Physiotherapy practice in the management of lymphoedema in South Africa

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A Dissertation submitted to the Department of Physiotherapy, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of MSc Physiotherapy by Dissertation.

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Declaration

I Carys Rhodes declare that this Dissertation is my own, unaided work. It is being submitted for the Master of Physiotherapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

Carys Rhodes
Name of candidate

Signature of candidate

18th day of June 2022 in Fourways

Dedication

I dedicate this dissertation to my children; may you be inspired to reach for the stars.

Abstract

Introduction: Lymphoedema is a condition that is underdiagnosed and underestimated worldwide. The condition is characterised by asymmetrical fluid accumulation in the face, trunk, limbs and genitals due to a deficient lymphatic system. If left untreated, lymphoedema can result in cellulitis, lymphangitis and in rare cases lymphangiosarcoma. These conditions can lead to severe illness, amputation and even death. People with lymphoedema also struggle with psychological and financial burdens. The timeous diagnosis and treatment of this condition is paramount to improving the patient's quality of life. Physiotherapists have an important role to play in the management of patients with lymphoedema.

Aim of study: To investigate physiotherapy practice in the management of lymphoedema in South Africa.

Methods: A two phase explanatory mixed method design study was undertaken. Ethical clearance was given by the Human Research Ethics Committee of the University of the Witwatersrand. The first phase was an online questionnaire which informed the second phase of the study which was online focus groups. The focus groups served to compliment and enrich the data obtained from the questionnaire. Four hundred and two qualified physiotherapists filled out an online questionnaire and nine of those physiotherapists participated in online focus groups.

Results: Physiotherapists consistently rated their knowledge as 'fair' when asked about perceived knowledge of certain aspects of lymphoedema and its management. Ninety-seven point three percent of physiotherapists (n= 367) indicated that they knew that physiotherapists could offer lymphoedema management, only 49.7% (n=368) knew how to treat the condition. Fifteen point eight percent of 146 physiotherapists had completed the certified 135 hour lymphoedema training. Sixty one percent of respondents reported that they receive less than 1 new referral a month (n=146), with 39.8% reporting that it takes up less than half of their patient load (n=143). Only 31% of physiotherapists offer complete decongestive lymph therapy (CDLT) (n=129). The focus group discussion revealed that the role that physiotherapists play in the management of lymphoedema is complex and requires further training, a multidisciplinary team and a biopsychosocial approach. Facilitators such as access to

internet resources and social media, the founding of a lymphoedema network in South Africa, advancements in the provision of garments and consumables and good patient-therapist relationships assist physiotherapists in their management of lymphoedema. Factors such as lack of education at an undergraduate level and post graduate level, prohibitive costs for both patients and physiotherapists, time pressure and the complexity of the patient group hinder physiotherapists management of lymphoedema.

Conclusion: Physiotherapists in South Africa have a fair self-reported perceived knowledge of lymphoedema as a condition but need further education on how to manage the condition to meet international standards. Most physiotherapists receive very few lymphoedema referrals, and they do not focus on it in their practices. Those who have done the 135 hour certification have a special interest in the field and see more patients than other physiotherapists. Most physiotherapists do not offer the gold standard of care, CDLT, but still treat patients with other modalities. Patient and practitioner access to internet resources, developments in the field, the formation of a lymphoedema network in South Africa and a good patient-therapists relationship facilitate physiotherapists in the management of lymphoedema. Factors that physiotherapists experience as a barrier to lymphoedema management include a lack of education, prohibitive costs of treatment, time pressure and the complexity of the patient group.

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Definition of terms

Bioimpedance: a method of measuring fluid in tissue by measuring tissue resistance to an electrical current. (Moffatt et al., 2006)

Biopsychosocial approach: viewing the patient's condition from a physical, psychological and social view point to create a holistic picture of their needs. (Eaton et al., 2020)

Complete decongestive lymphatic therapy: a treatment approach combining skin care, manual lymph drainage, compression therapy and exercise to manage lymphoedema. (Moffatt et al., 2006)

Filariasis: a tropical disease caused by a parasitic worm which is transmitted by mosquitos. (Pfarr et al., 2009)

Lymphatic fluid: a fluid rich in proteins, macromolecules and white blood cells which is transported by the lymphatic system. (Borman, 2018)

Lymphatic system: a collection of capillaries, ducts, vessels and nodes that create a transport system for lymphatic fluid**.** (Borman, 2018)

Lymphatic therapist: a healthcare practitioner that has completed the 135 hour certification course in lymphatic massage and management. (Armer et al., 2010)

Manual lymph drainage: a massage technique, using broad, light strokes to facilitate the movement of lymphatic fluid away from an area of congestion towards more viable lymph nodes. (Moffatt et al., 2006)

Patient load: the number and type of patients treated by a practitioner in a time frame. (Anderson et al., 2019; Munoz et al., 1990)

Perometry: a method of calculating limb volume by using an infrared laser to scan the shape of the limb. (Moffatt et al., 2006)

List of Abbreviations

Abbreviation	
AHPCSA	Allied Health Profession Council of South Africa
CDLT	Complete decongestive lymphatic therapy
HPCSA	Health Professions Council of South Africa
IPP	Intermittent pneumatic pump
KT	Kinesiology tape
LAOSA	Lymphoedema Association of South Africa
MLD	Manual lymph drainage
PASA	Physiotherapy Association of South Africa
PMB	Prescribed minimum benefits
REDCap	Research Electronic Data Capture
SASP	South African Society of Physiotherapy
SLD	Self lymphatic drainage
WHO	World Health Organisation

Chapter 1 INTRODUCTION

1.1 Background

Lymphoedema is a condition that is increasing in prevalence. It is estimated that around 250 million people worldwide suffer from the condition (Schulze et al., 2018), but as an under reported and under diagnosed condition, this number could be much higher (Rockson and Rivera, 2008). The exact number of people with lymphoedema in South Africa is unknown, but it is estimated that around 1,3 million people have the condition in South Africa, based on the World Health Organisation (WHO) statistics released in 2014 (Herbst, 2021). With the advance of modern medicine and specifically the treatment of cancer becoming more effective, the number of people being affected by the condition will continue to grow (Wolfs et al., 2020). A study by Hareyama et al. (2015) found an increase of 12.5% in the incidence of lymphoedema in patients who underwent lymphadenectomy due to cancer, over a ten year period. This increase is likely to continue, with cancer survivorship having increased from 58.5% in 1990 to 69.4% in 2011 (National Cancer Institute, 2019). Lymphoedema has far reaching implications not only for the patients with the condition, but also on global economies. If left untreated, lymphoedema can result in cellulitis, lymphangitis and in rare cases lymphangiosarcoma (Agbenorku, 2014). These conditions may cause severe illness, amputation and even death. Patients with lymphoedema may also suffer with psychological problems and a decreased quality of life related to living with the condition (Tidhar and Armer, 2018; Wedin et al., 2019). The economic burden of the condition cannot be overlooked, as the condition effects productivity, leads to time off work and places a financial strain on patients with the disease as well as the healthcare system (Eneanya et al., 2019).

Lymphoedema is a chronic condition characterised by the progressive swelling of one or more limbs, trunk, head, neck or genitalia, and can be from a primary or secondary cause. Lymphatic fluid is a cellular by-product which is drained by the lymphatic system via lymph vessels and ducts, to be excreted. In a system where the lymphatic system is compromised, protein rich lymphatic fluid can start to accumulate in tissues. This leads to swelling. The deficit in the flow of lymphatic fluid can be as a result of a primary

structural insufficiency which may present in different forms. It may be present from birth and can appear early in life (congenital lymphoedema), from the age of 2-35 years (praecox lymphoedema) or after the age of 35 (lymphoedema tarda). Secondary lymphoedema is caused after an identifiable disruption to a part of the lymphatic system, such as cancer, infection, trauma or surgery (Rockson and Rivera, 2008; Tidhar and Armer, 2018).

Treatment of lymphoedema includes both conservative and surgical interventions. Conservative treatments such as complete decongestive lymphatic therapy (CDLT), which includes manual lymph draining and compression therapy by bandaging and garment prescription remains the most common form of treatment for lymphoedema (Fialka-Moser et al., 2013). It is divided into an 'intensive phase' where the aim is to reduce limb volume and a 'maintenance phase' where the aim is to maintain the reduction in size of the limb. CDLT remains an effective treatment of lymphoedema (Ezzo et al., 2015). Kinesiology taping (KT), acupuncture, laser therapy, aquatic therapy and the use of pneumatic lymph pumps are other treatment modalities being used to treat patients with the condition (Tidhar and Armer, 2018). Surgical interventions such as lymphaticovenous anastomosis are now providing a more permanent solution to those living with the condition (Wolfs et al., 2020). However, conservative management by a healthcare professional who is trained in lymphoedema management remains the gold standard (Bahtiyarca et al., 2019).
The role of physiotherapy in the identification, treatment and management of lymphoedema is evident by the numerous studies describing treatments and positive outcomes (Della Justina et al., 2016; Lu et al., 2015; Torres Lacomba et al., 2010; Tzani et al., 2018). In 'The South African Multi-Disciplinary Lymphoedema Position Statement' compiled by the Lymphoedema Association of South Africa (LAOSA), physiotherapists are identified as key service providers, accounting for 43% of the total number of certified lymphoedema therapists in South Africa, alongside occupational therapists, nurses, orthotists, doctors and other Allied Health Professions Council of South Africa (AHPCSA) members (Davey et al., 2018). In an international study by Anderson et al. (2019) physiotherapists were the most frequently identified health professionals treating lymphoedema, followed by occupational therapists and massage therapists. International management guidelines such as the "Best Practice for the Management of Lymphoedema; International Consensus compiled by the Lymphoedema Framework have been developed to educate and assist

physiotherapists and other lymphatic therapists to achieve best possible outcomes (Moffatt et al., 2006). Research into what level of knowledge physiotherapists have about the condition, the treatment approaches available, or if management guidelines are being carried over into clinical practice in South Africa is limited. A study by Stout et al., (2009) and Dine et al., (2009) discussed the state of lymphoedema management in South Africa. Both of the studies found education and awareness to be lacking in the field and that treatment approaches were unique to the South African context as traditional medicine and western medicine overlapped.

There is a lack of research focused on lymphoedema, when compared to other major illnesses and diseases. As reported in a systematic review by Stuiver et al. (2015), most literature on lymphoedema is patient centred, focusing on efficacy of treatment, different treatment modalities, prevention of the condition quality of life and patient expectations (Tidhar and Armer, 2018). International studies mostly include populations with breast cancer. There is limited research focused on the practices of the health professionals administering the treatments. To gain insight into management practices of lymphoedema, practitioner centred studies are of value. Continued research into the management of lymphoedema from a practitioner's point of view can yield invaluable data on current practice standards, condition prevalence, shortcomings, advancements and needs within the field. Studies by Anderson et al., 2019; Armer et al., 2010; Fialka-Moser et al., 2013; Moffatt et al., 2003 and Schulze et al., 2018 are examples of quantitative studies that focused on health professionals managing lymphoedema. These studies describe treatment approaches utilised by lymphoedema therapists and physicians, the limitations they face with regards to resources, finances and education, and provide data on epidemiology within their patient population. A mixed methodology study by Davies et al. (2012) investigated the barriers and education needs of health care practitioners with regards to lymphoedema. In the study, physiotherapists identified a lack of knowledge relating to skin care, exercise prescription and identification of at-risk patients as being limiting factors when managing patients with lymphoedema. These studies provide a good platform from which further research into prevalence, current clinical practice, facilitators, barriers and needs of practitioners and patients can be conducted. Such research needs to be done regularly and across different countries, to provide up to date and relevant data. No research has been done on these aspects in a South African setting, resulting in a lack of information on how lymphoedema is impacting

patients and the health care system. With a growing repository of data, healthcare industries, educational bodies and financial institutions can make changes to better meet the needs of patients with lymphoedema. This is particularly relevant as the prevalence of lymphoedema, and its associated personal and economic impact, continues to increase globally.

1.2 Problem Statement

Research in the field of lymphoedema is lacking worldwide, especially in a South African context. Although management guidelines exist, it is unknown how physiotherapists in South Africa are managing patients with lymphoedema. A study investigating physiotherapy practice with regards to the management of patients with lymphoedema in South Africa would provide a current view of services being offered and treatment approaches being used, as well as offer a deeper insight into the limitations and barriers faced by physiotherapists. With this information policy makers, health care funders and educational institutions can make informed decisions on how best to continue to promote effective management of patients with lymphoedema.

1.3 Aim

To investigate physiotherapy practice in the management of lymphoedema in South Africa.

1.4 Objectives

To describe what physiotherapists' perceived knowledge is regarding lymphoedema and the management thereof.
To determine the lymphoedema patient load being seen by physiotherapists in a clinical setting.
To establish the treatment approaches of physiotherapists in the management of lymphoedema.
To explore the roles of, facilitators and barriers experienced by physiotherapists managing lymphoedema.

1.5 Significance

Lymphoedema is a condition that can be managed by physiotherapists. However, due to the lack of education and poor awareness of the condition, physiotherapists may not be aware of the role they can play in this field. International guidelines and advanced certifications in the management of lymphoedema exist to guide healthcare professionals and physiotherapists alike. In order to understand where the state of care for patients with lymphoedema stands in South Africa at present, we should look at how healthcare professionals are currently managing the condition. In this study, the focus is on physiotherapists. Physiotherapists are first line practitioners who have the ability to identify at risk patients, offer preventative care, diagnose and treat the condition and educate the patients, public and other healthcare professionals. By understanding the current perceived knowledge, patient load, management practice and individual experiences of physiotherapists managing lymphoedema, an improved understanding of current services offered to patients with lymphoedema can be achieved. Shortfalls can be identified, and the correction of these can result in improved care for patients with lymphoedema.

1.6 Outline of this Dissertation

Figure 1.1 shows the outline of this dissertation and the flow between the chapters.

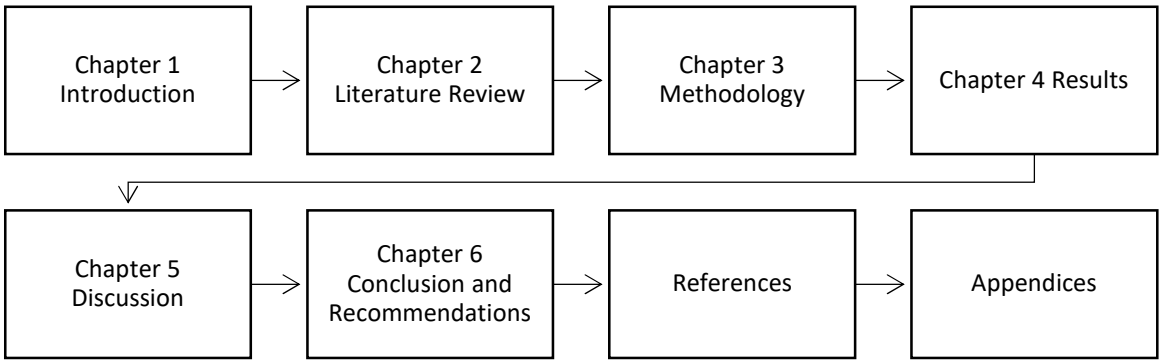


Figure 1.1: Outline of the dissertation

Chapter 2 LITERATURE REVIEW

2.1 Introduction

This chapter will review current literature that discusses how lymphoedema is managed worldwide. Sections on pathophysiology, prevalence, demographics, the burden of the disease, healthcare provision and clinical guidelines will be included. Books and articles were referenced from a variety of databases and online sources. Sources included but were not limited to databases such as Science Direct, Research Gate, PubMed, EBSCO and the University of the Witwatersrand's libguides. Keywords such as lymphoedema, prevalence, guidelines, treatment and quality of life were used. Articles were analysed according to how relevant they were to the topic, how up to date the article was, the reliability of the source the article was obtained from and how objective the article was, to only include the highest possible quality data.

2.2 Lymphoedema

2.2.1 Pathophysiology

Lymphoedema is a progressive disorder characterised by the swelling of one or more limbs, trunk, face and genitalia due to a deficient lymphatic system. The lymphatic system is responsible for removing excess protein rich lymphatic fluid from interstitial spaces, to be returned to the circulatory system, via a network of lymphatic capillaries, vessels, ducts and nodes (Borman, 2018). The lymphatic system plays an important role in fluid and fat transport and immunity (Grada and Phillips, 2017). Ernest H Starling (1896) described a process whereby two pressures, namely colloid osmotic pressure and hydrostatic pressure governed fluid movement across a capillary wall into the interstitial space. This is known as the Starling principle and contributed to the understanding of fluid homeostasis. It was understood that both the venous system and the lymphatic system were responsible for maintaining fluid balance. In 1989 Foldi et al published a paper detailing the pathophysiology of lymphoedema. He described potential insufficiency of the lymphatic system in terms of a 'transport capacity' which detailed three different pathophysiological causes of lymphoedema caused by an

imbalance in net capillary filtration and net lymphatic reabsorption. ‘Dynamic insufficiency’ occurs when the amount of lymph to be absorbed exceeds the lymphatic systems capacity. ‘Mechanical insufficiency’ describes a situation where there is a decreased capacity of the lymphatic system due to a pathological process. If there is an increase in fluid load and the lymphatic system capacity is also impaired a ‘safety-valve insufficiency’ occurs (Földi et al., 1989). All of the above situations lead to lymphoedema. It is widely accepted that around 10% of interstitial fluid reabsorption occurs at the venous end of a capillary by the lymphatic system. The rest is reabsorbed across the venous capillary wall (Grada and Phillips, 2017; Moffatt et al., 2019). An updated study done by Levick and Michel (2010) shows that in fact the lymphatic system is responsible for the reabsorption of fluid and macromolecules along the entire length of the capillary, and plays a much larger role in fluid homeostasis than previously thought. This new understanding highlights the interplay of different types of oedema and the lymphatic system.

2.2.2 Defining lymphoedema

The causes of lymphoedema can be primary or secondary in nature. Primary lymphoedema occurs when there is a congenital, intrinsic dysfunction of the lymphatic system. Secondary lymphoedema is when there is an external cause for the lymphatic system dysfunction, such as cancer, infection, filariasis or trauma (Borman, 2018). Primary lymphoedema is further categorised into congenital lymphoedema if it is present from birth, lymphoedema praecox which presents between the ages of one and 35 and lymphoedema tarda which presents after the age of 35 (Mehrara, 2019). Due to the possible presence of multiple factors and different types of oedema, lymphoedema is often hard to diagnose and under recognised by healthcare providers and in turn policymakers and medical funders (Keast et al., 2015; Logan et al., 1996). In some instances, lymphoedema is broadly characterised as ‘chronic oedema’ that is persistent oedema of three or more months. Other articles make the distinction that lymphoedema is very specifically only swelling linked to protein rich lymphatic fluid. A recent study by Moffatt et al. (2019) explores the relationship between lymphoedema and chronic oedema. In the paper it was suggested that indeed all types of oedema are related to the lymphatic system, as the system is responsible for removing up to 90% of interstitial fluid regardless of the cause of the oedema (Levick and Michel, 2010). Whether the cause of oedema is cardiac insufficiency, immobility, systemic

disease or obesity, the lymphatic system is responsible for transporting the excess fluid. Therefore, even with a healthy lymphatic system, the homeostatic balance can be overloaded, overwhelming and fatiguing the lymphatic system, resulting in chronic oedema or lymphoedema.

2.2.3 Epidemiology of lymphoedema

The prevalence of lymphoedema worldwide is difficult to describe. There are a few factors that make determining the prevalence of the condition difficult. The literature points to the ambiguity of making a diagnosis of lymphoedema as a key factor in this lack of prevalence data (Rockson and Rivera, 2008). Lymphoedema is consistently misdiagnosed due to a lack of knowledge on the topic from a public and healthcare professional standpoint. There are many co-morbidities that result in different types of oedema, and as such lymphoedema often gets overlooked, resulting in a skewed population size (Moffatt et al., 2019). Most studies are done on a small sample of the population, mainly those with lymphoedema secondary to breast cancer. Patients presenting with lymphoedema from different causes, at a community and primary healthcare setting are mostly being overlooked, which makes understanding the prevalence of lymphoedema difficult (Moffatt et al., 2003). In developing countries where access to healthcare is limited, and the knowledge of healthcare professionals on lymphoedema is lacking, there are even fewer reliable statistics to be obtained.

It is clear that lymphoedema is a global concern. Published works from Turkey, Australia, Israel, South Africa, the United Kingdom and America testify to the global nature of the condition. The incidence of primary lymphoedema is reported to be one in 100 000, with secondary lymphoedema being the most common cause of the disease, estimated at affecting one in 1000 Americans (Sleigh and Manna, 2021). Rockson and Rivera (2008) suggested that 1.33-1.44 per thousand people suffer from the condition, while more recent data from Gerez et al., (2020) proposes that there are around 140 to 200 million people with lymphoedema worldwide. Armer et al.'s (2020) study estimates that three to five million people in the United States and tens of millions of people worldwide have secondary lymphoedema as a result of cancer. Across all these studies one thing is apparent, that there are no clear comprehensive figures on the population of people living with lymphoedema.
In an effort to remedy this, The International Lymphoedema Framework has developed an international study; the Lymphoedema Impact and Prevalence International study.

The study aims to collect data on lymphoedema prevalence across multiple countries to shed light on the burden of the condition on healthcare structures and on those living with lymphoedema (Keast et al., 2019). Their method of obtaining data focuses on surveying healthcare professionals in different areas to gather information about patients already known to them in the healthcare system. This 'case ascertainment methodology' and improving assessment of prospective patients are providing important prevalence data (Moffatt et al., 2019). In a three year time frame, from 2014 to 2017, 40 sites across nine countries have collected prevalence data on a broad sample of the population with lymphoedema. The results of this international, ongoing study have provided data not only on prevalence, but also on quality of life of patients living with lymphoedema, challenges faced by children and adolescents with the condition, the parental impact for this young population, as well as specific experiences from the multiple participating countries (Dai et al., 2019; Gordon et al., 2019; Keeley et al., 2019; Mercier et al., 2019; Moffatt et al., 2019; Nairn et al., 2019; Nøerregaard et al., 2019; Quéré et al., 2019).

2.2.4 Lymphoedema and filariasis

The most common cause of lymphoedema globally is filariasis, especially in many southern hemisphere countries (Mehrara, 2019; Pfarr et al., 2009; Schwartz, 2020). In 2007 Addiss and Brady (2007) estimated that 16 million people suffer from lymphoedema in areas where filariasis is the leading cause of the condition. An article by Viehoff et al. (2015) commented on findings by the WHO which stated that around five million people could be suffering from the disease due to lymphatic filariasis alone.

2.2.5 Lymphoedema and cancer

Lymphoedema associated with cancer continues to be the most widely recognised, researched and funded area of lymphoedema. Lymphoedema secondary to breast cancer and other cancers is becoming more prevalent in both higher and lower socio-economic countries (Torgbenu et al., 2020). Patients who have had treatment for breast cancer, represent the biggest population of patients with lymphoedema secondary to cancer (Armer et al., 2020; Mehrara, 2019). It is estimated that 25-89% of breast cancer patients may develop the condition (Kayıran et al., 2017; Keast et al.,

2015; Vakharia et al., 2017). The American Cancer Association estimates that in 10-40% of patients newly diagnosed with breast cancer are likely to develop lymphoedema. The correlation between breast cancer and lymphoedema is so high, that many studies highlight the importance of preventing lymphoedema post mastectomy and early intervention to manage lymphoedema onset (Gençay Can et al., 2018; Stuiver et al., 2015). In South Africa it is estimated that one in 12 Caucasian women and one in 18 women of colour are likely to develop breast cancer. With the increasing incidence of breast cancer, comes an increase in breast cancer related complications such as lymphoedema (Wanchai et al., 2012). With the improvement in medical oncology and the improved survival rate of patients with cancer, lymphoedema is a condition that is growing in prevalence (Siegel et al., 2020).

2.3 The Burden of Lymphoedema

The burden of lymphoedema is felt across many aspects of not only a patient's life, but also within a societal, healthcare system and economic context. Physically, patients who have lymphoedema struggle with day to day activities and often report pain and discomfort (Keast et al., 2019; Kibar et al., 2017; Martindale et al., 2014). This altered ability to perform daily tasks has a direct impact on the way they interact within a social context. The patients psychosocial wellbeing is negatively affected and patients report feelings of frustration, hopelessness and embarrassment about their condition (Addiss and Brady, 2007; Maree and Beckmann, 2016). Eaton et al. (2020) discusses various psychological problems faced by woman with breast cancer related lymphoedema. Anxiety, depression, fear, fatigue and emotional distress were all highlighted as key areas of concern, which contributed to a decreased satisfaction in their quality of life (Mercier et al., 2019). Societal perceptions also have a role to play in the burden felt by patients with lymphoedema. There is a stigma associated with lymphoedema that is strongly linked to sexuality and body image, which changes the way people with lymphoedema interact with community members, friends and family (Eneanya et al., 2019). Literature suggests that the biopsychosocial problems faced by people with lymphoedema impact their lives for many years and impact their ability to be functioning members of society (Anbari et al., 2019).

With the physical and emotional burden, people with lymphoedema often find it difficult to continue working. Depending on the area of swelling and use of compression garments, certain jobs become difficult (Río-González et al., 2018). Eneanya et al.

(2019) found a decrease in productivity and work output in the cases in their study, which limited their earning capacity. Eaton et al. (2020) had similar findings, noting that patients with breast cancer related lymphoedema were less likely to return to work, or their return to work was delayed, when compared to patients who had had breast cancer but not lymphoedema.

The inability to work has a large knock-on effect on the economic burden felt by the patient, and society as a whole. Treatment costs for lymphoedema are high, as it is a chronic condition that requires continued care (Río-González et al., 2018). Dean et al. (2019) compared the 'out of pocket' medical costs incurred by patients with and without lymphoedema over a 12 month period. They found an increase cost of 112% in the population with lymphoedema. In some instances, due to loss of work or productivity, the burden of these costs were shared with family members, local organisations, or the public health sector. The financial impact on both patients and healthcare systems is evident in two studies by De Vrieze et al. (2020a), (2020b) which highlight the ongoing high cost of care for patients with lymphoedema. South Africa received a Health Care Index of 53 out of 89 countries when assessing infrastructure, professionals, competencies, cost, quality of care and government readiness by Ireland (2021) from CEOWORLD Magazine. According to Maphumulo and Bhengu (2019), factors such as a shortage of human resources, poor hygiene and infection control, a shortage of equipment and medicines contribute to the compromised nature of the healthcare system in South Africa. Considering these factors, the burden on the healthcare system in South Africa and resultant impact on the patients themselves could be significant as the need for lymphoedema management grown.

As the incidence of lymphoedema grows, so does the strain it puts on healthcare systems and healthcare professionals who are not adequately equipped to manage the condition. This leads to patients being inadequately managed, allowing unnecessary complications to arise, which drains resources. Patients who are mismanaged can suffer further physical, social and psychological problems.

2.4 Provision of Healthcare in Lymphoedema

The provision of care for people with lymphoedema remains a complicated issue. In some parts of the world specialist facilities exist where patients can get tailored care,

while in others a lack of resources, funds and knowledge means that the population with lymphoedema is overlooked. In South Africa, poor awareness of the condition, socio-economic status of the patients, financial constraints of the healthcare system and a lack of lymphoedema trained professionals all contribute to poor access to services (Marco et al., 2014). Stout et al. (2012) comments that the disparity in the provision of care is not limited to only low-resource countries but can be attributed to lack of epidemiological data and overall knowledge of the condition in the healthcare profession. Schulze et al. (2018) highlighted a concerning lack of specialised physicians in the field of lymphoedema in a literature review titled 'Worldwide assessment of healthcare personnel dealing with lymphoedema'. Their study found there to be a lack of tertiary specialised professionals, both in the clinical and research fields in the field of lymphology. Asia, North America and Europe stood out as continents with the largest number of lymphoedema specialists. Africa, Oceania and South America showed a lack of professionals in the field and an overall failing of healthcare provision to the population with lymphoedema (Schulze et al., 2018). Across all the countries investigated, lower socio-economic, more rural areas consistently showed a lack of professionals managing lymphoedema.

Educating healthcare professionals about the management of lymphoedema is key to providing patients with a high standard of care (Gerez et al., 2020). Studies by Anderson et al., (2019); Armer et al., (2010); Davies et al., (2012) and Gerez et al., (2020) undertook surveys amongst healthcare professionals to understand their perceived knowledge on different aspects of lymphoedema management. The results showed that there are many other healthcare professionals who have a role in the management of lymphoedema. Davies et al. (2012) surveyed general practitioners, nurses, occupational therapists, physiotherapists, dietitians, podiatrists, orthotists, radiographers and pharmacists working in primary care, community care, oncology and palliative care. Gerez et al. (2020) focused on nurses in a wound, osteotomy and incontinence clinic, while Anderson et al. (2019) and Armer et al. (2010) included massage therapists as well as the primary and other healthcare providers. Their studies showed that lymphatic therapists can be divided into two categories: 'generalists' and 'specialists'. Specialists are those professionals who have undergone further training in lymphoedema management and were often registered with a lymphatic network, or in fact worked in a lymphatic specific setting. In a South African context, there are no 'specialties' in physiotherapy but rather areas of special interest.

This group perceived their knowledge base as being quite good, with little need for further education on the condition (Davies et al., 2012). The generalist group included a mix of healthcare professionals that have not undergone any accredited training or specialisation, but still manage patients with lymphoedema. Within the generalist group it is highlighted across multiple studies that there is a great need for continued education. Most disciplines identified the need for further education of the diagnosis of the condition, current management, skin care and identifying at risk patients. Davies et al. (2012) and Gerez et al. (2020) noted that basic concepts of lymphoedema management and diagnosis were lacking in the majority of the nurses they surveyed. It appears that although there are lymphoedema specialists worldwide, the majority of healthcare providers fall into the generalist category and remain poorly educated about the management of lymphoedema (Keast et al., 2015). It seems that a lack of curriculum presented to healthcare professionals at a university level may be one part of the problem. This lack of formal education may have a twofold effect, resulting in healthcare professionals with a lack of knowledge of the field and in less researchers being drawn to the field to develop the overall knowledge base (Schulze et al., 2018; Thiadens, 1998).

2.5 Guidelines for Lymphoedema Management

Since the 1800's, practitioners have been managing lymphedema (Földi et al., 1989). Through the years various organisations, networks and associations have been formed to develop training programmes, and guidelines. Their aim continues to be the promotion of awareness and improvement of standard of care for the population with lymphoedema. Associations such as the National Lymphoedema Network, Lymphology Association of North America, International Society of Lymphology, the British Lymphology Society, the International Lymphoedema Framework and the LAOSA are just a few such organisations (Anderson et al., 2019). Each of them have developed professional guidelines to guide healthcare professionals and the public. The guidelines outline assessment and treatment protocols and are based on the gold standard of care namely CDLT. They are informed by research, healthcare professionals, patients and experts in the field of lymphoedema (Moffatt et al., 2006).

2.6 Current Clinical Practice

2.6.1 Assessment

Key to the correct management of lymphoedema is correct assessment and diagnosis. This is an area that needs research and standardisation (Moffatt et al., 2019). When trying to determine the cause of the oedema, Computerised Tomography Scans, Magnetic Resonance Imaging, Lymphoscintigraphy and Lymphofluroscopy can provide insight into the structures involved (De Vrieze et al., 2018; O'Donnell et al., 2020). In order to monitor and manage the condition consistently, reliable measurements of the affected areas need to be taken. Standardised measurement techniques enables patients to be easily compared, results in improved monitoring of treatment progress and more reliably estimates the prevalence of the condition (Torgbenu et al., 2020). Water displacement, limb circumference measurement, perometry and bioimpedance are recommended for the measurement of limb volume in a patient with lymphoedema (Hidding et al., 2016; Moffatt et al., 2006; O'Donnell et al., 2020). Each of these methods have their own strengths and weaknesses. Water displacement is the most reliable, but not the most hygienic method. The use of perometry is limited due to its cost. Limb circumference measurement is the easiest and most utilised, but not the most reliable way to monitor limb changes (Moffatt et al., 2006). The ability to reliably measure oedema of the head and neck remains a challenge. There is no standardised, validated outcome measure to perform these measurements. The most commonly used method is multipoint measurements with a measuring tape, which yields varying degrees of reliability and precision (Chotipanich and Kongpit, 2020; Deng et al., 2015; Purcell et al., 2016).

2.6.2 Treatment

2.6.2.1 Complete decongestive lymphatic therapy

Complete decongestive lymphatic therapy (CDLT) is the treatment of choice in the management of patients with lymphoedema (Marco et al., 2014; Poage et al., 2008). Skin care, manual lymph drainage (MLD), compression therapy in the form of bandaging and garment wearing and exercise make up the four main components of

the technique (Moffatt et al., 2006). CDLT is administered in two phases. Phase one is intensive, focusing on daily 45-75 minute treatments over a period of up to six weeks. Phase two is focused on maintenance and self care, where the patient wears a compression garment and does their own massage and bandaging (Leaird, 2011). In 1800 Dr Winniwater described a process of gentle massage to treat swelling. Many years later in the 1930's Dr E. Vodder advocated for a massage technique, namely MLD, to improve lymphatic return and decrease swelling in patients with lymphatic disorders. In 1985, thanks to the works of Dr Vodder, Dr Foldi developed CDLT a conservative technique to treat lymphoedema. Over the years the technique has been adapted by the likes of Casley-Smith and Leduc and is known by many names (complex physiotherapy, combined decongestive therapy, combined physiotherapy) but the basic principles of the treatment have remained the same (Leaird, 2011; Williams, 2010).

CDLT has shown to be of great therapeutic use in the treatment of existing lymphoedema and the prevention of lymphoedema post breast cancer. Torres Lacomba et al. (2010) used a modified CDLT regime to treat women who had undergone unilateral surgery with lymph node resection for breast cancer. They found that the incidence of developing lymphoedema was lower (7% versus 25%) in the group that had received MLD, exercise and education than those who had received education alone. Multiple studies and reviews have shown that CDLT is an effective treatment for patients with existing secondary lymphoedema relating to breast cancer (Devoogdt et al., 2010; McNeely et al., 2011; Randheer et al., 2011). The use of CDLT to manage lymphoedema in its many forms is also strongly supported by many clinical guidelines worldwide (Armer et al., 2020; Klose Training MLD Certification, 2018; Moffatt et al., 2006; O'Donnell et al., 2020).

A critique of research on all components of CDLT is that the studies are often small, mostly carried out on breast cancer patients and there are many factors that can affect the progression of lymphoedema in each study that are not taken into account. Factors such as the body's ability to resolve an acute bout of lymphoedema unaided, the number and type of lymph nodes removed, other medication interactions and changes in body weight can contribute to the skewing of results (Johansson et al., 2020). In most studies the components are investigated with the addition of other techniques,

making it hard to determine if the effect observed is a true reflection of the component being investigated (Devoogdt et al., 2010).

2.6.2.2 Skin care

Skin conditions are common in patients with lymphoedema. Swelling of tissues, and an increased presence of protein rich lymphatic fluid can decrease the integrity of a lymphatic patient's skin and put them at risk for developing infection (Ezzo et al., 2015). Throughout the treatment of the condition it is important to monitor and manage the patient's skin condition with appropriate cleaning, products and advice as to avoid complications that may arise as a result of injury or poor hygiene (Moffatt et al., 2006; O'Donnell et al., 2020).

2.6.2.3 Manual lymph drainage

Manual lymph drainage (MLD) is a massage technique, using broad, light strokes to facilitate the movement of lymphatic fluid away from an area of congestion towards more viable lymph nodes (Moffatt et al., 2006). The proposed efficacy and mechanism of effect continues to be studied, as there is little supporting evidence for its use. Using lymphoscintigraphy, Mortimer et al. (1990) showed that external pressure such as massage had a strong influence in the movement of lymphatic fluid in pigs. Another study by Kafejian-Haddad et al. (2006) assessed the efficacy of MLD on the lower limb by monitoring the movement of 'radioisotope technetium-99m-labeled dextran (99mTcDx)' with the addition of MLD. They found that with lymphatic massage there was a decrease in limb volume, but it did not have a significant effect on the transport of the isotope, proposing that the effect of MLD may be more on fluid dynamics at a vascular level than the lymphatic system. In a review of physical treatment modalities Devoogdt et al. (2010) concluded that there was 'no consensus on the effectiveness of MLD'.

Literature points rather to the combined used of MLD with other treatment modalities, as seen in CDLT. Ezzo et al. (2015) found that the addition of MLD with compression resulted in a further 7% decrease in limb volume than with compression alone, concluding that MLD is a safe and effective way to treat lymphoedema. There is some

research that shows that MLD can be of use in prevention of lymphoedema secondary to breast cancer (Zimmermann et al., 2012). Stuiver et al. (2015) found that in terms of prevention of lymphoedema in at risks patients, the use of MLD was more beneficial that no intervention at all, however it was more effective when done in conjunction with scar massage and compression. They also noted that MLD had other beneficial effects such as increased range of motion of the affected limb, which supports Williams (2010) suggestion that MLD can also positively affect tissue spasm, pain levels and fascial movement.

Simplified lymphatic drainage or self lymphatic drainage (SLD) is another type of lymph drainage massage that focuses on allowing the patient or carer to administer their own treatment over 10-20 minutes as opposed to lengthy MLD provided by a therapist (Moffatt et al., 2006). Bahtiyarca (2019) found that there was no significant benefit to the addition of SLD instead of MLD with compression and suggested that further research be done on the efficacy of the modality.

2.6.2.4 Compression therapy

Compression therapy in the management of lymphoedema has multiple physiological benefits. The increased external pressure on the limb results in decreased filtration and increased reabsorption at the capillary, improves lymph flow and has a positive effect on breaking down scar tissue and fibrosis (Leaird, 2011). In CDLT compression therapy is administered with the use of compression bandages and specialised compression garments.

2.6.2.5 Compression bandaging

There are different views on which type of bandage is best for CDLT. Some studies describe using ‘inelastic’ bandages, while others describe using ‘elastic’ bandages, but neither are absolutely defined which leads to ambiguity (Thomas, 2017). Oh et al. (2019) defines a bandage that elongates by 0-10% as being a no stretch bandage, 10-100% as being a short stretch bandage and 100% as being a long stretch bandage. Moffatt et al. (2006) advocate for the use of ‘non elastic’ bandages as the bandage of choice but shows that elastic bandaging can have its place when used on a less mobile

patient. The problem encountered with more elastic bandages is that the resting pressure is higher. ‘Short stretch’ or ‘no stretch’ bandages are commonly used for the high working pressure and low resting pressure achieved, which simulates a massage type effect and results in an increased passive lymph flow when active, while keeping pressures comfortable at rest (Bahtiyarca, 2019; Leaird, 2011). Guidelines suggest a multi layered bandaging technique be used, to ensure patient comfort and ample cushioning (Moffatt et al., 2006; Poage et al., 2008) and are to be worn full time in between MLD treatments in the intensive phase (Leaird, 2011). With such a discrepancy in the understanding of bandage types, it is hard to guarantee and reproduce expected pressure gradients on the limb with bandaging. A study by Karafa et al. (2018) investigated the effects of different grades of compression pressure using compression bandaging. Ninety-six women with upper limb lymphoedema post breast cancer were treated with compression bandages. They were split into three groups, receiving 21-30mmhg, 31-40mmhg and 41-60mmhg, respectively. Results showed that the smallest pressure was best tolerated, but also lead to the smallest decrease in lymph volume. Groups two and three had a similar reduction in lymph volume, but the higher pressure was poorly tolerated. Oh et al. (2019) investigated two different bandaging techniques and the effect they had on decreasing lymph volume and improving function in an upper limb post breast cancer lymphoedema. They found that the spica method, using ‘non elastic’ bandages was more effective than the spiral method in this regard, but was more uncomfortable for the patient to wear due to its tightness.

2.6.2.6 Compression garments

Compression garments are used in prevention, treatment and management of lymphoedema, as a more permanent form of compression. The principle of lymphatic compression garments is the same as that for compression bandages and can be tailor made for the patient. Prescription of compression garments can sometimes be challenging, as there are different types of fabric (flat or round knit), different compression classes (class one to four, ranging from 10-60+mmhg) as well as different styles (gauntlets, gloves, sleeves, pants, stockings) (Leaird, 2011; Pugh et al., 2017).

These factors can impact not only the efficacy of the garment, but also the patient’s compliance to wearing the garment (Longhurst et al., 2018). The Best Practice for the

Management for Lymphoedema by the Lymphoedema Framework (Moffatt et al., 2006) and the systematic review of lymphoedema guidelines carried out by O'Donnell et al. (2020) describes the use of garment prescription as part of CDLT, to be prescribed once the intensive phase of treatment is complete, and the limb volume has plateaued. While in some cases this can take two to six weeks, Karafa et al. (2018) found that the greatest reduction of lymphatic load with bandaging was found in the first week, with the subsequent weeks serving to maintain the volume, which suggests accelerate garment prescription may be more beneficial. A systematic review and meta-analysis done by McNeely et al. (2011) showed that there is moderate evidence to support the use of compression garments to reduce lymph volume in patients with upper and lower limb swelling. This suggests that garments can be used not only for maintenance of swelling, but also for prevention and treatment. Davies et al. (2020) promotes the use of compression garments for patients with subclinical manifestation of lymphoedema, as well as those who have already been diagnosed with lymphoedema. In a study by Ochalek et al. (2017), circular knit class one (15-21mmHg) sleeves were fitted to 45 women who had undergone surgery for breast cancer. The intervention, which included wearing of the garment and light daily exercises was done for a year and showed a decrease in the incidence of early upper limb swelling in this sample. Johansson and Karlsson (2019) have published preliminary results of a study in which two groups of patients with an early diagnosis of mild lymphoedema post breast cancer treatment were divided into two groups. One group was fitted with compression garments and one group was not. Both groups were monitored in terms of lymph volume of the limb. The study shows that mild lymphoedema can be treated with compression garments alone in the early stages.

2.6.2.7 Lymphatic exercise

Lymphatic exercises are aimed at improving lymphatic uptake, maintaining range of motion and decreasing swelling of a limb (Ezzo et al., 2015; Pugh et al., 2017). Literature suggests that therapeutic exercise should be prescribed for lymphoedema patients regardless of the stage and chosen treatment modalities. Gençay Can et al. (2018); Johansson et al. (2020) and Ochalek et al. (2017) used lymphatic exercises either as a stand-alone intervention or in combination with other CDLT techniques and found them to be beneficial in preventing or treating subclinical upper limb swelling after cancer treatment. A review by Davies et al. (2020) showed that exercise is a safe

and effective way to manage swelling for patients at a post-operative care stage, a subclinical stage, those at risk of developing lymphoedema and those already diagnosed with the condition. The above studies highlight that exercise must be slow and progressive, starting with just 15 minutes a day. The emphasis of the exercises is on gentle, through range movements, with minimal resistance. The exercises must be tailor-made for the patient and designed by a trained professional in the field.

2.6.2.8 Intermittent pneumatic pumps

Intermittent pneumatic pumps (IPP) are a device that is used to provide compression therapy with air compression through a sleeve. The device has multiple compression chambers in the sleeve and can be set to deliver different degrees of compression to the limb, which pulse proximally to distally (Zaleska et al., 2014). MLD as part of CDLT is the gold standard of care for lymphoedema, however intermittent pneumatic pumps have been suggested to be an easy to use, cost effective, easily accessible alternative or adjunct to improve lymphatic movement and uptake in a patient with lymphoedema (Desai and Shao, 2020). Although the benefits of using IPP from both a financial and limb volume reduction aspect have been documented, the use of such devices in practice remains limited. A study conducted in North America by Hunley et al. (2020) showed that only 16% of Canadian respondents and 50-67% of United States respondents had used IPP. There is conflicting evidence and an ongoing debate as to whether or not the pump stimulates lymphatic propulsion and uptake in the same way that MLD does, which results in its infrequent use. Uzkeser et al. (2015) conducted a study where IPP was added to conventional CDLT in 31 patients with upper limb lymphoedema post breast cancer treatment. Their findings could not find a significant difference in limb reduction with the addition of the IPP and concluded that it added no value to conventional CDLT. They also noted that the use of IPP may result in a more lengthy and costly course of treatment when compared to CDLT alone. Desai and Shao (2020) provided 128 patients with IPP to be used for 30 minutes twice a day in the comfort of their own home. They found that not only did the treatment show a decrease in limb volume of these patients over one year, but also an improvement in functional ability and quality of life. Their study suggests that there was a decrease in need for admissions, and hands on lymphoedema care, and as such the use of the IPP resulted in an overall decrease in cost of patient care. The use of IPP in conjunction with compression garments showed favourable results in a study by Zaleska et al. (2014),

and also resulted in increased tissue elasticity, which showed that tissue fibrosis may be positively influenced by the addition of IPP. In an effort to shed light on lymphatic fluid dynamics in IPP, Aldrich et al. (2017) used near-infrared fluorescence lymphatic imaging to investigate the movement of lymph through tissues before, during and after IPP. Their results showed increased distal to proximal lymphatic fluid transport in the subjects. The significance of the findings are limited due to the small sample size. Despite the varying evidence, both the 'Queensland Health Lymphoedema Clinical Practice Guide' and the 'Best Practice for Management of Lymphoedema Framework' provide guidelines for the use of IPP and acknowledge its potential use in the management of patients with lymphoedema.

2.6.2.9 Kinesiology taping

Research into the use of Kinesiology Tape (KT) to manage lymphoedema has yielded conflicting opinions. KT is used to decrease oedema by lifting the skin, guiding fluid towards areas of preferable drainage and allowing lymphatic fluid to flow more easily through the tissues (Hörmann et al., 2020). In situations where patients are non-compliant with compression therapy, KT may provide a viable alternate treatment modality (Gatt et al., 2017). Malicka et al. (2014) tested the effectiveness of KT on the reduction of early stage lymphoedema, when applied as a stand-alone treatment. One group received KT, and the control group did not. Their results showed that the test group had a significant reduction in limb volume with the application of KT. Smykla et al. (2013) investigated the effectiveness of KT as part of a more comprehensive programme including intermittent pneumatic pressure and MLD. All groups received the above treatment, and were then randomly allocated to either having compression therapy with short stretch bandaging, quasi- KT or KT. They found that there was no difference between the quasi-KT or KT group with regards to limb size and oedema reduction, with around 20% reduction seen in both groups. Overall, the use of compression bandages showed much more significant improvement in both these parameters (50%). This indicates that KT may have some therapeutic benefit in the management of lymphoedema but should not be used as a replacement for compression bandaging. In 'A meta-analysis of the effectiveness and safety of KT in the management of cancer-related lymphoedema' by Gatt et al. (2017), they noted that KT had a positive effect on symptoms such as pain and discomfort, limitations in function, heaviness, and stiffness of the affected area.

Some negative effects included an increase in skin complications and allergies. Quality of life scores were higher for patients with conventional compression bandaging than KT, and both KT and compression bandaging showed a decrease in limb volume. Current guidelines indicate that KT should be used with caution, as more research is needed, and should not be used as a replacement for short stretch bandaging (Davey et al., 2018; Davies et al., 2020; Moffatt et al., 2006).

2.6.2.10 Low level laser

The use of low level laser in treating lymphoedema is not highly recommended in guidelines due to the need for further research. Low level laser proposes to decrease inflammation is tissues, break down fibrosis and improve overall lymphatic mobility when used at a wavelength of 650-1000 nm (Baxter et al., 2017). Although there is some evidence that the use of laser does offer therapeutic value in decreasing pain, improving range of motion and decreasing limb volume in those with lymphoedema (Dirican et al., 2011), other papers note that the available research is not strong enough to conclude definitively that low level laser is a viable treatment for the condition (Mahram and Rajabi, 2011).

2.7 Summary

This literature review investigated lymphoedema with regards to pathophysiology and known epidemiology to gain an understanding of how lymphoedema presents and the current global picture of the disease. The review has shown that there are some discrepancies around prevalence data which need further research. With the available data, the overall burden of the disease was discussed from the view of the patients, the practitioners and global healthcare systems as a whole. The literature showed that the burden of the disease is great and multifaceted. Using international guidelines, and other studies, information about lymphoedema management was reviewed, which shed light on current international management practice. Using available literature, the research aims and objectives for this study were developed. The methodology used to meet these aims and objectives are discussed in the following chapter.

Chapter 3 METHODOLOGY

3.1 Introduction

In this chapter the methodology of the study will be outlined. The procedures will be described under the following headings: study design, study setting, participants, instrumentation and outcome measures, procedure, ethical considerations and statistical analysis. The study was a mixed method design and had two phases, a qualitative and quantitative phase. Each phase (phase one and phase two) will be discussed under the main headings. The methodology flow chart below (Figure 3.1) illustrates how the methodology of the paper used qualitative and quantitative methods to achieve the study objectives and answer the research question.

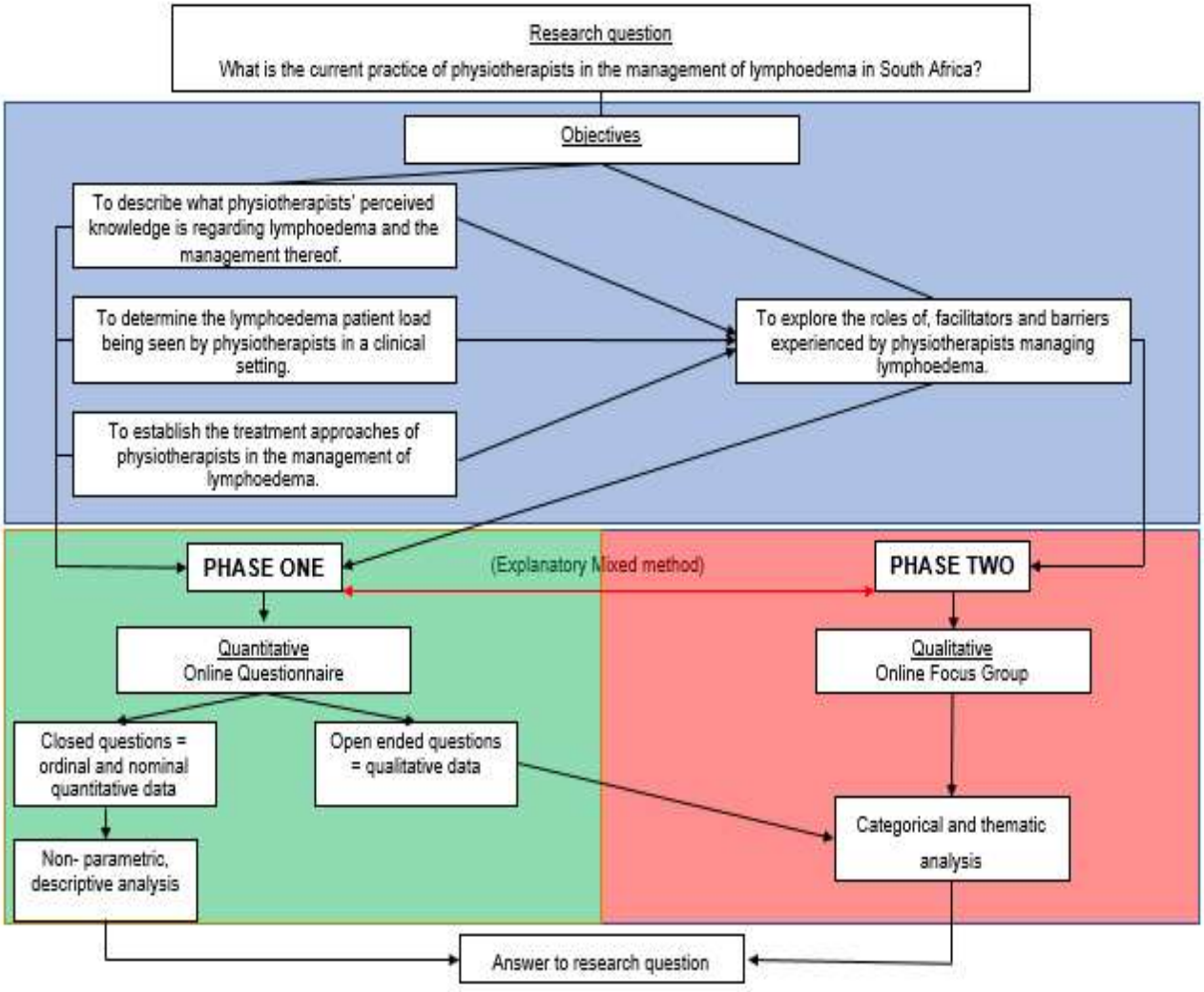


Figure 3.1: Methodology flow chart

3.2 Study Design

The study objectives represented different aspects of the concept of 'physiotherapy practice' as stated in the title. Some of these aspects could be adequately evaluated using quantitative methods such as perceived knowledge, patient load and treatment approaches. Investigation into the roles, facilitators and limitations experienced by physiotherapists in the management of lymphoedema needed a different approach. This aspect of the study was explored first in the quantitative questionnaire with open ended questions, and then expanded upon with a qualitative approach. By using a mixed method approach, multi-faceted, rich data was obtained to answer the research question.

The study was designed as an explanatory sequential mixed method design. QUANTITATIVE → qualitative. This design allowed the study to be carried out over two phases, where the first phase of quantitative data informed the second phase of qualitative investigation. The second, qualitative phase of the study in turn complimented the data obtained in the first, quantitative phase. This was done to achieve triangulation of the topic, complementarity and expansion of the data already obtained from the quantitative part of the study. The point of integration was determined at the analysis and results phase of the study. The theory drive was inductive, as there was no hypothesis to prove, rather phenomena, practices and patterns to describe (Creswell, 2003).

Phase one, the quantitative phase, of the study was a self-administered online questionnaire and had a cross-sectional design. Phase two, the qualitative phase, consisted of focus groups held on an online platform.

3.3 Study Setting

3.3.1 Phase one

The questionnaire was completed by physiotherapists in South Africa, conducted online at their own location. At a university level there is basic tuition into the causes of lymphoedema and demonstration of massage techniques used to manage the

condition, which qualifies all physiotherapists with a university degree to manage patients with lymphoedema.

3.3.2 Phase two

The focus groups were held on an online conferencing platform, Zoom. By doing online focus groups participants that were geographically distant and may not have otherwise been able to participate were included. Although there were challenges related to observing interactions between participants on an online platform, data obtained was rich and full of nuance. The online platform encouraged participants who may be less forthcoming in person, to participate freely (Moore et al., 2015). For the purpose of this study, it resulted in a more comprehensive overview of physiotherapists' experiences, as physiotherapists from different provinces and work settings could participate.

3.4 Participants

3.4.1 Source of participants

3.4.1.1 Phase one

Physiotherapists currently working in South Africa were asked to partake in the electronic questionnaire by means of an advertisement inviting them to do so. The advertisement was distributed to the South African Society of Physiotherapy (SASP) and was also distributed on various social media platforms such as Facebook and WhatsApp. These interactions targeted specific groups such as Physio Focus, the Physiotherapy Association of South Africa (PASA), the SASP and groups for healthcare providers, all of which had a large number of physiotherapists as its members. Emails were sent to members of the LAOSA, as well as all physiotherapists known to the researcher. This was done to distribute the questionnaire to as many physiotherapists as possible while keeping the POPIA act in mind. Although physiotherapists that did not fit the inclusion criteria were reached, it was left to their own discretion not to participate if they were not suitable. Snowball sampling techniques were encouraged.

An expert panel was required to pilot the self-developed questionnaire. The experts for this part of the study were physiotherapists who had a certification in lymphoedema management and are members of the LAOSA. Their contact details were sourced from the LAOSA website, which are freely available.

3.4.1.2 Phase two

In the questionnaire, participants who had been identified as treating patients with lymphoedema were asked to provide their email address if they were willing to participate in a focus group. This created the population from which the focus groups were created. The population consisted of a mix of therapists with two different levels of knowledge and expertise. Those who had completed advanced certification in lymphoedema management and those who did not, but still treated the condition. Emails were sent to these participants, inviting them to join in one of two focus groups held on Zoom.

3.4.2 Sample size

3.4.2.1 Phase one

Five expert participants were chosen for convenience to pilot the questionnaire before the questionnaire was finalised and distributed. Physiotherapists currently registered with the Health Professions Council of South Africa (HPCSA) provided a population of a possible 8058 participants (Health Professions Council of South Africa, 2020). The sample size for the study was calculated according to guidelines set out by Cochran (1963) with a confidence level of 95%, a confidence interval of 5%. The required sample size for the study was 367 participants. This calculation was done on Raosoft online sample size calculator (Raosoft, 2014).

3.4.2.2 Phase two

Two focus groups were held, with the first having four participants, and the second five participants. This composition was governed by the participants availability. The focus groups were made up of a mix of physiotherapists who had advanced certification in the management of lymphoedema and those who did not, but still treat the condition. The first focus group had two therapists with advanced certification, and two without. The second focus group had two therapists with advanced certification and three without. These participants were identified from the questionnaire.

3.4.3 Sample selection

3.4.3.1 Expert panel for pilot of questionnaire

Inclusion criteria to participate as an expert on the panel to pilot the questionnaire included physiotherapists who have an advanced certification in the management of lymphoedema and were members of the LAOSA. Non-probability, convenience sampling was used.

3.4.3.2 Phase one

To participate in the online questionnaire participants had to be physiotherapists who held a university degree in Physiotherapy, be working at government or private institutions, hospitals or clinics at the time the questionnaire was completed and able to communicate effectively in English. If the participant was not currently practicing in South Africa they were excluded. Non- probability, convenience sampling was used.

3.4.3.3 Phase two

Physiotherapists who were currently managing patients with lymphoedema were able to participate in the focus groups. This served as the inclusion criteria. There were no exclusion criteria. Participants were identified as physiotherapists currently managing patients with lymphoedema by their responses on the questionnaire. Non-probability, purposive sampling was used.

3.5 Instrumentation and Outcome Measures

3.5.1 Phase one

3.5.1.1 Self-administered questionnaire

The questionnaire was developed by the researcher using Research Electronic Data Capture (REDCap) software, version 11.2.2 (Appendix A) (Harris et al., 2019, 2009). It consisted of open and closed type questions. The questionnaire covered the following topics to answer the research question; demographic information of the participant, the participants` knowledge of lymphoedema management, details on patient load, such as number and type of patients seen by the participant and lymphoedema management approaches of the participant. The development of the questionnaire and the use of Likert scale type questions referenced other questionnaires from studies with similar study designs (Gracey et al., 2002; Grieve and Palmer, 2017; Reeve et al., 2007; Shimpi et al., 2014). Studies with similar aims and objectives such as the American Lymphoedema Framework Project online survey (Anderson et al., 2019), and the surveys used in 'Lymphoedema therapists: a national and international survey' by Davies et al. (2012) were also considered and certain questions were adapted for use in this questionnaire. The content of the questionnaire were guided by the "Best Practice for the Management of Lymphoedema; International Consensus" compiled by the Lymphoedema Framework (Moffatt et al., 2006), to ensure that the questions reflected current clinical guidelines. There was a short, open-ended question on the roles, facilitators and barriers experienced by the participant, which helped develop the body of the interview schedule for the focus groups.

Experts in the field from the LAOSA were consulted during the development of the questionnaire and piloted the questionnaire to assist in determining content validity, as described in section 3.6.1.

3.5.2 Phase two

3.5.2.1 Focus groups

To expand on the exploratory, quantitative phase of the study and further explore the opinions and experiences of physiotherapists relating to the research questions that were not expressed in the questionnaire, online focus groups were held. Semi-structured interviewing techniques were used to gain insight into the roles, facilitators and barriers faced by physiotherapists who treat patients with lymphoedema. An interview guide was developed and refined after the analysis of the quantitative data obtained in phase one of the study (Appendix B). This guide was used to facilitate the focus groups. An external facilitator was briefed on the topic and the researcher sat as a research assistant in the sessions.

Credibility, transferability, dependability and confirmability strategies were implemented to achieve trustworthiness of data. Credibility was achieved by collecting data with various methods. Written notes were taken on observations made in the group dynamic as well as the audio-visual recording which achieved triangulation. Throughout the focus group a member check was done where participants were asked to check a summary provided by the facilitator on topics discussed, to identify any mistakes in interpretation or to expand on any incomplete themes. By purposefully selecting a mix of physiotherapists that treat patients with lymphoedema from around South Africa, transferability of data was achieved. Detailed record keeping of the procedures undertaken during data collection and analysis established dependability. To remove researcher bias and achieve confirmability, the researcher fulfilled the role of the research assistant and used bracketing to remove their own beliefs and experiences from the process of collecting and analysing the data. This was important as the researcher is a physiotherapist who treats lymphoedema patients but does not have the advanced certification. The facilitator and researcher practiced reflexivity after each focus group by discussing notes taken and reflecting on each of their experiences of the group to evaluate the process and data collected (Giddings and Barbara, 2009; Nowell et al., 2017).

3.6 Procedure

3.6.1 Pilot study

Before commencement of phase one of the study, a pilot study was carried out on a sample of five conveniently selected physiotherapists who were certified lymphoedema therapists and members of the LAOSA to determine relevance of the content of the questionnaire, inform procedural aspects and advise on feasibility of conducting the questionnaire on a larger scale. They received an email inviting them to complete the questionnaire and give feedback on any inconsistencies, errors or difficulties they may have encountered. They were also asked to report on the length of time that it took them to complete, as well as how easy they found it to complete the questionnaire. The panel identified a typing error, reported that one of the questions were unclear and suggested the inclusion of another option in the level of physiotherapy qualification held. These corrections were made, and the questionnaire was resent to the panel. There were no further changes and the data from their responses was used as part of the study.

For the second phase of the study, the interview guide and technique was piloted by the facilitator on the researcher, who is a physiotherapist working in lymphoedema management, to allow improvement of content and delivery of the proposed schedule.

3.6.2 Main study

3.6.2.1 Phase one

In order to distribute the questionnaire to physiotherapists matching the inclusion and exclusion criteria, various databases were used. The SASP was contacted for permission to distribute an advertisement via email to their members. Once permission was given, the SASP sent one email to all its members with an advertisement to participate and the link to the questionnaire. Emails with the advertisement were also sent to members of LAOSA, whose details are freely available on the LAOSA database, and to all physiotherapists known to the researcher, by the researcher. Social media platforms such as WhatsApp and Facebook were used by the researcher

to share the advertisement and link to groups such as Physio Focus, the PASA, the SASP and a group for healthcare providers, all of which have physiotherapists as their members. The advertisement invited physiotherapists to participate in the study and included a brief overview of the study and inclusion criteria. The link directed participants to the questionnaire on the REDCap site. Included in the link to the questionnaire was a study information document explaining the purpose of the study, as well as explaining their rights regarding participation in the study (Appendix C). Consent to fill out the electronic questionnaire was indicated before continuing with the questionnaire. The link was made available for three months after the onset of the study. Follow up emails to physiotherapists who had expressed interest in participating and social media posts were done monthly by the researcher during this time to promote good participation. After the three months, the questionnaire was closed, and the data was collated and analysed by the researcher.

3.6.2.2 Phase two

From the questionnaire, participants were identified for the focus groups. Physiotherapists who were treating patients with lymphoedema volunteered their email addresses after the questionnaire. These respondents were contacted by email and invited to take part in one of two, one hour long focus groups that were held on an online platform, Zoom. If the respondent indicated their interest, they were sent a focus group consent form (Appendix D), a consent to audio visual recording form (Appendix E) and a focus group information document (Appendix F) to complete and return to the researcher. There was enough interest to hold two focus groups, with four and five participants respectively. The focus groups were held, in English, to explore the opinions and thoughts of physiotherapists who treat patients with lymphoedema on the roles, facilitators and barriers they face in their management of lymphoedema, as well as any other topics identified in the data obtained from the questionnaire that warrants further research. The participants in the focus groups were informed as to the time and date of the focus group and received email reminders. A meeting invitation to the Zoom meeting was sent to each participant in the days leading up to the focus group.

The participants followed the link and were admitted to the group by the researcher. Some participants chose to turn off their screens, but they were encouraged to leave them on to facilitate good dialogue and allow observation of body language. The

sessions were facilitated by an external facilitator and the researcher sat as the research assistant. After a welcome, rule and goal setting, verbal consent to participate and to be recorded was obtained. The discussion was semi structured, following a pre prepared interview guide which allowed for probing and theme expansion where necessary. Opening, follow-up, probing, specifying, interpreting and closing questions were used to lead a focused discussion (Kvale and Brinkmann, 2009). The sessions were recorded on Zoom and on a recording device. The recordings were transcribed by an external transcriber and checked by the researcher against the recordings and notes taken in the session. The researcher de-identified the data to protect the participant's anonymity. This was done after transcription, as the names of the participants were used in the focus group amongst the participants and so was audible on the recording. The consent form allowed for this. Field notes were taken during the discussion by the researcher (research assistant) and the facilitator to capture any key points to further expand on as well as participant interactions. After the focus groups the researcher and facilitator sat and discussed the session, allowing time for summarising, problem solving for the following session as well as debriefing and reflexivity.

3.7 Ethical Considerations

Ethical clearance for the study was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand before the start of the study. (Ethical Clearance number M200540).

Participation in the study was voluntary, and a participant could withdraw at any time. There was no remuneration for taking part in the study, and consideration were made to respect the participants time and possible incurred costs when participating in the study. It was anticipated that the questionnaire would take between 10-20 minutes to complete, and the focus group were held on an online platform, Zoom. There was no risk to participants in the study, and there was no direct benefit to the participant at this stage.

A study information document (Appendix C) explaining the rights of the study participants was included with the questionnaire. Consent to participate in the online questionnaire was obtained by all participants. The identity of the participants remained

confidential, as responses were captured numerically, and no identifying information was requested.

Participants in the focus group were provided with a focus group information document (Appendix F), consent to audio visual recording form (Appendix E) and a focus group consent form (Appendix D) to sign prior to the session. Consent from all participants was obtained. Verbal consent to the above was also given on the day of the focus group. The participants were allocated identifiers for transcription and publication purposes to maintain anonymity in all publications. The results of the study will be made available to all participants in the form of a publication.

3.8 Statistical Analyses

3.8.1 Phase one

Data from the questionnaire was collected on REDCap and exported to Microsoft Excel, version 2111, in raw data format. The data and coding were checked by the principal investigator and then exported to SPSS, version 27, for analysis by the researcher. Descriptive, non-parametric analysis was done on the nominal and ordinal data. Mean scores, frequency distributions, percentages and ratios were used to analyse and describe the data.

The answers to the open ended questions in the questionnaire, which were used to inform the development of the interview guide for the questionnaire, were coded and included in the data set to be analysed in the qualitative second phase of the study.

3.8.2 Phase two

The data from the focus groups was analysed in alignment with the method described by Creswell, (2003). The data were first read through and transcribed. The transcribed data were reviewed by the researcher to gain an overall view of the information before the data were deductively coded. Three pre-determined themes were set out; ‘roles’, ‘facilitators’ and ‘barriers’. These themes were based on the original research question and objectives. Data from the focus groups and questionnaire were coded to organise

the data. The data was organised further and categories and subthemes emerged within each theme. The data coding was checked by the researcher to ensure intra-coder reliability and to refine the process. An external party was not utilised due to financial constraints. Category-orientated analysis was done to provide insight into the research question of the study. Within each category case-orientated analysis was done to further explore the experience of the individual and delve deeper into any commonalities or differences that became evident (Rädiker and Kuckartz, 2020). The data were interpreted, and narrative passages with quotations were decided upon to report the results. Data saturation was determined to be when no new information or ideas were arising from the discussion. Data saturation was achieved in these two focus groups.

3.9 Summary

Using the above study design and methodological procedures, the researcher conducted this study to answer the identified aims and objectives. Phase one, the quantitative online questionnaire, provided data from which phase two could expand upon. The data collected from phase two, the qualitative focus groups, added further detain and depth to the findings of phase one. This mixed method approach was designed to best answer the research question. The data collected and analysed by the methodology described formed the body of results, which is reported on in the following chapter.

Chapter 4 RESULTS

4.1 Introduction

In this results chapter, the results obtained from the self-administered questionnaire (phase one) and focus groups (phase two) will be reported. The results will be divided into the following sections: participants of both phases, perceived knowledge, patient load and current practice of therapists (data gathered from phase one) and roles, facilitators and barriers faced by therapists when managing lymphoedema (data that was gathered from phase one and two). When analysing the data there was a small amount of missing data where participants had left out questions. In these instances, the analysis was done on the available data, adjusting percentages based on responses received.

4.2 Phase one

4.2.1 Participants

A total of 402 qualified physiotherapists who currently work in South Africa completed the online self-administered questionnaire. Most of these physiotherapists worked in private outpatient practices (70.6%, n=283), followed by private hospitals (39.8%, n=160). Participants from government hospitals (9.9%, n=40), clinics (4.7%, n=19), schools (2.7%, n=11) and home care facilities (10.1%, n=41) were also represented. Thirty-five percent (n=136) of 389 participants had more than 15 years of experience in the field, 23.4% (n= 91) had 5-10 years, 21.2% (n=82) had 1-5 years, 17.5% (n=68) had 10-15 years, and 2.8% (n=11) had less than one year. Each province in the country was represented, with Gauteng and KwaZulu Natal making up the largest number of responses with 43.3% (n=168) and 16.8% (n=65), respectively. Most respondents were currently working in a large urban area of >125000 people (60.3%, n=235). Table 4.1 gives a summary of the characteristics of the participants. Over half the 369 respondents (58.5%, n=215) confirmed that they do not manage patients with lymphoedema in their day-to-day practice.

Table 4.1: An overview of participants characteristics, shown by the most selected choices for each descriptor.

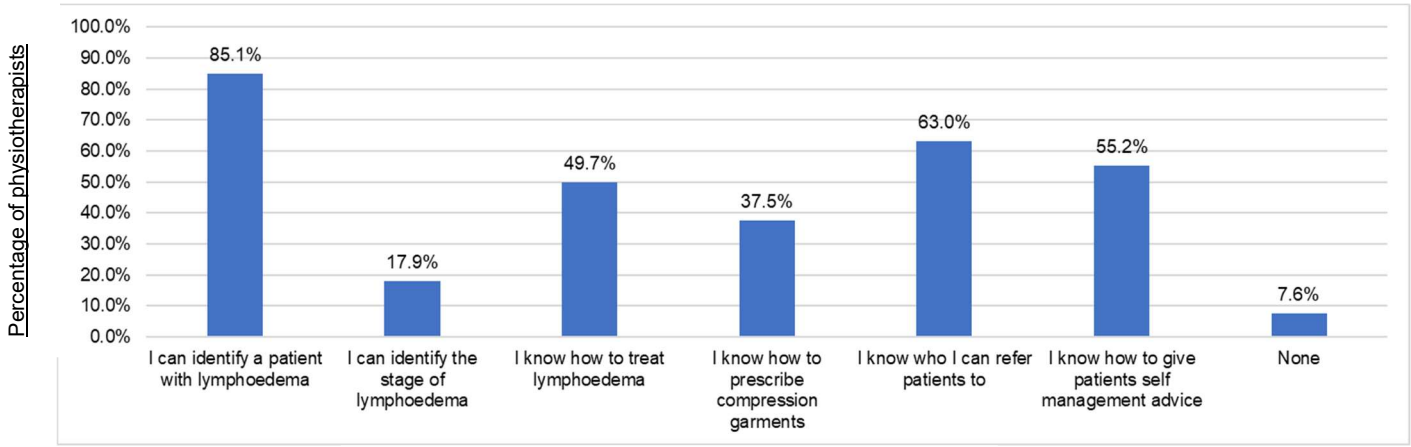
Characteristic category	*Total responses*	*Percentage and number of most chosen descriptor*	*Descriptor*
Current clinical setting	***402***	70.6% n=284	Private outpatient practice
Years of experience in physiotherapy	***389***	35.0% n=136	More than 15 years of experience
Province in which they work	***389***	43.3% n=168	Gauteng
Size of the community serviced	***388***	60.3% n=234	Large urban area >125000 people

4.2.2 Perceived Knowledge of Physiotherapists on Lymphoedema Management

The perceived knowledge of physiotherapists with regards to the pathology, characteristics, causes, stages, risk factors, treatment options and complications relating to lymphoedema was rated on a scale from no knowledge to expert, as per the Likert scale discussed in methodology. Across these sections, physiotherapists consistently rated their knowledge as 'fair', with 46.1% (n=167) of 362 physiotherapists indicating that their knowledge on the stages of lymphoedema was poor. This is shown in Table 4.2. Although 97.3% (n=357) of 367 physiotherapists indicated that they knew that physiotherapists could offer lymphoedema management, only 49.7% (n=183) reported that they had knowledge on how to treat the condition, as shown in Figure 4.1. Two hundred and sixteen physiotherapists identified that they referred patients with lymphoedema to other healthcare professionals if they were unable to manage them. They predominantly referred the patients to other physiotherapists (83.7%, n=181) or occupational therapists (18%, n=39).

Table 4.2: Physiotherapist's self-reported perception of their level of knowledge, about different aspects of lymphoedema.

	Total (n)	No knowledge	Poor	Fair	Good	Expert
Pathophysiology	***364***	2.7%	27.5%	47.3%	19.2%	3.3%
Characteristics	***364***	2.5%	20.6%	44.2%	28.0%	4.7%
Causes	***364***	1.6%	19.8%	47.0%	26.6%	4.9%
Stages	***362***	11.9%	46.1%	28.5%	8.6%	5.0%
Risk Factors	***365***	5.8%	31.0%	37.3%	21.1%	4.9%
Management options	***363***	3.3%	21.5%	46.8%	23.7%	4.7%
Complications	***357***	3.9%	34.2%	39.5%	18.5%	3.9%



(n=368)

Figure 4.1: Physiotherapist's self-reported knowledge on the different aspects of physiotherapy related lymphoedema management. (n=368)

Of 367 physiotherapists 2.7% (n=10) did not know that physiotherapists could manage lymphoedema, and 5% (n=11) out of 216 physiotherapists did not know where to refer patients to if they cannot help them. When the 216 participants who identified themselves as not currently managing patients with lymphoedema were asked why this was the case, 54.2% (n=117) of physiotherapists said they did not get referrals of patients with lymphoedema. Thirty-seven point five percent (n=81) of them said they did not manage lymphoedema as they did not have the correct training, 35.2% (n=76) were not confident in their skills, 30.1% (n=65) identified that it was not applicable in their current clinical setting, 27.8% (n=60) chose not to see patients with lymphoedema and 16.7% (n=36) reported that they did not know how to treat patients with lymphoedema.

Forty-one percent (n=153) out of 369 respondents reported that they did manage patients with lymphoedema. When looking at level of education, 146 responses were

captured, and only 15.8% (n=23) of them have completed the certified 135 hour lymphoedema training to enable them to do so. Most of the training received by these physiotherapists is clinical training on the job (43%, n=63), or they rely on what they learned at an undergraduate level (26%, n=38).

When asked what would encourage physiotherapists who do not treat lymphoedema to start treating such patients, two main categories emerged. Improved knowledge and training and increased referrals of these patients. Many therapists would like to improve their skills by either doing the full certification or a number of different smaller courses. Others indicated that if they were to receive referrals of lymphoedema patients, they would treat them, and further their skills in the field.

4.2.3 The Lymphoedema Patient Load Being Seen by Physiotherapists in a Clinical Setting

4.2.3.1 Number of patients

One hundred and forty-eight physiotherapists who identified themselves as managing patients with lymphoedema completed the question on sources of referrals. Fifty-one point four percent (n=61) of patients who come to physiotherapy for management do so by self-referral. Physiotherapists also get referrals from oncologists (44.6%, n= 66), general practitioners (41.9%, n=62), surgeons (38.5%, n=57), other physiotherapists (24.3%, n=36), other allied healthcare professionals (19.6%, n=29) and vascular surgeons (18.2%, n=27). Sixty-one percent (n=89) of 146 respondents reported that they receive less than one new lymphoedema referrals in a month, with 32.2% (n=47) receiving 1-5 new referrals in a month.

Of 150 responses, 16.7% (n=25) identified themselves as working in a practice that has a special interest in treating the condition. When evaluating how much of their clinical time is taken up with lymphoedema management, 85% (n=125) of 147 respondents reported that less than 20% of their average workday was spent managing patients with lymphoedema. Figure 4.2 shows that when it came to the number of patients seen, 85.7% (n=126) are seeing 0-5 lymphoedema patients a month, 6.8% (n=10) are seeing 5-15 a month, 4.1% (n=6) are seeing 30-60 a month,

2.7% (n=4) are seeing 15-30 a month and 0.7% (n=1) are seeing 60 or more patients a month.

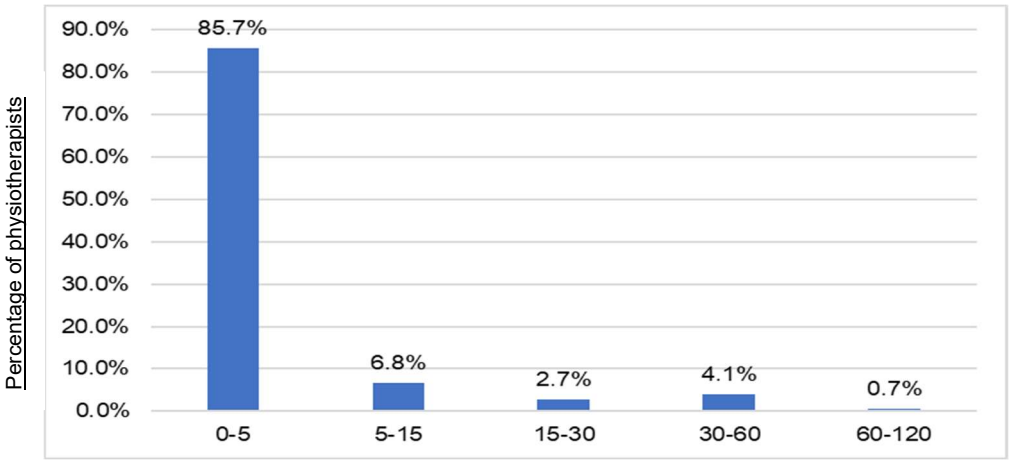


Figure 4.2: The number of patients with lymphoedema seen in a month by physiotherapists. (n=147)

4.2.3.2 Types of patients managed

Paediatric patients (under 12 years old) are managed by 7.4% (n=8) of 108 respondents, and adolescents (12-18 years old) are managed by 19.6% (n=21) of 107 respondents. The dominant patient population groups managed by the respondents are adults (18-65 years old) and geriatrics (older than 65 years). Fifty-five point nine percent (n=80) of 143 respondents reported that managing adult lymphoedema patients makes up more than half of their current patient load, with 39.8% (n=57) reporting that it takes up less than half of their patient load. Forty-seven point six percent (n= 62) of 130 respondents reported that managing geriatric lymphoedema patients makes up more than half their current patient load, with 41.5% (n=54) reporting it takes up less than half of their patient load as can be seen in Table 4.3.

Table 4.3: The distribution of different ages of patients with lymphoedema seen by physiotherapists, represented as a percentage of the total patient load seen.

	Total (n)	none	1-25%	25%-50%	50%-75%	75-100%
Paediatrics	***108***	92.6%	5.6%	1.9%	0.0%	0.0%
Adolescents	***107***	80.4%	16.8%	2.8%	0.0%	0.0%
Adults	***143***	4.2%	21.0%	18.9%	37.1%	18.9%
Geriatrics	***130***	10.8%	26.2%	21.5%	26.9%	14.6%

Primary lymphoedema is managed by 59% (n= 49) of 83 respondents, with 36% (n=30) reporting that these patients make up less than a quarter of their current patient load. Ninety-three point eight percent (n=123) of 131 respondents manage patients with lymphoedema secondary to cancer, with 61% (n=80) of them reporting that these patients make up more than half of their patient load. Seventy-five point seven percent (n=75) of 99 respondents manage patients with lymphoedema secondary to vascular disease with 58% (n=57) reporting that these patients make up less than half of their current patient load. Trauma accounts for 76% (n=70) of 92 responses for secondary causes of lymphoedema managed by physiotherapists, with 65.2% (n=60) of the therapists reporting that it takes up less than half of their patient load. Seventy-two point nine percent (n=62) of 85 respondents manage patients with lymphoedema secondary to obesity with 64.7% (n=55) reporting these patients make up less than half of their patient load. Seventy percent (n=59) of 84 respondents manage patients with lymphoedema secondary to cardiac disease with 59.5% (n=50) reporting that these patients make up less than half of their patient load. Lymphatic filariasis was reported to be the least common secondary cause managed, with 30.8% (n=21) of 68 physiotherapists having identified managing patients in this population.

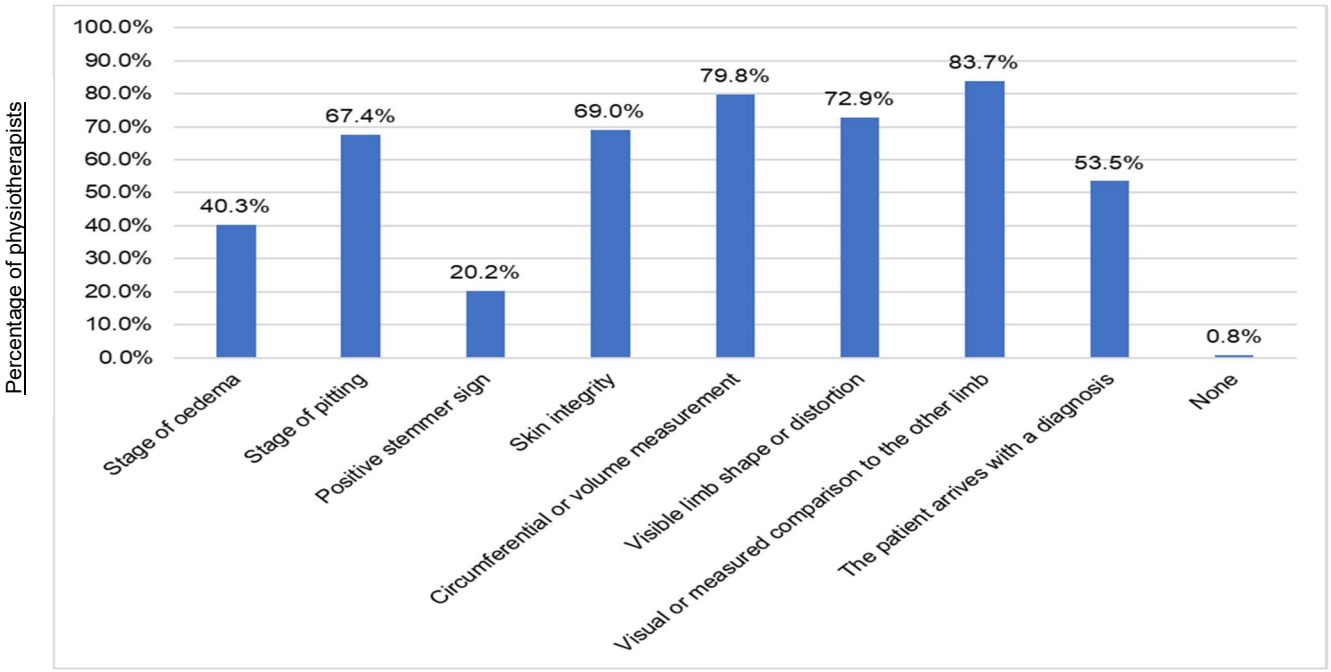
For physiotherapists managing patients with lymphoedema, the most commonly treated area of lymphoedema out of 137 responses was identified as the upper limb (94.2%, n=129) and the lower limb (95.3%, n=122). Forty-one percent (n=33) of 80 physiotherapists manage patients with lymphoedema of the head and neck. Forty-one point seven percent (n=33) of 79 respondents identified treating patients with truncal lymphoedema. Only 34.7% (n=24) of 69 respondents manage lymphoedema of the genital area as shown in Table 4.4.

Table 4.4: The distribution of anatomical areas treated for lymphoedema, represented as a percentage of the total patient load seen by physiotherapists.

	Total (n)	none	1-25%	25%-50%	50%-75%	75-100%
Upper limb	***137***	5.8%	22.6%	20.4%	27.7%	23.4%
Lower limb	***128***	4.7%	25.8%	25.8%	28.9%	14.8%
Head and neck	***80***	58.8%	28.8%	5.0%	3.8%	3.8%
Trunk	***79***	58.2%	26.6%	10.1%	1.3%	3.8%
Genitalia	***69***	65.2%	27.5%	5.8%	1.4%	0.0%

4.2.4 Current Physiotherapy Practice in the Management of Lymphoedema

One hundred and twenty-nine physiotherapists who identified themselves as managing patients with lymphoedema answered a question on what diagnostic tools they use in daily practice. Figure 4.3 shows the results. Comparison to the other limb, visual or measured is most used (83.7%, n=107), followed by circumferential or volume measurements (79.8%, n=102), visible limb shape or distortion (72.8%, n=94), observation of skin integrity (68.9%, n=89) and stage of pitting (67.4%, n=88). In 53.5% (n=68) of cases the patient arrives with a diagnosis. Knowledge of the stage of oedema (40%, n=52) and positive stemmer sign measurement (20.1%, n=26) are also used.

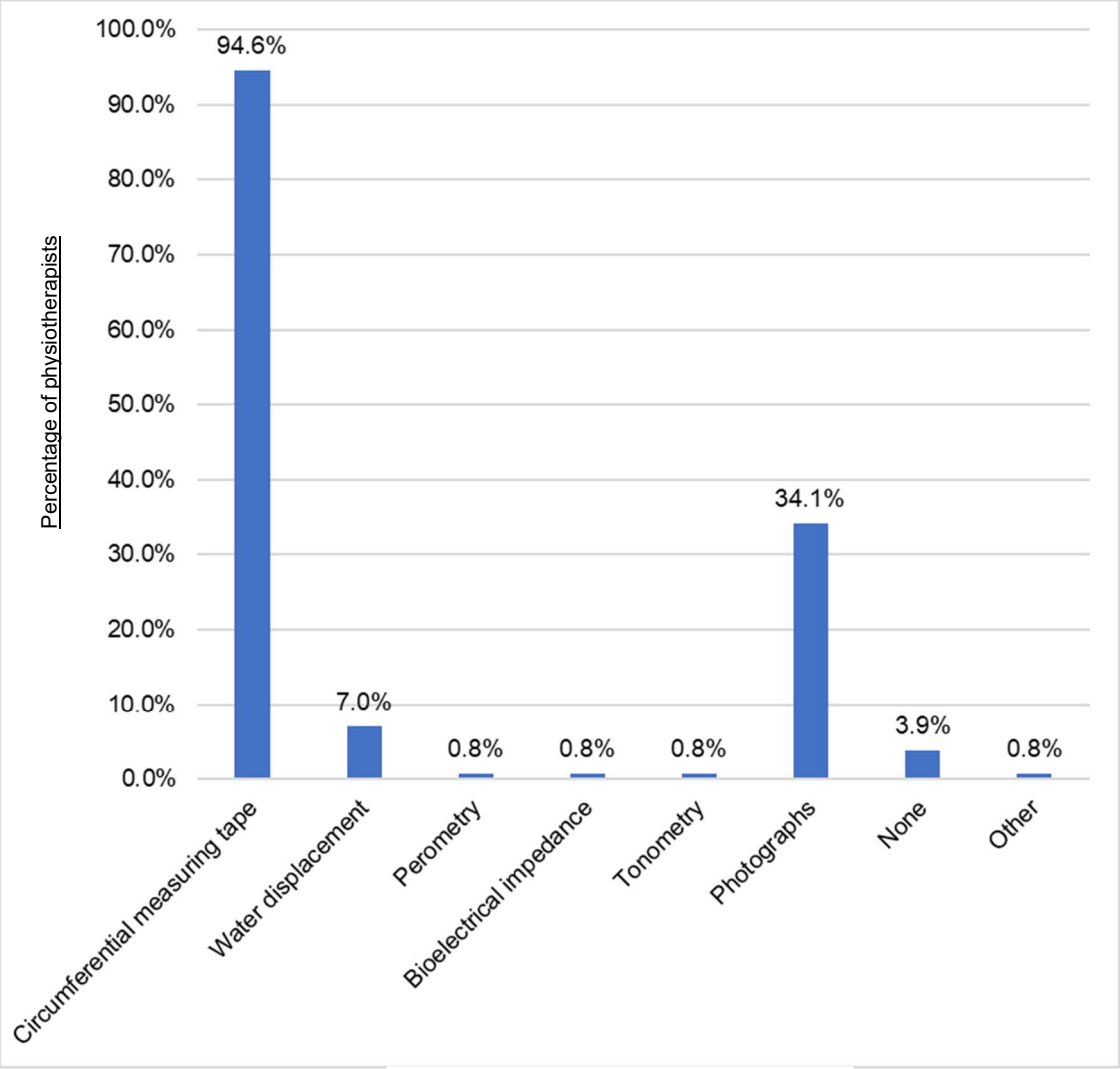


(n=129)

Clinical tools used to diagnose lymphoedema

Figure 4.3: The clinical tools physiotherapists identified using in the diagnosis of lymphoedema. (n=129)

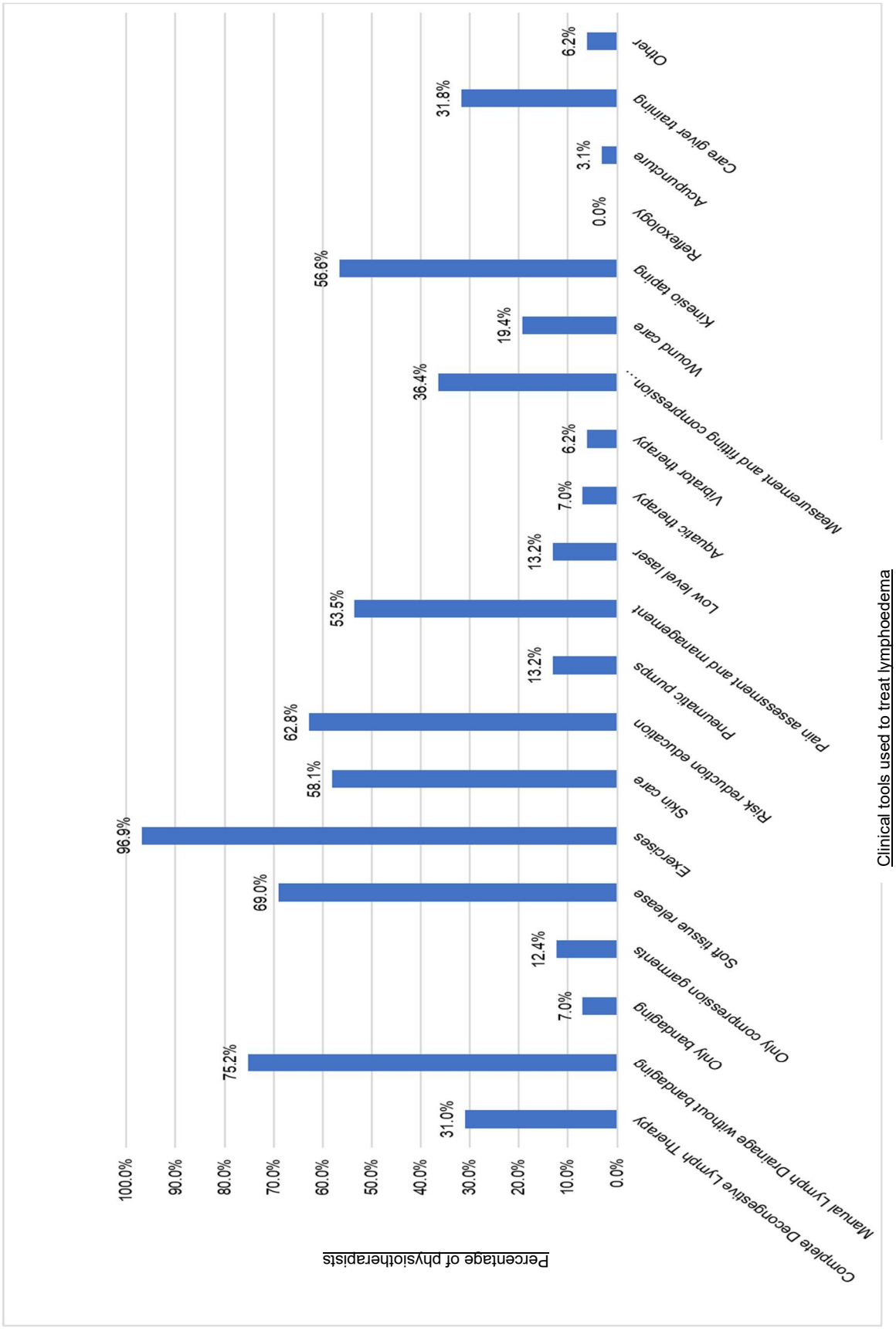
Figure 4.4 shows the clinical tools that physiotherapists use to assess lymphoedema. Circumferential tape measurements (94.5%, n=122) photographs for comparison (34.1%, n=44) and water displacement (6.9%, n=9) are the most common lymphoedema assessment methods utilised by the 129 respondents. Other factors such as range of motion, pain, functional ability and quality of life were all identified as additional factors assessed with lymphoedema patient management and are seen as 'other' in figure 4.4.



(n=129)

Figure 4.4: The clinical tools physiotherapists identified using in the assessment of lymphoedema. (n=129)

Figure 4.5 shows the clinical tools that physiotherapists reported using when treating lymphoedema. Treatments offered to manage lymphoedema by the 129 physiotherapists who responded, included exercises prescription (96.8%, n=125), MLD without bandaging (75.1%, n=97), soft tissue release (68.9%, n=89), risk reduction education (62.7%, n=81), skin care (58.1%, n=75), KT (56.5%, n=73) and pain management (53.4%, n=69). Only 31% (n=40) of the 129 physiotherapists offer complete decongestive lymph therapy. Seventy-nine point one percent (n=102) of the respondents reported that they send patients home with materials for education and home care.



(n=129)

Figure 4.5: The clinical tools physiotherapists identified using in the treatment of lymphoedema. (n=129)

4.3 Phase two

4.3.1 Participants

From the phase one participant group, nine participants took part in two online focus groups. All of the participants manage patients with lymphoedema with varying degrees of experience. Four of the participants had the full 135hr certification in lymphoedema management, with the remaining five only having knowledge based on undergraduate studies, hands-on training and short courses. One of the participants worked in a government setting, the rest in private practice. Of the group, four therapists had a special interest in lymphoedema management and worked predominantly with lymphoedema patients. The other five were more generalised therapists who saw lymphoedema patients occasionally.

4.5.1 The Roles of Physiotherapists Managing Lymphoedema

The transcribed data was analysed and out of 282 ideas, 13 codes were used to develop categories and subthemes under the predetermined theme of 'roles of physiotherapists managing lymphoedema'. Within the theme of 'roles' the following main categories emerged, becoming a lymphoedema therapist, working in the multi-disciplinary team, the biopsychosocial approach to the role and creating awareness and promotion. A report of these categories follows below. A summary table of findings can be found as Appendix G.

4.5.1.1 Becoming a lymphoedema therapist

What was consistent across all nine of the participants was that they had not actively sought out going into the field of lymphoedema.

> '*It's not something I looked to do but I needed to do it, it just happened.'- Participant 5'.*
>
> *'So, life chose me, this type of work chose me, I didn't choose it.' - Participant 6*

They all reported having had very little knowledge of the condition and the possibilities of treatment when they entered the profession (100%, n=9).

'I started working in a practice in JHB not knowing what lymphedema was. Participant 2.

Three of the participants had personal experience with lymphoedema which led them to find out more about the condition and possible treatment options available.

'I actually have lymphedema and I started as a patient when already a physio and ended up working in the practice where I was a patient' - Participant 1.

'At the beginning of last year my one arm started swelling due to the breast cancer I had. – Participant 8'

Two participants went overseas and were introduced to lymphoedema management and the others realised that they had to further their skills as they encountered patients with lymphoedema in their practice.

'I saw the need knowing that there is help out there for these types of patients and that is how my journey started.' - Participant 2

Four participants had a special interest in the field and had completed a full certification in lymphoedema and worked predominantly with lymphoedema patients.

'It holds a special interest for me.' – Participant 1

The rest had not had any further official training in the field and saw patients occasionally when they come into their practices.

4.5.1.2 Working in the multi-disciplinary team

All nine of the participants recognised that the patient profile is complex and requires many different specialities to come together to successfully manage the condition.

'I do think being part of a multi-disciplinary approach would be better.' - Participant 3

'Absolutely there must be a multi-disciplinary team involved, it's not something you can do on your own.' - Participant 2

'I think that if you do treat lymphedema patients you do end up working within a multi-disciplinary team' - Participant 1

'Every part of the team could give an input as per their own speciality' - Participant 6

In particular, oncologists were discussed 17 times, general practitioners were discussed 15 times and nurses were discussed 10 times as professions that are needed in the multidisciplinary team alongside physiotherapists. Although a

multidisciplinary approach is favoured, five of the physiotherapists are working alone and not within a network of professionals. The participants noted that the need for a professional team serves not only to improve patient care, but also as a referral structure to support all those involved.

> *'Because they are often referred by surgeons or oncologists and especially the (name of a hospital in Johannesburg) oncologists do refer patients so there is the multi-disciplinary team component' - Participant 1*

4.5.1.3 The biopsychosocial approach to the role

Therapists managing lymphoedema reflected that they needed to have a holistic, biopsychosocial approach to their patients.

> *'You are going to need to think about the patient holistically with this type of condition.' - Participant 4*

There was a consensus amongst the participants that the management of these patients required attention to not only their physical limitations, but also their emotional needs and functioning in society (100%, n=9).

> *'It seems like the condition is so complex and not just the physical.' - Participant 4*
>
> *'You have to be patient with them and a lot of the time a lot of emotions are involved as well' - Participant 7*

4.5.1.4 Creating awareness and promotion

The more qualified and experienced therapists also discussed the importance of physiotherapists taking on more of a role in promoting awareness of the condition and its management to other professionals and the public (33.3%, n=3).

> *'But in the bigger picture there is definitely a need for intervention and to just create more awareness.' - Participant 2*

4.5.2 Factors that Facilitate Lymphoedema Management for Physiotherapists

From the transcribed data, seven codes were used to identify categories in the theme 'facilitators when managing lymphoedema'. The importance of lymphoedema networks, internet resources for professionals and the public, recent developments in the field and the patient-therapist relationships were categories identified. These categories are reported below. A summary table of findings can be found as Appendix G.

4.5.2.1 The importance of lymphoedema networks

The physiotherapists working with patients with lymphoedema noted the importance of being part of a network when managing these patients (33.3%, n=3).

> *'A network of how we let the psychologists, nurses, wound specialists, OT's, physios that are in lymphedema to have a network where when you think a patient needs more psychological support you know who is trained and understands the condition and you can then refer the patient to them.' - Participant 7*

Membership with the LAOSA, working in oncology units and with support groups in particular were highlighted.

> *'The LAOSA, but it is not very old, maybe three or four years old and you pay a very minimal fee to be part of the group.' - Participant 6*

Two of the participants found that working within such a framework has allowed for a reliable referral system.

> *'A few of my patients are part of (cancer support group) and they will say that you need to go and get treated for lymphedema, go find out information and they will send them my way.' - Participant 1*

4.5.2.2 Internet resources for professionals and the public

The internet was identified as being an important facilitator in the management of lymphoedema patients (55.5%, n=5). The participants brought up that most patients,

when unsure where to find appropriate treatment turn to the internet to search for a suitable professional. It is an important source of referrals.

'A lot of people Google you, so it's important to have a social media presence as well.' - Participant 5

'Actually, a lot of people find us on Google.' - Participant 1

'I have a web page going.' - Participant 2

'A lot of my patients come through and say they googled it and this website came up and these are the physios, these are the practitioners that they can refer to.' - Participant 6

The four participants that are members of the LAOSA discussed the LAOSA's online network and how it provides a directory of professionals that can aid patients and other healthcare professionals find appropriate assistance.

'If you register with the LAOSA, your details are on their website so although a patient has to know about the LOASA to find your details.' – Participant 1

4.5.2.3 Recent developments in the field

Two of the nine (22%) participants discussed recent developments that have facilitated the management of lymphoedema in South Africa. One such development is the training of lymphatic management becoming available in South Africa, where previously it was only offered overseas.

'It's grown so much in the past ten years or five years at least since training started' – Participant 2

'2015, when training actually started in South Africa officially' – Participant 2

Both participants noted that there has been an increase in management options as there is an increased supply of locally produced bandages and compression garments.

'We have a lot more options in terms of compression which is the long-term maintenance for lymphedema.' – Participant 2

'Now we have more local bandaging' – Participant 1

One participant reported that they have increasingly seen that there has been an increase in awareness of the condition amongst healthcare professionals.

I have seen it since 2005 there is definitely much more awareness.' – Participant 1

'There is definitely more awareness being raised all over' - Participant 2

4.5.2.4 The patient-therapist relationship

One of the strongest facilitators identified by all nine of the participants (100%, n=9) was the patient-therapist relationship. Terms such as 'empowering', 'life changing' and 'rewarding' were used in discussions to describe this relationship.

> *'I can absolutely see the thankfulness in the patients and the life changing experience is exactly what you said in how it transforms them.' – Participant 6*
>
> *'I think that is a very important relationship, because that is almost where their healing starts to begin' - Participant 1*
>
> *'When you see the outcomes you experience this joy where after 10 sessions you see this significant change in the patient then you know it was worth all the time and effort you put in.' – Participant 7*
>
> *'Ok, I'm going to be that physio and in the end it makes a difference.' – Participant 7*

4.5.3 Barriers Encountered when Managing Lymphoedema

From the focus groups discussions 14 codes were used to analyse data to investigate participants experiences with regards to 'barriers to managing lymphoedema'. The categories that emerged were a lack of education and awareness, prohibitive costs, time pressure and complexity of lymphoedema management. A report of those themes follows below. A summary table of findings can be found as Appendix G.

4.5.3.1 A lack of education and awareness

All participants commented on the lack of education and awareness about the management of lymphoedema, from both a public and professional perspective, as being a barrier to care (100%, n=9). They all discussed that there is a shortage of lymphoedema therapists who have received further training and are managing patients with lymphoedema.

> *'I think we have about 120 therapists in South Africa at the moment that have a full certification and that is just not enough to deal with the amount of patients we have in the public and the private sector' - Participant 5*

Five of the nine participants acknowledged that they themselves were not confident in their level of knowledge and management skills and feel completely unprepared to manage the condition. Their basic knowledge comes from an undergraduate level, where they felt it was taught as an 'afterthought' and not enough time was focused on the condition.

> *'It is almost like when we were taught at University it was almost like an afterthought and it wasn't given the consideration it was due.' - Participant 4*
>
> *I didn't have the knowledge to guide her and didn't know that physio had such a big role to play in it.' – Participant 9*
>
> *'I see myself then as a physio not having had sufficient knowledge. We weren't equipped as pre-grad/under grad students.' - Participant 8*
>
> *'My understanding of the condition is quite limited in terms of prognosis. I feel limited in my management.' - Participant 4*
>
> *'As an undergraduate we focussed a bit on the different types of oedema and there was the general overall of what lymphedema is and how it differs from other oedema and very basic on the treatment, but nothing more' - Participant 7*
>
> *'I think it was definitely lack of education to the patient, as well as lack of knowledge/studies and our role in lymphedema as physios.' - Participant 9*

All of the participants noted that access to education about lymphoedema management remains a problem as there are few options available with regards to further training (100%, n=9). Five of the physiotherapists expressed that they would like to get involved in lymphoedema management but not become focused in the field and do the whole certification course.

> *I think it is a pity that we do not have easier access to courses, more inexpensive courses' - Participant 8*
>
> *'To me I don't want to become a full time lymphedema therapist, so if you could tell me I can go on a weekend course so that I know what I can do with people that walk into my practice.' - Participant 3*
>
> *'So even if the Universities cannot offer everything, all of the information in the under grad, if they can at least have CPD workshops that gives you the basic information that can be helpful with the patient that you do come across in your practice' - Participant 7*

Three of the respondents found that other health care professionals that they had worked with had a similar lack of knowledge and awareness. It was discussed that the public awareness of the condition is also poor (44.4%, n=4).

'If we can get other health care professionals to just be aware that there are therapists out there that will be a major breakthrough.' - Participant 2

'It is very new, there are very few Doctors or physicians who specialise in lymphedema, so there is generally a large population out there not knowing where to go to.' - Participant 6

4.5.3.2 Prohibitive costs

The financial aspect of managing lymphedema for the patients and the physiotherapists was discussed by all nine of the participants (100%, n=9). The ongoing cost of treatment, specialist bandages and compression garments used to manage the condition is a barrier for many patients and was raised by six of the nine participants (66.6% n=6).

'The bandaging alone is very expensive.' – Participant 1

'It's just with some chronic cases, not everyone is going to afford to come in as often as needed.' - Participant 4

'It's long term and it's a chronic condition. It becomes really, really expensive.' – Participant 6

The four more qualified physiotherapists have found that in situations where the patients have medical aid, some of the cost can be managed, however there is a large discrepancy between what the medical aids are willing to pay and the real cost of the treatment. One of the participants discussed that if the patient has lymphoedema secondary to cancer, the relevant paperwork can be done to apply for lymphoedema management to fall under Prescribed Minimum Benefit (PMB) cover, but that it is sometimes difficult to get cover for other causes.

'The thing that bothers me the most is the cost of bandages and garments, the amount of treatment that you have to give and Medical Aids don't always pay for it.' - Participant 6

'I find that I will treat patients maybe twice or three times a week for a couple of weeks rather than every day just to get away with the constraints of Medical Aid and finances.' - Participant 6

'You feel you should get value for your money, but Medical Aids however disagree. It's costly if the Medical Aids don't cover, but it's costly for you if you just charge what the Medical Aids say you should charge.' - Participant 1

All of the physiotherapists identified the cost of the training to become a certified lymphoedema therapist as being a large barrier to providing care to patients with lymphoedema (100%, n=9).

'The costs of training. I completely agree as a new physio in the public sector, the cost is something that stops us.' - Participant 7

'Then the challenge comes with training costs, because all the trainers are international and the one lady that lives here, it is still high cost training and it's two weeks out of your practice.' - Participant 2

'I have been trying to do a few of the smaller courses, but not any of the bigger ones due to financial constraints' - Participant 7

'One thing I do think is really difficult for a young physio to get into, to do a full lymphedema qualification, is the cost of these qualifications.' - Participant 5

4.5.3.3 Time pressure

Due to the chronic nature of the condition, it was raised by the participants that the treatment required a large time commitment from both the therapist and the patient. Five physiotherapists noted that the management of lymphoedema is very time consuming in terms of admin and treatment (n=9). Two participants felt that they were not able to give lymphoedema management the time it needs, as they felt pressure to see as many patients as possible and so compromised on time with lymphoedema patients.

'We have a lot of patients who would benefit from the lymphedema approach, but because of our lack of time and our lack of resources we are pushing to get through the patients.' - Participant 7

Another two participants have found that for the patient the commitment of this time can be difficult as some patients cannot take the time off work and other commitments.

'Because it is a high intensity treatment, so people have to take off work every day or two or three days a week. Time limitations in terms of people's work can be a challenge.' - Participant 2

4.5.3.4 Complexity of lymphoedema management

The participants in the groups all acknowledged that the management of lymphoedema is complex and requires a lot of physical and emotional output from the therapists (100%, n=9). Factors such as transport problems, specialised mobility needs, psychological fallout and financial constraints were discussed as being difficult aspects that added to the complexity of lymphoedema management from a patient perspective (66.6%, n=6).

> *'The biopsychosocial model is so important now and it seems like the condition is so complex. You are going to need to think about the patient holistically with this type of condition.' - Participant 4*
>
> *'You have to be patient with them and a lot of the time a lot of emotions are involved as well, because it's affecting their quality of life so badly.' – Participant 7*

Five of the nine participants discussed that physiotherapist responsibilities relating to lymphoedema management also requires a lot of paperwork, admin and correspondence with medical aids and suppliers.

> *'To manage a lymphedema only practice is not that simple. There is a lot of admin around it.' - Participant 2*

All of the participants acknowledged that lymphoedema management is both physically and emotionally demanding for both the patients and the physiotherapists (100%, n=9).

> *'And that is difficult, it is really difficult and tiring. I found myself, if I have too many lymphedema patients in a day, I really am exhausted, both physically and emotionally.' - Participant 6*
>
> *'But I find it is ongoing, you never really discharge a patient because they will always come back. I find you always end up have a very long relationship with your clients.' - Participant 5*

One participant discussed that some patients struggle to deal with the complexity of the management process and cannot stay committed to the treatment plan, resulting in noncompliance.

> *'As it is quite an intensive treatment, a lot of patients fall off the wagon because it is hard to be bandaged every day, it's hard to wear compression every day,*

it's hard to have a chronic condition that needs to be managed constantly.' - Participant 1

4.4 Summary

This chapter reported on the findings of both phases of the study. An in-depth discussion of this data and how it relates to the aims and objectives of this study will follow in chapter five, discussion.

In phase one it was discovered that physiotherapists rate their perceived knowledge of lymphoedema and the management thereof as being 'fair' and that 49.7% (n=183) of the respondents know how to manage lymphoedema. Most referrals for lymphoedema management are from self-referral (51.4%, n=76) and 61% (n=90) of physiotherapists receive less than one new referral a month. Eighty five percent (n=125) of respondents reported that less than 20% of their average workday was spent managing patients with lymphoedema and they mainly treat adult or geriatric patients with lower and upper limb, secondary lymphoedema. Physiotherapists favour comparison to the other limb, visual or measured when diagnosing lymphoedema (83.7%, n=107) and circumferential tape measurements (94.5%, n=122) in assessment of the patient. Forty of the 129 physiotherapists offer complete decongestive lymph therapy (31.0%) as a treatment option.

In phase two data about the role of physiotherapists in the management of lymphoedema were gathered and four key categories emerged. Becoming a lymphoedema therapist, working in the multi-disciplinary team, the biopsychosocial approach to the role and creating awareness and promotion. Under the theme of facilitators to the management of lymphoedema, the importance of lymphoedema networks, internet resources for professionals and the public, recent developments in the field and the patient-therapist relationships were categories identified. Barriers to the management of lymphoedema revealed four categories, a lack of education and awareness, prohibitive costs, time pressure and complexity of lymphoedema management.

Chapter 5 DISCUSSION

5.1 Introduction

The following chapter will reflect on and discuss the findings of the study in greater detail. The study's objectives were to describe what physiotherapists' perceived knowledge is regarding lymphoedema and the management thereof, to determine the lymphoedema patient load being seen by physiotherapists in a clinical setting, to establish the treatment approaches of physiotherapists in the management of lymphoedema and to explore the roles, facilitators and barriers experienced by physiotherapists managing lymphoedema. The four objectives will be discussed both with regards to the current findings and current literature on the topic.

5.2 Perceived Knowledge of Physiotherapists on Lymphoedema Management

Physiotherapists in South Africa have a mixed understanding of the management of lymphoedema. While a small percentage of the respondents rate their perceived knowledge as 'good' or even 'expert' the majority of respondents showed a worrying lack of perceived knowledge on important topics such as pathology, characteristics, causes, stages, risk factors, treatment options and complications relating to lymphoedema. This echoes findings by Davies et al. (2012) and Gerez et al. (2020) who both found that when investigated, the perceived knowledge of healthcare professionals who should be managing patients with lymphoedema was lacking.

Although 97.3% of physiotherapists in this study (n= 357) indicated that they knew that physiotherapists could offer lymphoedema management, only 49.7% (n=183) know how to treat the condition. This leads one to question why such a discrepancy exists. It could be explained by the level of education received by physiotherapists about the topic, both at an undergraduate level and at post graduate level or it could be due to the disinterest of physiotherapists in treating the population. Currently in South Africa, undergraduates are informed about different types of oedema and are taught basic

management skills, including massage and elevation. Lymphoedema is highlighted as one of those oedemas, but it is not a primary focus of the curriculum.

The lack of comprehensive education and awareness about lymphoedema at an undergraduate level has the potential to foster a worrying cycle of ignorance and stagnation in the field of lymphoedema management in South Africa. Schulze et al. (2018) proffers that a lack of comprehensive education in the topic at a university level can lead to therapists being unaware of the benefit of treating the condition and therefore lead to them not pursuing it in their career. If fewer physiotherapists fulfil the role of lymphoedema management, their role within the multidisciplinary team will cease to exist.

5.3 The Lymphoedema Patient Load Being Seen by Physiotherapists in a Clinical Setting

Physiotherapists are getting referrals for lymphoedema management from multiple members of the multidisciplinary team. Oncologists, general practitioners, surgeons and other healthcare professionals are all referring patients which indicates that there are the beginnings of a multidisciplinary approach to lymphoedema management. However, 61% of physiotherapists report receiving less than one new lymphoedema referral in a month (n=146). Although patients with lymphoedema are being referred to physiotherapy for treatment, the number of patients that are being referred is surprisingly low considering the high estimated prevalence in South Africa. Either the population with lymphoedema is not large in South Africa, or there is a poor understanding of lymphoedema as a condition and possible management options within the healthcare profession. The literature indicates that the prevalence of lymphoedema is estimated to be 140 to 200 million people worldwide (Gerez et al., 2020). Although there is limited data on the prevalence of lymphoedema in South Africa, the number of new cases of cancer in South Africa in 2020 was 108168 cases (“IARC Globocan. South Africa Fact Sheet,” 2020). Cancer and its treatment are one of the leading causes of secondary lymphoedema and so there is potentially a growing population with lymphoedema in South Africa. Khutjwe (2018) found that 29.7% of 155 patients undergoing radiotherapy for gynaecological cancer in a hospital in Johannesburg developed lymphoedema. There could be a large percentage of

patients with lymphoedema that are not receiving the correct treatment. This reflects findings from the study by Moffatt et al. (2003) where they found that the provision of care to all patients with possible lymphoedema is not being provided. This leads one to conclude that a lack of awareness within the healthcare profession may be the culprit for the poor referral rates as was also found by Rockson and Rivera (2008) who discussed that healthcare professionals continue to misdiagnose patients with lymphoedema which results in the patients receiving the incorrect care.

With referrals being poor, lymphoedema patients make up very little of physiotherapists patient load in a month across South Africa. Most physiotherapists (83.3%) are working in a more generalised practice (n=150) and the time dedicated to managing patients with lymphoedema is only taking up less than 20% of their average workday. This could be because the patient load is being distributed amongst other healthcare professionals such as nurses, occupational therapists and massage therapists who also have a role in lymphoedema management, as was noted by Anderson et al. (2019). With so few lymphoedema patients being seen by physiotherapists it seems reasonable that physiotherapists are not spending much time developing their interest and skill set in the field.

Patients who are aged 18 years and older make up most of the lymphoedema patient population for physiotherapists in South Africa. There are only a few physiotherapists who are seeing children and adolescents for lymphoedema management. This is in keeping with the fact that paediatric lymphoedema is quite rare and very poorly identified, as is seen in work by Connell et al. (2014) and Todd et al. (2014). Of the physiotherapists that are managing lymphoedema patients, most of their patient load is made up of lymphoedema from a secondary cause. This is seen in other studies by Anderson et al. (2019) and Armer et al. (2010) who also found that more than 80% of the patients seen by lymph therapists were of a secondary cause. While 59% (n= 83) of physiotherapists identify managing primary lymphoedema patients, these patients make up a small percentage of their patient load. Consistently across the literature, cancer is the biggest cause of secondary lymphoedema in patients seen by therapists. The same is found within this data set, with 93.8% of 131 participants identifying cancer as the biggest cause of their patients lymphoedema. This is unsurprising as worldwide improvements in oncological care are resulting in an increase in cancer survivors, and an increase in secondary complications such as lymphoedema (Siegel et al., 2020). The data shows that physiotherapists are seeing a broad range of patients with

lymphoedema of the upper limb, lower limb, trunk, head and neck and genitalia. However it is lymphoedema of the upper and lower limb that are the most common areas treated, as is seen in other practitioner surveys by Anderson et al. (2019) and Armer et al. (2010). Anderson et al. (2019) reported that 53% of patients treated by the therapists in their study (n=950) had upper limb lymphoedema and 30% had lower limb lymphoedema. Similarly Armer et al. (2010) found that 59% of patients treated by respondents in their study (n=415) had lymphoedema of the upper limb, and 30% of the lower limb.

5.4 Current Physiotherapy Practice in The Management of Lymphoedema

When looking at the current practice of physiotherapists in the management of lymphoedema, the results of this study were compared to international standards set by different guidelines. These guidelines were set out by lymphoedema associations such as the National Lymphoedema Network, Lymphology Association of North America, International Society of Lymphology, the British Lymphology Society, the International Lymphoedema Framework and the LAOSA.

Methods of diagnosis and assessment of the oedematous area tend to be prone to subjectivity and easy to perform. Visual or measured comparison to the opposite limb, observation of skin integrity and circumferential or volume measurements are all routinely used. Although these methods may be unreliable, they are recognised as being the most commonly used in international literature and guidelines due to their ease of use (Moffatt et al., 2006).

When looking at the current treatment techniques being used by physiotherapists in South Africa, we see that there are very few therapists that are following international guidelines. Only 40 of 129 (31%) physiotherapists use CDLT to manage patients with lymphoedema. With complete decongestive lymphatic therapy being the gold standard of lymphoedema management as supported by Armer et al. (2020) and Marco et al. (2014), this is a concerning finding. It seems that physiotherapists do not have the correct education or skill set to manage lymphoedema appropriately. This finding follows with the fact that only a few physiotherapists move into lymphoedema as a special interest in South Africa and furthering their education into the field (15.8%,

n=146). Most physiotherapists who are managing lymphoedema are providing treatment based on their knowledge received in 'on the job' training and undergraduate training. Treatment such as exercises prescription (96%, n=129), MLD without bandaging (75.1%, n=129), soft tissue release (68.9%, n=129), risk reduction education (62.7%, n=129), skin care (58.1%, n=129), KT (56.5%, n=129) and pain management techniques (53.4%, n=129) are being used. Although all of the above modalities offer value to the patient, and a few of them make up the components of CDLT, the results show that there needs to be an improvement in the overall education of physiotherapists with regards to lymphoedema management in order to standardise care to patients and meet international guidelines.

5.5 The Roles of Physiotherapists Managing Lymphoedema

Literature shows that physiotherapists play an important role in managing patients with lymphoedema (Lu et al., 2015; Torres Lacomba et al., 2010). However, the role of physiotherapy in lymphoedema management is not well understood in South Africa and the data from this study indicates that there are not many physiotherapists that are fulfilling the role. From the focus group discussions, it was found that physiotherapists are not being drawn into the field straight from university as they do not have enough knowledge about the condition. They are rather discovering the need for patient care through clinical practice. The development of the role for most physiotherapists seems to be quite per chance, as was highlighted in the focus group discussions. Two distinct groups of physiotherapists emerged from the data with regards to lymphoedema management. Physiotherapists with a special interest and certification in lymphoedema and more generalist physiotherapists. These roles are similarly described by Davies et al. (2012) who found that there were two types of clinicians that manage lymphoedema. The 'specialist clinicians', who had a special interest in lymphoedema management and further qualifications in the field and 'generalist clinicians' who had no further education in lymphoedema management.

There are a lack of physiotherapists furthering their education into the field of lymphoedema. There are very few physiotherapists who have had further 135 hour standardised training in lymphoedema management, which enables them to better manage the condition as a 'special interest'. The majority of physiotherapists have had

no further training in the field but continue to see lymphoedema patients with the skills they have. As discussed in a study by Schulze et al. (2018) the number of therapists who are specialists in the field of lymphoedema management is lacking worldwide. The findings of this study are in alignment with this global trend.

Focus group discussions showed that physiotherapists with a special interest in lymphoedema in South Africa have taken on a much more in-depth role in the field of lymphoedema. These physiotherapists have pursued further education into the field and often work within a multidisciplinary team to manage their patients. The data of this study showed that for some physiotherapists the management of lymphoedema is a passion, and they have dedicated most of their workload to the field. The participants in the study indicated that their role extends further than that of just providing treatment, but they are also filling the gap of advocating for awareness and education on the topic for both the public and other healthcare professionals. The focus groups revealed that the physiotherapists who manage patients with lymphoedema are protective over their role, and strongly believe that lymphoedema management should only be undertaken by fully certified therapists. Although they do acknowledge that basic knowledge provided to all physiotherapists would improve patient care for those suffering with lymphoedema. The lymphoedema physiotherapists with a special interest in the field believe that one needs a certain amount of passion, training and experience to manage patients with lymphoedema as the role is complex and requires skills in a biopsychosocial patient approach. Studies by Eaton et al. (2020); Maree and Beckmann (2016); and Mercier et al. (2019) are in alignment with this view and discuss various psychosocial problems such as anxiety, depression, sexuality and isolation that patients with lymphoedema struggle with.

In contrast to the lymphoedema focused role fulfilled by a few physiotherapists, there is a second, larger generalist group of therapists who seem to play more of an incidental role and manage patients that come their way with whatever knowledge they have at their disposal. The focus group discussions revealed that the physiotherapists from this group do not feel they have enough knowledge on the topic and are not always confident to provide treatment. This group was similarly described by Davies et al. (2012). Discussions in the focus group revealed that they do not often take on an educational role outside of their own patient group. Their role includes seeking out better qualified therapists to assist in comprehensive management of these patients.

Some physiotherapists in this group reported being satisfied to help patients with what skills they have, but many of them would like to upskill themselves, provide better care and grow lymphoedema within their practices. This ongoing need and desire for further education in the management is echoed in literature (Davies et al., 2012; Stout et al., 2009) where healthcare professionals expressed that their education needs were not met.

There needs to be a middle ground, between lymphoedema certified physiotherapists and generalist physiotherapists, to develop a comprehensive role for physiotherapists who manage lymphoedema in South Africa. Physiotherapists from the focus groups feel that there is a divide between the two subgroups of physiotherapists in terms of education level and level of participation in the field. There are many physiotherapists in generalist practices that do have a small amount of knowledge about lymphoedema but do not feel confident enough to pursue a role in lymphoedema management, as it is perceived to be too specialised for generalist physiotherapists. Similar sentiments were found in focus group discussions by Davies et al. (2012), where generalist clinicians were not confident in their ability to manage lymphoedema. This perception needs to change as in its current state, the role of physiotherapy in lymphoedema management and the provision of care for lymphoedema patients seems lacking in South Africa, according to the results of this study.

5.6 Factors that Facilitate Lymphoedema Management for Physiotherapists

Due to the relative infancy of the field of lymphoedema in South Africa there are only a few, seemingly simple factors that physiotherapists identify as being facilitators to lymphoedema management. From the focus group discussions, facilitating factors was described to include aspects that benefit the profession at large, those that assist individual physiotherapists and those that enrich the patient's experience of care. Many of these facilitating factors are set to continue to develop and should ultimately result in the promotion of lymphoedema management in physiotherapy in South Africa.

Professional lymphoedema networks provide support, knowledge, and guidance to the public and fellow healthcare professionals on specific conditions. With the formation of

the LAOSA, physiotherapists feel that they are following the lead of our international counterparts and now have a platform to offer support to the population with lymphoedema and other healthcare practitioners. Across the world, different lymphoedema associations and organisations have very successfully promoted and provided research into the field of lymphoedema (Armer et al., 2010). The development of such an association in South Africa not only provides a source of referral and ongoing education about the topic but it also facilitates and adds legitimacy to the role physiotherapists play in lymphoedema management in South Africa.

The presence of a lymphoedema network goes hand in hand with the importance of being available and active on the internet and social media. Access to information online is an important way for physiotherapists to promote their skills, educate the public and other healthcare professionals, collaborate with fellow professionals and get more lymphoedema referrals, as was highlighted in the focus groups. The internet also serves as a repository for research, data and information as the field develops and further research is done. As web sites, online booking software and social media options continue to develop, the potential for physiotherapists to use these tools to benefit and facilitate their role in lymphoedema management is unlimited. One such example is the LAOSA's online database where therapists from all over South Africa can be searched for.

With awareness around the field of lymphoedema growing in South Africa, so does support from medical product suppliers, corporate and educational bodies. It is this positive cycle that will continue to facilitate the development of lymphoedema awareness and care. One of the most important developments in the last 13 years is the availability of the 135 hour certification in lymphoedema management being provided locally, as was also discussed by Stout et al. (2009). With training becoming locally available there has already been an increase in the number of certified therapists practising lymphoedema management. It is highlighted in many other papers, that the provision of education could have a positive effect on the number of physiotherapists moving into lymphoedema management and improved healthcare access to the population with lymphoedema (Gerez et al., 2020; Schulze et al., 2018). More local production of consumables has also been an important development in the field. With more products being made in South Africa, the procurement process for key consumables has been optimised, which has allowed Physiotherapists to provide

appropriate care to more patients. As companies have set out to sell their lymphoedema products in the healthcare sector, the physiotherapists have been able to market the availability of management for lymphoedema alongside them. This has had a positive knock-on effect on the practices of physiotherapists in terms of referrals and overall awareness.

Sometimes one of the most powerful facilitators for the success of a patient's treatment can be as simple as a human relationship. The focus group discussions identified the patient-therapist relationship as a key experience that is shared by many physiotherapists, not only in the field of lymphoedema. In lymphoedema especially, the focus group participants described that the therapeutic relationship can be strong and long lasting as treatment is long term and requires a biopsychosocial approach. When this relationship is a positive one with shared goal setting and clear communication, it can be an important facilitator to the management of the patients lymphoedema and the overall outcome of the treatment

The success of lymphoedema management in South Africa will come from a broad view of how the profession utilises and continues to develop all the facilitating factors at their disposal. It is heartening that such facilitators exist, as it shows that there is room for growth for lymphoedema management in South Africa.

5.7 Barriers Encountered when Managing Lymphoedema

As with any developing field, there are many barriers faced in the execution of duties. The barriers experienced by physiotherapists in lymphoedema management show that there is still a lot of work that needs to be done to promote access to physiotherapy management for all patients with lymphoedema.

The lack of education in lymphoedema continues to be a barrier to progress in the field. This lack of education is found on many levels. The focus group participants perceived there to be a lack of knowledge amongst physiotherapists about what can be done to manage the condition. Davies et al. (2012) found the same to be true in their study 'Lymphoedema education needs of clinicians; a national study'. Participants of both this study and that by Davies et al. (2012) focus groups felt that sufficient in-depth

knowledge is not being imparted at an undergraduate level, and very few clinicians (in this case specifically physiotherapists) continue into further education on the topic of lymphoedema. This means that there are few physiotherapists that offer lymphoedema management, resulting in a shortage of trained professionals and poor access to lymphoedema management for those who need it. Other healthcare professionals such as doctors, surgeons and other allied health care practitioners suffer the same fate. Because lymphoedema is poorly understood, it is underdiagnosed and treatment options are overlooked, resulting in many patients receiving the improper care. Morgan et al. (2012) and Tidhar and Armer (2018) made similar observations in their studies where they discussed that patients with lymphoedema are not getting the appropriate care they need. Physiotherapists in the focus groups suggested that the ignorance of the public is another hindrance to quality care, as they do not know where to turn, what to expect or what the future holds which can derail their progress.

It was evident in the focus group discussions that cost constraints are another factor that severely limits both the patients access to care and the therapist's ability to provide it. Financial limitations can be partly to blame for the lack of further specialisation into lymphoedema, as the courses are expensive, and require time to be taken out of clinical practice. Many physiotherapists cannot afford this cost and so either manage patients with what little knowledge they have or choose not to go into the field at all. Even for certified lymphoedema therapists, the ongoing costs of managing patients with lymphoedema can be prohibitive. The consumables are expensive to keep in stock, and often medical insurance schemes make it difficult to get financial compensation for the care the patient needs. Physiotherapists in the focus groups reported that their patients with secondary lymphoedema due to cancer are able to motivate for lymphoedema care, but for other patients, especially those with primary lymphoedema, the medical aids are less forthcoming in the provision of funds. De Vrieze et al. (2020) found in a study of patients with breast cancer related lymphoedema that up to 20% of treatment costs fell to the patient as out of pocket expenses, as health insurance only covered 80%. This financial stress results in interruptions in the patient's treatment plan and limitations in treatment options. Some physiotherapists feel that it is too risky financially to take on lymphoedema patients due to this uncertainty around payment for treatment and so are deterred from going into lymphoedema management. The cost of managing lymphoedema can be a large barrier for physiotherapists and patients alike. Patients can require intensive daily

treatment, bandages and compression garments. The management of the condition requires many sessions, with ongoing maintenance sessions throughout the patient's life, which means the cost of treatment for the patient becomes a burden. Bandages and garments are costly and are required lifelong. Over and above the cost of treatment there are practical costs such as transport and loss of earnings due to time off work. All of this adds up to a large monetary outlay which the patient often cannot afford or, if the patient has medical aid, may not be covered in full. As lymphoedema is a lifelong condition, this financial burden is felt for years to come. Dean et al. (2019) also found that the cost of lymphoedema to be a barrier to lymphoedema management in their studies. The focus group discussions revealed that some physiotherapists felt that after paying for the training, possibly having to outlay practice funds for bandages, spending clinical time doing a large amount of admin and having to deal with non-payment by medical aids and patients, the remuneration gained from treating these patients may not be worth the time spent in the field.

Not only is lymphoedema management expensive but it also requires time commitment from both the patient and the physiotherapist. Having to commit to a lifelong management of a condition can be daunting and patient compliance can be a challenge They are required to take time off work regularly and especially during the intensive phase, where daily treatments are needed, this time away from work can be a problem. As De Vrieze et al., (2020) discusses, the time commitment required for the intensive management of lymphoedema may lead to patients having to change from full time to part time employment. The time required to treat patients with lymphoedema is difficult for some therapists who have a busy workload as patients can require daily, hour long treatment sessions. Physiotherapists in the focus group found that it was often more financially beneficial to see twice as many patients without lymphoedema in the time it would take to see one patient with lymphoedema. So, the situation becomes difficult, as neither party can fully commit to the time required, and ultimately the patients' progress suffers.

The complexity of lymphoedema management can be difficult for both physiotherapists and patients. Some physiotherapists feel they are not equipped to take on the physical, logistical, social and psychological needs of a patient with lymphoedema, which forms such an integral part of their recovery, as was highlighted by Eneanya et al. (2019). Where the patient-therapist relationship can be a facilitator, it can also be a barrier if

the relationship breaks down and there is lack of commitment from both parties. Focus group participants discussed that some patients struggle to deal with the many complex factors in the management of their condition and become noncompliant to the treatment plan. Ostby and Armer, (2015) highlighted that there are numerous factors that contribute to a patient's compliance to lymphoedema treatment. The severity of the condition, the time required for treatment, the demands of daily life, the patients' beliefs and experiences and family support all have a role to play. A multidisciplinary team approach to lymphoedema management can help address some of these factors and lead to optimum treatment outcomes.

The barriers faced in the management of lymphoedema require a holistic approach to resolve, as these problems cannot be overcome by physiotherapists alone. Educational bodies, medical funders, employers, all healthcare practitioners and the patients themselves will have to work together to enable the better functioning of the system as a whole.

5.8 Summary

This chapter has taken the data from the results obtained from the questionnaire and focus group and discussed them with regards to the objectives of the study. Figure 5.1 shows the how the discussion of each objective relates to each other to answer the research question and give an overview of current practice in the management of lymphoedema. The findings of the study will be further summarised in the conclusion chapter.

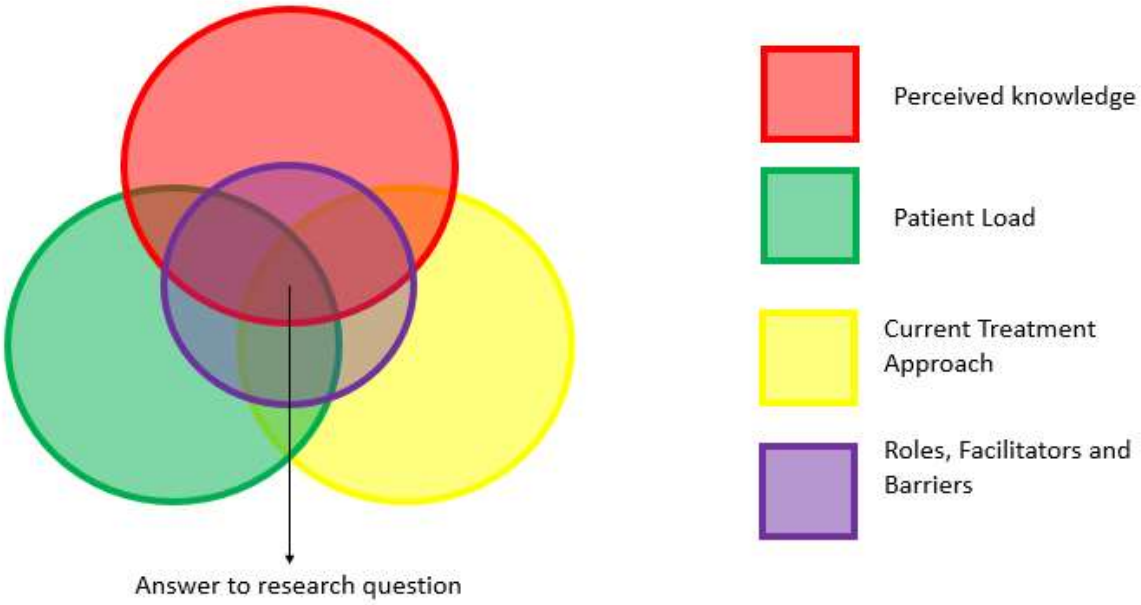


Figure 5.1: The relationship between the four objectives.

The lack of perceived knowledge in the field, the poor referral rate and inadequate management of lymphoedema in South Africa highlights that more needs to be done promote the management of lymphoedema in this country. There appears to be a diverse range of patients who require care, but at this stage there are very few physiotherapists available to offer the gold standard of management as specialists. The role that physiotherapists play in the management of lymphoedema is mostly incidental and there is scope for growth within the profession. Physiotherapists are equipped to manage patients with lymphoedema from a biopsychosocial aspect and can form a key member of the multidisciplinary team, which is invaluable to the management of patients with lymphoedema. To further physiotherapy in the field of lymphoedema there needs to be a movement towards awareness and promotion of the condition and the benefits of its management, undertaken by physiotherapists themselves, which would benefit both the profession and patients alike. There are barriers such as lack of education, financial constraints and time pressures and the complexity of lymphoedema management. However, by creating networks, both professional and social, capitalising on what the internet has to offer, staying abreast of recent developments and harnessing powerful patient-therapist relationships, there is a place for physiotherapists in the future of lymphoedema management.

Chapter 6 CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

This study set out to explore the current practice of physiotherapists in lymphoedema management in South Africa. Perceived therapist knowledge, patient load, treatment approaches, roles, facilitators and barriers to management were all explored in order to gain a broad picture of the topic.

6.2 Conclusion

This study shows that more work needs to be done in South Africa in the field of lymphoedema management in terms of awareness, access to care and education from a physiotherapy perspective. While there are patients with lymphoedema that require care, there is a lack of perceived knowledge and poor awareness amongst physiotherapists as to how to treat them according to international standards. The lymphoedema patient load for most physiotherapists is low, with a poor number of referrals, which is disproportionate to the proposed number of patients with lymphoedema in South Africa. The patients they do see make up a diverse range of the population with both secondary and primary lymphoedema, across all age groups and with many anatomical areas affected.

There is a large disparity in the level of perceived knowledge amongst physiotherapists, with the majority of therapists treatment approach falling short of the gold standard of care. A shortage of physiotherapists with a special interest in lymphoedema, and further training in the field is having a negative impact on overall access to quality lymphoedema management.

Physiotherapists are faced with barriers such as cost and time pressures and a lack of education and skills in managing a complex patient group. These barriers are making it difficult for some therapists to fully fulfil the potential role they can play in managing patients with lymphoedema.

However, there are some positives. The formation of the LAOSA, current developments in access to local education and consumables, information access via the internet and a rewarding patient therapist relationship that act as facilitators are encouraging physiotherapists to continue to pursue a career in lymphoedema management.

The heart of lymphoedema management comes down to the patient and the therapist and the journey they embark on to manage the patients lymphoedema. Physiotherapists are well equipped to cultivate strong, lasting relationships with their patients, and it is well within their scope of practice to continue to successfully manage patients with lymphoedema and the various needs they present with.

Current physiotherapy practice in lymphoedema management in South Africa is a growing field of interest. While there are barriers to overcome, the role physiotherapists play in the management of these patients will continue to evolve and flourish. There is an ongoing need for lymphoedema education and management in South Africa, and with the help of our international counterparts who are guiding the way, we will undoubtedly continue to see improvements in advocacy and provision of care to this patient population.

6.3 Recommendations

The lack of further qualified lymphoedema physiotherapists points to a few fundamental problems that need to be addressed. There needs to be an emphasis on educating all physiotherapists in order to bridge the gap between physiotherapists with a special interest in lymphoedema who are experts in the field and the generalists who know very little. Educational institutions should be approached with clear evidence of need of education in this field to develop a way forward, starting with fundamentals at an undergraduate level. When this becomes a reality, and there are more physiotherapists moving into the field, awareness of the condition will grow amongst the medical and public communities. We can then strive to achieve international standards of care.

The financial burden of treating these patients also needs to be addressed by consulting with medical funders and policy makers to allow the treatment of these patients to be viable for physiotherapists and patients alike. If there can be a better balance between the cost of management versus the amount covered by medical aids, more patients will be able to seek help for their condition. It would also allow physiotherapists to fully engage in the field, as managing these patients would become financially viable from a business perspective. Once the financial strain is eased, time pressures will be less tenuous for both patients and physiotherapists and this would result in improved patient care.

6.4 Further Research

Further prevalence studies would greatly assist to demonstrate the need for such educational, medical and financial discussions. Once we can accurately report on the number of people with the condition in South Africa we can begin to understand the scale of the problem being faced by the healthcare community. To build onto this study, a more objective investigation into the current practices and knowledge of physiotherapists can be done.

6.5 Strengths and Limitations

The study design, that of a mixed methodology, adds strength to the study. The addition of focus groups gave a unique insight into the daily experiences of physiotherapists working in the field. The information gathered helped to add depth to the data collected in the questionnaire to better understand the topic. A limitation of this study was the poor response rate on some of the questions in the questionnaire. A personal face to face appeal could have improved the response rate. It was also challenging to observe inter-participant responses on the online platform, especially as some of the participants chose to have their cameras off. This could have been improved if the focus groups had been held in person.

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APPENDIX A

QUESTIONNAIRE

Study Title: Physiotherapy practice in the management of lymphoedema in South Africa

Demographics

1. What setting do you work in?
   - Private hospital
   - Government hospital
   - Private outpatient practice
   - Clinics
   - Schools
   - Home care

2. How many years of experience do you have?
   -less than 1 year
   - 1-5 years
   - 5-10 years
   -10-15 years
   -over 15 years

3. What province do you work in?
   - Gauteng
   - Mpumalanga
   - Eastern Cape
   - Western Cape
   - Northern Cape
   - Limpopo
   - Kwa Zulu Natal
   - North West
   - Free State

4. How would you describe the area you service?
   - Large urban > 125 000
   - Urban town 10 000-125 000

- Small Town 3000-9 999
- Rural < 3000 but within 30 minutes of a town
- Remote rural, over 30 minutes away from a town

Knowledge

5. How would you describe your level of knowledge on the following aspects of lymphoedema? (Options; no knowledge, poor, fair, good, expert)
   - Pathophysiology
   - Characteristics of the condition
   - Causes of lymphoedema
   - Classification/ staging
   - Risk factors to developing lymphoedema
   - Management options
   - Complications of lymphoedema

6. What knowledge do you have about the physiotherapy management of lymphoedema? (Tick more than one if applicable)
   - I know how to identify a patient with lymphoedema
   - I know how to identify the stage of lymphoedema a patient has
   - I know how to treat lymphoedema
   - I know how to prescribe compression garments
   - I know what the complications of lymphoedema are
   - I know which complimentary health professionals I can refer my patients to
   - I know how to give patients appropriate advice relating to self management

7. Do you treat patients with lymphoedema?
   -Y/N

If no, answer questions 8 and 9. If yes answer questions 10-27

8. Why do you not treat patients with lymphoedema? (Tick more than one if applicable)
   - Not applicable in my clinical setting
   - I do not get lymphoedema referrals
   - I do not know how to treat lymphoedema
   - I am not confident in my ability to treat lymphoedema
   - I do not have the correct training
   - Lymphoedema is not my field of interest, so I choose not to
   - Other

9. If you have a patient with lymphoedema referred to you and you cannot help them, where do you refer them to for management?
   - Another physiotherapist
   - A GP
   - A vascular specialist
   - A surgeon
   - An OT
   - A nurse
   - I do not know where to refer them to

   Thank you for your participation in this study

10. Describe your highest lymphoedema training.
    - Training in University
    - Additional 135hr training through an accredited lymphatic therapist course
    - Unaccredited CPD lectures
    - Clinical training on the job

11. Are you registered with the Lymphoedema Association of South Africa (LAOSA)?
    - Y/N
12. Do you work in a practice that specialises in lymphoedema management?
    - Y/N

13. What is your role in the management of patients with lymphoedema? (Tick more than one if applicable)
    - Prevention advice to those at risk of lymphoedema
    - Identification of patients at risk of developing lymphoedema
    - Diagnosing lymphoedema
    - Provide Treatment
    - Prescription of compression garments
    - Provide a home exercise and care programme
    - Referral to other services or professionals

Patient Load

14. How many patients with lymphoedema have you seen in the last month?
    - 0-5
    - 5-15
    - 15-30
    - 30-60
    - 60-120
    - 60+

15. On average, how many new referrals do you get per month?
    - 1-5
    - 5-10
    - 10-20
    - 20+

16. How much of your work time is taken up by your lymphoedema role?
    - <20%
    - 20-40%
    - 40-60%
    - 60-80%
    - 80-100%

17. What percentage of the patients you see are in the following categories? (Must add up to 100 percent)
    - Paediatric <12

- Adolescents 12-18
- Adults 18-65
- Geriatrics 65+

18. What percentage of the patients you are treating present with lymphoedema from the following causes: (must add up to 100 percent)
    - Primary
    - Oncology
    - Trauma
    - Obesity
    - Other medical conditions

19. What percentage of the patients you see have lymphoedema in the following areas? (Must add up to 100 percent)
    - Upper Limb
    - Lower limb
    - Head and neck
    - Truncal
    - Genital

20. Where do your lymphoedema referrals come from? (Tick more than one if applicable)
    - Oncologists
    - Surgeons
    - Vascular specialists
    - Other physiotherapists
    - Other Allied Healthcare professionals
    - GPs
    - Self-referrals
    - other

<u>Treatment Approach</u>

21. What clinical tools do you use to diagnose lymphoedema? (Tick more than one if applicable)
    - Stage of oedema

- Stage of pitting
- Positive stemmer sign
- Skin integrity
- Circumferential or volume measurements
- Visible limb shape or distortion
- Comparison to the other limb, visual or measured
- The patient arrives with a diagnosis
- None
- Other

22. What measurement methods do you use to assess lymphoedema? (Tick more than one if applicable)
    - Circumferential tape
    - Water displacement
    - Perometry
    - Bioelectrical impedance
    - Tonometry
    - Photos
    - None
    - Other

23. What else do you assess with your lymphoedema patients? (Tick more than one if applicable)
    - ROM
    - Pain
    - QOL
    - Function
    - Other

24. What types of treatment do you offer? (Tick more than one if applicable)
    - Complete decongestive lymph therapy (CDLT)
    - Manual lymph drainage without bandaging
    - Only bandaging
    - Only compression garments
    - Exercises
    - Skin care

- Risk reduction education
- Pneumatic pumps
- Pain assessment and management
- Low level laser
- Aquatic
- Vibrator therapy
- Measure and fit compression garments
- Would care
- Kinesio tape
- Reflexology
- Acupuncture
- Soft tissue release
- Care giver training
- Other

25. Do you send the patient home with materials for education and home care?
    - Y/N

26. What facilitators aid you in the management of patients with lymphoedema?

27. What barriers do you face with the management of patients with lymphoedema?

Thank you for participating in this study.
If you have worked in the field of lymphoedema for two or more years and would like to participate in a focus group to further explore the roles, facilitators and barriers experienced by physiotherapists in the management of lymphoedema, please leave your email address below.
Name:
Email Address:

APPENDIX B

INTERVIEW GUIDE FOR FOCUS GROUP

Study Title: Physiotherapy practice in the management of lymphoedema in South Africa

Welcome

- Introduction of the group facilitator and assistant
- Thank you for participating

Purpose for the focus group

- What the research topic is
- Why the focus group is being held
- How the information will be used

Guidelines

- The focus group will be recorded
- Please try and take it in turns to talk, and talk clearly
- There are no right or wrong answers, we are interested in your opinion
- Please listen respectfully to others
- Make sure your phones are on silent
- Explain the roles of the facilitator and assistant
- Encourage a discussion with each other

Introduction

- Introduction of all participants
- Brief description of clinical setting they work in

Questions

- Tell us about the role you play in the management of lymphoedema.
- How do certain factors facilitate your management of patients with lymphoedema?
- What kind of barriers do you encounter when working in lymphoedema management?
- In your opinion, are there things that could be addressed to remedy these barriers?

- How do you see the future of physiotherapy in the management of lymphoedema?

Closing questions

- Is there anything else you would like to add to the topic discussed?
- Offer a brief summary and ask if the summary is correct.

APPENDIX C

STUDY INFORMATION DOCUMENT

Study Title: Physiotherapy practice in the management of lymphoedema in South Africa

Dear Physiotherapist

I, Carys Rhodes, am currently completing my masters in Physiotherapy at the University of the Witwatersrand. The focus of my study is to investigate how physiotherapists in South Africa are managing patients presenting with lymphoedema. I would like to get feedback from as many physiotherapists working in South Africa as possible, and I would greatly appreciate your participation in this study.

The objectives for the study are as follows:

- To describe what physiotherapists' perceived knowledge is regarding lymphoedema and the management thereof
- To determine the lymphoedema patient load being seen by physiotherapists in a clinical setting
- To establish what treatment approaches physiotherapists are using to treat patients with lymphoedema
- To investigate the roles of, facilitators and barriers experienced by physiotherapists managing lymphoedema.

About the study

The study is to be conducted in two phases, from July-December 2020.

The first phase is an online questionnaire, which can be completed over a period of 3 months and should take 20-30 minutes to complete. Consent is not required to complete the questionnaire.

The second phase of the study is online focus groups to further explore the experiences of physiotherapists that treat patients with lymphoedema. Multiple focus groups will be held on an online platform and will each take an hour to an hour and a half. The focus groups will be recorded and transcribed by an external transcriber, from which the data can be analysed. There will also be a research assistant present to take notes and help facilitate the group.

Who Can Participate?

Any physiotherapist in South Africa who is currently practicing in the country may complete the questionnaire.

Physiotherapists who treat patients with lymphoedema will be invited to participate in the focus groups. If you would be prepared to volunteer to be a part of the focus groups, there will be a section at the end of the questionnaire where you can leave your details to be contacted at a later date. If you require further information about the focus groups, please don't hesitate to contact the Principle researcher.

Risks and benefits

There are no risks in taking part in the study. Although there is no immediate benefit gained from participating, it is hoped that the study may produce data that can benefit the profession of physiotherapy in the future.

Ethical considerations

Participation in the study is entirely voluntary and you can withdraw at any time.

In both phases of the study, participant numbers will be allocated to ensure anonymity and confidentiality of the participants. These identifiers will be used for all data collection, analysis and publications. In the questionnaire the participants name and email address may be included, and this personal information will only be available to the Principle researcher for the purposes of forming the focus groups. In the focus groups confidentiality cannot be guaranteed, as you will be able to see and meet the other participants, the Principle investigator and the research assistant. Before transcribing the sessions, each focus group participant will be allocated a participant number, as to remain anonymous. The identity of all participants, as well as any personal information will be kept confidential, on a password protected computer, on a password protected online storage and in hard copy in a safe at the Principle researchers' office but may be divulged if required to by law.

There will be no remuneration for participation in the study.

All data collected will only be used for the purposes of the study but may be shared with supervisors or other researchers in the future.

For any further information please contact the Principle researcher on **caryswoodlandphysio@gmail.com**, or 0836219661. Alternatively you can contact the study supervisors Dr Corlia Brandt and Monique Keller at **corlia.brandt@wits.co.za** and **Monique.keller@wits.co.za** accordingly.

If you have any concerns about how the research is being conducted please contact Professor Clement Penny, Chairperson of the Human Research Ethics Committee (Medical) on 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za. The telephone

numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Kind Regards
Carys Rhodes
Physiotherapy Department
University of the Witwatersrand

APPENDIX D

PARTICIPANT CONSENT SHEET FOR FOCUS GROUPS

Study Title: Physiotherapy practice in the management of lymphoedema in South Africa

1. I have been given a Study Information Sheet which explains the nature and processes involved in this study, which is attached hereto.
2. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory.
3. I believe I fully understand why the study is being conducted and what the intended outcomes will be.
4. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment.
5. I understand that participation will cost me my time.
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons.
7. I understand that the focus group session will be recorded and transcribed, and that all personal information will be kept confidential by the Principle researcher.
8. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

Principle researcher Carys Rhodes on **caryswoodlandphysio@gmail.com**, or 0836219661,

Supervisors Dr Corlia Brandt and Monique Keller at **corlia.brandt@wits.co.za** and **Monique.keller@wits.co.za**

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at **Clement.Penny@wits.ac.za**.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: **Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za**

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

APPENDIX E

CONSENT TO AUDIO AND VISUAL RECORDING

Study Title: Physiotherapy practice in the management of lymphoedema in South Africa

For the study 'Physiotherapy practice in the management of lymphoedema in South Africa', the roles, facilitators and barriers of physiotherapists working with patients with lymphoedema will be explored in focus groups. The focus groups will be held on an online platform and will have 6-8 participants. These sessions will be facilitated by the Principle researcher and research assistant and will be recorded with video and audio, in order to transcribe the session for later analysis.

These recordings will be stored on the password protected computer of the Principle researcher. The recordings will be backed up to the cloud. The Principle researcher and transcriber will have access to the recordings, only for the purposes of the study. The recordings will be kept for five years before being destroyed. The results of the data analysis will be published in a dissertation and journal articles. The data may be shared with supervisors, participants and fellow researchers.

By signing this document, you

1. Understand why and how the recordings will be used
2. Understand how the recordings will be stored and treated
3. Consent to being recorded during the focus group

Contact details:

Principle researcher Carys Rhodes on **caryswoodlandphysio@gmail.com**, or 0836219661,

Supervisors Dr Corlia Brandt and Monique Keller at **corlia.brandt@wits.co.za** and **Monique.keller@wits.co.za**

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at **Clement.Penny@wits.ac.za**.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: **Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za**

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

APPENDIX F

FOCUS GROUP INFORMATION DOCUMENT

Study Title: Physiotherapy practice in the management of lymphoedema in South Africa

Dear Physiotherapist

Thank you for volunteering to take part in a focus group as part of a study to investigate how physiotherapists in South Africa are managing patients presenting with lymphoedema.

The objective of the focus group will be to explore the roles, facilitators and barriers experienced by physiotherapists who work in lymphoedema.

About the focus group.

Two to three focus groups will be held comprising of 6-8 participants. The focus group will be held on an online platform in October/November. Each focus group will take an hour to an hour and a half.

The focus groups will be facilitated by the Principle researcher and a research assistant will be present to take notes. The session will be recorded and transcribed by an external transcriber. From these transcriptions the data will be collated and analysed for the writing up of a dissertation and publications.

Who Can Participate?

Any physiotherapists who treat patients with lymphoedema and indicated their interest to participate in the questionnaire can participate. The participant must have access to a computer and internet in order to join the online session.

Risks and benefits

There are no risks in taking part in the focus group. Although there is no immediate benefit gained from participating, it is hoped that the focus group may produce data that can benefit the profession of physiotherapy in the future.

Ethical considerations

Participation in the study is entirely voluntary and you can withdraw at any time.

In the focus groups confidentiality cannot be guaranteed, as you will be able to see and meet the other participants, the Principle investigator and the research assistant. Before transcribing the sessions, each focus group participant will be allocated a participant number, as to remain anonymous for any further data analysis and publications. The identity of all participants, as well as any personal information will be kept confidential,

on a password protected computer, on a password protected online storage and in hard copy in a safe at the Principle researcher's office but may be divulged if required to by law.

There will be no remuneration for participation in the study.

All data collected will only be used for the purposes of the study but may be shared with supervisors or other researchers in the future.

For any further information please contact the Principle researcher on **caryswoodlandphysio@gmail.com**, or 0836219661. Alternatively you can contact the study supervisors Dr Corlia Brandt and Monique Keller at **corlia.brandt@wits.co.za** and **monique.keller@wits.co.za** accordingly.

If you have any concerns about how the research is being conducted please contact Professor Clement Penny, Chairperson of the Human Research Ethics Committee (Medical) on 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Kind Regards

Carys Rhodes

Physiotherapy Department

University of the Witwatersrand

APPENDIX G

SUMMARY TABLE OF FOCUS GROUP RESULTS

Theme	Category	Subtheme	Quotes
Roles of physiotherapists in the management of lymphoedema	Becoming a lymphoedema therapist	Not intentional	It's not something I looked to do but I needed to do it, it just happened.'- Participant 5
			'I started working in a practice in JHB not knowing what lymphedema was.' - Participant 2
			'So, life chose me, this type of work chose me, I didn't choose it.' - Participant 6
		As a result of personal experience	'I actually have lymphedema and I started as a patient when already a physio and ended up working in the practice where I was a patient' - Participant 1
			At the beginning of last year my one arm started swelling due to the breast cancer I had' – Participant 8
		Becoming more skilled	It holds a special interest for me. – Participant 1
			I saw the need knowing that there is help out there for these types of patients and that is how my journey started' - Participant 2
	Working in a multidisciplinary team	To successfully manage the condition	'I do think being part of a multi-disciplinary approach would be better.' - Participant 3
			'Absolutely there must be a multi-disciplinary team involved, it's not something you can do on your own.' - Participant 2
			'I think that if you do treat lymphedema patients you do end up working within a multi-disciplinary team' – Participant 1
			'Every part of the team could give an input as per their own speciality.' - Participant 6
		Important for referrals	'Because they are often referred by surgeons or oncologists and especially the (hospital in

			Johannesburg) oncologists do refer patients so there is the multi-disciplinary team component' - Participant 1
	The biopsychosocial approach to the role	Emotional aspects	'It seems like the condition is so complex and not just the physical.' - Participant 4
			'You have to be patient with them and a lot of the time a lot of emotions are involved as well' - Participant 7
		Holistic, biopsychosocial view	'You are going to need to think about the patient holistically with this type of condition.' - Participant 4
	Creating awareness and promotion	Important part of the role	'But in the bigger picture there is definitely a need for intervention and to just create more awareness.' - Participant 2
Factors that facilitate lymphedema management for physiotherapists	The importance of lymphoedema networks	Reliable referral system	'A few of my patients are part of (cancer support group) and they will say that you need to go and get treated for lymphedema, go find out information and they will send them my way.' - Participant 1
		Important for support	'The LAOSA, but it is not very old, maybe three or four years old and you pay a very minimal fee to be part of the group.' - Participant 6
			'A network of how we let the psychologists, nurses, wound specialists, OT's, physios that are in lymphedema to have a network where when you think a patient needs more psychological support you know who is trained and understands the condition and you can then refer the patient to them.' - Participant 7
	Internet resources for professionals and the public	Important source of referrals	'A lot of my patients come through and say they googled it and this website came up and these are the physios, these are the practitioners that they can refer to.' - Participant 6
			'A lot of people Google you, so it's important to have a social media presence as well.' - Participant 5
			'I have a web page going.' - Participant 2
			'Actually, a lot of people find us on Google.' - Participant 1

		Online network	'If you register with the LAOSA, your details are on their website so although a patient has to know about the LOASA to find your details.' – Participant 1
	Recent developments in the field	More access to training	'2015, when training actually started in South Africa officially' – Participant 2
			'It's grown so much in the past ten years or five years at least since training started' – Participant 2
		Promotion and awareness	'There is definitely more awareness being raised all over.' - Participant 2
			I have seen it since 2005 there is definitely much more awareness.' – Participant 1
		More management options	'We have a lot more options in terms of compression which is the long-term maintenance for lymphedema.' – Participant 2
			'Now we have more local bandaging' – Participant 1
	The patient-therapist relationship	Rewarding for patients and physiotherapists	'I can absolutely see the thankfulness in the patients and the life changing experience is exactly what you said in how it transforms them.' – Participant 6
			'I think that is a very important relationship, because that is almost where their healing starts to begin' - Participant 1
			'When you see the outcomes you experience this joy where after 10 sessions you see this significant change in the patient then you know it was worth all the time and effort you put in.' – Participant 7
			'Ok, I'm going to be that physio and in the end it makes a difference.' – Participant 7
Barriers encountered when managing lymphoedema	A lack of education and awareness	Topic not covered in depth at an undergraduate level	'It is almost like when we were taught at University it was almost like an afterthought and it wasn't given the consideration it was due.' - Participant 4
			I didn't have the knowledge to guide her and didn't know that physio had such a big role to play in it.' – Participant 9
			'I see myself then as a physio not having had sufficient knowledge. We weren't equipped as pre-grad/under grad students.' - Participant 8
			'My understanding of the condition is quite limited in terms of prognosis. I feel limited in my management.' - Participant 4

			‘As an undergraduate we focussed a bit on the different types of oedema and there was the general overall of what lymphedema is and how it differs from other oedema and very basic on the treatment, but nothing more’ - Participant 7
			‘I think it was definitely lack of education to the patient, as well as lack of knowledge/studies and our role in lymphedema as physios.’ - Participant 9
		Poor awareness amongst other healthcare professionals	‘If we can get other health care professionals to just be aware that there are therapists out there that will be a major breakthrough.’ - Participant 2
			‘It is very new, there are very few Doctors or physicians who specialise in lymphedema, so there is generally a large population out there not knowing where to go to.’ - Participant 6
		A lack of professionals with a special interest in the condition	‘I think we have about 120 therapists in South Africa at the moment that have a full certification and that is just not enough to deal with the amount of patients we have in the public and the private sector.’ - Participant 5
		Access to further education options	‘I think it is a pity that we do not have easier access to courses, more inexpensive courses’ - Participant 8
			‘To me I don’t want to become a full time lymphedema therapist, so if you could tell me I can go on a weekend course so that I know what I can do with people that walk into my practice.’ - Participant 3
			‘So even if the Universities cannot offer everything, all of the information in the under grad, if they can at least have CPD workshops that gives you the basic information that can be helpful with the patient that you do come across in your practice’ - Participant 7
	Prohibitive costs	Cost of treatment	‘The bandaging alone is very expensive.’ – Participant 1
			‘It’s just with some chronic cases, not everyone is going to afford to come in as often as needed.’ - Participant 4
			‘It’s long term and it’s a chronic condition. It becomes really, really expensive.’ – Participant 6

		Shortfall from medical aids	'The thing that bothers me the most is the cost of bandages and garments, the amount of treatment that you have to give and Medical Aids don't always pay for it.' - Participant 6
			'I find that I will treat patients maybe twice or three times a week for a couple of weeks rather than every day just to get away with the constraints of Medical Aid and finances.' - Participant 6
			'You feel you should get value for your money, but Medical Aids however disagree. It's costly if the Medical Aids don't cover, but it's costly for you if you just charge what the Medical Aids say you should charge.' - Participant 1
		Cost of further education	'The costs of training. I completely agree as a new physio in the public sector, the cost is something that stops us.' - Participant 7
			'Then the challenge comes with training costs, because all the trainers are international and the one lady that lives here, it is still high cost training and it's two weeks out of your practice.' - Participant 2
			'I have been trying to do a few of the smaller courses, but not any of the bigger ones due to financial constraints' - Participant 7
			'One thing I do think is really difficult for a young physio to get into, to do a full lymphedema qualification, is the cost of these qualifications.' - Participant 5
	Time pressure	Patients time commitment	'Because it is a high intensity treatment, so people have to take off work every day or two or three days a week. Time limitations in terms of peoples work can be a challenge.' - Participant 2
		Physiotherapist time commitment	'We have a lot of patients who would benefit from the lymphedema approach, but because of our lack of time and our lack of resources we are pushing to get through the patients.' - Participant 7
	Complexity lymphoedema management	Patient complexity	'The biopsychosocial model is so important now and it seems like the condition is so complex. You are going to need to think about the patient holistically with this type of condition.' - Participant 4
			'You have to be patient with them and a lot of the time a lot of emotions are involved as well, because it's affecting their quality of life so badly.' – Participant 7

		Physiotherapist's duties	'To manage a lymphedema only practice is not that simple. There is a lot of admin around it.' - Participant 2
		Physical and emotional demand on physiotherapists	'And that is difficult, it is really difficult and tiring. I found myself, if I have too many lymphedema patients in a day, I really am exhausted, both physically and emotionally.' - Participant 6
			'But I find it is ongoing, you never really discharge a patient because they will always come back. I find you always end up have a very long relationship with your clients.' - Participant 5
		Noncompliance	'As it is quite an intensive treatment, a lot of patients fall off the wagon because it is hard to be bandaged every day, it's hard to wear compression every day, it's hard to have a chronic condition that needs to be managed constantly.' - Participant 1

APPENDIX H

UNIVERSITY OF THE WITWATERSRAND

R14/49 Ms C Rhodes

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M200540

NAME: (Principal Investigator)	Ms C Rhodes
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Medical School University
PROJECT TITLE:	Physiotherapy practice in the management *of* lymphoedema in South Afrisa
DAYE CONSIDERED:	
DECISION:	2020/05/29
CONDITIONS:	Approved unconditionally
SUPERVISOR:	
APPROVED BY:	Dr C Brandt and Ms M Keller
DATE OF APPROVAL:	Dr CB Penny, Chairperson, HREC (Medical) 2020/07/01

This clearance certificate is valid for 5 years from tha date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and ONE COPY returned to the Research Office Secretary on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above- mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearfv progress report.** When a funder requires annual re- certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in May and will therefore reports and re-certification will be due early in the month of May each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature — Date: 13 July 2020

APPENDIX I

TURNITIN REPORT

Turnitin Originality Report

Processed on: 06-Feb-2022 5:29 PM SAST
ID: 1755906916
Word Count: 31685
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C Rhodes 0704276M By Carys Woodland Rhodes

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