despite my lymphedema.

My experiences as a child, adolescent, and woman who has lived/is living with primary LLL informed and infused, compelled, and confused my interest in the experiences of others who are growing up and living with primary LLL in today's socially mediated, internet

environment. This environment did not exist when I was growing up and making meaning of living with the disease, sometimes hiding, sometimes disclosing, and rarely wholly exposing my difference to others. I am and have been, as long as I can remember, conscious that I am different and must live differently than if I were not born with lymphedema. I devote significant personal resources toward managing the physical aspects of my disease and sometimes consciously, sometimes not, I devote significant cognitive and emotional resources toward managing the psychosocial aspects of living with the disease. This disease affects everything that I do and everything that I do affects the way that this disease manifests in me.

In 2015, while a physician who specialized in vascular medicine examined my legs and feet, and toes, I realized that ten or so years had passed since any of my healthcare providers requested that I remove my compression garments so that they could assess the skin on my lower limbs directly. I left the clinic feeling disappointed that the physician offered nothing beyond the prescription for decongestive therapy that I requested except for a warning to avoid infections. Her warning, I presumed, was triggered by what she saw of the skin on my feet and toes. I felt ashamed when I left her office. These experiences with my providers reflect participants' perceptions of marginalization reported in qualitative research about adults living with lymphedema in the United States (Bogan et al., 2007; Ridner et al., 2012). That is, non-specialist physicians have too little interest in lymphedema or time to stay up-to-date with emerging treatments, and view the condition more as an inconvenience or cosmetic concern for those afflicted than a potentially life-threatening disease. Particularly disturbing to me as a nurse educator is that nursing and medical education curriculum devote scant resources and time to providing care to people with lymphedema (Rockson et al., 2004).

I am most disappointed in myself. For long periods, distracted by other aspects of my life, I have failed to provide optimal care for my legs and feet. Consequently, after now sixty-three years with lymphedema, the changes on the skin of my feet and toes may be irreversible. However, I proudly claim <knock-on-wood> that, except for a plantar wart on the bottom of my foot, I have had no other infections in my legs or feet and, for the most part, have lived my life without interruption (Charmaz, 1991) from health crises related to lymphedema. Until recently, I am embarrassed to admit that, though a well-educated nurse, I failed to stay abreast of medical knowledge about lymphedema, and I have made minimal effort to access therapeutic modalities as they emerged.

When I read about the work of lymphedema advocates/activists, I feel chagrined that others have championed more for lymphedema research and reimbursement for treatments than have I, when, as a person with lymphedema, seasoned nurse, and nurse educator, I was well-positioned to participate in advocacy work. Until beginning this research study, I participated minimally in *Lymphedema World*, an emic term applied to the space on the internet, conferences, and advocacy events where people with lymphedema turn to one another for information and social support. I have since begun to embrace the opportunity to live openly in Lymphedema World. While conducting data collection for this study, I participated in the 2018 LE&RN Lobby Day and Walk, in Washington, DC, advocating for legislative funding for lymphedema research. In 2019, I joined the board of the Lymphedema Advocacy Group, and I participate in activities to encourage legislators to pass the Lymphedema Treatment Act (116th Congress: S. 518, H.R. 1948), which will require Medicare to cover the costs of compression. In the summer of 2019, after completing data collection for this research study, I attended the International Lymphedema Framework conference and met many scholars who write about lymphedema—my heroes.

Before I reached my 40s, I budgeted little of my time and attention toward caring for my legs and feet, long-resolved to the prevalent 20th-century medical attitude that one can do little about lymphedema and that lymphedema does not matter. Enabled by the relative stability of the condition in my legs and feet, I have grown comfortable in the mental fortress I have constructed to protect myself from vulnerability to stigma, disappointment with healthcare providers and therapeutic interventions, and anxiety about the future of my health. All told, at my current age, lymphedema is not necessarily the worst of my worries. I will more likely experience infirmity or death from other health concerns. However, lymphedema challenges my ability to address those concerns and I wonder how it contributes to those concerns.

Today, observing an expanding Lymphedema World on the internet, I watch, mystified, and discomfited, as people living with lymphedema choose to expose parts of their bodies on limited- and unlimited-access social media sites, static websites, and personal blogs, despite the stigma associated with disease and disfigurement. I know, in an embodied way, the emotional and physical burdens carried by people living with lymphedema. I know the labor and expense of the ongoing project of daily compression, remedial exercise and skincare, finding time for elevation, and using a lymphedema pump an hour almost every day. I know about arranging medical and decongestive therapy appointments, ordering compression garments and other medical supplies, fighting with insurance companies for coverage for tools to manage my lymphedema, and the logistical strategizing necessary to find adequate time to care for my legs while working full time, pursuing my education, and managing personal and family responsibilities. I know what it is like to dedicate seven weeks to wearing multi-layered bandages for 23 hours a day, after an hour of treatment by a therapist, five of seven days per week. I know what it is like to lie awake, hurting and frustrated, because I need to re-wrap the

bandages around my toes—requiring me to undo and redo all the wraps. I know insult-added-to-injury, makes-me-cry anger when taking time every year to obtain documentation from a healthcare provider to submit to my flexible benefits plan administrator that certifies I *still* have lymphedema—an incurable disease—when applying for reimbursement for compression garments for which I paid out-of-pocket because my insurance plan would not cover more than four pairs a year.

I know gratefulness that my physical situation is no worse than it is and that I have the education and financial means to seek treatment successfully—privilege and social capital others with lymphedema may not enjoy. I appreciate the patience that my family, friends, and others in my circle demonstrate with me despite this time-consuming, pursuit-challenging, obstinate disease that also, by association, imposes upon them. I view my discomforts as somewhat trivial since feeling well is typical for me. I think about health and illness as fluid, contextual, and contingent states that are not necessarily determined by the presence of symptoms or lack thereof (Harris, 2015). Like Inga Clendinnen (2001) states in her autobiography about being struck with an incurable liver disease, I resist biomedical diagnostic categorization as ill, and my understanding of lymphedema is informed more by "an array of embodied socio-cultural meanings and motivations" (Harris, 2015, p. 1697) than by what I read in medical journals. I view myself as more abled than disabled, more normal than not, with ample opportunity to improve my overall health, as well as the health of my legs and feet.

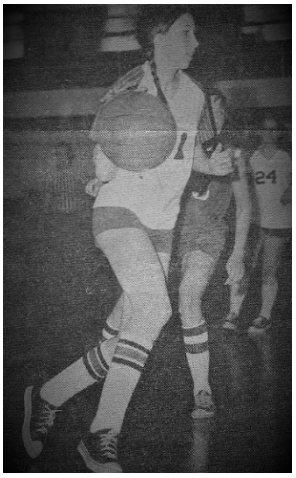
I know self-consciousness at the pool, in the locker room, at the shoe store, on the stage, and when in bed with a lover. I know the child whose mother scuttled her away after she pointed her inquiry and the flicker of eye contact with an adult at the moment she realizes my ankles are more than just thick. I know shame for being different and meta-shame (Ellis, 1998) for feeling

stigmatized about a relatively "picayune" (Goffman, 1963, p. 130) minor bodily stigma while others, far more afflicted than I, have little control over the exposure of theirs. From this embodied knowing, I believed that people who live with primary LLL have stories to tell about growing up and living with the disease—such as those people, like blogger Alexa, who expose themselves publicly while living privately with lymphedema.

My perspective, emic to the experience of growing up and living with primary LLL, motivates me to overcome the challenges of researching with people who have a rare disease. I assert that one reason few scholars conduct this research is that, spread thinly, we are an inconvenient population to sample and we make ourselves available to researchers via few-and-far-between treatment clinics, only after our lymphedema becomes advanced and complicated (Bogan et al., 2007). Most lymphedema scholars focus on symptom burden, quality of life, and treatment outcome measures—all important concerns to me. Nevertheless, I am motivated to focus on what has plagued me most about lymphedema. That is, I feel plagued with the relentlessness of living with it in a world mediated by a fashion- and body-conscious culture and the on-going project of self-management, all of which is relatively invisible to medical professionals and others around me.

At first, I resisted this study, understanding that, ethically, to undertake this work, I must disclose that I have lymphedema (Patton, 2015). Most of my life, I avoided complete exposure of my legs and feet, even to those with whom I was intimately or medically involved. Social circumstances that may expose my lymphedematous legs and feet are particularly challenging for me. For example, at the backyard pool party, I would rather stand out from the crowd by sitting in the shade in pants and shoes than to stand out from the crowd by joining in the fun—my legs

and feet exposed. Truth be told, because of the awkwardness of the situation, I would rather forego the event altogether, but I am there for the people I love.



At times my motivation to pursue life overcomes my motivation to avoid exposure, such as when I played high school basketball in shorts and bright white, knee-high "tube" socks that emphasized the size and tree trunk shape of my ankles. Not so long ago, I lounged on a beach in Jamaica, knowing that, while there, the only thing that mattered was sharing the sand and surf with my family—most of the time, my feet bare, but buried in the warm sand. These situations warranted the risks of exposure in my "impression management" plan (Goffman, 1963). In Erving Goffman's (1963) terms, to pass as normal is something for which I usually strive. Concealing my lymphedema is a form of controlling my body and my social identity (Charmaz, 1991; Frank, 1997). However, this control comes with costs (Newheiser & Barreto, 2014)—costs I sometimes regret. Self-limiting my choices have negatively affected my educational and social opportunities, my career, my relationships, my physical and emotional development, and, ultimately, my identity.

Researcher self-disclosure to participants and in publications, such as this chapter, is typical and expected in interpretivist research that draws on feminist approaches (Finlay & Gough, 2008), but this does not allay my anxieties about intra-disciplinary critique (Bishop & Shepherd, 2011) from fields less familiar with interpretivist approaches. Nor are my anxieties allayed about exposing my bodily vulnerability and undoing any of the notions of the normative body that others may yet hold about me. In an early proposal related to this research topic, I wrote that it would be necessary for me to undertake a reflective process that may be uncomfortable at times. To that, my advisor replied, "Yes, if it is to be meaningful and life-

changing for you" (L. Bailey, personal communication, May 07, 2015). At the time, I was not yet ready for life-changing regarding my lymphedema and I needed to do emotional work to propose and move forward with this study.

Goodall (2009) writes that research conducted in association with narratives contributes to our knowledge about how we do the work of being human and try to make sense of it. He claims that narrative is an epistemology or a way of knowing and that in his search to understand more about life with his father, "Telling the story as a story as a quest of knowing, became the act of knowing itself, that was what I needed and, that story is what I found" (p. 15-16). I wrote my way to emic to the topic of this research, that was what I needed, and the story is what I found. Now that I have finished the study, I believe that not to have conducted the study would represent a significant cost to the meaningfulness I have come to ascribe to being stuck with the unfortunate disease of primary LLL. This dissertation is one of those times that, along with the narrators, I chose to disclose my disease. It was life-changing, and I believe, disclosure was worth it.

Conclusion

In this chapter, I offered a transparent view of my positionality in relation to the research topic, as well as my perspective on researcher subjectivity and reflexivity. Waters (2009), writing biographies of adults with primary lymphedema, expressed concern that insider-researchers sometimes experience criticism for being advocates, rather than legitimate researchers. She wrote that while finishing her dissertation, she "became unwell with a condition which may predispose me to secondary lymphedema" (p. 161) and that she felt less powerful in her ambition to lobby on behalf of those with lymphedema because "it is acceptable to do battle on behalf of others but not for oneself" (p. 161). I do not share her concern regarding lobbying on behalf of

others with lymphedema, nor even for myself. Many researchers, such as Harris (2015), Kiesinger (1998) and Malacrida (1998), who write about conducting studies about diseases and disorders that they shared with their participants, inspired me to do this study, in hopes that I will help others with primary LLL. I took the words of Peshkin to "capitalize on rather than exorcise" (Glesne and Peshkin, 1992, p. 104) my subjectivity as a way into conducting this research—a long-overdue study.

CHAPTER III

REVIEW OF LITERATURE

There are three parts to this chapter. In the first part, an overview of the medical aspects of living with lymphedema, I describe the lymphatic system and the condition of primary lymphedema. I also include a description of the medical treatments and self-management of the disease. By devoting a significant part of this chapter to the complex medical aspects of primary lymphedema, I provide the reader with foundational knowledge about the experience of *living with* the tenacious, time-consuming, and tedious medical aspects of the disease. In the first part of the chapter, I emphasize key biological terms with italics to alert the reader that a definition follows. In the second part of the chapter, I provide an in-depth review of qualitative research studies published about the experience of living with primary lymphedema to foreground the findings from this study.

In the third part of the chapter, I extend the background in the introductory chapter to provide a brief discussion about the contextual factors related to living with lymphedema in the United States as the last half of the 20th century merged into the 21st, and through the first two decades of the century, to provide context for the lives of the narrators. I hope that, upon reaching the end of the chapter, the reader has developed a sense of urgency about the level of opportunity available to people to mitigate the insidiously progressive nature of lymphedema and live well with the disease. My overall purpose for the review of the literature is to facilitate the reader's understanding of the physical and psychosocial consequences of the disease, provide a contextual frame for the experience of growing up and living with primary LLL, and provide the

salient factors relevant to the design of the study. All parts of this chapter are a prelude to the broader scope of a more comprehensive project about living with primary LLL in the United States, intended to be helpful to people with the disease or caring for people with the disease.

I layer "intertexts" (Lather & Smithies, 1997, p. *xvii*) throughout the chapter—single-spaced blocks of text set apart with italic emphasis. The intertexts are auto/biographical slices (Bailey, 2005, para. 1) and excerpts from my researcher journal that are narratives about my experiences with primary LLL. Lather and Smithies (1997) considered such intertexts as "bridges and breathers" (p. *xvii*) necessary to foreground researcher investments central to the feminist research project they undertook related to women living with HIV/AIDS (Lather & Smithies, 1997). My intent is for the intertexts to serve as a mechanism to enhance the reader's understanding of the clinical facts that I provide—to give those facts life (de Chesnay, 2015)—while providing a breather from the dense biological and medical facts contained in the chapter. By including these intertexts, I extend disclosure of my positionality in relation to the research topic.

The Lymphatic System and Primary Lymphedema

Lymphedema is the most commonly encountered disease state of the lymphatic system and affects as many as 140 - 240 million people worldwide (Rockson, 2018a). The lymphatic system is one of the least well-known systems of the human body. Since the turn of the century, scientists have developed technology that enables them to view the tiniest parts of the lymphatic system. Consequently, scientists have greatly expanded the knowledge base about the lymphatic system and the condition, lymphedema. In this section, I provide a brief description of the lymphatic system and lymphedema, with a focus on primary lymphedema, and the standard, conservative treatments and self-management prescriptions.

The lymphatic system plays an essential role in circulation, as well as defending the body against infection and illness. Here, I provide a brief overview of the lymphatic system's role in circulation, and later I will discuss how an impairment in the lymphatic system affects the ability to defend against infection. With a normally functioning lymphatic system, the outward flow of fluids from the bloodstream to the interstitial spaces slightly exceeds the inward flow from the interstitial spaces back into the bloodstream. The lymphatics take up the leftover fluid and filtrate the body produces and it flows toward the heart and re-enters the bloodstream to circulate. Since the fluid flows in one direction in the lymphatic system, scientists and healthcare providers commonly describe lymph flow as *lymphatic drainage*. An emic way that people describe the lymphatic system is to call it the sewer system of the body because it removes cellular waste. When the "sewer system" does not drain adequately, as with lymphedema, a protein-rich fluid containing cellular waste products accumulates in the *interstitium*, the contiguous space surrounding the cells. As the fluid and waste products accumulate, the affected body part swells. The emic term people use to describe the mixture of fluid and waste products left behind in the interstitium in stasis is *sludge*. For an extended description of the lymphatic system, see Appendix A.

Lymphedema is a condition that occurs whenever the transport rate of interstitial fluid through the lymphatic vasculature is unable to accommodate the rate of interstitial fluid production. Physicians and scientists have established a conventional distinction among primary and secondary causes of lymphedema. *Primary lymphedema* is caused by abnormal development and/or dysfunction of the lymphatic system due to intrinsic or unknown factors. *Secondary lymphedema* is associated with direct invasion by cancer and/or obstruction of the lymphatic vascular channels and nodes by a tumor or because of infection, trauma, obesity, or treatment for

cancer. Recently researchers suggest that the boundaries that separate the categories of primary and secondary lymphedema may be indistinct. For example, primary cases often declare themselves after a secondary provocation (Rockson, 2018a).

Primary Lymphedema: A Rare Disease

In this section, I focus on the disease of primary lymphedema: prevalence, classification, etiology. I follow with sections about progression of the disease, symptom burden and complications, and self-management prescriptions. I end this section with brief descriptions of several forms of secondary lymphedema, a much more common form of the disease, to provide perspective for how public understanding of various forms of secondary lymphedema may affect the ways that people with primary LLL view their disease and how others may view them.

Physicians can diagnose primary lymphedema by history and examination. People may experience delayed diagnosis because onset can be insidious and progression slow (Mortimer et al., 2018; Schook et al., 2011). When examination findings are equivocal, physicians can use imaging techniques, such as lymphoscintigraphy to confirm the diagnosis. The technique allows the nuclear radiologist to view detailed images of the lymphatic system. Physicians may perform diagnostic testing to rule out other diseases that may cause edema. For people who have family members with lymphedema, they may recommend genetic testing. Diagnosis does not require investigation by a specialist, and the wait to see a specialist may translate to delayed treatment (Szuba, 2018), not to mention the expense of travel and more medical fees. Understanding prevalence, classification, and etiology may be helpful in the diagnostic process.

Prevalence of primary lymphedema. Smeltzer et al. (1985) estimated that primary lymphedema affects 1-1.5 per 100,000 persons in the U.S. less than 20 years of age. The authors based their estimate on an extrapolation of the number of cases diagnosed with primary

lymphedema amongst the average population of Rochester, Minnesota, between the years of 1955 and 1974, providing 355,470 person-years of observation. The formula the researchers used to make their estimate helps put the rarity of the disease into perspective. There were only four cases diagnosed in persons under age 20 for all those person-years during the twenty years.

Since the study by Smeltzer et al. (1985), discovery about and classification of primary lymphedema have yielded significant changes in understanding about the disease. Rockson and Rivera (2008), referencing small observational studies that estimate prevalence (Sitzia et al., 1998; Williams, Bergl, & Twycross, 1996) indicate that the condition is "neither common nor rare" (p. 148). Government agencies track only a few types of rare diseases. Because primary lymphedema may develop after birth, it is difficult to determine the exact number of people who are affected. Consequently, scholars understand the prevalence in the United States no better than when Smeltzer and colleagues published their study in 1985. Nevertheless, in 2018, Keeley and Moffatt claimed that primary lymphedema is a rare condition.

Classification of primary lymphedema. Although newer classification systems exist that scientists base upon observable characteristics and genetic studies, healthcare providers continue to use developmental terminology to define the onset of primary lymphedema: infancy (birth to 1 year), childhood (1 to 9 years), adolescence (10 to 21 years), or adulthood (> 21 years) (Greene & Schook, 2012). I based the participation criteria for my current research study on this classification system, recruiting only participants who developed lymphedema before 22 years of age. As it happened, recruitment yielded five narrators who first experienced swelling during childhood or adolescence, but not during infancy or at birth, as I had.

Schook et al. (2011) reviewed 138 records of children with onset of lymphedema before age 21, seen in their clinic over ten years. The authors found no significant gender difference

among the cohort. Age of onset was infancy, 49.2%; childhood, 9.5%; or adolescence 41.3%. Boys most commonly developed swelling in infancy (68%); girls usually developed swelling during adolescence (55.3%). Lymphedema involved an extremity (81.9%), genitalia (4.3%), or both (13.8%). The condition affected the lower limb(s) most commonly (91.7%) and 52.9% of the patients evaluated had bilateral disease (Schook et al., 2011).

Etiology of primary lymphedema. Discovery of the genome at the turn of the century, as well as advances in imaging technology, have enabled researchers to classify over 20 types and sub-types of syndromic and non-syndromic primary lymphedema (Connell et al., 2013). However, much uncertainty about the etiology of the disease and whether a person with primary lymphedema can pass it on to the next generations remains. Primary lymphedema occurs as sporadic (scattered or isolated) and hereditary (regularly occurring) types, as well as types that are associated with syndromes, in which lymphedema is not the predominant symptom. In 2018, Mortimer et al., reported that scientists had discovered 12 genes that cause non-syndromic and syndromic conditions where the dominant feature is lymphedema. The mode of inheritance can be variable. If only one parent passes a disease-causing gene on to their child, the genetic mutation is autosomal dominant. If both parents must pass on a gene to cause disease, the genetic mutation is autosomal recessive. Another possibility is that individuals may have a *de novo mutation*, a genetic mutation that is present for the first time. Parents with a de novo mutation can pass lymphedema on to their children (Mortimer et al., 2018).

An individual can inherit a disease-causing mutation for lymphedema that does not express, or never manifests. In such cases, the individual may pass the gene on to the next generation, with the possibility that lymphedema will manifest. Moreover, there may be variable expression within families, with different members of the family experiencing differences in

severity and manifestations of lymphedema. Scientists do not know the precipitating factors for the manifestation of the overt appearance of primary lymphedema. However, with many types of the disease, there may be a protracted phase of apparently normal lymphatic function (Mortimer et al., 2018).

When I was about fifteen months old, my parents took me to Texas Scottish Rite Hospital for Crippled Children, searching for answers about my swollen feet. My parents told me that the physicians conducted several tests, including a biopsy of the skin on my shin. The physicians informed my parents that, based on the biopsy, I had no lymphatic vessels below my knees but that everything else was okay. The diagnosis they offered was Milroy's disease, though no one else in our family displayed the symptoms of the disease for which scientists had established an autosomal dominant inheritance pattern. With this in mind, my Mother doubted the diagnosis. She has since wondered if she did something to cause my lymphedema while she carried me inside her womb.

Most of my life, I have wondered why lymphedema happened to me and whether I could pass it on. The most glorious words I have ever heard came after my obstetrician delivered my daughter. She said, "Debbie, your daughter is beautiful, and her feet are perfect."

Progression of Primary Lymphedema

Before the 21st century, scientists, physicians, and lay people considered lymphedema to be a static condition—one of simple lymph fluid stasis that results in larger than normal limb girth. Throughout the last decade, they have come to understand lymphedema as a dynamic, ever-evolving interplay between the lymphatic system and the entire soft tissue of the affected region. Since recognizing the progressive and degenerative nature of the disease, physicians and people with lymphedema understand that they can mitigate progression and manage the disease to avoid disfigurement and disability.

Usually, with primary LLL, swelling starts at the dorsum, or top, of the foot and around the ankle. In the beginning, the swelling may recede at night, and return by the end of the day. Of the original cohort of patients (N =138) studied by Schook et al. (2011), 85% followed up at the clinic an average of 7.3 ± 9.2 years later. A review of their records revealed that over one-half of

the patients (57.9%) experienced enlargement or worsening of symptoms and 23 percent of the patients who first presented with unilateral lower extremity lymphedema subsequently developed bilateral disease. The authors found that the age of onset did not influence the progression and morbidity of the disease. Only two of the patients developed functional impairment.

Progression of the disease occurs because lymph stasis affects the behavior of the tissue cells in the affected region, resulting in the activation of inflammatory processes that lead to disfiguring changes and increase the risk for infection. Beneath the skin, inflammatory processes encourage the development of *adipose cells* or fat. In addition to adipogenesis, inflammation contributes to the thickening of the connective tissue surrounding the lymphatics and the lymphatics become progressively *fibrosed* (scarred) and occluded, further reducing the uptake of lymph by the lymphatics. Over time, the adipose deposition and tissue fibrosis contribute to an increase in the size of the affected region, which becomes less responsive to conservative treatments. Lymphedema is not just fluid, like with other types of edema, but also proteins, fat, and other cells the lymphatic capillaries are unable to drain due to the impaired lymphatic system. These other cells convey a more "solid" texture to the edema, and it is difficult to displace the tissue by applying pressure. When tissue can be displaced, medical professionals refer to it as *pitting* (Mortimer, 2018). An emic way of describing the quality of the tissue of a region affected by lymphedema is to say that it is "hard" or "soft." When narrator Arial references the quality of the tissue of her leg affected by lymphedema, she shares that on a "bad day," it feels hard, and on a "good day," it feels soft.

Several visible signs on the skin provide evidence of the progression of the disease. *Dermal lichenification* occurs due to overproduction of keratin in the skin, causing an increase in skin thickness and exaggeration of the usual skin markings—such as cracks, wrinkles, or

scales—giving skin a leathery or bark-like appearance. *Exaggerated skin folds* formed by bulging skin, and subcutaneous tissue may follow. When excessive in size, under the influence of gravity, the skin folds, referred to as massive localized lymphedema, can become pendulous and impair mobility. *Skin fissures* are breaks in the epithelium that develop between the adjacent skin lobules at the fold (Mortimer, 2018). The slit-like fissures in the skin can be superficial or deep, and are prone to breakdown and moisture accumulation, increasing the risk for infection (Fife et al., 2017). *Papilloma,* wart-like protrusions, caused by expanded or dilated lymphatic capillaries, develop over time. Papilloma can range in size from only a few millimeters to larger than a person's toes (Mortimer, 2018).

The medical community refers to the exaggerated skin creases, hyperkeratosis, and papillomatosis that develop as lymphedema progresses as *elephantiasis* because the changes bring elephant hide to mind. Elephantiasis is an animal eponym—typical of many that dermatologists use to help them distinguish between diseases (Jindal, Jindal, Kumar, Gupta, & Jain, 2014). A particularly distressing symptom of lymphedema is lymphorrhea, a watery fluid that leaks from engorged lymphatic capillaries in the dermal layer of the skin. These engorged lymphatics may or may not be visible. If not, the person experiencing lymphorrhea may not be able to identify the source of the fluid but will only be aware of a watery fluid leak (Mortimer, 2018). Lymphorrhea is challenging to absorb with dressings. Consequently, lymphorrhea is disruptive to a person's daily routine until it resolves.

Symptom Burden of Primary Lymphedema

Traditionally, scientists and healthcare providers have viewed lymphedema as a non-life-threatening diagnosis with the potential for serious complications (Rockson, 2018a). Researchers have illuminated a broad constellation of symptoms common to people with lymphedema. Work

by Viehoff et al. (2015a, 2015b) suggests that some symptoms may be universal regardless of the type of lymphedema, while others may be unique to the area of the body affected by lymphedema. Recently, the internet has enabled researchers to recruit substantial sample sizes of people with primary lymphedema to survey studies administered online, and generate findings about symptom burden.

Lymphedema is a multidimensional disease, with symptoms in the physical and psychosocial domains, and its signs and symptoms exceed circumferential or volumetric increases in limb size. For example, the tonicity or firmness of the swelling may affect levels of pain and discomfort, or the ability to move the affected body part (Schrale & Ryan, 2011). It is possible to experience lymphorrhea and skin changes without an increase in circumferential change, which can contribute to infections (Carlson, 2014). The most common physical symptoms reported by participants with primary lymphedema who responded to a survey administered online by Stolldorf, Dietrich, & Ridner (2016) included swelling, heaviness, tightness, pain, and fatigue. Common (≥ 66%) psychosocial symptoms reported included concerns about looks, decreased physical activity, and sadness. Respondents reported the highest median levels of intensity and distress in the areas of health insurance, body image, and sexuality. Other common symptoms reported included hardness. Less common, but frequently reported (≥ 50%) symptoms by the group include achiness, lack of self-confidence, lost body confidence, can't do hobbies or leisure activities, and less social activities.

Recurrent soft-tissue infection is one of the most troublesome aspects of lower limb lymphedema. The skin constitutes the first line of defense against infection. Changes in the skin result in failure to defend against pathogens. Once bacteria gain access to the interstitial spaces, it thrives in the protein-rich fluid contained within those spaces. Further, lymph drainage plays

an essential role in tissue immunosurveillance. Consequently, people with lymphedema are at particular risk for infection of their affected region(s) (Fife et al., 2017).

Cellulitis is a sudden, noncontagious, bacterial infection of the skin, characterized by redness, swelling, and heat, accompanied by pain and tenderness. Cellulitis can be challenging for healthcare providers to distinguish from other causes of inflammation. Providers treat cellulitis with oral, or if necessary, intravenous antibiotics. Cellulitis can become systemic and life-threatening and require hospitalization (Mortimer, 2018). Authors (Deng et al., 2015; Okajima et al., 2013; Schook et al., 2011) report that between 8.8% to 44.8% of people with primary lymphedema experienced at least one episode of cellulitis. Deng et al. (2015) also found that 27.1% had experienced at least one hospital admittance due to cellulitis. Fungal infections, such as *tinea pedis* (athlete's foot), and viral infections, such as *human papilloma wart virus* (plantar warts), may be challenging to avoid and resolve as well (Mortimer, 2018).

Conservative Management of Primary Lymphedema: An Ongoing Project.

Due to the condition's progressive nature, early treatment offers the best outcome and with no cure, self-management must go on for life. Self-management for lymphedema represents a significant burden (Armer et al., 2018; Ridner et al., 2018). In this section, I provide an overview of physiotherapy treatment and self-management practices to emphasize the complexities involved. Unless otherwise noted, I draw from *Lymphedema Management: The Comprehensive Guide for Practitioners* by Zuther and Norton (2018) for the content in the overview.

Complete decongestive therapy. Physicians may prescribe complete decongestive therapy (CDT), a noninvasive, multi-component approach to reducing the volume of the lymphedema that has accumulated, before fitting a person with compression garments. The

treatment approach consists of two phases, an intensive phase, conducted by a certified therapist, and a self-care or maintenance phase, conducted by the person with lymphedema and/or their caregiver. Scientists have not been able to describe the exact mechanisms of the two phases of CDT but the underlying pathophysiological foundation of CDT supports that both phases may be able to (a) improve the function of lymphatic vessels, (b) soften the fibrosclerotic indurations (scarring), (c) reduce increased connective tissue, (d) cleanse the skin to prevent opportunistic infections, and (e) reduce associated symptom burden.

Intensive phase. The intensive phase of CDT consists of manual lymph drainage (MLD), skin/nail care, multi-layer, low stretch bandaging, and exercises. Ideally, therapists schedule sessions daily, five days a week, for four to six weeks, depending upon the severity of the lymphedema. During each session, the therapist conducts manual lymph drainage (MLD), a hands-on treatment using a light pressure to encourage the movement of lymph from a swollen body part to a region of the body where normal lymphatics can uptake lymph. Therapists also encourage exercises consisting of abdominal breathing and muscle contraction and relaxation, intended to facilitate lymphatic flow in the abdominal area. Therapists perform skin and nail care following MLD, and then they bandage the affected region with multiple layers of bandages to prevent reaccumulation of lymph between treatment sessions. The person in treatment may wear the bandages for almost 24 hours, taking them off only long enough to bathe and return for the next session. The therapist teaches the person with lymphedema, or their caregiver, to apply the wraps on days no therapy sessions are scheduled. Toward the end of the intensive phase, the therapist measures their client for compression garments.

At the end of the intensive phase of therapy, the person should have the necessary skills to perform exercises, skincare, self-MLD, and bandaging independently. People are more likely

to adhere to therapy if they hold enough knowledge regarding their condition. Zuther and Norton (2018) recommend teaching people about the causes of lymphedema to help them fully understand why self-management is necessary and recommend informing people about the consequences of *not* practicing self-management, as well.

In 2005, I completed seven weeks of decongestive therapy—one hour, five days a week. Every morning, an hour before my treatment, I removed my wraps and took a shower, while my husband and 13-year-old daughter re-rolled the eight short-stretch bandages (5 meters), four cotton battings (5 meters), and two long, gauze toes wraps (4 meters) to facilitate reapplication by my therapist. I was fortunate to have the summer off from work to devote to this therapy and get back on track with managing my lymphedema. Sequestering myself at home in the bulky, hot wraps, I busied myself with indoor projects, including painting three different rooms. By week seven, we saw a significant reduction in the volume of my legs, improvement in the condition of the skin, and, on my wraps, four different colors of paint.

Maintenance phase. The person with lymphedema conducts the maintenance phase of decongestive therapy beginning immediately after completion of the intensive phase. Their goal is to prevent reaccumulation of lymphedema with consistent, diligent self-management. Ideally, the person or their caregiver should perform the MLD protocol that they learned from the therapist during the first phase of CDT, at least once a day for 10 to 15 minutes, directly preceding the exercise program and skincare the therapist taught them and followed by donning of compression.

Compression garments are medically necessary to prevent the re-accumulation of fluid in the tissues. Medical grade compression varies greatly from non-prescription garments that are available from a local pharmacy. Medical grade compression features gradient pressure rather than localized areas of higher pressure, and higher overall levels of compression. Manufacturers measure the compression in garments in millimeters of mercury (mmHg). The higher the pressure is, the tighter the garment will fit, and the more difficult they are to don and doff. There are different compression levels (15-20 mmHg, 20-30 mmHg, 30-40 mmHg, and 40-50 mmHg),

depending on the person's needs. For a point of reference, the anti-embolism compression garments that healthcare providers prescribe to prevent blood clots provide only 10 to 15 mm Hg pressure, and athletic tights may go as high as 20 mm Hg of pressure, but usually do not contain gradient pressures.

By using made-to-measure garments, commonly referred to as "custom" garments, the therapist can provide optimal fit and order gradually reduced sizes of the garments to fit the lymphedematous limb(s) as they reduce in size. To assure an effective and more comfortable fit, a therapist or certified compression fitter may require measurements with each new compression garment order, necessitating at least one office appointment, extended delivery time, and additional expense. On the other hand, standard size compression garments are available from durable medical supply stores and, if online, ship quickly. Standard size compression comes in fewer widths and lengths, and measuring for fit is more straightforward than measuring for custom compression garments. However, standard size garments are not sufficient nor comfortable for every person with lymphedema. Standard size garments come in a relatively wide range of colors and are less expensive than made-to-order garments. Manufacturers recommend that people wash their compression garments daily to help retain their elastic properties as well as remove perspiration, oils, dirt, bacteria, and dead skin that accumulate inside the garment from normal wear.

My preferred pair of compression garments (knee-high, 20 – 30 mm Hg) costs approximately $85.00 a pair. My insurance company will pay for two pairs of compression garments every six months. Fortunately, I can afford to purchase several more pairs per year to reduce the frequency with which I do laundry, and all my pairs of compression retain efficacy for a longer time since I wear each pair, in rotation, less frequently. The typical color range for compression is black, beige, chestnut, chocolate, cinnamon, and white. Some styles come in colors such as amethyst, cool gray, magenta, pewter, pink, royal blue, and navy blue. Joy!

Manufacturers and therapists recommend that people avoid wearing compression garments at night because they may compromise blood circulation with leg elevation. Consequently, to maintain the effect of therapy, people with lymphedema must wrap their legs with multiple-layer bandages when not wearing compression garments. Alternatively, they can wear compression alternatives to save time and increase comfort. One type of device, developed since the turn of the century, provides gradient compression with nonelastic, adjustable bands working on the hook-and-loop principle. Another type of compression alternative, sometimes referred to as a nighttime garment, is a custom fit boot that contains foam chips within the layers of the garment. The chips help to break up fibrosis and channel lymph fluid toward functional lymphatics. Compression alternatives are custom-made and expensive.

Miscellaneous self-management practices. People take up a variety of practices for optimal self-management of lymphedema that are not included as necessary components of CDT. I include some of the recommended practices here.

Sequential intermittent pneumatic compression. Pneumatic compression devices administer intermittent pressure via a multi-chambered sleeve that goes over the affected region to facilitate the movement of lymph toward a region with functional lymphatics. People use their pumps for one to two hours per day, one or two times a day.

Elevation. A person with Stage I lymphedema may be able to reduce the volume of their lymphedema with simple elevation at night. People, regardless of the stage of their lymphedema, should elevate their limbs whenever possible to reduce hydrostatic pressure and may find the practice helps to reduce symptom burden.

Nutrition and hydration. Researchers have been unable to provide evidence to support a specific diet for lymphedema. However, therapists recommend a balanced diet to achieve and

maintain a healthy weight to reduce the risk factors associated with obesity. Even though lymphedema is a high-protein fluid, there is no need to restrict protein. Restricting water will not help and may worsen the lymphedema.

Risk reduction. Cellulitis is an ever-hovering threat for people with lymphedema—especially for people with leg lymphedema. I provide a short, but representative, list of actions that Zuther and Norton (2018) recommend to reduce risk: Avoid walking barefoot, scratches from pets, cutting cuticles, scrubbing the skin, ice and heat packs, saunas, hot tubs, whirlpools, hot showers and baths, massage, cosmetics that irritate the skin, sunburn, clothing and jewelry that is too tight, and…the list goes on. In addition to the list of things to avoid, the authors recommend using insect repellants and sunscreen and carrying an alcohol swab, antibiotic ointment, and dressing. Risk reduction requires people to adjust their lifestyles and plan thoughtfully for activities. In my study, for instance, narrator Audra adheres to most of the "avoids" her therapist taught her but continues to go to a carefully selected salon for pedicures with a technician with whom she nurtured a trusting relationship. She exclaimed, "Lymphedema takes everything, not this, too!"

My mother wrapped my legs and feet in elastic wraps bandages while I was young. Eventually, she gave up her effort to keep my legs and feet compressed, and by the time I started first grade, I was no longer wearing compression. At that point, I believe my mother was happy to help me avoid trauma to my skin. I remember her screaming at me one summer afternoon as I climbed through a rusty, barbed-wire fence while wearing shorts, intent on joining my friends in the wooded area behind our house. At the time, I did not understand either the fear behind her scream or the dimension of mothered watchfulness and anticipation that my lymphedema added to her life.

I have since taken up the emotions my mother projected that summer day, and I am ever conscious of the potential danger to my feet, especially when bare. Almost every day of my life, I have felt a little anxiety about the water temperature when stepping into the shower or tub. Most of the day, I wear compression and/or shoes. When I go bare, which is not often, it feels delicious! I love the coolness of my tile floors, the tickly swish of my bathrobe around my legs, and the smooth, fresh sheets on my bed.

Adherence to self-management prescriptions. People with lymphedema navigate a particularly complex treatment and self-management regimen (Ridner et al., 2018). The World Health Organization (WHO) defines adherence as the extent to which a patient's behavior matches the mutually agreed upon recommendations from his or her healthcare provider (Adherence to Long-term Therapies: Evidence for Action, Section 1, n.d. Retrieved from https://www.who.int/chp/knowledge/publications/adherence_report/en/). The term indicates a collaborative relationship between patient and provider and is the result of bi-directional communication. Lack of adherence to self-care could profoundly affect more than the volume of lymphedema, including levels of function, psychological well-being, confidence in body image, and activity. Nevertheless, published studies addressing lymphedema self-care practices or adherence are scarce (Ridner et al., 2018).

Based on the pathophysiological foundation of CDT, Deng et al. (2015) investigated the association of self-care, symptom burden, and infections in people with primary lymphedema. They defined self-care as self-MLD, compression, skin care, and exercises. Approximately 50% of survey respondents ($N = 830$) reported that they spent more than thirty minutes a day on self-care. Approximately two-thirds (68.9%) of respondents conducted some daily self-care, with compression garments the most frequently used (48.1%). Only 13.7% of the respondents conducted all the self-care activities prescribed for the second phase of CDT. One-third of the respondents reported that they conducted no self-care activities.

Deng et al. (2015) found statistically significant associations between several methods of self-care and symptom burden. The group of respondents that reported using compression garments ($n = 357$) had lower percentages of reports of pain (69.5% vs. 79.5%), x^2 [1], 0.77, $p = .002$), poor range of motion (64.1% vs. 71.8%, x^2 [1] = 4.95, $p = .026$), and numbness (53.2% vs.

76.8%, x^2 [1] = 16.36, $p < .001$). They also reported an association between the number of symptoms reported and infection. The six symptoms examined in the study included swelling, heaviness, stiffness, pain, poor range of motion, and numbness. Those who reported having had an infection had a median of six symptoms (IQR: 4-6), while those not reporting an infection had a median of four symptoms (IQR: 3-5, Mann-Whitney test, $z = 7.80$, $p < .001$). Furthermore, except for swelling (experienced by almost all of the respondents), the presence of each of the individual symptoms was associated with a self-reported infection (x^2 [1] > 20.94, $p < .001$). Due to limitations associated with their study, the researchers were unable to identify causal relationships among self-care, symptoms, and reported infections.

Looking through the Lens of Secondary Lymphedema.

The lay public and medical community are most familiar with secondary lymphedema because it occurs much more often than primary lymphedema. Common knowledge about the different forms of secondary lymphedemas informs the frame through which people may view their disease and through which others may view them. One example is lymphatic filariasis, the most common form of secondary lymphedema. Lymphatic filariasis occurs when mosquito larvae penetrate the skin and make themselves at home in lymphatic vessels and nodes, living there for five to ten years, reproducing. Scientists, physicians, and laypersons commonly refer to the clinical manifestation of filariasis as elephantiasis. The disease is common in endemic areas in 81 countries, but not in the United States (Rockson, 2018b). However, entering the term into an internet search engine yields images of people with grossly enlarged and disfigured limbs. Some healthcare providers use the term “elephantiasis” to describe the advanced stage of all types of lymphedema. Narrator Arial, though she grew up in the United States, remembers school peers pointing and exclaiming, “Elephantitis, elephantitis, elephantitis,” contributing to

the stigmatization that she felt about the unexplained swelling in her leg. I note here that "Elephantitis" is not a clinical term and is often misused by laypeople when they reference advanced lymphedema.

Other forms of secondary lymphedema may be associated with the stigma of life-threatening cancer, age, and obesity. For example, the overall incidence rate of lymphedema after treatment for cancer is 15.5%, with individual rates varying by type of malignancy (Cormier et al., 2010). Lymphedema is common in people who are morbidly obese and obesity may be a factor leading to lymphedema amongst people with other long-term conditions, including those who are wheelchair users (Keeley & Moffatt, 2018). When her physician first told narrator Anya that she had lymphedema, she was only familiar with the lymphedema experienced by the morbidly obese people on the television series, "My 600-lb Life." Lipedema is disproportional obesity characterized by bilateral, symmetrical swelling of one or more regions of the body. With time, lymphatic distortion causes a secondary component of lymphedema (Szolnoky, 2018). Researchers estimate that 20-30% of people with advanced chronic venous insufficiency, associated with aging, develop lymphatic dysfunction, leading to lymphedema (Cavezzi, 2018). Narrator Audra's school peers referenced their grandmothers' swollen legs as "an old people's disease" when learning about her diagnosis. Chronic venous insufficiency, common among the elderly, may have caused their swelling.

When I was about ten-years-old, my curiosity drove me to my mother's hidden library of nursing textbooks. Secretly, I pulled a book from the cabinet and devoured the pictures of people with grossly disfigured bodies, including pictures of people with lymphedema of gargantuan proportions. The worst of the pictures were of people who suffered from filariasis-related elephantiasis. I remember reading that the people in the pictures had worms in their bodies and I felt disgusted. Sometimes, the people in the photographs bore open sores, not unlike the pictures of the lepers in bibles, about whom I read, "The leper who has the disease…shall cover his upper lip and cry, 'Unclean, unclean.' He shall remain unclean as long as he has the disease; he is unclean; he shall dwell alone in a habitation outside the camp" (Leviticus, 13:45, Revised Standard Version).

Not yet able to distinguish between my future-lymphedema-self and the people pictured in my mother's books, rejection was always already there. The threat of rejection for having a disfiguring, unclean-looking disease was my being-in-the-world reality, thrown there from the start (Heidegger, 1962/2008). Today, I understand that, only by good self-management, my future-lymphedema-self will differ from the people in those pictures. I am offended-to-tears that physicians and scholars continue to use the word "elephantiasis" to describe late-stage lymphedema. On the other hand, I feel a particular affinity to elephants, a remaining trace of my under-nuanced childhood concerns.

Summary. I began this part of the chapter with a fundamental description of the lymphatic system and lymphedema. I finished this part with a discussion of the physiotherapy treatments and self-management modalities prescribed for people with primary LLL to provide a foundation for the section that follows regarding the experience of living with primary lymphedema.

The Experience of Living with Primary Lymphedema

Researchers interested in lymphedema have focused most of their research on the experience of adults living with breast cancer-related lymphedema of the arm(s), a much larger population than the population of people living with primary lymphedema. During the last decade, recognizing a gap in the literature about the experience of living with primary lymphedema, and that having lymphedema in different locations may affect people differently, researchers have published a few related studies in peer-reviewed journals and journals published by organizations concerned with lymphedema. I provide a detailed review of these studies, identifying the threads of common findings and findings unique to each. I will connect these findings to the life stories of the narrators I collected in the chapters that follow. I begin with the research about the experiences of adults living with lower limb lymphedema, including adults with primary lymphedema. Then I turn to research studies about the experience of living with the disease, conducted with children, adolescents, and their parents.

Adults Living with Lower Limb Lymphedema

Ryan et al. (2003) interviewed 82 women who experienced lymphedema of the lower limb(s) after treatment for cancer, who were living in Australia. Their findings are relevant to women with primary LLL and may be relevant to men, as well. Participants focused on the way that lymphedema affected their lifestyle, including financial burden, changes to clothing, changes to activities, and even experiencing a denial of employment because of the visibility of their legs. The participants who wore compression garments found them uncomfortable and/or unattractive, and "unbearable in the summer" (p. 420). They reported that they felt motivated to perform their time-consuming daily massage and exercise routines if they had seen pictures or encountered someone with severe lower limb lymphedema.

The authors (Ryan et al., 2003) reported that the women in the study emphasized the cost of new clothing, including footwear. Thirty-eight percent of their participants reported that they altered their shoe wardrobe (increased size and broadness, shoes for comfort over appearance, no high heels, adjustable elasticized shoes, etc.) to accommodate the size of their feet. Thirty-three percent of the participants reported buying larger size garments, and 27% reported a change in the type of clothing they wore, including loose-fitting garments for comfort and appearance. The women reported significant changes to what they wore, with 79% reporting that they wore long pants and skirts exclusively to disguise the appearance of their swollen legs or unflattering compression garments. Twelve percent of the women reported that swimsuits and shorts would "never be worn" (p. 421), and about shoes, 9% of the women interviewed reported that fashionable shoes were no longer possible because of comfort and appearance. Ryan and colleagues concluded that the costs of leg lymphedema were more than financial and included social and mental implications.

Williams et al. (2004) used a phenomenological approach to describe the experiences of fifteen men and women, seven of whom had primary lymphedema, who were living in the United Kingdom. The participants related stories of uncertainty and anxiety around the experience of diagnosis, and long delays between first experiencing symptoms and receiving a diagnosis. They shared that they felt a sense of isolation and an impact on personal relationships, including the stigma associated with the visibility of the condition and communicating with others about the disease. Williams and colleagues illuminate the experiences of living with non-cancer related lymphedema, reporting that younger female participants with primary lymphedema indicated difficulties with self-image, all of whom talked of how they kept their legs hidden and had difficulties with wearing skirts and finding shoes to fit. Generally, the authors found, the men and older women seemed less worried about their appearance.

The article by Williams, Moffatt, and Franks (2004) is the first qualitative research study that I found that included participants with primary lymphedema. Some glimmers of data resonate. I remember an event that occurred when I was in my junior year of high school. The basketball coach had just put me on the bench when I heard a girl, sitting in the row behind me, discussing her ankle injury. She said to her friend, "Look at my ankle swelling…it looks like Crow's ankles!" I felt stigmatized, no longer able to deny that people talked about my legs. I did not play after that and I still feel resentment toward that girl!

Bogan et al. (2007) conducted a qualitative research study focused on the experiences of seven adults who were living with noncancer-related lymphedema in the United States, ages 36 to 76. They had lymphedema for five to 75 years and received treatment as inpatients for advanced and complicated lymphedema that was causing disability. The authors concluded that their findings demonstrate the broad impact of living with lymphedema within diverse U.S. contexts, including the medical community's profound lack of recognition and resolution of lymphedema. Lack of recognition and resolution translates into the progression of the swelling

and subsequent susceptibility to infection, decreased mobility, social isolation, and loss of independence.

All of the participants in the study by Bogan et al. (2007) were undiagnosed and untreated for many years and, when finally diagnosed and able to access effective treatment, they experienced a turning point—the return of hope—and then, with treatment, experienced drastic improvements of their conditions. The participants described returning home and setting about making room for the substantial physical effort of daily self-management and the mental effort of staying motivated to self-manage and cope with their disease. They also reported that various measures of success served as motivators for complying with their self-management programs, including times without cellulitis, being able to wear "real" clothes, avoiding embarrassment, and improved mobility and function.

Despite positive outcomes of treatment and self-management, Bogan et al. (2007) report that the participants believed that lymphedema negatively affected their ability to maintain jobs, their feelings about their physical appearance, ability to buy clothing, and self-image. The researchers conclude that body image and stigma are significant concerns for older people with extreme cases of noncancer-related lymphedema of the lower limbs. Their conclusion contrasts, in part, with that of Williams et al. (2004), who concluded that younger women seemed more worried about appearance than older women and men. However, this contrast may relate to the narrow range of participants the researchers included in the studies.

The narratives of one man who participated in Bogan et al.'s (2007) study, a 70-year-old with lymphedema since infancy, demonstrated the potential for a temporal approach to research to illuminate the experiences of growing up and living with primary LLL. He reported hearing the term lymphedema only 20 years before participating in the study after having lived with the

condition for 50 years. He reported that, as a child, he "never thought of it as a handicap," but as just having big legs, "like having a big nose" (p. 217). As a teenager, however, repeated infections eventually harmed his self-confidence, and he reported beginning to view his lymphedema as "a real disadvantage," thinking, "nobody will ever want to marry me" (p. 217).

The older man in Bogan, Powell, and Dudgeon (2007), who had primary lymphedema at birth, brings the issue of sexuality and partnership to light for people with lymphedema. How do people handle starting new intimate relationships when they have an ostomy, scars—something visible only when naked? As for me, I offered a warning about my lymphedema before getting naked. Well…naked except for my socks. Socks usually took a while longer. Timing for that warning must be just right. You do not want to bring up your lymphedema early in a relationship and seem presumptuous about how the relationship will go. On the other hand, you do not want to invest too much time and emotion into a relationship if your lymphedema will be a deal-breaker.

Waters (2009) found no published qualitative research studies focused exclusively on the experiences of living with primary lymphedema and committed her doctoral dissertation to investigating the life stories of people with advanced and complicated stages of the disease. She used a biographical approach to capture their retrospective views of growing up with primary lymphedema and asked participants to reflect on how it affected their lives. Waters' dissertation title, "Unknown Stories: Biographies of Adults with Primary Lymphoedema," foretells the situation of her findings, since she has not published these findings in a peer-reviewed journal, no systematic reviews include her dissertation, nor do authors reference her work in the background to their research about primary lymphedema.

Eight participants living in the United Kingdom between the ages of 41 to 72 participated in one interview with Waters (2009). They had lymphedema in one or both legs or, in the case of one participant, in both legs and arms, the trunk, and face. The three men and five women reported their diagnosis between the ages of ten and 33 years of age, some of them long after they first noticed swelling. Waters' (2009) findings echoed those of Bogan et al. (2007) and

Williams et al. (2004) about the experience of living with noncancer-related lymphedema regarding marginalization in healthcare, relationship issues, loss of career and leisure opportunities with resultant occupational deprivation, and challenges of daily self-management.

Harding (2012), a therapist working in a lymphedema specialty clinic in the United Kingdom, recognized the body image concerns her patients with primary lymphedema experienced. She interviewed one woman and six men to learn about their experiences of living with the disease through adolescence. She characterized her participants as "young people" and reported their age range as 16 to 40. The participants developed lymphedema between the ages of nine to 15, and the length of time of their diagnostic journeys was two to 11 years. Even though many years had passed since adolescence for some of them, they were able to recall memories from the time in adolescence when they developed lymphedema—memories that still seemed intensely painful.

Like Bogan et al. (2007), Williams et al. (2004), and Waters (2009), Harding (2012) found that her participants had struggled to secure a diagnosis, find appropriate treatment, and encountered unhelpful attitudes of health professionals. For example, the female participant exhibited distress when recalling that a physician told her, "You have got a pretty face, deal with it, nothing anyone can do, it's just one of those things" (p. S8). According to Harding, this difficulty seemed to relate to a general lack of professional awareness of lymphedema.

School experiences also arose in Harding's study. Her participants perceived that their school experiences differed from those of other adolescents and that lymphedema did not seem to share the high profile of other diseases, such as cancer, resulting in school staff failing to express understanding of their situation. For example, one participant reported that her doctor prescribed curtailment of sporting activity. Her teacher, she said, sent her inside rather than

allowing her to participate passively. Another participant reported feeling despair at a teacher's reaction to the trousers and shoes he needed to accommodate his large leg, while another teacher questioned wearing shoes that did not comply with the school policy.

Harding (2012), like other researchers studying lower limb lymphedema, found issues with self-esteem and self-image that her study participants indicated affected their choices. She reports that the participants demonstrated evidence of a desperate need to keep their lymphedematous limb(s) hidden to avoid rejection and that this need affected all aspects of their lives—fashion, education, relationships, and physical activities. The participants reported shopping trips for clothing were a nightmare and that they discontinued swimming and water aerobics because of embarrassment. They described their limbs as "disgusting" and "ugly" (S10). Finally, they reported that, as adolescents, they perceived themselves as abnormal or as "freaks" (p. S10). One participant reported that clothing was not the only covering method employed, sharing, "I've tried everything from shark bites to broken legs" (p. S10).

I add one more article to this review about adult participants with leg lymphedema that illuminates issues salient in my study. Winch et al. (2016) published a report about a qualitative study, entitled "You're naked, you're vulnerable!" in which they focused on sexuality and lower limb lymphedema. The female participants in the study, half of whom had primary LLL, reported lymphedema-related threats to their appearance and confidence, or body image. The women claimed that it was their negative evaluations of body image that made sex a crisis, resulting in less openness and adventurousness and more worry during sex. Many of the women perceived that their sexual well-being was related to the bond with their partner. The single women valued acceptance strongly and faced an additional burden of fear about support forthcoming from sexual partners. The women reported embracing coping strategies such as

focusing on the positives in their relationships and reframing their experience through comparisons to others in worse health.

Building on the work of other researchers who found that women who have lower limb lymphedema experience body image concerns, Winch et al. (2016) suggest that the condition could affect a woman's sense of femininity. They reported that one participant, in her late 50s, with primary LLL, put it, "I'd like to have the choice to look nice in a nice, ah, evening dress, or a cocktail dress. I don't ever do that anymore. You just don't feel so feminine" (p. 126). A woman, in her late 40s, with primary LLL, reflected, "I wasn't able to wear really nice shoes and really nice sort of strappy sandals," linking her visual beauty to her perceived attractiveness, "it wasn't an attractive foot, and therefore I really didn't feel attractive" (p. 126). Some participants reported choosing to expose their lymphedema and/or compression garments in public. One woman with primary LLL, in her early 30s, said "I've just got to the point, guys, where I can get out in shorts and not think everyone's looking at me" and, about her self-management practices, "…I'm happy to look after myself but I have to balance my psychological well-being with my physical well-being" (p. 126).

During Winch's (2016) interviews, four of the women discussed how social norms and expectations linked to their embarrassment and self-consciousness, identifying advertising as a key source of unrealistic standards for beauty. The authors reported that one woman with primary LLL, in her early 60s, identified that a supportive environment could mitigate concerns about appearance. They suggest a link between body image and control of lymphedema, or self-management, to sexuality in women with lymphedema of the lower limbs, but report that they were unable to assess the relative contribution of body image to sexual well-being. Theorizing about the control-sexuality link, they write that control of lymphedema might be particularly

salient to the women that they interviewed because preventing disease progression depends heavily on successful self-management, with social norms for controlling physical appearance as essential for them as for the medically well.

"You're naked, you're vulnerable!" (Winch et al., 2016) about says it all, as far as I am concerned. Since a well-put-together outfit includes a pair of appropriate shoes, I consider whether I have the "right" shoes to go with an outfit. In other words, I dress from the shoe up. I was especially troubled about what to wear when approaching graduation from college in 1979. My fellow business students and I were strongly advised to dress for interviews in a black or navy blue, two-piece suit, with a skirt that stopped just above the knee, nude stockings, and black or navy pumps. I would have rather died than wear what they suggested! Consequently, I only applied for jobs that did not require a "business uniform." I felt marginalized by the experience.

Children Living with Primary Lymphedema

Mason, Upton, and White (2008) conducted a review of the literature for research about the experiences of children living with primary lymphedema. They did not find any qualitative studies about the experiences of children or adolescents. However, based on their review of the quantitative literature and case studies, they suggested that the specific needs of children and adolescents with primary lymphedema might differ from those of adults with lymphedema. Further, they claimed experiences with lymphedema at a younger age could have "lifelong psychological implications which may impact the individual's future management of the condition and the extent to which patients are able to lead full and active lives as adults" (p. 51).

The only related qualitative research study Mason et al. (2008) found was conducted by Todd et al. (2002) with participants who were parents of children with lymphedema. Todd and colleagues interviewed six parents of four children with primary lymphedema, ages 7 to 13, treated at a lymphedema specialist center in the United Kingdom. The study provides evidence from parents that primary lymphedema may have negative consequences on body image and social and educational experiences. The parents' narratives indicated to the researchers that children experienced altered body image and self-consciousness associated with wearing

compression garments, including being different from other children, being unable to wear the clothes they wanted, difficulty in adhering to wearing compression garments, and feeling frustrated and upset. Parents expressed concerns about their child's future, including worries about the progression of the condition, anxiety about school, and their child's coping.

Parents in the study by Todd et al. (2002) reported difficulty obtaining a diagnosis and treatment, and even derogatory comments from unknowledgeable medical professionals who offered misleading advice and having to pursue information about lymphedema independently. When asked about support mechanisms, parents cited the lymphedema specialist clinic and family members as favorable support. However, regarding family support, one participant reported that a grandmother expressed "…she's born with it and just has to get on with it" (p. 449) and that family members see the problem but do not stop to think about it. One parent reported difficulty with school administrators who failed to provide support regarding her child's inability to wear the required footwear for the gym.

Todd, Welsh, and Moriarty (2002) was tough to read…sobs welling up in my chest, tears in my eyes, thinking about what it must have been like for my parents. I remember the time I went bowling with a group of friends and had to rent a pair of wider boy's shoes. They were a different color from the girls' shoes and I was sure everyone in the bowling alley noticed. I do not remember saying I wanted to chop my legs off, like one child in the article said, but I imagined that amputation might become medically necessary, or at least, that I would end up in a wheelchair. How was I to know? I didn't know anyone else with lymphedema and the doctors didn't seem to know much either.

Moffatt and Murray (2010) published the first qualitative study about the experiences of children, and their families, living in the United Kingdom who had primary lymphedema, interviewing twenty children and adolescents, as well as their parents. Their findings, like findings of Todd et al. (2002) and studies other researchers conducted with adult participants, highlight dismissive physicians and significant delays in diagnosis and, in some cases, difficulty with finding information about the condition. Contributing a new understanding about the impact

on families with children with lymphedema, the authors report the high costs of traveling to specialty centers—both financially and regarding disruptions to family routines. The parent participants reported attempts to "normalize" life for the family and affected child and that the other children in the family sometimes helped with the management of the lymphedema.

Congruent with the findings of Todd et al. (2002), Moffatt and Murray (2010) report the concerns of children regarding compression garments that they perceived resulted in bullying at school, and that parents took up advocacy roles for their children regarding school experiences. Parents described an inherent tension regarding giving the child freedom to undertake normal childhood activities and the fear of harm or an infection, and difficulty relinquishing control for self-management to the child as they reached adolescence. Interviews also revealed that parents perceived that body image and ability to fit with a peer group had become major problems for their children and that some of the children coped by avoiding disclosure and avoiding exposure by wearing trousers. The adolescents reported frustration with buying fashionable clothing and shoes, and some of them refused to wear their compression consistently.

Moffatt and Murray (2010) reported that discussions with the younger participants revealed that, despite their lymphedema, they had many dreams for life. They played sports but recognized that their lymphedema reduced their effectiveness, causing them frustration. The children and adolescents expressed a desire to meet with others who shared the condition. The authors report their impression that "on the whole, the families showed acceptance of their situation" and coped by comparing their condition to others with more serious health concerns. Courage and resilience demonstrated by children and their parents when faced with challenges was a key finding of the research.

Interested in how young people with lymphedema make the transition to adulthood, Hanson et al., (2018) solicited the views of twenty female and male participants with primary lymphedema, ages eight to 21, served by an Australian lymphedema specialty clinic. Their findings echo those of other authors regarding struggles within the healthcare system, body image concerns, and other psychosocial challenges. A unique finding that as young people made the transition to adulthood, they enjoyed taking responsibility for self-management but that the transition to adulthood often undermined their progress in managing treatment independently. They also found that decongestive therapy caused frustrating restrictions and social isolation. In response, the authors reported that adolescents sometimes prioritized their social life and emotional well-being by taking a break from their treatment.

Finally, Moffatt, Aubeeluck, Stasi, Mestre, et al. (2019) explored perceptions and barriers of self-management with children with lymphedema, ages five to 18. The researchers asked younger participants to draw pictures representing their bodies and self-management modalities and asked adolescents to use a camera to capture photographs that depicted their experience of learning about self-management. Discussing the art with the participants yielded findings that self-management for children, adolescents, and their parents is complex. Particularly notable is that the participants expressed a deep longing for a cure and recognized that having lymphedema altered their lives due to limitations in playing sports and wearing fashionable clothing and shoes. The authors concluded that relationships with professionals and other children with lymphedema and simplifying self-management techniques was critical to the participants.

Summary of Related Qualitative Research Findings

The studies I reviewed in this section indicate that children, adolescents, and adults with primary lymphedema experienced concerns with body image and stigmatization, which may

result in attempts to hide lymphedematous limbs. Participants of all ages and genders reported difficulty finding stylish clothing and shoes and choosing clothing and shoes that obscured their lymphedema and compression garments from view. They report that compression is uncomfortable and stigmatizing. They also report that these concerns may affect the choices they make about life pursuits. Children and their parents report that it was necessary to engage directly with school staff regarding exceptions to policies related to lymphedema, in particular, to clothing and shoe exceptions. Older adolescents and adults reported self-consciousness when establishing new relationships with romantic partners.

Except for the female participants in the studies by Ryan et al. (2003) and Winch et al. (2016), adult and parent participants reported difficulty accessing a diagnosis and appropriate healthcare. The participants related experiences in which physicians minimized their concerns. They attributed these experiences to providers' lack of knowledge about lymphedema. The participants in the studies by Ryan et al., (2003) and Winch et al., (2016) may have experienced faster times to diagnoses when their lymphedema was secondary to cancer treatment. The child and adult participants, recalling their experiences in school, reported experiencing a lack of understanding from school staff, peers, and, in some cases, family members.

Participants in several studies reported that positive relationships with certified lymphedema therapists were helpful toward learning to cope with lymphedema and self-management. The participants seemed to view treatment as successful when they had extended times without cellulitis; they had more choice about their clothing; they were able to avoid feelings of embarrassment, and experienced improved mobility and function. These measures served as motivators for complying with their self-management programs. Several authors

reported that child and adult participants practiced reframing their experience through comparisons to others in worse health, as a way of coping.

Medico-Historical, Sociocultural, and Geographical Contexts

The medico-historical, sociocultural, and geographical contexts in which people with primary LLL live affect their opportunities for living well with the disease. Following is a brief, general overview of the contexts in which the narrators of this study grew up and are living with primary LLL. As I retell their life stories in the next chapter, I provide details about their particular contexts.

Lymphedema: Paradoxically Ignored

Gaspare Aselli, who first illustrated the lymphatic system in 1622, reported that a milk-like substance discharged from the vessels he dissected from the abdomen of a dog. After that, scientists devoted their attention to the heart, arteries, and veins of the circulatory system, and three hundred years passed before they discovered that the lymphatic system is responsible for returning protein molecules from tissues back to the bloodstream (Choi, Lee, & Hong, 2012). In 1934, Drinker, Field, and Ward discovered that blocking lymphatic vessels led to swelling, and they gave the resulting condition a name, lymphedema. For most of what remained of the twentieth century, scientists and physicians largely ignored the lymphatic system, considering it invisible and difficult to study, separate from, and less important than the circulatory system.

The field of lymphatic research has recently experienced a near explosion of interest after centuries of passive neglect. Investigators recognize that a critical obstacle in the study of the lymphatics has been its visualization. Since the turn of the century, enabled by new technology and information sharing opportunities via the internet, scientists have made landmark discoveries about the development and pathology of the lymphatic system, elevating the importance of the

lymphatic system to human health and well-being. Despite these advances in the description of its pathomechanism and the improvement of treatments, lymphedema remains uncured. In the United States, the healthcare system, health care coverage, and physicians and their educational programs, continue to largely ignore lymphedema and lymphatic diseases despite established commonality and morbidity.

According to Rockson (2017), "the evolution of modern medical practice has not been kind to the lymphatic patient" (p. 315). Though scientists have established that the progression of lymphedema can be halted or significantly slowed through treatment, many lymphatic patients find their physicians ill-equipped to provide the care and solace that they seek. Moreover, the United States healthcare system denies access to beneficial treatments, such as compression garments, to large numbers of Americans. Barriers also exist for access to other self-management tools, such as intermittent pneumatic compression devices, shown to improve well-being and reduce utilization of medical resources and costs of care (Rockson, 2017).

According to Moffatt, Keeley, & Quéré (2019), healthcare providers and government agencies can improve the care of people with lymphedema and related disorders only when all relevant parties recognize lymphedema as a neglected public health problem, particularly providers. To address this concern, the International Lymphedema Framework (ILF), launched an international epidemiological initiative (LIMPRINT), designed to estimate the prevalence and impact of chronic edema in heterogeneous adult populations in several countries. The ILF published the results of the studies, included in the initiative, in a special issue of *Lymphatic Research and Biology*, May 2019. The studies provide new data on the prevalence of chronic swelling and the devastating impact it can have on health-related quality of life.

Recognizing a need to help people with lymphedema to find comprehensive, effective services within the United States, LE&RN is poised to certify Centers of Excellence in the Diagnosis and Treatment of Lymphatic Diseases in 2020. Certified Centers of Excellence will offer the best possible multi-disciplinary clinical care and services to people with lymphatic diseases and provide professional and lay education in the geographic areas where they serve. (Centers of Excellence, n.d. Retrieved from https://lymphaticnetwork.org/treating-lymphedema/centers-of-excellence/). The LE&RN initiative is a starting point toward comprehensive service in the United States.

Many people are constrained geographically and financially to physicians their medical insurance providers designate—the "gatekeepers" of care. Though in some states, lymphedema therapists may serve clients without a prescription from a physician, most insurance providers require prior authorization for coverage. Prior authorization comes only with an established diagnosis of lymphedema. In other words, the physician must offer the key to the gate. Unfortunately, as Rockson et al. (2004) suggest, people with lymphedema encounter physicians who lack the preparation to diagnose lymphedema and hold the belief that lymphedema is insignificant and/or not treatable. If this is the case, unless a person possesses the financial and social capital and persistence to jump the gate, they go undiagnosed or misdiagnosed, and consequently untreated or mistreated. Once diagnosed, according to best practice, a physician should refer a person with lymphedema to a therapist certified in lymphedema therapy. The Lymphology Association of North America (LANA) lists at least two certified lymphedema therapists in every state (Find a LANA Certified Therapist. Retrieved from https://www.clt-lana.org/search/therapists/). Depending on where a person lives, gaining access to a therapist can represent a significant financial and time burden.

Lymphedema World on the Internet

One of the factors that may influence the lives of people growing up and living with primary LLL, in today's sociocultural context, is the internet. Early in the 21st century, the internet and the World Wide Web became household words, and every day, more and more people are accessing the internet (Markham & Baym, 2009). Social networking technologies and services are emerging at a noteworthy pace, and mobile technologies (smartphones, tablets) and applications are proliferating quickly. According to Hewson, Yule, Laurent, and Vogel (2016), the internet is shifting from a relatively static space for the dissemination of published final documents to a "massively connected, fluid, interactive, participatory, collaborative space where content is constantly in flux and under revision" (p. 5). Web 2.0 facilitates participatory information sharing, interoperability, user-centered design, and collaboration on the World Wide Web and people with lymphedema. The health professionals who treat people with lymphedema have more opportunities to learn about treatment from anywhere, such as the webinar series offered by LE&RN (https://lymphaticnetwork.org/video-resources), launched in 2015.

A Web 2.0 site allows people with lymphedema to interact and collaborate in social media. Even static websites that allow only passive viewing of content offers empowering opportunities for patient education and exploration of treatment options. With these opportunities, people with lymphedema are better prepared to exercise agency and become the "Chief Executive Officers" of their care. To test this assumption regarding people with lymphedema, Deng et al. (2013) conducted a survey, posted to the National Lymphedema Network website between 2006 and 2010, to examine sources of educational materials and knowledge levels of people with primary (n = 517) and secondary (n = 1025) lymphedema. Participants reported a variety of sources used for obtaining information about lymphedema, and

76% of the participants favored dedicated websites. Survey participants with primary lymphedema reported lower knowledge levels about lymphedema, treatment approaches, and complications than participants with secondary lymphedema. The authors report that the main source of information for people with primary lymphedema was the internet and not their physicians.

During the last two decades, organizations such as the National Lymphedema Network (NLN) (www.lymphnet.org), Lymphedema Education & Research Network (LERN) (www.lymphaticnetwork.org), and the Lymphedema Treatment Act Advocacy Group (LAG) (www.lymphedematreatmentact.org) have increased the internet profile of the disease of lymphedema, with their official websites and initiatives. Together, these websites offer substantial information for laypersons and health professionals. They include up-to-date directories of links to other websites, including national and international lymphedema-related organizations, treatment providers and resources, product manufacturers and supply companies, therapist directories, and blogs by professionals and non-professionals. Finally, lymphedema-related organizations have developed face-to-face networking opportunities through advocacy events and educational conferences.

The capacity of the internet to connect people with lymphedema—especially those with the rare, primary form of the disease—has elevated the presence of laypersons in Lymphedema World. Social media outlets, such as Facebook, Twitter, and Instagram, online social networking services, are utilized by individuals, as well as organizations and businesses related to lymphedema, to share news, links to relevant websites, photographs and videos, and personal stories. Several women, who have primary LLL, maintain active, public blogs and companion Twitter and Instagram feeds, to help others to live well with lymphedema. For example, Alexa,

who hosts *The Lymphie Life* (www.thelymphielife.com), also maintains an Instagram feed. To help support her blog, she hosts a web shop to sell t-shirts, coffee cups, and other paraphernalia bearing the phrase, "Stay elevated!" or "Living the Lymphie Life." She devotes a significant number of blog posts to up-to-date reports on relevant research, new treatments, and events related to the Lymphedema Treatment Act. Bloggers like Alexa, as well as the many, many people who are active on the internet, are living life with primary lymphedema, connected in a way not possible twenty years ago.

Researchers who focus their work on the internet report heavy use of internet media sites by people with chronic illnesses. Suris, Akre, Berchtold, Belanger, and Michaud (2010) conducted a cross-sectional survey of a nationally representative sample of adolescents engaged in a Swiss post-mandatory school. They found that adolescents reporting a chronic illness or disability were significantly more likely to have accessed the internet for health-related matters, than were their peers. Kingod, Cleal, Wahlberg, and Husted (2017) conducted a systematic review to investigate how people with chronic illness experience online peer-to-peer support and how their experiences with those online communities influence the daily life of living with illness. They found that online peer-to-peer communities provide a supportive space regarding daily self-care related to chronic illness and a valued space within which to strengthen social ties. For individuals who are inclined to use the internet and social media, the experience of primary lymphedema can be much less lonely.

Summary. Lay and professional lymphedema champions are making great strides toward improving support for people with primary lymphedema in the U.S. healthcare system. In Appendix B, I provide a timeline of initiatives undertaken in Lymphedema World since the turn of the century, to provide more context relevant to the lives of the narrators. This timeline is by

no means comprehensive, nor recognizes all the work that individual and organizational champions have done on behalf of people with lymphedema.

Conclusion

I have described the lymphatic system, the condition of primary lymphedema, and treatment and self-management of the condition to provide a foundation for understanding the experience of living with the disease. I have reviewed the qualitative literature relevant to the experience of living with primary lymphedema. I have also described some of the medico-historical, sociocultural, and geographical factors within the contexts in which women and men are growing up and living with primary lymphedema.

CHAPTER IV

METHODOLOGY

In this chapter, I discuss the epistemological, theoretical, and methodological perspectives that informed the research I conducted to study the lives of five individuals who grew up with and are living with primary LLL, as well as detailed descriptions of the methods that I used to conduct the study. I organize this chapter in the following way: (a) restatement of the purpose of the study and research questions; (b) epistemological and theoretical underpinnings; (c) a description of life history methodology; (d) research methods (selection of participants, data collection, and analytical techniques, including reflexivity); (e) quality criteria; and (f) relevant ethical concerns.

Purpose Statement and Guiding Research Questions

The purpose of this study was to understand the life histories of men and women who grew up with and are living with primary LLL and, in doing so, illuminate the ways in which lymphedema affects their lives. Given the constitutive nature of emergent design in qualitative research, when I began this study, I offered this purpose statement tentatively and understood that it was subject to change (Sparkes & Smith, 2014) as I studied the lives of the narrators. I began with an overall research question and three guiding questions and expected the formulation of my research questions to be iterative (Patton, 2015) and to evolve and crystallize as the study proceeded (Agee, 2009). The problems that I identified and foreshadowed reflected the literature about growing up and living with lymphedema, my impressions from social media related to living with primary LLL, and my personal experiences with lymphedema than they

were those of the narrators. Due to the nature of the earliest interviews I conducted, and my desire to allow the narrators to privilege the memories they believed were essential to their life stories, I added a fourth guiding question.

The overall research question that I used to serve as a navigational tool (Agee, 2009) was *how do young adults with primary LLL understand the experience of growing up and living with the disease against the backdrop of sociocultural and medico-historical contexts?* I used the following sub-questions to direct the focus of the study:

1. What do the life histories of women and men with primary LLL reveal about how they make sense of growing up and living with the disease?
2. What do the life histories of women and men with primary LLL reveal about the challenges of navigating the U.S. healthcare system and how those challenges shape their lives?
3. What do the life histories of women and men with primary LLL reveal about how they navigate the social and emotional challenges of growing up and living with the disease and negotiate the complexities of school, work, and relationships, and how those challenges and complexities shape their lives?
4. What do the life histories of women and men with primary LLL reveal about how they navigate the physical challenges of growing up and living with the disease and negotiate the complexities of self-management, and how those challenges and complexities shape their lives?

Locating the Research Study within the Qualitative Paradigm

> I am convinced that the desire to formulate truths is a virulent disease. It has contracted an alliance lately in me with a feverish personal ambition, which I never had before, and

> which I recognize as an unholy thing in such a connection. I actually dread to die until I have settled the Universe's hash in one more book…! Childish idiot—as if formulas about the Universe could ruffle its majesty and as if the commonsense world and its duties were not eternally the really real (Library of America, William James, Writings: 1902-1910, 1902/1987, p. 1344).

Qualitative Research

Based on the nature of the research problem and guiding research questions, I elected to conduct a qualitative research study. Qualitative research is an umbrella term for a wide variety of research approaches that locates the observer in the world. Denzin and Lincoln (2017) affirmed their latest definition of qualitative research as follows:

> Qualitative research consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. (p. 3)

The authors emphasize that qualitative researchers are using a widening variety of empirical materials and deploy a widening range of interconnected interpretive practices—each practice making the world visible in a different way (Denzin & Lincoln, 2017). The inquiry I conducted fits within this definition.

My Epistemology and Theoretical Perspective

I use Crotty's (2013) research framework, consisting of the elements of epistemology, theoretical perspective, methodology, and methods, to explicate how I anchored (Jones, 2002) my research study within the qualitative paradigm.

Epistemology: Social constructionism as a way of knowing. According to Crotty (2013), epistemology is "a way of understanding and explaining how we know what we know" (p. 8). Constructionism provides philosophical grounding for the inquiry I conducted regarding the kind of knowledge that is possible to pursue, acquire, and construct. Subscribing to social constructionist epistemology, I proceeded with the view that human beings construct all knowledge while interacting with the world, "developing and transmitting meaning within their social context" (p. 42). Constructionism rejects the objectivist view of knowledge that holds that meaning, and therefore reality, exists apart from human consciousness and is absolute (p. 8). Instead, constructionism holds that there is no objective truth waiting for us to discover it. Per this understanding of knowledge, I believe that humans generate meaning while engaging with the world, our subjectivity "indissolubly bound up" (Crotty, 2013, p. 48) with our knowledge pursuits.

Related to the study that I conducted, my epistemology emerges from my understanding that I (the subject) became conscious of my lymphedema (the object), as a small child. I began constructing ever-evolving meaning about living with the disease, in a world I first viewed from the arms of my parents, and then other relatives, healthcare providers, and anyone encountered—their views also constructed amongst the inevitable dimension of historical and sociocultural contexts. Thus, I believe I constructed my perspectives about lymphedema, not in isolation, but against a backdrop of shared understandings, practices, and language (Schwandt, 2015).

Therefore, I approached the research design of this study with a constructionist epistemology oriented toward pursuing a multi-perspective, intersubjective understanding of the experience of growing up and living with primary LLL through interaction with others (Berger & Luckmann, 1966) who grew up with and are living with primary LLL. I believed that the narratives and artifacts they would offer constitute the empirical material I needed to understand how they create meaning out of their experiences (Chase, 2010). Based on these beliefs, I pursued understanding, necessarily in relationship with the life story narrators who participated in my study, who have stories to tell and voices of their own, and I listened to their stories, oriented to their particular biographical experiences (Chase, 2010; Cole & Knowles, 2001; Goodson, 2017) while practicing self-reflexivity about my listening presence in the relationship.

Crotty (2013) claims that social constructionism is realist and relativist. For those of us with primary LLL, the consequences of the disease, no matter how much we wish otherwise, is a "really real" (James, 1902/1987, p. 1344) part of our lives. Nevertheless, we hold tentatively the sense we make of the brew of bodily processes and consequences that we call "lymphedema" against socially constructed understandings of bodies and conditions in the world that are always contextual, historical, and shifting. Approaching the pursuit and creation of knowledge through a social constructionist lens, I proceeded from the understanding that each of us makes sense of our lymphedema differently while dealing with our own 'really real' relative to others in our social networks. We also interpret our experiences against and through the various changing historical and sociocultural contexts in which we live.

Theoretical perspective: Interpretivism. Interpretivism is the philosophical stance, or theoretical perspective, I chose to shape the methodology for this research study, which I conducted using the life history approach. According to Crotty (2013), an interpretivist approach

to research "looks for culturally derived and historically situated interpretations of the social life-world" (p. 66). Constructionist epistemology embeds within the theoretical perspective of interpretivism the notion that we construct meaning, construct meaning socially, and that meaning is relativist. The assumption guiding interpretivism—that we produce our social world through meaningful interpretations—provided context for the study process, a basis for the rationale for decisions about the methods I chose, and the criteria for evaluating the "goodness" of the research study (Crotty, 2013).

To summarize, I hold relativist ontology (multiple realities), and subjectivist and constructionist epistemology (co-creation of understanding). When conducting the research study, I relied upon a dialectical and interpretive approach to fulfill my intent to appreciate what is happening in the social, historical, and cultural contexts in which the narrators are living with lymphedema. That is, similar to the experience described by Kiesinger (1998) when writing Abbie's life about her experiences with weight issues, while the narrators offering their life stories are "grappling with making sense of their lives" (Charmaz, 2004, p. 981), I grappled to make sense of theirs, as well as mine in relation, and in the process of the study, we grappled together. Then, as Kiesinger described, to finish the project, I grappled on alone, to construct their life histories.

Methodology: Life History Research

The Long History of Life History Research

Life history research methodology boasts a long history and retains much of its original notions, though life historians agree, there is no one, particular way to conduct life history research (Cole & Knowles, 2001; Goodson, 2017; Goodson & Gill, 2011; Hatch & Wisniewski, 1995; Merrill & West, 2009). After the world wars, practitioners of various social science

disciplines, working independently in North America and Europe, began developing a viewpoint which Miller (2000) refers to as "the biographical perspective" (p. 2). This perspective focused upon the entire lives of people or a significant portion of their lives, rather than a "slice of an individual's situation located at the present" (Miller, 2000, p. 3). With broadened focus, sociologists also began to foreground questions of time and space concerning life experiences or personal history (Miller, 2000). According to de Chesnay (2015), a nurse researcher, the biological perspective of life history methodology, using patient narratives as data, facilitates understanding of the patient-storyteller within the context of the culture of the patient and community. This approach lead to new solutions that healthcare providers can use to develop better interventions and policies.

Life historians (Cole & Knowles, 2001; Goodson & Gill, 2011; Miller, 2000) attribute the first attempt to bring a biographical perspective to the social sciences to German hermeneutic philosopher and sociologist William Dilthey (1833-1911), though authors acknowledge that sociologists first used life history methodology when interviewing indigenous peoples of the Americas (Miller, 2000). The concern Dilthey promoted for life and lived experience likely influenced Robert Park to bring concern about lived experience and the biographical perspective to the first Department of Sociology in the United States at the University of Chicago (Miller, 2000). Authors who write about life history methodology (Cole & Knowles, 2001; Miller, 2000) credit W.I. Thomas and Florian Znaniecki of the Chicago School, with publishing the landmark life history account, *The Polish Peasant in Europe and America*, between 1918 and 1920, and establishing life history as a bona fide research device (Goodson, 2017). After that, between the world wars, American researchers began waging the paradigm wars in academic hallways and at conference lecterns (Crotty, 2013; Miller, 2000). That is, though not necessarily anti-positivist,

researchers who subscribed to the distinctly qualitative life history approach "did not attach primacy to aggregate data" (Miller, 2000, p. 5) and moved toward more constructivist ideas of how society creates order (Merrill & West, 2009).

After World War II, researchers watched the rise of the paradigm of quantitative survey and data analysis to study sociology and psychology, while academia set aside life history methodology and the rest of the qualitative paradigm, because life history "persistently failed the 'objective tests'" (Goodson & Sikes, 2001, p. 14) under modernism, it languished. Life history research originated, in part, as the "'qualitative backlash' against the dominance of the quantitative approach" (Miller, 2000, p. 6) while a new generation of qualitative researchers was heralded to academia in the 1960s by the work of C. Wright Mills (Merrill & West, 2009). Contemporary researchers (Chase, 2010; Merrill & West, 2009), who use life history and other biographical methods, anchor their work with a quote from *The Sociological Imagination* (Mills, 1959/1970). In the book, Mills (1959/1970) wrote, "Social science deals with problems of biography, of history, and of their intersections within social structures…these three—biography, history, society—are the coordinate points of the proper study of man" (p. 159). Toward the beginning of the next decade, the 1970s, Mills' book and his dictum to explore the symbiotic relationship between history, biography, and social structure (pp. 247-248) were instrumental in laying the groundwork for the resurgence of biographical methods (Miller, 2000). A working group on life history method, led by Daniel Bertaux, began to meet in the late 1970s, and, in 1984, the group developed the International Sociology Association's Research Committee 38, 'Biography and Society' (http://www.biographyandsociety.com).

Atkinson (1998) examined the turn of sociologists and other researchers toward narrative as a way of understanding health. Researchers, seeing narrative as material and metaphoric

discourse, or life as narrative, boosted narratives of suffering and illness to a special status in qualitative health research. According to de Chesnay (2015), when the researcher views the patient-storyteller within the context of the culture of the patient and community, their life stories can tell us how they interpret their health conditions, make decisions, and solve the many problems they experience. For example, researchers have used life history methodology to focus on the chronology of illness, enabling them to understand the sequencing of events such as adaptation to disability (Frank, 1997; Frank, 1981; Harrison, Angel, & Mann, 2008) and drug use (Boyd, Hill, Holmes, & Purnell, 1998). They have also used the methodology to explore the life histories of people growing up and living with a specific disease (Admi & Shaham, 2007), living with a rare disease (Haylen, 2016), and the interaction among personal events, sociocultural frameworks, subsequent actions, and coping (Gramling & Carr, 2004). These researchers establish the efficacy of life history methods for the study of health and illness (de Chesnay, 2015).

Life history methodology has become a time-honored tradition (Hatch & Wisniewski, 1995) where researchers discuss methodological issues such as relationship and voice, rigor, representation, and ethical considerations (Cole & Knowles, 2001; de Chesnay, 2015; Goodson, 2017; Merrill & West, 2009). Munro (1998) argues that acknowledgment of the subjective, multiple, and partial nature of human experience by sociologists has revived life history research. The aim of life history is for the researcher to elicit an account of a person's life story in their own words and explore the effects of social structure on people (Mandelbaum, 1973). Once considered weaknesses by authors (Cole & Knowles, 2001; Hatch & Wisniewski, 1995, Munro, 1998), the lack of representativeness and the subjective nature of life history methodology are now considered life history's greatest strengths.

Contemporary Life History Research: Exploring Lives in Context

What is life history research? Cole and Knowles (2001) provide the following passage in *Lives in Context: The Art of Life History Research* that was useful for grounding my understanding of the broad aims of life history research. They write,

> In as much as is humanly possible, life history inquiry is about gaining insight into the broader human condition by coming to know and understand the experiences of other humans. It is about understanding a situation, profession, condition, or institution through coming to know how individuals walk, talk, live, and work within that particular context. It is about understanding the relationship, the complex interaction between life and context, self, and place. It is about comprehending the complexities of a person's day-to-day decision-making and the ultimate consequences that play out in that life so that insights into the broader, collective experience may be achieved. Always, lives are understood within their respective and collective contexts and it is this understanding that is theorized. To understand some of the complexities, complications, and confusions within the life of just one member of the community is to gain insights in the collective…every in-depth exploration of an individual life-in-context brings us that much closer to understanding the complexities of lives in communities. (p. 11)

Using life history research, the researcher can explore the individual's *whol*e life story and locate it within the wider social, historical, and cultural moment for understanding a life-in-context (Cole & Knowles, 2001). Samuel (2009) offers a concise description of the life history researcher as one who structures "the process of telling stories to yield rich, in-depth details about the specific life experiences, memories, and interpretations that the individuals [in the

study] produce" (p. 4). The purpose then, for life history research, is for the researcher to use these experiences, memories, and interpretations to reconstruct narrators' lives.

Characteristics of life history research. Life history research shares many elements with narrative inquiry and some other forms of non-positivist oriented qualitative inquiry, including interviewing and a focus on the relational epistemologies of the researcher/researched relationship. For example, life history approaches emphasize the importance of the relationship between the researcher and narrators, on how researchers collect data. According to Cole and Knowles (2001),

> …the task with each participant is to try to get as close as possible to apprehending, understanding, and rendering elements of a life as it is influenced by and intersects with pervasive and subtle forces or influences of context. This is a considerable responsibility, but one that can be shared, to some extent, by research participants. (p. 71)

The process of turning the life story into a life history inures an added dimension to the characteristics of life history methodology.

The researcher/researched relationship. Cole and Knowles (2001) posit that for a successful life history project, the prolonged engagement between researcher and participant is necessary because it is not realistic to expect anyone to reveal the richness of life in one or two interviews. Relationship, to them, at least in part, becomes a function of time spent in the researcher/researched relationship, as well as serving as a critical element in life history research. Munro (1998) argues that the epistemological assumption of life history is that knowledge is situated and that the researcher and researched construct knowledge socially and intersubjectively.

Authors who write about life history research refer to participants in various ways: collaborators, co-researchers, informants, interlocutors, narrators, participants, among others. These terms may reflect the researcher's stance regarding their theoretical perspective and beliefs about inquiry, the purpose of the study, and the group that is the focus. Also, according to Goodson (2017), the term a researcher uses to refer to the researched suggests the nature of the researcher/researched relationship regarding empathy, self-disclosure, and exposure. The term a researcher chooses also suggests mutuality in figuring out the research process and acknowledging authority over the storyline and interview text. Regardless the researcher's stance on the researcher/researched relationship, Merrill and West (2009) strongly encourage humanistic approaches that reflect care, sensitivity, and respect. Cole & Knowles (2001) encourage the researcher to "do all that they can to challenge the hierarchical principles and practices that traditionally define the relationship between researchers and those whom they research" (p. 27). Goodson (2017) refers to such participants as life story givers, implying that the individual is offering up their life, as told, to the researcher for the researcher's purposes, and suggests that the researcher needs to honor this gift as such. Moreover, Goodson posits, offering a life story, versus a small "slice" of life, or the data they might offer during a guided interview in a project during which researchers interview several participants, is much riskier for the life story giver, raising ethical concerns to which the researcher must attend.

Life story. Life history research relies primarily upon the life stories of the narrators, and in some life history work, life stories may be the only source of data (Goodson, 2017).

Thinking with and through stories. Goodall (2009) writes that "narratives are our way of knowing" (p. 15), contingent upon thinking with and through stories. Bochner's epistemology (2001) echoes such investments in stories and writes that one of the main lessons that illness

narratives teach us is "about the struggle between personal and cultural meanings" (p. 147). He claims that stories have a type of interstitiality—an ability to navigate between how we structure our reality and how our culture constructs its reality. Instead of claiming generalizability and cool objectivity, knowledge in this formulation is relational and focused on a type of "narrative truth." Bochner rejects the criticism that narratives cannot adequately represent "the facts of one's life" noting that,

> It is within the frame of a story that facts gain their importance. Life stories may be based on facts, but they are not determined by them. The facts achieve significance and intelligibility by being articulated within a temporal frame that considers what came before and what comes after. (pp. 153-154)

Thus, for Bochner, narrative truth is pragmatic truth—it holds true if useful to believe. The question then, he claims, is not whether the narrator told the story the way things were. Instead, the question is, what do narratives do, what consequences do they have, to what uses they can be put?

What makes a story a life story? Connelly and Clandinin (1990) define narrative as a particular type of discourse, and they named it "story." Riessman (2008) claims that the word, *story*, is used interchangeably with *narrative*, but it seems that most life historians generally use the term *story* when writing about life history research (Hatch & Wisniewski, 1995). Hinchman and Hinchman (1997) offered a provisional definition for both terms, "…as discourses with a clear sequential order that connect events in a meaningful way for a definite audience and thus offer insights about the world and/or people's experiences of it" (p. *xvi*). This definition includes the features that life historians, Goodson and Gill (2011), claim are essential to life history research: temporality, meaning, social encounter, and a focus on the significance of social

interaction in the construction of narratives and transformation of human experience into meaning.

Atkinson (1998) offers one of the most influential examples of conducting a life story interview in his methodological text, *The Life Story Interview* (1998). He defines life story as

> …the story a person chooses to tell about the life he or she has lived, told as lived completely and honestly as possible, what is remembered of it, and what he or she wants others to know of it, usually as a result of a guided interview by another. (p. 8).

The life story account, then, is constructed, a representation of life as lived, that the interpreter living the life-in-context interprets and reconstructs in a particular historical moment (Denzin, 1989). Despite the life story being a reconstruction, the personal narrative (life story) can provide a perspective on and understanding of individuals' experiences (de Chesnay, 2015). Life stories constitute the essential components people use to reconstruct and remember their experiences to help develop a comprehensive understanding of their lives.

Soliciting life stories. Life historians often describe giving their participants freedom to tell their life stories in the way that they choose at the beginning of the research process, before transitioning to semi-structured interviews (Goodson, 2017). Cole and Knowles (2001) suggest thinking of the first interview as a negotiation of the relationship, which will serve to develop rapport and to build trust and clarify issues of confidentiality and anonymity. Life historians conduct conversation-like interviews that allow the participants to "move back and forth" in their narrative and meaningfully organize, describe, and explain key life events and situations within the wider significance of their life stories and artifacts (Atkinson, 1998; Miller, 2000).

According to Goodson (1995), while the giver is narrating their life story, the researcher seeks to elicit their stories and perceptions and listens rather than interrogates actively. After the

narrator gives their life story, the researcher and the life story-giver shift to a collaborative relationship, and the story-giver becomes more a general investigator than a teller of stories, while the researcher becomes actively involved in textual and contextual construction, rather than just listening. For example, one of the narrators in this study, Arlo, demonstrated a shift from the story-giver to the investigator by generating questions about his life between conversations, seeking answers independently, and bringing his discoveries to our subsequent conversations. The distinction between life story and life history is that life history begins with a life story and seeks to build upon the information given. Building on Arlo's life stories given in the first two interviews, I brought my clarifying questions about his life stories to the third conversation, as well as topics we had not yet touched on, to help build his life history from the stories he had already shared.

Using artifacts to elicit life stories and provide context. In life history research, artifacts take on important roles in the understanding of a life and may illuminate a life in unexpected ways (Cole & Knowles, 2001). An artifact has a temporal quality, meaning that it "'speaks' of actions at a particular time and place" (Cole & Knowles, 2001, p. 85) and has a meaning that is much larger than its obvious meaning or use. These objects or documents may include photographs, videos, personal documents, scrapbooks, and/or art, depending on the person. Those relating to the narrator's life context might include documents related to history, an institution or organization, schools, family, and communities. Interpretivism holds that objects have no inherent meanings, but that humans form meaning about objects individually, in relation to others in their social network, and in context. Thus, any object in a person's life can become meaningful. Artifacts, assert Clandinin and Connelly (1994), "become triggers to our memories" (p. 420) and can provide researchers with valuable insights into the lives of their participants.

Again using narrator Arlo as an example, after our first conversation, while comparing photographs of himself as a boy, for the first time, he realized that the way he posed for photographs changed after he developed lymphedema in one of his legs.

Today, the ubiquitous nature of digital, mobile technology adds a new dimension to the idea of artifacts—one of utility. Narrators can capture an image of an artifact with their mobile device and then bring the image of the artifact, rather than the artifact itself, to a guided conversation to share with the researcher. Narrators may bring a traditional scrapbook or memory box, containing material artifacts of all types, including photographs. On the other hand, narrators may share a digital scrapbook, or "app," such as Facebook, in which they curate artifacts, and access by logging on to the internet with a digital device. Narrators Abie and Arial readily shared photographs stored on their telephone apps during conversations.

Building life history from life story. Goodson and Gill (2011) claim life history, at its best, aspires to be a narrative exchange between equals, two people searching together for meaning and understanding, "to locate the selves within their respective stories and in their broader social and historical contexts" (p. 44). Cole and Knowles (2001) refer to this process as "exploring the context" (p. 79). By this, they mean an in-depth understanding of the focal context within which the participants' lives are situated. However, they write, the context itself is not the unit of analysis. Instead, they write, it is a reference point, the essential backdrop that helps to understand the participant's life and experience. Hatch and Wisniewski (1995) emphasize that "an analysis of the social, historical, political, and economic contexts of life history by the researcher is what turns a life story into a life history" (p. 125). Therefore, the researcher plays a significant role in interpreting the stories. Biesta, Hodkinson, and Goodson (2005) make this point clearly when they argue that life history research is more than the collection of stories

about individuals' lives. To support this argument, they claim that a preoccupation with the individual life story and its analysis is not enough and, echoing the words of C. Wright Mills (1959), claim that what is central to life history is the relationship between the individual and wider structures.

According to Goodson (2017), a signal that the research conversation has moved from life story to life history is when the researcher and narrator move toward a grounded conversation and away from the initial life story. By grounded, Goodson means the researcher and narrator approach the question of why the narrator told their life story in particular ways about particular historical moments. The researcher and narrator, collaborator, or giver-turned-investigator, locate the wider meaning of life history by using other sources of data to triangulate the life story. In this way, the researcher and narrator contextualize the life story in time and place or space. Though explained as conceptually and methodologically distinct, Goodson and Gill (2011) describe these phases as shading into one another with an overlapping period, at which point the interviewer and interviewee begin to probe and question the stories more actively and collaboratively. During conversations with the narrators, especially the second and third, I returned to some of their stories and asked them if they had thought more about the factors that contributed to the experiences they shared in their stories. Narrator Anya, for example, came back to the second conversation with nuanced suggestions about how and why physicians failed to diagnose her lymphedema for 18 years. All the narrators were forthcoming regarding the structural and cultural factors that contributed to their feelings of stigmatization and marginalization while living in a body- and fashion-conscious world.

It is this move from the life story to life history, during which the interviewer and the interviewee undertake interpretation that distinguishes life history research from other types of

narrative research. In other types of research, after the researcher completes the interview(s), only the researcher interprets and makes sense of the data or the stories collected and heard. The analysis and theorization, or the hermeneutical endeavor, is solely the responsibility of the researcher. The life history approach involves prolonged narrative exchanges, sharing mutual interpretations, and testing emerging theories collaboratively. The emerging narrative is the result of an exchange during which the researcher and narrator work with new understandings and new data, and thus a new consciousness. In other words, they ground their understandings of the life narrative and interpretations in the dialogic encounter (Goodson & Gill, 2011). I usually returned to the second and third conversations with a theory to test, and the narrators expanded on their stories, affirming or disconfirming my theories. For example, narrator Audra, with words and tone I will never forget, disconfirmed my theory about why she was not wearing compression before she developed cellulitis and raised my consciousness about the covert signals that physicians send to their patients with, "Deb, you have to understand…!" I realized, through her explanation, that I had received the same signals from physicians.

Methods Used: Doing Life History

In this section of the chapter, I describe the methods I used to conduct a study to explore the lives of four women and one man who grew up with and are living with primary LLL, using life history methodology. This section includes a discussion about the methods I used to recruit and select the narrators, collect the data, and to analyze and interpret the data to construct the narrators' life histories. I follow with a discussion of the strategies I used to maximize trustworthiness of the study and end the chapter with considerations given to conducting ethical research with narrators with a rare medical condition.

Selecting and Inviting Narrators to the Study

Between August 2017 and May 2019, I recruited and invited prospective narrators to the study, who met the participation criteria, using the purposive and intensity sampling approach. I invited them because they are intimate authorities on the experience of growing up and living with primary LLL and possess a deep understanding of the particular issue or phenomena (Labaree, 2006) but were not *extreme* cases (Patton, 2015). For example, all of the narrators have lymphedema, but it is not disabling for them.

Initially, I invited women between the ages of 18 and 65, with a medical diagnosis of primary lymphedema of one or both legs, for whom swelling began before the age of 22. Due to lagging recruitment, I obtained IRB approval to broaden participation criteria to increase the potential for recruitment and began inviting men, individuals with secondary lymphedema, and individuals with primary lymphedema of the arms. I also obtained IRB approval to use new recruitment strategies, including offering a $50.00 VISA gift card as an incentive, develop a blog, and seek institutional approval to recruit from public clinics which serve individuals with lymphedema. I recruited two more narrators shortly after receiving approval for the new recruitment strategies and, therefore, I did not implement the strategies related to the blog nor public clinics.

Recruiting narrators. In life history research, researchers may invite prospective narrators who are known to them or who are recommended to them to participate in their studies, or they may "start from scratch" (Cole & Knowles, 2001, p. 66). I preferred to conduct research conversations in person and attempted to recruit prospective narrators who lived near my home. After six months, I had not recruited any narrators and extended my recruitment efforts to

prospective narrators who lived beyond those geographical areas with a plan to use internet video conferencing software for research conversations.

My goal was to include five narrators in the study. Life history studies typically involve a small number of narrators in "the in-depth exploration of an individual life-in-context that brings us that much closer to understanding the complexities of lives" (Cole & Knowles, 2001, p. 11). Unlike researchers conducting some types of studies, researchers (Atkinson, 1998; Cole & Knowles, 2001; Goodson & Gill, 2001; Miller, 2000) using the life history approach consider generalizability of research findings to populations irrelevant, and therefore sample size and representativeness of the sample, a "nonissue" (Cole & Knowles, 2001, p. 65).

Recruitment strategies. Due to the rarity of primary lymphedema, I anticipated that I would need a complex set of recruitment strategies. I developed a Facebook Recruitment Page, which I set for public view after receiving IRB approval (Appendix C) for the study. The page included information similar to the information contained in the 1-page Participant Recruitment Flyer (Appendix D), with the addition of a banner image of myself as a child, wearing compression bandages on my legs to treat my lymphedema. I sent email requests to social media and website owners, lymphedema therapists, and lymphedema related organizations and asked them to distribute the recruitment flyer and/or link to the Facebook page. All of the distributable recruitment documents contained a link to the Facebook page. My actions are an internet version of "snowball sampling" (Browne, 2005), a method of recruiting people by word of mouth who are often members of hidden populations that can be difficult to identify or access. Only a few Facebook owners responded affirmatively to my request. Nevertheless, I noted a surge of visits to the page.

The most effective recruitment strategy that I used was word of mouth. In other words, I invited prospective narrators whom I knew to have primary lymphedema. I met one of them while participating in a LE&RN event, and I learned about the other four from people with whom I had talked about my study. After learning about these individuals, I either directed them to the Facebook page myself or asked my contact person to direct them to the Facebook page. I recruited six narrators, and five of them completed the study. Though I knew of eligible prospective narrators through their social media websites, I did not recruit any of them, since the protection of their anonymity seemed untenable. After the first approved modification to extend the participant criteria to individuals with secondary lymphedema, I recruited and conducted one research conversation with a narrator with secondary lymphedema. I was unable to schedule a second conversation with her.

Disclosing my positionality. I disclosed my personal experience with lymphedema in all my recruitment material. Harris (2015) suggests that disclosing her drug-using history and/or hepatitis C prompted interest in her research study, as one participant commented, "…you know what I've been going through, and I know what you've gone through, even though we have totally different lives. We're still connected by, by that virus" (p. 1691). Moore (2015) claims that disclosing that he was once overweight when recruiting overweight men to his research study, was helpful in the recruitment process, and Malacrida (1998) believed that disclosing her own experiences with perinatal loss helped her to recruit participants for her study on that topic. The alternative—not to disclose—would have been dishonest, antithetical to my governing theoretical perspective, and would have risked harm to the relationship between the narrators and myself (Few, Stephens, & Rouse-Arnett, 2003). I suspect that, at least in part, the narrators were

willing to offer their time for the unusual opportunity to connect with another person with primary lymphedema.

Guided Conversations

One of the most utilized methods of data collection for life history research is interviews or guided conversations (Cole & Knowles, 2001). In the section that follows, I discuss the strategies I used during guided conversations, including those I used to achieve the trustworthiness of the research.

Setting the scene. Once a prospective narrator sent an email message to me indicating interest in the research study, I responded with a suggestion that we arrange a time for a phone call. Goodson and Gill (2011) claim that setting the scene for life history research is of "enormous importance" (p. 37). With their claim in mind, I hoped to accomplish three aims with the call: (1) ascertain the person met the participation criteria; 2) assure that they understood the time commitment for the study; and 3) and demonstrate that they might be comfortable having a research conversation with me. I used the IRB-approved telephone script to structure the conversation and cover the required elements. I also requested an email address to which to send a copy of the Participant Consent Form and Telling Your Story Guide.

With all but one of the narrators, the telephone conversations drifted quickly to the narrators offering life stories. I took this as a sign of enthusiasm and assured them that they had an important life story to tell. I also offered a bit of reciprocal information about my lymphedema. At the end of the telephone conversation, I solicited further questions, responded, and then negotiated an agreement for the date and time for our first guided conversation. One of the prospective narrators was relying upon a work phone to communicate with me. I suggested that we meet briefly in the cafeteria of the large hospital where she worked to discuss

participation. This strategy demonstrated my willingness to accommodate her schedule and personal circumstances so that she could participate.

Location of guided conversations. I conducted guided conversations with two of the narrators using internet video conferencing software because of the distance between our homes. The narrators and I conducted the conversations from private rooms in our respective homes. We established rapport quickly, and the conversation seemed hindered, only briefly, when one of us experienced issues with our technology. I conducted the research conversations with the other narrators in places they chose, including a private meeting room on a college campus, a private meeting room at a hospital, and a quiet restaurant.

Using the conversation guide. I conducted three guided conversations with each narrator, lasting in between one to two-and-a-half hours per conversation. I conducted the conversations over five weeks to four months, for a total time of six to nine hours with each narrator. I met with one of them during one of her lunch breaks. She expressed a desire to continue our conversation that day, and I waited an hour for her to finish her workday so that we could resume our conversation.

I began each conversation with informal "chit-chat," and we talked about how much time we were both available for our conversation on that day. I began the first conversation by reviewing the consent form and obtaining the narrator's signature if the narrator had not already sent a signed form to me by email. Then, together, we completed the Demographic and Lymphedema Information Form. At the beginning of the second and third conversations, I reminded them of their participant rights and asked if they had any questions about the process.

During the conversations, I kept my question guide available as a reference. I developed my question guide from a review of the literature and my own experiences. Though the narrators

were aware that I had a guide, I assured them that I wanted them to tell their life story the way they chose. I also encouraged them to begin anywhere that they wanted, because life history research invites narrators to organize the telling of their own stories with events that they believe to be important. I asked questions about their health, as well as clarifying questions about their stories, throughout.

When it seemed that the narrators had told all their stories about lymphedema organically, I used questions from the guide to extend the conversation and achieve the depth and breadth of their life stories. During the second interview, I used information from the first interview to become intentional about exploring the context, grounding the conversation (Goodson, 2017), as we moved from life story to life history. However, the narrators often revealed contextual information (Cole & Knowles, 2001) and information about their experiences with lymphedema in a fragmented nature throughout the conversations. I interpreted the fragmented nature of our conversations to mean that they were emphasizing the events that occurred to them as important at the time of telling or were extending the stories already told.

Using artifacts to provide contextual information and elicit narratives. I invited narrators to bring material and digital objects to each guided conversation to interrogate the object itself as a provider of contextual data and/or to elicit narratives. They took time between conversations—a gift to the research endeavor—to select artifacts to bring to conversations. We explored the meanings attached to the artifacts to uncover how *they* viewed the experience the artifacts represented and the significance of that experience to their lives (Riessman, 2008).

Recording guided conversations. I captured the narrators' perspectives (Patton, 2015) about their lives by recording all guided conversations using a digital recording pen supplemented with a notebook, and I used the recording software and the microphone on my

mobile telephone as a back-up recorder, in case of pen failure. The advantage of using the pen with the appropriate notepaper is that, when I made notations about body language and non-verbal behaviors, the notes were "anchored" to the digital counter on the pen, making it easy to associate notes with the time on the recording. This strategy enabled me to pay as much attention to the narrator as possible during the guided conversations, taking only strategic and focused rather than verbatim notes throughout (Patton, 2015). Frequently, I experienced a need to jot a quick note about something the narrator said to which I wanted to return so as not to interrupt the narrator's story. At times, I made notes about something I did not want to forget. When that occurred, I asked the narrator to give me a moment to make the note because I thought it might be essential to their life history and took care to avoid interrupting their train of thought.

Time between conversations. I usually began transcription of the conversations within a day of the conversation and completed them within a week after each conversation. By listening to the conversations a second time, I was better able to reflect upon the conversation and make notes to build upon for the next conversation (Cole and Knowles, 2001). I sent the transcript to the narrators and asked them to conduct a "member check" for meaning and accuracy at least a week before the next scheduled research conversation. On a printed transcript, I highlighted information that was not clear to me or about which I wanted to learn more.

Conducting more than one conversation with each narrator was methodologically productive in at least three ways. First, the time between interviews enabled me to use the printed and highlighted transcript during subsequent interviews with each narrator to achieve clarity, where needed. I discovered this strategy to be especially helpful if a narrator offered no feedback about the transcript that I sent to them for "member check." Early in the second and third conversations, I asked the narrators if there was something on the transcript that they wanted to

clarify or if they had thought of something they wanted to share. Then I asked about the parts that I highlighted on the printed transcript. Most of the time, they had more to add about the stories that I highlighted. In a sense, then, I assured the accuracy of the transcript as well as expanded the stories and deepened my understanding by conducting a "guided" member check. The notes I took when reviewing the transcripts and listening to the conversations, and the sections that I highlighted, suggested the direction and tone of the subsequent guided interviews, becoming starting points for those conversations, and seeking clarification of questions that arose from earlier initial analysis (Cole & Knowles, 2001).

A second benefit of having multiple guided conversations with each narrator was that, between conversations, they had time to reflect upon their lives. The previous guided conversation stimulated memories for them, and reflection time provided opportunities to make meaning of their memories. Some narrators returned to subsequent conversations indicating that they wanted to share something before our research conversations ended. I took their requests to mean that they held trust in the relationship and appreciated the purpose of the research study. I consider the independent, reflective work they conducted between conversations, and later shared with me, as co-investigators (Cole & Knowles, 2001), to be one of their greatest gifts to the research endeavor.

The third benefit of multiple research conversations was that I had time to deepen my relationships with the narrators by demonstrating respect, interest in their stories, and trust in them by offering reciprocal information about our shared experiences. I was timely with expectations, honored the complexity of their lives by rescheduling appointments for conversations when needed, and I demonstrated protection of their anonymity when communicating electronically. I returned to our second and third conversations with more

questions about stories they shared during the previous conversation, signaling that I thought the stories were important and that I wanted to assure that I understood what they meant. All queried me about the nature of my lymphedema and self-management practices at some time or another. I reciprocated with brief responses, demonstrating my trust in them.

Embodied presence during guided conversations. Based on my orientation to the life history process and emic positioning, my theoretical and methodological choice was to co-construct a reciprocal nature to conversations with the narrators (Cole and Knowles, 2001) through an intertwining of the corporeal with the social. The material and tangible aspects of our lymphedema emerged as a particularly recognizable aspect of corporeality for us. As such, embodied narratives arose from this intersection of corporeality and discourse (Harris, 2015), such as when Narrator Arial shared that she was having a "good leg day," raised her pant leg, and offered an opportunity to feel her leg. At times, the research conversation became one of "mutual consideration" (Harris, 2015, p. 1693) when narrators and I exposed our lymphedematous limbs or the products we use to manage our lymphedema. I also recognized narrator clothing and body positioning during the interviews that they likely intended to obscure their limbs, such as the way that narrator Anya tended to tuck her puffy feet far beneath her chair. This recognition, I believe, was due to activation of my somatic mode of attention or "culturally elaborated ways of attending to and with one's body in surroundings that include the embodied presence of others" (Csordas, 1993, p. 138), enhanced by my own experience with living in a body with lymphedema.

Our bodies served as a site of scholarly investigation as well as a site of meaning-making (Patton, 2015). Pillow (1997) discovered the centrality of the body in her research on pregnant teenagers and their experiences. Acknowledging their changing bodies, how they experienced

their bodies, structural responses to their changing bodies, and the perceptions of others toward their bodies became central to her research. Realizing that it would not have been possible to understand much about their experiences without focusing on their bodies, she developed a body-centered methodology that allowed her to ask and answer research questions that would have otherwise remained invisible. Because I live in a body with primary LLL, my somatic experience was an enhancement toward developing the body-centered aspects of my study. For example, narrator Arlo expressed appreciation that we were able to contribute equally to "shoe talk." When discussing athletic shoes, we required little explanation about the way that padded tongues on athletic shoes tend to fold forward on us rather than lying against the curve at the junction of our ankles and feet.

Field notes. I jotted field notes soon after guided conversations that captured details I observed about the narrators and the conversation settings. I also wrote reflections about how the interviews seemed to go. For example, I noted when I talked over a narrator or failed to recognize that something may have gone unsaid. My field notes included my initial analytic insights and interpretations, my feelings, reactions, and reflections about the personal meaning and significance of my observations. I tried to be mindful of my embodied experiences as part of the data (Ellingson, 2017) and capture them in words in my field notes as best I could.

Data Analysis: Making Sense of Lives in Context

Cole and Knowles (2001) write that there is no one or best way to make sense of and represent lives in context. The data analysis process in life history research mirrors techniques used in all qualitative research, including simultaneous data collection and analysis (Labaree, 2006; Suarez-Ortega, 2013). I used thematic analysis (Riessman, 2008), immersing myself in the data, incubating and working inductively, to discover important patterns (descriptive findings),

themes (topical findings based on patterns), and interrelationships (Patton, 2015). I also used reflexivity on my positionality and embodiment (Banister, 1999; Ellingson, 2017; Harris, 2015), as an analytic lens throughout the research study (Patton, 2015).

I began constructing the narrators' life histories after completing data collection, focusing on each case, rather than across cases (Riessman, 2008, p. 53). Cole and Knowles (2001) encourage life historians to read narrator transcripts with increasingly penetrating lenses during analysis. I reread the transcripts while listening to the interview recordings since as much as a year had passed between conversations and writing life histories. I interrogated their narratives for what (thematic analysis) rather than how (structural analysis) they were spoken (Riessman, 2008, p. 19) and used open coding to mark events they narrated, emotions projected, and behaviors observed during conversations. While reading, I constructed a lifeline (Gramling & Carr, 2004) for each narrator that included critical personal events and events related to their lymphedema, noting the geographical context for each event.

With the lifeline in hand, during the second and third, more in-depth readings, patterns and themes began to emerge and helped to start filling in and adding shape and texture to my understanding of the narrator (Cole and Knowles, 2001). I began "brooding" from the very first conversation with a narrator about how the narrator's experiences might be linked until I reached the point where it "made sense" and "felt right" (Plummer, 1983, p. 99). I was able to uncover crucial plotlines about their journeys with lymphedema. At this level, I sought to make meaning of the narrator's lives in context—a broader and more contextualized interpretation related to the year during which they first noticed swelling, when a physician established a diagnosis for their swelling, and when they began treatment. I deductively connected the events in their lives to the sociocultural, medical, and geographical contexts of those events based on historical literature.

Eventually, the themes and connections I made provided meaning and structure, and their story unfolded.

I constructed a life history, or in-depth, case-study description, for each narrator emphasizing the stories they conveyed that seemed significant to them. My intent for these substantial life histories—between 13 and 20 pages each—is to do justice to their cases so that the reader may get to know the details of each unique case (Patton, 2015). I reduced the large volume of raw information gathered during the three conversations with the narrators, sifted the trivial from the significant, identified significant patterns within each set of stories, and then constructed a framework for communicating the essence of what the data revealed about each of the narrators (Patton, 2015). My intent for using these strategies was to fairly represent and communicate the data aligned with the purpose of the study.

I begin each of their stories with a short description of their entry into the research study and then recount their stories about the time when their swelling began, a theme that I labeled "first swell." Then I proceed thematically to achieve coherence of their life story. I ordered the presentation of the themes to reflect the idiosyncratic manifestations of their experiences with the condition and the variation in their life courses. Aligned with my research questions, I also present their stories with the necessary sociocultural, medico-historical, and geographical context for understanding each of their cases. I include the emotions they expressed and their webs of social relationships amidst critical incidents related to their swelling. For some, these incidents led to epiphanies—"existentially problematic moments in the lives of individuals" (Denzin, 1989, p. 129)—about their lymphedema.

I constructed a layered account (Goodall, 2008), in my (re)presentation and interpretation of their life histories and used in vivo phrases as headers, to frame the sections that followed. I

included their narratives in the (re)presentation of their life histories that provided thick, rich detail (Geertz, 1988). By doing so, I offer an opportunity for "intimate involvement, engagement and embodied participation with stories" (Smith & Sparkes, 2008, p. 21) and invite alternative interpretations alongside mine (Riessman, 2008). I removed extraneous words (i.e., uh, hum, like, you know) and repetitions to provide a seamless flow to the final representations.

The narrators' life histories provided a foundation for cross-case pattern analysis (Patton, 2015) and findings. The narrators' life histories suggested common, sometimes interconnected, themes. To identify these themes and generate substantive insight into the phenomenon of growing up and living with primary LLL, I worked back and forth between each case, inductively looking for actions, perceptions, experiences, relationships, and behaviors that were similar enough to be considered a manifestation of the same thing, and minimized idiosyncrasies (Patton, 2015). I used a gendered lens and critical theorizing throughout to understand their lives in sociocultural and medico-historical contexts. Once I completed the inductive analysis, I placed their stories in broader context with the other narrators' stories to present my findings and connected my findings to current theoretical knowledge. Finally, I used my findings and the connections between findings to answer the research questions.

Ongoing reflexivity. My reflexive journal involved constant contemplation about my research endeavor, from the review of the literature to the design of the study and throughout data collection, analysis, and interpretation. My journal entries were an indispensable source of data for understanding the intersubjective nature of the study. Cole and Knowles (2001) wrote,

> We research who we are. We express and represent elements of ourselves in every research situation. The questions we ask, the observations we make, the emotions we

> feel, the impressions we form, and the hunches we follow all reflect some part of who we are as a person and researcher. (p. 89)

Cole and Knowles (2001) emphasize that preparatory work, such as the work I conducted in Chapter II regarding my positionality, is crucial for heightening awareness to preconceptions, beliefs, and social location, and "grinding the research lenses we wear" (Cole & Knowles, p. 89), and that this heightened awareness is also essential throughout the research process.

Maximizing Trustworthiness

Lincoln and Guba (1985) defined trustworthiness as that quality of an investigation (and its findings) that make it noteworthy to audiences and explained that trustworthiness criteria (credibility, transferability, dependability, and confirmability) were parallel, quasi-foundational, and intended as analogs to conventional criteria (internal validity, external validity, reliability, and objectivity) (Guba & Lincoln, 1989). Next, I discuss each of the trustworthiness criteria and then the strategies that I used to achieve these criteria and demonstrate trustworthiness.

Credibility. According to Lincoln and Guba (1985), credibility addresses "the issue of the inquirer providing assurances of the fit between respondents' views of their life ways and the inquirer's reconstructing and representation of same" (Schwandt, 2015, p. 308-309). The authors recommend the strategies of prolonged engagement, persistent observation, triangulation, and member checks to achieve credibility.

Prolonged engagement and persistent observation. I was not in the field with the narrators and therefore relied on prolonged engagement, rather than persistent observation, to enhance credibility of the study. Prolonged engagement in the field is the key to achieving the development of multi-layered (Morrow, 2005) descriptions that are detailed, expressive, and explicit explanations. I provided thick, rich descriptions (Geertz, 1988) in the narrator's life

histories, relying mainly upon the narrators' words and my observations of the narrators during the conversations. Lincoln and Guba (1985) claimed, "prolonged engagement provides scope," (p. 304). I conducted guided conversations with each narrator three times, over five weeks to four months, allowing me to reflect between conversations and return to subsequent conversations for clarification and deepening of the narrators' life stories, which promoted a better understanding of the phenomenon. In terms of engagement, I was mindful to identify characteristics and elements of the narrator's life story, and the narrator while telling their story, to elucidate the dimension of salience to the research purpose.

Triangulation. According to Mathison (1988), triangulation of multiple sources of data "provides evidence for the researcher to make sense of some social phenomenon, but that the triangulation *strategy* does not, in and of itself, do this" (p. 15). With triangulation, the researcher filters convergent, inconsistent, and contradictory evidence through knowledge gleaned from immediate data, the context of the study, and understandings of the larger social world to construct meaningful propositions about the social phenomenon under study. Mathison charges the researcher with extending the triangulation process beyond data collection to reporting convergent, inconsistent, and contradictory data explicitly, as well as reporting data collection procedures. In doing so, she claims, the "logic and plausibility of explanations are public and open to discussion" (p. 17). Consistent with Mathison's conception of triangulation, and useful in life history methodology, Munro (1998) writes that triangulating data is not intended to verify the truth, but to establish as broad a context as possible for understanding life histories. To this end, I triangulated data from various sources, including transcripts, artifacts offered by the narrators, my reflective memos, and contextual data publicly available from lymphedema organizations and journal articles. Although this study did not rely on field observations, often

important in triangulating data, it reflected intent to establish the broad context in which the narrators have lived their lives with lymphedema.

Member checks. I offered the narrators opportunities to perform "member checks" to verify that I recorded their stories as told as a gesture of respect for their authority over their own stories. As discussed earlier, I also provided the transcripts to the narrators as an opportunity to reflect upon their stories between conversations to scaffold subsequent conversations.

Peer debriefing. Another strategy that I used for enhancing the credibility of my findings is that of "peer debriefing" (Patton, 2015, p. 665), or consultation with my dissertation advisor to explore aspects of the inquiry that might otherwise remain only implicit to me (Lincoln & Guba, 1985). I needed to submit to a process that "keeps the inquirer honest" (Lincoln & Guba, 1985, p. 308), including responding to searching questions about methodological, legal, ethical, and other relevant matters, probing my positionality as a lens, exploring meanings, clarifying interpretations, and exploring for disconfirming evidence (Lincoln & Guba, 1985). To facilitate this process, my advisor read much of my data and offered her reflections on the data and my analytic processes.

Transferability. Lincoln and Guba (1985) write that it is the researcher's responsibility "to provide the database that makes transferability judgments possible on the part of potential appliers" (p. 316). To facilitate transferability to readers with whom the narrators' life histories may resonate, I provided a thick, rich description (Geertz, 1988) of each narrator's unique characteristics and situations as well as the sociocultural, medico-historical, and geographical contexts within which they lived.

Dependability. Lincoln and Guba claimed that dependability focuses on the inquiry process and "the inquirer's responsibility for ensuring that the process was logical, traceable, and

documented" (Schwandt, 2015, p. 299) and encourages the researcher to take into account both factors of instability and factors of phenomenal or design-induced change (p. 299). With their charge in mind, I supported my findings, interpretations, and recommendations with data and assured that findings and interpretations are internally coherent (Lincoln & Guba, 1985, p. 318).

Confirmability. Confirmability, Lincoln and Guba (1985) wrote, is "concerned with establishing the fact that the data and interpretations of an inquiry were not merely figments of the inquirer's imagination" (Schwandt, 2015, p. 309). To achieve confirmability, I made discernable links between the characteristics of the data and my interpretations (Schwandt, 2015). I also kept a log of dates of exchanges for each narrator to document the general research process and a reflexive journal containing interpretive, reflective memos.

Ethical Considerations

In this sub-section, I discuss the ethical considerations that every qualitative researcher must address. I also flag the ethical issues that confront life history researchers regarding the nature of the relationship between the researcher and the narrators. After full approval by my dissertation committee, I submitted all required documents for approval to the Institutional Review Board (IRB) of Human Subjects of Oklahoma State University (Appendix C), including two requests for modifications to participant selection criteria and recruitment strategies.

Securing and assuring informed consent. Before beginning the first recorded, guided conversation, I reviewed the consent form with the prospective participant, emphasizing their risks of participation, benefits, confidentiality, participant rights, and researcher and IRB contact information. I took care to fully disclose my research aims and assure that the prospective participants were aware of the research process as well as my intentions regarding how I might use their life stories in the research report, and possibly other publications and presentations. One

goal for securing informed consent was to solidify the voluntary nature of the research project and to provide full disclosure for how the research process and final presentation might affect them. Before the second interview, I provided the narrators a copy of the signed consent form, and I reminded them that they need not answer any questions that they felt uncomfortable answering nor elaborate on any detail during the interview that made them feel uncomfortable. I also reminded them that their participation was voluntary, and I emphasized that they could withdraw from the research study at any time without consequence.

Ensuring privacy. To ensure privacy, I conducted all the guided conversations in a setting where only the narrators and I were in the immediate proximity and in which the narrator expressed comfort with privacy.

Use of pseudonym and de-identification of data. Primary lymphedema is a rare disorder, and, as such, required that I take particular care to de-identify their data to achieve anonymity. I chose pseudonyms for each narrator, beginning with the letter "A" as a reminder that I intended each life history to be anonymous. I took care to change the names of places, organizations, and other information (geographical location, occupation, etc.) that may expose a narrator's identity. Despite meticulous data cleaning, with life history research, the contextual identifiers in the narrators' life stories will remain. Therefore, I considered whether specific quotes and examples could lead to readers identifying narrators and whether readers might identify those associated with the narrators (Kaiser, 2009).

Data recording and storage. I recorded the data I collected with a code system with which I linked each narrator's name to a number used to identify their demographic and lymphedema history questionnaire, interview digital recording file, transcript file, and notebook taken to the interviews. As a result, the narrator's data is only identifiable by the coded numbers.

During the data collection process, I kept all hard copies of data, except for the data code key, in a locked file cabinet, in my home office, accessible only to me. I stored the key that lists the narrators' names, code numbers, and contact information in a small home safe, accessible only to me that I keep in a separate room. Upon completing the study, I will destroy all identifying information about the narrators.

Digital data security. Concerned for prospective narrator privacy on the recruitment Facebook page, I blocked the comment function and provided a link to my university email address. I also offered the Facebook messenger function to contact me. I advised narrators against using workplace or other non-private computers and email addresses to communicate with me to reduce the risk of confidentiality breaches. Finally, I obscured the faces of individuals in photographs the narrators submitted before archiving them electronically.

Researcher relationship with narrators. There are no strict rules and prescriptions for ethical conduct in life histories (Guba & Lincoln, 1994), and research ethics are situated and contingent on the research context (Plummer, 2001). Life history research is a relational process (Cole & Knowles, 2001; Goodson & Gill, 2011). I intended to develop relationships with the narrators based on mutual respect, trust, and 'mutual benefit' (Hatch & Wisniewski, 1995) and shared stories about my experiences with lymphedema judiciously. I believe that sharing those stories helped to nurture the trust that developed between us.

Ethics are involved in finding a balance among my roles as researcher, nurse, and person with lymphedema. I hold medical knowledge from my role as a nurse that could aid narrators' healthcare needs and felt obligated to encourage them to seek care. I used my clinical judgment to determine the degree to which I should facilitate their access to care, commensurate with the

acuity of their need. Fortunately, none of them revealed an acute need, and I was able to limit my assistance to referring them to helpful websites.

Also critical was practicing ongoing reflexivity regarding how the narrators in my study were responding to me as a nurse and as a researcher, as well as my other subjectivities (race, age, etc.), and I worked intentionally to minimize power imbalances. I communicated that, though I am a nurse, I am not a lymphedema specialist. Since I am a nurse, it was conceivable that narrators would be wary about sharing stories about their experiences with medical professionals within the healthcare system. I was able to offset this concern by prefacing questions about their experiences with a simple statement such as, "Participants in other research studies about lymphedema have shared both positive and negative experiences with healthcare. How has it been for you?" This approach seemed to work well since the narrators shared stories about unsatisfactory encounters with their providers.

Due to the dialogic nature of the interviews, I also found it difficult to subdue my role as nurse during conversations with the narrators, especially when compelled by their stories about dramatic or grievous experiences with the healthcare system and apparent knowledge deficits about decongestive therapy, self-management, and Lymphedema World. Generally, noting excursions away from listening to stories and toward my nurse assessment and teacher behaviors while transcribing, and recognizing how much more of their lives about which I wanted to learn, helped to mitigate these behaviors in subsequent conversations while still reciprocating with brief responses to narrator inquiries.

Limitations of the Study

All life history research is limited. The purpose of this study was to offer insight into the life histories of men and women who grew up with and are living with primary LLL. As such,

their life histories are but a glimpse into the overall experiences of growing up and living with the disease. As with most life history research, the small sample size, in deference to depth of data collection rather than breadth, will limit generalizability, but I believe it is reasonable to expect my findings to have potential for transferability to others in similar situations such as living with a disfiguring but easily hidden disease and adults with other types of lymphedema.

Another limitation is that narrator recall of life stories may be selective, and ultimately, I am dependent upon narrators for authenticity and veracity. Though I used guiding research questions with the intent to direct the general topics of the narratives, I am beholden to the narrators' life stories as told—the truths that they constructed and chose to narrate. Second, life history methodology relies on the ability and willingness of narrators to articulate their understanding of their experiences and participate in the co-interpretation of their life histories. Perhaps, the most significant limitation is the constraints of my subjectivities for crafting the histories of the narrators. For example, in response to their narratives about grievances with the healthcare system, my enthusiasm to learn about the medical aspects of their experiences shaped the data collection process.

Conclusion

This research study focuses on how five individuals understand their lives growing up and living with primary LLL. In this chapter, I described my epistemological stance and the research methodology that I used to guide the research and the methods I used to conduct the study. I outlined the strategies I employed to maximize trustworthiness and the measures I took to ensure an ethical researcher/researched relationship. In the next chapter, Chapter V, I provide the life histories of the narrators.

CHAPTER V

NARRATOR LIFE HISTORIES

Before beginning this research study, I had met only two people who have primary lymphedema. I may have met others, but, like me, they were not disclosing or exposing their lymphedema. I relished the opportunity this study offered for me to sit with others with whom I share a rare condition, and I believe all the narrators felt the same. Despite the condition we have in common, many aspects of our experiences with the condition differ. For example, as Arlo pointed out, I have never known life without lymphedema, and he suggested that this factor alone might have contributed to our experiences differing significantly. Nevertheless, many aspects of our experiences with living with lymphedema are similar, and my voice intertwines with those of the narrators (Kvale, 1996) in my representation of their stories.

The life histories of the five narrators in this study—Audra, Arlo, Abie, Anya, and Arial—vary broadly related to lymphedema such their age at the time of our conversations, the age at which they developed swelling, and age when healthcare providers established a diagnosis of primary LLL. Table 1 below represents a demographic matrix that illustrates narrator diversity. I arranged the table in the order the narrators entered the study and the order I present their life histories. All names are pseudonyms.

The average age of the narrators at the time of entry into the study was 32 (19 years old to 40 years old). The average age they first noticed swelling of their leg(s) was 13 (8 years old to 17 years old). The average number of years they experienced swelling is 19 years (5 years to 30 years).

Table 1 – Demographic and Lymphedema Data Matrix

Narrator	Gender	Ethnicity/ Race	Age*			Number of years with swelling	Number of relatives with primary LLL	Number of Children
			RC	FS	MD			
Audra	F	African-American	40	17	18	23	0	0
Arlo	M	White	40	10	10	30	1	4
Abie	F	White	19	14	14	5	0	0
Anya	F	African-American	29	8	26	21	0	2
Arial	F	White	33	15	32	18	0	3

*Age: RC - At the time of the research conversation
FS - At the time the narrator first noticed swelling
MD - At the time a medical professional established diagnosis of primary LLL

Physicians established the diagnosis of primary LLL for three of the narrators within a year after the narrators first noticed swelling. Remarkably, two narrators lived with swelling for 17 to 18 years before a physician documented the diagnosis of primary LLL in their medical records. None of them reported that they have associated symptoms that might indicate that their lymphedema is part of a syndrome. None reported that a physician had diagnosed a specific subtype of primary lymphedema, based on imaging or genetic studies. Only one of the narrators, Arlo, knows of a family member with lymphedema. Some of the narrators live with uncertainty about their lymphedema, including whether their condition developed due to a preventable inciting event. All developed lymphedema while living in the U.S. and conducted their search for a diagnosis and treatment within the U.S. healthcare system.

Audra: Lymphedema Doesn't Have Me

Audra stood with her husband, awaiting the opening ceremony of the LE&RN fund-raising walk. I noticed that, like me, she was wearing full-length, wide-legged pants, despite the

heat and humidity expected for the day. I suspected she had lymphedema in at least one leg. After we introduced ourselves, our "lymphie talk" came quickly, carried along by our mutual, ongoing search for strategies to manage our lymphedema more easily. She enthusiastically described some of the lymphedema-related awareness activities in which she had participated. When Audra shared that her lymphedema developed when she was 17, I shared that I was researching growing up and living with primary lymphedema. I offered my email address, suggested that she take time to think about participating, and asked her to send a message if she wanted to learn more about the study.

Audra wrote to me a week later, claiming, "It was great meeting fellow lymphies" and "I look forward to meeting, learning, and advocating more to educate others about lymphedema." Because we lived so far from one another, we arranged to meet using video conferencing software, and, as she put it, "our journey" together began. She wrote,

> *I am willing to help give you a vivid picture of my life (it is very colorful)…Lol. I honestly don't mind sharing my pictures. I think pictures help tell the story. I feel so inspired! I am truly excited for the both of us.*

Audra's enthusiasm for helping to increase awareness of lymphedema by sharing her story with the world was evident. Her story was about emerging from hiding and accepting responsibility for self-managing her lymphedema.

First Swell: "Mom, I can't get out of my jeans!"

It started at 17. I was walking home from school with my friends, and I had on jeans. I remember they were blue, Guess jeans. I think those were my favorite pair of jeans. When I got home, I was trying to take my jeans off but they couldn't come down. They wouldn't come…they wouldn't budge, basically…they wouldn't come past, yeah, past my hip. I'm like, "Mom, I can't

get out of my jeans!" She was trying to pull my jeans from the bottom, and we were unable to get them off. Then we looked and realized that I was kind of swollen like, pretty much swollen in the jeans. So she called the ambulance.

I soon learned that, indeed, Audra tells a lively, colorful story, inclusive of he-saids, she-saids, and, even, I-saids, accompanied with entertaining voice changes to imitate the person who said. While we talked, she relaxed into our conversation, calling me by my nickname, "Deb." The day she first noticed that her leg was swelling, as she described in the excerpt above, was just a typical day in her self-described "normal" teenage life, "getting over my parents." She described feeling a little self-conscious about being taller than the boys, but said that she was happy with her looks, "stylin" in her blue, peg-legged, form-fitting Guess® jeans (https://en.wikipedia.org/wiki/1990s_in_fashion). When reflecting on the day, Audra could not recall any warning signs that something was awry.

Audra cannot remember all the details of the day that lymphedema began but vividly remembered that the expensive jeans, treasured because they helped her to fit in with the crowd, were destroyed as emergency personnel cut them off her body. We speculated that they did so to assure adequate circulation and assess for life-threatening causes of edema: heart and/or kidney failure, deep vein thrombosis in the leg, reactions to a bite or allergen, or an infection. In the Emergency Department, a nurse gave her intravenous Lasix, a diuretic prescribed to reduce edema. After ruling out life-threatening conditions, the Emergency Department physician discharged Audra to her primary care physician, sending her "shocked" and confused, to the first of many unsatisfactory medical encounters about the swelling in her leg.

About a year after her swelling began, Audra caught a glimmer of the value of knowing others who are also affected by lymphedema. Emotionally, she shared that while sitting in the

lymphedema surgeon's waiting room, she encountered another woman who had primary LLL. The woman, a schoolteacher, and mother of three boys assured Audra that she could have an active and productive life. Audra remembers crying in relief. Perhaps, at that point, no one, but another woman with lymphedema, could have offered such reassurance. Finally, Audra felt understood. In the late 90s, social media had yet to take off, and the opportunity to learn about others who have the same condition was rare. I cried a little when Audra told this story, understanding that growing up in areas without lymphedema centers likely means few opportunities to encounter others with the disease. I understood that, though she was still hiding her leg, she wanted someone to *see* her.

Medical Encounters: "It was like no big deal."

The primary care provider at the healthcare maintenance organization (HMO) documented "edema" in Audra's medical record and recommended that she elevate her leg, drink lots of water, avoid salt, and wear compression bought from the drugstore. The physician left Audra and her mother with the impression that her edema "was not a big deal" and that she should get on with life. Audra's mother refused to accept the idea they could not help her daughter's unexpectedly, inexplicably, swollen leg. She insisted that the physician refer her to a specialist outside the HMO.

The specialist inquired if she had experienced trauma to her leg, and Audra told him that, three years earlier, a surgeon repaired a hernia, a muscle weakness in her groin on the same side as her swelling. The specialist suggested that she might have sustained inadvertent damage to her lymphatic system during the surgery. Dismayed by this suggestion and desperate to find a cause for the swelling, Audra and her mother visited the surgeon to explore the possibility, hoping for a solution. Audra imitated the emphatic response of the surgeon to their query, "Oh, no. No! Why

would a leg swell up three years later after a hernia repair? I do hundreds of hernia repairs." I asked Audra how she felt after her visit with the surgeon, and she indicated that she felt "dismissed," claiming, "I'm damaged!"

About a year after Audra first experienced swelling, a specialist prescribed an imaging study and diagnosed her with primary LLL. The specialist referred her to a surgeon in another state who was performing a "new" surgery for lymphedema. The surgeon left Audra and her mother with the impression that all she could do was elevate, drink lots of water, avoid salt, and wear compression. Now, two decades later, after learning how to self-manage, Audra feels appalled that none of the physicians she saw taught her that her leg would get bigger and harder if she did not wear her compression, nor that she would be at risk for infection.

Recently, in 2013, one physician rose above the detached concern typical of physicians practicing amidst the time constraints of a profit-based HMO (Halpern, 2001) and offered Audra the empathetic care she deserved. The provider, acknowledging he knew little about lymphedema or its treatment, developed a strong partnership with Audra. She shared information with him that she discovered from internet searches about possible therapists, treatments, and products. Perhaps most important, the provider offered the impression to Audra that lymphedema *is* a big deal that requires significant investment in self-management, and he collaborated with her to assure the most favorable treatment outcomes possible.

Several factors may have contributed to the less than adequate care offered to Audra during the first few years after she developed lymphedema in 1995. First, the typical medical school curriculum offers little information to students about lymphatic diseases (Rockson et al., 2004) and few physicians develop this expertise. Second, before the turn of the century, when lymphedema began emerging as an important medical agenda, medical professionals tended to

view lymphedema as a cosmetic problem with little significance—a problem about which patients and their physicians could do little (Rockson et al., 2004). Third, insurance companies had just begun to reimburse for decongestive therapy in some states, training opportunities for therapists were new, and only a few lymphedema treatment centers existed in the country (MacDonald, 2006). Finally, lymphedema-related information available on the internet was related, mostly, to breast cancer-related lymphedema. Audra's earlier physicians gave her the impression that lymphedema was not a big deal. Taking their cues, she turned her attention to the tasks of emerging adulthood and let the active pursuit of information about her lymphedema fall aside.

Grappling with Othering: "Oh, my, gosh! Look at her leg!"

Soon after her lymphedema developed, Audra returned to school and shared with her best friend that she had "edema." Her friend responded, "That's an old person's disease!" and compared Audra's swelling to her grandmother's swelling. Feeling stigmatized, Audra decided not to share what had happened with any other friends and wore long pants or long dresses to school the remainder of the year. With only three months left of the school year, Audra was able to negotiate an informal agreement to help in the "front office" rather than participate in her physical education class and expose her leg. Audra sent a photograph to me in which she was accepting her high school diploma. In the photograph, her ankles were visible beneath her gown, and I could barely tell that one of her ankles was larger than the other. Audra wrote that this was probably the last day that she wore a short dress, believing that the length of her gown, which covered her calves, made her swollen leg less noticeable to others. Her strategy required little explanation because I believed the same about my graduation gown.

After high school, Audra "got on," busying herself with work and college courses. She chose to remain near her parents, who were divorced, lived near one another, and, while she was growing up, shared custody and visitation. Audra took classes at a local university while working full-time. She chose to pursue jobs with flexible dress codes so that she did not have to wear business clothes—knee-length skirts and pumps—that would reveal her swollen leg. Instead, she worked at jobs providing security or waiting tables—jobs that required pants as part of the uniform. When I commented that those jobs required extensive time on her feet, Audra reminded me that her frame of reference included the physicians telling her that her lymphedema was no big deal.

Audra shared that she had been strategic about hiding her leg for as long as she has had lymphedema and was grateful that maxi skirts and "flowy" pants have been available and in style. She offered her wedding as an example of hiding and said she never thought about wearing anything other than a long dress for the ceremony. Laughing, she shared that when it came time for the traditional garter ceremony, the wedding coordinator was rushing around, frantically asking, "Where's the garter? Where's the garter?" Audra said her only response was, "I forgot! I forgot!" As we laughed together, I wondered if she forgot the garter subconsciously. I refused a garter ceremony during my wedding reception because I wanted to avoid exposing my legs to guests, the shape of them the antithesis of the shapely legs represented in most images of a groom removing the garter. American brides and grooms commonly include the garter ceremony in their wedding receptions. How could the wedding planner have known the tradition might require strategic forgetting?

Understanding that Audra had struggled to disguise her leg and/or compression, I asked her to tell me about a hard time. She told me,

I guess for fear of judgment, fear of people looking at you like you're an alien, like, "Oh, my, gosh! What's wrong with her?" The type of person that I am, I like to talk to anybody. But I also will find myself shutting down emotionally if someone just comes off rude or disrespectful or something like that…I actually overheard my husband, one of his cousins, say…I was playing with a baby, my husband's niece. I was sitting on the porch. One of his cousins was like, "Oh, my, gosh! Look at her leg!"

When I probed further, Audra voiced no ill will toward the cousin. She understood that the cousin spoke from ignorance and insensitivity and did not realize Audra could hear her. Nevertheless, this understanding did not attenuate Audra's hurt feelings. She avoided telling her partner about the event, explaining that it hurt too much to talk about it.

Audra, upon recommendation from her therapist, pursued water aerobics and indoor cycling at the gym. Though lymphedema had been her companion for over two decades, these activities, usually conducted in a swimsuit or athletic shorts, created ambivalent feelings,

I've done water aerobics, but I was, in the back of my mind, like, "Oh, my, gosh! Everybody is looking at me." I think I stopped going, mostly because I felt embarrassed. It's just, I think for me, it's just that I don't want everybody to be staring at me like that. But, I really do love it and I told my husband that I'm going to go back. I've got to the point where now I don't care if they stare. They're going to stare anyway. So, I'll just do it. Even my cycling class, at first, I was worried about that. But, now I'm just like, "Oh, well." [Said quietly, with lower pitch] They see it, they see it. If they ask, they ask.

Audra seems resigned about the curious gazes of others; her desire to do good for herself is overcoming her need to hide her lymphedema.

Though she has an acute sense of privacy and self-consciousness about her difference, Audra has begun to reach out to others with empathy. She told me of a time when she saw a woman step onto an escalator wearing a long skirt, covering swollen legs donned in compression garments. She hurried up the escalator to catch the woman, introduced herself, and said that she recognized her lymphedema. The woman shared that her lymphedema was the result of gynecological surgery. Audra said that the encounter caused her to wonder, again, if her surgery caused her lymphedema—secondary lymphedema rather than primary lymphedema.

Intimacy with Lymphedema: "…he's probably going to see. I have to tell him."

At age 23, Audra met the "love of her life." It was during her 5-month convalescence after a severe break of her "good leg" that she met her partner, whom her sister had invited to dinner. Audra believes that he was unaware of her lymphedema at that time. The volume of stagnant lymph in her leg was probably abating, at least partially, since she was spending her days with her legs elevated, and it was still early in the disease process. Audra shared that, four or five months later, when she realized that they might, sometime in the future, become intimate, she told him about her leg. Audra was uncomfortable discussing her lymphedema with him initially and embarrassed about the possibility that he would see the waist-high compression that she was wearing. She explained that she decided to tell him because, "…if we're going to sleep together, then he's probably going to see. I have to tell him." Probing gently, I asked her what she was afraid of, and she replied, "Afraid of the same thing like with everybody else, like, 'Oh, something's wrong (emphasis). She's flawed (emphasis). Poor (emphasis)…' Then him not being…maybe like, 'Oh…well, I want to be with someone that can wear miniskirts.'" Audra reported that her husband did not say much after she told him and suggested that it was because

he was the type of person who likes to think things over before responding. In 2009, five years after meeting, the couple married.

Family Support: "Biggie Smalls! Biggie Smalls!"

I asked Audra to describe how her blended family—with several stepsiblings and her younger brother—responded to her lymphedema. She described her family as a sound support system. Laughing, she shared a story about her brother, "You know siblings are siblings. I remember my younger brother, he would call me…I don't know if you know the rapper called Biggie? He's from New York, Biggie Smalls. He would call me Biggie Smalls. He would call my legs Biggie Smalls." Recognizing the potential harm of this teasing, I asked her to expand. She explained, "Well, it was funny because it was just the family." Her explanation resonated with me, remembering that my younger siblings sang, "Debbie has fat feet" to the tune of "My dogs have fleas," whenever I tuned my ukulele. Perhaps, confident in the unconditional love of our families, their teasing was not threatening to us.

Growing up, she lived near her maternal grandmother and viewed her grandmother as someone with whom she could safely share her feelings about her lymphedema and from whom it was okay to receive sympathy—someone with whom she could be authentic. She imitated her grandmother from whom coddling was acceptable, "Baby, put your feet up!"

A Turning Point: "God, just see me through this."

At several points during our time together, Audra brought up "down times" related to her lymphedema and having to wear compression. She described coming home after work, day after day, and going to bed. Audra also gained weight during this time of her life. Audra acknowledges that, for many years, she wore her compression inconsistently and, in about 2010, fifteen years after first developing swelling, began experiencing occasional episodes of cellulitis.

During these downtimes, one life-threatening bout with cellulitis threatened her life, and she is motivated to "never go back there again."

The event unfolded quickly. During the summer of 2013, Audra drove her husband to the airport for a weekend away with friends. Deciding that the day was too hot and humid to wear her compression, as she had decided on other days that summer, she was bare-legged, and her leg had become particularly swollen. Audra became very ill and decided to leave her family's cookout and drove herself to the urgent care center. She described her experience,

> *I was just feeling a little heated. And it was really hot that day. I remember not having an appetite after seeing all those hamburgers and hot dogs. I started feeling really sick there, and I didn't want to worry my family because I knew they were going to shoot fireworks. I remember myself crying and hoping the police pulled me over. I needed help. I felt bad, but I didn't know why I was feeling so bad. And I had vomited three times. And I remember, when I arrived at the urgent care center, I was literally shaking.*

The triage nurse at the center recognized that Audra was exhibiting signs of an infection and quickly sent her to a room for evaluation for sepsis, a life-threatening infection.

While the medical professionals conducted the evaluation, Audra recalls that she was "in and out" but remembers that her body was hot while she felt cold and that the nurses would not give her a cover, even though she kept asking, "Please, can I have a sheet. I'm freezing!" She also remembers thinking that she was experiencing just another bout of cellulitis, but that "they never said it was from lymphedema. No one even addressed my lymphedema." Early the next morning, the physician transferred Audra to the hospital critical care unit, where they inserted a central line in a vein that led to her heart. She remembers that they wanted to give her blood, but that she refused, not having her partner at her side to help her with that decision. I suggested,

based on the information she shared, that physicians were concerned that she would develop or had developed septic shock.

Audra remembers that later in the nine-day hospital stay her leg began to "leak" lymph from her pores, saturating the bed. She remembers calling out to the nurses, "I'm leaking, I'm leaking!" and asking them to re-wrap her leg with towels, not knowing that she was experiencing lymphorrhea. Audra's nurses may have been unfamiliar with lymphorrhea since she does not remember them using the term to refer to the leaking lymph or acknowledging that Audra had lymphedema.

The physician discharged Audra to her home, where nurses administered intravenous antibiotics for another month. She missed numerous workdays while recovering from the infection. About her experience, she shared

> *It affected me in a way where the whole time that I was there in the hospital, I kept saying my prayers. I said, "God, just see me through this." I was like, "When I get out of this, I promise, I'm a live right. I'm a do good. I'm a…whatever I need. If I need to change my eating habits. I want to live!*"

Audra realized that not wearing her compression may have contributed to her illness and prayed that if God helped her to survive, she would change her habits and begin wearing her compression consistently.

When I asked her about not wearing her compression, she responded, "Like I said, compression was never like 'you need this for your survival' or anything like that. It was never told to me that way." Audra acknowledged that being busy with life also interfered with wearing her compression, sharing, "I wasn't as compliant, no. If I just left out one day and I didn't have my stockings on, or I was rushing to work one day, and I didn't have my stocking on, I would

just go on with the day without it." She also described a sense of hopelessness about her lymphedema,

> *It was. I guess I got to the point where I'm like, "Nothing's going to change. It's just going to be what it is." I guess I got to a point where I was just sad. It could have been a depressive state, a state of just, not trying to deal with it.*

The frightening hospital experience facilitated the epiphany Audra experienced regarding the association of infection with poor self-management of lymphedema. She realized that wearing her compression garment, making self-management a priority, was better than dying, and the trajectory of her life changed.

Learning to Self-manage: "I'm like garmented up, 24 hours a day."

Audra was a hard worker, and frugal, and by the age of 21, owned a condominium. Later she purchased and sold a franchise for a small business. Eventually, Audra certified in a healthcare field and took a position that allowed her to sit while working. She persisted and finished her baccalaureate degree eighteen years after graduating from high school. Audra described herself as "always active" and explained that these activities kept her standing and walking, or sitting at a desk in class or work, and on public transportation, for long days during the week. Most of the time, her legs positioned below the level of her heart, and only intermittently, she wore the waist-high compression with one leg that a physician prescribed. Over the years, her leg became less and less responsive to elevation, more enlarged, and fibrotic.

After her experience with sepsis, a physician referred Audra for complete decongestive therapy (CDT) to reduce the volume of fluid and fibrosis in her leg before fitting her with custom compression. Audra's physical therapist secured approval for reimbursement from Audra's HMO, amounting to one-hour treatments, five days a week, for four months. Her partner went to

two appointments to learn how to help with bandaging on weekends. Audra highlighted a critical factor that enabled her to participate in therapy, sharing, "I worked 6:00 am to 2:30 pm, and I said, 'This had to be God' because the facility was only about a 15-minute drive from my job. So I would rush from work at 2:30, and I would get there on time." The proximity of the clinic allowed her to attend therapy sessions without taking sick leave or even, as some people would have to do, quit her job.

However, wearing multi-layer bandaging on her leg, she shared, drew the attention of her co-workers,

> *People in my office…you would hear them say something or trying to look or something like that. My thing is, if you want to look if you're not going to ask and you're just going to speculate, I'm just going to let you speculate because I'm not going to sit up there and break down my whole health history. I would rather someone be straightforward with me versus, like, "Oh, my, gosh, oh, my, gosh!" That's a turn off for me.*

This kind of attention, while Audra was attempting to right her life with lymphedema, created feelings of resentment toward her co-workers. Nevertheless, covering her bandages with near-floor length skirts, she persisted in her therapy, and her supervisors got her a stool upon which to elevate her leg. After the first phase of decongestive therapy, Audra and her partner proceeded with the second phase of therapy—maintaining the limb volume reduction that the therapist achieved by wearing her compression garment during the day and wrapping at night. Her partner helped her to wrap at night, working the process into his daily routine, and sometimes prodding her with, "Come on…let's get this going."

Learning to self-manage lymphedema is a process (Palmer, 2006). In 2016, Audra was managing her lymphedema but was struggling with consistency. The size of her leg had not

reduced as much as she hoped, and she realized that she needed therapy again. She scheduled another round of decongestive therapy with a different therapist. Audra and her new therapist decided to add custom, inelastic garments designed for wear at night, instead of wrapping. She chose pink garments because she wanted to look "cute." However, Audra said, the therapist recommended that she occasionally wrap to apply pressure to the nooks and crannies of her ankle and foot where edema tended to collect to minimize fibrosis. She began wearing two compression garments at the same time to maximize the effects of therapy and ease the donning process. A physician prescribed a lymphedema pump, and Audra's HMO approved the purchase. Still, she has had a few more bouts with cellulitis. However, she recognizes the signs and symptoms early and is quick to make an appointment with her primary healthcare provider when she needs antibiotics.

Audra recognizes that her leg feels better when she wears her compression consistently and says that now, she is "garmented up 24/7." I asked her to tell me about a "good lymphedema day" and a "bad lymphedema day." She shared:

> *A good day is when I get up, and my leg is jiggly from having to wrap it overnight. I realize there's no infection, no anything. A bad day is, I was up on my legs all day. I remember one day, I was washing my garment…It was rainy the other day. I wore two compression garments, so both got wet at the same time, and my overnight garment was drying. I was like, "oh, my, gosh! Everything is wet all at the same time." I was laying in the bed, trying to keep my leg elevated.*

The story that Audra shared about the rainy day indicates that she has developed a strong understanding of the dynamic nature of lymphedema and she realizes that even one day without her compression means that she will lose ground toward maintaining the volume reduction that

she, her partner, and her therapist have achieved. Further, Audra's story demonstrated that, within the routines of her busy life, self-management had become a priority for her.

Stepping into Lymphedema World: "You have lymphedema, lymphedema doesn't have you."

Audra's second therapist told her about the Lymphedema Treatment Act, and Audra registered with the Lymphedema Advocacy Group in 2016. Since then, she has participated in several LTA-related events advocating to pass the bill, while getting to know other advocates. She also participated in a LE&RN event, advocating for lymphatic and lymphedema research and a LE&RN fundraising walk. Audra began following bloggers who write about living well with lymphedema and values those opportunities to relate to others.

Audra shared that she was developing a plan to become more active in Lymphedema World. She expanded,

> *My angle is gonna be just to tell my story and use that platform to motivate people to know you can still live a normal life and still be able to be a person with lymphedema; but lymphedema doesn't have to have you. You can still go and do everything you want to do because you can still travel, you can still go and be sociable, go for a walk in the park, go and do whatever you want to do.*

Audra began formulating her plan after her gym instructor approached her with an authentic interest in learning more about lymphedema. Her instructor invited her to appear on her podcast to talk about becoming fit while living with lymphedema. Regarding her instructors' invitation, Audra explained that she was not yet ready to share in a public forum. We agreed that stepping into Lymphedema World is an emotional process that takes time. Audra shared, "Just to be a part

of something that, you know…you shielded…for so long and just to realize that you can actually make a difference."

Audra has noticed that she was in the racial minority at all the lymphedema-related events she has attended. This under-representation concerns her and, referencing other people of color, she wondered aloud, "Are they not aware or do they not get lymphedema as often?" We agreed that it is difficult enough to have a rare disease; being a person of color in the U.S., increases the difficulty of having a rare disease. These concerns fuel Audra's determination to increase awareness about lymphedema amongst people of color and to encourage them to live well with the condition. She shared her dream,

> *I want to use my platform to show my social side. The things that I do outside of this. Yes, I am a person that has lymphedema; but I'm also a person that loves doing stuff for other people. That loves my community and loves helping out. So it's just gonna be something that brings awareness and educates a little bit, just from my standpoint: As a minority woman being born and raised in a city, having this disease that is kind of rare.*

In the meantime, Audra persists in living with lymphedema while not letting lymphedema have her. Her philosophy, "I guess, with age and with maturity, you just accept it as a part of life and I just kind of roll with it, you know. Even I find myself being more open to talking about it."

Arlo: Lymphedema Lying in Wait

I included a short description of my doctoral dissertation topic when introducing myself on the first day of class. After class, a student responded that she knew someone who might participate in my study. I asked her to forward the participation recruitment flyer to her friend. Ten days later, Arlo used the messenger app associated with the Facebook recruitment page to

contact me. He affirmed that he has primary LLL and offered to help me. We scheduled our first conversation per internet video conferencing software because we lived so far from one another.

During our first conversation, Arlo seemed comfortable and excited about participation. His four children, whom he homeschooled, were distracted elsewhere. I saw a youngish-looking, middle-aged man, dressed casually, sporting a full beard. Middle age was beginning to show itself with gray lacing through his beard and mustache, and some recession of his hairline at the temples. I also saw his badges of individuation, a large tattoo covering one lower arm, a smaller tattoo on the other, and black earlobe gauging. He had set up so that I would not see his legs. Nor could he see mine.

It was soon clear to me that Arlo had given some thought to his story before our first conversation. He said, "So many memories came flooding back from that whole time!" He offered thoughtful reflections on life challenges he had experienced. Only a few hours after we finished our first conversation, Arlo sent a dozen scanned pictures to me by e-mail, annotating each with his reflections. Throughout our three conversations, Arlo drew upon his observations of his pictures and the memories they elicited. He also made time between conversations to talk with his mother about his early days with lymphedema and drew upon these conversations, as well.

During our second conversation, after reviewing the transcript from the first conversation, Arlo reflected on his experience with the research process:

> *I don't feel like I've told those stories to anybody else. I appreciated that you were there to listen, and I feel like this will help people. But it's hard to look back at some of that stuff because it brought up some moments that weren't so great, and it brought up some*

moments that made me look at it and say, "Man, you were worried about stuff that wasn't even really an issue."

Arlo's lymphedema story, though painful for him to tell, and sometimes for me—painful to hear, resonating as it did—was a story of overcoming life-long concerns about what others thought about his lymphedema with a shift in perspective that opened up his world.

First Swell: "…something about that particular thorn bush."

Arlo described his early childhood as typical for an only child growing up in the rural, southern town in which his parents grew up and married. He was an active, happy, outgoing child, doing well in school, playing baseball, participating in 4-H, and playing outside with friends almost every day. On a happy day in 1987, when Arlo was ten years old, he tangled himself in a thorny bush and scratched his limbs. He narrated the event:

I would absolutely, 98%, say that's what happened because we were running around in the woods and I had shorts on, and I got tangled up in thorns. It ripped my legs up, you know? We came home and cleaned them off and put medicine on and everything…I've been scratched before. But you know, it's pretty bad, it often made me wonder if it was something about that particular thorn bush. I mean, that's just grasping. Well, I've grasped for straws my whole life. It was the next day that my leg was swelling up.

When Arlo awoke the next day, one of his legs had swelled. His other leg began to swell a few months later. He is sure his encounter with the thorn bush initiated manifestation of the lymphedema that was lying in wait.

The day after the encounter with the bush, Arlo's mother drove him to the nearest physician, twenty minutes down the road. He remembers her approaching the receptionist urgently when they arrived, insisting that the physician see him right away, as if the sooner the

physician saw him, the more difference it would make. His mother expressed her concern to the physician that her son had lymphedema, like his father. At the time, Arlo's family had no idea that his father's lymphedema might be heritable. The physician immediately diagnosed Arlo with primary LLL and prescribed waist-high compression.

I was surprised to learn that Arlo's father had primary LLL. Arlo believes that individuals in earlier generations also had lymphedema, but that his father did not know who they were because no one revealed it. Arlo implied, "What's to say a great, great grandparent was ashamed of it, or whatever reason, and just never said anything?" Arlo's implication was consistent with findings in another qualitative research study about primary lymphedema (Bogan et al., 2007), in which individuals sometimes viewed their "big legs" as a normal variation rather than an illness or they hid their lymphedema from others because they felt ashamed. Arlo understands that he inherited his lymphedema from his father. However, like Audra, he wonders if his injuries from the bush incited his lymphedema and if he might have escaped lymphedema altogether, had he not been scratched by a bush, or by that *particular* bush.

Family Support: "It was hard for her to deal with."

After our first conversation, Arlo decided that he wanted his mother's perspective about the day he developed lymphedema, and he called her to talk about it. He recounted his mother's response:

> *She said she never, in her life, had that feeling before. She said she just didn't understand how, whatever rules the universe allowed, that to happen to my dad. And, seeing how it affected my dad and then for it to happen to me, as well. She said she still can't explain that feeling, but she said she sat on the side of the road for, I don't know how long, and*

just screamed and cried and yelled at herself, yelled out to whoever. It was hard for her to deal with.

Arlo realized that his mother had shielded her feelings from him while moving forward with self-management tasks. We speculated together about why his father refused to go to the doctor with them that day and decided that it might have been too difficult for his father to face.

Arlo's father told him that his grandmother had wondered if a blood transfusion that she received during pregnancy had caused her son's lymphedema. This story is consistent with findings by Todd et al. (2002) that mothers of children with primary lymphedema report wondering if their child's illness was their fault. It is also consistent with my own mother's concerns that she caused my lymphedema by exposing my fetal body to dangerous gases while working in an operating room. Arlo indicated he was disappointed that his father seemed unable to offer emotional support to him regarding his lymphedema but acknowledges that his father offered practical support, such as taking him for compression fittings. Arlo indicated that, presently, they are close, see each other often, and encourage one another to care for their legs.

Learning to Self-manage: "A catch-22."

Soon after diagnosis, Arlo's physician prescribed custom compression garments and elevation. Arlo remembers that his parents diligently assured that he complied with the prescriptions. Lymphedema therapy training had just arrived in the U.S. when Arlo's swelling began. With no certified lymphedema therapist available in his geographic area, they relied upon a staff member at the medical supply store to measure him for waist-high compression garments. Frequent garment fittings disrupted his family's schedules several times a year.

Regarding his waist-high compression garments, I wondered aloud, "how does a boy manage to go to the bathroom with such tight, waist-high compression?" and asked him if they made compression garments with a fly front. He responded,

> *When I first got 'em, it was just a cover over the, let's call it the penis area. But when I put them on, the pee hole was up at my belly button. So you would have to pull down and like I told you before, they keep up above my…up to my ribcage. I would have to pull that tight and hold it down with both hands and just hope for the best, pretty much. Or, I'd pull them all the way down and sit on the toilet, which was a nightmare as well, because they were so frigging tight. It's hard to sit on a toilet when your legs are completely shut together. It really was a nightmare.*

Arlo shared that, because of his compression, he used the stalls in the boys' bathroom at school rather than the urinals like the other boys. This isolating situation seemed to impose upon his developing masculinity. Another part of the burden of wearing compression garments was the hot and humid climate where Arlo grew up. Few homes had central air conditioning, and he described the "fricking process" of getting ready for school: Taking a shower, air-drying with a fan, throwing on baby powder before donning his garment.

Wearing compression interfered with Arlo's experiences of special events. He told of a fishing trip with his uncle to which he had looked forward. His uncle promised his parents that Arlo would wear his garment while away. Unfortunately, his garment was very uncomfortable because, in the small boat, he could not straighten his legs nor stand, and he was in pain from the garment gathering behind his knees. Arlo indicated that the photograph captured while on the fishing trip elicited more bad memories than good. About the picture, Arlo said, "That's what I see when I see that picture. You know? That's kind of sad."

Wearing compression garments was not the only difficult adjustment Arlo had to make for his lymphedema. He noted that in many of the pictures he saw of himself, he was elevating his legs on a stool, table, or some other convenient platform. "You have to elevate! Elevate, elevate, elevate!" meant more than simply propping up his feet whenever he was sitting. To him, it meant propping up his feet when he might have been upright, moving, and spending time with friends. Arlo remembers receiving other instructions from the physician about avoiding injuries, insect bites, and sunburns to prevent cellulitis. These instructions meant to Arlo that "hanging out" with his friends outside was not care-free.

Consistent with research about children and young people with primary lymphedema (Hanson et al., 2018; Moffatt & Murray, 2010), Arlo remembered tension in his household about wearing his compression garments. Realizing that his mother likely bore the brunt of self-management, he solicited her views and shared a bit of their conversation:

> *She said, "Well, what would you have done? That's what the doctors were saying you needed. And even though you were saying that it was hurting you, they were making it seem like if you didn't have [the compression], it would just get so much worse." They saw my dad, and they just automatically assumed that that would be me if I did not do these specific things. That was always kind of a fear growing up. It was kind of a constant, scary thing, and what little bit of knowledge we had of the disease was that I had to do these specific things. Talking to her, she was getting teary-eyed about it because she's like, "I hate that you felt that way."*

Arlo was glad that he talked with his mother about these tensions between them regarding self-management, and he communicated his appreciation to her. They also talked about the threats he heard directly from the physician about wearing compression, "You're gonna end up just like

your dad" and remembers that the admonishment "freaked me out." In retrospect, he suggests that the physician should have expressed this concern to his parents privately.

As Arlo transitioned into adulthood and out of his parents' home, he stopped wearing his compression garment. His behavior reflects concerns expressed by Hanson et al. (2018) that the transition to adulthood is a time when adolescents with primary lymphedema are at risk for sub-optimal self-management. Arlo recognizes that his choice contributed to the progression of his lymphedema and many episodes of cellulitis. I asked him to describe how he currently cared for his legs. Arlo indicated that he is satisfied with the effects of elevation and over-the-counter compression that he sometimes wears to maintain the condition of his legs at an acceptable size. Arlo defined acceptable as "better than before" and "better than my father's legs" and claimed that he had not had an episode of cellulitis since receiving disability benefits.

Arlo shared several different ways that he cares for his lymphedema, claiming it takes some experimentation to know what works for *his* lymphedema and, "There's certain things I do that I keep it managed. Mine fluctuate. In the morning, they're great, you know, and then later on through the day, if I don't compress, they're…I mean, I know you know how it feels." Arlo believes that several changes he has made have helped, including losing weight, cutting back on sodium and carbonated beverages, and quitting smoking. In sum, Arlo claims, "I don't even know how to explain it. I feel like the things I've done have contributed to my legs getting a little better, instead of just sitting around waiting on a cure."

Arlo shared his thoughts about decongestive therapy. He indicated that he had been "pushed toward it" and that "I just don't know enough about it, and I feel like maybe I should look more into it." In a later conversation, he indicated that he would like to explore the therapy when his children are older, and he has more free time, and acknowledged, "I feel like that might

be beneficial a little bit, but you just gotta stay on top of it. And I'm just not a stay on top of it person." Arlo represented his view of decongestive therapy with an analogy: "It's like cleaning a window with spit. You're never really gonna get that nice shine to it."

Arlo believes that his efforts to prevent infection are worthwhile. For example, he explained that he is proactive about hiking trips, claiming, "When we go hiking, I have to make sure I have a first aid kit available because it's easy for my legs to get scratched and it seems like the older I get, they're almost paper-thin—it doesn't take much to scratch them up. It doesn't just bleed a little bit, put compression on it and the blood, it clots, or anything, it's liquid that's coming out." By liquid, he meant lymphorrhea.

Arlo stands firm on his belief that he is doing well with his lymphedema and does not need to "chase all the treatments" about which he has heard. He relates his attitude to the disappointing treatments his father pursued. He explains,

> *I know that times are changing, and I know that there's been more studies on it and everything. But I've also seen him, for my whole life, getting no kind of answers. It's usually somebody trying to sell him the next product or suggesting things for him to do. I mean, he knows how it is, and he's dealt with it, and I think that attitude has rubbed off on me. I just don't think at this point in lymphedema history that there's enough out there to be done for me that's gonna make a difference. I just don't.*

Arlo described his philosophy of self-management as "living for the now" and feels that he is "keeping it under control." He said, "This is the catch-22 with it. You either have that choice of staying off your legs 24/7, or trying to live a normal life."

Grappling with Othering: "I'm wearing freaking pantyhose!"

Thinking about his childhood and adolescence, Arlo shared, "on top of already hiding that I had lymphedema, I'm hiding the fact that I'm wearing freaking pantyhose" and, about elevation, "You almost feel like you're being a lazy person because you're not telling anybody why you're not participating." About his compression, Arlo reminisced,

> *I had to wear these specific stockings for my legs that were a nightmare, and I automatically always felt like people knew I had them on. Leggs pantyhose, basically. They weren't stockings for compression. They were stockings for burn victims. Oh my god, it was a nightmare! On top of already hiding that I had lymphedema, I'm hiding the fact that I'm wearing freaking pantyhose! Not only am I wearing pants all the time, I'm wearing these burn victim stockings, you know? It was a nightmare.*

Arlo viewed the compression garments as an imposition on his developing masculinity since they were so much like the pantyhose that only the women in his life wore. He was also concerned that the compression garments associated him with the victims of burn injuries, lending yet another note of stigmatization to his experience.

Arlo believes that he turned toward hiding after an early attempt to manage impressions about his lymphedema by talking to his class at school. He explained, "As soon as I said I had a disease, somebody started making fun of me, 'Oh, he's got a disease like AIDS!'" Arlo believed that his attempt to normalize his disease and assure his peers that he was the same boy as before his legs started swelling, had failed. However, he does not remember anyone in the classroom ever bringing his lymphedema up again and realizes the stigmatization he felt was mostly of his own making. Looking back on the experience, Arlo commented, "Really, those kids in the 5th grade were just kids being dumb." I asked Arlo if he lost friends because of his lymphedema. In

retrospect, Arlo perceives that if he lost friends over the event, it was more because of the way that *he* responded to their teasing than their decision not to be a friend to someone with a disease.

Arlo never knew his father without lymphedema and believes that the modeling his father provided regarding living with lymphedema may have contributed to his self-stigmatization during his childhood. Arlo perceives that his father was extremely self-conscious about his legs and sometimes saw him express anger toward those whom he felt were judging him for his difference, when, according to Arlo, no one was expressing judgment directly. Arlo claimed, *"*I distinctly remember having a sinking feeling of how everybody's gonna treat me because I have this problem."

Looking at a series of annual photographs made in his baseball uniforms, Arlo noticed that the postural stances he took in the photographs before and after he developed lymphedema differed. His photographs demonstrated a strategy he devised for hiding his lymphedema, the first of many. In the photographs taken before lymphedema, Arlo stood with a bat on his shoulder and his feet spread apart. In the photographs taken after diagnosis, he stood with his smaller leg crossed over the front of his more swollen leg, and he held his bat, supported in front of him, partially obscuring his legs. He recalls that he "acted out" on the day of the photographs, to try to avoid having his image captured. Arlo also remembers that his parents responded, "Your legs aren't that bad. They're not that bad, don't worry about it." However, he said he felt like the "little girl on Willy Wonka when she blew up after eating the blueberries" (https://wzlx.iheart.com/featured/chuck-nowlin/content/2019-07-11-willy-wonka-blueberry-girl-dies-at-62/). Arlo quit playing baseball after he developed lymphedema. He joined the band class to play tuba, in place of a physical education class, rationalizing, "Every sport, you're kind of exposed. I mean basketball, you're in shorts. Football, you're in short pants. Baseball, you're in

short pants with a tight stocking on the bottom. There were no school-offered sports that didn't showcase my legs, and that kept me away from it."

Arlo narrated a critical incident that occurred in high school, underscoring the extreme actions he took to avoid exposure of his compression to his peers:

> *One of the worst moments I had with my lymphedema…around 10th grade, 16 years old. I was in my auto mechanic class, and I jumped the fence. When I did, my jeans ripped from the inseam down my legs. I lost my mind! I didn't know what to do! I ran to the agricultural room and put on a pair of those pants they keep for the peanut boil. These pants are dirty. I just remember putting those pants on and sweating like, "How am I going to explain this to anybody?"*

Arlo's story demonstrated his panicky, urgent feelings poignantly in that moment of potential exposure of his compression. All of Arlo's stories of the strategies he used to avoid exposure suggest that his mind was often on alert about exposure. At the very least, his concerns were likely a significant distraction from his school experiences.

The clothing options that were stylish in the hip-hop era of the 90s, when Arlo was in high school and transitioning to adulthood, helped Arlo to hide his legs. He explained,

> *The 90s were great for me because baggy jeans started being a thing, and for me, it was like, "Oh, my God!" I could literally go anywhere, and nobody would have a clue that I have lymphedema. But my dad was super against baggy clothes. I'm telling him that I want to wear these more because I can cover my legs up. And he's just like, "No, you don't dress like that." As a young person in my late teens, I was a nightmare. I was doing drugs, I think I was just trying to prove how normal I was. At the same time, I didn't push too far because I was definitely afraid of going to jail. I didn't want people in jail to know*

I had lymphedema. That's how scared I was; I stayed out of trouble because of my legs. My legs have had a weird relationship with me in my life. I felt like I would have got in more trouble if I didn't have lymphedema.

Arlo recognizes that his father was more concerned about the crowd that his baggy jeans were allowing him to fit in to, than the look of the baggy jeans, and acknowledges that his father may have been right. Arlo believes that his self-consciousness about his lymphedema may have inhibited him from making choices that might have caused serious trouble.

As Arlo transitioned to adulthood, his concern about the stigma associated with having a disease took on a different aspect. After high school graduation, in 1997, Arlo opted for outdoor, manual labor in the construction field. He now believes his decision had severe repercussions for his lymphedema. Not only was he working long days on his feet, without compression, in summer heat and humidity, but he was also going out with friends at night and not elevating his limbs. Consequently, this did not allow time for the functional portion of his lymphatic system to drain away the lymph that had collected in his legs during the day. His lymphedema grew worse, setting him up for episodes of cellulitis.

Me in my late teens, early 20s, getting off work, going fishing all night with my friends. They never knew I had lymphedema. It meant waking up the next morning so swollen up that I'd miss work. And what did people think? "Oh well, you were out drinking last night. You missed work because of that." You almost have to act like you're an alcoholic because you're lying to your employer, you're lying to your friends. "Why aren't you coming to work?" And it was because of my legs. Nobody knew.

Arlo hid the health implications of his legs from his employer(s) and co-workers. He preferred them to think that he was missing work because he was hung-over than because he had a disease that might render him unable to do the job.

The process of finding and keeping work became increasingly difficult for Arlo because of the randomness of cellulitis episodes. "Even telling people I have primary lymphedema when applying for jobs," he claimed, "kind of scared them into not wanting to hire me. So that was a little crappy." However, Arlo emphasizes that, when he worked, he avoided letting lymphedema limit his pace or productivity at work.

Arlo and I co-commiserated about the trials and tribulations of clothing our lymphedematous legs and feet. He described difficulty finding boots to fit for work and having to make do with alternatives to those the other workers were wearing. He said that he is not a "style guru" but does not want to look different from everyone else and would like to be able to put a complete outfit together, unhindered by concerns about pants and shoes. I noted that, like me, he tends to exaggerate with a sense of humor, our defense mechanism against feelings about a life task that was, sometimes, deeply hurtful. Once, he laughed and said, "You used to be able to go just buy a pair of Levi's. Now you've got boot cut, super slim boot cut, super skinny, relaxed fit. It's like all these things that make no sense. Relaxed-skinny. What the hell is relaxed skinny?" He also had a lot to say about shoes,

> *This is something that's changed with shoes. Shoes used to have really puffy sides and puffy tongues. It was almost impossible to find a pair of regular shoes, but recently, I've noticed they're making a lot more lightweight shoes like jogging shoes almost that are very, very thin. I bought a pair of sneakers not long ago, I don't wear sneakers often, but I bought a pair not long ago that I can put right on and I'm amazed by it.*

The type of shoe Arlo wears makes a difference. For example, the Velcro attachments of his slides do not overlap enough. The shoes stay on but do not look as intended.

Arlo said that he is more likely to wear shorts, now that he was almost 40 than when he was younger. However, there are still instances during which he wishes he had been wearing his pants, which he described as his armor against stigmatizing stares. He narrated a situation during which he wished he had been wearing his armor,

> *We take the kids to summer programs at the library. It was another one of those scenarios where you're in a room full of people and everybody's…I feel, has access to look at me. But, for some reason, all of a sudden, I had that feeling. I feel like people are staring at my legs, and I just felt uncomfortable. I didn't feel like I had any kind of panic attack or anything, I just felt, "Wow, I really wish I had jeans on right now because…" Then I can feel like I can be care-free me, it's like putting armor on and going into battle. Putting armor on versus not wearing anything. You feel a little bit more protected. You have more control over what people can see and what they can do to you.*

Arlo admits he still sometimes struggles with the self-consciousness that was common when he was younger and "over consumed with the what-ifs." As an adult, concerns about stigmatization continue for Arlo, and he realizes that when he chooses to hide, he limits his opportunities.

Intimacy with Lymphedema: "Lights off…and never knew the difference."

In his late teens, connecting to romantic partners became important to Arlo. He described his usual approach of hiding his lymphedema from partners:

> *With any kind of sexual relations, it was more of lights off, sit on bed, and take pants off, pull legs into bed, and none of them ever knew the difference. If she did know, she never said anything. I never showed my ankles. If I went to the pool, I would usually jump in the*

pool first, like I was just super enthusiastic to go swimming. Get out of the pool and have a super long beach towel that I can wrap around the waist, and it went down to my feet. It's hard enough to be comfortable with a new person, but then, you're starting the relationship off lying.

Arlo seemed confident that he had been able to hide his lymphedema from his romantic partners. We talked about why this was so important in relationships with women, and he decided that revealing that he has a disease might diminish his image as a healthy, strong man, and he worried that the appearance of his legs would cause them to turn away from him. When Arlo was in the hospital for treatment for cellulitis, or what he called, "sick with his legs," he was dating the woman who would become his wife. He realized that it would be challenging to continue to hide his lymphedema from her, so he disclosed to her. Arlo shared that, since disclosing to his wife, he has never felt so accepted by anyone and that her acceptance helped him to stop hiding as much as before.

A Turning Point: "Once I got the RA, I don't know what changed."

When Arlo turned 25, he began experiencing the signs and symptoms of rheumatoid arthritis (RA), and keeping up with jobs in construction became difficult. He tried other jobs but, between episodes of cellulitis and exacerbations of RA and the side effects of the medications his physicians prescribed to achieve remission for his RA, he missed many days of work. It took two years of doctors' visits and testing for him to receive the diagnosis of RA. Eventually, applying for disability to help provide for his family seemed his best option. It took five years while working sporadically, to receive a judgment for disability for his RA at age 32. Though Arlo introduced his lymphedema as a factor that impaired his ability to work, he believes the judge

based his decision entirely upon the effects of RA. Arlo also believes that had he only had lymphedema, he would still be working full-time, in a role that was better for his legs.

Arlo's RA significantly affects his day-to-day life and has a muddling effect on his life story, as it relates to his lymphedema. We set about wading through the mud to consider how developing RA both advantaged and disadvantaged his efforts to manage his lymphedema. Arlo indicated that donning and doffing compression is complicated when his RA has flared, affecting the strength of his shoulders, hands, and wrists, and causing pain. On the other hand, because he receives disability for his RA, Arlo spends less time on his feet in the heat and humidity, and he is better able to manage his lymphedema. Arlo also believes that developing RA was a turning point in his life. He shared,

> *[Lymphedema] shaped my life. There's no way around it, things I've done, things I haven't done are, most of the time, associated with primary lymphedema, in one way or another. I had to stop that trend. It happened all the way up into my mid-20s. Once I got the RA, I'm like, "Why am I worried about this thing so much? Why am I letting this one thing base my decisions on so many other things?" And I mean, I look at it now, and it's absolutely mad. The decisions I made, the jobs I didn't and did take. Mentally, I kept myself from doing a lot of things because of my lymphedema.*

Arlo believes that developing RA has helped him to put his lymphedema into better perspective, as well as enabled him to care better for his legs.

Parenting with Lymphedema: "A diamond out of the dust of having diseases that suck."

Arlo referred to his children frequently during our conversations, and I came to understand the importance of his role as a father. In 2011, when Arlo began receiving disability for RA, he and his wife decided to homeschool their four children. Arlo views his opportunity to

homeschool their children as a "diamond out of the dust of having diseases that suck." I asked Arlo how he thought living with his lymphedema might affect his children, understanding that this area of life is tangled with living with his RA. His answer came quickly:

> *They do know that I am limited to some of the things I can do. I try not to make excuses because of that, with either disease, but they have to know it's not, "We can't do that today because I don't want to do it. It's because I physically can't today."*

I noted that it was painful for Arlo to talk about how he thought his "diseases that suck" affected his children. Arlo prefers to live a physically active life with his children—outside, if possible. Arlo offered an example for when he was unable to be active with his children that seemed to resonate with his childhood with his father. He indicated that, sometimes, he is unable to go outside to play ball with his children because his shoulders "lock-up," and he is not able to catch or throw a ball.

Before Arlo developed lymphedema, his father's lymphedema had advanced so much that his father was unable to play ball with him. His father traveled halfway across the country for a surgery that the family anticipated would return his mobility, and Arlo was looking forward to his father playing ball with him again. Unfortunately, the surgery was not as successful as anticipated, and Arlo remembers feeling very disappointed. He does not want to disappoint or short-change his children because of his chronic conditions. Arlo mentioned situations that required sacrifice on behalf of his children to the detriment of the health of his legs. For example, he shared that if he did not have children, he would probably never eat at the table so that he could elevate his legs while eating. Because his family always tries to eat dinner at the table, he "grins and bears it through those times" because he wants them to have memories of eating together and not focusing on "dad's legs, dad's legs."

I asked Arlo what he taught his children about his lymphedema and he replied quickly, *I did try to explain to them what primary lymphedema was, but to be honest with you, they care so little about it that I could be talking to them about a cavity, and I'd probably get the same response. They don't judge me with my legs at all. It's nice to live with a group of little people that have never…I've never had that feeling from them like I feel I get from some people. And they never talk about it, really.*

Arlo expressed that, as he felt from his wife, his children accepted him for who he is, without regard for his lymphedema. Arlo believes that one positive aspect of growing up and living with lymphedema is his sensitivity to the plights of others with body differences, and he does not tolerate his children making fun of others because of how they look. He teaches them that what is on the inside of a person is what is essential.

Carefully, I asked, "Do you think your children have connected that you and your dad have it and that there's a possibility for them?" His answer seemed to catch in his throat before he responded, "They do know that. I don't know why, when I had kids, that I didn't think more about that. It's kind of a selfish move on my part because I know for a fact that I have two diseases that could very well pass on to them." Arlo acknowledged the possibility that one or more of his children could develop lymphedema, and then went straight to the dilemma that is likely on the minds of every parent with primary lymphedema. That is, whether it is ethical to have children if there is a chance they will inherit the disease. Arlo expanded, "I don't know how I would deal with that. But I accept responsibility if that happens. I knew going into it that it could happen, and it's just something we would have to deal with if it came about." Arlo indicated that as soon as he and his partner discovered that they were expecting a child, they began talking to physicians about the possibility that the child would inherit the disease. He

recalled them telling him that there was no "test" for the disease and that "more than likely they have primary lymphedema, and it just hasn't been triggered."

Arlo described what he was doing to minimize triggers:

> *I'm ultra-protective about them cutting their legs. We don't go barefooted, at all. Well, see, my oldest daughter shaves her legs. It is very scary, and I've had to discuss it. I've had to be very open with them, and didn't want to scare them at all, but told them, "You have to be careful in the woods, around anything sharp. If you cut your legs, we have to clean it immediately." Any time my kids get a bad cut on their legs, which is few and far between, or a mosquito bite, or whatever, I have a feeling in the pit of my stomach that's just like, "Oh, I hope we don't look down and notice puffiness."*

Arlo's narrative of watchfulness for his children suggests that he lives with ongoing fear that they might develop lymphedema.

I asked Arlo if he could imagine how he and his wife would respond should one of his children develop lymphedema and how his personal experience might affect his response. He said,

> *I'm going to end up seeing it from three different angles. I think that I would be able to handle it a little bit better because I know it's a possibility. I don't want them to have the feelings I've had. I don't go around them saying, "Oh, when I was young with lymphedema, I beat myself up." I don't want them to have those preconceived notions. I don't ever once want them to hear me say negative things about myself, and then them get it and then go down that same path.*

By "three different angles," Arlo meant that he had experienced lymphedema as the child of a person with lymphedema, experienced lymphedema himself and, should one of his children

develop the disease, he would experience lymphedema as a parent, as well. Arlo's response indicates that he understands how his father's role modeling influenced his own life and how he, in turn, might influence the life of his children. As we talked further, Arlo indicated that he and his wife would pursue treatment for his children more aggressively than he does for himself.

Living in the World with Lymphedema: "I take it serious, but I don't take it real serious."

Reflecting on our work together, Arlo indicated that he was in a better place with his lymphedema than he was when he was younger. He extolled the virtue of equanimity versus rumination while acknowledging that when he does think about his lymphedema, it still sometimes hurts. Arlo believed that it was beneficial for him to take time to reflect on his life. He realized that his concerns about stigmatization limited his life and made his world smaller. As he has gotten older, and begun to transcend those concerns, so not to limit the lives of his children, he has opened the world for himself, and in turn, opened the world to his children.

Abie: The Fault in Our Stars

Abie was participating in other research when she shared with the researcher that she developed primary lymphedema in both lower limbs five years earlier. The researcher told her about my study, and Abie sent an email message expressing interest. We scheduled time in an office on her college campus for our first conversation. In the meantime, she set about collecting artifacts. Abie arrived with her laptop for notetaking, her college entrance essays, and photographs of herself and her family. Dressed in a way that was typical of other young women I saw on campus—in ankle-length jeans—she impressed me as happy and healthy. She seemed enthusiastic about sharing her life stories.

When we met, in 2019, Abie, a first-year biology major with aspirations for medical school, had begun her second semester at the university after a very successful first semester.

Abie grew up with both parents in her home, her father working outside the home, and her mother working inside the home to care for Abie and two younger siblings. The youngest of the cohort of narrators, by ten years, Abie shared memories about engagement with the medical community and her school experiences with rich detail. However, we struggled to tease the effect of her lymphedema on her life away from the effect of her other chronic conditions.

Animated, Abie expressed appreciation for the opportunity to reflect upon her experiences. About talking with me, her first experience with another person who has primary LLL, she offered, "…and you're like, 'Okay, yeah, I know what you're talking about. It's not like I have to explain *every little thing* to you.'" I knew what she meant…we agreed that we do sometimes lose patience while attempting to explain the little things to others. We also agreed that sometimes the little things seem incomprehensible to those who do not have lymphedema. Abie saw her participation in the study as an opportunity to make a difference for other young people who have lymphedema.

First Swell: "I went out of my way to make sure it didn't affect anything."

Abie shared that she had been troubled with illnesses since she was a baby. One of her visible chronic diseases, a rare, genetic, autoimmune disorder, became evident when she was a child, and the disease required frequent engagement with the medical community. In the seventh grade, physicians diagnosed Abie with RA and she required intravenous infusions of a medication to achieve remission. In the eighth grade, Abie developed myositis, an inflammatory condition of the muscles in her legs. I saw an angry-looking, red, biopsy site on her calf in the photograph that she showed to me. I also saw significant swelling well beyond the biopsy site. Abie reported that her leg swelled so much that recovery took longer than expected and her surgeon asked her to minimize time on her feet. Family members and friends had noticed, in the

past, that Abie's legs and feet seemed to swell; the swelling after the biopsy was the worst ever. Abie also experienced a cut on her foot about this time that took longer than expected to heal.

Abie's physician attributed her slow healing to the medicine she was taking for her RA. The physician also suspected that Abie's swelling was associated with her autoimmune diseases. After the biopsy, since Abie's swelling was not resolving as expected, the physician thought it best for her not to return to soccer. She remembered, "I was pretty upset. I enjoyed it, I liked being a midfielder." Confusion about her swelling continued for her physicians,

> *My doctor says that there is a possibility that those two are correlated, but they were like, "But we don't know how." One thing that confused them was my lymphedema was pitting edema, and my [other] swelling wasn't. They were like, "they're the same, but different." They were like, "We don't know, it could be a part."*

Abie's rheumatologist was suspicious that she had primary LLL and referred her to a cardiovascular surgeon. The surgeon established the diagnosis and referred her to a local lymphedema therapy clinic. Abie's mother contacted a surgeon in another state to explore the possibility that surgery might be appropriate for treating her lymphedema. However, the results of Abie's lymphoscintigraphy did not provide proof the insurance company required that Abie needed the surgery, and she and her parents tabled the idea.

Family Support: "We're her advocates because she's 13!"

Abie believes that, by the time her lymphedema manifested, her parents were well prepared to navigate the healthcare system on her behalf. She also notes that her parents were competitive athletes in high school, contributing to a family code of discipline, persistence, and resilience. Years before her lymphedema manifested, her family had moved to a large

metropolitan city within an hour drive of one of the state's largest health sciences centers, including a nearby hospital that focused entirely on treating children.

A local certified lymphedema therapist scheduled Abie for daily decongestive therapy to reduce the volume of swelling in her legs. During the therapy sessions, her mother learned how to conduct manual lymph drainage and wrap Abie's legs. After therapy, Abie felt hopeful that she and her mother would be able to prevent the progression of her lymphedema and avoid limitations on her life due to the disease. I asked Abie to tell me how she experienced her therapy. She said that she found it difficult to relate to the other people in the waiting room, most of whom were older and told her that their lymphedema was secondary to cancer. She said that they seemed curious about how such a young person could have lymphedema, and she answered their questions as gracefully as she could. Abie and her mother's research revealed that many people go years with lymphedema before receiving a diagnosis and beginning treatment. They were grateful for her opportunities.

Abie believed that her lymphedema therapist, and most physicians she encountered during this time, were helpful as she was developing an understanding of her new disease. However, she remembers her appointment with the surgeon who established her diagnosis of lymphedema, to be her worst ever encounter with a medical professional.

> *My mum was talking to him about how I also have myositis and how I got taken out of soccer, and he was like, "you're using it as a crutch." And, I was like, "what?" I went out of my way to make sure my conditions didn't affect anything. His comment really hit me hard because that's the one thing I'm trying to avoid. Up until eighth grade, I didn't want anyone knowing 'cause I didn't want them to treat me differently. And, then in eighth grade, with the lymphedema, it was like, "I can't hide this." Then he told my*

parents it was their fault that I was how I was. I left there crying, and my parents were pissed. They were like, "Are you serious? We're her advocates because she's 13!" I wanted to be a rheumatologist, and he told me, "That's a good goal to have, but it's never going to happen."

Abie felt misunderstood and stigmatized by the surgeon. With her parents' encouragement, she had fought most of her life to transcend her visible and invisible chronic conditions, excel in school, and remain involved in school activities and sports. She often went the extra mile to help her coaches and teachers to avoid the appearance of taking advantage of accommodations for her chronic conditions. She felt deeply insulted by the surgeon since she had shared openly with him, only to have him criticize her. Mostly, she resented the limitations the surgeon projected for her life related to her chronic conditions.

Learning to Self-manage: "…if you don't fix it immediately, it'll just get worse and worse."

The therapist fit Abie with custom compression for both legs—one pair, waist-high, and one pair, knee-high. About her compression, she recalled, "Typically, my mom would like, 'You're wearing them.' She was like, 'We paid money for them. They're gonna help you. I don't care if you're wearing Nike shorts, you're wearing them!'" When I first met Abie, she was wearing form-fitting, ankle-length jeans. I was disconcerted after noting good definition of the bones and tendons of her ankles but that she was not wearing compression. Abie explained that she had good days and bad days, "Because sometimes it'll just be the day. But, it's mainly caused by injury, heat. Like when it gets bad. But typically, I have to use a lymphedema pump every day." When I asked if she wears compression, she responded,

No, because I also have it in my toes. I was getting ingrown toenails, and then those would get infected, and it would just get worse. I had to go to an urgent care center and

get it lanced because it was so bad one time. They were like, "In our opinion, it'd be best if you didn't wear those because it's causing more of an issue."

Her rheumatologist suggested that it might be best for Abie not to wear the compression. She said, "My rheumatologist was like, 'Based upon the pictures I've seen, it's like a damned if you do, damned if you don't situation.'"

Abie's lymphedema pump was expensive—hundreds of dollars of co-pay—after insurance reimbursement. Abie expressed a strong sense of stewardship for the pump, "Yeah. I don't try to beat it up because this has got to last for a while." Abie indicated that integrating the pump into her day was relatively straightforward:

I had this thing that made my braces stay on track. I would just do my pump, and I would have that thing on during the first hour. I do homework, so like killing three birds with one stone. Also, because it was in our living room back home for the longest time, my mom could make sure I was doing it.

By her final year in high school, Abie and her parents were confident that she was ready to manage her multiple chronic conditions independently and transition to college.

Since moving to campus, Abie continues to "multi-task" and studies while using her pump. She says that she relies upon the pump to keep her lymphedema under control, but it has been difficult to use every day. She prevaricated regarding her commitment, saying, "Yeah, but…it's not like a super, super big deal if I miss a day or two." In her dormitory, she has to store it under her bed, pull it out, and then reconnect it every time that she uses it, making it more inconvenient than it was to use at home.

Abie has taken more responsibility for understanding her lymphedema, as she has grown older, though she has not learned how to conduct MLD, nor how to wrap her legs. She offered her philosophy on self-management:

> *When I first started, I thought it was all the same, and it just got progressively worse to where it's like you have a leak in your roof, if you don't notice it and fix it immediately, it'll just get worse and worse. Where the damage is irreversible, you can't fix it.*

Abie acknowledges that daily self-management will mitigate the progression of her lymphedema.

Grappling with Othering: "She's just bullying her, this one."

Abie missed seventy days of school during her 8th-grade year. Scheduling multiple medical appointments for her RA, myositis, and lymphedema treatments, while keeping up in school well enough to meet her high academic standards, was difficult. With her mother's help, Abie assured that she communicated responsibly regarding her absences. However, Abie felt that some teachers were suspicious of her behaviors and motives, relating, "They thought that I was like, just doing it for attention. Especially because, like, the worst one for me was in eighth grade, and they were like, 'Oh, she's a middle school girl. She's wanting attention.'" One teacher seemed to be offended by Abie's decision to prioritize her time and attention to other classes. Abie explained,

> *I had one teacher who was not helpful at all. She would pull me out of class and be like, "Why haven't you finished this project?" I was like, "Oh I'm working on it, I came in after school yesterday, remember? I'm trying to catch up. I'm not purposely doing this to you." One day, I had missed a day, and she knew it, and I was catching up on my work. She pulled me out with the group of kids who hadn't finished that assignment and was like, "When are you guys gonna come in?" She used to wear a mic around her neck, too.*

Everyone in the classroom could hear what she was saying. I was undergoing lymphedema therapy, so I was already uncomfortable.

Abie continued, more animated than usual, sharing other stories that emphasized her frustration with some of her teachers. I share one more of Abie's stories regarding negotiating school policies related to hallway presence, as emphasis regarding the emotional stress that engagement with this particular teacher added to her already overloaded life:

The counselor called my teacher and let her know, "Hey, Abie saw the nurse; her mum will be coming to pick her up soon. Just FYI, so you're not taken by surprise." I told my teacher, "I went to the nurse. This might happen during your class period—it'll probably be towards the middle to the end." [Then], one of the aides walked in with a pass, and she was like, "what is this?" So she was like, "Abie, this is for you, I need you to go to the nurse and clarify." I had to walk across the school because the nurse's office was in the middle of the school. My mum was in the nurse's office, and both of the nurses were like, "Yeah, you're fine, tell her it's for you and everything is under control, it's according to protocol." The nurses told my mum, "She's just bullying her, this one. There is no reason. She knows. I told her about the situation. She was doing this to be difficult." I had to go back to my teacher, let her know, pick up my stuff, and then she told me, "Let me know when you're on your way out." So I had to go to my locker to grab my backpack, walk to the other side of the school to tell her I was leaving, and then go to the nurse's office where my mum was waiting. I could barely walk, and my mum was so upset!

Because her teacher made things difficult for Abie, her parents complained, and the principal "had to tell her this is an issue."

The narratives Abie shared imply that the teacher was attempting to hold Abie responsible for course requirements and school policies and procedures. However, they also suggest that she was asking Abie to jump through unnecessary hoops, contributing to Abie's discomfort. Abie felt frustrated and offended, thought the teacher could have been more sensitive to her situation, and better protected her privacy. Abie believed she was as responsible as possible to her school responsibilities while addressing her medical needs—needs that were not her fault.

Abie also expressed appreciation for several teachers who seemed to go the extra mile on her behalf. She appreciated the physical education teacher who recognized that running in the football stadium during the humid heat of the day would not be suitable for Abie's legs and, instead, allowed her to stay in the gym and use a stationary bike. The same teacher walked laps with Abie around the perimeter of the gymnasium when her other students were participating in an indoor activity that seemed unsafe for Abie.

Abie recounted stories indicating that she also had advocates among the school staff. Her 8th-grade counselor suggested to Abie's parents that a 504 plan would be appropriate for her, and, together, they negotiated a plan with the principal. Covered under Section 504 of the Rehabilitation Act, a civil rights law, schools develop the plans to provide children with disabilities the support that they need to succeed in school. The purpose of the plans is to prevent discrimination and protect the rights of children with disabilities in schools (Understanding 504 plans, n.d. Retrieved from https://www.understood.org/en/school-learning/special-services/504-plan/understanding-504-plans). Abie and her parents attempted to manage the year without enacting the conditions in the 504 plan, but eventually, at the counselor's encouragement, moved forward with it. Abie received an accommodation for the long sessions of standardized testing,

allowing her to get up and walk around every 45 minutes or so. Another accommodation enabled Abie to wear shorts or baggy sweat pants when wearing her wraps for decongestive therapy.

The 504 was a mixed bag for Abie. Intended to protect Abie's educational record about attendance policies and assignment due dates, she and her parents debated the merits of revealing the 504 to teachers before it became necessary. Abie felt concerned about the possibility of discrimination from teachers and other students because she did not believe that they understood her diseases. Her experience aligns with the findings of authors who study children and lymphedema (Harding, 2012; Moffatt & Murray, 2010). The authors suggested that school staff did not understand lymphedema as much as more common diseases children experience, such as cancer. Abie and her parents decided that Abie should write a 1-page letter to each of her teachers informing them about her diseases, in hopes that transparency would be helpful. Abie continued this practice throughout secondary school.

Strategic Hiding: "I don't want people to walk on eggshells around me."

For the most part, Abie was able to hide her chronic conditions from others. However, she realized that she could not hide the wraps used to treat her lymphedema. She knew that when she wore the wraps to school, she would attract unwanted attention. To minimize the attention she expected to receive on her first day at school in wraps, she posted a photograph of her legs in wraps on her social media page. Abbie believed that this strategy effectively reduced the attention she received after arriving at school, though she had to devote energy to assuring that, though she was wearing "casts," her legs were not broken. Posting the picture of her legs in wraps resulted in positive support from friends on her social media page.

Teachers were not the only people who upset Abie at school. She shared a conversation between peers that she overheard:

They were talking about me, "She's lying, I don't understand why she gets to do the light bar, and we don't. We're out here doing the actual work. And why was she even volleyball manager?" This was the first period in the eighth grade. That's all I could think about. They think I'm lying, and I'm being overly dramatic. I downplayed everything because I didn't want to be too different. I don't want people to walk on eggshells around me. I was like, I have to go to the nurse. My legs were really swollen that day. My mom picked me up because it was hurting to walk. I got in the car and I just had a massive meltdown.

Abie did not remember any other times when she overheard students talking about her. However, this incident confirmed her suspicions that they were. Abie had friends who understood her circumstances when she wore wraps, and they adapted to her situation so that she felt included.

Despite the support that Abie felt from her parents, her counselor, physicians, and friends, she began having panic attacks. She shared a memory of a panic attack triggered by concern about her lymphedema. All her panic attacks, however, were not associated with an illness, but instead, with her concerns about what people thought of her, and the potential for stigmatization regarding her diseases. Her physicians and parents recognized that there might be an association between her panic attacks and symptoms of her autoimmune disorders. However, she did not seem sure about which came first, the panic attacks, or the symptoms of the disorder.

I asked Abie what advice she would give to other young people who developed lymphedema and needed to wear wraps in school. She offered three suggestions:

- "People are going to stare at your casts when you go through lymphedema therapy, no matter what. So you might as well dye them. Dye them any color you want."

- “Don’t listen to other middle school girls. Because they’re only worried about what other people think about themselves. People aren’t going to care.”
- “Have fun. Be adaptable. Make sure you can find ways to be able to participate.”

Transitioning to College: “Oh! Well…you see this?”

By the time Abie entered her final year of high school, she and her parents believed that she was ready to self-manage all her chronic conditions independently. Hanson et al. (2018) and Moffatt and Murray (2010) found that transition to independent self-management can be difficult for adolescents with primary lymphedema. The burden of self-management, added to the new tasks of navigating the social and academic opportunities of university life, has been a challenge for Abie. Through trial and error, and taking time to pause and consider how she is doing along the way, she believes that she is meeting this challenge with success.

Abie and her mother met with a counselor in the Student Disabilities Services Office and obtained a 504 plan. The conditions listed in her plan include priority enrollment so that she can select courses scheduled to accommodate longer walking times on days that her lymphedema is worse than usual. The conditions also include the use of the testing center for an extended time if her diseases flare, interfering with concentration. She has yet to use this option. Abie explained that the 504 plan also assured assignment to a dormitory with a private room room and the ability to control the temperature in her suite. These options enable Abie to perform her self-management routine, comfortably, without feeling self-conscious. I asked Abie to tell me how other students responded to her 504, and she replied, “If they know I applied in January, they’re like, ‘How’d you get such a good dorm?’ I’m like, ‘Oh, I have a 504.’ I’m not ashamed of it, and I’m like, ‘Oh! Well, you see this?’” while pointing to her legs.

Transitioning from school to college, in some ways, seems to have made self-management easier than when Abie was learning to self-manage amidst the constraints of the policies and procedures of middle and high school that gave her limited choices about clothing, meals, and what she could carry with her. For example, at college, Abie carries water with her all the time so that she can stay hydrated, and she can select lower sodium nutrition options. Even when out with friends, Abie reported, she often opts for a salad. Abie's lymphedema is mild enough that she can dress to fit in with the crowd. She said that she wears "a lot of leggings" and "that's *some* compression," acknowledging the value of a bit of compression.

Abie told me of a "bad lymphedema day" when wearing a popular style of shoes—booties with heels—dampened the fun of a class excursion. Abie shared, "I walked eight miles! Because I didn't know I was going to be walking anywhere else. That was bad. I mean, it didn't hurt. Well, it was starting to at the end. But, it was more because of the pressure of wearing them." Abie reported that she had deep indentations in her skin from her booties at the end of that day. She indicated that, had she known she would be walking so far, she might have chosen a different pair of shoes that were more "lymphedema-friendly."

Abie is learning, through trial and error, "what my limits are…like if I'm in a situation where I could have a problem, I take precautions before and after." Thinking ahead about what her day will bring and how the day will affect her lymphedema is an essential tool in Abie's lymphedema toolbox. However, thinking about her lymphedema can also interfere with spontaneous shifts in plans with friends. Sometimes, on days when Abie knows that she needs to use her lymphedema pump before sleeping, she opts not to go out with friends. She is open with her friends but has not invited anyone to spend time with her while she uses her pump.

Social Media: "Mutualism! That's what it's called. I'm like, it's not parasitism."

Abie uses social media judiciously when it comes to her lymphedema. For example, she said, "Not that I hide my health issues, but I don't constantly post about it and things like that. I'll update my friends, or I'll text them like, 'oh, a bad day.'" I asked Abie if she spent much time on lymphie websites or reached out to anyone else with primary lymphedema who was her age, and she said that she had not. Abie appreciates a website, called *The Mighty*, devoted to dealing with chronic illnesses of all sorts (http://themighty.com), and has found content posted there about lymphedema. She thought about the place that social media might hold in her future.

> *I don't feel like I need to have someone my age to be able to survive, but it would be nice having someone with a similar issue you could relate to. I haven't felt like I needed to. I should probably do that. Well, because it's probably helpful for them, too, if they find someone. It's like a mutual benefit from it. I can't remember what that relationship is called in biology…Mutualism! That's what it's called. I'm like, it's not parasitism.*

Abie shared some ideas that she had read about on *The Mighty* that she found meaningful and comforting and, she thought, "mutually beneficial." For example, she taught me about Spoon Theory, a disability metaphor proposed by chronic illness blogger, Christine Miserandino (Spoon theory, n.d. Retrieved from https://en.wikipedia.org/wiki/Spoon_theory). On her blog, *But You Don't Look Sick*, Miserandino wrote that she once explained to a friend that the spoons she had spread before her on the table between them represented the finite units of energy that she had available to spend during the day, given her invisible, chronic illness. Miserandino's post led to the adoption of the label "spoonie" by many people with chronic illness. Abie read about the metaphor on *The Mighty* and identified with the label. She suggested that a balanced relationship

with others on the web that offered useful content would best fit her life and needs, given her finite units of energy and all that she wants to accomplish.

Abie knew only a handful of students when she came to campus, ones who knew about her chronic conditions. One of her old acquaintances seemed particularly intrusive during her first semester, ostensibly to assure her welfare. She shared,

> *A kid that I went to high school with came here, too, and we were acquaintances. We became friends last semester. [He] became very, "I'm watching over you." We did a Life360 Circle, which was fine. But, then [he] started watching it, and he would get alerts. He would get alerts when I would leave my dorm and come back to it. Then he'd be like, "You left late for a class." I was like, "What?!?" At first, I was like, "Whatever." Then I was like, "Okay, this is kind of getting a bit…"*

Life360 Circle (http://www.life360circle.com) is a telephone app that enables members to track the locations of each other's telephones. Abie was open with her friends about her chronic conditions, but she did not appreciate this sort of expression of concern from the friend, and they no longer hang out. She has made other friends with whom she shares about her lymphedema if the issue comes up. Most of them "know I have health issues, but they never press on about it."

When I asked Abie whether she was dating, she said, "It just kind of never came up." I did not probe further about dating but asked Abie if she had thought about what she might tell someone with whom she would be intimate in the future. She replied, "I don't know. I've wondered about that, and I wouldn't know how to be like, 'Oh, by the way…' I'll face it when I face it." At the time of our conversations, lymphedema—which, for Abie, is still mild—was not the chronic condition that concerns her most regarding partnering.

Making Her Contribution to the World: "I don't like being told I can't do things…"

Abie is sure about the way she wants to make her contributions to the world and is determined not to let the limitations imposed by her chronic conditions stop her. She offered her college entrance application essays to me to read. About the essays, she explained, "It was like, write about something that shaped you. I felt like I was taking the easy route, but lymphedema really has. In middle school, I was like, 'Oh, my goodness. Why me? Why did this happen to me?' Now I'm just like, 'It's whatever. What can I do about it?" I read Abie's well-written essays before our last interview and highlighted some sections that I wanted to ask her to expand on. In one section, she used Hercules and his battle with the hydra to represent all the chronic conditions that she had had to deal with as a child and adolescent. She explained how the metaphor worked for her and why she thought to write about Hercules,

> *I instantly went to the Hercules cartoon from Disney. I loved that movie as a kid. My dad still quotes, "Hercules, Hercules!" I think it's important for kids to have a role-model, to try to be like, especially when they're stressed. I'm also used to not having definitive answers because I grew up with that. I know that's really frustrating for a lot of people, and that's one thing that was really frustrating for my parents because they're like, "How can there not be an answer?" My doctors were like, "We may never know. Medicine is advanced, but not as advanced as it should be."*

Abie shared that at times her parents grew tired of dealing with the "hydra" and the frustration of not getting answers from physicians. Sometimes, Abie was aware that her mother cried, overwhelmed by all that Abie was facing and the care that she needed.

In her essay, and during our conversations, I noticed that Abie referenced her diseases as "health issues," and I asked her if she saw herself as having chronic illnesses. We decided we

were both more comfortable with simply saying that we have chronic conditions, which sounded more neutral than "illness." I also asked her if she saw herself as having a disability, and she replied, "Sometimes it does disable me, so I'm not ashamed of it. It's like, 'What can I do?' Besides what I'm doing, sometimes, there's just nothing you can do." She expanded:

> *I'm aware of my limitations. Because everyone has limitations, and as much as I hate that I have them, and I know I can't do things. There's only so far you can stretch that rubber band, and you also don't want to make it worse. I could really mess up, granted not mess up like, "Oh, my, goodness, I could die." But I could just cause my lymphedema to go haywire, and then my arthritis gets irritated.*

Abie has learned the implications of having multiple chronic conditions that interact within her body. In one of her essays, Abie projected that she was handling her conditions well and that her conditions would not impose on her success in college. She expanded on the essay:

> *I knew if I said I didn't let it define, I didn't let it affect me in any way, that'd be a lie. No matter what happened, you may not let something define you, but it still causes you to think about it, and say "Maybe, okay, I'm gonna do this instead." No matter what the situation, everything has that effect. The reason why I'm pursuing medicine is because of my experience with my health issues and with my lymphedema. I didn't want anything to be seen as a disadvantage, so I would try to do everything. I'm also motivated by spite. I don't like being told I can't do things, so I'm like, "I'm going to prove you wrong." I'm also compassionate like I want to help others, but that's a little bit more of the fire. I don't make it who I am entirely, but it shaped me to who I am.*

Like Arlo, Abie recognizes that growing up with lymphedema has shaped the person that she is becoming, and she intends to use that shaping for the good of others. She seems to have a clear

understanding of the limitations imposed upon her by her "health issues" and believes that, with proper management, those limitations will not prevent her from reaching for the stars.

Abie shared that her family and her faith helped her to cope with her chronic conditions and stated, "He wouldn't give me more than I could handle type thing." She also indicated that she read fiction novels as an "escape," explaining further,

> *One book I read was about two adolescents who meet in the hospital, there for treatment for cancer. "The Fault in Our Stars" by John Green. But, yeah, I remember they were talking about how they thought, "Why me?" I don't have that, like, "Oh I could die from it." Like someone with cancer. But some of their things, I'm like "I get that." I could relate to the character. And granted, I was like, "I'm not as serious as cancer," but I could see where she was coming from. Like the thinking pattern as hers. There's always gonna be someone worse than you. Instead of looking on how everything has gone wrong, you're like, "okay, well, this is the situation." It's better than it could have been.*

I was not surprised that Abie offered that, though her illnesses "sucked," relative to others, things were better than they could be. She felt a connection to the characters in *The Fault in Our Stars* who had no control over their illnesses and had wondered, "why me?" She understands her lymphedema as an inexplicable fault in her stars.

Anya: It's Hard to Focus When Doing Life

I learned about Anya from a nurse friend when we were catching up at a social event. I followed up with an email to my friend, attached the participant recruitment flyer, and requested that she pass it on. I heard from Anya a few weeks later. After exchanging a few text messages, with an unexpected delay between each one—Anya using her work telephone—it became clear that making time to participate in this study would be challenging for her. I offered to meet her at

her place of employment, instead of a recruitment phone call. We met in a quiet, out-of-the-way corner of the large cafeteria, I told her about my study, and we reviewed the consent form together.

Anya, a 29-year-old single mother of two, had learned three years earlier that the swelling in her legs and feet was from primary lymphedema. She showed me her ankles and feet, and I showed her mine, pointing to my problem areas, and demonstrated my compression. Anya was not wearing compression, and I could see a fold at her ankles and mounds arching high over her feet, spilling from her ballerina-style shoes, her left foot worse than her right. She expressed excitement about getting to know another person who has primary LLL. We arranged to meet for her first interview at her place of employment during her lunchtime the next week. Her story, I was sure, was long overdue.

Anya reserved an empty computer lab for our first conversation. We sat facing one another with no table between us to shield our lower halves. She tucked her legs under her chair, tugging at the material covering her thighs to lengthen her slacks—gestures intimately familiar to me—the embodiment of a woman hiding her lymphedematous limbs. I wondered if she believed she had been successful at hiding, and my heart went out to her, knowing that she was camouflaging, at best, the edematous mounds over her feet, evidence of her vulnerability. I decided to proceed gently since her diagnosis was virtually new to her and suspecting that she would frame her story against a background fraught with medical and personal challenges.

First Swell: "I just accepted that I had bad feet."

Anya remembered that her left leg began swelling when she was eight years old, in 1998. She grew up with divorced parents in the metropolitan city where we both lived, wrapped in the love of a large, extended family. She described herself as "a regular kid running around or

watching way too much television. Doing a lot of homework." Medically insured, Anya's father entrusted the care of his family to a local physician practicing family medicine, who treated Anya for childhood asthma. Anya remembers that she began her menstrual periods when she was seven or eight years old, her body developing much more quickly than those of her peers. At about the same time, her family noticed that her left leg was swelling. Anya remembered that the physician said her leg was swelling from "water-weight" due to her menstrual cycle and the extra weight that she had put on. The physician first treated Anya with a diuretic, which she took only a short time due to headaches. The edema continued, and the physician concluded that Anya, an active child, must have suffered an injury of her ankle, and the edema was a lingering consequence of the injury. Anya suggested that her parents accepted his conclusion because they had been satisfied with his care throughout the years, and they trusted him.

Looking back, Anya believes that, as with her asthma, her parents would have been diligent about managing her swelling, if the physician had established the diagnosis of primary LLL. "That's a long time to go undiagnosed," I observed, and she replied,

> *Yeah, that was, I don't want to say negligent because, what, I was eight so almost exactly 20 years ago. It's really, really, stinky, like really crappy. Because I'm like, if I had known about this stuff when I was younger, it wouldn't have gotten as bad as it is. Because I know my parents would be on me, especially my dad, he's on me now, "Why is your foot not wrapped?*

I listened to Anya's tone as we talked, expecting resentment toward her physician. Instead, I heard graciousness. She liked the physician and did not blame him for not knowing about lymphedema.

When Anya was 14, she and her family began noticing that her other leg was swelling, but still, her physician offered nothing new about the swelling. At 16 years of age, Anya became pregnant, her daughter born in 2007. With the support of her parents, she chose to raise her baby and entered a program offered by her school district, designed to help teen mothers graduate from high school. When Audra was pregnant, her feet swelled more than usual, and after she had the baby, the extra swelling did not go away. She recalled, "I was like, oh yeah, they say your feet get bigger once you have kids. So I just always made some kind of excuse for it." About the attention she gave to her feet, Anya explained,

> *I was sixteen, going into my seventeenth year, had a baby, and I'm in high school. This was never my plan, and my feet was just back burner. I have fat feet, okay? If it goes away, it goes away. Now I have to figure out how to feed this kid and make good grades.*

Backgrounding her feet, Anya graduated from high school and began college classes. Soon she decided it was too difficult to raise a baby, work part-time, and go to college, so she withdrew from classes.

Anya took jobs that included caring for children at a daycare center and working the counter at a fast-food restaurant. She was standing on her feet for long hours at a time. Eventually, Anya secured a position as a clerk, but she was required to wear shoes with a rubber sole that would grip the floor. She had difficulty finding such shoes to fit and bought tennis shoes that laced up. Since her foot was long enough, Anya was able to find a man's shoe to fit that was wider than a woman's shoe. Over the years, the mounds on top of her feet increased, and she was unable to tie the shoes to the top. It was also becoming increasingly difficult to wear dressy shoes for church or going out with friends. Anya shared,

I know there was a time when I just couldn't wear my shoes anymore, and it was driving me crazy because I loved heels, and I would wear them all the time, and I'm like I can't wear my shoes. It hurts. It literally hurts. After so long, I'll take them off for a little bit, thinking my feet will go back down, and they swell more. I'm just like, I can't do this! I just accepted that I had bad feet. It's like accepting anything else. When you just get in a mindset of, "Oh, this is not going to happen." Even though if you push a little more, you could probably make it happen. I was at that kind of defeated place.

Feeling defeated, Anya accepted that she just had "bad feet" and that her weight was causing her feet to swell. She was also beginning to experience other weight-related concerns, such as hypertension. With pressure from her physicians and family and a desire for a long-term, romantic relationship and father for her daughter, she tried losing weight, believing that weight loss would also help her feet.

Medical Encounters: "No one said anything."

Unexpectedly, when Anya was twenty years old, she developed a blood clot in her left leg, and a physician admitted her to the hospital for a few days. Anya does not remember that any of the medical professionals at the hospital discussed the significant amount of edema in both her legs and feet during the hospital stay nor during follow-up visits related to the blood clot. Anya saw many physicians over the years for various reasons, and yet, to the best of her recall, none of them expressed an interest in exploring the reason for her swelling or indicated that the swelling was a significant concern. Importantly, no one offered anything to counter her perception that it was obesity that was causing her legs and feet to swell.

In 2015, about four years before our work together, when Anya was 25-years-old, she became pregnant with her son. Again, during her pregnancy, her legs swelled more than usual.

Anya remembers that her obstetrician acknowledged her swelling and seemed particularly worried. She repeated what the obstetrician said, "Oh, you know, you're swelling just because you're so far along in your pregnancy." Anya remembers that her obstetrician wanted to put her on bed rest because of the swelling, but that she refused, telling the obstetrician, "No. My feet don't hurt. My legs don't hurt, and I have to work."

Soon after her son was born, Anya saw a new physician in family practice. The physician was concerned about Anya's blood pressure and asked her to go to the emergency room for treatment. While finishing her medical documentation and making necessary arrangements on Anya's behalf, the physician mentioned the diagnosis of lymphedema that she read in Anya's medical record. Surprised, Anya asked the physician to explain the term, and the physician offered a brief explanation about the disease. Anya was concerned and confounded. She remembers,

> *The fact that the way the doctor just read it like it was just there. I was like, "What is that?" I was like, "I know I'm here for something else, but what is that?" She's like, "You've never heard of this?" I was like, "Obviously not." I'm like, "Give me a quick explanation of it, please!"*

During a follow-up visit, the physician explained the disease to Anya and urged her to find a physician who specializes in lymphedema and to seek physical therapy. Anya found a vascular specialist who practiced near her workplace.

Anya remembers that, after hearing the comprehensive history that she provided, the specialist seemed incredulous that no physician had established a diagnosis of lymphedema when she was younger. To the best of her knowledge, she told the specialist, her left leg began swelling at about the same time that she started her periods. She repeated part of their

conversation, "'He's like, you just found out?' I was like, 'yeah.' He was very shocked; he's like, 'No one?' I was like, 'No one said anything.'" Based on her history, the specialist suspected that she had primary LLL and sent her for a lymphoscintigraphy to confirm the diagnosis. Anya was overwhelmed by the specialist's warnings that, without treatment, her legs and feet would worsen and that an infection could threaten her life.

I asked Anya how it felt to have a medical diagnosis that explained her swollen legs and feet. She replied,

> *It was a relief to have a name for it, finally. I think it was liberating. I'm wondering, just how everyone would take me with actually having some kind of diagnosis. Like, what are people gonna think, what is it gonna look like in the future? Am I just gonna give up fully, and my legs are going to be huge to where I can't walk around, or am I going to actually fight through this and do what I'm supposed to? I'm like, this is not as big a deal as other diseases. And so, you know, I just downplayed it pretty much.*

Having an established medical diagnosis raised Anya's level of concern about her legs. She came to understand that, though her extra weight in childhood did not help with her lymphedema, it did not cause her lymphedema. Anya understood that her limbs were in serious trouble, but consoled herself with the thought that other people have far worse conditions.

I asked Anya to describe her emotions regarding how long it took her to receive a diagnosis. She took time to think before responding,

> *That is a big thing. This is the professional who has gone to school and learned all about this stuff, and I'm just the person who's putting my whole life in your hands. I'll have my moments where…just the doctors and how they didn't say anything. Honestly, I feel like*

none of my doctors did it on purpose. They were just stuck in their ways…now do I wish that the doctors would have been more persistent and had more knowledge? Of course.

Anya was working through her anger and disappointment about the delayed diagnosis. She recognized that, had her lymphedema been diagnosed earlier, her life might have been different. About the primary care physician who told her that she had lymphedema she said "She showed me the key."

Learning to Self-manage: "It's hard to focus when you're doing life."

A month or so after receiving a diagnosis from the vascular specialist, Anya met her first certified decongestive therapist. Anya's descriptions of her experiences with the therapist portrayed a positive and enlightening time for Anya, during which she felt the therapist respected her situation. The therapist was able to acquire approval from the insurance company for Anya to undergo therapy, but the company would not cover bandaging supplies. Anya could not afford the out-of-pocket expense of purchasing the supplies all at once, and the therapist agreed for her to purchase a few of the supplies at a time. In the meantime, her therapist taught her about lymphedema while conducting manual lymphatic drainage and skincare. Anya believed that her therapist understood that her financial concerns would interfere with standardized therapy and was intent on helping as much as possible. Eventually, Anya decided she needed to delay further treatment, explaining,

Honestly, her being my first therapist is one of the reasons I stayed. I kept doing it, and just when it got difficult, that's when I was like, "I got to give up like for a little bit, at least. Back-burner for it." I was like, "I know the consequences, but I just got to knock everything else out."

A year later, in 2018, when Anya returned for therapy, her first therapist had taken another job. Anya relates that her second therapist insisted on conducting therapy according to the standard of care since, by then, Anya had purchased all her bandaging supplies. Anya's supervisor agreed to adjust her work schedule so that Anya could walk cross campus for her treatments at the end of her workday.

Before beginning therapy with the second therapist, Anya had had an automobile accident, losing her car and suffering a back injury, causing pain for which she needed physical therapy. The co-pays required for treatment of her back injury, relying upon other people for travel, and the time off from work for therapy interfered with her intent to fulfill her commitment to treatment for her legs. She told me, "I'm trying to space out my appointments because I'm doing physical therapy for the wreck. So much time off is a killer. I'm like, I need to keep my job, so it's like I know I need the physical therapy, yeah, yeah…those co-pays. Lord, help me!"

Anya found it challenging to wear the wraps applied by the therapist. She attributes her inconsistent adherence to wearing the wraps to the demands of mothering, fatigue, the discomfort of the wraps, and the heat of the wraps interfering with sleep. Anya also shared that she did not have a shoe to wear with her wraps and, instead of a shoe, covered her wraps with a plastic bag. Because of her back injury, her therapist asked that she use crutches while wrapped. Anya described her therapist as insistent, and she thought that the therapist might have been frustrated with her. She was feeling overwhelmed by competing concerns and day-to-day living when, on a rainy day, her wraps got wet. She removed them and stopped going to therapy. The therapist had not yet fitted her for custom compression.

Anya was also struggling to address other urgent health concerns that seemed to compete with her lymphedema for attention, including sleep apnea, insulin resistance, and hypertension.

Anya mentioned these concerns often during our conversations, indicating that her lymphedema "had kind of taken a back burner because everyone's worried about my weight and my heart." All of the health concerns, and the financial responsibilities that came with her health concerns, weighed on Anya's heart, and she indicated that she recently had two "anxiety attacks" and had never had them before the diagnosis of her lymphedema.

The two therapists have adequately schooled Anya about her lymphedema, and she understood that her legs could look better if adequately treated. She seemed to possess a fundamental understanding of the long-term consequences of not treating her lymphedema. She said, "I have so much built up that I'm just…sometimes I'll look down at my legs, and I really feel like this is a losing battle." Anya sometimes feels hopeless but tries to be positive about her opportunity to make her legs better. Anya's situation was underscored when I encountered her, inadvertently, working in a department store one Sunday afternoon. During our next conversation, she verified that she works there one day every weekend to help with bills. Perhaps, due to my struggles to adhere to self-management standards, I felt as if my questions seemed a bit like an inquisition. So, I decided not to press. Instead, I disclosed what I was feeling to her about our shared experiences. Anya affirmed that she was treading water with parenting and financial concerns, detracting her attention from her legs and the treatments she knew she should be doing and that, "It's hard to focus when you're doing life."

Parenting with Lymphedema: "Mom, I just don't want your legs to be amputated…"

Anya used her telephone to share several photographs of her children and a few stories about her daughter's accomplishments and her son's antics. Anya connected her need for treatment and self-management to her children's best interests, recognizing that she needed to retain her mobility to participate in physical activities with them. However, she also viewed her

responsibilities to her children—the time they take up and their financial needs—as one of the barriers to self-management. She shared a concern that her daughter expressed,

> *That's why I need to find my compression, is because my daughter is going to want to do stuff. She wanted to do the marathon again this year. Last year, I was like, "Yeah, babe, we'll do it next year." My daughter, she's gotten to where she is a worry-wart like me, so she just is concerned. "Mom, I just don't want your legs to be amputated because you're not doing what you're supposed to do."*

Anya mentioned that the wraps, at first, concerned her daughter but that her daughter learned how the wraps would help her legs. Even at 11 years of age, her daughter recognizes that Anya will prevent future complications if she takes care of her legs in the present. Anya appreciates gentle nudges from her daughter to care for her legs.

Anya's daughter was approaching puberty at the time of our conversations. I asked Anya to share her thoughts since it was during puberty that her lymphedema developed. She replied, "I watch on the regular. I mean, obviously, I hope it does skip her because she's still trying to learn to be herself." Anya, however, had done little research about the heritability of her lymphedema nor talked with the vascular specialist about the possibility that her daughter might inherit lymphedema. Nevertheless, this concern was ever-present for Anya.

Lymphedema and Intimacy: "It's a part of me, so 'If you don't like it, okay.'"

I asked Anya if she had reflected on how her life might have differed had she not had lymphedema when she was a child. She took a moment, and then replied, "Well, it definitely would have affected my choices. I know that I would not have had my daughter as early as I did. Because I wanted a boyfriend and to be liked and to feel loved." Anya related her need for

romantic connection with her body image concerns and considered whether the connection affected her choices about sexuality and, then, ultimately, her life trajectory.

I asked Anya to tell me more about how her lymphedema affected her relationships. She described going to clubs, meeting someone who seemed interested, and then leaving before the lights came on because she did not want them to see her feet. She described a specific experience,

> *…and then I saw someone who was kind of cute, and we ended up sitting next to each other, and I was like, "Oh my gosh, he's going to look at my feet." I'm just like, "If he looks at my feet and is disgusted"…you know. I feel like my bottom half is very much a reason I don't get even noticed, or I get noticed, and they're like, "Yeah, no," they're not into it. Because you can't have weight and then swollen limbs, too, because then it's a big no. They're like, "Oh, she's big for real. I'm feeling this, but what is that?"*

Reflecting on her experience with dating, Anya seemed sad that her lymphedema affected her opportunity to attract prospective partners but resigned, shared the philosophy she had developed, "It's a part of me, so 'If you don't like it, okay.'"

Anya also talked about how she experienced her lymphedema in the context of longer term relationships. She indicated that her partners varied regarding their attention to her legs and feet. On the one hand, she reflected, some do not mention her lymphedema, as if it did not exist. On the other hand, one was overly attentive to her legs. She explained, "At the end of the day, especially [with] relationships, I want to make sure that if you're my partner, you're my partner first, and we can be on each other about stuff. We also need to know when to lay off." Anya seemed bothered that the partner did not attend to her as a whole person, before attending to her legs and feet, as if her legs and feet were the priority in their relationship.

Striving in the World with Lymphedema: "I'm going to keep living my life to the fullest…"

Anya seems to have days when she feels positive about her opportunities to improve her quality of life for herself and her children. About eight weeks after our second conversation, Anya and I arranged to meet at a quiet restaurant for our last conversation. Already at a booth, I watched Anya traipse perkily through the door, dressed in a knee-length summer dress, wearing her ballerina-style shoes, and no compression, her legs bare from the knees down. She seemed happy and excited. Her excitement, Anya said, was because she was driving a new-to-her car and that, after our meeting, she was going to a family reunion. Anya was looking forward to seeing her relatives. She seemed relieved when she shared that she had just moved to the home of her godmother, and hoped it would be more comfortable than her previous situation, while she attempted to resolve some financial concerns. Anya also shared that she had just enrolled in an online university program and hoped to finish a degree in human resources, her education reimbursable by her employer. She indicated that she chose that degree because she wants to help other people at work with their personal situations. I was glad to hear her good news and understood that getting a degree was a life-long dream that had been waylaid by unexpected parenthood.

Anya shared that she had been reflecting on how her life had been affected by the medical care she had received:

> *...but even my doctors now, or before I found out, they didn't really say anything. It was, "It's weight, it's water, cut out salt." And that's the only thing they mentioned. That's part of the reason I'm doing the interviews because awareness needs to be brought.*

Anya agreed with my suggestion that it seemed like the physicians could not see past her obesity to see her lymphedema.

I shared a phrase with Anya that is popular in Lymphedema World: I have lymphedema, lymphedema doesn't have me. She responded,

> *Like, it doesn't have me, as in it's not going to stop me from anything, and I'm going to keep living my life to the fullest, and do absolutely anything and everything I want. That's a perfect quote. I'm going to write it down.*

I asked Anya, "What do you think is the most important thing about you to go into your story?" She seemed to value this opportunity and took only a moment to reply, "I think I could say I'm a hard worker and that I put family first. Over the years, I have needed to also put myself first when it came to my medical situations, and I don't, which will change. Definitely change, because I have two little people looking up to me." Anya's response reflected her belief that in taking care of herself, she is preserving her capacity to care for her children.

Arial: Stronger Now

One of my nursing students expressed interest in learning more about my dissertation topic. Intrigued, I asked her directly if she knew someone with lymphedema. She told me that a physician had recently established the diagnosis of primary LLL for her cousin's wife, Arial, but that Arial had had lymphedema since she was a teenager. I asked my student to forward a copy of the recruitment flyer to Arial and encourage her to contact me. A month later, Arial called and seemed to burst with the details about her journey with lymphedema.

Arial was 15 years old when she began noticing swelling in her left leg but that it was almost 17 years after she first noticed swelling that a physician documented the diagnosis of primary LLL on her chart. I also learned that Arial was a stay-at-home mother of three children and that she was receiving disability payments from social security for RA. She seemed enthusiastic to meet with me, and we made an appointment. Two weeks later, Arial was waiting

at the table in the restaurant when I walked in. At first glance, she looked like an older teenager. She was wearing jeans, a t-shirt, and tennis shoes, and her long, dark, lustrous hair was escaping from the loose bun she had pinned to her head. I soon learned that Arial appreciated the opportunity to get to know another person with primary LLL.

First Swell: "The leg was too much for them."

Arial grew up in small, Midwestern towns that were less than an hour from a large health sciences center. Arial had an older brother and sister, and, during her young life, her parents struggled to meet the financial needs of their family. When Arial was a toddler, she experienced second and third-degree burns on her feet and legs. Arial recalls nothing about the event and relied upon a photograph she kept on her telephone to describe her injuries and treatment. The leg on which she sustained the burns that required grafts was the same leg that swelled the most. She told me that her scars were "so faint now that they were easier to cover with make-up than acne."

By her sophomore year in high school, in 2001, Arial had grown to five feet, nine inches tall and, she said, "I was like a hundred pounds soaking wet, so I was teeny-tiny." With her mother's encouragement, Arial began pursuing a modeling career. Arial developed a portfolio, took jobs as a runway model in Las Vegas, and planned for work in Japan when her left leg began to swell. Arial described the gradual swelling in her leg as "not that noticeable." However, because she was participating in school sports and wearing shorts, people noticed, and her "go-to" explanation was that she had suffered an injury.

Concerned that the swelling was not going away, Arial's mother took her to see several physicians. None of them indicated that she had lymphedema, prescribed therapy or a diagnostic study, nor referred her to someone else for a diagnostic work-up. Arial remembered that "we

weren't getting anywhere with doctors." Arial and her mother, however, experienced cognitive dissonance, realizing that if she had just hurt her leg, as suggested by physicians, the swelling should have gone away already. They turned to the internet. They found information about swelling and "elephantitis" but nothing that led them to primary lymphedema. Reflecting, Arial realizes that at the time, she and her mother were not armed with the right verbiage or medical understanding to find an explanation for her problem.

At about the time that Arial's leg began to swell, a physician diagnosed her sister with a disabling disease. Arial also narrated an event that was devastating to the family, resulting in temporary separation of the family, and a move to a new town. She and I agreed that we would not include this event in her life story since the event involved other members of her family and was not directly relevant to her lymphedema. However, we thought it necessary to note that, though the event occurred a few years before development of her lymphedema, and with her sister receiving a devastating diagnosis, her parents lacked the necessary margin in life to pursue a definitive diagnosis regarding her swelling, against the constraints of their medical coverage, financial situation, and family crisis.

Arial's enlarging leg sidelined her modeling career. I hoped to ascertain how much of a loss her modeling career seemed to her. She showed me a few professional headshots and photographs of herself on the runway that she kept on her telephone. She indicated that she has since enjoyed unpaid modeling gigs and indicated that the organizers were accommodating about her leg, positioning her body so that her leg did not show or had her wear boots. I asked her to reflect on the time of early swelling and the effect of losing her modeling career. She responded,

> *…I mean, I think it had a big part, but I wasn't really pursuing it either. I liked to do it and everything, but I've never really been one to really like to show off. If that makes*

sense? Yeah. So, I have anxieties and especially around a bunch of people, so I think that was a part of it. And, of course, the leg, too. The leg was too much for them.

Her explanation also offered a glimpse into her personality and, possibly, her preference regarding exposing her lymphedema.

Before her senior year of high school, when Arial was 16 years old, she became pregnant and married the father of her baby. Theirs was a short marriage, but Arial finished high school, and they had a healthy baby girl. In 2007, when Arial was 20 years old, she met her current husband. He joined the military, finished basic training, and they moved together to a military base in another state. While there, Arial worked as a leasing agent at an apartment complex. She said, "I'd have to go up and down the stairs, and we were required to wear heels and look nice." She said that she negotiated wearing a blazer, slacks, and heeled boots, to hide her slowly, and distressingly, enlarging leg.

Encounters with the Medical Profession: "Finally, "Lymphedema, to a T."

Arial saw a physician at the medical clinic on the military base. The physician, familiar with the devastating injuries experienced by soldiers, suggested that she might have lymphedema secondary to the burns she experienced as a toddler. The physician referred Arial to a physical therapist, but Arial did not believe the therapy was helping and dropped out. She later learned that the therapist was not doing decongestive therapy, according to standards.

Yeah, they did a massage. I was telling the one that I went to recently about all this, and she goes, "it doesn't sound like they did it right." They did a massage, and they moved my leg around a little bit, then they pushed real hard. They squeezed it from the bottom to the top, and then they were like, "okay, you're done." And that was about it. They sent some stuff home, and this is what you need to do at your house or at home. I told her all

that, and she's like, "that doesn't sound like they did it right." And it seemed like my lymphedema was getting worse. I think they were just regular physical therapists because whenever I walked in, they were kind of like, "What's this for?" And I told them, "lymphedema, possible lymphedema," and they were like looking off of this chart that they had, "All right, I gotta do this, and I gotta do…"

I was disappointed to hear Arial's story, knowing that a few certified lymphedema therapists practiced within a 100-mile radius of the base at that time. The physical therapist who saw her, for some reason, failed to suggest therapy with a therapist certified in lymphedema therapy.

When Arial and her husband returned to their home state, they decided to have children. Soon after her second son was born, at age 27, a rheumatologist diagnosed her with RA. She developed joint pain, redness, and swelling around her joints, and her left leg was swelling more than usual. She also noted that her right leg was beginning to swell. The rheumatologist attributed the swelling in her left and right legs to RA. He started her on medications to put her RA in remission. However, the way her legs swelled was confusing to Arial and her physician. She said, referencing her right leg, "…and then as soon as I got my first steroid shot, it went down." And I'm like, "Wow!"

Another rheumatologist helped Arial to achieve satisfactory remission of her RA, and her pain and joint swelling improved. The rheumatologist realized that if the swelling in her left leg was from RA, it should have reduced as well. Finally, in 2018, suspicious that Arial had primary LLL, the rheumatologist referred her to a certified lymphedema therapist. The therapist indicated to Arial that she had "lymphedema to a T" in her left leg and, likely in her right leg, as well. After the rheumatologist established the diagnosis of lymphedema and RA, Arial applied for

disability. Arial believes that her lymphedema may have factored into the decision to grant her disability, claiming that the evaluating physician seemed surprised about the size of her left leg.

During the summer of 2018, Arial experienced an episode of cellulitis that was distressful, and her encounters with the medical professionals from whom she sought help were distressful as well. Her husband's parents invited family and friends to a pool party. Just before leaving for the party, she shaved her legs with a disposable razor and scraped some skin from the shin of her left leg, the leg that swelled the most. She remembers, "…I was like, 'Oh, I'll just put a Band-Aid on this.' Didn't think anything of it. I knew I shouldn't [shave with a razor] 'cause I was always told don't do that." She described the next two days,

> *It was hurting before two days, but two days later is when it really started swelling and getting that fever and all of that. Yeah, I just, I mean, because that came on so quick I didn't know what it was. Because we were both like, that's not part of lymphedema. Because it started, it was just like little spots at first, and then it just went up my leg.*

Arial and her husband decided to go to the urgent care center nearest their home. Despite telling the physician there that the swelling in her leg was due to lymphedema, the physician was concerned that she might have a life-threatening blood clot in her leg. Though she asserted that her rheumatologist had referred her to a lymphedema therapist and that she had experienced swelling in her leg for over a decade, the physician referred her to the hospital emergency department for a diagnostic ultrasound. The physician in the emergency department also expressed concern about a blood clot and forwarded her RA as an explanation for her symptoms as well. Arial expressed her frustration,

> *He was in there, not even five minutes. He didn't really act like he cared. He was like, "It's just a flare-up of your RA." And I'm like, "Okay, this is not a flare-up. I know the*

difference." And he was like, "Well, it's red hot, whenever you flare up, right?" Yeah, and I was like, "This isn't normal. This is an infection." And they're like, "Okay, well, we'll do all the tests, and we'll make sure." It was cellulitis. So I was like, I'm glad I pushed for it 'cause they were trying just to blow it off, say it was nothing.

To have to advocate for herself aggressively, when feeling so poorly and self-conscious about her leg, multiplied the stress of the situation. Arial was hardly able to ambulate on her leg, remembering it, "hurt when blankets touched it. I mean, it hurt bad. And it swelled up huge." The week that followed was tough for Arial and her young family because it was disruptive to their schedules, and she was hardly available to them. Looking back on the experience, and after tapping into the internet for information about cellulitis and lymphedema, she realizes that she was fortunate that the episode did not require hospitalization. Arial believes that the pool water way have infected the shaving wound, and she had not been swimming since.

Grappling with Othering: "Elephantitis, elephantitis, elephantitis!"

I asked Arial to think back to the time when her leg first began swelling and tell me about how other students at her high school responded. She recalled, "Well, when I was younger, and it first started, everyone was like, 'Elephantitis, elephantitis, elephantitis!'" In high school, she wore pants, long skirts, and dresses all the time, including during her physical education classes. She said, "I didn't like having to explain it. Because at the time I didn't know. I didn't know what was going on." For Arial, part of the stigma of being different from her peers was not being able to explain her difference to others.

Arial's first marriage ended in divorce, and Arial indicated that she had wondered if her partner's feelings about her leg contributed to their divorce. I asked her to tell me how her leg affected her relationship with her current partner. Arial shared that her current partner had

experienced a physical disorder that caused disfigurement during his teens. His disfigurement was treatable with surgery, but he was self-conscious about the scars that linger. He was also self-conscious about recent weight gain. She believed that his experience with stigmatizing body difference helped him to understand her experience.

Family Support: "Coming around…"

It was 17 years before the diagnosis of lymphedema was established for Arial, though by her early twenties, she suspected that she had a disease called lymphedema. Arial felt supported by her family, especially her mother, who worried if she had somehow failed her daughter. She also felt supported by her second husband, who seemed to understand how she felt about her lymphedema and recognized the burdens her chronic diseases presented. However, Arial sensed that, without a diagnosis that came from a medical authority, her explanation for her burdens seemed not to be legitimate in the eyes of her husband's family members. In particular, Arial did not feel that her in-laws understood how her leg could intrude on fulfilling her family responsibilities. She said that she felt like her husband's parents were "coming around" now that physicians had established diagnoses for her disorders.

Strategizing to Hide: "Aren't you hot?"

For the most part, Arial seemed comfortable with her casual wardrobe. She attributed this to being a stay-at-home mom. She described what dress-up meant for her, "I do, occasionally, obviously, do my makeup, and I'll dress up and stuff. But as far as, like, dress up, dress up, it's jeans and a nice shirt. I don't really wear skirts." She also told me that she sometimes had difficulty finding jeans to wear because she is so tall and thin. I noticed, though, that the jeans she was wearing were form-fitting, but had enough extra material below her knees to disguise the difference in the girth of her legs. She replied, "I have tight pants on today because my leg

actually isn't too bad. But, I'm still kind of like, nervous." Arial believed that wearing form-flattering pants risked exposing the inequitable sizes of her legs, and she was self-conscious in the jeans. It was a lymphie conundrum: Show off her figure and risk exposing her leg versus wearing loose pants that did nothing to flatter her figure but armored her against stigmatizing stares.

Arial added, "I actually just bought a pair of jeans that are size eight. And, that's another thing, you know, I don't like to try stuff on because even though you're in a fitting room, you're still, like, the bottom part is still showing, you know?" I knew what she was talking about exactly. I shared that when I shopped, I carried a large tote bag to place next to the door when trying on clothes, to obscure the view of my ankles and feet beneath the door. She thought that was a good idea.

I asked her to tell me about her experiences shopping for shoes. She said, "That's fun, too. You know, we went to [athletic store], and I was looking around, making sure nobody was looking, you know…" She indicated that she could no longer wear heels and that she only has three pairs of shoes in her closet that she could wear. I noticed that she was wearing a pair of tennis shoes with elastic across the top rather than ties and asked her if they were a wide width. They were not, but she indicated, "they stretched a lot."

Arial showed me a photograph of her legs in boots, and I could see that they were tight. We commiserated together about the difficulty in getting boots to zip past our ankles, and yet not need "wide" shaft boots. She contributed, "I've actually busted quite a few boots. Yeah, trying to get the zipper pulled up. Or, I'll hurt my finger trying to get it. You know, so I started getting pliers, or I'd get my husband to do it. And, he's like, 'Oh my God!'" Usually, boots camouflage our ankles well, if not for that zipper that sticks where it folds.

Arial shared that, during her last years in high school, after her leg began swelling, and she decided not to participate in sports, she still had a physical education class. She chose to wear long, knit pants to class and contend with people asking, "Aren't you hot?" The heat and humidity of the summer continue to plague Arial in her jeans. She shared a story.

> *Yeah, I hear that all the time. I had to go to the zoo with my sons for a field trip, and everybody was in shorts because it was warm and everything and I'm sitting here in jeans and my boys just like, "Mom, aren't you hot?" 'Cause I'm sitting here, I mean I had sweat…Like yes, I'm very hot, but, you know.*

I knew, exactly, the shopping trials Arial experienced, as well as the conundrums of wearing long pants in the humid summer heat of our state. I asked her to tell me about the choices she made related to this sort of conundrum. She said that if her children really wanted to do something, then she would, but wore long pants despite the heat and humidity.

> *I've kind of almost gotten used to always hiding it. I'm used to it. So, I mean, there's days like today, and I'll wear them. I wish I had shorts or something on, but then I have…Let's see, I think it was last year or the year before, I don't know, I was helping my husband, and he told me to go outside at our house, and my leg was all swollen, but I was like, You know what, I'm gonna wear shorts.*

Arial and I explored her experiences of exposing her leg in a variety of contexts. In the narrative above, Arial demonstrated a progression from *always* hiding to choosing to expose in a limited context, with encouragement from her partner.

Learning to Self-manage: "What's it gonna be when it gets down the road?"

The lymphedema therapist that Arial saw recommended decongestive therapy for Arial. Arial and her husband added up co-pays for the projected number of sessions, considered the

logistics of scheduling sessions and balancing family needs, and the remaining balance on her medical bills for her RA. They determined that, at least for a while, therapy was unmanageable for them. The therapist recommended a ready-made, thigh-high garment for her left leg. Arial is not comfortable with the garment because it slides down her thin thigh. She does not feel that she can afford another, custom-fit garment. Since her visit to the therapist and at the urging of her rheumatologist, Arial uses a less expensive compression garment from a discount store and believes that the compression helps manage the volume of lymph in her leg.

Devoting time and resources to self-care is difficult for Arial. She indicates she would instead buy for her children or clothing for her husband to help him present himself well and to grow his business, than for herself. She said, "That's just how I am." Arial also noted that she tends to be active—she does not sit for long—and with two young, very active boys in her home all the time, there is much work to do around the house. These two characteristics, or preferences, she believes are at odds with devoting time and resources to self-care.

Arial is especially aware that the heat and humidity of the summer cause her to have a "bad lymphedema day." Consequently, she struggles with balancing the needs of her boys to play outside. For example, when the boys want to go to the park to play, she would prefer they play in their yard, where she can better meet her privacy needs, elevate her leg, and stay shaded. When I asked her, "What is something that you haven't been able to do because of your lymphedema that you would have liked to do?" Without hesitation, and later bringing it up again, Arial responded that she knows her husband would like for her to go with him to a particular outdoor event. She feels guilty about not joining him at the event but does not believe she will enjoy it because she would be on her feet for hours in the humid heat. The day of the event would be a "bad lymphedema day."

Arial acknowledges, “I’m bigger than I was when I was younger” and, using her hands to show me, “On a good day, like today, it’s just up to about right here. And, on a bad day,” again, showing me, “it can get up to here, sometimes even up into here,” her hands encasing her knee. She also indicated that her feet and toes get “puffy.” I wondered if better management of her leg—helping it appear to be healthy to others—might motivate her. I listened for cues about how much Arial valued this possibility, in her answers to my questions about daily living and heard few. She seems satisfied *enough* to wear jeans and a nice shirt for dress-up, or a long skirt or dress for church and, though burdensome in the heat and humidity, jeans during outdoor activities. Paying to go to the pool with her children or working out at a gym are activities that would reveal her leg that Arial will not be doing, “anyway.” Arial has her reasons for her choices, including the pain of her RA and finances. These are her “anyways.” *Anyways* help her to be satisfied *enough* with how her leg looks.

In the past, before receiving the diagnosis for her RA, Arial focused on her leg so much that she felt her husband was annoyed. She explained,

> *For a long time, it was always about the lymphedema. That would drive him insane, and that would drive me insane because that would be the focus. And I would be like, “well I can’t do that, I can’t do that.” So, it was mainly about the leg, you know? I can’t do this, I’m not supposed to do this. We thought that was what I had, and I would always just go online and try to figure what I’m supposed to do. And, then it got to a point where it’s…kind of overwhelming…all the stuff you’re supposed to be doing, so I kind of just like, okay. I’m going to get away with what I need to do, I guess.*

Before diagnosis, but after having lymphedema mentioned to her, Arial became convinced that lymphedema caused her swelling and she began to do research on the internet about the disease. With no help from physicians, she tried to find her way with the disease.

I learned during our third conversation that Arial was pregnant. I asked Arial, "Can you imagine how decongestive therapy would ever fit into life? If money were no object, how would you fit that in?" She replied, "Probably wouldn't, especially with a baby. It's just, you just don't know. You don't know what's going to happen, you don't know which one would be right, you don't know which one would…it's just always kind of scary." Arial could not imagine fitting decongestive therapy into her life. Further, her experience with the physical therapist who treated her lymphedema inappropriately had also left her unconfident in her ability to select a therapist.

I noted, throughout our conversations that, even though the lymphedema therapist assured her that she also has lymphedema in her right leg, Arial always referred to her leg, rather than her legs. Her left leg was, in my view, significantly larger than her right. I asked, "Are you worried that, as time passes, your legs will get worse?" She replied,

> *I do worry about that because I mean, I am…well, tomorrow I'll be 34. So it's getting older, and I'm already…I'm not saying by any means bad, but it can swell pretty bad. And then I'm just like, "What is it going to be when it gets down the road?"*

Parenting with Lymphedema: "Oh, gosh. Please don't be lymphedema."

Arial and I realized that teasing apart the effect that each of her conditions had on her family would be difficult. A stranger, looking at Arial, would not notice that she suffers from RA. She and her rheumatologist had been so successful at achieving remission, I could hardly tell that she had RA. However, sometimes she still has "flares," and on those days, she hurts more and finds being active with her children more difficult. Because the signs of her RA are

usually so subtle, we were able to focus on her lymphedema and its possible meaning for her children's lives. She battled with herself when her children wanted her to go outside in the heat to play. This internal battle, she thought, might be caused by feeling as though she was letting her children down.

I asked her how much her children understand about her lymphedema. She shared:

> *Any time it swells pretty decently, they'll see the bump. They call it the bump on my foot because it'll go like this, you know (making an arc with her hand). They're like, "Mom look, look, look!" and they'll just laugh. You know it doesn't bother me because it's my kids. But if they get a little too rough I'm like, "Okay that hurts. Let's not do that." But yeah…They're curious about it, they don't understand 'cause they're like, well mine doesn't do that and I'm like, "It's good yours doesn't do that. Let's just keep it that way. Let's hope."*

Before our second conversation, while in the car with one of her sons, Arial was swiping through her phone gallery looking for photographs to show me. Her son looked on and commented that her leg looked "gross." Arial said his comment was not hurtful, explaining, "I have talked to them a lot about that, because I've had other people say it to me, and it bothered me because they said it. But my boys, it doesn't bother me." It was important to Arial to use such moments as "teaching moments" for her sons. She has also experienced teaching moments with her teenage daughter, sharing, "I want them to know—especially my daughter—that it doesn't really matter as far as what you look like."

Arial told me that she was aware that her teenage daughter had talked with other family members about her lymphedema. Her daughter was about the same age that she was when her leg began swelling. I asked her if she thought her daughter was worried that lymphedema would

happen to her. She told me that her daughter recently sent her a text message with a picture of her ankles and feet and asked her mother if her feet looked swollen. Arial said that she assured her daughter that it was just a normal response to the heat. When Arial was sharing the story about her boys referencing her "bump," I noticed that she ended her story with, "it's good yours doesn't do that. Let's just keep it that way. Let's hope." I responded, "That's what you're saying on the outside. What were you thinking on the inside?" She replied, "On the inside, I was thinking, 'Oh gosh, please don't be lymphedema.'"

I asked Arial to tell me about a time when someone said something to her about her leg. With intense emotion, she narrated a recent event,

> *There was one time at a grocery store, and there was teenagers laughing about it and, you know, it's just teenagers, but my boys were little, little, little, little, little, tiny boys. And the boys were laughing about it and everything and they're like, "Oh, my, gosh! I can't believe your leg is so big!" I had pants like this on, but you could tell my leg was bigger because it was stretched out quite a bit. I was just like, "You know, if this ever happened to you, let's see if you speak the same way about someone else whenever something like that is happening."*

Rather than walking away from the exchange, as she usually would, Arial confronted the boys. To Arial, her actions were more about teaching her children that she would not tolerate making fun of others than standing up for herself or, as her husband suggested, wanting to start a fight. She wanted her children, as well as the teenage boys, to understand that their actions have hurtful consequences.

Standing Up in the World with Lymphedema: "I'm a lot stronger now."

When we neared the end of our work together, I asked Arial, "Overall, what do you want people to know about you?" I waited a bit for her answer but she seemed stumped. Understanding how essential her roles as spouse and mother seemed to her identity, I asked her how she thought she was managing her roles as wife and mother while dealing with her chronic conditions. She thought for a moment before replying.

> *I'm dealing with them better than whenever I was first diagnosed. I just feel like I don't complain as much as I used to, if that makes sense. It's not that I don't want to sometimes, but I just…with everything else, just life in general, it's just kind of like, what is my worry? Why is my pain or worrying more important than my kid's pain or worry? Or, my husband's pain or worry? It's not the end of the world. I mean life is going to go on, and you just have to learn how to deal with it in your own way. I mean, just try to treat yourself if you can. And, if you can't, then try to love yourself again.*

It seemed that one of the ways that Arial coped with her lymphedema was to affirm her situation as better than those of others. Her comments reminded me of her husband's earlier annoyance about her focus on her lymphedema. I asked, "What do you think your husband thinks about how you deal with your lymphedema now? What would he say if someone asked him about it?" She took a moment to wrangle her emotions, her face flushing, and responded, "Now over the years he'd probably say…" and she began to cry quietly, thinking of the birthday card she'd just received from her husband, and said, "He wrote that I'm a lot stronger now."

Conclusion

The life histories of Audra, Arlo, Abie, Anya, and Arial demonstrate the unique ways that primary LLL may affect the lives of children, adolescents, and young adults amidst various

geographical, social, and medico-historical contexts and within the culture as the 20th century turned into the 21st. Each narrator was the focus of analysis as they described their experiences with pLLL. In the next chapter, Chapter VI, I further analyze, compare, and interpret their individual life histories to generate cross-case themes and findings (Patton, 2015). I also describe relevant connections to the literature.

CHAPTER VI

FINDINGS

In this chapter, I turn to thematic analysis across the life histories of four women and one man who grew up with and are living with primary LLL, which developed in childhood or adolescence. The narrators' life histories suggested common, sometimes interconnected, themes. To identify these themes and generate substantive insight into the phenomenon of living with primary LLL, I conducted cross-case thematic analysis (Patton, 2015), following the methods I described in Chapter IV. I divided this chapter into three parts: 1) Striving to Matter To and For Others and Self, 2) Complexities, Complications, and Confusions: Difficulties along the Journey, and 3) Lymphie Conundrums: Grappling with Normalizing/Othering. I begin each section with a description of the conceptual links between the themes discussed within. I follow each finding with my interpretations and explanations and note relevant connections to the literature. I also consider the contexts (medico-historical, sociocultural, and geographical) in which each of the narrators grew up and are living their lives to find meaning in their experiences. In the next chapter, I use my findings to answer the research questions.

Striving to Matter To and For Others and Self

"Matter," used as a verb, is a word that English-language speakers use commonly to describe importance or significance, or lack thereof. Research and theory on the psychological construct of mattering is still at an early stage. Nevertheless, when included in investigations as a variable, the construct yields new findings and new insights (Flett, 2018). Flett (2018) writes that the feeling that you matter to someone, for most people, can be intense, expanding:

> The joy and contentment inherent in feeling that you are significant to someone is entirely different from the upset and resentment that boils up inside when someone treats you like you don't matter. No one likes to be made to feel as if they are invisible or insignificant and the sense of being disrespected and not mattering can elicit angry reactions and strong resentment. No one likes to feel as if her or his voice is not being heard. (p. 3)

I use mattering as a conceptual frame for making sense of the stories the narrators shared about feeling significant or insignificant to others. The patterns in their stories about mattering include distinct strands related to mattering for others, acknowledgment of lymphedema burden, mattering to healthcare providers, advocating because *we* matter, and my legs matter to me.

Mattering for Others

The narrators emphasized that they meet their commitments to their children, their long-term partners, and in their work, school, and other communities, despite lymphedema. They believe that meeting commitments matters significantly for others. However, the condition challenges their effort to meet those commitments. I use the term "despite" in the discussions that follow to reflect an attitude demonstrated by all narrators but explicated directly by Abie. She describes herself as driven to achieve goals "out of spite," regardless of the burdens of lymphedema. Their stories shed light on nuances in the theme of Mattering for Others, including the internal conflict between parenting and comfort, co-investments in long-term partnerships, and controlling lymphedema to meet commitments in work, school, and community.

Internal conflict between parenting and comfort. For narrators who are parents, ensuring that children have "normal" experiences takes priority over their own physical and social comfort. However, they feel conflicted about participating in their children's' activities

when the activities are outdoors in the heat and humidity or compel exposure of their limb(s). Internal conflict emerges from one of the most emotionally infused patterns in the data because the narrators believe that, as parents, their presence matters significantly to their children. The intensity of the conflict seemed to relate to the importance narrators attached to participation in particular activities. How much they expected to suffer while participating also contributed to the conflict.

The narrators indicated that their lymphedema rarely affected their ability to perform the usual, day-to-day tasks of parenting but that they sacrificed physical comfort daily on behalf of their children. For example, Arlo is committed to sharing the evening meal with his family at the dinner table, though he would prefer to elevate his feet. He believes the family tradition matters to his children. Arial described her daily struggle to elevate her feet while keeping up with two active young boys and managing her household. Anya noted that, after work, she devoted her energy to her children and home rather than bandaging her legs. By the time she finished reading her child to sleep, she often fell asleep without wrapping; her child had tucked in beside her.

The narrators emphasized stories about events that required them to be outside in the heat and humidity and/or compelled them to expose their limbs and sacrifice physical and/or social comfort. They viewed these activities as particularly crucial to their children or believed that they were the best, or only, person to accompany their children. For example, Arial described her discomfort when wearing long jeans to the zoo. She felt she needed to be there for her boys just like the other moms and preferred to suffer in long jeans rather than expose her leg. She also described her discomfort about revealing her leg at a pool party. She decided to go to the party and wear a swimsuit "because the boys wanted to go so bad." She chose to be in the pool with the boys to ensure their safety, despite her preference to avoid exposing her limb.

With sadness, the narrators also shared stories about times when they chose not to participate in events because they anticipated physical or social discomfort that they were unwilling to endure. For example, Anya opted not to participate in a 5K fundraising walk with her daughter because she knew her legs would hurt. Her daughter was disappointed. They worried about such circumstances and choices, because they wondered if their choice affected their children's' lives negatively, in ways that matter, and they feel guilty about those times. Their experiences are consistent with findings of those parenting with chronic illnesses (Thorne, 1990) that reveal that women with chronic illness experience internal conflicts between the obligation of mothering and managing their disease, and they struggle with availability to their children.

Co-investments in long-term partnerships. The narrators in long-term partnerships contributed to their partnerships in ways that matter, despite their lymphedema. Their contributions are entangled with those of their partners to meet their shared goals. They recognize that they must adjust their investments of time, energy, and financial resources to minimize how lymphedema imposes on their goals for their partnerships. For example, Arial acknowledges the challenges of managing her household, with lymphedema *and* a flare of her RA, and at times worries that her partner's parents view her as falling short on the housework. However, she feels supported by her partner, and since her physician established a diagnosis of primary LLL—legitimizing her discomfort—she believes his family is "coming around."

Arlo and Arial worked full-time during the beginning of their partnerships. With support from their partners, they applied for and received benefits from Social Security Disability Insurance for their RA. Their partners appreciate their opportunities to invest time and energy in raising their children and managing their households rather than working outside the home. They

acknowledge their disability for RA has been good for their lymphedema, as well. When Arial's physician referred her to a lymphedema therapist to confirm her diagnosis, her partner took time from work to join her during the meeting with the therapist. They were hopeful that the therapist could confirm her diagnosis and suggest strategies that would improve her quality of life and, in turn, that of their family. They were not able to invest in therapy at the time, given other family and health priorities. Instead, Arial began wearing over-the-counter compression garments and taking care to avoid infection.

Audra's experience with life-threatening cellulitis catapulted her and her partner's co-investment in self-management of her lymphedema to another level of commitment. They seem to have developed a strong and mutual understanding that, if her lymphedema progresses, her future capabilities to contribute to the partnership will be at risk. They realize that it is through decongestive therapy and effective self-management that she will be able to continue to do so. Together, they invest time, energy, and financial resources in educational and advocacy activities, and self-management. Importantly, Audra indicated that her partner gently holds her accountable for self-management and helps her to wrap her leg occasionally.

Controlling lymphedema to meet commitments at work, school, and community. In order for people to be healthy, happy and productive, they need to feel like they matter in work, school, and their communities (Flett, 2018). The narrators contribute significantly to their communities as employees, students, and volunteers, in ways that matter, despite their lymphedema. They control their lymphedema with investments of time, energy, and resources to avoid interference with their contributions. Audra shared that she participated in advocacy work for lymphedema while working full-time. Arlo and his family were devoted to their mission to clean the beaches near their home, and he enjoyed homeschooling his children and managing the

household. Abie expressed a strong sense of responsibility to meet her academic and leadership commitments at school. Anya believed that people at her full-time job saw her as a hard worker and especially good at problem-solving, and Arial was volunteering at her children's school while managing her household.

Arlo was proud that he could "keep up" with the outdoor construction job he held before taking disability despite his lymphedema, but acknowledged that the situation, especially in the summer, was hard on his legs and likely contributed to episodes of cellulitis. Abie collaborated with her physical education teacher to find alternative ways for her to participate in class, rather than in outdoor activities in the heat and humidity. Arial talked about the difficulty of walking required for some jobs and volunteering to help with her sons' outdoor school activities. Anya was striving to "catch-up" with financial obligations by working an extra day a week at a job that required standing most of the shift. Unfortunately, the situation left her "behind" on her lymphedema care. Audra was grateful that she had been able to certify for an occupation that enabled her to work with her feet elevated whenever she wanted, and eventually, work from home, allowing her to control her lymphedema better.

Lymphedema interfered with work when they experienced cellulitis, but fortunately, decongestive therapy sessions did not. Audra missed over a month of work when hospitalized for cellulitis but was fortunate to have sick leave to accommodate her absences. She believed it was a "God thing" that her work-day ended in time for her to go to therapy without taking sick leave because she had so little leave left after her battle with cellulitis. Anya was able to negotiate her work hours to accommodate therapy sessions without taking leave because she had already dedicated her sick leave to other concerns. On the other hand, Arlo reported feeling a threat to his job security when he missed work because of cellulitis. The threats they experienced related

to job retention echo findings in the literature expressed by other participants with lower limb lymphedema (Bogan et al., 2007; Waters, 2009; Williams et al., 2004).

Abie completed decongestive therapy while in middle school. Nevertheless, she was committed to performing academically at her usual high level despite her lymphedema and found creative ways to stay involved in extracurricular activities in ways that matter. It was challenging to navigate school policies and procedures due to absences and wearing multi-layer bandaging on her legs. Consequently, she and her parents decided to seek formal accommodation. I will discuss her experiences with navigating schooling in the next part of the chapter.

Acknowledgment of Lymphedema Burden by Those Who Matter Most

In the previous section, I explored findings of the ways that the narrators strove to meet commitments that mattered for other people, despite their lymphedema. All believed that there are people in their lives who can see the invisible emotional and physical burdens of the disease that they bear while meeting their commitments. It matters to the narrators that certain people notice and acknowledge their burdens. Flett (2018) writes that mattering "is a feeling that for most people is intense—the feeling that you matter to someone" (p. 3) and emphasizes that the feeling is particularly strong when you realize that you are special to someone who matters to you. The stories reveal nuances in the ways others noted and acknowledged their burdens, including ongoing concern from parents, partner acceptance and acknowledgment of burdens, children's' awareness of lymphedema, acknowledgment of personhood, and connection with others with primary LLL.

Ongoing concern from parents. The narrators' parents may remember more details about their early experiences with swelling than they do. They are the primary individuals in their lives with whom they share their whole lymphedema-life history and who remember their

limbs before they swelled. Moreover, lymphedema "happened" to their parents, as well, and they have their own stories to share. The experience of participating in this study stimulated three of the narrators to co-reflect with parents about their early days with lymphedema. The narrators believe they matter to their parents and that they understand their burdens.

Arlo was intentional about co-reflecting with his mother upon the tensions that self-management created for them. The stress they experienced is consistent with the findings of scholars who have conducted qualitative research about parenting children and adolescents with primary lymphedema (Hanson et al., 2018; Murray & Moffatt, 2010; Todd, 2002). Arlo also realized that his mother kept her feelings to herself when he was a child to avoid adding to his burden. Arial and her mother visited about their experiences seeking a diagnosis. Her mother wondered if she was to blame for the swelling, consistent with concerns expressed by participants in the study by Todd et al., (2002) about parenting children with lymphedema. Abie was able to reflect with her mother about her frustration and grief over Abie developing yet another chronic disease. It mattered to Arial and Abie that their mothers shared their feelings with them.

The narrators believe that their parents advocated for them when they first swelled to the best of their ability, and it mattered to them still, as adults, that their parents showed ongoing interest in their lymphedema. Audra recognized how challenging it was for her mother to press for a diagnosis against the constraints put up by their health maintenance organization. Arlo remembers the ferocity with which his mother demanded the physician's immediate attention when they arrived unannounced at the clinic. Abie appreciates that her parents stood up for her when a surgeon challenged her capacity to overcome her chronic conditions to become a physician. Anya remembers that her parents kept returning to their primary care provider about

her swelling. Arial remembers searching for answers about her swelling with her mother at bookstores, the library, and on the internet. These experiences reflect the challenges encountered by other participants in the literature when searching for a diagnosis and treatment (Moffatt, Aubeeluck, Stasi, Bartoletti, et al., 2019; Moffatt & Murray, 2010; Todd et al., 2002).

As the narrators transitioned to adulthood, their parents relinquished responsibility for the pursuit of diagnosis, treatment, and/or self-management. However, they continue to communicate to their children that they still "see" their burdens and that their burdens matter significantly to them. Abie's mother continues to offer welcome help with negotiating the health care system and facilitating her transition to college. Arial's mother acknowledges her feelings about how her leg appears. Anya's parents express interest in her new diagnosis, treatment, and self-management prescriptions. She appreciated their concerns about the discomfort of her swelling throughout her life, but now, she indicated lovingly, they annoy her with nudges about wearing her compression garment.

Arlo and Audra have been managing their lymphedema independently for decades, but they still appreciate the interest their parents express. Audra was surprised to learn that, a few months before our conversations, her mother directed inquiries regarding her lymphedema to Audra's partner. It seemed to matter to Audra that, though she was an adult, her mother still thought and inquired about her lymphedema. Arlo and his father encourage each other regarding care for their lymphedematous legs, and they enjoy the "lymphie jokes" they share, such as "snakes don't bite me because they'll get a watered-down drink!"

Partner acceptance and acknowledgment of burdens. The narrators with long-term, intimate partners, emphasized the value of their partners' acceptance and acknowledgment of the physical and emotional burdens of lymphedema. For the narrators with committed relationships,

a feeling that their partner accepts their lymphedema matters more than acceptance from others. Accepting their lymphedema means finding them attractive despite the appearance of their limb(s) and understanding how their lymphedema shapes who they are and how it affects their lives. The narrators expect their partners to balance acknowledging with ignoring lymphedema, and not letting caretaking behaviors dominate the relationship.

Helping with self-management, learning about the disease, and participating in appointments were partner behaviors that demonstrated care to the narrators. For example, Audra's partner participates directly in her self-management tasks occasionally, though she bears the bulk of the responsibility. He travels with her to lymphedema-related conferences and events when his work schedule allows, and he participates in some sessions so that he can learn more about the disease. Anya has not been married but involved in several long-term romantic relationships. She described variances in how men engage with her regarding her lymphedema—some too focused on her swollen limbs, while others ignore them. It matters that her partners acknowledge her lymphedema burden, but not so much that discussion of her limbs dominates the relationship. She especially appreciated the partner who rubbed her feet at the end of the day. What better way to demonstrate acceptance than to lovingly touch her swollen feet?

Arial enjoyed sharing that her partner demonstrated his understanding of her emotional burdens by privately joking about a brochure containing images of attractive models wearing compression garments. She believes that he understands how wearing a compression garment interferes with feeling feminine and beautiful. She was overcome with emotion when describing that, on a birthday card, he wrote about her strength in navigating her chronic conditions. His actions were especially important to her because she realizes that, at times, she probably annoyed him by "whining" about her swelling and having no diagnosis. Arlo indicated directly that his

partner's acceptance matters more to him than the acceptance of anyone else. Her acceptance, he believes, has made it easier to expose his limbs in public.

Children's awareness of lymphedema. The narrators felt their children's understanding, and awareness of their burdens mattered. As their awareness and understanding grew, they adopted care-taking behaviors to help with those burdens. Arial shared that her boys expressed that her foot looked different from their feet and openly observed the "puff" on her foot, sometimes exploring her foot with their hands. Arial reported that she learned that her teenage daughter asked other family members about her lymphedema to try to understand it and what it meant for her mother. Anya's daughter, just entering her teen years, expresses concerns about her physical burdens. However, most important to Anya is that her daughter seemed to recognize her emotional burdens when she encourages her to dress up and look her best so that she can feel good about herself.

Arlo's family presents a unique situation since his father has lymphedema, and the children are aware that they, too, could inherit the condition. Arlo chuckled when he described the attitude of his younger children, sharing that his lymphedema seemed to be of no more concern to his children than a dental cavity. His older children, in their teens, enact that his burdens matter to them when they remind him to elevate when possible and to avoid scratches and insect bites. However, Arlo takes care to limit their focus on "Dad's legs! Dad's legs!"

Acknowledgment of personhood. The narrators appreciate the authentic interest in their disease and recognition of burden by others, but it matters that others first acknowledge them as persons. For the most part, with the disease hidden beneath pants, the public does not see the burden of lymphedema. The narrators did not welcome attention to their lymphedema in all circumstances, especially when the focus dominated relationships. All the narrators indicated

that, though they want the people they care about to recognize the burdens of their lymphedema, they also want them to view them holistically and to respect their boundaries. Once they feel acknowledged as a person, they may share their burdens to help the person to understand the choices they make to achieve physical and social comfort.

The narrators shared stories about people to whom they felt their emotional and physical burdens mattered. Abie shared photographs of her school friends who organized activities in which she could participate while wrapped in bandages. She saw their actions as unselfish and believed that their friendships were more important than the events they could have done without her. Anya was particularly appreciative of a long-time friend who has been a sounding board for her frustrations and struggles for diagnosis and adjusting to chronic disease. Anya believes her friend understands her burdens and appreciates that she can put her lymphedema aside and focus on having fun. Audra appreciated the authentic interest of her cycling coach, who queried her about her leg privately.

Arial shared that her sister-in-law seemed to understand her hesitation about exposing her lymphedema on the beach. Nevertheless, she encouraged her to go with her to enjoy the sand and surf. Once they were at the beach, her sister-in-law stood up for her when others were staring. Her actions demonstrated to Arial that her company mattered more than how her lymphedema appeared to others. Arial also relayed that she explained to a mother at her son's school that she did not wear shorts because of her lymphedema. Arial felt that the friend was empathetic, and she believed that disclosing her lymphedema strengthened their relationship.

The narrators offered examples of unwanted attention that foregrounded their lymphedema over who they were as people. Abie shared that a group of friends at college appointed themselves to look after her and did so intrusively using a digital app on their mobile

devices. She received their interest as overbearing and inappropriately threatening to her boundaries. She drastically decreased the time she spent with her friends and severed the digital connection that enabled them to track where she was, and the situation was resolving. Audra felt resentment toward co-workers because she suspected they talked about her leg behind her back. Her suspicions interfered with authentic relationships with her co-workers. Her preference would have been for them to speak to her directly about her lymphedema. By the time she scheduled herself for decongestive therapy, she already felt so resentful toward them that she preferred not to discuss her situation with them at all, claiming "it was none of their business."

Connecting with others with PLL. Living with rare primary LLL can be a lonely experience, and the opportunity to connect with another person with the disease, face-to-face, is precious. The element of joy and instant connection the narrators and I experienced during our work together is evidence that no one recognizes the burdens of primary LLL like another with primary LLL. Concerns that may seem like "little things" to others are "big things" to us. We were able to talk about those things without fear of seeming superficial or petulant. It was as if being present with one another, even if only by video conferencing software, was a valuable exchange of energy on a secret channel of communication. The opportunity to connect with people with other types of lymphedema at support groups and in medical waiting rooms and/or to connect online abound. Those connections are not as valued by the narrators as a face-to-face connection with someone else with primary LLL.

I was the first person with primary LLL that Abie, Anya, and Arial had met face-to-face, and Audra and Arlo have met only a few. All expressed appreciation for the opportunity to talk about their lymphedema with me. Numerous times they would share something, followed by "you know?" They used the phrase to signal common knowledge that needed no explanation.

The recognition of shared understanding about our burdens was so compelling that we often veered off-topic to talk about the practical aspects of living with lymphedema. Our shoe talk—what it feels like to shop for shoes at a store, the frustrations of finding stylish shoes that fit, how the shoes we wear may dictate what we do or how others view us—is not something that we experience harmonically with someone who does not have primary LLL. Sometimes, we talked about the practical aspects of self-management. Audra and I shared a moment about choosing the color of our night-time garments for our legs, laughing when we realized our conversation seemed silly—her choosing pink to "look cute" and me, choosing purple, like Barney, the dinosaur (https://en.wikipedia.org/wiki/Barney_%26_Friends). Without saying so, we shared understanding that being able to select the color of our garments when we had little choice about having lymphedema was anything but silly.

I asked the narrators if they believed it would have made a difference for them to meet a person who had primary LLL when they were younger. All agreed that it would have been good to have felt understood by someone else with the disease, to be part of a community who shared the condition, not to feel so isolated and invisible, and "different." Audra, between tears, demonstrated the value of connection when she shared that she met a woman in the waiting room of a surgeon, a year or so after she developed lymphedema. The woman, who disclosed her lymphedema, also shared that she was a wife, mother, and schoolteacher. The sense of relief that Audra felt after learning that the devastating diagnosis of lymphedema need not cost her everything that mattered to her, as she began her adult life, was profound, and her sense of loneliness somewhat assuaged. Perhaps this experience motivates Audra now to travel across the country to meet others with lymphedema during advocacy events and conferences.

Though all the narrators had spent time viewing websites dedicated to lymphedema, none seemed to invest much time viewing related Facebook groups, or Twitter and Instagram feeds. Arlo stated that he did not expect to learn much more from Facebook groups than he already knew but appreciated a group focused on shoes. Anya shared that she was surprised to see so many Facebook groups devoted to lymphedema. Only Audra tuned in to blogs about living with lymphedema. She shared that the content she found at *The Lymphie Life*, the blog produced by Alexa, resonates with her.

Mattering to Healthcare Providers

The narrators first experienced swelling between five and thirty years before participation in this study in the later part of 2018 and early part of 2019. In 2004, Rockson and colleagues reported that most U.S. medical schools devote only one-half of an hour of the curriculum to lymphatic diseases. Moreover, he claims, some physicians respond to lymphedema with misdiagnosis, mistreatment, and dismissive attitudes. At the very least, physicians should be able to offer an accurate diagnosis and refer to a therapist for treatment, even non-specialists (Rockson et al., 2004; Mortimer et al., 2018). Further, Stout et al. (2013) reported that America had yet to develop a framework to support people with lymphedema. All narrators expressed concerns about the way physicians addressed their lymphedema and lack of support from the healthcare system. Their stories shed light on nuances in the theme of Mattering to Healthcare Providers, including life-altering delays mattered, feeling dismissed lingers, message received: "self-management does not matter," and collaborative relationships matter.

Life-altering delays mattered. The narrators shared stories that indicated that the American healthcare system failed them in some way, giving them the impression that their lymphedema, nor the emotional, social, and physical toll of the disease on their lives matter.

Moreover, to the narrators, delays in medical diagnosis and/or adequate treatment for their lymphedema affected their lives significantly—even altering the trajectory of their lives. After diagnosis, the narrators struggled within a healthcare system that was minimally prepared to serve people with primary LLL. They experienced treatment delays for infections, unnecessary and costly diagnostic studies, and few resources to which they could turn for answers and support, affecting the overall quality of their healthcare experiences and their lives.

The state of medical knowledge and the availability of lymphedema services in the historical and geographical context in which the narrators developed lymphedema shaped their lives in ways that mattered. For example, Arlo's physician established a diagnosis in 1987, a decade before Ko et al. (1998) published the first article in an American medical journal about decongestive therapy (MacDonald, 2006), a treatment modality newly adopted in America. A contextual factor that likely facilitated early diagnosis is that his father was known to the physician to have primary LLL. Audra's swelling began in 1995 when she lived in a large city with a university research hospital where she could seek a valid diagnosis. Though physicians diagnosed them early during the disease, treatment by therapists was inaccessible, and compression garments were distressingly unsightly and uncomfortable for much of the time following their diagnosis, affecting their young lives in ways that mattered. In contrast, Abie was promptly diagnosed in 2014 when she lived in a large city where decongestive therapy was convenient. Abie's diagnosis and initiation into decongestive therapy and compression went optimally, and her self-management options, including a pneumatic compression pump, were conducive to mitigating the intrusion of self-management on her life.

The American healthcare system failed Anya and Arial inexplicably and egregiously. They remembered their limb(s) swelling first in 1998 and 2001, respectively. At the time, they

lived near a large city that was just beginning to offer lymphedema therapy. Regardless, with the recognition that swollen limbs mattered, and persistence, their providers could have pressed against the constraints of medical insurance and referred Anya and Arial to other physicians. Had they done so, Anya and Arial might have been diagnosed early and offered self-management. The healthcare system continued to fail them as they received care in clinical agencies many times over the years. To the best of their recall, not one medical professional, *of any type*, followed-up on the swelling observed when conducting standardized assessments of the pulses in their feet and ankles during hospitalizations. By the time physicians established a diagnosis, they had been suffering physically and emotionally for well over a decade and a half, and their disease had progressed significantly. Both Anya and Arial wonder how their lives might have unfolded differently had they been diagnosed when their swelling began and believe that early diagnosis would have mattered to the course of their disease. Looking down at her feet, Anya thinks about the lost years of treatment and sometimes feels hopeless, realizing that getting her lymphedema under control has become formidably complex and challenging.

The narrators' stories provide support for the concerns projected by Moffatt et al. (2019) that, even in contemporary times, two decades after the problem was first identified in the literature (Todd et al., 2002), a poor understanding of the epidemiology of primary lymphedema compounds the suffering for children and their families who require accurate diagnosis, genetic screening, and appropriate treatment. In a study conducted in 2019 with 26 parents from several countries, Moffatt, Aubeeluck, Stasi, Bartoletti, and colleagues report that parents of children with primary lymphedema found the journey to diagnosis and treatment to be complicated. Their finding reflects the experiences of parents who participated in studies in the two decades after the turn of the century (Moffatt & Murray, 2010; Todd et al., 2002), and adult participants with

primary lymphedema living in the United Kingdom (Waters, 2009, Williams et al., 2004), and in the United States (Bogan et al., 2007).

When four of the narrators first sought answers for their swelling, lack of healthcare provider familiarity with primary LLL resulted in misdiagnosis and, and sometimes, mistreatment and/or delayed treatment. Providers treated three of them with diuretics though they exhibited no symptoms of a systemic problem indicating need. Diuretics have limited benefit in primary lymphedema involving only lymphatic vascular insufficiency (Rockson, 2018c). Diuretics came up repeatedly for some of the narrators in emergency departments and provider offices, requiring them to assert their understanding that the medication was ineffective for their condition. Lack of provider familiarity with primary lymphedema was also evident in urgent care clinics and emergency departments when three of the narrators sought evaluation and treatment for an infection. They had to emphatically and repeatedly state that lymphedema caused their swelling, rather than another condition, and sometimes to no avail. Consequently, treatment for their cellulitis was delayed by expensive diagnostic studies to rule out other conditions, and their experiences were fraught with confusion and frustration and prolonged fear about their infections worsening while they waited for treatment.

Feeling dismissed lingers. The narrators, at some time or another, felt dismissed by physicians, science, insurance providers, and the U.S. healthcare system. I repeat part of the quote by Flett (2018) that just as intense as mattering, "is the feeling that you don't matter" (p. 3). Consistent with this quote, feeling dismissed was hurtful for the narrators. The messages they received from their physicians was that the swelling did not matter. Their feelings of neglect and marginalization are consistent with those of participants in other studies (Bogan et al., 2007; Waters, 2009) and stimulated feelings of anger when talking about their experiences. Feeling

dismissed lingers and seemed to generate a sense of mistrust about the healthcare system providing for their needs in the future.

Audra was the first narrator to use the word "dismissed" to describe her feelings. As one example, she and her mother suggested to a surgeon, who performed her groin surgery, that the surgery might have caused her swelling. Her perception was that the surgeon did not consider, even for a moment, that he might have inadvertently caused her lymphedema by damaging her lymphatic nodes. Audra felt the surgeon dismissed her concern as if none of what was happening to her mattered to him. Twenty-six years later, she still feels angry about her visit with the surgeon. Anya and Arial agreed that Audra's word "dismissed" described how they felt about physicians who offered no explanations for their swelling nor offered to refer them to someone who could. They felt like their providers did not care about them as people.

All the narrators were aware that primary lymphedema had not received as much attention as secondary lymphedema in the research, medical, and lay communities, contributing to feeling dismissed as a group of people with a particular condition. Arlo, the narrator with the most extensive experience with lymphedema, was strident in his message that science should invest according to a disease's effects rather than how many people have a condition. He feels that science has devoted attention to other diseases that are rarer than primary lymphedema and/or impose less on people's lives. Arlo realized that his childhood understanding that the disease was incurable resulted in a feeling of being dismissed as a person with an illness that did not matter. Now, feeling dismissed is not just about him and his father, but also, potentially, about his children.

Message received: "Self-management does not matter." Taking cues from their healthcare providers, some narrators came to believe that self-management did not matter much.

They reported that few providers had devoted time to address their lymphedema during office visits. Even after a diagnosis with a chronic and potentially life-threatening disease, unless explicitly requested by the narrators, there were no objective assessments of their limbs or direct conversations about their lymphedema and self-management during office visits. The messages read in the behaviors of their providers were that self-management does not matter and that the providers did not believe that their lymphedema could be better. Their lymphedema seemed not to be a priority for their providers. Based on the messages they received, it seemed that their lymphedema need not be a priority for them either.

Audra pinpointed the issue succinctly when she shared that she did not know she was supposed to wear compression all the time, adamantly expressing, "Deb, you have to understand. They didn't tell me!" Audra was *underwhelmed* with what her healthcare providers taught her about wearing compression, and therefore, she did not understand its importance for preventing progression and cellulitis. In Audra's case, failure of the physicians to educate her or refer her to someone who could provide adequate education almost resulted in the loss of her life due to cellulitis. None of the narrators recalled referral to educational resources, including internet resources, except for Anya, whose physician handed her a brochure to take home and read and emphasized her risk for cellulitis. Her experience supports findings by Deng et al. (2013) that people with primary lymphedema turn more to the internet for information about their disease than their physicians.

Collaborative relationships matter. The narrators all seemed to accept that, due to the rarity of the disease, all healthcare providers do not know everything about primary LLL. With that in mind, they have embraced the idea that a collaborative relationship with a healthcare provider is most likely to achieve favorable outcomes that matter to their lives. Physicians hold

the keys to the gate to treatment and desirable outcomes. Unfortunately, insurance company reimbursement policies that reinforce the "gatekeeper" role may present obstacles for people who are dissatisfied with their provider's attitude regarding collaboration, making it difficult for them to open the gate to therapy and achieve favorable outcomes. The narrators have learned that having collaborative providers matters, and they have begun to assert themselves to find those who are eager to help.

The narrators have all begun to understand what it means to collaborate with a provider. Audra was grieving the retirement of her provider, with whom she felt she had a collaborative relationship and was feeling uncertain about the willingness of the next provider to collaborate. She hopes that her next provider will exhibit a desire to learn and respect her ideas. The others were learning to develop similarly collaborative relationships, including Anya, whose provider affirmed her anger about delayed diagnosis, and Arial, whose provider humbly acknowledged his lack of knowledge about lymphedema and referred her to someone who did. Abie feels confident that collaborative relationships with her providers will enable her to manage her chronic conditions and achieve her life goals. Arlo expressed that he is searching for a specialist who might know more than him about primary LLL and can collaborate with him to improve his quality of life.

Advocating Because *We* Matter

At a collective level, Flett (2018) writes, groups of people can also experience the same reactions and responses to feelings of mattering or not mattering that are felt by individuals. Those in the study all viewed themselves as part of the collective of individuals diagnosed with primary lymphedema. Though none viewed their lymphedema as disabling but instead, as Abie put it, "limiting," they also saw themselves as part of the broader collective of individuals who

experience disfigurement and disability. They…no *we,* want everyone to know that we matter, and acting individually or collectively gives meaning to living with the disease. Their stories shed light on nuances in the theme of Advocating Because *We* Matter, including advocating to increase awareness of primary lymphedema and advocating for others with disfigurement and disability.

Increasing awareness of primary lymphedema. All wanted to help increase awareness about the disease and shared stories about how they were doing so. The internet was offering the opportunity to be part of collective action. Two of the narrators had submitted their personal stories to an advocacy organization, and one was also participating in fundraising events, and even traveling to advocate directly with members of Congress. All believed that disclosing their lymphedema to even one person mattered toward the collective effort of increasing awareness. Rather than living as victims of their fate, they are choosing to help improve the lives of others living with the condition.

Audra noted the underrepresentation of people of color in Lymphedema World activities she attended and wondered if lymphedema does not affect people of color as much as others. Her comments raise visibility about racial dynamics in advocacy events, which may relate to long-known disparities in U.S. healthcare that result from economic, political, social, and psychological processes (Braveman, 2006). She has come to believe that her positioning offers her a unique opportunity to make a difference for others in ways that matter. She shared her plans to develop a platform to educate others, from her perspective of living with lymphedema as a woman of color.

Narrators believed they could teach their healthcare providers about primary LLL and that by doing so, in turn, might help others with the condition. Their confidence in doing so

seemed related to how long they have been aware of their diagnosis. I noticed that Arlo emphasized the word "primary" when talking about his disease, likely something he was used to doing with health professionals to distinguish the condition from the more commonly known secondary lymphedema. Audra's advocacy activities were helping her to develop comfort in explaining the condition. Abie, with her background in biological sciences, was confident in her ability to provide essential descriptions of the disease. Anya and Arial indicated they were beginning to share their stories with others and felt more comfortable doing so, now that they had a medical diagnosis. Both were still relatively new to the diagnosis and, sometimes, found it was easier to tell people to "google it!"

All indicated that they participated in this study because they believe the story of growing up and living with primary LLL needed telling to increase awareness among healthcare providers. They hoped that by telling their stories of grievance with the healthcare system, they would make a positive difference in the journeys of other people who have the disease. According to Weitz (2017), individuals are most likely to participate in health social movements when they come to believe that medical authorities have failed to protect them from diseases, to identify their diseases, or treat their diseases appropriately.

Advocating for people with disfiguring and disabling diseases. The narrators saw themselves as advocates for others with disfiguring and disabling diseases, who were less fortunate than themselves, reflecting their tendency to use downward comparisons (Meltzer & Rourke, 2006) as coping strategies. Their use of this coping method is typical of young people with chronic illness and disability (Meltzer & O'Rourke, 2006) and reflects research findings about living with primary lymphedema (Bogan, et al., 2007; Hanson, et al., 2018; Waters, 2009).

Their acts of advocacy took various forms that they believed might make a difference for others in ways that matter.

Downward comparisons also seemed to function to disavow their right to feel bad about their condition. For example, Arial shared, "There are people that have worse things wrong, and then I feel bad, 'cause then, I'm like, why am I worried about, you know, I don't know." Her comment aligned with the other narrators' comparisons to those who are less fortunate, and they were grateful that their situation was no worse than it was. Specifically, they compared themselves to people with advanced lymphedema and people with mobility concerns.

Each shared at least one story about feeling stigmatized for how they looked or for having a disease, and they indicated that they believed their experiences sensitized them to the plights of others with stigmatizing diseases. Abie wrote in her college entrance essay that her experiences had shaped her desire to become a physician so that she can help others live well with chronic conditions. The narrators who are parents shared ways that they taught their children to stand up for people with body differences. Arlo explained,

> *When we describe people, we don't describe them by color, by diseases, by whatever. I don't feel like we need to label each other like that to describe somebody. I feel like I've taught them enough to know that bad things do happen to people.*

Arlo teaches his children to look beyond appearance and disease to the person embodied. Arial shared a story about confronting teenagers who were making fun of her swollen limb in the presence of her husband and young boys. Apparently, for Arial, her action was no small act of resistance toward the sense of stigmatization that she had been experiencing. She explained, "I mean, in a way, it didn't bother me, but in a way, it did because I didn't want my kids to see that."

As this theme emerged in the data, I began to wonder why narrators believed so strongly that they are in a position to advocate for those that they perceived to be less fortunate than themselves. I conclude that with our disfigurement safely hidden beneath our pant legs, we roam this earth amongst the well-figured and -abled but with the kind of hurt in our hearts that we believe others less fortunate than ourselves also carry in theirs. The source of our pain is hidden, but not theirs. Discreditable, but not yet discredited (Goffman, 1963), we advocate for those who cannot hide and are at higher risk for stigmatization.

My Legs Matter to Me

The narrators in this study are beginning to feel various levels of acceptance about their lymphedema and compassion for themselves. They were intimately familiar with the characteristics of their particular limb(s), though they did not always understand what those characteristics meant. At different points along their journeys with the disease, they began to enact an understanding that prioritizing care for their limb(s) matters to how they will live the rest of their lives. In addition, they were beginning to understand how their lymphedema affects the lives of their loved ones, in ways that matter. They make room for lymphedema care in their lives, in their own ways, while striving to assure that lymphedema does not take away the lives they want to live.

Regardless of their situation with the disease, each of them has their own "really real" of lymphedema and what matters to them about the condition. They based their "real" primarily upon what they can see and feel about their swollen limb(s) and the interaction of their limb(s) with materialities (compression garments, pumps, clothing, etc.) and the environment (temperature, humidity). They used the terms "hard" or "soft" when describing the tension of their skin on their shins, "puffy" to describe mounds on feet and toes, "rough," "ashy," and

"flaky," to describe their skin. They used the impressions their shoes left on their skin, girth (measured with their hands) of their calves, the fit of their shoes and pants as outcome measures for "good days" and "bad days" (Charmaz, 1991)—their outcome measures for self-management. They seemed adept at anticipating the days when they would be uncomfortable—their limb(s) "heavy" or "achy" and planned accordingly. What is real to them changed as their disease progressed, and they developed a more in-depth understanding of the pathophysiological processes occurring within their skin.

They remember what their limb(s) were like before swelling, and sometimes viewed the disease as a malevolent entity that "took away" or "stole" their real limbs. It also stole various tangible and intangible aspects of life they might have enjoyed. It took big things such as occupational opportunities, athletic achievement, and confidence in body image and overall health; it took small things such as "cute" high heels and spontaneous outdoor play—all things that mattered to them. It took away the life the young narrators anticipated for themselves and even changed the trajectory of their lives. All the narrators expressed some anger about the "fault in their stars" that gave them lymphedema. They cope with faith, family support, downward comparison, and directing their energy toward living and assuring lymphedema "doesn't take everything." For the most part, they keep their anger tucked inside and go on with life, despite their lymphedema. Each has developed some resignation to the stare of others and the requirement for self-management. They try not to let their condition matter so much that it dominates their lives. In other words, as Audra says, "I have lymphedema, lymphedema doesn't have me!"

Complexities, Complications, and Confusions: Difficulties along the Journey

In *Lives in Context,* Cole and Knowles (2001) use the phrase "complexities, complications, and confusions" (p. 11) to capture the notion that life histories consist of numerous expected and unexpected difficulties with which humans must grapple along their journeys. In this part of the chapter, I present sets of inductively derived themes about the difficulties with which the narrators grappled along their journeys related to lymphedema. Then, I use the terms offered by Cole and Knowles as conceptual anchors for deductively categorizing themes, serving as a meaning-making device for understanding the lives of the narrators as they walked, talked, learned, and worked in context. I begin each section by describing the conceptual linkage of the findings within each category of the themes.

Complexities: Self-managing amidst Life

In this section of the chapter, I discuss nuanced findings of the complexities of *living with* lymphedema. Norman (2010) defines complexities as intricate and interrelated variables that serve as obstacles to successful self-management of disease. Ostby and Armer (2015) published findings from a literature review about the complexities of self-management, adherence, and barriers to adherence for women with breast cancer-related lymphedema. Several factors they identified are relevant to this study. In this section, I discuss findings of the complexities in their journeys, including the complexity that lymphedema adds to already complex lives, "articulations" with other conditions, putting lymphedema on the "back burner," acknowledgment of complexities by therapists, and formal accommodations for school and college.

Lymphedema adds complexity to complex lives. As noted previously, the narrators fulfill life roles that matter significantly to them. They looked forward to these life roles as they

grew up, claimed them, and enjoy them. The roles they fulfill come with complexities to manage, and from time to time, doing so is challenging, notwithstanding their lymphedema. Managing complexities requires time, energy, and/or financial resource budgets that, for some of them, are already stretched to maximum capacity. Those associated with lymphedema—decongestive therapy and self-management—push the limits of their budgets even further. Here, I emphasize the complexities of scheduling therapy sessions and managing costs.

Scheduling therapy sessions and integrating them into their day for an extended amount of time seemed extraordinarily complicated and viewed as prohibitive by some. Therapy session appointments are typically available during business hours. Audra, Abie, and Anya were able to schedule their sessions around their school and work schedules, but they experienced their therapy days as stressful. Audra described a day with treatment: Pack a change of clothes and toiletries, go to work wearing bandages, unwrap and shower after arriving at the physical therapy clinic, and re-roll the bandages before therapy. By the time her therapy session was over, and she drove home, she felt exhausted. Abie and Anya described similar experiences. Abie also shared that after therapy, and before school the next day, she still had to complete the school work that she missed. Anya still had to care for her children. Both shared that they first began experiencing panic attacks while in decongestive therapy.

Arlo and Arial viewed the demands of therapy on their schedules with their children as prohibitive. Their partners were not available to take up child care responsibilities since they worked hours that coincide with those of therapists. Arlo and Arial believed that placing their children in others' care would significantly affect their children's lives or impose substantially on the individuals providing care in their stead. They also expressed concern about how they were going to manage their responsibilities if committing a significant chunk of time to therapy.

The other complexity I highlight as prohibitive is the costs of therapy and self-management tools. Even though medically insured, paying for treatment was a significant challenge for some and, ultimately, was a determining factor in initiating or completing decongestive therapy. For example, Arial indicated that she could not return for treatment until she paid for her consultation with the therapist, out-of-pocket. Anya's therapy experience was prolonged while she purchased her bandaging supplies because her insurance would not cover them. After some time in therapy, with co-pays for each session, she had to "cry uncle" because she could no longer prioritize her funds for treatment.

Paying for self-management tools was also challenging for Anya and Arial. I was surprised to hear that Anya used her tax refund to pay for the alternative compression garment her physician prescribed. Her medical insurer might have covered most of the cost of the expensive garment but probably only after multiple decision appeals. Arial felt that the garment the therapist prescribed was too expensive and did not file for reimbursement from the insurance company. Her insurance might have covered a large portion of the cost of the garment. Neither Anya nor Arial seemed clear about what their insurance companies would cover related to their lymphedema. They indicated no physician's office, medical supply company, or therapists' clinic offered to help with insurance reimbursement.

"Articulations" with other conditions. The narrators negotiated other chronic conditions alongside primary LLL, increasing the complexity of living with the disease. Their experiences align with the finding of Ostby and Armer (2015) that other chronic conditions increase the complexity of lymphedema self-management for breast cancer survivors. Abie, who developed multiple autoimmune diseases and lymphedema by age 13, presented a nuanced view of her experience with chronic illness. Borrowing from the animated musical fantasy produced

by Disney, *Hercules* (Hercules, 1997. Retrieved from https://en.wikipedia.org/wiki/Hercules_(1997_film), Abie frames her multiple conditions as "hydra," after the serpentine water monster that regenerated its ugly heads. She explains that all her autoimmune diseases, like the "hydra" of the water monster, articulate to affect the others requiring a Herculean effort to manage them effectively. Her metaphor works well as a frame for the experiences of others in the study—all of whom have multiple conditions that interact to make decongestive therapy and/or self-managing lymphedema complex.

One example is RA, which causes pain and stiffness of the joints, challenging the ability to don and doff compression garments and, when flared, increasing edema. Arlo explained that this process becomes difficult when his RA flares and his shoulders become stiff. Anya experienced a back injury that affected her balance. Consequently, her decongestive therapist asked her to use a walker during treatment to prevent a fall-related injury. This meant she needed to arrange for handicapped parking and an alternate way to carry her belongings. Her back pain also made it difficult for her to find a comfortable position for elevation.

Anya and Arial alluded to having difficulty with prioritizing family funds for lymphedema therapy and compression, instead of their need to address painful medical problems. They explained that these conditions affect their abilities to fulfill their life roles in the present and, thus, are a priority to address, rather than the long-term, future consequences of lymphedema. Anya, responding to the more urgent messages her physicians were sending, expressed concern that her obesity and related diseases, hypertension, and sleep apnea will lead to life-threatening heart disease. Overwhelmed, she did not think that she could address all her conditions at once. As another example of complexity, between our conversations, Arial learned about an unexpected, but beautiful, life complexity—she was pregnant! Edema is a common

manifestation in pregnancy that increases lymph load (Muzaffar, Hussain, & Harroon, 2013). With impaired lymphatic drainage, pregnancy may worsen lymphedema.

Keeping lymphedema on the "back burner." The narrators in this study found adherence with prescribed self-management practices to be a significant challenge, given the complexities of their lives. Consequently, at some times in their lives, most kept their lymphedema on the "back burner." Their experiences align with those of others with primary lymphedema (Bogan et al., 2007; Deng et al., 2015). For those of us in the health profession, who understand the mandatory nature of self-management for preventing the progression of lymphedema, it may seem that the narrators' lives intruded upon self-management for lymphedema. This data suggests it goes the other way: therapy and self-management intrude upon already complex lives, and, as Anya put it, she had to put lymphedema on the "back burner."

At some time in their lives, all but Abie had suppressed any sense of urgency that they might have about self-management, in deference to competing priorities for their time, energy, and financial resources. When queried gently about sub-optimal self-management, their explanations centered on other priorities, not liking the look and feel of their compression, and not understanding why it is essential. I note that Abie, unlike the others, was blessed with opportunities for decongestive therapy and comprehensive education, comfortable compression, and a lymphedema pump while still in the first stage of the disease. The other narrators have lived many years without the same opportunities, and their condition has progressed.

Arlo is very aware of what further progression may mean to him and his family. He questions whether the burden of decongestive therapy and optimal self-management is worth the reduction in symptom burden he might achieve, explaining,

Of course, my legs could be a little smaller. But like we said, it's just gonna go right back up. It's good enough for right now, and it would be unfortunate if things happened in the future, but I'm not usually one that thinks about the future as much. I kinda just live for the now, and that's a good thing and a bad thing. This is the catch 22 with it. You either have that choice of staying off your legs 24/7 or trying to live a normal life. That's the problem. You shouldn't feel ashamed of it.

Arlo accepts responsibility for his decisions about leaving optimal self-management on the back burner while wearing marginally effective over-the-counter compression and taking extra time to elevate his legs whenever they feel uncomfortable. He also expresses self-compassion for choosing to live a "normal" life and that his lymphedema is "good enough for now."

Acknowledgment of complexities by therapists. The standards for effective therapy, established by the Lymphology Association of North America, were challenging for the narrators to accommodate in their complex lives. When lymphedema therapists connected with these realities, the therapists became valuable resources to living well with lymphedema. Therapists must balance the "inconvenient truth" (Effective CDT – LERN, n.d. Retrieved from https://klosetraining.com/2018/05/18/effectivecdt-lern/) that practicing according to standards is the most effective way to reach optimal decongestion for their clients with the inconvenient complexities in their client's life. If the client and therapist fail to collaborate effectively to negotiate these complexities and achieve coherence regarding their goals for therapy, the client may disengage from a valuable resource for managing their lymphedema.

The approach a therapist uses with clients could make or break the therapeutic relationship. Though Anya's second therapist was attempting to practice according to standards, Anya could not adhere, and she discontinued therapy, feeling negative about her relationship

with the therapist. On the other hand, her first therapist, acknowledging that Anya was unable to afford bandaging supplies, treated her as best she could while waiting for Anya to purchase her supplies, little by little. In the meantime, during sessions with the therapist, Anya learned more about her lymphedema. Though Anya discontinued therapy with the first therapist before acquiring all her bandages, she was eventually ready to return to treatment with a positive attitude. In Anya's case, then, it seems that some therapy, though not optimal and aligned with the "inconvenient truth," was better than no therapy, and left her open to further treatment whenever she could gather enough resources.

Some therapists offer more than hands-on therapy and extend their service to coaching the client to help them problem-solve the complexities of self-management and insurance reimbursement. For example, Abie's therapist was instrumental in assisting her in obtaining a lymphedema pump so that she could better integrate self-management into her busy, active life. Together, Audra and her second therapist evaluated the reasons she was unable to adhere to self-management practices after her first experience with treatment. Consequently, they decided to pursue a convenient and comfortable night-time compression garment instead of self-bandaging.

Formal accommodations for school and college. Academics and self-management can conflict. The complexities of lymphedema may result in a child or adolescent having difficulty complying with school policies and procedures, especially when decongestive therapy is needed. Abie's case suggests that formal accommodation can help manage the complexities of school and college if necessary.

Abie's stories emphasized the frustration she experienced with meeting expectations to adhere to school policies and procedures during decongestive therapy. When she and her parents became concerned about some teachers' treatment of her, they negotiated a 504 plan to protect

her opportunity for the highest level of achievement in school. The plan made exceptions for absence for medical appointments, turning assignments in late, and allowed her to wear sweats or shorts, and alternative shoes with her leg bandages. Findings by scholars (Harding, 2012; Murray & Moffatt, 2010; Todd et al. 2002) who studied the experiences of children with primary lymphedema suggest that school experiences may be attributable to lack of teacher understanding about the physical and psychosocial effects since it is rare.

Transitioning to adulthood may challenge self-management practices (Hanson et al. 2018). Abie and her mother, giving careful consideration to what might help her self-manage successfully at college, decided to negotiate another 504 plan. Her plan gave her priority enrollment to ensure adequate time for walking between classes. Additionally, the housing authority assigned Abie to a dormitory that provided a private bedroom in which she controls the thermostat. Her accommodations allow her to use her lymphedema pump comfortably and privately. Finally, her accommodations will enable her to stand for short periods during long testing and/or utilize the testing center.

Complications: Disruption and Transformation

In this section of the chapter, I discuss the strand of themes related to the complications the narrators experienced during their lives related to their lymphedema, biographical disruption and transforming brushes with cellulitis infections. Cole and Knowles (2001) describe complications as unexpected situations that cause life to be challenging. Central to the stories of all the narrators, unexpected swelling in their limb(s) was a biographical disruption that changed their lives forever. Three experienced one or more cellulitis infections that disrupted their day-to-day lives for a time, leading to transformational changes in their perspectives about self-management and/or risk-reduction.

A biographical disruption. Changes in the appearance of their limbs contributed to a disruption in the narrators' embodied orientation to the world (Engman, 2019), changed their daily habits, and may have even altered the trajectory of their lives. Bury (1982) describes biographical disruption as a fundamental rupture in the fabric of everyday life and the resulting disruption of the narratives about the future that people use to understand themselves and the trajectories of their lives. Researchers have paid most attention to the experience of biographical disruption in adults, with the assumption that a chronic illness acquired early in life is not a biographical disruption because chronic illness is a *part* of biography and self-concept development from a young age. These life histories demonstrate that the development of swelling and/or diagnosis of lymphedema represented a biographical disruption—the disruption occurring during childhood or adolescence.

Arlo's life history provides a clear case of biographical disruption in childhood; the effect that self-management had on his day-to-day disrupted and interfered with the developmental tasks of childhood. For example, Arlo resented the refrain, "Elevate, elevate, elevate," because, as a child, it meant that he could not play outdoors with his friends as much. The disease also disrupted the occupational future he imagined for himself, possibly changing the trajectory of his life. He dreamed of becoming a professional baseball player, but viewing self-management with compression and baseball as incompatible, he gave up his dream. Eight years after his diagnosis, the military rejected Arlo's application. He remembered the experience as a "slap in the face" and "Really? I can't even serve my country?"

Appearance standards required by some occupations can limit opportunities and signal biographical disruption. For example, lymphedema derailed Arial's hopes for a career as a runway model at age 13. All, especially the women, experienced constraints in occupational

pursuit related to appearance standards. For example, in the years when Audra, and then later Anya and Arial, were emerging into adulthood and beginning to look for work, specific jobs required that women wear skirts and heels. Though a job dress code may not prohibit a person from exposing swollen limbs, it is certainly possible that swollen limbs may detract from the job. Moreover, like me, the person with lymphedema may want to avoid attention their limb(s) might attract if exposed. Those in this study exercised their agency by opting for jobs with which they could wear long pants or skirts and avoid attention. They viewed some occupations as impossible pursuits that, without lymphedema, might have been possible.

Self-management competed for time and attention the narrators could have directed toward accomplishing developmental tasks and developing their talents, representing a biographical disruption. Abie shifted her priorities from sports and other extracurricular activities because they might cause harm to her newly vulnerable limbs. Audra, about to graduate from high school when she developed swelling, was focused on achieving the tasks of emerging adulthood, work, taking college classes, partnering, and seeking independence from her parents. Instead, she was compelled to spend her time searching for answers and integrating self-management practices. Her desire to hide her swollen limb affected her job search as well.

Anya experienced biographical disruption differently than the other narrators since she grew up believing that the swelling in her limbs was part of being overweight. As an 8-year-old, she contended with inexplicable swelling of one of her limbs, along with precocious puberty and rapidly developing breasts. These changes increased her self-consciousness and affected the activities in which she was willing to participate. She remembers, at fourteen, her other limb began swelling and coming to accept that her limbs were “big” like the rest of her. She described

receiving a diagnosis at age 26 as a "relief." She also shared that she struggled with adjusting to thinking about her limbs as diseased and treatable, rather than overweight.

Transformative Brushes with Cellulitis. Cellulitis is a common complication of primary LLL (Deng et al., 2015; Okajima et al., 2013; Schook et al., 2011) and for three of the narrators, an unexpected, challenging situation—every time it occurred. The complication of cellulitis had a way of forcing lymphedema off the back burner, at least temporarily, moving them toward changes in how they lived with lymphedema, making big and small changes in self-management practices and risk-reduction.

Audra, Arlo, and Arial reported experiencing one or more bouts with cellulitis, and physicians treated Audra and Arlo in a hospital. They seemed to carry guilt about the disruption of their families' day-to-day lives and the financial costs that resulted from the infections. For Audra, who almost died from cellulitis, this guilt may have motivated her decongestive therapy and adherence to compression therapy. Arlo's experiences with cellulitis and resulting threats of unemployment are consistent with the experiences of participants in other studies (Bogan et al., 2007; Williams et al., 2004) for whom cellulitis impaired ability to work. Since receiving disability, Arlo has practiced marginally effective self-management but elevates more and pays much attention to reducing his risks for cellulitis. He has experienced no cellulitis during the five years since he began receiving disability benefits and believes that his legs are better than when he was working.

Arial, newly diagnosed, is still learning about reducing risks for infection. Though initially very frightened by her episode with cellulitis, she continues to shave her legs with a disposable razor. When Arial described developing cellulitis after shaving and going to the swimming pool, I remembered how my mother cried when she learned that, at age 12, I had used

her razor to remove the fine, sparse, blond hairs from my legs. I did so despite her strident warnings about scarring and risk for infection. I just wanted to look like the other girls in my grade. The history of women removing body hair is steeped in misogyny when looking back at the gender's history of conforming to hair-removal standards. These standards began in the early 20th century with advertisements by Gillette urging women to remove objectionable hair from their armpits. Women started shaving their legs, as well, during World War II when skirts began rising (https://www.vogue.com/article/body-hair-new-generation-not-shaving). For many American women, gendered pressures from entrenched discourses might win out over the risks someone takes with their swollen limbs by shaving with a razor. Arial is exploring alternative ways to remove hair from her legs, is more alert to early signs of infection, and she and her partner feel better prepared to handle subsequent episodes of cellulitis.

Confusions: Lingering Uncertainty about Cause and Heritability

In this section of the chapter, I discuss nuanced findings related to the ways that the narrators experienced confusion along their journeys with lymphedema. Patterns in the narrators' stories indicate that cognitive dissonance (Festinger, 1957) about the cause of their disease lingers for life, and they experience uncertainty about heritability.

Cognitive dissonance lingers for life. The narrators were motivated to pursue answers about their swelling by cognitive dissonance. Festinger (1957) postulates that inconsistent cognitions elicit an aversive state of arousal. In turn, the aversive state produces a desire to reduce the underlying inconsistency and to maintain a state of constancy. After their physicians established a medical diagnosis, the narrators had many questions, and some of them felt that the answers they had received made little sense. Parents of children who developed lymphedema before the turn of the century, such as the experiences of most parents shared here, had nowhere

to turn when the answers they received from physicians about the swelling their children experienced left them confused (Moffatt & Murray, 2010; Todd et al., 2002). As already stated, because primary lymphedema is a rare disease, relatively few healthcare providers hold expertise or experience with the disease. Only a few large American cities boast lymphedema specialty clinics that serve children and adolescents. Consequently, people with primary lymphedema may experience delayed medical diagnosis and sub-par treatment (Bogan et al., 2007).

The narrators' parents experienced systemic and structural constraints when pursuing the resolution of dissonances, such as geographical location far away from comprehensive centers with expertise in pediatric lymphedema. They also may have experienced limiting socioeconomic circumstances, lack of medical capital, restrictive insurance policies and procedures related to coverage, and lackadaisical decision-making by physicians about diagnosis and referral. Taking cues from physicians that the swelling did not matter, Anya's and Arial's parents gave up their search for answers. However, the answers the physicians gave them about their swelling—menstrual-related water retention, old musculoskeletal injuries, a third-degree burn incurred a decade earlier—made no sense to either Anya or Arial. Anya finally accepted the answer that her limbs were big because she was overweight, but it made no sense to her or her family that one limb would enlarge five years before the other. Arial was never confident in the answers she received and continued to search for an explanation.

Audra's cognitive dissonance is particularly distressing since she suspects a surgeon damaged her lymph nodes, causing her lymphedema. Damage to the blood vascular system is a known complication of groin hernia surgery, but not damage to the lymphatic system (Chowbey et al., 2006). However, inadvertent damage to lymph nodes in the area is undoubtedly within the realm of possibility. It is also possible that, based on the blurred boundary between primary and

secondary lymphedema (Rockson, 2018a), her lymphedema was incited rather than caused by the surgery. Arlo struggles with cognitive dissonance about the thorny bush that damaged his skin and wonders if the particular type of shrub incited the disease that was lying in wait to manifest. He often wonders if he would have developed lymphedema, if not for that bush. Taking cues from her physicians, Abie wonders if her lymphedema is somehow related to her other autoimmune diseases.

The rarity of the disease and the vacuum surrounding information about it makes it all the more mysterious and their wonderings were somewhat ineffable. What did they do to deserve this? Faith in God seemed to help Audra, Abie, Anya, and Arial cope with their cognitive dissonance about the mysterious development of their lymphedema and the sense of ineffability that remained. They believed that God would not give them anything they could not handle or that God had a reason that is unknown to them. These sentiments reflect the narrative shared by Bogan et al. (2007) from a participant who indicated he believed that he inherited primary lymphedema from a parent because God knew he could handle it better than his siblings. Arlo, on the other hand, wondered why God would allow something like lymphedema to happen to a child. His way of resolving his "why me?" question was to abandon the faith in which his parents raised him.

Uncertainty about heritability. For those in the study who are parents, uncertainty about heritability contributes to worry and watchfulness for their children. Only in the last two decades have researchers begun to identify the genes associated with primary lymphedema. Currently, scientists have not identified genes for all forms of the condition. By no means, then, can a parent feel confident that they may pass a lymphedema-causing gene on to their children (Mortimer et al., 2018), even if tested. The available genetic testing is expensive and not

reimbursable by insurance. Therefore, the pursuit of definitive answers might be a costly waste of financial resources.

Those who are parents experience substantial worry about whether they could pass their condition on to their children. This concern seemed to be most intense when one of their children neared the same age at which the narrator first manifested swelling. Healthcare providers have not indicated to Anya nor Arial that their children might inherit their disease, nor have they indicated that they would not. Arlo is aware that he inherited it from his father. However, he has not pursued further understanding about the chances that he will pass it on to his children.

Some situations created heightened alarm about their children and resulted in overt and/or covert inspection of their child's legs. Arial shared a time that her daughter sent her pictures with concerns that her feet looked swollen, creating a moment of alarm for Arial. Anya is worried that her daughter, who is approaching puberty, will also develop lymphedema and expressed concern about her daughter's identity development should her concern manifest, saying, "She's just figuring out who she is." Based on his theory that a scratch triggered his swelling, Arlo is intentional about reducing risks for his children.

Lymphie Conundrums: Grappling with Normalizing and Othering

In this part of the chapter, I explore Lymphie Conundrums, the narrators' concerns about stigmatization, rejection, and discrimination, hiding to pass as normal and its costs, and straddling the lymphie conundrum with clothing. I borrowed the term "Lymphie Conundrums," from Alexa Ercalano's post that I covered in the introduction of the study, about the conundrums people with primary LLL sometimes face.

As evident in the theme of "Mattering," the narrators strive to live "normal" lives despite their lymphedema. They viewed their non-normative swelling as making them different from

their peers, as Other. They and/or their peers associated their swelling with common conditions such as old age swelling, lymphatic filariasis, obesity, AIDS, and disabilities that required special education classes. These associations reinforced their constructions as Other. While striving to live normal lives, circumstances often arose that compelled disclosure or exposure of their non-normative limb(s), raising their concerns about rejection and unfair treatment. They learned that, paradoxically, neither concealing nor revealing yields "normal" since there are potential costs associated with both options. Alexa sought reconciliation of the paradox by resolving to avoid the costs of hiding and living life to the fullest, amidst the stares of others.

Concerns about Stigmatization, Rejection, and Discrimination

The narrators, regardless when they developed lymphedema—the 80s, 90s, or into the 21st century—were primed to experience a sense of stigmatization about their swollen limb(s), overlaid on top of the typical struggle to achieve body ideals that are common in Western society. Their swelling occurred as they developed their body image within the sociocultural context, cued by the omnipresent and unremitting messages about body ideals and pressures to conform. The appearance of their limbs prohibited achievement of those ideals, adding to whatever degree of distress that they may have already felt about their bodies. Many adolescents display some dissatisfaction with their bodies, and a high level of body dissatisfaction is a significant threat to wellbeing, which can lead to eating disorders, depression, etc. (Markey, 2010). All in my study indicated that they were self-conscious about some aspects of their bodies (overweight, taller than the boys, etc.), as well as their limb(s), but were also pleased about other aspects. They indicated that, as adults, their overall body image was more positive than negative. None shared that professionals had treated them for disorders related to body dissatisfaction.

By the time they developed swelling—the youngest, eight years old—they were well aware of the stigmatization experienced by people whose bodies do not conform (Smolak, 2011). Stigma refers to the social disgrace of having a deeply discrediting attribute (Goffman, 1963). Some illnesses and disabilities produce relatively little stigma, while visible disfigurement is a factor that increases stigma (Weitz, 2016). Children with visible disfiguration are at higher risk for stigmatizing experiences than are other children (Masnari et al., 2012). Those with physical differences and disabilities are, on average, less liked than their peers (Latner & Strunkard (2003). Congenital or 'acquired' differences negatively impact self-esteem, and compromise social and emotional development and functioning (Rumsey & Harcourt, 2004). The threat perceived by the narrators was real.

All shared at least one critical incident that occurred during childhood or adolescence, and sometimes in adulthood that caused them to feel stigmatized regarding their swollen limb(s) or for having a disease. They attributed decisions to avoid disclosure and exposure, in part, to these incidents. Their choices, in turn, negatively affected how they functioned socially due to worry about rejection. For those exploring romantic relationships, their worry was particularly acute when they expected to expose their bodies. However, with time with a partner, their worry, for the most part, eased. The narrators' stories are consistent with findings by other scholars (Todd et al., 2002; Harding, 2012; Murray & Moffatt, 2010; Waters, 2009; Winch et al., 2016). They indicated their worries about stigmatization and rejection are ongoing.

The only derogatory descriptors the narrators used about their bodies during our conversations surfaced when telling a story that included what they thought others were thinking about them. None used a derogatory term, such as "ugly," to directly describe their limb(s) like the participants in other studies used (Harding, 2012; Murray & Moffatt, 2010; Todd et al., 2002;

Waters, 2009) when describing themselves to researchers. This restraint might be due to a concern about extending their self-stigmatization to me and perpetuating the stigmatization that they have felt from others.

When I was developing this study, I intended to study the experience of young women with primary LLL—based on my perception that body image concerns in this fashion-conscious world might plague young women, in particular. However, Arlo taught me that boys and young men may experience a comparable level of concern. According to Lonergan et al. (2019), young men may be just as concerned with their body image as young women. Jankowski (2016) reported that men appear less likely or willing to disclose dissatisfaction than women, at least not directly or immediately. The feminization of the topic has hindered attempts to gain insights into the experiences of boys and men. It may leave male children, adolescents, and adults with lymphedema at risk of body image concerns, with nowhere to turn for support. It is understandable then that Arlo indicated that he had never talked about his body image issues with anyone besides myself, and the contribution of his stories to the study was a particularly valuable gift. Young men also found the right opportunity with Harding (2012), a researcher who was also their lymphedema therapist, and they seemed to openly share their concerns about how their limbs looked, even using violently derogatory descriptors.

Hiding to Pass as "Normal" and Its Costs

Most of the time, the young adult narrators can obscure their lower limb(s) from public view and they exposed and disclosed judiciously to present as "normal." As they grew older, they came to understand that, when faced with lymphie conundrums, there were costs to hiding for themselves and others. Scholars have found that due to concerns about body image and stigmatization, children, adolescents, and adults with lower limb lymphedema tend to hide their

swollen limbs and compression garments (Bogan et al., 2007; Greene, 2015; Hanson et al., 2018; Harding, 2012; Moffatt, Aubeeluck, Stasi, Mestre, et al., 2019; Moffatt & Murray, 2010, Smeltzer et al., 1985; Ryan, 2003; Todd et al., 2002; Waters, 2009; Williams, Moffatt, & Franks, 2004; Winch et al., 2016). However, little is known about the costs of hiding swollen limbs and/or compression garments to pass as normal.

The size and shape of lymphedematous limbs and/or the appearance of compression garments can be immediately recognizable to others as a person belonging to a stigmatized group—a person with a diseased, non-conforming body—at worst, and, at best, an object of curiosity. According to Goffman (1963), the intention of hiding is to avoid discredit to image and to "pass" as "normal." Adults with stigmatized identities and positionings regularly face prejudice, stereotyping, and discrimination that has a considerable negative effect (Crocker, et al, 1998). Even as a child, Arlo seemed to understand cultural stigma and, like other children and adults with primary lymphedema, he protected himself from stigmatization using clothing and elaborate strategies. The other narrators report doing the same.

All the narrators disclose judiciously, in part because they are unsure how others will respond to their disclosures. The meaning of the terms of illness, disease, and disability are far from obvious in public discourse. Typically, when some think about the terms, they think that something is wrong—a deficit—within an individual's mind or body. Disclosing a disease might result in assumptions about what people can and cannot do, stereotyping them as incompetent and unreliable, and viewing them as "less than," as "Other." Some of the narrators expressed concern that disclosure may result in discrimination in the workplace that occurs against people who are disabled (Katz & DeRose, 2010). However, none reported experiencing those situations.

Exposure for the narrators is a complicated, agentic act—to control what others see of them when presented with lymphie conundrums. They exposed themselves to suit their situations, depending upon the perceived threat of stigmatization and their comfort with the social situation. Controlling what others see of them, depending upon the social scene before them, was incredibly important to them, especially when they were younger. For most narrators, some scenarios were associated with anxiety, especially when they lacked control over how much they exposed or were unsure of others' responses to their limb(s). All believed that they were becoming more comfortable with exposure over time, and some were more comfortable than others. They seemed far more comfortable with exposure to their immediate family members than to others.

Meyer (2003) wrote, "concealing one's stigma is often used as a coping strategy, aimed at avoiding negative consequences of stigma, but it is a coping strategy that can backfire and become stressful" (p. 681). It may result, instead, in reduced wellbeing. Newheiser and Barreto (2014) highlight that concealing (versus revealing) stigma can, ironically, diminish belonging, and impair interactions with others. They explain that feelings of inauthenticity and reduced general self-disclosure lessen a sense of belonging—a cost of hiding. Arlo most strongly expressed his concerns about belonging while growing up but all of the narrators, at some point in time, depending upon the circumstances, coped by concealing. As adults, they acknowledge that the strategy cost them opportunities to live a more fulfilling life. Now that they are adults, they are striving to transcend the lymphie conundrums and minimize the costs of hiding.

I extend this concern of costs to the narrator's family members, especially their children and long-term partners. The narrators who were parents shared emotional stories about opting out of activities because an activity would compel exposure of their limbs. They carried

significant guilt about the choices they made to avoid exposure if they perceived it cost their family members, especially their children. Whether or not these incidents affected their children negatively is unknown. However, the guilt the narrators carried about the choices they made regarding these conundrums added to their lymphedema burden.

Straddling the Lymphie Conundrum with Clothing

Using clothing and shoes to obscure their limb(s) from public view was important to the narrators; they felt intensely frustrated about the task. Their apparel and shoes allowed them to present themselves as normal whenever their clothing was styled appropriately for the occasion. When it was, they were able to avoid the lymphie conundrums. Finding apparel to fit and obscure the view of their swollen limb(s) and look stylish and emphasize their most attractive features was challenging. As their lymphedema progressed to the point that shoes and pants did not fit as readily, the complexity of the task increased and it became even more difficult to straddle the lymphie conundrum. Fitting themselves with shoes for particular reasons, such as work, a school activity, or special occasion required time and effort to seek options and, sometimes, required acceptance of shoes that differed noticeably from the expected. Their experiences with fitting themselves align with those of other participants in studies about lower-limb lymphedema (Bogan et al., 2007; Harding, 2012; Hanson et al., 2018; Todd et al., 2002; Williams et al., 2004; Winch et al., 2018).

Shoes that are typically available at "brick and mortar" stores are fitted to a "normal" foot with a certain length, width, and depth, with a limited amount of stretch to assure optimal fit. All the narrators seemed to prefer to make do with the shoes they could find to fit in traditional stores rather than purchase more expensive shoes from online stores that serve people who need shoes that are wider with more depth. The descriptions they gave of their difficulties with shoe

fit are consistent with the fibrotic tissue changes that occur beneath the skin of the toes, feet, and ankles as the disease advances. For example, Audra and Arial talked about the difficulty of finding a pair of shoes that would fit both of their feet comfortably. Boots are near-perfect devices for obscuring lymphedema, but Arlo's ankles no longer fit in the cowboy boots he longed to wear that was consistent with the way he preferred to brand himself. Arial described using a shop tool to grip the zipper pull of her boot to zip it past her ankle. The mounding arcs on the tops of Anya's feet, developing over eighteen years, significantly limited her options for purchasing shoes that would obscure her puffy feet. Eventually, the only shoes that she could afford and wear comfortably exposed rather than obscured, the tops of her feet. Unless wearing very long pants or skirt, she was well past the lymphie conundrum.

Most indicated the process of shopping for shoes and clothing is emotionally uncomfortable because exposure was likely. Arlo made light of a recent experience shopping for jeans that would not be too tight on his legs. However, he was serious about the "hassle." Arial also shared stories about being self-conscious while changing clothes in a "private" dressing room—one that would reveal her limb beneath the door. She was also intentional about assuring no one was watching when she tried on shoes at the sporting goods store.

Some found that it was not only complicated but crucial to find shoes and apparel that met occupational dress codes. For example, both Arlo's and Anya's jobs required them to wear a particular type of shoe for work safety. Arlo had to wear boots that were intended for a different kind of situation but still met the code, while Anya had to buy a shoe marketed to men. The shoes they purchased differed noticeably from those of their colleagues. Similarly, Arial held a job for which the work uniform was a knee-length skirt and high heels. She negotiated to wear

professional-looking slacks and lymphedema-friendly flats. The clothing and shoes she was expected to wear when modeling exposed her swollen limb, and her career was derailed.

All the narrators talked about wanting to find shoes that looked stylish, indicating that they believed the style of their shoes affected the image they wanted to project. Anya, in particular, stated that she missed being able to wear high heels. Audra shared that sometimes she did not care what other people thought about her shoes, and she chose to wear a "cute" shoe on her unaffected foot, and a complimentary shoe on the other. Arlo said he would just like to be able to put a nice outfit together like a regular guy. Abie discovered that the stylish booties she chose to wear on a field trip, though they fit at the beginning of the day, were not "lymphedema-friendly." They became uncomfortable toward the end of the long day of walking, impairing her ability to enjoy her day. She vowed to plan better in the future for such situations, which will increase the complexity of what to wear, while still trying to be stylish and fit in with her peers.

Conclusion

I have transformed the data found in the life histories of four women and one man with primary LLL into thematic findings by conducting cross-case pattern analysis (Patton, 2015) of their life histories. I have also related these findings to research relevant to living with the condition. In the next chapter, Chapter VII, I answer the research questions and offer practice implications, attach significance to what I found, and offer recommendations for research.

CHAPTER VII

DISCOVERIES AND IMPLICATIONS

"This is the professional who has gone to school and learned all about this stuff, and I'm just the person who's putting my whole life in your hands."

"I take it serious, but I don't take it real serious."

"It's not the end of the world. I mean life is going to go on, and you just have to learn how to deal with it in your own way. I mean, just try to treat yourself, if you can. And, if you can't, then try to love yourself again."

"I'm also motivated by spite. I don't like being told I can't do things, so I'm like, 'I'm going to prove you wrong.'"

"I am a person that has lymphedema; but I'm also a person that loves doing stuff for other people. You know you can still live a normal life…go and do whatever you want to do."

In Chapter VI, I offered a cross-case analysis of the life histories of a group of narrators, four women and one man, who live with primary LLL that developed in childhood or adolescence. In this chapter, I provide a brief overview of the study's purpose and methods, answer the research questions, offer practical and theoretical implications, attach significance to my findings, and recommend further research. I end this chapter with a reflection upon my experience as a researcher, emic to the research topic.

The purpose of this study was to collect, preserve and understand the life histories of young adults who grew up with and are living with primary LLL in the United States and, in

doing so, illuminate the ways in which lymphedema affects their lives within their sociocultural and medico-historical contexts. The overall research question that I used to serve as a navigational tool (Agee, 2009) was *how do young adults with primary LLL understand the experience of growing up and living with the disease against the backdrop of sociocultural and medico-historical contexts?* I used the following sub-questions to direct the focus of the study about adults ages 19 to 40:

1. What do the life histories of women and men with primary LLL reveal about how they make sense of growing up and living with the disease?
2. What do the life histories of women and men with primary LLL reveal about the challenges of navigating the U.S. healthcare system and how those challenges shape their lives?
3. What do the life histories of women and men with primary LLL reveal about how they navigate the social and emotional challenges of growing up and living with the disease, and negotiate the complexities of school, work, and relationships, and how those challenges and complexities shape their lives?
4. What do the life histories of women and men with primary LLL reveal about how they navigate the physical challenges of growing up and living with the disease and negotiate the complexities of self-management, and how those challenges and complexities shape their lives?

To answer the research questions, I used life history research methodology, situated within the interpretivist paradigm, which enabled me to explore the lives of the narrators against the sociocultural and medico-historical contexts in which they live. I solicited their stories during three guided conversations with each narrator separately, conducted over five to 16 weeks. I

invited them to share memorabilia such as documents, photographs, and other artifacts, related to their lives with lymphedema. I transcribed the 25 hours of conversations resulting in 775 pages of transcripts. I offered opportunities to the narrators to read and reflect on the transcripts between conversations and adjust and extend the information contained therein.

I kept a researcher self-reflexivity journal throughout the study to foreground key elements involved in being a research instrument (Patton, 2015), central to the interpretivist (Crotty, 2013) qualitative process. I gave significant attention to exploring my positionality before beginning the study and throughout all phases of the study, because, I, too, have primary LLL, as well as considerable experience as a nurse and nurse educator. Using open-coding, I analyzed the life stories of each of the narrators to build their life histories. Analysis of patterns across their life histories revealed three main findings with sub-themes: 1) Mattering To and For the Lives of Others and Self, 2) Complexities, Complications, and Confusions: Difficulties along the Journey, and 3) Lymphie Conundrums: Grappling with Normalizing/Othering. I now turn to my findings to answer the research questions.

Discoveries

In this section, I answer the research questions based on my findings discussed in Chapter VI. I draw from the multiple interconnected themes for answers because they offer insight into more than one question.

Research Question 1: What do the life histories of women and men with primary LLL reveal about how they make sense of growing up and living with the disease? The life histories reveal that they make sense of growing up and living with the disease by questioning and processing, comparing and contrasting, embracing vulnerability, and humanizing disease.

Like a scratch in a phonograph record, swelling limbs were a biological disruption (Bury, 1982) to the music of life they expected to hear. They grew up expecting to live a life that matters—the lives imagined in the bodies they had before they developed swelling in childhood or adolescence. The stories reveal they experienced distress about perceived losses—large and small—related to swelling and that they shifted their orientation to life to accommodate their new circumstances. They went about the developmental tasks of youth, their increasingly larger limb(s) in tow, hoping to experience as much of the life they imagined for themselves before swelling. Their stories also revealed a strong pattern of commitment to contribution at school, work, family, and community as students, parents, employees and/or volunteers, in ways that matter for others, despite their lymphedema.

They made sense of their condition through questioning and processing. From the beginning, they asked, "why did this happen?" and "why did it happen to me?" Those questions and many more remain unanswered. Some narratives revealed lingering uncertainty about the reasons for the disease: Was it the bush that scratched the leg? Was it about the hernia repair? Is this related to my autoimmune diseases? They made sense of their lives with the support of significant others. Faith in God helped some transcend the limitations on their understanding of their circumstances: "He wouldn't give me more than I could handle." Eventually, they achieved some peace in resignation: "I'm just like, 'It's whatever. What can I do about it?'"

The life histories revealed a pattern of comparing and contrasting, a cognitive device they used to navigate sense-making about their circumstances. Using this device, they examined how their lives were the same or different, before and after swelling and/or diagnosis. They considered how their bodies looked and felt, the intrusions of the disease on day-to-day experiences, and how they perceived that others viewed them. They also used downward

comparisons (Meltzer & Rourke, 2005) to consider their circumstances relative to others they perceived "to have worse things wrong," such as people with advanced lower limb lymphedema ("Dad's is worse") and immobilizing diseases ("At least I can walk"). Though downward comparisons seemed to help them make sense of their circumstances, and hone perspective, several seemed to disavow their right to feel unhappy about their circumstances in comparison to others: "…and then I feel bad."

The life histories also surface other comparisons focused on the embodied condition of their limbs over time, before and after decongestive therapy, and as they assimilated, adjusted, and/or discarded self-management practices. Narratives revealed that they compared and contrasted the effect of significant changes in their lives, including the development of diseases that were more disruptive to their lives than their lymphedema. Doing so yielded perspectives that lymphedema was not so adverse to life, after all. Comparing and contrasting helped them to negotiate embodiment of the disease, and its intrusions, but also the blessings evident in their lives: "Instead of looking on how everything has gone wrong, you're like, 'okay, well, this is the situation. It's better than it could have been.'"

The life histories revealed patterns of embracing vulnerability when connection mattered most to them. The life of their dreams included supportive friendships, intimate partnerships, children, and/or meaningful occupations to which they could contribute as a whole person—authentically and significantly. They understood that they would make those connections only if they faced the dark emotions that accompanied vulnerability to rejection and courageously dropped their armor (Brown, 2012) to disclose their disease and/or reveal their swollen limbs. Judiciously and tentatively, they shed their armor according to circumstance. Generally, others responded with expressions about their significance while also acknowledging their burdens, and

they felt accepted despite the disease they embodied. However, several accounts highlighted that embracing vulnerability did not come easily nor immediately and, especially with intimate others, was fraught with insecurity. When rejection occurred, they wondered if it was related, at least in part, to their lymphedema. Deeply hurt, but hopeful for new connections, they moved on. As put in one account, "It's a part of me. 'If you don't like it, okay.'"

Finally, the life histories reveal a pattern of humanizing disease as a result of developing empathetic orientation toward others with disfiguring diseases and disabilities. Lessons anchored in experiences from beneath the gaze of others were sensitizing to those they viewed as less fortunate than themselves. The stories revealed their sensitivity compelled acts of advocacy—small and large, individual and collective—that claimed, "*We* Matter, Too!" The stories were marked by examples of teaching children to treat others well; to stories of connecting with others with similar embodied conditions; to moving beyond "the surface" of bodies to focus on "the heart." Disclosing and sometimes exposing their limb(s) when advocating gave meaning to living with the disease. They found meaning in their goals to increase awareness of primary lymphedema, and, ultimately, they hoped to help others living with the disease. Advocating, then, represented an act of resistance to sociocultural norming that demands dignified treatment for all humanity.

Research Question 2: What do the life histories of men and women with primary LLL reveal about the challenges of navigating the U.S. healthcare system and how those challenges shape their lives? The life histories of the narrators differed vastly across the time during which lymphedema began emerging as an important medical agenda in the 21st century. Before the turn of the century, when some of them began swelling, lymphedema advocacy organizations were just developing, therapists were not yet training in significant numbers, and

medical insurers were just beginning to cover treatment for lymphedema (See Appendix B). During the last decade, much has changed, and opportunities for effective lymphedema management are expanding. Nevertheless, lessons in the life histories reveal that challenges continue for some. These include medical professionals' lack of knowledge and complacent attitudes; structural and person-centered limitations on comprehensive care and insurance coverage; and limited professional attention to emotional and socio-cultural aspects of living with lymphedema. Also, despite the growth of advocacy organizations and the opportunity to connect with others with the disease online, only one narrator had steady contact with others with her condition.

A primary pattern revealed in the life histories is the significant lack of knowledge among medical professionals about lymphedema, complacent attitudes, and/or that "awareness needs to be brought." The stories revealed that physicians prescribed various interventions (cold therapy, elevation, diuretics, low-sodium diet, and weight loss) and then failed to refer to specialists when swelling persisted. Other physicians applied the general diagnosis of lymphedema with no effort to determine the cause, and a surgeon declined to consider that surgery may have caused it: "Oh, no. No! Why would a leg swell up three years after a hernia repair?" Some surfaced that medical professionals *of all types* failed to follow up on the unusual swelling that was evident during physical examinations suggesting interfering biases about people with swollen limbs, low socioeconomic status, and obesity. An obstetrician documented a diagnosis of primary LLL where it laid fallow until discovered by another physician almost a year later: "The fact that the way the doctor just read it like it was just there."

The life histories also revealed patterns that suggest physicians in urgent care clinics and emergency departments, where treatment for cellulitis was sought, ignored desperate pleas to

heed histories of years of swelling and established diagnoses of primary LLL: “I have lymphedema! I have lymphedema!” and “He was in there, not even five minutes. He didn’t really act like he cared. He was like, ‘it’s just a flare-up of your RA.’” They insisted on conducting expensive diagnostic tests to rule out other causes of swelling and redness without acknowledging patient insight. The life histories also revealed that the overt and covert messages sent by professionals are that swelling and self-management does not matter: “Compression was never like ‘you need this for your survival’ or anything like that. It was never told to me that way” and “it was like no big deal.” The narratives reveal that, even for those who had had a diagnosis for years, feelings of dismissal linger. Some experienced consequent anger about not mattering to healthcare providers and inadequate information to fully understand and manage their condition.

Examination of contextual factors in the life histories reveal patterns of structural limitations to comprehensive lymphedema care. Not until a decade after the turn of the century, did a few have access to medical experts with state-of-the-art diagnostic imaging, genetic testing, availability of certified lymphedema therapists, and effective, comfortable compression garments: “I had to wear these specific stockings for my legs that were a nightmare.” A primary pattern revealed in the life histories is that even today, scheduling therapy sessions, sometimes an hour away from home, amidst the complexities of already complex lives with school, work, and children, was challenging: “So much time off is a killer.” And sometimes, patterns in the narratives revealed that proximity and scheduling were prohibitive complexities: “I’m like, I need to keep my job.”

The life histories revealed that person-centered constraints on financial resources were barriers for treatment that were exacerbated by medical insurance providers’ reimbursement

policies and procedures. For example, there was no coverage for bandages for decongestive therapy, custom compression garments required payment upfront to durable medical providers, and therapy session co-pays accumulated: “Those co-pays. Lord, help me!” The stories also reveal that insurance policies and procedures can be prohibitively complex to navigate without a background in healthcare: paying out of pocket for alternative compression garments with tax refunds and buying over-the-counter sports compression rather than submitting to insurance for coverage for custom garments.

The life histories surfaced that medical professionals paid little attention to the emotional/social aspects of embodied living with lymphedema that was evident in the stories: “When I was young with lymphedema, I beat myself up.” Patterns in the stories even provided evidence of experiences that might have been treatable mental health concerns: “panic attacks” and “downtimes.” Nevertheless, no life histories revealed recommendations for psychological support, as if the emotional and social aspects of living with lymphedema were invisible to providers, disenfranchising the narrators of their feelings and communicating that lymphedema did not matter.

Finally, the life histories revealed little meaningful connection to others with whom they share the disease and they lacked the advantages the connections might offer for emotional support, learning how to access care, and learning to self-manage effectively. Though opportunities for an online connection with others with the disease abound, the life histories revealed little effort to make and maintain such connections that could aid in living with the condition. Only one account revealed an effort to connect with others with the disease in person through advantageously located LE&RN and LAG events and prioritization of time and personal funds for travel to national conferences. No other accounts revealed awareness of geographically

accessible, affordable, and relevant support groups or advocacy organization chapters, nor in-person educational opportunities.

Consequent to the challenges listed above, all life histories reflected what I see as unnecessary emotional and physical suffering for longer and in more forms than is just. The life histories were consistent in this regard. Failure to provide medical attention, provision of accessible treatment, and lack of comprehensive insurance reimbursement contributed to delayed diagnosis and/or inadequate treatment for some, resulting in unnecessary progression of the disease. Not only has modern medical practice "not been kind to the lymphatic patient" (Rockson, 2017), modern medical practice, sluggish research interest, and legislative failure to close the gaps in insurance coverage for bandaging and compression has perpetrated injustice to people with primary LLL. For some, those injustices have translated to the unnecessary progression of the disease, increased emotional and physical symptom burdens, and life limitations. People with primary LLL live lives that matter and failure to resolve injustices related to their healthcare have and will continue to result in grievous harm. Moreover, the limited in-person opportunity for supportive connections with others with this rare disease translates into lost opportunity for help to overcome these injustices.

Research Question 3: What do the life histories of women and men with primary LLL reveal about how they navigate the social and emotional challenges of growing up and living with the disease, and negotiate the complexities of school, work, and relationships, and how those challenges and complexities shape their lives? The life histories reveal a pattern of navigating the social and emotional challenges with the following strategies: troubling embodiment, strategic hiding, strategic trust, and directing energy toward living. I follow a discussion of these patterns of navigation with those revealed about negotiating the complexities

of school, work, and relationships. I then discuss how these challenges and complexities shaped their lives.

The life histories reveal patterns of troubling embodiment, including the emotional challenges of negotiating a condition that not only shifts the size and feel of limbs on a given day and does so under the constant awareness of the external gaze on the body. As one account reflected, "I didn't share with my other friends…I feel like I've been in hiding for so long." The accounts revealed emotional navigation of several elements, including a preoccupation with approaching and caring for limbs that shifted each day, throughout the day, a body emerging in accounts as unstable and uncertain, at risk for infection, and potentially carrying flawed genes. Would this be a "good day" or not? How long could the limb(s) stand being in the sun and humidity? How much should I push back if my partner wants a longer walk than I feel like I can do? Will my shoes fit? Can I safely shave my legs? Will my children inherit this disease? Heart-wrenching narratives revealed patterns of emotional resonance with the embodiment of the disease, or the "really real," amidst objectification and stigmatization ("Elephantitis, elephantitis, elephantitis!" and "Oh, something's wrong. She's flawed.")

There were patterns in the narratives that indicated a social element to troubling embodiment such as resistance to photographs, quitting the track team, panic attacks associated with concerns about what other think, tension with parents over self-management, and worries that swelling contributed to the dissolution of a marriage. Finally, the embodiment of the need for compression garments challenged gender identities: Using the bathroom stall rather than the urinal on the wall and feeling unfeminine and unattractive in waist-high, one-legged, "skin-toned" compression garments that did not match their skin.

The life histories revealed prominent patterns of attention devoted to navigating the lymphie conundrum with strategic hiding, including dressing to pass as normal rather than Other. Narratives were abundant in descriptions of strategies such as wearing yoga pants rather than shorts in gym class, "forgetting" the garter for the wedding reception, leaving night clubs before the lights come on, and efficiently dropping a large, ankle-covering towel at the edge of the pool, and jumping in before anyone can see.

Their narratives revealed strategic thinking, including evaluating circumstances for the risks for stigmatization and discrimination, weighing costs versus benefits of disclosure and/or exposure, and making elaborate plans to obscure the public view. Narratives revealed that enjoying time with family at the beach, cycling and swimming at the gym to regain health, and assuring child safety at the pool represented high stakes for living that promoted decisions to expose. Narratives also revealed that situations that might yield stigmatization and marginalization tended to promote hiding, such as quitting the track team to avoid wearing shorts before an audience and lying about cellulitis to a supervisor.

The life histories reveal patterns of strategic trust in others, such as wearing a swimsuit to a pool party and posting photographs of bandaged limbs on social media. When they decided to trust, they tended to disclose bits of information or exposed layers of their garments and limbs before complete exposure because "he's probably gonna see. I have to tell him." Narratives revealed that, as relationships became important, they approached disclosure and exposure with trepidation, measuring the responses of others and adjusting accordingly, like when explaining the wearing of long, heavy jeans on a hot, humid day but not yet revealing the leg beneath until authentic interest was demonstrated and reciprocated with accounts of similar concerns. As one narrative revealed, it can go the other way as well, exposing before disclosing: wearing form-

fitting yoga pants at the gym and then explaining the swelling evident beneath when a trainer privately approaches with caring interest about what she sees.

The life histories revealed that, with time, maturity, and resignation to the stare, they began to devote more energy to living rather than hiding, such as trick or treating in a wheelchair wearing bandages or wearing two different styles of shoes to celebrate being "cute." The narratives revealed patterns of approaching exposure with resignation, such as "Now I'm just like, 'Oh, well. They see it, they see it. If they ask, they ask.'" As one narrative underscored, even after becoming comfortable with exposure in shorts, 30-year-old mental scripts were unexpectedly revived when feeling like everyone in the room was staring.

They negotiated the complexities of school, work, and relationships in the following ways:

- **School.** The life histories revealed negotiating complexities at school with the exercise of agency to disclose and expose. Narratives highlighted classroom presentations about a new diagnosis, writing teachers a letter at the beginning of the year describing the disease and school-relevant effects, and changing classes to avoid wearing shorts. Some narratives also surfaced long-held resentments about stigmatizing school experiences. One account reflected that a 504 plan helped deal with teachers' lack of understanding about the condition and helped to negotiate school policies when needed in both K-12 and university environments.
- **Work.** The life histories revealed varied "work stories" about negotiating complexities. In one painful account, the narrator explains a preference of pushing through discomfort rather than sharing the reality of the condition and exposing self to risk for stigmatization and discrimination. The narratives revealed occupational choices that enable avoidance of

attention to limbs, but that may not be healthy options, such as those that require long hours of sitting or standing, or working in heat and humidity. The life histories reveal work stories of adjusting occupational choices to work from home or to make home and children their work. Other examples include giving up vocational goals due to social and structural constraints such as military restrictions on lymphedema and appearance standards in the fashion industry. Stories reveal they negotiate complexities at work by hiding with clothing, sharing about their disease and treatments strategically, noting and managing stigmatizing behaviors of others, and avoiding disclosure when they anticipate discrimination. Stories also revealed negotiating body differences at work amidst dress code norms, including safety codes that required particular types of shoes.

- **Relationships.** The life histories reveal that they negotiate relationships by seeking a balance between significant others caring for the disease they embody and recognition of the person embodied—acknowledging lymphedema burdens, but acknowledging personhood above all. The narratives about relationships reveal that they appreciate the ongoing concern of parents while accepting responsibility for self-management from them as they transitioned to adulthood. The narratives also reveal that relationships with long-term partners are negotiated by adjusting responsibilities to enable self-management. Adjustments include co-investing in education and decision-making about treatment and self-management tools, sharing feelings about their circumstances, and participating in activities with partners even when not physically or emotionally comfortable. Narratives about relationships with children reveal mindful storying of lymphedema to avoid burdening them with the disease and to promote tolerance for body differences. Narratives also reveal internal conflicts between parenting and achieving

emotional and/or physical comfort. Sometimes, narratives revealed patterns of exercising agency to opt-out of family activities when hot and humid, or clothing options are too limited for comfort and then feeling guilty for doing so.

The life histories revealed social and emotional challenges when navigating the complexities of school, work, and relationships. Accounts reflected shame about their bodies from sociocultural conditioning, as well as mental energy invested in navigating lymphie conundrums to achieve sociocultural norms. These investments may have come at a high cost to physical, social, and emotional development and may have come at a cost to significant others, as well. Narratives surfaced that, with maturity and reflection, came regret about apparent and imagined costs of putting their energy into hiding rather than living.

Research Question 4: What do the life histories of men and women with primary LLL reveal about how they navigate the physical challenges of growing up and living with the disease and negotiate the complexities of self-management, and how those challenges and complexities shape their lives? The life histories reveal a pattern of navigating the physical challenges with the following strategies: Flexible selection, monitoring and adjusting, and accepting less than optimal outcomes. I follow a discussion of these patterns of navigations with the patterns revealed about negotiating complexities. I then discuss how these challenges and complexities shaped their lives.

The life histories revealed that they practiced flexible selection to navigate physical challenges in two areas: clothing and physical activity. When their clothing options were uncomfortable physically or emotionally, they sought the next best options to fit in with peers and enhance their most attractive features. The life histories also reveal that when activities were physically uncomfortable, or unsafe, they found alternative ways to contribute to their schools,

family, and work: playing in the band rather than playing football, doing the housework rather than the yard work, or changing jobs.

The life histories reveal that they monitored the effects of the components of the second phase of decongestive therapy (skincare, exercise, compression), as well as other self-management strategies such as lymphedema pumps and elevation, and adjusted accordingly. The narratives surface that, when necessary, adjustments are based on the cost to benefit ratio of those strategies to reducing their symptom burdens: Wearing a "lymphedema-friendly" shoe in anticipation of a long day standing and walking while on a field trip. The stories also reveal a pattern of opting out of physical activity depending on how their legs feel or on the environment: Watching children play in the yard while sitting in the shade, legs elevated, rather than walking with them to the park.

The life histories reveal navigation of physical challenges by accepting less than optimal outcomes for self-management in deference to other life priorities. A pattern is evident of relying heavily upon elevation and over-the-counter sports compression and tight leggings to minimize swelling and achieve "good enough." One narrative suggested discounting of the value of optimal self-management outcomes with comforting justifications: Inability to fit leg into form-fitting pants that no longer fit because of weight gain, "anyways." Another narrative suggested that accepting less than optimal outcomes might be protection against dashed hopes: "It's like cleaning a window with spit. You're never really gonna get that nice shine to it." A strong pattern revealed in the life histories suggested that adjusting outcomes to achieve "good enough" helped them to balance self-management with living their lives, the "Catch 22."

They negotiated the complexities of self-management in the following ways:

- **Parental advocacy.** The life histories revealed that parents played an integral role in seeking diagnosis (arranging and driving to appointments), decongestive therapy (learning to wrap), and adherence to self-management strategies (supervising self-care). The narratives revealed that parents were their strongest advocates: pressing constraints of an HMO for diagnosis, insisting upon immediate attention from a physician, negotiating a 504 plan. Two narratives reflected parent-child tension about self-management with memories of firm supervision: "It was expensive, you're gonna use it!" and "Elevate! Elevate! Elevate!"
- **Education by therapists.** The life histories revealed reliance upon therapists for effective education about their disease and self-management. The narratives suggest that effective education can go a long way toward convincing a person that investing resources in therapy and self-management will work, as well as convincing of the consequences of not doing so: "it's like you have a leak in your roof, if you don't notice it and fix it immediately, it'll just get worse and worse. Where the damage is irreversible, you can't fix it" and "I know the consequences, but I just got to knock everything else out." One narrative reflected that experiential learning related to increasing symptom burden reinforced lessons learned from therapists: "That's why I need to find my compression, is because my daughter is going to want to do stuff."
- **Prioritization.** The life histories revealed that they prioritized their time, energy, and financial resources in their already complex lives depending upon what mattered to them most (children, painful "articulating" conditions, tasks of emerging adulthood)—sometimes pushing decongestive therapy and self-management to the back burner. The life histories also revealed that the establishment of a diagnosis and episodes of cellulitis

often motivated them to prioritize differently, at least for a time. One narrative reflects that life-threatening experiences with cellulitis can result in an epiphany about self-management that stimulates a turning point, raising self-management in priority: "When I get out of this, I promise, I'm a live right. I'm a do good."

The life histories revealed that their lives were shaped by how they navigated the physical challenges of lymphedema and negotiated complexities of decongestive therapy and self-management. The physical challenges sometimes forced adjustments to the usual human tasks of styling themselves with clothing, participating in activities, and occupational choice, affecting their day-to-day experiences, and possibly changing the trajectory of their lives. How they negotiated self-management strategies had minor to significant effects on the course of their disease, with expected increases in symptom burden when not self-managing effectively. The increase in symptom burden affected their lives and those of their loved ones. Two of the narratives reflect feelings of "hopelessness" and that it is "too far gone" to improve their conditions, and thus increased physical challenges. Other narratives, represented by some of the statements in the prologue to the chapter, indicated a sense of hopefulness that lymphedema need not be limiting.

Implications

Implications for Practice

The data collected for this study has various implications for areas of practice: Education and Counseling, Healthcare and Lymphedema Therapy, and Advocacy Organizations. I address them separately.

Education and counseling. The data indicate that navigating school policies can be problematic for children and adolescents with lymphedema. To ease problems, school

administrators can evaluate policies about clothing for curricular and extracurricular activities and revise to increase the inclusivity of physical differences with clothing implications. For example, long rather than short skirts or pants and shoes that come in a broad range of widths. School administrators can also facilitate opportunities for parents and their children to bring teachers and staff members into the knowledge loop about primary lymphedema and promote understanding, minimize barriers to success in school, and reduce emotional stressors. Arranging 504 plans may be necessary to ensure fair exceptions to attendance policies, testing, and dress codes and may facilitate emerging adults in maintaining self-management practices while transitioning to college life.

The data also reveal that lost dreams and body image concerns can profoundly affect the life of a child, adolescent, and young adult with primary LLL and warrant swift and ongoing counseling to mitigate adverse effects on physical, social, and emotional development. For the most part, primary LLL needs not to be life-limiting. However, sociocultural and structural constraints do exist, such as military eligibility, school and work dress codes, and appearance conventions. Extracurricular activities and occupational pursuit warrant guided evaluation of compatibility with lymphedema. When incompatible, losses related to real and perceived limitations warrant grief counseling and redirection toward pursuits for which there are no restrictions. A counselor may also assist a young person in navigating lymphie conundrums with realistic assessments of risks for stigmatization, the costs and benefits of disclosure and exposure, and in preparing them to negotiate relationships with peers and intimate others.

Healthcare and lymphedema therapy. I address implications for healthcare providers and lymphedema therapists together, as it relates to the care of people with primary LLL and both phases of CDT, to honor the contemporary ideal of collaborative care. The narrators' life

histories reveal challenges with managing the complexities that they bring to the therapeutic relationship amidst the standards for conducting decongestive therapy, as well as communication issues with their healthcare providers. I offer five implications for medical practice and CDT.

First, the narrators experienced challenges with fitting CDT sessions into their schedules since therapy schedules corresponded to their school and work hours, as well as to the work hours of those willing to provide childcare. Some of the narrators viewed the situation as prohibitive. More flexible scheduling for therapy sessions, such as early morning hours or evening hours, may help children, adolescents, young and middle-aged adults, with multiple commitments, to schedule therapy sessions.

Second, the narrators' stories reveal that the time, energy, and financial commitment of CDT and navigating insurance reimbursement can be overwhelming. Early consultation with a health coach to help develop reasonable plans for accommodating therapy amidst other commitments may facilitate the successful completion of the first phase of decongestive therapy. It may also help to avoid financial investment in treatment sessions prior to readiness to act and maintain the results of therapy. A health coach, or other designated person, can help smooth insurance reimbursement hassles, enabling therapists and physicians to equip their clients with the most convenient and effective self-management tools early in the maintenance phase of therapy. Learning to adhere to self-management practices is a process (Palmer, 2006). A health coach, available for regular and intermittent consultation, can facilitate the process by providing problem-solving support and scaffolding self-regulation skills, facilitating successful completion of therapy and the integration of self-management practices into complex lives.

Third, the data also shows that the narrators' physicians left most of the educational process about lymphedema up to the therapists to whom they referred their clients. As a result,

the narrators left their physicians' offices with a distressing knowledge gap about their disease and treatment and a sense of overwhelm. Physicians and therapists can remedy this situation by collaborating to assure that informational resources, reviewed for accuracy, comprehensiveness, and applicability to primary lymphedema, are immediately available to the client. A health coach, in collaboration with the physician and therapist, can help to expand understanding about the disease and reinforce the importance of treatment, while the client waits for initial consultation with a therapist. Moreover, such support may increase follow through with initiation of therapy.

Fourth, the narrators' stories indicated that they had difficulty prioritizing their time, energy, and financial resources for CDT and self-management over other commitments, especially their children. Motivational interviewing (Rollnick, Miller & Butler, 2008) by the physician, therapist, and/or a health coach related to therapy outcomes that are particularly meaningful for the client may be helpful. For example, motivational interviewing may help the client to connect their effort to manage their lymphedema with highly personal and tangible outcomes, such as physical comfort when playing with children and avoiding the budgetary stress of treating cellulitis. Including significant others in motivational interviewing may facilitate co-investment in lymphedema treatment.

Finally, the narrators' stories indicate that they read covert, as well as overt, messages sent by their healthcare providers regarding their lymphedema. The overall impression the narrators received, when their providers did not address their swelling, is that their providers do not believe that self-management of lymphedema is essential. Healthcare providers who provide primary care for people with lymphedema can serve as accountability touchstones. For example, they can observe and palpate their limbs during *every* appointment—a parallel assessment to

those used to hold patients accountable for self-management of other chronic diseases, such as psoriasis, RA, venous insufficiency, etc. Direct assessment of swollen limbs, as well as girth measurements and/or photographs, will send a clear message that self-management matters.

Advocacy organizations. Advocacy organizations, such as the American Lymphedema Framework Project, Lymphedema Education & Research Network, and National Lymphedema Network, have accomplished much during the last two decades to address the concern of under-researched, underdiagnosed, and undertreated lymphedema. However, the data reveal there is still a long, long way to go to meet the needs of individuals with primary LLL. The narrators' stories suggest implications related to educational resources for providers, patients, and the public.

Provider education. Medical champions and advocacy organizations have substantially increased educational opportunities for healthcare providers who wish to develop expertise in lymphedema. However, the healthcare providers that people with new, noncancer-related swelling turn to *first* are more likely their primary care providers. Review articles and presentations in journals and conferences relevant to the practice of primary care may facilitate early diagnosis of primary LLL by non-specialists better than educational opportunities sponsored by advocacy organizations, professional journals and conferences marketed to specialists. In other words, there is a need to direct some educational opportunities to the most likely first points of contact for patient care of the person with new noncancer-related swelling: pediatricians, obstetricians and gynecologists, primary care providers in family practice, etc.

The data revealed that there were multiple opportunities for nurses to intervene regarding the swelling of the two narrators who experienced delayed diagnosis, contributing to their feeling that their swelling did not matter. Little is taught in nursing program curriculum beyond breast

cancer-related lymphedema, yet nurses in hospitals frequently encounter clients with chronic edema from a variety of causes (Quéré, et al. 2019). They can learn to recognize and document the visible and palpable signs of lymphedema (Thiadens, 2011). Recognizing lymphedema as a nursing problem and teaching nurses the various causes of the condition, as well as the treatments available to mitigate suffering, can catapult them toward advocacy for their clients with unmanaged lymphedema. By advocating, they can help close the gap between providers with prescriptive authority and lymphedema therapists, into which people with lymphedema often fall. Moreover, with more knowledge about lymphedema, nurses can reinforce teaching about self-management and risk reduction. Advocacy organizations can partner with nursing organizations such as the American Nursing Association and the National League for Nursing to expand pre-and post-licensure educational opportunities for nurse generalists about all forms of lymphedema.

Patient education. The data indicate that educational resources available to the narrators failed to resolve their confusion about primary LLL. Some of the narrators were overwhelmed by the volume of information about lymphedema on the internet. They were also confused about applicability to primary LLL and lacked confidence in some social media sources. Advocacy organizations can address this concern by posting more in-depth and up-to-date information specific to primary lymphedema and/or indicating *directly* when general lymphedema content applies to people with primary lymphedema. Reaching the specificity necessary to address all the topics about which the narrators (and their parents) were confused, such as heritability, will be difficult since there are so many types and sub-types of primary lymphedema, and science is still discovering essential knowledge about those types. Instead, advocacy organizations can include

links to comprehensive websites—perhaps the websites of clinical agencies that offer services specific to primary lymphedema—and label the links accordingly.

Public education. The data revealed that the term "elephantiasis," was used by peers as a tool for overt stigmatization of a 15-year-old narrator. The term, currently used as a medical eponym for advanced lymphedema by the staging system published in the International Society of Lymphology (2016) consensus document and as part of the diagnostic label in the International Statistical Classification of Diseases and Related Health Problems (Elephantiasis, n.d. Retrieved from https://icd10cmtool.cdc.gov/?fy=FY2020&q=Elephantiasis), is infiltrating public vernacular due to content aligned with these sources and distributed on webpages intended to educate the public about lymphedema. Though a handy medical memory aid, the term, along with relevant photographic images, has become objectifying and associated with shame. On behalf of their members with lymphedema, advocacy organizations can encourage use of clinical terms in revised staging systems and disease labels, rather than use of the eponym. Eventually, extinction of the term in the medical and popular media, in medical offices and school hallways, may follow.

Significance of the Study and Implications for Future Research

This study sheds light on the phenomenon of growing up and living with primary LLL. It stretches and nuances the research literature on the experience of living with the disease, adherence to self-management, and children with disfiguring chronic illness. This study adds to the growing qualitative literature on primary lymphedema, detailed in the literature review. This life history study, a first in the primary lymphedema literature, enabled the in-depth study of the experiences of living with primary LLL in childhood, adolescent, and young adulthood, including epiphanies, turning points, and transformations.

Findings from this study stretch understanding of body image concerns and highlight that boys and men may experience concerns that compare to those of girls and women. The findings deepen understanding related to negotiating shoes and apparel and navigating relationships with peers and intimate others. The study also offers nuanced findings regarding vulnerability to stigmatization, rejection, and discrimination at school, the workplace, and in public. This study adds that the choices children, adolescents, and young adults with primary LLL make when navigating lymphie conundrums about disclosure and exposure may come at costs to themselves and significant others, even affecting life trajectories. An opportunity exists to explore further the ways people with lymphedema navigate decisions about disclosure and exposure and the costs and benefits to doing so.

This study adds depth to understanding the complexities of living with primary LLL during childhood, adolescence, and young adulthood and how those complexities may become barriers to decongestive therapy and self-management. The study affirms that many of the barriers to adherence found in the literature regarding breast cancer-related lymphedema, and children and adolescents with primary lymphedema, apply to young adults with primary LLL. The study illuminates that, though young adults with primary LLL are concerned about the progression of their disease, they tend to prioritize scarce time, energy, and finances to other commitments over CDT and self-management. Consequently, they rely upon less effective strategies for self-management such as elevation and over-the-counter compression. An opportunity exists to explore further the barriers to adherence by adolescents, as they transition to adulthood, as well as barriers to adherence by young adults with multiple commitments. Finally, there is an opportunity to examine their perceptions about the consequences of

nonadherence and the significance of the location of lymphedema to choices about adherence to self-management prescriptions.

This study reveals that, like the parents, siblings, and spouses who are affected by loved ones living with lymphedema, the children of individuals with primary LLL may be significantly affected. This study is the first to highlight the in-depth experience of a child who inherited lymphedema from a parent, as well as the experiences of parenting children as a person living with primary LLL. The study also reveals that parents with primary LLL experience significant worry about the heritability of their condition even when an inheritance pattern is not evident within the family. There is a need for further research about parenting with primary lymphedema, living with a parent with primary lymphedema, parenting a child with primary lymphedema, and the experiences of families with heritable primary lymphedema.

The findings of this study align with the findings of Deng et al. (2013) that people with primary LLL relied more upon the internet for information than their healthcare providers and reported less understanding about their disease than do people with secondary lymphedema. It stretches those findings by highlighting that the narrators' found the information on the internet to be overwhelming, too general, and insufficient to resolve their confusion about their disease. A surprising finding in this study, given that Deng and colleagues found that people with primary lymphedema utilized social media for education about lymphedema, is that most of the narrators reported little investment in social media related to lymphedema. On the other hand, all the narrators valued face-to-face interaction with another with primary LLL. More research is needed about how best to meet the learning needs of people with primary lymphedema. Research may also lead to effective strategies for helping them to wrestle with the particularly embodied reality of primary lymphedema, its particular manifestations and conundrums.

This study affirms concerns forwarded in the medical literature and qualitative literature about the experiences of living with lymphedema that the condition is underdiagnosed and undertreated, and adds the voices of young adults with primary LLL to those of adults with secondary lymphedema, and their healthcare champions, about this concern. Their voices offer something new to the conversation. That is, the covert and overt messages they read in the behaviors of healthcare providers is that their swelling and self-management does not matter. Moreover, their voices indicate that those messages contributed to their lack of urgency about CDT and self-management. I also suggest that one narrator's stories about encounters with the medical profession imply that she may have been a victim of bias regarding people with lymphedema, low socioeconomic status, race, and obesity, resulting in delayed diagnosis. Qualitative research that explores the contributors to delayed diagnosis and marginalization of people with lymphedema by healthcare providers is warranted.

Finally, illness accounts are storied in particular ways (Frank, 2007; Riessman, 2008). This research offered analysis of accounts of experiences and context. There is opportunity to further theorize these accounts as a particular kind of narrated embodied experience using the tools of illness narrative analysis and genres (Frank, 2007; Lorde, 1980; Riessman, 2008), including the lay literature and online accounts, in the form of blogs, as autopathography (Couser, 1997).

The research reveals how much this type of research encounter can matter for me, and others, who live with this complicated embodied condition that is constantly changing. This study tied primary LLL to the literature on educational and health psychology, with threads related to human development and adherence to self-management of chronic illness. Finally, this research demonstrated that lymphedema shapes lives as well as limbs.

Implications for Theory

Three implications for theory arise from this study. First, scholars rarely consider the concept of biographical disruption in regard to children and adolescents. This research implies that developing swelling as a child or adolescent, and taking up self-management practices meet the criteria given for biographical disruption. Moreover, the data collected in this study indicate that biographical disruption can occur as the result of a change in appearance affecting orientation to life and opportunities. Second, the data suggest that a slow rate of progression of the disease challenges the application of contemporary conceptualizations of models related to adherence to self-management, such as Leventhal's Common Sense Model of Illness (2019)—particularly regarding the perception of threat. Third, the attention to "good" lymphie days and "bad" lymphie days offers insights into the shifting awareness of parts of the body for people who live daily with primary lymphedema. It is worth theorizing further how this experience differs and aligns with other chronic conditions, including secondary lymphedema.

Researcher Reflection on Research Experience

This research journey has been an emotional one, from beginning to end. Though the qualitative literature on growing up and living with primary lymphedema is limited, the material available resonates with me acutely with each reading. Similar to the kinship I felt with the participants in those studies I reviewed, I also felt a strong connection, shared understanding, and allegiance to the narrators in this study. A difficult part of this journey has been to negotiate my multiple selves as researcher, nurse, and person who grew up with and lives with primary LLL while engaged with the narrators and the data they offered. Even more difficult has been the grappling with the dominant medical discourses about the "oughts and ought-noughts" of self-management, and the unremitting sociocultural messages that drove my choices about disclosure

and exposure, and how those discourses and messages shaped my life. Also, I have done this grappling while developing a keen understanding of the relative lack of medical, academic, and government investments in the condition of primary lymphedema and how my life (and limbs) have been subsequently shaped.

In the proposal of this research study, I referred to Cole and Knowles (2001) who write, "the business of life history work is complex and consuming, exhilarating and elusive, demanding and defining, even tiring and tedious, but with understanding the lives of others comes the possibility of understanding oneself" (p. viii). A better understanding of my own life has undoubtedly occurred here. In particular, I feel more integrated as a person with primary lymphedema, and the process of this research has catapulted me toward advocacy for others with lymphedema in new ways.

Patton (2015) writes about distinguishing the signal from the noise, or the trivial, in the data. I suspect that, as a person with primary LLL, I am sensitive to the noise amongst the signals. In other words, the data others might see as trivial, I see as signal. For example, while transcribing the first conversation with Audra when she described herself as "always active" with work, school, and recreation during the years she was not self-managing optimally, I imagined and later validated with her that she intended to project that lymphedema was not holding her back and that she was living her life significantly, while also bearing significant symptom burden. I hope that by highlighting the not-so-trivial noise *as* the signal, as well as more apparent patterns signaled in the data, I have contributed a nuanced view of the experience of growing up and living with primary LLL to the work of compassionate researchers who also believe that *primary lymphedema matters, too*.

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APPENDICES

APPENDIX A

The Lymphatic System, Lymphedema, and Therapy: An Integrated Tutorial

When people think about the lymphatic system, they might think of the lymph nodes in their neck that swell in response to an infection. They might think of someone who had cancer that spread through the lymphatic system to another part of the body, or they may think of someone who experienced cancer, such as lymphoma. This cancer originated in the infection-fighting cells of the immune system and spread throughout the body using the lymphatic system as the primary route of travel. Indeed, protecting the body from invading organisms and cells gone awry is a vital role of the lymphatic system. Another essential role of the lymphatic system is to transport degraded extracellular molecules and cellular debris away from the tissues and back into the bloodstream for eventual elimination (Suami & Kato, 2018).

Most people are also aware that the circulatory system consists of the heart, the arteries that carry blood to the tissues throughout the body, and the capillaries that connect the arteries to the veins that return blood from the tissues back into the bloodstream. The capillaries do their work—the dynamic exchange of fluid, nutrients, and metabolic byproducts—in the interstitium, the contiguous space that surrounds the tissue. The blood in the circulatory system consists of *plasma*, which is the straw-colored liquid component of the blood—mostly water. The plasma holds red and white blood cells, proteins, glucose, platelets and clotting factors, electrolytes, hormones, and carbon dioxide in suspension until delivered to the cells through the thin walls of the blood capillaries (Suami & Kato, 2018)

The fluid in the interstitium is rich in protein, fat and lipids, immune cells, and large extracellular molecules. Fluid, carbon dioxide, and other cellular waste products return to the bloodstream by crossing back into the blood capillaries. The blood capillaries are unable to retrieve all the fluid, and the protein molecules and degraded cellular products are too large to cross back into the blood capillaries from the interstitium. Whatever the blood capillaries leave behind, the lymphatic vasculature can retrieve. The *lymphatic vasculature* serves as a one-way drainage system from the interstitium that returns the fluid, proteins, and cellular waste to the bloodstream. Fifty to 100% of plasma—approximately three liters—exits daily from the bloodstream into the interstitial spaces that surround the cells. The lymphatic vessels must take up the excess capillary filtrate and macromolecules in the interstitial spaces for return to the circulatory system. This process helps the body maintain *homeostasis* or stable equilibrium between interdependent physiological processes. Therefore, the lymphatic system performs an essential role as part of the circulatory system (Suami & Kato, 2018; Zuther & Norton, 2018).

Lymphedema therapists base treatments and self-management prescriptions on understanding anatomy and intrinsic and extrinsic forces that facilitate the flow of fluid from the bloodstream into the interstitium and back into the bloodstream again through the blood and lymphatic capillaries. Fluid flows out of the blood capillaries into the tissues, governed by the net outcome of opposing pressures across the capillary walls. The two pressures involved in the process are the hydrostatic pressure gradient and the colloid osmotic (oncotic pressure) gradient. The *hydrostatic pressure gradient* is the physical pressure inside the capillary compared with the physical pressure outside the capillary. This pressure is higher in the legs when standing up than when lying down. The *colloid osmotic pressure* arises from the attraction of water by proteins.

The *pressure gradient,* then, is due to the difference in protein concentration between the plasma in the capillaries and the fluid in the interstitium (Suami & Kato, 2018; Zuther & Norton; 2018).

Therapists think of the lymphatic system as divided into superficial and deep layers, separated by the *fascia* that connects the skin to the underlying tissues. The lymphatics in the superficial layer drain lymph from the skin and *subcutaneous tissue*, or fatty tissue, while the lymphatics in the deep layer drain muscle tissues, tendon sheaths, nervous tissues, the membranes that cover the bones, and the joint structures (Zuther & Norton, 2018). The lymphatic vasculature is composed of three elements: lymph, lymphatic vessels, and lymph nodes. Once interstitial fluid enters the lymphatic system, it becomes lymph. *Lymph* is usually a clear and semifluid medium. Lymph fluid is composed of *lymphatic loads* containing all substances that leave the interstitial spaces via the lymphatic system, including water, proteins, white blood cells, and various cell fractions (Suami & Kato, 2018).

Anatomists refer to the vessels in the lymphatic vasculature as lymphatic capillaries, pre-collectors, and lymph collectors. The superficial lymphatic vessels begin as blunt-ended *lymphatic capillaries* that form a one-way system that weaves through tissues collecting lymph fluid to return to the bloodstream. Using microscopes, with super-resolution, anatomists can see the initial lymphatic capillaries, the smallest lymphatic structures—only 20 to 70 micrometers wide—located in the surface layer of the skin. The lymphatic capillaries consist of only a single layer of partly overlapping lymphatic *endothelial cells*, specialized cells that line the interior surface of blood and lymphatic vessels. Gaps exist between the endothelial cells to facilitate entry of the interstitial fluid and large proteins into the lymphatic capillaries. Attached to the outer edge of the endothelial cells are bundles of fine, threadlike, semi-elastic fibers that anchor the surface of the lymphatic capillaries to adjoining connective tissues. These anchoring fibers,

called *filaments*, prevent the lumen of the thin-walled lymph capillaries from collapsing. The filaments push (or pull) the lymphatic endothelial cells apart in response to muscle activity or a pressure increase from fluid collecting in the interstitium, opening the capillaries to receive the fluid (Suami & Kato, 2018; Zuther & Norton, 2018).

The *precollectors*, slightly larger capillaries, connect the lymph capillaries to the lymph collectors. The lymph flows through the precollectors into the *collecting vessels*, which transport lymph to the lymph nodes. The lumens of the lymph collecting vessels—up to 200 micrometers wide—also contain numerous *valvular structures* spaced every few millimeters. Between the valves of the collecting vessels is a functional unit, called a *lymphangion*. The autonomic nervous system stimulates the lymphangions, and they contract rhythmically, in a coordinated manner, at a rate of about 10 to 12 contractions per minute, while the body is at rest. An increase or decrease in lymph flow volume and pressure within the vessels regulates the rate and amplitude of the contraction of the lymhangions. The wave-like contractions of the lymph collecting vessels facilitate lymph flow toward the central region of the body. Scientists refer to this mechanism as the *intrinsic pump* (Suami & Kato, 2018; Zuther & Norton, 2018).

Manual lymph drainage (MLD) is a gentle manual treatment technique that specially trained and certified therapists use to manipulate the anchoring filaments and stimulate the intrinsic pump. During the working phase of the technique, the therapist stimulates the subcutaneous tissues, resulting in the manipulation of the anchoring filaments of the lymph capillaries and the smooth musculature in the lymphangions. The therapist uses a light, directional pressure to move lymph fluid in the appropriate direction. Zuther & Norton (2018) describe the amount of pressure applied as that one might use while stroking a newborn's head. During the resting phase, when the therapist releases the pressure, the elasticity of the skin

moves the therapist's hand passively back to the starting position, and the lymphatic capillaries absorb tissue fluid from the interstitial spaces (Zuther & Norton, 2018).

Whenever skeletal muscles that surround the collecting vessels contract, they squeeze to propel the lymph fluid through the collecting vessels. The valves in the collecting vessels serve a bit like a series of one-way, swinging doors that inhibit backward flow. The collecting vessels deliver the lymph to the lymph nodes that filter the fluid for debris and other offending matter. Anatomists categorize lymph nodes as "regional" or "interval," depending upon their anatomical characteristics. *Interval lymph* nodes are located along the course of the deep lymph collecting vessels. The *regional lymph nodes*, associated with the legs, are in the groin regions where several lymph nodes concentrate as a group. From the lymph nodes in the groin, larger lymphatic vessels in the abdomen carry the lymph toward the thorax, where the venous system retrieves it and returns it to the bloodstream (Suami & Kato, 2018). Extrinsic factors, such as positioning, mechanical stimulation, deep breathing, and exercise, can augment the rate of lymph flow through the system (Zuther & Norton, 2018).

To summarize, with a normally functioning lymphatic system, the outward flow of fluids from the bloodstream to the interstitial spaces slightly exceeds the inward flow from the interstitial spaces back into the bloodstream. The leftover fluid and filtrate enter the lymphatics and flows back into the bloodstream. Since the fluid flows in one direction and does not circulate, scientists and healthcare providers commonly describe lymph flow as *lymphatic drainage*. When the system does not drain adequately, as with lymphedema, a protein-rich fluid containing cellular waste products accumulates in the interstitium, the contiguous space surrounding the cells. As the fluid and waste products accumulate, the affected body part swells.

APPENDIX B

A Timeline of Lymphedema Related Initiatives

Initiatives conducted since the turn of the century promise hope for people living with lymphedema in the United States. The table that follows includes selected initiatives and provides context for growing up and living with primary lymphedema since the turn of the century. Unless otherwise noted, I draw from MacDonald (2006) for the content in the table.

MacDonald, J. (2006). An American history of lymphoedema management. *Journal of Lymphoedema, 1*(1), 10–11.

Year	Initiative
Late 1980s	Lerner founded the Lerner Center in New York City. Klose, a certified manual lymph drainage/complete decongestive therapy (MLD/CDT) instructor, and graduate of the Foldi Clinic in Germany, joined Lerner at the center.
.1987	Thiadens, a nurse working with patients with lymphedema, opened The Aurora Clinic in San Francisco.
1988	NLN was founded by Thiadens to serve as an information resource for patients and medical professionals. (www.lymphnet.org)
1990s	Certification courses to conduct Complete Decongestive Therapy (CDT) sponsored throughout the nation by Lerner, Klose, Norton, and Zuther. Development of lymphedema treatment clinics followed.
1997	Florida became one of the first states to approve insurance coverage for 10 CDT treatments.
1997	CDT was placed under existing physiotherapy Medicare codes with an option for extension for more sessions.
1998	Ko, Lerner, Klose, and Cosimi published article describing CDT as a treatment for extremity lymphedema—the first in an American journal. Ko, D. S. C., Lerner, R., Klose, G., & Cosimi, A. (1998). Effective treatment of lymphedema of the extremities. *Archives of Surgery, 133*(4), 452–458. doi:10.1001/archsurg.133.4.452
1998	Chaite founded the Lymphatic Research Foundation (LRF) to promote research about treatments and cures for lymphedema and other lymphatic diseases. (Our Founder, n.d. Retrieved from http://lymphaticnetwork.org/about/our-founder)

Year	Initiative
1999	Lymphology Association of North American (LANA) founded under leadership of Feldman to promote standards for lymphedema management and to establish and maintain certification for professionals administering CDT. LANA has since earned accreditation by the American National Standards Institute (ANSI) for the CLT-LANA® credentialing program for therapists. (https://www.clt-lana.org/)
2002	Through work of LRF, the National Institutes of Health recognized lymphedema as a significant medical disease requiring funding for lymphology research.
2002	LRF published the first issue of *Lymphatic Research and Biology,* the first international, peer-reviewed, medical journal devoted to lymphatics and lymphatic disease. (www.liebertpub.com/loi/lrb) Rockson, S. (2003). The birth of lymphatic research and biology. *Lymphatic Research and Biology*, *1*(1), 1–2. doi:10/csxb63
2002	Granger, Skeff, Chaite, and Rockson conducted a mini-workshop during the annual meeting of the Association of Medical Colleges (AAMC) regarding lymphedema and treatment. Rockson, S. G., Granger, D. N., Skeff, K. M., & Chaite, W. (2004). Lymphatic biology and disease: Is It being taught? Who Is listening? *Lymphatic Research and Biology*, *2*(2), 86–95. doi:10/cpm288
2002	Rockson organized the seminal conference devoted to the subject of lymphatic research and biology, *The Lymphatic Continuum*. Spurred increased awareness of importance of lymphatic mechanisms in the continuum of human biology and disease. Rockson, S. G. (2002). The lymphatic continuum. *Annals of the New York Academy of Sciences, 979*(1), 1–4. doi:10/b8vdqc
2002	The International Lymphedema Framework (ILF), a UK-based charity, was founded to improve the management of chronic edema and related disorders worldwide. Comprises member countries that subscribe to the ideals of the ILF and have developed their own independent organization. Aims: (1) sharing of expertise and resources; (2) supporting individual countries to develop a long-term strategy for the care and management of chronic edema. (www.lympho.org)
2005	In 2005 and 2006, LRF established a post-doctoral fellowship awards program to encourage research (https://lymphaticnetwork.org/about/history/)
2008	LRF established first-ever endowed Chair of Lymphatic Research and Medicine at Stanford University School of Medicine, California, held by Stanley G. Rockson (https://lymphaticnetwork.org/about/history/)
2010	Ferguson founded LAG to fight for federal legislation to change Medicare law to cover compression garments and bandages, in hopes that insurers will follow. (https://lymphedematreatmentact.org/about-the-bill/background-information/)
2010	ILF published focus document on care of children with primary lymphedema. (www.lympho.org/portfolio/care-of-children-with-lymphoedema/)
2010-2012	Patient registry and tissue bank established by LRF o support genetic research. (https://lernregistry.stanford.edu/)

Year	Initiative
2013	In 2013, the LRF became the Lymphedema Education & Research Network (LE&RN). (www.lymphaticnetwork.org)
2015	The American Lymphedema Framework Project (ALFP) joined the ILF, six years after the first stakeholder meeting with intention to contribute to global as well as U.S. initiatives to improve healthcare for people with lymphedema. (https://www.alfp.org/about)
2016	LE&RN declared March 6, 2016 as the first World Lymphedema Day. (https://lymphaticnetwork.org/wld/)
Ongoing	Lymphedema Treatment Act (LTA), S. 518 and H.R. 1948 garnered more support than any other health care bill in the 116th Congress. On 12/12/19 the LTA was passed in the House of Representatives as part of H.R.3, the House Drug Pricing bill. (https://lymphedematreatmentact.org/about-the-bill/current-status/)
Ongoing	The first and only summer camp for children fighting lymphedema in the United States was first hosted in Oklahoma, July 2019 (Westbrook, CLT, and Director). The camp is now hosted by Brylan's Feat, an organization founded by Williams to serve as a resource and advocate for children and their families impacted by lymphedema. (https://www.brylansfeat.org/campwatchme)
Ongoing	ILF directs significant effort toward primary lymphedema with The Children's Project including (1) Developing structured education program for children and their families; (2) Developing a quality of life tool for children and young people; (3) hosting a camp for children with lymphedema; (4) a research project designed to try to understand the challenges of self-management for children, adolescents, parents, and professionals. (www.lympho.org/childrens-project/)
Ongoing	LE&RN, recognizing a need to help people with lymphedema to find comprehensive, effective services, is poised to certify Centers of Excellence in the Diagnosis and Treatment of Lymphatic Diseases in 2020. (Centers of Excellence, n.d. Retrieved from https://lymphaticnetwork.org/treating-lymphedema/centers-of-excellence)

APPENDIX C

Oklahoma State University Institutional Review Board

Date:	Monday, August 21, 2017
IRB Application No	ED1794
Proposal Title:	Growing up and living with lymphedema
Reviewed and Processed as:	Expedited

Status Recommended by Reviewer(s): Approved Protocol Expires: 8/20/2018

Principal Investigator(s):

Deborah Crow
900 N. Portland, HT203K
Okla. City, OK 73107

Lucy Bailey
215 Willard Hall
Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

☐ The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1.Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval. Protocol modifications requiring approval may include changes to the title, PI advisor, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2.Submit a request for continuation if the study extends beyond the approval period. This continuation must receive IRB review and approval before the research can continue.
3.Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of the research; and
4.Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Dawnett Watkins 219 Scott Hall (phone: 405-744-5700, dawnett.watkins@okstate.edu).

Sincerely,

Hugh Crethar, Chair
Institutional Review Board

Oklahoma State University Institutional Review Board

Application Number:	ED-18-105
Proposal Title:	Growing up and living with lymphedema
Principal Investigator:	Debbie Crow
Co-Investigator(s):	
Faculty Adviser:	Lu Bailey
Project Coordinator:	
Research Assistant(s):	

Status Recommended by Reviewer(s): Approved

Study Review Level:	Expedited
Modification Approval Date:	02/26/2019

The modification of the IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46. The original expiration date of the protocol has not changed.

Modifications Approved:
Modifications Approved: All participants will receive a Visa gift card valued at $50.00 as compensation for completion of the study.

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved.
2. Submit a status report to the IRB when requested
3. Promptly report to the IRB any harm experienced by a participant that is both unanticipated and related per IRB policy.
4. Maintain accurate and complete study records for evaluation by the OSU IRB and, if applicable, inspection by regulatory agencies and/or the study sponsor.
5. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

Sincerely,

Oklahoma State University IRB
223 Scott Hall, Stillwater, OK 74078
Website: https://irb.okstate.edu/
Ph: 405-744-3377 | Fax: 405-744-4335| irb@okstate.edu

Oklahoma State University Institutional Review Board

Date:	07/31/2019
Application Number:	ED-18-105
Proposal Title:	Growing up and living with lymphedema
Principal Investigator:	Debbie Crow
Co-Investigator(s):	
Faculty Adviser:	Lu Bailey
Project Coordinator:	
Research Assistant(s):	
Processed as:	Exempt Continuation

Status Recommended by Reviewer(s): Approved
Continuation Approval Date: 07/31/2019

The continuation of the IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

Requirements under the Common Rule have changed. This study meets criteria in the Revised Common Rule, as well as, one or more of the circumstances for which continuing review is not required. Therefore this study has been converted to the Revised Common Rule. As Principal Investigator of this research, you will be required to submit a status report to the IRB triennially.

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be approved by the IRB. Protocol modifications requiring approval may include changes to the title, PI, adviser, other research personnel, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a status report to the IRB when requested.
3. Promptly report to the IRB any harm experienced by a participant that is both unanticipated and related per IRB policy.
4. Maintain accurate and complete study records for evaluation by the OSU IRB and, if applicable, inspection by regulatory agencies and/or the study sponsor.
5. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

If you have questions about the IRB procedures or need any assistance from the Board, please contact the IRB Office at 405-744-3377 or irb@okstate.edu.

Sincerely,

Oklahoma State University IRB

APPENDIX D

Recruitment Flyer

Attention: Men and Women with Lymphedema!

Share your life story and be a part of an important research study!

Men and women, between the ages of 18 and 65 years, diagnosed with lymphedema prior to the age of 22 are invited to participate in a research study.

The purpose of this research study is to understand the life histories of men and women with lymphedema of the lower limbs and in doing so, illuminate the ways in which growing up with and living with lymphedema shapes their lives.

Volunteers for this research study will tell their life stories by participating in between two to three, face-to-face interviews or internet video conferences (SKYPE, FaceTime, Google Hangout), lasting one to three hours, over six weeks to six months, depending on their schedule and at their convenience. The investigator will invite volunteers to share photographs and other memorabilia to help tell their stories.

Participants will receive monetary compensation.

Note: The principal investigator, Deborah Crow, was born with lymphedema in both legs. She is conducting this study as part of her PhD Dissertation.

For more information:
Email Deborah Crow at deborah.crow@okstate.edu or call 405.417.1283
Email Dr. Lucy Bailey at lucy.bailey@okstate.edu
Facebook Page: https://www.facebook.com/Research-Study-Growing-Up-and-Living-with-Primary-Lymphedema-105527686696017/?ref=aymt_homepage_panel

VITA

Deborah Elaine Crow

Candidate for the Degree of

Doctor of Philosophy

Dissertation: ILLUMINATING THE EXPERIENCES OF GROWING UP AND LIVING WITH PRIMARY LYMPHEDEMA: A LIFE HISTORY STUDY

Major Field: Educational Psychology

Biographical:

Education:
Completed the requirements for the Doctor of Philosophy in Educational Psychology at Oklahoma State University, Stillwater, Oklahoma in May, 2020.

Completed the requirements for the Master of Science in Nursing at University of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma in 1990.

Completed the requirements for the Bachelor of Science in Nursing at University of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma in 1983.

Experience:
August 1989-May 2019
Nurse Educator, Oklahoma State University-Oklahoma City

May 1986 –August 1989
Staff/Charge Nurse, Critical Care/Telemetry, Presbyterian Hospital, Oklahoma City

May 1983-May 1986
Charge Nurse, Medical-Surgical, Deaconess Hospital, Oklahoma City

Professional Memberships:
Board Member, Lymphedema Advocacy Group, 2019-present
Member, National Society of Health Coaches, 2019-present
Member, Lymphedema Education & Research Network, 2018-present
Member, National Lymphedema Network, 2017-present
Member, American Nurses Association, 1989-present