

HEAD AND NECK CANCER SURVIVORS' PERCEPTION OF LYMPHEDEMA CARE

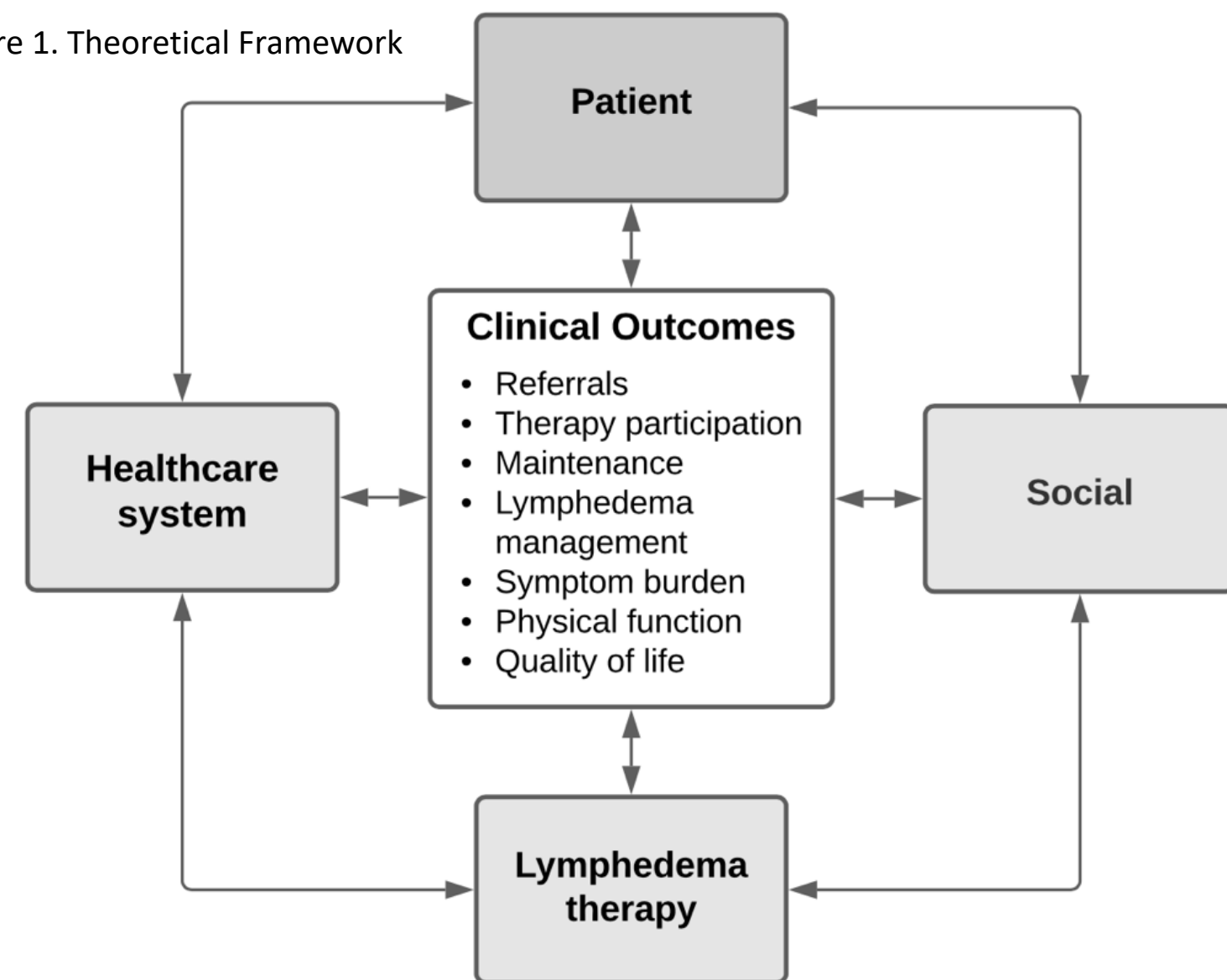
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INTRODUCTION

Secondary lymphedema and fibrosis occurs in > 90% of head and neck cancer (HNC) survivors.¹ Identification and treatment are essential. Treatment of HNC related lymphedema is fraught by numerous barriers.² We conducted a phase 3 randomized multi-site trial in HNC survivors with treatment naïve lymphedema comparing usual care to advanced pneumatic compression device (APCD). Here in we report a qualitative analysis of participants treatment experience.

Figure 1. Theoretical Framework



METHODS

Semi-structured interviews were audio recorded and transcribed after participants completed the 6th-month visit (N=14 usual care, N=23 APCD). Questions addressed treatment experience, perceptions of care, barriers, and facilitators. A hierarchical coding system was developed and refined using the interview guide and preliminary review of the transcripts. Transcripts were coded by experienced qualitative researchers. The coded transcripts were analyzed using an iterative inductive-deductive approach and based on our theoretical framework (Figure 1).

RESULTS

We identified seven major themes pretraining to lymphedema therapy and APCD. Each these revealed barriers and facilitators. These are described below.

Treatment Efficacy

Barriers:

For patients receiving usual care, the perception that they were unable to conduct manual lymph drainage effectively

For patients using the device, failure of the device to cover involved soft tissue

Facilitators:

For all patients, objective and subjective evidence of improvement in lymphedema encourages ongoing therapy

External confirmation of improvement of lymphedema or its sequelae by family, friends and health care providers was encouraging

Self- Efficacy:

Barriers:

For all patients, the lack of knowledge about expected outcomes of therapy

Lack of understanding about how to perform manual lymphatic drainage or use the device

Facilitators:

Providing adequate knowledge and education about various aspects of therapy

Adherence:

Barriers:

Completing priorities and co-occurring therapy negatively impacted adherence for all patients

Facilitators:

Establishing a routine or structure

For usual care, a supportive therapeutic environment and quality education

Motivation:

Barriers:

Lack of therapy efficacy results in decreased motivation

Facilitators:

Evidence of therapy efficacy and symptom relief

For all patients, acceptance of the ongoing need for home self-care of lymphedema

Psychological Response

Barriers:

For the device, patients may experience anxiety

Patient on usual care report frustration associated with lack of self-efficacy compared to CLT

Facilitators:

Communication and quality care enhanced confidence

For the device, patients experienced relaxation and decreased stress

RESULTS, cont.

Daily Life

Barriers:

Interference with vocational and avocational activities

Facilitators:

Increased ease of performing daily activities as result of improved function and decreased symptoms

Satisfaction:

Barriers:

For usual care, logistical challenges (travel, scheduling, ect...)

For usual care, lack of continuity of care and fractured teamwork

For the device, challenges with fit, discomfort and use

Facilitators:

For usual care, a positive therapeutic relationship and quality education

For the device, the logistical convenience of the home setting

CONCLUSION

We identified distinct treatment barriers and facilitators for usual lymphedema care and treatment with APCD. Barriers identified in this study highlight practice changing opportunities to address system issues and develop interventions to enhance care and quality of life. Utilization of both treatment strategies may allow tailoring of treatments thus optimizing outcomes.

Actionable Opportunities:

- Comprehensive education about lymphedema, treatment options, expectations and how to assess response
- Ongoing assessment of patients' manual lymphatic drainage skills
- Help establish a sustainable schedule of self-care
- Provide positive feedback to patients regarding improvement
- Help navigate logistical challenges
- Optimize interdisciplinary team collaboration
- Optimal treatment may include both lymphedema therapy and APCD as these strategies are complementary in their strengths and weaknesses

References:

1. Ridner SH, Dietrich MS, Niermann K, Cmelak A, Mannion K, Murphy B. A prospective study of the lymphedema and fibrosis continuum in patients with head and neck cancer. *Lymphatic research and biology*. 2016 Dec 1;14(4):198-205.
2. Ridner SH, Dietrich MS, Deng J, Ettema SL, Murphy B. Advanced pneumatic compression for treatment of lymphedema of the head and neck: a randomized wait-list controlled trial. *Supportive Care in Cancer*. 2021 Feb;29:795-803.