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Barriers in Cancer Related Experiences: Where OTs Can Fill in the Gaps

Zoe Hoberman-Kelly

Introduction: Residual complications, diminished functional performance, and cognitive hardships are among the myriad of secondary health challenges experienced by cancer survivors (Lage & Crombet, 2011). Late-stage health conditions after cancer-related-treatment including secondary lymphedema can impede multiple dimensions of life.

What is Secondary Lymphedema?

Lymphedema is a protein rich swelling. Secondary lymphedema can be caused by some types of cancers and related treatments (O'Toole et al., 2013). Lymphedema is a disease rather than a symptom, and is chronic and progressive.

Qualitative Research: The aim of this project was to explore patients' experiences of occupational disruptions to health and wellbeing associated with cancer and related-treatment. A secondary purpose was to demonstrate the added value of OT services within the cancer-care continuum.

Methods:

- Qualitative data collection
- Data analysis
- Narratives
- Manual transcription

Participant	Cancer Type	Stage	Lymph Removal	Current Status	Age	
					Onset	Study
Amy-Ray	Breast	III	12 Nodes	Remission	73	89
Caitlin	Breast	IV	17 Nodes	Pancreatic & Liver	61	63
Chris	Stomach	II	None	Remission	75	76
Jackie	Breast	IV	28 Nodes	Stomach	56	57

Navigating Treatment and Care

"Well, it's kind of like the old elephant in the room, you know? Who's got the trunk and who's got the tail? That is really how I felt, and that is how I feel about my Lymphedema. Because they [doctors] are all kind of looking at it (symptoms of cancer) through their own slice, but not as a totality thinking. But it's kind of like, how this whole thing fits together. I think it's um, not a level of comprehensive care you would live to have. You dream of kind of having it, and it is a shot in the dark for most people." –Jackie

Cognitive Decline and Profound Fatigue

"I'll have chemo again on Tuesday and it's going to fatigue me a whole lot more, and then sometimes it will be 2-3 days before I can take a shower because I don't have the energy to do it." -Caitlin

"It kind of makes me mad, you know? That I didn't say to myself 'wait a minute, there is something wrong with me that I am feeling this weak'. To be unable to walk 100-ft. without being totally exhausted? I wasn't smart enough. I didn't put two and two together, I should have known something was wrong." –Chris

Gaps in Care

"Doctors are expected to see more, do less. Expected to handle the psychosocial behavior health because we don't have enough mental health to handle that whole end of it. And they (doctors) are being stuck with all of it. You can't adequately address someone's health when you're expected to address all these problems in a 15-minute visit." – Jackie

Additional Findings: Cancer survivors require increased supportive care services to meet their unique needs including:

- Psychosocial concerns
- Incongruences within care
- Coexisting morbidities
- Education literature

Conclusion: Findings include a patient-driven desire for a more inclusive and intimate level of care. Considerations spanning from initial diagnosis through facilitation of end of life care are important aspects of the disease management process. Increased face to face time with health professionals remains needed. Secondary health complexities continue to impede participation levels, causing compromised quality of life.

Relationship to OT: Supportive teams that are accessible across genders, ages, and socioeconomic demographics are needed for increased evidence-based care services. OTs are able to help alleviate gaps within care and work together with other health professionals to make a more cohesive and supportive cancer-care team.

Narratives suggest there are psychosocial opportunities for OTs to provide supportive services that target mental health hardships, cognitive deterioration and energy conservation techniques.