MULTIFACTORIAL CHALLENGES TO ENGAGEMENT IN LYMPHOEDEMA MANAGEMENT: DISENGAGED PATIENTS’ PERSPECTIVES FROM A METROPOLITAN HOSPITAL OUTPATIENT CLINIC IN AUSTRALIA

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Introduction: The optimal management of lymphedema often involves complex decongestive therapy where patients’ engagement, adherence and motivation are pivotal factors in management success (Tzani, Tsichlaki, Zerva, Papathanasiou, & Dimakakos, 2018). Anecdotally, failure to engage in lymphedema management has more often been attributed to patient noncompliance rather than an understanding of other contributing factors or challenges faced by patients that can impact on management outcomes. There remains a paucity of studies that use a mixed methods approach to gain greater insight into the challenges faced by people with lower limb lymphedema. This is particularly the case for a traditionally hard to reach cohort: patients who are disengaged from a physiotherapy lymphedema program.

Aim: This pilot study aimed to explore participants’ perceptions of a lower limb lymphedema management service program in order to improve engagement of current and future patients.

Method: A mixed method research design was adopted involving six participants who were purposively sampled from a fee-free metropolitan tertiary public hospital in Australia. Findings from semi structured interviews, resilience and quality of life instruments were triangulated and emerging results summarised.

Results: The age of the participants ranged between 51 and 72 years, and they presented with more than one decade of symptoms. All participants were obese and four (67%) had diabetes. Preliminary findings reveal that, over time, they reported a range of challenges/barriers impacting on their adherence to the program; these included physical, social and psychological barriers associated with their chronic condition. Physical barriers included access to the outpatient clinic. Social barriers included increased isolation within the home leading to growing dependency on family/other supports. Fear of falling was a key psychological barrier impacting upon their mobility and confidence. Two clear coping strategies emerged: first, disassociation, with study participants referring to ‘the legs’, as a disembodiment, limiting a more holistic management view. Second, a pronounced resignation about their condition, evident in a lack of motivation and reluctance to engage in or try different approaches to lymphedema management. Despite most participants being morbidly obese, body weight management was not raised by them within the interviews. Measures for greater program adherence and implications for further research are further outlined within the paper.

Conclusions: Findings of this pilot study presented a deeper understanding of the challenges associated with lower limb lymphedema; information that will facilitate the development of a more relevant and patient-centered lymphedema management service program in a clinical setting.