

## RESEARCH ARTICLE

# Lower limb chronic edema management program: Perspectives of disengaged patients on challenges, enablers and barriers to program attendance and adherence

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**Data Availability Statement:** All relevant data are within the paper and its Supporting Information file. Additional data are available upon request due to ethical considerations such as protecting participant and hospital confidentiality, imposed by the Sir Charles Gairdner Osborne Park Health Care Group Human Research Ethics Committee. As a result, interview data are not publicly available. Interested researchers may contact the ethics office via email at [HREC.SCGH@health.wa.gov.au](mailto:HREC.SCGH@health.wa.gov.au)

## Abstract

### Background

Chronic edema (CO) is a progressive, physically disfiguring and currently incurable condition. A multifaceted program has been recommended to manage the swelling. However, there is little evidence investigating patients' perspectives following the program, particularly for those who have poor adherence and/or are disengaged.

### Aim

To investigate the perceived challenges faced by disengaged participants with lower limb CO by identifying their enablers and barriers to participating in a Physiotherapy CO program.

### Method

An exploratory qualitative approach was used. A purposive sampling strategy was adopted to recruit participants. Those with more than three months swelling and who had low adherence and/or attendance (disengaged) to the CO program were invited to participate. Semi-structured interviews with six participants from a CO clinic in a tertiary hospital were conducted. Data were thematically analyzed and findings in terms of enablers and barriers were subsequently reflected in the light of a theoretical framework.

### Results

All six participants were morbidly obese (BMI  $47 \pm 4$  kg/m<sup>2</sup>) with multiple chronic comorbidities. Enablers and barriers detected included physical, psychological and social factors that

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interplay to present multidimensional challenges that influence the participants' adjustment to managing their CO. For the disengaged participants in this study, their under-managed lower limb CO was a progression towards being housebound and having a gradually increasing level of disability.

## Conclusion

This study has identified the multidimensional challenges faced by low adherent and/or disengaged participants with lower limb CO to participating in a hospital-based CO program. Perceived enablers and barriers included physical, psychological and social factors. These were mapped using a health behavior change theoretical framework. Understanding these challenges has implications for developing a multidisciplinary approach aimed at enhancing patient engagement and participation in the physiotherapy CO program.

## Introduction

*Mentality plays a big part in it. You've got to have confidence in the people who are doing things for you. You've got to look at it as an optimist, if you're going to look at it as a pessimist then you are not going to get better. You have to feel like you can keep going (P2).*

Chronic edema (CO) has been defined as swelling in the tissue that persists beyond three months, and is considered a progressive, physically disfiguring and incurable condition [1, 2]. It is a major clinical problem that impacts on an individual's physical and psychosocial well-being [3–5]. Unmanaged CO predisposes the individuals to possibly hospitalization, leg ulcers/wounds, and recurrent cellulitis [4, 6, 7]. Accordingly, a previous study reported a CO prevalence rate of 28.5% amongst hospital inpatients [4]. According to the most recent and largest epidemiology international study on CO, the 'Lymphedema IMPact and PREvalence INTernational' (LIMPRINT), that involved collaboration across nine countries and 13,141 participants, there was a higher prevalence of 38% (723 patients) amongst acute hospital inpatients [8, 9]. Significant risk factors associated with CO were reported to be advancing age, obesity, immobility and comorbidities including diabetes mellitus [9]. One of the complications of CO involves sustaining wounds commonly in the lower limb impacting on the individual's mobility [9, 10]. Chronic edema was significantly associated with a history of cellulitis [9], namely that patients with and without wounds suffered at least one event of cellulitis compared to those without CO.

Literature also extensively describes the profound debilitating impact of CO on people's physical and psychological well-being [11–14]. Compared to their peers without CO, those with the condition present poorer psychological adjustment and lowered health-related quality of life [15]. The impact of CO on health-related quality of life was reported to be worse in those with lower limb edema compared to those with upper limb edema [10] in the aforementioned LIMPRINT study.

Currently, CO is incurable but can be managed. Complex Decongestive Therapy, a multifaceted program consisting primarily of compression therapy has been recommended as best practice [16–19]. When recommendations within the program are consistently adhered to, the positive outcomes anticipated are i) a successful reduction in swelling, ii) decreased morbidity,

and iii) improved functional outcomes [20]. Despite the benefits, not all patients engage in or adhere to the recommendations in the clinical program for management.

Adherence to therapy and recommendations for a long-term condition are considered essential but described as a complex multidimensional challenge [21–24]. Adherence is beneficial for patients' health and has economic benefits [24]. Albeit in another area of research, a systematic review of compression therapy for people with leg ulcers reported low adherence rate and recommended further research to investigate patients' perspectives and factors impacting on adherence [25]. Trust in the health professional was found to be pivotal for leg ulcer treatment [26]. Suggestions to investigate coping strategies or trial cognitive coaching have been proposed as measures to improve adherence amongst individuals with CO [13, 27, 28]. However, there is relatively little evidence on enablers or barriers specifically related to engagement and adherence with a CO program [3, 14, 29] or indeed little application of a theoretical framework in understanding the challenges faced. Using a theoretical framework to evaluate a complex challenge has been recommended [30, 31]. An established theory offers a coherent evidence-based insight into the influences of health behavior and can elucidate mediating factors or strategies towards behavior change in implementation approach later [30, 31].

Therefore, an in-depth investigation into perspectives of individuals with CO who are non-adherent and/or disengaged to a CO management program, based on their unique lived experience and reflected using a theoretical framework, is required [32]. Subsequently, the understanding of the challenges people with CO face during a CO program and the factors that influence their adherence or non-adherence to the program, will contribute to the development of a more relevant and patient-centered program. Hence, a CO program that is better attuned to the individual's needs.

### **Aim of the study**

The primary aim of the pilot study is to explore the perceived challenges faced by disengaged patients with lower limb CO through the framework of enablers and barriers to participation in a physiotherapy CO program.

## **Methodology**

### **Ethical considerations and approvals**

Ethical and governance approval were sought and granted by the Sir Charles Gairdner Osborne Park Health Care Group Human Research Ethics Committee (RGS000000706). This included permission to access the participants' relevant medical records and costings. All participants were given a copy of the Participant Information Sheet and subsequently provided written consent.

### **Design**

The research used a concurrent/convergent mixed method research approach. This involved the use of qualitative and quantitative approaches concurrently within the study [33]. A mix of these approaches facilitated triangulation of the findings and importantly, provided insights to enhance comprehensiveness in understanding participants' perspectives [34]. This paper will report the qualitative findings.

### **Chronic edema program setting**

This project was undertaken at a teaching hospital located in metropolitan Perth in Western Australia. It is a 607-bed public teaching hospital. The Lower Limb Lymphedema Outpatient

Clinic (herein, the clinic) is a specialty fee-free service within the hospital's physiotherapy department operating since 1993. This service currently involves three part-time physiotherapists, but no medical doctor nor other allied health staff. Patients are eligible for treatment if they reside in the hospital catchment area and/or are referred by a doctor within the hospital.

The CO program offered includes assessment and best practice management [17, 35]. With the development of new technologies over time, the clinic has expanded to offer a broad range of clinical services for CO management. Strategies are primarily based on a) compression therapy (e.g. multi-layered bandaging, compression stockings, compression wraps and stiff self-adhesive bandages e.g. 3M™ Coban™ 2 Compression System); b) education on self-management strategies including manual lymphatic drainage massage and exercise; and c) referral to podiatry and other relevant referral, and/or for further investigations. Factors impacting on management of the condition, including the impact of weight on CO, were highlighted during the initial phase of the program.

## Recruitment

A purposive sampling strategy, specifically, "Homogeneous Sampling" was used to recruit participants [36]. This involved selecting a sub-group of current or previous patients from the clinic, who shared common characteristics and had the potential to provide information-rich data for an in-depth understanding of the research inquiry. The inclusion criteria were:

- Lower limb edema of more than three months duration
- Recurrent presentations/referrals to the clinic
- Disengagement (i.e. low adherence) with the program, including one or more of the following:
  - Attendance to  $\leq 50\%$  of scheduled clinic appointments, or not attending (disengaged)
  - Low uptake or adherence to prescribed therapy recommendations without valid reasons
  - Self-reported low compliance or adherence to recommendations

Criteria to exclude individuals from participating were:

- Active malignancy (e.g. undergoing active treatments such as radiotherapy or chemotherapy).
- Insufficient English language competency.

## Data collection and procedure

Potential participants (i.e. those who met the eligibility criteria) were identified by the team's physiotherapists and contacted to ascertain their interest in being involved in the study. Participants who agreed to take part in the study were offered to choose their preferred venue for the interview. Subsequently, interested participants were interviewed and provided socio-demographic details including information related to their condition. Data on edema type, chronicity of lower limb edema and source of referral were also collected.

## Materials

**Interviews.** Face-to-face, semi-structured interviews were conducted by the primary researcher (LK). The recorded interview was guided by an interview guide and additional field notes were taken. The interview guide (available as Supporting Information) was derived from

previous literature [14, 37–39] and expert advice. Questions and prompts during each interview were tailored to describe and facilitate the participant's reflections and lived experience, specifically seeking information on their experience with the program in the clinic (e.g. treatment, care received, management strategies outside of the clinical setting and perceived progress of their condition) and personal considerations (perceived assessment of management success, challenges, control over their condition and subsequent impacts and potential changes).

**Theoretical framework COM-B model linked with TDF.** The COM-B model is an acronym for Capability, Opportunity and Motivation factors that may affect Behavior. The model posits that behavior is influenced by these three core constructs and any change in health behavior will be dependent upon associated mediating factors [40]. The COM-B model's constructs are:

- Capability–(Physical): Physical capacity to perform the behavior e.g. skill or strength;
- Capability–(Psychological): Psychological capacity to perform the behavior (e.g. knowledge or comprehension);
- Opportunity–(Physical): Opportunity afforded by the environment involving physical 'affordance' and resources;
- Opportunity–(Social): Opportunity afforded by interpersonal influences, social cues and cultural norms that influence the way that we think about things;
- Motivation–(Reflective): Reflective processes involving plans (self-conscious intentions) and evaluations (beliefs about what is good and bad);
- Motivation–(Automatic): Automatic processes involving emotional reactions, desires (wants and needs), impulses, reflex responses.

Another theoretical model Theoretical Domains Framework (TDF) is an evidence-based framework that has several domains encompassing behavior change techniques (Table 1) including affective and emotive constructs [41]. The TDF complements and expands the COM-B model to identify and evaluate techniques of behavior change for application or later implementation. The COM-B and TDF approaches have been applied in a wide range of healthcare research such as smoking cessation behavior, health professionals' adherence to low back pain guidelines, falls prevention program and adherence to hearing aids [42–45]. In the current study, the COM-B model is mapped against the TDF domains (Table 1) to aid the interpretation of findings.

**Data analysis.** All qualitative data were de-identified and transcribed before importing into NVivo12 [46], a qualitative data management tool to facilitate analysis. Initially, the qualitative data were analyzed using thematic analysis [47] through an inductive iterative process whereby text segments with possible common meaning are identified in the transcript, coded and sifted. During this process, attention to the nuances of the dialogue and deeper insights are drawn from the data and emerging themes are proposed [48]. Using investigator triangulation to enhance trustworthiness (credibility) of the findings, a second team member (AB) also examined the data independently, and the emerging themes and areas of agreement /disagreement were discussed with the primary researcher (LK) [47, 49].

Following thematic analysis, the findings were interpreted deductively and reflected in the light of the COM-B model and TDF component constructs [40, 41]. Themes and outcomes were determined by consensus between the two researchers before sharing with other team members. These were further categorized as enablers or barriers.

**Table 1. Mapping of the COM-B model to the TDF constructs relevant to the study.**

COM-B Construct		TDF Domains	TDF Component Constructs	
Capability	Physical	Skills	An ability or proficiency acquired through practice	Ability to do compression bandaging. Ability to don on or remove stockings on their own.
	Psychological	Knowledge Skills	An awareness of the existence of something	Knowledge of CO. Ability to monitor for early signs of infection.
Opportunity	Physical	Environmental Context and Resources	Any circumstance of an individual's situation or environment that discourages or encourages the development of skills, independence, social competence and adaptive behavior	Access to medical appliance and resources. Environmental stressors e.g. transport possibilities and constraints
	Social	Social Influencers	Any interpersonal processes that can cause individuals to change their thoughts, feelings or behaviors	Experience of social acceptance, Access to social support, Comparison to others (social comparison), Subject to social stigma.
Motivation	Reflective	Beliefs about Capabilities	Acceptance of the truth, reality or validity about an ability that a person can put to constructive use	Self-efficacy, Self-confidence.
		Optimism	The confidence that things will happen for the best or that desired goal will be attained	Optimism, Pessimism
		Beliefs about Consequences	Acceptance of the truth, reality or validity about outcomes of a behavior in a given situation	Resigned to the fact that there is no cure for CO
		Intentions	A conscious decision to perform a behavior or a resolve to act in a certain way	Intention to return to clinic and therapy
		Goals	Mental representation of outcomes or end states that an individual wants to achieve	Action planning, Goals
	Automatic	Emotion	A complex reaction pattern involving behavioral and physiological elements which the individual attempts to deal with a personally significant matter or event	Fear, Anxiety, Depression, Stress
		Social Role	A coherent set of behaviors and displayed personal qualities of an individual in a social setting	Social identity e.g. grandparent, spouse

COM-B: Capability, Opportunity, Motivation-Behavior Model; TDF: Theoretical Domains Framework

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## Results

### Characterizing participants

The sample size (n = 6) of this small pilot study was determined by the nature of the patient cohort and the funding grant. Six semi-structured interviews were conducted from September to October 2018. Five interviews were conducted at the participants' home and one at the clinical setting. Two of the participants' spouses were present throughout the interview session and were given the opportunity at the end of the session to add further comments.

Participant characteristics are presented in Table 2. Their age ranged between 51 and 72 years with a median [interquartile range] of 66 [60 to 71] years. Four (67%) participants living in identified higher socio-economic areas [50]. The participants' presentation would be deemed as complex cases with more than one decade of CO and with multiple chronic comorbidities since the onset of CO. According to the participants' medical records, the diagnosed comorbidities included Chronic Obstructive Pulmonary Disease, obesity, congenital conditions such as Milroy's Disease, Rothmund-Thomson Syndrome and diabetes (Type 1 and Type 2). All the participants were morbidly obese, and four (67%) had diabetes. Other characteristics of participants including marital status and details on their medical conditions are provided in Table 2.

Thematic analysis identified some further common characteristics not collected as demographics. Over 80% of participants ceased attending the clinic as their condition progressed. Participants frequently described a preference for the management that they initially received

**Table 2. Participants' characteristics.**

Characteristic	n = 6
Age (yr)	66 [60 to 71]
BMI (kg/m <sup>2</sup> )	47 [44 to 48]
Number of comorbidities per participant	7 [6 to 8]
Time since initial assessment (year)	8.5 [3.5 to 15.5]
Gender, n (%)	
Female	2 (33.3)
Socio-Economic Status, n (%)	
Lower (2–3 Decile)	2 (33.3)
Higher (7–8 Decile)	4 (66.7)
Level of education, n (%)	
Secondary	2 (33.3)
Trade Certificate	2 (33.3)
Tertiary	2 (33.3)
Marital status, n (%)	
Married	4 (66.7)
Divorced/separated	2 (33.3)
Living arrangement, n (%)	
With spouse/friend	5 (83.3)
Alone	1 (16.7)
Employment, n (%)	
Retired	5 (83.3)
Part-time	1 (16.7)
Edema type, n (%)	
Primary	3 (50.0)
Secondary to cancer and surgery	2 (33.3)
Mixed	1 (16.7)
Chronicity of lower limb edema, n (%)	
≤ 10 years	2 (33.3)
>10 to ≤ 20 years	2 (33.3)
> 20 years	2 (33.3)
Source of referral, n (%)	
Dermatology	2 (33.3)
Vascular	2 (33.3)
Orthopedic/Infectious disease	1 (16.7)
Cardiology	1 (16.7)
Attendance at clinic	
Not attending/disengaged	4 (66.7)
Infrequent	2 (33.3)

Data are presented as median [interquartile range] unless otherwise stated. Abbreviation: BMI (body-mass index)

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in the clinic which included, a period of bandaging before being fitted with stockings despite being aware that other treatment options are now available. While the participants adhered to some self- management strategies, one-third of participants with multiple comorbidities chose to manage these conditions at the expense of managing their lymphedema. All participants reported difficulty physically accessing the clinic. There was in general, a perceived lack of control over their condition and all participants were subsequently resigned to progressive

worsening of lower limb CO, including severe limitations with regards to mobility to the point of being housebound or disabled. All participants were mindful that there is no cure for CO but were on a day-to-day basis dealing with physical, psychological and social impacts. However, despite these, no participants in the study mentioned their weight (obesity) in relation to CO.

### Applied model constructs

In the COM-B model, the first construct is capability both physical and psychological, each have enablers (positive factors) and barriers (negative factors) (see Table 1 and Table 3) that were examined in the study.

**Capability- physical.** No physical capability enablers were identified, indicating that the long-term impact of CO is debilitation, namely lack of or reduced physical capacity (Table 3). Participants, however, identified numerous barriers including a reduced physical capacity to walk and move due to lower limb CO and a heightened fear of falling. These factors negatively impacting on their mobility, independence, lifestyle choices, self-efficacy and ultimately their health-related quality of life. The concern with severe physical limitation as a barrier was prevalent throughout the study. “The biggest trouble I’m finding with the legs is that they feel heavy and I can’t walk a long way now” (P6). Everyday activities such as grocery shopping were reported to be challenging. This is objectively reflected by a spouse of one of the study participants:

**Table 3. Enablers and barriers to adherence to the CO program as identified and reflected by the COM-B model and the TDF component constructs.**

Enablers	Barriers	Examples
<b>Capability- Physical</b>	<b>Capability- Physical</b>	
None reported	Decreased physical skills Multiple chronic co-morbidities	Decreased capacity to walk Fear of falling Loss of independence Obesity, diabetes, etc.
<b>Capability- Psychological</b>	<b>Capability- Psychological</b>	
Knowledge/procedural knowledge on self-management strategies e.g. bandaging	Lack of practical knowledge by medical practitioners	Reduced confidence in GP to deal with their infections
<b>Opportunity- Physical</b>	<b>Opportunity- Physical</b>	
Access to medical appliance, aids and latest options	Difficulty access to hospital clinic physically	Limited disabled parking Limited hospital internal transport service Bus stop is too far from clinic
Tailored program to individual’s needs and capability	Limited appropriate personal resources	Limited choice of safe fitting footwear and clothes
<b>Opportunity- Social</b>	<b>Opportunity- Social</b>	
Positive health provider-patient relationship	Social stigma	
Continuity of care	Social pressure	
Partner’s social support	Social comparison	
<b>Motivation-Reflective</b>	<b>Motivation-Reflective</b>	
Belief that therapy and medical appliance helps to reduce CO	Pessimism	Fatalistic attitude
	Belief that there is no cure	Resignation, Resilience
	Lack of Motivation, Intention and Goals	Diminished self-efficacy
<b>Motivation-Automatic</b>	<b>Motivation-Automatic</b>	
To feel competent in social role Strive to stay positive	Emotion	Fear, Hurt, Depression, Anxiety

COM-B: Capability, Opportunity, Motivation-Behavior Model; TDF: Theoretical Domains Framework

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She can only walk 50 meters. She gets pain and sits down. We find it easy to go to places with free wheelchairs . . . it also means her life is pretty much housebound whether she likes it or not. We have to hire a wheelchair to go to the zoo, go to the shops or anything like that (P4's spouse).

Over time, there was a growing need, and sometimes unease, with the use of mobility aids (e.g. wheelchair, or walker). One of the participants (P2) expressed frustration with "I hate going in a wheelchair". Ambivalence about using mobility aids was commonly discussed:

I am just too young [50 years old] for a walker (P4).

I don't feel so steady on my legs anymore and I feel like I am going to fall over. And if I fall over, my knees are so sore I can't kneel to get up. If I am down, how am I going to get up? So, the walker does help get a bit more confidence walking with it (P3).

As identified in the previous comment, a fear of falling was raised throughout the study. Hence, the participants have adapted or altered their daily activities, or even stopped doing what they used to do. As one described his daily routine as "Because you can't move, mine goes from sitting to sleeping, then sleeping to sitting" (P5). Others demonstrated how CO can be such a debilitating condition in the long term, leading to a loss of independence and physical capacity. "I can't lift my legs, so my friend comes in every day and helps me to get into bed" (P2) and "Things like playing tennis. I know that's impossible now. I just can't do it" (P6).

Unsurprisingly, given their physical limitations from CO and multiple comorbidities (including obesity), these participants struggled to apply or use the medical appliances and aids (e.g. stockings provided to manage their lower limb CO). P3 described in her earlier years of experience with stockings "very hard to put it on. . . I persevered for a few months, but it is hard". This perspective has a psychological aspect, which points to another construct (capability-psychological) of the COM-B model.

**Capability- psychological.** Enablers and barriers associated with psychological capability as outlined in Table 3 relate to knowledge and awareness in the study were related to attendance at the CO clinic. These translated into comprehending and applying knowledge of CO, self-management strategies (e.g. bandaging, massage, wound care and exercise), monitoring for infection, and requirements of ongoing care of their legs. In contrast, a barrier expressed by all study participants was the lack of practical knowledge and awareness by medical practitioners on ways to treat their CO and on referral pathways, leaving them in most cases solely reliant on the clinic.

**Opportunity- physical.** This COM-B model construct looks at opportunities that are afforded by environmental context, resources and social influences (Table 1 and Table 3). There were more barriers than enablers identified.

Physical enablers discussed by all the study participants included that the CO treatment program was tailored to their needs and preferences and that they had access to most medical appliance options. Barriers identified in the interviews included physically accessing the hospital clinic. Those who drove to the hospital mentioned that it was a challenge to access hospital disabled parking due to its limited availability. Those who used public transport reported that the distance between the bus stop and the clinic was too long and walking that far was not easy. Another identified barrier discussed by few participants was their difficulty in finding appropriate clothing and safe footwear when they ventured outside of their house.

**Opportunity- social.** Social influencers including a positive health provider-patient relationship, continuity of care, and a supportive spouse/partner were important enablers suggested. All the participants acknowledged the clinic and health professionals' expertise in

identifying and addressing their CO, providing flexible and tailored solutions. This was particularly relevant when study participants were actively engaged and adhering to recommendations at the clinic. Besides, having the same health professional in attendance at the clinic all the time was reported to be “psychologically relieving” (P5).

Social stigma was identified as a barrier to adherence to therapy. Fear of being ridiculed when wearing medical appliance in public such as “He’s just wearing bandages so that he can get a seat [comments by other passengers in the bus]” (P6) was recounted by one study participant. Associated with these comments was the frustration about “having to explain it [his condition] over and over again” (P6) to acquaintances. This effort could reflect an act of dealing with social pressure and maintaining social acceptance (Table 1 and Table 3).

**Motivation- reflective.** The third construct of the COM-B model is motivation, which includes reflective and automatic processes as well as associated enablers and barriers. Reflective aspects relate to beliefs and intentions while automatic responses entail unconscious desires and impulses.

Whilst participants expressed beliefs that therapy helped with reducing swelling in their legs, their pessimism and resignation towards recurrent setbacks were barriers to their well-meant intentions. Therapy helped to reduce the size of their legs and aided them to continue to function (i.e. attending work, socializing and so forth). This was largely related to persistently wearing stockings in the early years of the condition.

Over time, with their reduced physical capability, their sense of self-efficacy was gradually eroded and evoked a sense of resignation with an increasing reliance on their spouse and family. P6 vividly described this:

My self-confidence is diminished due to my physical limitations when previously I walked a lot without tiring . . . I don’t feel safe driving because I don’t feel I can lift my legs to get to the pedals [brake] quickly enough if someone came in front of me. She [spouse] always has to do the driving and even when she is not feeling up to it [unwell]. I can’t help her with that because I don’t feel comfortable.

All participants expressed a lack of control and resilience over their condition because they did not see a cure. Consequently, highly reported was a degree of resignation to just accept the condition and live with it.

I’m controlling it to the degree, where I don’t have to stay in bed all day. Like I control it to the point where I live a life but I can’t control it to a point where I’m going to cure it or I’m going to get better. I don’t know whether it’s possible to live that. . . There is no cure so there is nothing you can do (P1)

“I’d say I tolerate it [CO] as I don’t have any choice. The legs haven’t really got any worse, but it is hard to say I have got control of it” (P6). Consequently, motivation towards therapy, including attending the clinic and accepting new or alternative treatment options declined.

**Motivation- automatic.** There was a gamut of emotive enablers and barriers displayed that were less conscious. On the one hand, participants expressed a compulsion to feel competent in fulfilling their social role with their family (e.g. as a grandparent, or spouse; striving to stay positive) and a yearning for independence was expressed.

When you are doing things for yourself, it’s a big plus (P2).

I’d rather do it myself [drive to the hospital]. I would still like to be independent (P3).

My biggest thing is I like to be independent and keeping everything under control makes me happiest because I am not looking for great outcomes or anything except maintenance. Maintaining what I've got now (P5).

On the other hand, having CO over a long period has had both a reported physical and an emotional effect and toll on study participants. While the physical impacts have been explored throughout, for other participants its impact was an inhibitor, namely that CO "changed my whole state of mind" (P2). Emotions expressed and detected from the interviews included emotional pain, depression, fear, and anxiety; they were seen as having a long term impact. "Seeing something visually can affect you emotionally. . . . Hurt, I look and think I used to [be] called elephant legs when I was in school" (P4).

Interestingly, utterances by the male participants were inclined to talk more often about "the legs" and rarely as "my legs". In addition, weight was associated with the legs and not associated with their body weight despite participants having higher than average Body Mass Index (BMI) (Table 2). Hence, there appeared to be a coping strategy with a disembodiment of their legs and body weight in their comments. In relation, diet was not uttered during the interviews as a strategy to manage their CO. Only one of the six participants had current obvious intention to manage their CO and mentioned goal setting and CO action plan.

## Discussion

Low adhering and/or disengaged patients have broadly been deemed as non-compliant [24], however, the findings of this pilot study have shown that can be an oversimplification. By exploring participants' perspectives, this study has revealed multifactorial issues (enablers and barriers) that complicate adherence and attendance at the CO clinic. This finding confirmed reports in the literature that adherence in a chronic condition is a complex multidimensional problem [21, 24]. Further, the progressive nature of lower limb CO, compounded by patient disengagement from therapy inflicted a profound, long-term, debilitating effect on this small cohort.

Evident in the pilot study was an overwhelming negative impact of lower limb CO on health-related quality of life, independence, psychological distress, expectations, as well as resignation and inevitable permanent disability of participants in their later years. Despite adherence to treatment and self-management strategies at an early stage following diagnosis, managing lower limb CO long term has been challenging. Findings from this study were consistent with other similar research [12, 14, 51]. In an Irish study, data was collected using a questionnaire, the cohort was younger (average 54 years old) with the majority living in the countryside [12]. That study supports the findings of this pilot study in establishing that CO impacts on social functioning and leads to social isolation. Findings in two other interview-based studies conducted in UK [14] and Israel [51] were similar to this pilot study. Tidhar and Armer [51] found that while participants related success with no exacerbation in the CO, their expectations of "getting better" faded over time. Watts (2016) also pointed to the management of CO as challenging due to physical and functional constraints being entangled with psychosocial impacts, including social stigma [14]. However, the absence of reporting on the age of their participants, BMI profiles and the length of time with the condition limited the ability to compare characteristics with the sample cohort. While these studies described various consequences of CO, none looked beyond narrative nor towards an analytical identification of the challenges using a theoretical framework.

The current study has applied the theoretical framework COM-B model linked with TDF (Table 1) in understanding capability, opportunity and motivation factors as the lens for

interpreting patient disengagement in therapy via perceived enablers and barriers. The study found that the enablers and barriers encompass physical, psychological and social factors impacting on the participants' adherence to therapy. These factors entwined as complex multi-dimensional challenges that impacted participants adjusting to living with a chronic condition [24, 52, 53]. Importantly, some of the factors were internal (personal realm) and others as external factors beyond their control. On the personal level, having a supportive partner was found to positively facilitate communal coping [53] towards adjusting to CO. Externally, the major barrier for these participants was a lack of capacity to access the hospital physically to seek therapy. This is consistent with the LIMPRINT study where nearly one-third of the participants (35%) reported distance as preventing access to treatment [10]. This is a cohort of individuals with multiple chronic conditions, including unhealthy weight. Though the conversation of weight and CO was raised earlier during the program, there was and currently is still no service including information available to address obese patients' diet or weight issues. Obesity is not necessarily unique to this cohort, as it has been estimated that 63% of Australian adults are considered overweight or obese [54]. There is growing evidence that being obese is a significant risk factor for CO [9, 55, 56] however it was infrequently highlighted by the study cohort.

Efforts to facilitate behavior change in people with lower limb CO would benefit from being guided by a health behavior change theoretical framework(s) [57]. This would heighten the appreciation and learning from current practice in people with other chronic conditions, such as those with cardiac disease, or diabetes and gerontology [58–60]. Participants were keen to participate and be heard, their anecdotes indicated limited awareness of appropriate management of CO amongst the medical practitioners; a finding that is consistent with studies conducted in Canada, USA, UK and the global LIMPRINT study [3, 61, 62].

Tinetti and colleagues [63] urged patient-centered care for the cohort of people with multiple comorbidities by advocating that health providers treat the individual, and not the disease, through tailoring care to the individual's priorities, rather than strictly following practice guidelines. The current study highlights the need for ongoing patient-centered care. Understanding the contextual factors, as illustrated by the enablers and barriers, influencing the individual's adjustment to and management of chronic illness [52], can be an important first step towards successful management of lower limb CO.

The current study is not without limitations. The sample size is small, and the participants who agreed to take part in the study happened to be those who are morbidly obese. Participants self-selected to the study and from the outset, there was no expectation that overweight would be a common comorbidity. Therefore, we did not select or control for this factor, so this aspect is essentially a random and therefore novel finding. However, people with lower limb CO are a "hard-to-reach" population [14, 64], evident by most of the participants' preference to conduct interviews in their home settings. We believe that the sample for our exploratory qualitative study reflects many of the findings from other empirical studies as identified, except for obesity. The views of a marginalized cohort of mostly older people with CO who are housebound and disengaged have been reported [65]. In that sense, the largely qualitative findings reflect the experience of a small sample of morbidly obese participants from a lower limb CO physiotherapy clinic in a metropolitan area of Western Australia; and therefore, caution should be taken when trying to generalize our findings.

## Conclusion

This study has identified the multidimensional challenges, perceived enablers, and barriers faced by low adherent and/or disengaged participants with lower limb CO to participating in a

hospital-based CO program. These were mapped using a health behavior change theoretical framework, adding a new dimension to the extant literature. The challenges mapped included physical, psychological, social and motivational considerations. Enablers included: participants' knowledge of self-management strategies; positive health provider-patient relationship; access to medical appliances; and tailored program. Barriers included: decreased physical function; lack of medical practitioner knowledge; transport constraints; lack of appropriate personal clothing and footwear; and perceived lack of control over CO. Understanding these challenges has implications for developing a multidisciplinary approach aimed at enhancing patient engagement and participation in a physiotherapy CO program.

## Supporting information

**S1 File. Interview preparation and interview question guide.**  
(PDF)

**S2 File. NVivo higher level nodes and sub-nodes.**  
(PDF)

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