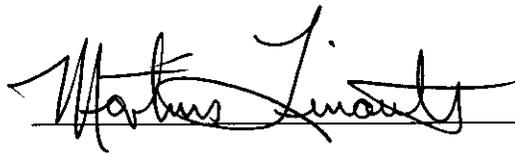


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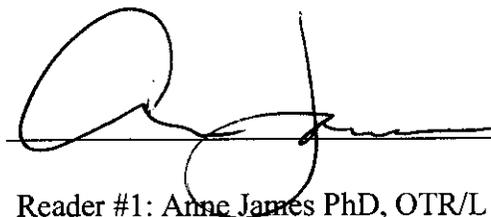
An Occupational Therapy Case Study

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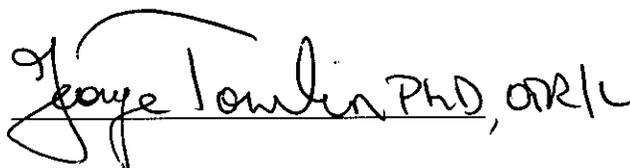
This research, submitted by Jamie L Palmer, has been approved and accepted
in partial fulfillment of the requirements for the degree of
Master of Science in Occupational Therapy from the University of Puget Sound.



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Primary Lymphedema with Intestinal Lymphangiectasia: An Occupational Therapy Case Study

Primary lymphedema (hereafter referred to as PL) is a rare condition and often disfiguring impairment affecting 1 in 6,000 people, more commonly women in the United States (Donaldson, 2006). PL occurs spontaneously when the lymph vessels are unable to adequately drain lymph fluid, and usually develops in the extremities (“Lymphedema,” 2009). PL develops because lymph nodes or vessels are missing or abnormal and do not function the way they should (Donaldson, 2006). The limb edema may impact participation in daily activities, including social participation. Other possible factors such as limb function, cosmetic changes, and self-image may also be impacted by PL. Research about the optimal treatment approach for patients with PL is limited (Symvoulakis, Anyfantakis, & Lionis, 2010).

Intestinal lymphangiectasia (hereafter referred to as IL) is also a rare condition that occurs in the first decade of life affecting the formation of the lymph vessels in the lining of the small intestine, disrupting the flow of lymph fluid (Ruiz, 2007). “IL is defined as a disease characterized by hypoproteinemia, edema, and lymphocytopenia, resulting from dilatation of intestinal lymphatics and loss of lymph fluid into the gastrointestinal (GI) tract” (“Intestinal lymphangiectasia,” 2010, para. 3). This disease can lead to immunologic abnormalities, the loss of body fluids as well as affecting iron levels. (“Intestinal,” 2010, para. 3).

In some cases, PL is accompanied by IL. The combination of PL with IL (hereafter referred to as PL-IL) is extremely rare. There are only a few known diagnosed individuals with PL-IL in the United States. The amount of research for PL-IL is more limited than PL.

There are complicated health factors that impact treatment and limit treatment approaches for people with PL-IL. One such factor is that lymphatic ducts do not filter fluids properly (or at all), so therefore lymphatic drainage treatment has to be approached carefully in order to prevent

the treatment itself from being life threatening by forcing fluids into non-functioning areas. Treatment methods used for PL, such as complete decongestive therapy (CDT), have been documented as effective treatments (Cornell, 1998), however, not for the specific diagnosis of PL-IL. The combined diagnosis of PL-IL complicates treatment approaches since lymphatic system components (such as the chylous duct) that are responsible for returning the lymphatic fluid (chyle) to the bloodstream are absent.

PL-IL limits the occupational performance of individuals by decreasing independence in all performance and interfering with quality of life (“Lymphedema,” 2009). Severe edema and complications related to the lymphatic system such as skin integrity, decreased range of motion, and sometimes lack of strength, impair the ability to be independent in activities of daily living (ADLs) such as dressing, and may lead to the need for costly clothing adaptations.

Occupational therapy for patients with PL includes CDT intervention methods. Traditional CDT is one intervention that can be applied to help maximize function and lessen the complications such as skin integrity and decreased limb function due to edema related to PL.

CDT involves manual lymph drainage (MLD), application of compression bandages, decongestive exercises, skin care, and daily compression garment use (Weissleder & Schuchhardt, 2001). CDT is more beneficial when all components are applied versus only incorporating some components.

Occupational therapy treatments, such as modifying tasks to compensate for impairments, may also be effective for people with PL, however, the use of task adaption has not been well documented for PL-IL. Examples of task adaption may include using compensatory strategies or modifying the environment in which the task is completed.

There are many factors and complications to consider when treating individuals with CDT who are diagnosed with PL-IL. Occupational therapists need to modify CDT treatment strategies as they proceed through the course of treatment. This makes treating such clients challenging and risky, as well as the outcomes unpredictable. Different approaches to treatment, however experimental, and their outcomes need to be carefully documented and analyzed, both for monitoring individual clients as well as providing case studies that may guide therapists treating such individuals in the future.

Background and Significance

PL is a condition resulting from congenital abnormality or dysfunction of lymphatic vessels (Symvoulakis et al., 2010). Obstruction of normal lymph flow causes more lymphatic destruction which predisposes patients to recurrent infection (“Lymphedema.” 2009). PL is a chronic, constant and potentially disabling condition leading to a long-term burden for patient’s life in terms of physical, social, and emotional state. It has also been reported that patients with lymphedema exhibit an excess of psychological distress and poor levels of psychosocial adaption when compared to the general population (Symvoulakis et al., 2010).

IL occurs in childhood with bilateral peripheral edema and persistent diarrhea, resulting from dilatation of intestinal lymphatics and loss of lymph fluid into the gastrointestinal (GI) tract (“Intestinal”, 2010). The pathophysiology of IL is unknown (Hokari, Kitagawa, Watanabe, Komoto, Kurihara, Okada, ... & Miura, 2008). IL results in a failure of lymphatics to grow, especially in deeper mucosal areas (Hokari et al., 2008). A loss of protein adds to the development of edema (Abramowsky, Hupertz, Kilbridge, & Czinn, 1989).

Due to the limited awareness of PL-IL, patients may experience suffer PL for an extended period of time without a diagnosis and treatment, which could lead to serious

complications such as skin changes and infections (Hodges, 2009). A late diagnosis also complicates effective management for these patients. A close collaboration among health professionals, with a high level of awareness, may help promote optimal overall management of persons with PL (Symvoulakis et al., 2010).

Interventions

CDT for Primary Lymphedema. One approach occupational therapists use to treat PL is complete decongestive therapy (CDT). This treatment is now recognized as an effective approach to manage lymphedema of the extremities (Crane, 2009). CDT consists of two phases. Phase one is the intensive phase, which consists of manual lymphatic drainage (MLD), compression bandaging, thorough skin and nail care and decongestive exercise (Crane, 2009). Phase two is the maintenance phase. MLD provides gentle pressure, circular movements and massage movements that facilitate the directional flow of the fluid, which helps to reduce edema, ease discomfort, and restore mobility that may be, limited due to the swelling in the limbs (Hodges, 2009).

The decreased lymph in the extremities gained from intensive CDT can be maintained through the patient's consistent use properly fitting custom made compression garments (Crane, 2009). Patients must continue their home programs, which include MLD, compression bandaging, skin care, and decongestive exercise for life. Due to the progressive nature of PL, CDT started in the early stages of the disease produces the best results (Weissleder & Schuchhardt, 2001).

The initial treatments using CDT may be uncomfortable, as edema is usually at its worst and the skin is very tender (Hodges, 2009). This can complicate patient compliance to initial treatment procedures. However, the goal of this approach is to decrease swelling overtime,

thereby reducing the pain. To increase patient compliance, patients need to be aware of the possibility of pain associated with initial treatment procedures. This insight may increase successful outcomes such as maintaining edema reduction.

Another challenge of CDT is patient compliance to both phases of treatment. If phase one of treatment is successful, the quality of life improves for that person (Weiss & Spray, 2002), however, some individuals do not follow phase two CDT recommendations (Boris, Weindorf, & Lasinski, 1997; Dennis, 1993; Ko et al., 1998) and must repeat phase one CDT treatment, thereby impacting time, cost, and the person's quality of life.

Treating individuals who present with IL in addition to PL presents health care practitioners with additional challenges. IL complicates CDT treatment as the lymph vessels are improperly formed, leading to poor transportation of lymphatic fluid to thoracic duct. The fluid then leaks back in to the intestine and prevents fat and proteins from being absorbed into the bloodstream (Ruiz, 2007). The combination of PL-IL results in missing lymphatic system components, which could interfere with successful traditional CDT methods. These complications increase the need for documented research indicating how modified CDT methods can produce positive outcomes for this combined diagnosis.

Quality of life. Quality of life includes both subjective and objective aspects of performance (American Occupational Therapy Association, 2008). Quality of life refers to the way a person perceives and values their health and wellness, including the physical, emotional, leisure, and social aspects of life. Specifically, how a person perceives and values their health and wellness as it relates to the ability to fulfill daily tasks, role performance, social function, freedom from pain and an overall sense of well-being (Donaldson, 2006, & Vuillemin et al., 2005).

Occupational therapists play a unique role in addressing quality of life. Occupational therapists evaluate a person's quality of life by measuring outcomes related to life satisfaction or progression towards meeting client centered goals, hope, self-concept, health and functioning, and socioeconomic factors (American Occupational Therapy Association, 2008). Occupational therapy also plays a role in psychosocial treatment. Occupational therapists help to create, promote, establish, maintain and modify habits and routines to maximize an individual's performance in activities (American Occupational Therapy Association, 2008).

Quality of life is essential because it provides a person with a purposeful life. To maintain a successful quality of life, PL needs to be managed and monitored for the long-term impact it can have on a person's functional and emotional well-being (Symvoulakis et al., 2010).

Occupational therapy approach to quality of life can result in successful outcomes for the person. An outcome includes important components related to health, intervention, perception of health, and life and care satisfaction (American Occupational Therapy Association, 2008). Successful outcomes related to function, health, and satisfaction can lead to engagement in meaningful activities.

However, research on CDT is lacking evidence, particularly in ways to improve quality of life for occupational therapy patients with PL-IL. Therefore, the purpose of this study was to describe the course of occupational therapy treatment and outcomes for one individual with PL-IL, including ongoing intervention with occupational therapy treatment using CDT and outcomes related to functional, meaningful quality of life.

Method

Research Design

The design used for this study was a case study. Since this is a rare diagnosis, the case study method allowed for in-depth data collection of one diagnosed individual (hereafter referred

to as Lilly, a pseudonym) and an opportunity to observe and report modified treatment protocols. The case study provided an educational protocol for therapists treating pediatric lymphedema patients. In this specific case study, the methodology allowed an investigation of the meaningful characteristics of the person's life events as they relate to PL-IL. Multiple data sources were used to provide construct validity, more convincing evidence, and rich detail and enable occupational therapy practitioners to use data from the case to guide treatment of other individuals with PL-IL.

Participants

Three key participants were recruited for this study: Lilly, a seventeen year old European-American girl with a diagnosis of PL- IL, Lilly's mother, and Lilly's occupational therapist (OT). Lilly, her mother, and her OT were contacted to gather information regarding Lilly's diagnosis, treatment, experience of treatment, and the impact that PL- IL has had on her quality of life. Lilly was a client of a local OT lymphedema specialist who proposed the idea of conducting a case study on this client.

Lilly's occupational therapy records were examined for the study. Also, subjective perspectives of effectiveness and ineffectiveness of the treatment process were collected from Lilly, her mother, and her OT by interview.

Data Collection and Procedure

The study began by gaining approval from the university Institutional Review Board (IRB) and medical center IRB to complete the study. Once approval was granted, Lilly, her mother, and her OT were contacted by phone by the lead investigator to be invited to participate in the study. The participants' contact information was collected through a staff person at the clinic.

Some of the questions in the interviews were personal in nature and required answers that were difficult to provide. When this occurred, the participant in the interview took a break. To lessen anxiety or perceived pressure to participate in the study, participants signed written consent forms to participate sent by mail rather than in person.

Interviews. The primary data source for this case study was collected via interview. The study began with a practice pilot interview with Lilly's OT as a preparatory step before formal interviews. Interviews were audio recorded. Written field notes were also taken during interviews.

The researcher interviewed each of the participants twice, using a structured format. The second interviews were conducted to provide member checking of prevalent themes revealed from the first interviews. Member checking allowed for clarification of identified themes in order to strengthen internal validity and accuracy of identified themes as well as to gain additional information not obtained in the initial interviews. The objective of the interviews was to gather information about the description of treatment, insight from the participants' experience, and to gain perspective on how PL-IL can impact quality of life from the perspective of Lilly, her mother, and her OT. Lilly's OT was questioned regarding the course of treatment, successful and unsuccessful interventions, and steps taken in the process of clinical reasoning due to the rarity of PL-IL. Also, the occupational therapist's insider perspective on the progress of treatment, as well as the encouraging and discouraging experiences associated with Lilly's therapy process, were documented.

The interview questions were derived from issues raised by all three participants, as well as observations of treatment sessions, activities of daily living (ADLs) such as grooming and dressing, and instrumental activities (IADLs) such as tennis and Keyboarding. For a list of

interview questions refer to Appendix A. Flexibility in how questions were asked was built into the plan prior to conducting interviews in order to obtain more in-depth information and understanding of the participants' experience. The structure of the interview questions was intended to capture the challenges and successes faced by Lilly, her mother, and her OT. The style of questioning was adjusted during the interviews when the questions were unclear.

Medical Records. After the first set of interviews, Lilly's occupational therapy records were reviewed. Occupational therapy records included 90 occupational therapy clinical notes from the initial treatment session on June 18, 2009 through March 24, 2011. Information on CDT treatment was documented by indicating how many times MLD, compression bandaging, kinesio tape application, sequential circumferential measurements, custom measurement and fitting for garments, caregiver training, skin care, exercise, and ADLs occurred during the 90 treatment sessions. Quantitative data was collected through documented sequential circumferential volumetric measurements taken during an observed treatment session to provide evidence for effectiveness of MLD treatment.

Direct Observations. Direct observations provided insight into the limitations imposed on an individual's quality of life by PL-IL. Direct observations included two treatment sessions at Lilly's occupational therapy clinic, one home observation of ADLs and IADL, and one community observation at Lilly's school tennis match. Treatment observations and interviews of the three participants during treatment sessions documented the process of treatment completed by Lilly's OT, Lilly's preference of treatment, and Lilly's reaction to treatment methods. Quality of life was measured during both observed clinic sessions using an evaluative instrument, The Quality of Life Scale (Burckhardt & Anderson, 2003). Lymphatic fluid volume reduction values were also collected during one observed treatment session to demonstrate effectiveness of MLD

treatment. Observations at Lilly's home included performance abilities during dressing tasks, and grooming tasks such as make-up application, hair grooming, brushing teeth, and keyboarding was also observed. School observations focused on performance skills during a tennis match, as well as social interaction and participation. For field notes of observations refer to Appendix B.

Data Analysis

A thematic analysis was used to organize qualitative data that focused on the description of PL-IL, CDT outcomes, educational components, quality of life, and the overall experiences with treatment. Primary data were analyzed by identifying key words and coding those key words into prevalent themes. Prevalent themes were organized and sorted once developed and supported by quotes from all three participants. Prevalent themes were also defined and supported by all data collected. Conclusions were drawn based on connections revealed from primary data and supportive data (occupational therapy records and observations). Occupational therapy records were organized in chronological order starting with the initial treatment session to last day of data collection and descriptive statistics were used to represent frequency with, which each treatment activity occurred over 90 treatment sessions.

Results

Qualitative Data Results

Four prevalent themes emerged from the interview data: lifelong adjustment to establishing a routine, lack of awareness across health professionals, need for customized treatment, and well adapted individual. The four themes were established from each of the three participant's interviews. Common key word descriptors that were used by participants to define their experiences are summarized for each theme (Table 1). Although all of the experiences are

interrelated, the information will be presented in separate themes and supported by direct quotes as well as observations and occupational therapy records where appropriate.

Lifelong Adjustment to establishing a routine. Lifelong adjustment was defined by each participant as a need to incorporate necessary therapy activities into an already established way of life. Lilly and her mother found adjustment difficult to establish and maintain without ongoing therapist support, but realized it is necessary for a healthy life. Lilly's mother reported, "I think therapy should be the rest of her life because things are going to change and be new." Lilly reported, "Like taking everything that I have learned and just sitting down and refocusing on how I can apply this to my life and how can I work with it." Lilly's OT recognized Lilly's and her mother's difficulty but still encouraged them to try and make small adjustments that would lead to better outcomes over time. Lilly's OT reported, "I think she knows by now it is not going to be a quick fix and it is going to be a chronic lifelong condition she has to deal with."

The participants recognized the importance of the development of a routine. Lilly reported, "Therapy is the base of my life right now and it really keeps me keep on track and keeps reminding me how important this is and that we don't want it to get any worse, but get better and maintain." Lilly's mother reported, "I know she doesn't like wearing garments, but I think once you get used to it, it gets easier."

The participants discussed factors that have contributed to struggles in order to develop a routine. The first factor was time management. Inconsistent schedules since initial treatment due to daily life activities and insurance issues have contributed to difficulties with time management related to establishing a routine. Lilly reported, "I think life gets in the way. We all get busy. Instead of doing MLD, you want to go to your friend's house, you have homework or sports. You have to go and do, but you know you have to do this."

Lilly's mom reflected on her experience with life struggles and how those struggles have impacted the development of a routine.

We started making sure we were on a routine for a while and we got it down a little bit but Lilly's OT says you have had it for so long and it is going to take a long time to get everything down. It worked for a while and school and everything started back up and we both kind of went our separate ways.... When you were all excited because you finally found someone you knew could guide you in the right direction and then the wait game between insurance and the doctors put us off track. We were excited but then it went to the waiting game again and we got discouraged and pushed it over to the side.

Another factor that has impacted routine was Lilly's age. All three participants believed if therapy could have started earlier, Lilly would be on a routine and currently have better outcomes. Lilly's mother reported,

Once we were there at the clinic with her OT, if we would have known we could have had the full treatment and everything was taken care of, and we could have seen the doctors maybe a little sooner to make sure everything was going properly, I think we could have been on a great routine.

Lilly's OT commented, "If we would have had an early intervention, we would probably have better outcomes now. But since I got her at such a late stage, it is definitely impacting how well we are doing now."

All three participants reflected on the impact Lilly's age has had on establishing a routine. Lilly reported, "In my teenage years it is hard to get on a routine and you are just now

learning about everything and it is hard to focus on what I have to do with other things in my life.” Lilly’s mother echoed her daughter’s sentiment when she said, “I know we need to get on a routine, which ... being 16 or 17 years old, to get onto a routine is a little tough.” Lilly’s OT reported, “Maybe it is the age she is at ... if she sees her skin and tissues getting worse ... when she becomes more comfortable with age ... who she is ... not in high school anymore, maybe then she will partake ... more.”

Participants made some suggestions as to what might have helped with the development of a routine. Lilly felt being around others with PL and learning from those who have experienced PL treatment would be helpful for developing an understanding of why life-long adjustment is important. Lilly referred to an experience she had at The National Lymphedema Network International Conference in Orlando Florida by stating how motivating it was. “Conference inspired me to keep going to treatment and keep doing every day things and not have lymphedema change my life.” Her mother agreed and felt that once results could be visual and compression garments were comfortable for Lilly, she would be more encouraged to maintain a routine. Lilly’s mother reported, “We haven’t seen the results to get us excited and push to go further. The next goal ... get into garments she is comfortable with ... I think she will put them on, leave them on and get into a routine”

The participants also reflected on aspects of therapy that were most important and why routine is necessary. Lilly reported, “The best thing ... is get a really good manual drainage and talk to your therapist about the struggles you are having or any compromises you may need to learn to help you stay on track and stay on a routine.” Lilly’s mother reported, “We have got to start pushing because it is not good for her arms to be that way so we have got to start looking at her health and long-term care.” Lilly’s OT reported, “She probably does understand that it is a

chronic condition, but it is going to take some hard work and diligence on her part to take care of it.”

Lilly not only has these external struggles with developing a routine, but she also has difficulties internally with self-efficacy that impact establishment of a new routine into an already adjusted way of life. She knows how to care for herself and realizes that her condition is chronic and life-long, but her confidence and motivation interfere with her success to transfer from an adjusted way of life to a healthier way of life. Lilly reports she knows what to do, but observations at home and in the community revealed she did not wear her garments in the community or when she participated in daily activities at home. She wore her garments during the initial interview, however, during the second interview.

Lack of awareness across health professionals. During the interviews, the participants explained how lack of awareness across health professionals has impacted treatment options and available resources that could provide therapists and patients with information about how to approach and provide the best treatment options. The lack of awareness contributed to sub-themes: lack of research and knowledge about PL-IL. The lack of awareness, research and knowledge lead to delayed treatment for Lilly, which linked to her difficulty establishing a routine.

The participants described the lack of awareness as uncertainty of how to approach treatment for patients with PL-IL. The uncertainty is linked to lack of research and knowledge about PL-IL. Health professionals realize there is something wrong but are not sure how to safely treat patients with PL-IL. Lilly reported, “Obviously there is something wrong, but they were never willing to figure out what they could do to help. Instead of saying, let’s try this or I’ll send you to someone else, nothing was done.” Lilly’s mother suggested, “If your doctor is not

sure, get another opinion. If the therapist doesn't want to touch her, find another one. Always keep asking questions.”

PL-IL is so rare that many clinicians have not come across it in treatment. Health professionals are not aware of the symptoms or precautions that accompany PL- IL, so they may not be aware of the additional concerns associated with PL-IL, which could result in the patients not receiving treatment for their PL. Lilly reported, “The doctor plays a big role ... but what if your doctor doesn't know about lymphedema? Well, it goes untreated ... gets worse instead of catching it as soon as possible and managing it and learning the steps.”

The health professionals need knowledge of PL-IL to identify the need for additional testing, such as a MRI, to determine direction of fluid drainage. By not identifying the direction of fluid drainage initially, additional time consuming appointments before intensive therapy may be required. The extra steps needed to receive the specialized therapy affect early treatment and type of treatment patients receive. Lilly's mother reported,

The first time we were supposed to go to intensive therapy through our own insurance, that therapist didn't even know what she was doing. So once we got another intensive therapy treatment approved, we couldn't do it because it hurt my daughter too much. So we looked into more options, but now we are to the point that we have used up all of our intense therapies for once in a lifetime.

If awareness of PL-IL was increased, then therapists and patients would be more motivated to gain knowledge of PL-IL. Lilly reported,

The National Lymphedema Network Conference really inspired me because I

could see the before and after. Having all the doctors there really brought to my attention all the different options out there. Knowing that you are not the only one in the world gives you a sense of relief.

Lilly's mother agreed with Lilly's statement by stating, "It was nice to hear another pediatrician who really knew what he was talking about and learn more about it."

Lilly's OT reflected on the importance of research, awareness and education for PL-IL. It can get pretty involved ... making sure the treatment you are doing is safe. More research is needed for all lymphedema care, but especially for the pediatric population and especially for diagnoses that are rare. For people to know there is hope and treatment available for kids to improve their quality of life and improve their functional independence. For patients to find motivation in someone else's struggle.

For occupational therapists that treat PL to just have the knowledge of what PL is, how they can go about treating it, and level of involvement. For providers to provide some sort of reference point for how to initiate therapy and engage pediatric patients with treatment.

Receiving treatment from a certified therapist who treats individuals with PL is a key factor to successful outcomes. Lilly reported, "When we saw my current OT and she is lymphedema certified, that was a key factor. She knows what to do because she works with it every day." Lilly mother reported, "I wanted someone that would show me, tell me, and guide me in the right direction for how to do MLD, garments and not just hand me paperwork to go home and read."

The more opportunities for educating and communicating with other health professionals, the more awareness will develop for patients and the medical field. Lilly's mother reported, "She

keeps learning more about herself and lymphedema in the community and teaching the community, she will wear compression garments and educate people.” Lilly’s OT stated, “I think by teaching others, she is seeing what she needs to do to take care of herself. I think the doctor and specialist need to communicate a lot to work out what is best for their patient.”

Need for Customized Treatment. During the interviews, the importance of customizing treatment due to rarity of PL-IL was described. Customized treatment was defined as modifying treatment methods typically used for PL to accommodate for the additional lymphatic changes associated with the IL, conquering treatment challenges related to treatment tolerance, and addressing keys to success. Supportive evidence was provided by observations and documented treatment activities that demonstrated frequency with, which those activities occurred over the course of 90 occupational therapy treatment sessions.

Therapists need to understand that treatment needs to focus on both diagnoses, PL and IL. Lilly’s mother stated,

It isn’t just the lymphedema in her arms. She has other things too. Everybody is different and she is different because she has other issues. She is not just a lymphedema issue. It is other things we have to watch out for ... that put us behind.

Possible keys to success for increasing tolerance and outcomes are taking the extra steps to find answers. Lilly’s mother reported, “After we found out about the MRIs to see where the fluids were going, we got to look at it differently, so our goals are different now. The fluid does not need to be where it is.”

Treatment needs to be customized for Lilly so she can tolerate CDT treatment to achieve reduction. Lilly’s OT describes Lilly’s tolerance, steps taken and customization of CDT treatment:

When I first met her, we were doing weekly intensive compression bandaging, which she did not tolerate very well, so we had to modify treatment a great deal for her to tolerate the type of compression we have been doing. Maybe there is a reason it is painful and she can't handle it. I would bandage her for a week straight, but ... it is pretty painful for her and she won't keep the bandages on. Bandaging would reduce far better than compression garments. Compression garments are going to kind of hold her.

The therapists documentation for Lilly's course of treatment included data from nine different treatment activities including, MLD, compression bandaging, kinesio tape application, caregiver training, skin care, exercise, practice of activities of daily living (ADLs), sequential circumferential measurements of both upper extremities, and custom garment fittings.

Percentages of treatment activities were calculated to represent the frequency for each treatment activity that occurred over 90 treatment sessions (Figure 1). The percentages indicated do not represent time of therapy used to complete each activity, but rather the frequency of occurrence over the 90 treatment sessions.

MLD occurred during 94% of treatment sessions. MLD was applied more often than other treatment activities within the data collection period due to MLD being the most preferred and tolerated treatment activity by Lilly. Kinesio tape application occurred one time within the data collection period, but due to Lilly's decreased tolerance to pain associated with its application, the activity has not been repeated. Also, compression bandaging occurred less often than MLD due to limited pain tolerance required for best outcomes. Sequential circumferential measurements, as well as custom garment fittings, take 50 minutes to complete, therefore these treatment activities occurred less often. Also, Lilly's OT reported that Lilly performed exercise at home and in the community and thus was not represented by clinic data.

Bandaging has never been a tolerable treatment method for Lilly as evidenced by documented occupational therapy records. Modifications have been successful to lessen pain and discomfort when bandaging, but traditional CDT bandaging is still not an option for Lilly. Lilly reported during an observed treatment session that she was tolerant of daily skin care and use of night time garments two nights a week, but not to traditional short stretch bandaging. Lilly's mother reported, "It seems tighter on her and she is in more pain. But now that we are bandaging over the nighttime garments, she doesn't have that pain."

Not only does treatment need to be modified to yield results, CDT treatment has to be approached carefully due to medical concerns of where fluid may be going. Lilly's OT used MLD to push fluid proximally to distally starting with the chest, neck and progressing down the extremity to the fingertips. She takes this medical precaution due to uncertainty of where Lilly's fluid is draining due to the missing lymphatic system duct. Lilly's OT also used a special urea cream to hydrate and condition her skin following treatment. Lilly's OT reported,

If we were doing a lot of decongestive therapy that fluid is eventually going to be pushed into organs and need to be processed by kidneys and go through the blood vascular system. We found she is missing something called the chylous duct ... a lot of the fluid we are pushing traveled potentially under the muscle fascia. So, we are able to get a reduction, but she is probably not maintaining that reduction because she is missing some vital components to her lymphatic system. She has some ascites, ... which is a concern. If we are pushing fluid from her arms, we want to avoid overwhelming the heart, the lungs or the abdominal cavity with fluid. My precautions and protocols are mostly medically oriented.

Outcomes are defined differently for patients with PL-IL. Sequential circumferential measurements were documented at the beginning and end of one treatment session during the data collection period to show specific outcomes of MLD after one application. MLD was modified from 20 to 50 minutes during one treatment session to allow for MLD treatment and measurements to be taken of both extremities; however, MLD is typically completed for 50 minutes (25 minutes for each upper extremity). Lilly's right upper extremity measured before MLD at 4826.26 mL and after MLD at 4632.46 mL, indicating a 194.22 mL reduction of the right upper extremity. Left upper extremity measured before MLD at 4770.58 mL and after MLD at 4663.89 mL, indicating a 106.69 reduction of the left upper extremity. The OT reported that the left extremity was frequently more swollen than right upper extremity thus providing different outcomes for each extremity. Even though MLD was modified, Lilly still showed reduction in lymph volume of both extremities. Lilly's OT stated,

Measurable outcomes are harder to track, but in terms of the health of her tissues, even if they are still larger, would be a better outcome. If she is infection free with healthy tissue and ultimately being reduced, then that is a good outcome. If we can get her to maintain where she is at and also get her more compliant, ... get a better reduction. For her ... maintenance is progress and even just small amounts of progress at a time ... as long as she is not getting worse."

Customized treatment needs to include a person's preference, self perception, and level of comfort. Lilly stated, "It just looks too medical. It feels like a medical device, where if it was a cool design or color, I think other people and even kids would be more, let's put on our garments." A person's self-perception can influence their decision to wear compression garments in the community. Lilly's OT stated, "I think her primary factors that inhibit her are the

insecurity about the garments, the pain with the bandaging.” The level of comfort can impact the effectiveness of the treatment methods. Lilly’s OT stated, “Garments are measured so large ... accommodate for her size ... if they get too tight she won’t wear them. We have customized the custom to the best of our ability ... to get her into a garment that is appealing and effective.”

Well-adapted individual. Interviews with all three participants revealed Lilly is a well-adapted individual in spite of the PL-IL, which can interfere with daily functional ability to participate in activities. Since Lilly has grown up with PL-IL, she has adapted to the diagnosis to fit into her life and not allowed PL-IL to control her life.

The Quality of Life Scale was administered during treatment two sessions. Lilly scored 16 out of 16, indicating, according to Burckhardt and Anderson (2003), that she has no difficulty with physical well-being, relationships with other people, social, community activities, personal development fulfilment, recreation or independence.

Lilly’s Quality of Life Scale score was supported by observations of participation in activities at home, including jacket don and doff, brushing teeth, make-up application, hair grooming, and keyboarding. She did not wear compression garments during any of the observations. She alternated equally between both upper extremities to complete activities. Her jackets have been modified by sewing pant legs onto arm sleeves to accommodate for her swollen upper extremities. She reported no difficulties while performing any activities but does prefer not to wear compression garments during activities due to comfort, limited circulation, effects on her range of motion, and finger sleeves that limit her functional ability. Lilly stated,

I think I have adapted, but since I have lived with it all of my life, I don’t really know any other way, but I don’t think it has affected me. I think since I have lived with it all

my life, I don't really know a difference. I don't know what it feels like to not have lymphedema and not do anything without lymphedema.

Lilly's mother stated, "She knows her limits. She knows what she can and cannot do and she has always been that way. If something is going to put her where ... she is going to get hurt, she will not be in that situation."

Lilly's OT discussed her overall functional independence.

She absolutely astounded me because she was so functionally independent and had such a severe health condition. I was surprised a 15 year old could go that long without having care for her arms that were quite edematous. I saw a pretty happy, well-adjusted, young woman. Her range of motion is great with her arms. She really doesn't have any limitations. Her fine motor is even magnificent with swollen fingers. She is such a driven, productive, human in society, regardless of this disfiguring condition. She has lived with it for so long, she has some really good coping mechanisms. She has adapted to having severe upper extremity edema and she is also well-adjusted it terms of ... of a typical 15 to 17 year old.

PL-IL may not interfere with Lilly's functional ability, but PL-IL has impacted with her self-perception in the community. Lilly was observed while competing in a tennis match at school. She did not wear compression garments before, during or after the tennis match or use any adaptations to equipment. She reported no weakness or pain during the tennis match. She kept her sweatshirt pulled over her hands and did not remove her sweatshirt at any time during the match. Lilly's mother reported, "What we do now is just make sure her shirts and stuff go over her garments and are long enough so people can't see them."

Discussion

Lifelong adjustment to establishing a routine, lack of awareness across health professionals, need for customized treatment, and well-adapted individual are prevalent themes that appear to define PL-IL for Lilly, her mother, and Lilly's OT. The interviews provided the foundation for the themes, and the occupational therapy records and observation data provided supportive data for the themes.

One of the interesting paradoxes is the theme related to life-long adjustment to establishing a routine. Lilly recognizes the need to change to achieve and maintain a successful routine, but she is conflicted by her need for continued guidance from her OT in order to make a change. She also struggles with the idea of adjustment and how to incorporate a new way of life into an already existing way of life.

Compromises and responsibility on the part of Lilly and her mother must be maintained to establish a routine. Lilly has made compromises in her clothing, diet, and activities due to PL-IL, however, adjustments in time devoted to daily treatment activities still needs to be carefully considered and incorporated. PL-IL should not define the person, however, lifelong adjustment to the challenges and demands of living with PL-IL are essential for Lilly's overall health. Compromises with time leads to more responsibility, which could prevent negative effects such as infection. Treatment and routines can be overwhelming at first, but once established and practiced daily, routines can become manageable.

Lilly did not receive specialized occupational therapy services for PL-IL due to lack of awareness of her condition. According to Symvoulakis, Dimitrios, and Anyfantakis (2010) and Hodges (2009), due to some physicians' limited awareness of PL, the patient suffers with their condition for a long time without a diagnosis, whereby the delayed treatment is an important

contributor to the ineffective management and increases likelihood of complications for patients with PL.

The lack of research available and communication among health professionals about PL-IL limits the extent of education available for patients and medical providers. According to Symvoulakis et al. (2010), a close collaboration among health professionals, with a high level of awareness, may help promote optimal overall management of persons with PL. The lack of research and communication leads to uncertainty about signs and symptoms and how to administer treatment to pediatric individuals with PL-IL. Unfortunately, this uncertainty also leads to patients receiving inadequate and improper care from providers who do not have the specialized education to offer the most valuable and accessible treatment for these patients. Patients become discouraged that specialized treatment, as evidenced by Lilly in this case study, is difficult to attain, and if found, might not be covered by insurance, leaving patients without specialized early intervention treatment options. According to Weissleder and Schuchhardt (2001), CDT started in the early stages of the disease produces the best results. A solution to the lack of accessible lymphedema specialists, who are knowledgeable about PL-IL, would be to include IL education as a part of the certification process for lymphedema specialists.

Not only has Lilly face challenges related to lack of awareness across health professionals, she also needed to adjust habits and routines. However, a lack of motivation is connected to her comfort and struggle with tolerance to treatment activities, which has contributed to maintaining lymph volume in her extremities, but has not resulted in significant lymph volume reduction. The lack of lymph volume reduction has impacted Lilly's competency and reassurance that she could effectively manage her condition for a life-time without the assistance of her OT.

Lilly needs customized treatment since she has the dual diagnosis of PL-IL rather than PL alone. The missing chylous duct, as well as the unknown direction of the lymphatic fluid drainage, complicate traditional CDT treatment. Lilly's treatment has been customized so she can tolerate bandaging and wear compression garments, however, she still does not comply with wearing compression garments outside the home or during functional activities.

Lilly is well-adapted and functionally independent, but lacks some psychosocial aspects necessary to adjust her habits. The lack of competence and self reassurance is linked to Lilly's psychosocial issues, which contribute to her lack of self-efficacy to establish and maintain a routine. She requires supervised management of her lymphedema to prevent future complications and to maintain her health. She is not independent in the management of PL-IL nor does she comply to wearing compression garments in the community due to issues with self-perception. She knows what to do and how to do it, but struggles with confidence and self-assurance to maintain success without guidance.

According to Symvoulakis, Dimitrios, and Anyfantakis (2010), physicians need to assess not only the severity of the physical limitation but also the related psychosocial aspect and consider the burden PL can have on effective interventions. Individuals with PL-IL not only have difficulties with compliance to treatment protocol due to difficulty establishing a routine, but they also have psychosocial limiting factors, such as self-efficacy and self-perception which impact motivation.

Psychosocial issues such as self-efficacy and self-perception should be examined by future researchers to determine the effectiveness of therapeutic relationship and use of therapeutic use of self and how it could impact confidence and management of life-long chronic conditions. Occupational therapists understand the need to modify treatment methods such as

CDT. However, it would be interesting to see how therapeutic use of self could be used to provide motivation and confidence so clients can adjust habits and routines to better manage chronic conditions such as PL-IL.

Implications for Occupational Therapy

Occupational therapists should educate, communicate, collaborate, and advocate for their clients with PL-IL to increase awareness and knowledge about PL-IL so future patients may not have to go through the same struggles as Lilly. If PL-IL is recognized early by recognizing the signs and symptoms, then routines can be established earlier and life-long adjustment limitations could be minimized.

Individuals diagnosed with PL-IL face complications related not only to PL but to IL as well, making CDT treatment approaches more complicated. It is essential to remain client centered and provide the client with options for treatment. This approach will permit the creation of a routine that the patient will be comfortable with and compliant to. If CDT treatment is modified, it will better meet the demands of these individuals experiencing PL-IL.

A person's quality of life is not only measured by their ability to be functional but by their self-perception and self-efficacy needed to maintain changes to establish routine. A person needs to be independent in his or her life as well as their care to promote lifelong adjustment success. A routine is harder to develop once adaptation has been established, but compromise can lead to better outcomes for the individual. It just may take time to establish a new routine into an already existing functional way of life.

Limitations

The study would have benefited from three interviews versus two with each participant to clarify themes revealed from the second interviews. The inclusion of third interview for each

participant would have allowed member checking of supportive evidence from the second interviews.

Future Research

Health professionals treating people with PL-IL would benefit from more studies on individuals with PL-IL to examine the effects that early intervention could have on the development of routine and compliance to treatment activities. This study attempted to acknowledge the importance early intervention could have on routine and quality of life but no conclusions could be made due to Lilly not receiving early intervention services. Possible implications for how early intervention could make a difference on self-perception and maintaining lifelong adjustment would be beneficial for future therapists to understand in order to effectively treat individuals who face similar issues. Health professionals should address occupational therapy treatment approaches to provide these individuals with an opportunity to continue living life to the fullest extent possible.

Health professionals could develop a single subject design protocol that could be used with a series of patients with PL-IL to provide evidence of effective or non-effective treatment protocols. Evidence could include sequential circumferential measurements and therapy units used for each treatment activity during treatment sessions to determine frequency over time and outcomes of treatment activities.

Conclusion

The purpose of this case study was to describe the course of treatment for PL-IL through the experience of Lilly, an individual diagnosed with PI-IL. By exploring the experiences of Lilly, her mother, and her OT, an insider's perspective has been documented and made available to those who may face similar challenges and may keep persons with PL-IL from encountering

the same issues in seeking effective specialized occupational therapy treatment. This study provides an educational source for therapists who treat pediatric clients to help determine the course of treatment for these individuals. This study also revealed factors regarding achieving lifelong adjustment and routine with treatment activities. A person's age, tolerance, and time should be considered and modified to best fit the patient to maximize compliance. Psychosocial factors need to be considered in the treatment process. Psychosocial factors such as self-efficacy and self-perception limit effectiveness of intervention outcomes. By receiving specialized care and modified CDT treatment, these individuals could establish more effective routines and better maintain lifelong adjustment to treatment activities to produce more successful long-term outcomes. By describing the course and experience of Lilly's treatment process for PL-IL, it has been shown that ongoing occupational therapy treatment interventions such as CDT can be modified to produce more effective and safe outcomes to promote more functional, meaningful, and quality lives for individuals with PL-IL.

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Appendix A

Lilly's first interview questions date and time: February 9, 2011 at 4:00 to 5:00pm.

Interview consists of structured questions such as:

- In your own words, please describe your diagnosis?
- What resources did you find helpful when learning about your diagnosis?
- How has your diagnosis affected how you live your life?
- How has this diagnosis affected your independence in daily activities?
- What is your understanding of what occupational therapy is?
- What perceptions about treatment did you have after your first meeting with your occupational therapist?
- What is the best approach for communicating information to you about your treatment?
- What goals did you seek for yourself to achieve from therapy before you started therapy?
- Did those goals change once you started therapy? How and Why?
- How can therapy help you to achieve those goals?
- Describe the course of your treatment.
- Do you have any concerns about your treatment or the process of treatment?

Explain?

- What have you learned about yourself through the treatment process?
- Do you feel following treatment protocol is important? Why or why not?
- What helps motivate or gets in the way of your motivation to follow protocol?
- As the patient, how would you reflect on the effective and ineffective treatment outcomes?
- How have these effective and ineffective outcomes of therapy impacted your life?

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- Do you feel therapy is beneficial for you (due to risk of infection, risk prevention, preventing form getting worse)? In what ways?
- How has having your family involved (mom, dad, grandmother) impacted your treatment?
- How involved are your friends?
- How comfortable are you with wearing your garments around your friends?
In the community?
- After going to conference, how did being exposed to other individuals with similar diagnoses change your view of your diagnosis?

What impacted you the most by going to conference?

What difference did it make to how you view treatment?

Have you made any changes to how you follow treatment protocol after going to conference?

- Since starting OT, when people ask you about your day, how has your answer changed from before you were receiving services to now?
- Once you go to college, will you still go to therapy?
- How do you think your compliance will be once you leave home and move to college (will you still follow through with protocol)?
- What have you learned about occupational therapy so far from this experience?

Lilly's Mother's first interview date and time: February 9, 2011 at 5:00 to 6:00pm.

Interview consists of structured questions such as:

- In your own words, please describe your daughter's diagnosis?
- What resources did you find helpful when learning about this diagnosis?

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- How has your daughter's diagnosis affected how you live your life?
- How do you believe this diagnosis has affected your daughter's independence in daily activities?
- What is your understanding of what occupational therapy is?
- What perceptions about treatment did you have after your first meeting with your daughter's occupational therapist?
- What is the best approach for communicating information to you about your daughter's treatment?
- What goals did you seek for daughter to achieve from therapy before you started therapy?
- Did those goals change once therapy started? How and Why?
- How can therapy help your daughter achieve those goals?
- Describe the course of your daughter's treatment.
- Do you have any concerns about treatment or the process of treatment?

Explain?

- What have you learned about yourself and your daughter through the treatment process?
- Do you feel following treatment protocol is important? Why or why not?
- What helps motivate or gets in the way of your motivation to follow protocol?

Your daughter's?

- As the parent, how would you reflect on the effective and ineffective treatment outcomes?
- How have these effective and ineffective outcomes of therapy impacted your life?

Your daughter's?

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- Do you feel therapy is beneficial for your daughter (due to risk of infection, risk prevention, preventing form getting worse)? In what ways?
- How has having your family involved (husband, mom) impacted your daughter's treatment?
- How involved are your friends?
- How comfortable do you believe your daughter is with wearing her garments around her friends?

In the community?

- After going to conference, how did being exposed to other individuals with similar diagnoses change your view of your daughter's diagnosis?

What impacted you the most by going to conference?

Your daughter?

What difference did it make to how you view your daughter's treatment?

Have you made any changes to how you enforce or follow treatment protocol after going to conference?

- Once your daughter goes to college, will she still go to therapy?
- How do you think her compliance will be once she leaves home and moves to college (do you think she will follow through with protocol)?
- What have you learned about occupational therapy so far from this experience?

Lilly's occupational therapist first interview date and time: February 16, 2011 at 3:00 to 4:00pm. Interview consists of structured questions such as:

- Describe your client's course of treatment.
- What perceptions did you have about this client after first seeing her?

Meeting her family?

- What is the best approach for communicating with your client?

With the family?

- What goals have you set for yourself to achieve with this client in therapy?
- What goals has your client set for herself to achieve in therapy?
- Since this is such a rare diagnosis, what if any concerns in providing treatment to this client do you have?

What preliminary precautions or protocols did you take/ follow initially with this client?

Currently?

- How do you communicate with your client's doctors to coordinate treatment?

How do you access your client's past medical treatment?

Do you find this information helpful for your treatment? How?

- What resources do you find helpful when learning about this diagnosis?
- How has treating this rare diagnosis impacted your view of occupational therapy treatment and outcomes?
- How do you apply therapeutic use of self when treating this client?
- How has having your client's family involved (mother, husband, grandmother) impacted your client's treatment?
- As the treating therapist, how would you reflect on the effective and ineffective treatment outcomes?
- Do you feel therapy is beneficial for your client (due to risk of infection, risk prevention, preventing from getting worse)? Why or why not?

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- How important is following treatment protocol?
- How do you motivate your client to participate in therapy/ follow protocol?
- What do you believe impacts a client's ability to have a functional, meaningful, and quality life with this diagnosis?
- How important is early intervention?

Why do you feel early intervention is important?

- How do you express the importance of early intervention and life-long management to your clients?
- After going to conference, how did being exposed to other individuals with similar diagnoses influence your client's view of her diagnosis?

What difference if any did attending conference make to how you go about providing your client's treatment?

Have you made any changes to your treatment protocol after going to conference?

- What do you believe this study will bring to occupational therapy?

Lilly's and her mother's second interview date and time: March 7, 2011 at 4:30 to

6:30pm. Interview consists of structured questions such as:

- Intense treatment at first but now since know more about treatment- would bandaging be a possibly for treatment? Why or why not?
- If bandaging as well as wearing compression- do you believe you would see more of a difference in reduction?
- Would treatment be more beneficial?
- Is wearing compression in the community a possibly if it is comfortable garment?
- Attractive garment?

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- Unnoticeable?
- How can the garment be altered to make you feel more comfortable wearing the garment in the community?
- What can be done in treatment and outside of treatment to help build a routine?
- How can this study reach out to others who may be experiencing similar problems (lack of knowledge, difficulty developing routine)-
- How can your experience help others avoid these difficulties?
- What is the best thing that can come from this study?
- What else needs to be done to educate others about this diagnosis?
- What opportunities to learn should be provided?
- What are they?
- What do you feel needs to be done to improve treatment outcomes?
- The ideal garment for you would look like?
- Do you feel it is difficult to keep your diagnosis separate from your life (friends, activities) is it a concern?
- How can this be overcome?
- If you were meeting someone for the first time, how would you describe you diagnosis; your experience? (person with lymphedema and without)
- Would you recommend treatment?
- What do you feel is the most important part of treatment?
- How can the importance of therapy be promoted?
- How do you advocate for yourself to the insurance company?
- Get more services?

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- Express benefits?
- How hard is it to find a lymphedema specialist?
- How many are in the area?
- How did you find Heidi?
- How important is ongoing treatment and lifelong management?
- How can you be successful?
- Do you know what CDT is?
- What parts of it do you find the most successful?
- Easy to manage?
- How can treatment make you more functional?
- Build self confidence?
- Does your diagnosis impact your quality of life?
- Treatment impact quality of life?
- How positively or negatively?
- Gaps in treatment due to insurance impact routine?
- If able to consistently get to treatment- what difference do you believe this would have made?
- How can you overcome insurance limitations?

Lilly's occupational therapist's second interview date and time: March 9, 2011 at 4:00 to

5:00pm. Interview will consist of structured questions such as:

- Intense treatment at first but now since know client's more about treatment- would bandaging be a possibly for treatment? Why or why not?
- If bandaging as well as wearing compression- do you believe you would see more of a

difference in reduction?

- Would treatment be more beneficial?
- Do you believe wearing compression in the community is a possibility if it is comfortable garment?
- Attractive garment?
- Unnoticeable?
- How can the garment be altered to make her feel more comfortable wearing the garment in the community?
- What can be done in treatment and outside of treatment to help build a routine?
- How can this study reach out to others who may be experiencing similar problems (lack of knowledge, difficulty developing routine)-
- How can her experience help others avoid these difficulties?
- What is the best thing that can come from this study?
- What else needs to be done to educate others about this diagnosis?
- What opportunities to learn should be provided?
- What are they?
- What do you feel needs to be done to improve treatment outcomes?
- What would the ideal garment for her look like?
- Do you feel it is difficult for her to keep your diagnosis separate from your life (friends, activities) is it a concern?
- How can this be overcome?
- If you were meeting someone for the first time, how would you describe her diagnosis; your experience? (person with lymphedema and without)

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- Would you recommend treatment?
- What do you feel is the most important part of treatment?
- How can the importance of therapy be promoted?
- How do you advocate for your client to the insurance company?
- Get more services?
- Express benefits?
- How hard is it to find a lymphedema specialist?
- How many are in the area?
- How did she find you?
- How important is ongoing treatment and lifelong management?
- How can she be successful?
- What parts of CDT do you find the most successful?
- Easiest to manage?
- How can treatment make her more functional?
- Build self-confidence?
- Do you believe her diagnosis impacts you're her quality of life?
- Treatments impact her quality of life? (intensity, lack of)
- How positively or negatively?
- Gaps in treatment due to insurance impact routine?
- If able to consistently get to treatment- what difference do you believe this would have made?
- How can you overcome insurance limitations?
- Is there a difference in reduction and management for school schedule versus summer?

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How?

- What do you believe impacts the difference

Appendix B

Observation Field Note Guides

Clinic Observations:

- Measurements before treatment-
- Measurements after treatment-
- Treatment method-
- Education/ training-

Client-

- Caregiver-
- Process of treatment-
- Compliance to treatment-
- Precautions taken-
- Therapeutic use of self-
- Effectiveness of treatment-
- Preferred treatment-
- Special equipment-

Community Observations:

- Garments before-
- Garments during-
- Garments after-
- Dominant UE-
- RUE used mostly to-
- LUE used mostly to-

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- Adaptations to equipment or uniform-
- Precautions taken-
- Any weakness or pain-
- Where-
- Perception of self around others-

Home Observations

BUE Dressing/ jacket

- How completed-
- Which arm used first-
- Use both UE-
- Adaptations used-
- Jacket modified by-
- Any difficulties-
- Wore garments/ how long/ what type-

Make-up Application

- How completed-
- Which UE used mostly-
- Use both UE-
- Type of grasp used-Adaptations used/ if any-
- Any difficulties-
- Wore garments/ how long/ what type-

Hair Application

- How completed-

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- Which UE used mostly-
- Use both UE-
- Type of grasp used-
- Adaptations used/ if any-
- Any difficulties-
- Wore garments/ how long/ what type-

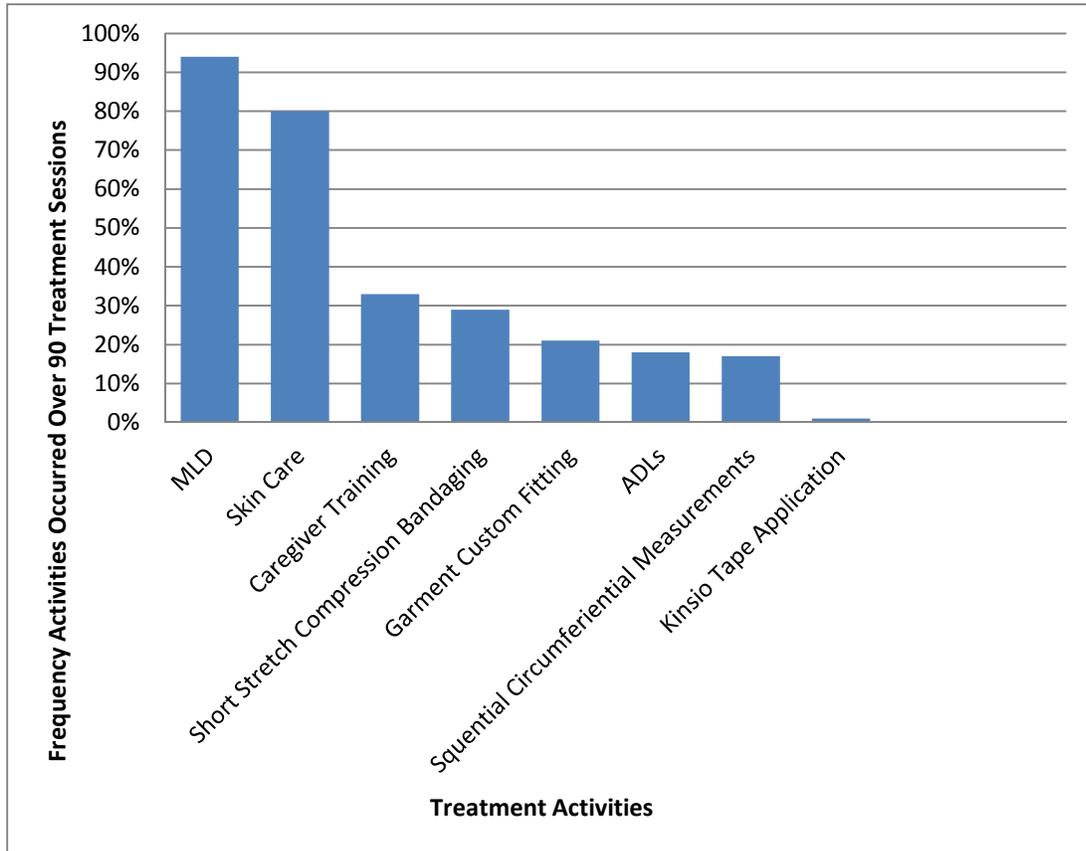
Typing/ Computer

- How completed-
- Which used mostly-
- Use both UE-
- Type of typing style-
- Adaptations used/ if any-
- Any difficulties-
- Wore garments/ how long/ what type-

Table 1

<u>Themes</u>	<u>Key Words</u>
Life-long adjustment to establishing a routine	Routine, time management, struggle, age, uncertainty, confidence, support, motivation, expectations, pain, comfort, choice, suggestions, and compromise
Lack of awareness across health professionals	Knowledge, education, guidance, uncertain approach, certified therapists, accessibility, early intervention, team approach, motivational factors, communication, and support
Need for customized treatment	Rare condition, not just lymphedema, treatment tolerance factors, treatment challenges, medical barriers, fluid drainage concerns, modified MLD, goals, baby steps, and keys to success
Well-adapted individual	Function, independence, well-adjusted, community, social, confidence, and self-perception

Figure 1



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