

Lived experience of having lymphedema after treatment of head and neck cancer: A qualitative study

Coralie R. Arends, Lisette van der Molen, Michiel W.M. van den Brekel, Martijn M. Stuiver, Klaske van Sluis

Department of Head and Neck Oncology and Surgery, Netherlands Cancer Institute. Amsterdam Centre for Language and Communication, University of Amsterdam. Department of Oral and Maxillofacial Surgery, Amsterdam University Medical Centre. Centre for Quality of Life and Division of Psychosocial Oncology and Epidemiology, Netherlands Cancer Institute. Centre of Expertise Urban Vitality, Faculty of Health, Amsterdam University of Applied Sciences.

Quote Theme 1: *“Sometimes I think when things are a bit more tense: ‘Does that also affect my voice more?’ I wonder about that. And I have a bit of tinnitus. I’ve had it since [the lymphedema] started. [...] Sometimes it seems a little worse. And then I think: ‘Does that have to do with the fact that I’m a bit more swollen?’ But I can’t judge that very well.” (Rose)*

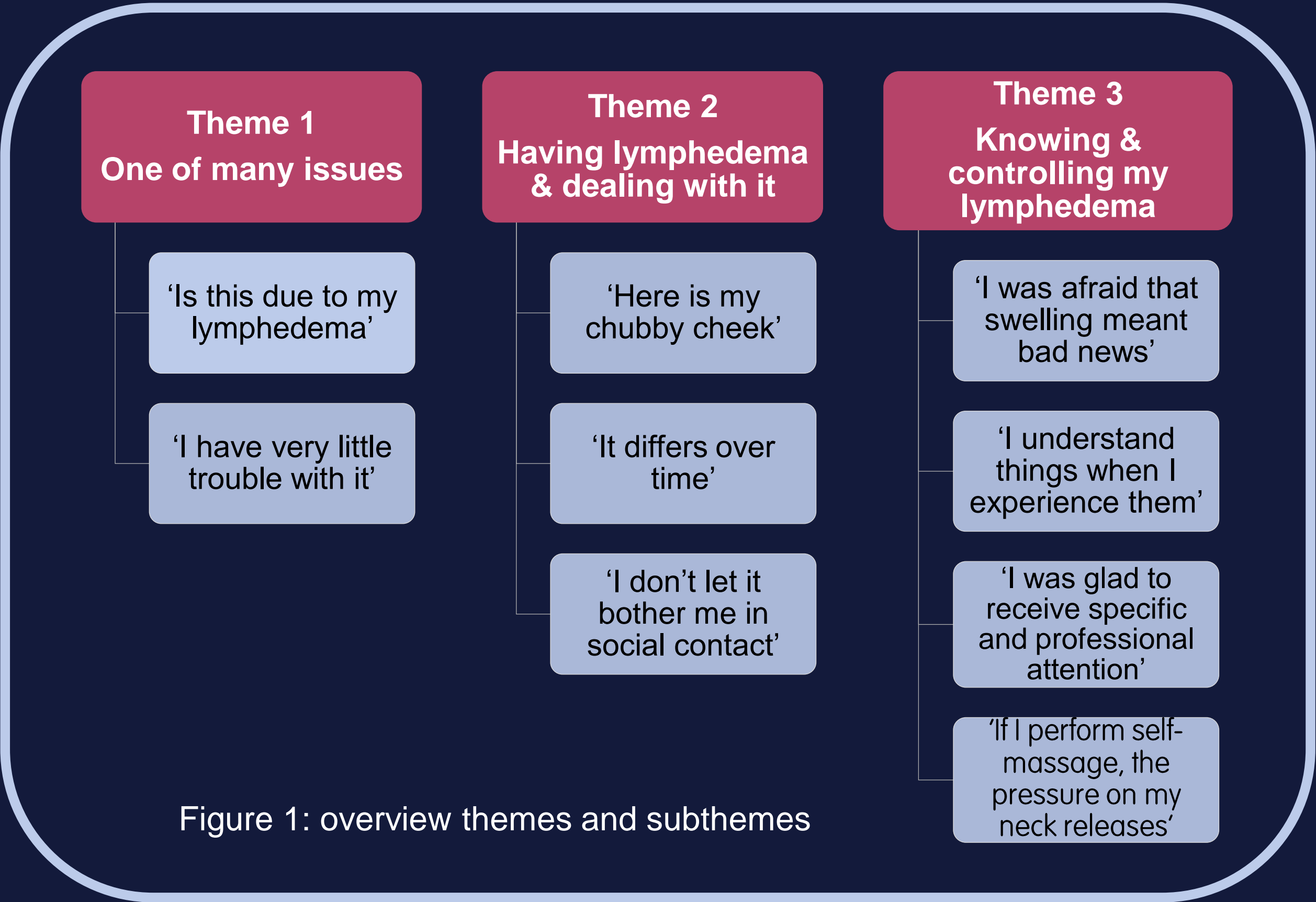
Conclusions: HNL is part of a larger palette of residual symptoms after HNC treatment. Participants showed high therapy compliance and used self-management techniques effectively.

Purpose: To explore the lived experience of patients with head and neck lymphedema (HNL) as a residual symptom after head and neck cancer (HNC) treatment.

Quote Theme 2: *“Horrible. To put it crudely: like having a dog’s head. Like those bulldogs, those square ones, well that’s how I feel as well.” (Alice)*

Methods:

- Semi-structured interviews
- Currently disease-free
- Convenience sampling
- Braun and Clarke thematic analysis



Quote Theme 3: *“I am very busy with it. The swelling puts pressure against the bottom of my skull [...]. I sit like this [shows how he massages his cheeks].... At a certain point, it is as if a door opens, [...] that pressure is gone [...] it is such a good feeling. Quite honestly, a true relief because that pressure is gone. And I am getting better at doing that.” (John)*

Take home message! Timely, accurate information about lymphedema helps reduce patient anxiety, promotes self-reliance, and improves quality of life.