

“Welcome to my world!”

A Mixed-method Study of Parents’ Lived Experiences in Raising Children with Primary Lymphedema

M. ELISE RADINA, PhD, CFLE

Professor and Chair
Family Science and Social Work
Miami University



Student Research Team

» **MARY MARTIN**

» Social Work major

» **LAUREN RAMSEY**

» Biology major

» **LINDSAY CLARK**

» College of St. Louis, Optometry student

» **ALYSSA ODDO**

» Social Work major

» **DANIELLE JONES**

» Public Health major

» **KRISTIE CORDEIRO**

» Biology major

» **Meghan Day**

» Biology major

» **KAYLIE KAWAMARA, BS**

» Graduate Student, Belmont University

» **RACHAEL HERRIMAN, BS**

» Medical student, Wright State University

» **BRIANA DEER, BS**

» Medical student, University of Missouri- Kansas City

» **SARAH RICH**

» Nursing, Youngstown State



Primary Lymphedema



Study Aim

To gain in-depth understanding of parents' lived experiences of raising children who are living with primary lymphedema.



Data Collection

Participant Recruitment

Surveys

- » Demographic Information
- » Breast Cancer and Lymphedema Symptom Experience Index (Fu, 2009)
 - › Symptom occurrence
 - › Symptom distress
 - › Effect of symptoms on normal daily activities
 - › Effect of symptoms on mood/psychological distress
 - ▶ Parents' perception of child and self-assessment

Semi-structured Interviews

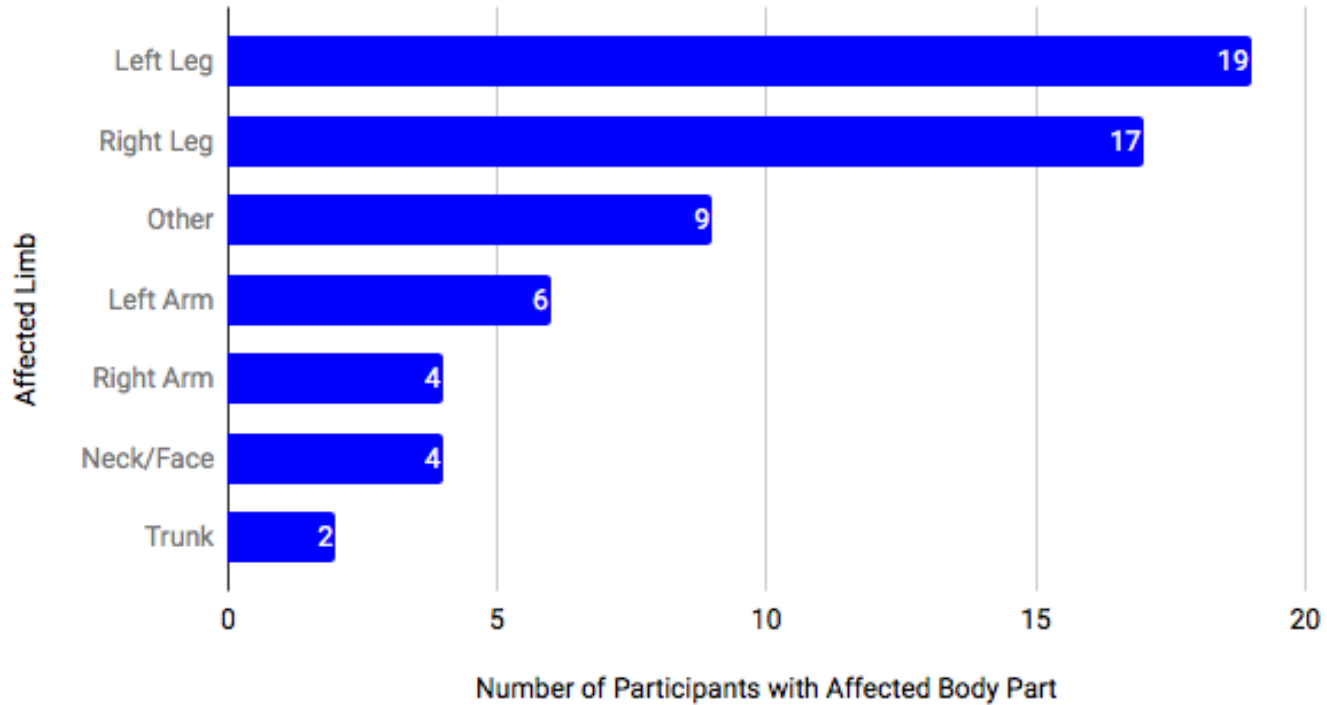


Demographics of Participants and their Children

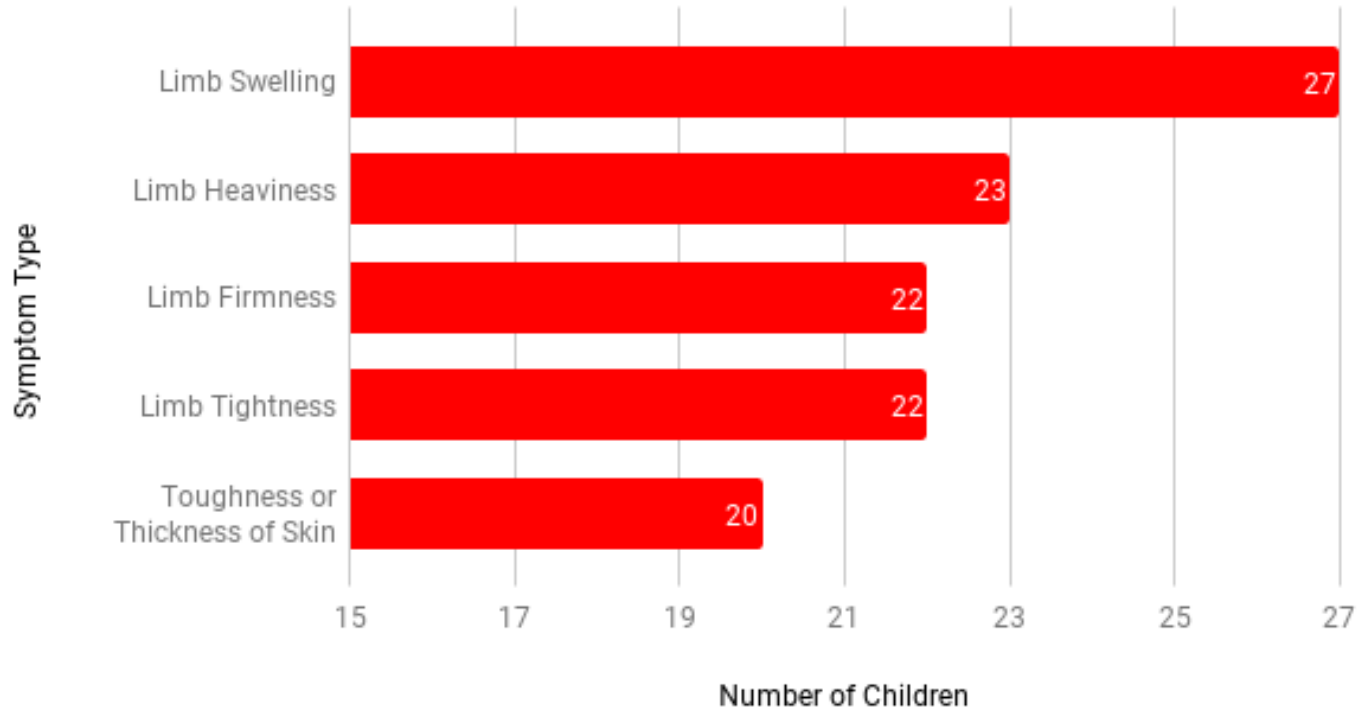
	Parents (N=27)	Children(N=27)
Age	Ages 25-34 (6), 35-44 (11), 45-54 (7), and 55-64 (3)	The mean age was 11
Age of Diagnosis	N/A	15 were diagnosed under 1
Ethnicity	26 white, and 1 other	25 white, and 2 other
Gender	26 females, and 1 male	12 females, and 15 males



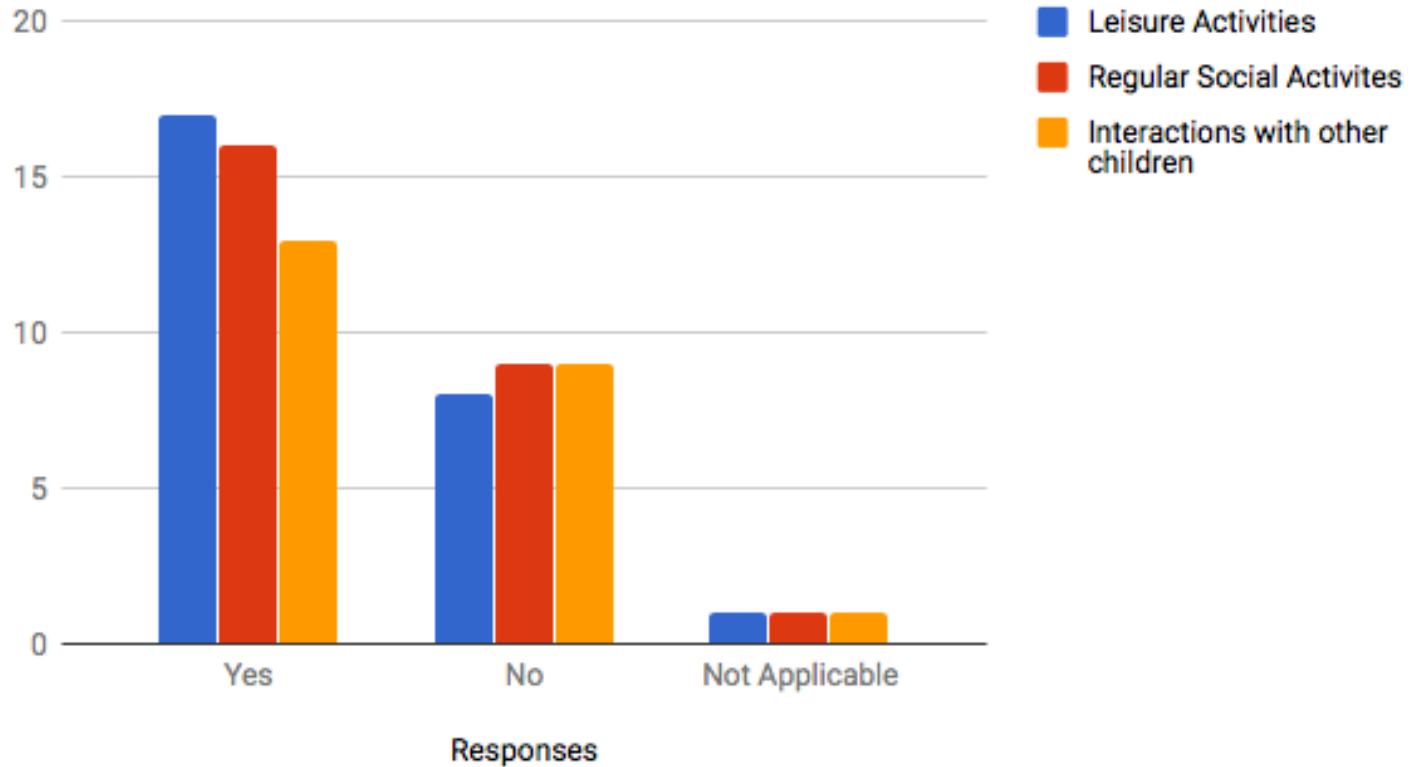
Affected Body Part



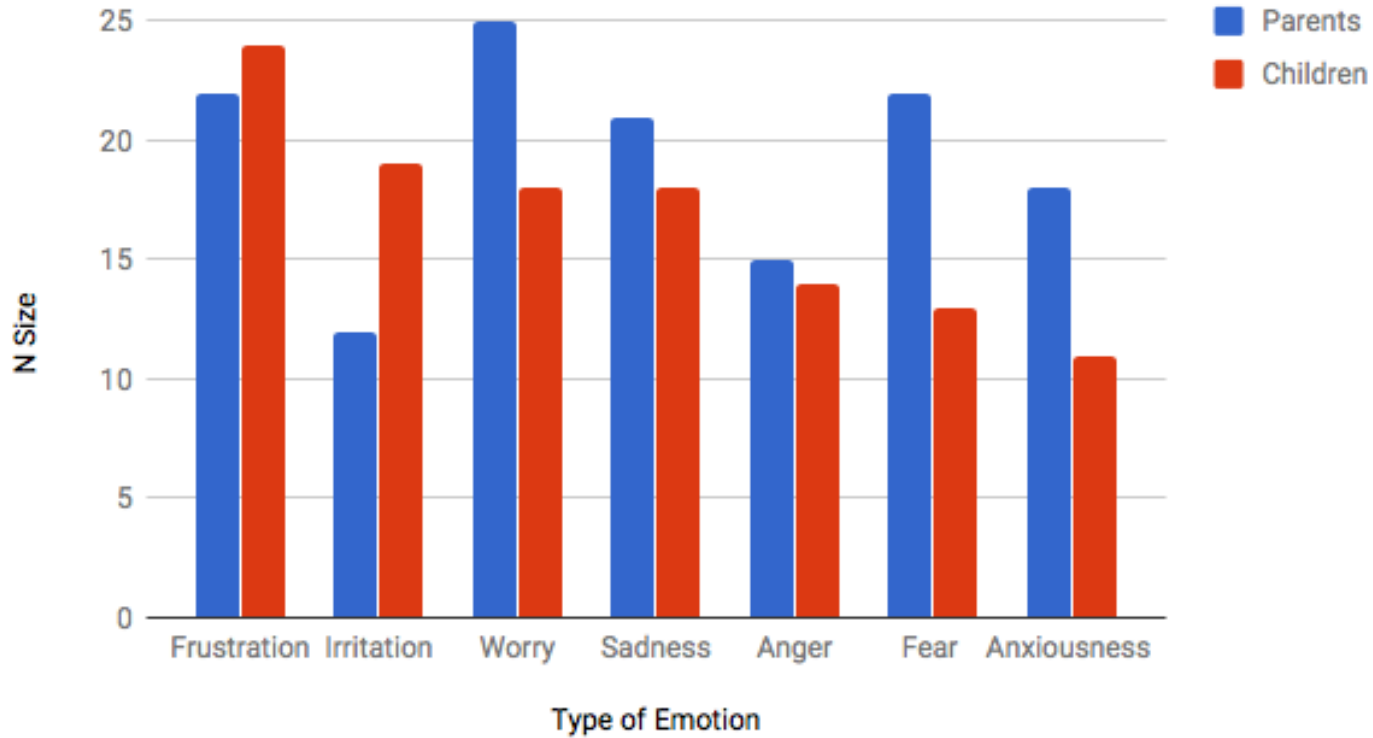
Child's Most Frequent Symptoms



Effects on Child's Normal Daily Activities



Effects on Parent and Child Emotions



Qualitative Analysis Process

Parent interviews (n = 27)

» Preliminary results

Six coders reviewed interview transcripts

For each transcript coders identified major themes

Compared major themes across transcripts to identify overarching themes



Three Major Themes

1. Lack of knowledge
1. Daily Life Changes and Struggles
1. Sources of Support
 - a. Where support was found
 - b. Where support was not given



Conclusions/Future Directions

Raise awareness universally about lymphedema - creating educational resources about lymphedema for parents, children, and professionals.

Future Directions for Research

- » Emotional and interpersonal impact of families' frustrations on the family system.
- » Outcomes of social media/web based resource use and misuse around lymphedema.



Discussion Questions

What theoretical perspectives may be particularly applicable to exploring how families cope with caring for a child with primary lymphedema?

What are some creative ways to engage children like this in learning about lymphedema and advocating for themselves?



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