

An Exploration of Self-Care Practice and Factors Influencing
Self-Care among People Affected by Leprosy in Nigeria using
Social Practice Theory

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree
elsewhere

Abstract

A social practice theory (SPT) perspective was adopted in this study to explore how leprosy self-care has been practised in a leprosy village in North Central Nigeria. The study contributes to clarifying how SPT assists in improving the knowledge and understanding of the facilitators and barriers to leprosy self-care practice. Although key stakeholders have recommended self-care in improving the quality of life of people affected by leprosy, its implementation has not been effectively sustained, and no study has been conducted in this setting to explain the reasons for this low uptake.

This is a hermeneutic phenomenological qualitative study (Vagle, 2018) to explore factors influencing leprosy self-care practice. Data from people affected by leprosy were collected through 20 semi-structured interviews. In addition, over 16 hours of non-participant observation (Baker, 2006) of self-care clinics and self-care groups were carried out. The research aimed to explore participants' perceptions and experiences of self-care and, at the same time, identify the factors which shape and influence their self-care practice. Data were thematically analysed as described by Braun and Clark (2006). The empirical data indicates that healthcare worker support is critical for sustaining leprosy self-care practice. It also highlights the importance of ensuring leprosy patients have adequate self-care knowledge and skills about leprosy self-care practice. The data analysed reveals that leprosy self-care materials could be subdivided into two broad categories, 'replaceable' and 'irreplaceable' materials. This categorisation highlights the need to ensure that self-care materials are available, affordable, appropriate, and culturally acceptable to people affected by leprosy.

An overarching finding of this study is that factors that affect leprosy self-care are dynamic and interconnected and could occur in a continuum conceptualised as the leprosy self-care continuum (LSCC). The LSCC suggests no absolute presence or absence of factors but indicates various degrees of positive (enabler) or negative (inhibitor) influence. This finding informs the need for tailored and individualised leprosy self-care interventions, with continuous monitoring to ensure appropriate responses as the patient's situation and context change. This thesis argues that leprosy self-care policy should be reconceptualised from changing individual leprosy patient behaviour to modifying broader practices of leprosy self-care. It proposes that leprosy self-care practice from an SPT lens can enhance the experiences of people affected by leprosy by identifying competing and complementary factors to self-care. This research adds a novel theoretical contribution to the broader literature on leprosy self-care by applying SPT (Shove et al., 2012; Shove, 2009) in examining how people affected by leprosy experience self-care daily. Finally, this work makes an empirical contribution to the under-researched field of leprosy self-care (Odia and Omofonmwan, 2013) by extending current thinking on how leprosy self-care is implemented.

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List of Abbreviations

AIDS	Acquired Immunodeficiency syndrome
BNI	British Nursing Index
CEO	Chief Executive Officer
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COR-NTD	Coalition for Operational Research on Neglected Tropical Diseases
FCT	Federal Capital Territory
FMOH	Federal Ministry of Health
HCW	Healthcare Worker
HIV	Human Immunodeficiency Virus
ILEP	International Federation of Anti-Leprosy Associations
IPFCC	Institute for Patient and Family-Centred Care
LSCC	Leprosy Self-Care Continuum
NCD	Non-communicable Disease
NGO	Non-governmental Organisation
NLR	Netherlands Leprosy Relief
NTBLCP	National Tuberculosis and Leprosy Control Programme
NTD	Neglected Tropical Disease
MB	Multibacillary
MDT	Multi Drug Therapy
PB	Paucibacillary

PT	Participant
PEP	Post Exposure Prophylaxis
SPT	Social Practice Theory
TLMN	The Leprosy Mission-Nigeria
WASH	Water Sanitation and Hygiene
WHO	World Health Organisation

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CHAPTER 1

Study Background

1 Introduction

This thesis expands the current understanding of the factors influencing leprosy self-care from a social practice theory (SPT) lens. Hence, this Chapter provides the background to the research problem while outlining the current leprosy situation globally and in Nigeria. Furthermore, it explains how leprosy self-care is organised in Nigeria; and describes the concept of self-care within the global context of managing chronic conditions. Finally, the Chapter also presents a justification for this research and concludes by outlining the dissertation structure.

1.1 Introducing the Research

Evidence of leprosy self-care practice effectiveness in improving the health and well-being of persons affected by leprosy abound in literature (Benbow and Tamiru, 2001; Chakraborty et al., 2006; Ebenso et al., 2009; Darlong, 2021). However, previous studies indicate that the implementation of leprosy self-care has not been effectively sustained as several national self-care programmes have collapsed (van Brakel et al., 2010). Similarly, these studies on leprosy self-care have been primarily underpinned by behavioural theories that emphasise the deliberative character of a sovereign, rational being (Michie et al., 2014). Moreover, studies conducted outside Africa focused mainly on self-care processes and their effectiveness. Contrarily, this qualitative phenomenological study explored how self-care was practised among people affected by leprosy in Nigeria through in-depth interviews and observations. Also, this research aimed to deepen the knowledge of the factors that facilitate or inhibit self-care practice

among people affected by leprosy. A unique aspect of this study is its novel application of SPT (Shove et al., 2012) to investigate how competencies, materials, and the meanings people affected by leprosy associate with self-care, interact to initiate and sustain their practice.

1.2 Background to the Research Problem

1.2.1 Epidemiology

Leprosy, also known as Hansen's disease, is a stigmatising, infectious, chronic disease caused by the bacterium *Mycobacterium leprae* (Norman et al., 2016). Clinically, it manifests as skin lesions, peripheral nerves, and eyes (Norman et al., 2016). It is one of the leading causes of disabilities among communicable diseases (Bennett et al., 2008). The disabilities associated with leprosy are more than physical impairments and include social participation restrictions, activity limitations, discrimination, and stigma. Some physical impairments related to leprosy include reduced visual acuity, claw hands, foot drop, and chronic plantar and palmar ulcers (Wilder-Smith and Van Brakel, 2008). The World Health Organisation (WHO) classifies leprosy-related impairment into three categories: Grade 2 represents visible impairments or deformities (e.g., ulcers, loss of vision); Grade 1 represents a loss of sensation in the hand or foot; while Grade 0 represents no impairments (Brandsma and van Brakel, 2003).

Leprosy is believed to be transmitted by droplets when an infected person coughs and sneezes and the droplets come in contact with a susceptible person (Job et al., 2008). However, not everybody who encounters an infected leprosy patient gets the disease, as it only affects those with compromised immunity (Job et al., 2008). Therefore, leprosy transmission is mainly dependent on the susceptibility of individuals. It also depends on how close individuals

(members of the same household, neighbours, and social contacts) are to an untreated index case. The highest risk occurs among household contacts (Moet et al., 2006; Bakker et al., 2005). Given this, leprosy patients are often found in clusters of households, families, neighbourhoods, and regions (Moet et al., 2006; Bakker et al., 2005). Post-exposure prophylaxis (PEP) against *Mycobacterium leprae*, using single-dose Rifampicin, is a promising innovation for preventing leprosy transmission among contacts (Richardus and Oskam, 2015). Depending on the bacillary load, World Health Organisation (1988) classifies leprosy as multibacillary (MB) or paucibacillary (PB). MB leprosy is a more severe disease characterised by multiple (more than five) skin lesions, skin infiltrations, thickened dermis, plaques, or nodules. In contrast, PB leprosy is milder and has few (up to five) reddish or pale skin lesions (World Health Organisation, 1988).

Multi-drug therapy (MDT), a combination of antibiotics, effectively treats leprosy. MDT is administered for six to twelve months, depending on the severity of the disease (World Health Organisation, 2019). MDT not only cures leprosy patients but also reduces its spread within the population. After the first dose of MDT, the transmission of leprosy is interrupted. Thus, a patient can no longer transmit the disease to others after the treatment regimen's first dose. PB patients are cured after six months of treatment, while it takes 12 months to cure MB patients.

Today, WHO lists leprosy as one of the skin-related neglected tropical diseases (NTDs). NTDs are generally infectious conditions prevalent in low-income and resource-constrained population countries. They are neglected because they have not received equitable attention like other diseases (World Health Organisation, 2010). People at risk or affected have little political voice,

live in hard-to-reach places like slums, shantytowns, and conflict areas, and have limited access to treatment (World Health Organisation, 2010a).

1.2.2 Global Leprosy Situation

Globally, the number of new leprosy cases diagnosed annually since 2010 has been over 200,000. Half of these have some form of impairment that could lead to disability and stigma (World Health Organisation, 2021). In 2019 alone, 202,185 new cases were notified from 115 countries. (World Health Organisation, 2021). However, at the end of 2020, the number of new cases dropped by 37.1% to 127,396 compared to 2019. This change is likely due to a reduction in case-finding activities occasioned by the COVID-19 pandemic (World Health Organisation, 2021).

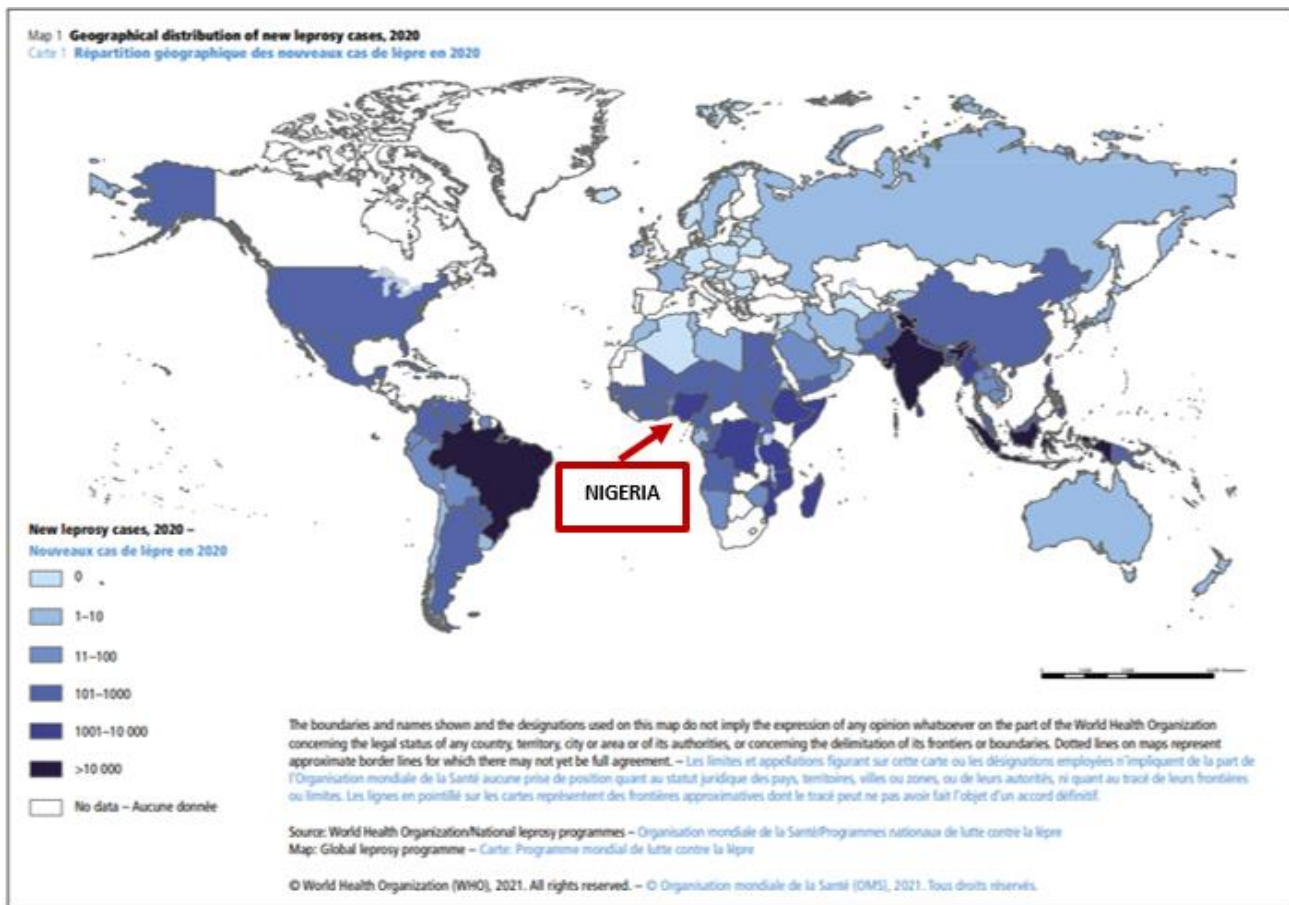


Figure 1.1: Global Leprosy Distribution in 2020 (Source: World Health Organisation, 2021)

1.2.3 State of Leprosy in Nigeria

Nigeria is ranked 10th among the 23 global leprosy priority countries. These 23 countries account for more than 95% of leprosy cases globally (World Health Organisation, 2021). In 2019, Nigeria notified 2,424 new leprosy patients (World Health Organisation, 2021). Figure 1.2 shows a trend of essential leprosy indicators showing a steady decline in new leprosy cases detected, with a spike in 2019 due to active case-finding exercises initiated 2019. However, compared to 2019, the total number of new cases dropped sharply by 40.5 % to 1417 in 2020 due to a

suspension of active case-finding activities occasioned by the impact of COVID-19. Active case finding has since recommenced, and this trend is expected to reverse.

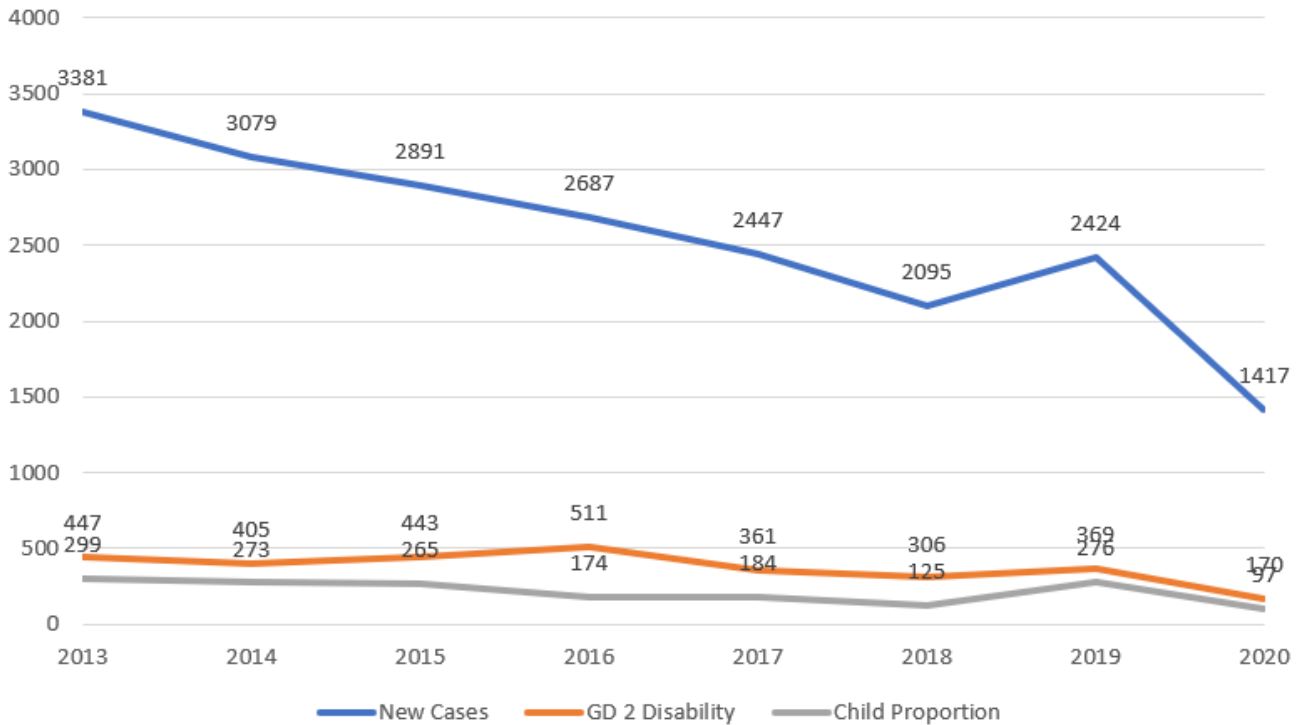


Figure 1.2: Trend of Essential Leprosy Indicators for Nigeria (2013 – 2020) (Source: World Health Organisation, 2021)

Geographically, leprosy distribution is uneven (See Fig. 1.3). leprosy shows a close relationship with precarious living conditions. It tends to persist in locations with high social inequality, low educational level, and high levels of malnutrition and poverty (Kerr-Pontes et al., 2006). Furthermore, of the 2,424 new cases detected in 2019, 369 (15.2%) had WHO Grade 2 disability against 306 (14.6%) reported in 2018. This variation of figures can be said to be an indication of the National Leprosy Control Programme's ineffectiveness in detecting cases early. These large

numbers of leprosy patients who develop Grade 2 disabilities continue to add to the pool of leprosy patients needing self-care.

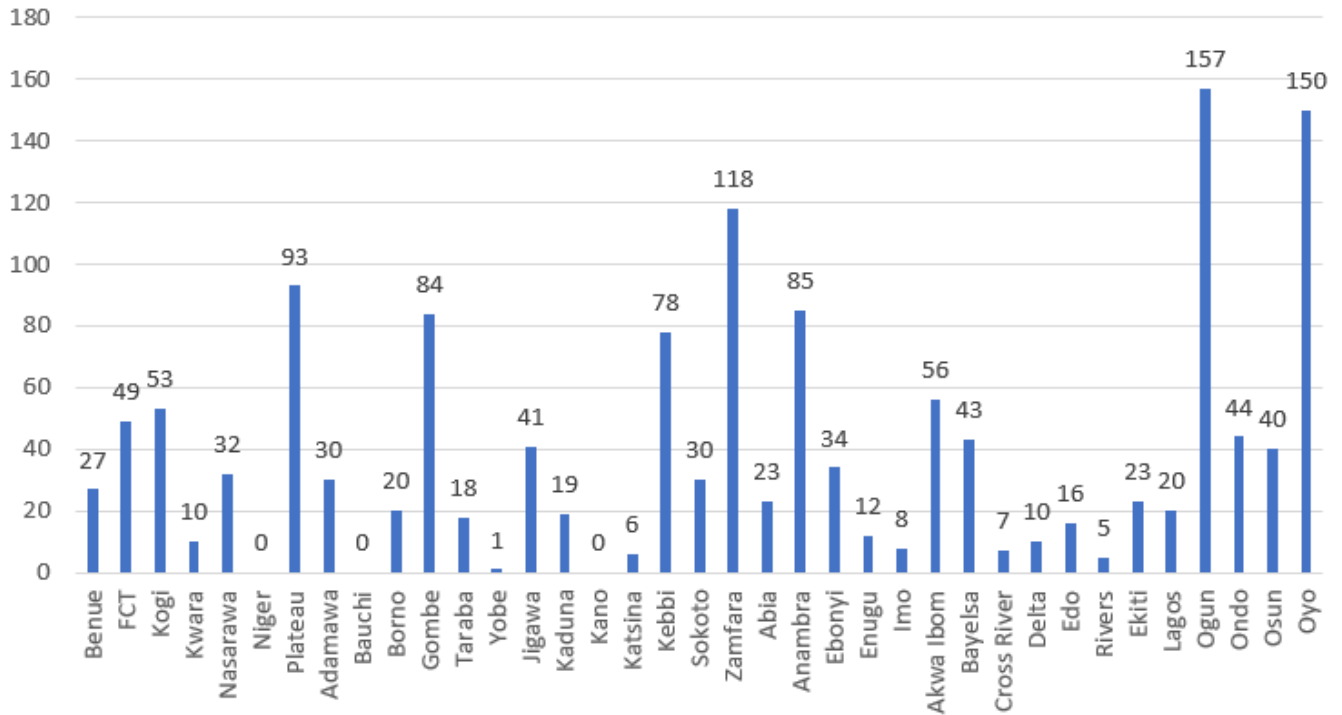


Figure 1.3: New Leprosy Case Notification by State in 2020 (Source: Author)

1.2.4 Leprosy, Disabilities, and Stigma

1.2.4.1 *Leprosy-Related Disabilities*

Among infectious diseases, leprosy is one of the leading causes of disfigurement and physical disabilities (van Brakel et al., 2012). These commonly occur in the muscles of patients' hands, feet, and eyes (van Brakel et al., 2012). *Mycobacterium leprae*, the causative agent for leprosy, triggers long-lasting granulomatous inflammation of the nerves, which supply the affected muscles leading to permanent damage (Wilder-Smith and Van Brakel, 2008). Despite the

availability of an effective treatment for leprosy, MDT, the diagnosis of leprosy is often too late when Grade 2 disability and irreversible impairments have already occurred. Late reporting and diagnosis are primarily due to weak leprosy control programmes, dwindling expertise in diagnosing leprosy, and the stigma associated with the disease (Chaptini and Marshman, 2015). Consequently, many patients would sustain nerve damage and develop physical disabilities such as chronic ulcers, contractures, clawed hands and feet, and occasionally, blindness. These physical disabilities usually require chronic and long-term care in the form of self-care to limit further damage due to secondary infection and optimise functionality (Wilder-Smith and Van Brakel, 2008).

1.2.4.2 Leprosy-Related Stigma

One of the significant consequences of the physical deformities and disabilities caused by leprosy is stigma and discrimination (van Brakel, 2003). In the literature, many definitions of stigma and related phenomena exist. In this study, stigma is defined as a social process that occurs when discrimination, loss of status, separation, stereotyping, and labelling coexist in a power dynamic that facilitates them (Link and Phelan, 2006). This definition is adopted due to extensive use in health-related stigma and its emphasis on the import of a power differential in stimulating stigma. Other critical triggers for leprosy stigma include myths and misconceptions about its cause, false beliefs and perceptions about the disease, ignorance, and fear of infection (Arole et al., 2002). Three kinds of stigma have been related to people affected by leprosy: experienced or enacted stigma, perceived or anticipated stigma, and self-stigma or internalised stigma (Weiss et al., 2006; van Brakel, 2003). Enacted stigma refers to prejudice and discriminatory acts against people affected by leprosy. Perceived stigma relates to when a person

affected by leprosy develops fear within themselves. Such fear stems from a belief about possible adverse reactions, discrimination, and cruel treatment from society, friends, and family members. At the same time, self-stigma usually results from both enacted and perceived stigma consequences. After a while, people affected by leprosy believe what people say or think about them, leading to low self-esteem, low self-efficacy, and loss of dignity (Weiss et al., 2006; van Brakel, 2003).

The impact of stigma on the psychosocial life of its sufferer is multifarious. First, it makes a person feel shame or fear, which leads to anxiety and depression, amounting to reduced social participation, isolation, and exclusion (Rafferty, 2005). Stigma may make a person conceal their disease and not seek treatment early. By the time they get diagnosed, visible and irreversible deformities will have developed, further reinforcing their stigma (Heijnders, 2004). Given the interplay between stigma and physical deformities, proper self-care plays a critical role in breaking this vicious cycle of stigma in the lives of people affected by leprosy.

1.2.4.3 Leprosy-Related Stigma in Nigeria

Leprosy stigma continues to be a significant concern in Nigeria despite reductions in the trend of new cases detected. Health education and socioeconomic rehabilitation are Nigeria's main strategies to combat leprosy-related stigma (Ebenso et al., 2007). Despite these interventions, leprosy patients still face significant barriers due to stigma (Ebenso et al., 2007). For instance, there are reports of leprosy patients who lost their jobs. Others reported being barred from taking part in family and community events (e.g., birthdays, naming ceremonies and weddings). Leprosy patients have also reportedly encountered various obstacles while trying to access

community resources such as schools, clinics, water points, and places of religious worship (Ebenso et al., 2007).

In a recent study conducted in Northern Nigeria, Dahiru et al. (2022) identified four primary causes of stigmatisation among persons affected by leprosy. These include perceived poor personal hygiene of those affected; fear of infection; fear of disability and deformity; and local beliefs and misconceptions about leprosy (such as the notion that leprosy is hereditary, incurable, or highly infectious) (Dahiru et al., 2022). These causes illustrate how challenging it may be to recognise and address leprosy-related stigma in a country with a diverse socio-cultural population like Nigeria.

1.2.5 Self-Care in Chronic Conditions

A general lack of consensus exists in the definition of self-care in chronic conditions (Hoy et al., 2007; Ryan and Sawin, 2009). Self-management, self-treatment and adherence are often interchangeable and usually not clearly defined (Riegel and Dickson, 2008). For this study, self-care is defined as actions individuals *"take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents"* (Barlow et al., 2002, p. 177). Barlow et al. (2002) created this definition of self-care in the context of primary health and in relation to the self-management of diabetes, asthma, and arthritis. However, it has since been widely used in numerous additional chronic disorders. This definition is adopted because it provides a holistic approach, views self-care beyond just meeting physical needs, and addresses the social, emotional, and psychological challenges faced by people affected by leprosy.

The prevalence of people who live with various chronic conditions such as diabetes, heart disease and arthritis, has increased. This increase in prevalence of chronic condition is driven by unhealthy lifestyle, poor physical environment, unplanned urbanization, and social change (World Health Organisation, 2010b). In addition, there is a growing scarcity of service providers globally (Dey, et al, 2012). With this development, chronic conditions are now a key focus of health systems (Dowrick et al., 2005). To sustain patients' freedom and quality of life for extended periods of time, more focus has been placed on methods for managing chronic conditions. Hence, the paradigm for managing chronic conditions is changing from the conventional provider-patient approach to one in which patients with chronic disorders are actively involved in directing their own treatment in collaboration with healthcare professionals (Holman and Lorig, 2000; Bodenheimer et al., 2002).

While being unique in their presentation, several chronic conditions, such as arthritis, diabetes, and heart disease, share common challenges in managing them. These include engaging in effective interactions with health care providers; adjusting to the psychological and social demands, including complex lifestyle adjustments; maintaining proper levels of nutrition, diet, and exercise; managing complex medication regimens; monitoring physical indicators; and dealing with symptoms and disability (Wagner et al., 2001). The field of self-care is thus concerned with identifying and delineating common patient-centred approaches to addressing these challenges (Barlow et al., 2002; Swendeman et al., 2009). Irrespective of the chronic condition, the deployment of a standard set of skills has been shown to improve health outcomes and effectively manage their illnesses (Lorig et al., 1999)

1.2.6 Leprosy Self-care Programme in Nigeria

Leprosy self-care in Nigeria is currently implemented under the Prevention of Disability intervention of the National Tuberculosis and Leprosy Control Programme (NTBLCP) and remains a strategic focus of the programme (Federal Ministry of Health, 2010). The NTBLCP is primarily responsible for developing policies concerning leprosy self-care in Nigeria.

Self-care practice in leprosy is lifelong and involves caring daily for the eyes, hands, and feet at home (International Federation of Anti-Leprosy Associations, 2006; World Health Organisation, 2009). After practising self-care at home, people affected by leprosy meet in groups on agreed dates, at least three to four times weekly, to support and monitor each other's progress. Self-care group sessions are often held in open, public, and easy-to-access venues, e.g., under a tree in the middle of the village and constructed shed. Easily accessible venues encourage and challenge others to adopt the practice of self-care.

Table 1.1: Self-care practice for people affected by leprosy

	Self-Care Practice
Eyes	<ul style="list-style-type: none">• Check both eyes daily for redness and keep them moist by deliberately blinking frequently.• During the day, wear hats and sunglasses to protect the eyes from dust and other foreign bodies.• At night, wear eye shields to prevent the eyes from dryness and foreign bodies from entering the eyes.
Hands and Feet	<ul style="list-style-type: none">• Inspect the hands and feet daily for signs of injury.

	<ul style="list-style-type: none">• Soak hands and feet in water for about 30 minutes, smoothen hands and feet with a rough stone to remove callus, and oil hands and feet to prevent the skin from drying out.• Cover open wounds with a clean cloth and rest the limbs to facilitate healing.• Wear assistive and protective devices to aid function, protect from injury and promote healing.
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(Source: Netherlands Leprosy Relief, 2007)

A typical self-care group consist of eight to twelve members. Its membership is voluntary and open to persons affected by leprosy with visible or non-visible deformities of the hands, eyes or feet. The self-care group's overall objective is to assist people affected by leprosy in identifying methods that improve their physical well-being; prevent and manage visible deformities (Netherlands Leprosy Relief, 2007). During group meetings and caring for themselves, members are encouraged to talk about self-care, provide emotional and psychological support, and are trained to identify complications and make appropriate referrals.

Each self-care group comprises a group coordinator, facilitator, leader, and group members. The self-care group coordinator is a government or non-government healthcare worker (HCW), usually from the NTBLCP or development partner, who is experienced in the Prevention of Disability interventions and is responsible for providing self-care training. The self-care group coordinator assists in collecting baseline disability data of group members and monitors group functions. The self-care group facilitator is usually a community member, who does not have

leprosy, and volunteers to assist self-care group members in finding solutions to challenges they face in carrying out self-care. For example, self-care group facilitators ensure an appropriate venue is provided within the community for group activities. The group leader is always a person affected by leprosy and is appointed by the group. They assist members in organising group meetings, keeping attendance records, and leading group meetings. Their task also includes stimulating active participation in group activities; and encouraging individual group members to attend group meetings and continue self-care at home (Netherlands Leprosy Relief, 2007).

1.3 Relevance of the Study

Proper implementation of leprosy self-care practice reduces the number and severity of ulcers (Benbow and Tamiru, 2001; Chakraborty et al., 2006) and increases the self-confidence and emotional support of the affected people (Darlong, 2021). Proper self-care implementation also improves individual members' physical health and general condition (Ebenso et al., 2009). Despite the effectiveness of leprosy self-care and recommendations from the International Federation of Anti-leprosy Associations (ILEP) and WHO, self-care uptake and implementation has been sub-optimal as several self-care interventions implemented through national government leprosy programmes have not been sustainable (van Brakel et al., 2010). This situation is particularly worse in low-income countries. Also, recent studies in the leprosy field called for further research *"Identifying effective and feasible strategies for self-care programmes in low endemic areas"* (Khazai et al., 2019, p. 17). Besides, no study in Nigeria focused on identifying the factors that influence the engagement of people affected by leprosy in their self-care practice, hence the need for this study. This dearth of research on leprosy self-care in

Nigeria may not be unconnected to the generally weak culture of research in this part of the world (Odia and Omofonmwan, 2013).

Proper leprosy self-care practice empowers people affected by leprosy to improve their physical, mental, psychological, and emotional well-being (Deepak et al., 2013; Tsutsumi, 2004). It is led and sustained by the active involvement of people affected by leprosy. This intervention's importance underscores the need to understand the factors that would promote or hinder self-care among people affected by leprosy in Nigeria. Understanding these factors would provide the NTBLCP with relevant evidence to enhance self-care research, improve policy, and scale-up self-care interventions in the country. It will also provide data to facilitate future interventions to develop and expand self-care for people suffering from physical disabilities due to other NTDs.

1.4 My Interest in the Phenomenon

As a health professional, I have promoted leprosy self-care across Nigeria for about two decades. My interest in leprosy began during my community medicine experience while training for a medical degree and visiting a leprosy community, Ekpene Obom, in Akwa Ibom State, Nigeria. Later, I joined The Leprosy Mission-Nigeria and was seconded to Zamfara State Ministry of Health as the State Programme Manager for Leprosy and Tuberculosis Control. I had responsibility for providing medical and managerial support for leprosy control in the State; this included designing interventions for the prevention and management of leprosy disabilities, including facilitation and support to self-care groups.

After four years, I was promoted to Medical Advisor of The Leprosy Mission-Nigeria (The Leprosy Mission-Nigeria). I carried out supervisory visits to several State Leprosy Control Programmes to track self-care implementation among people affected by leprosy. During these visits, I observed many physical, emotional, and economic challenges people affected by leprosy face in implementing self-care. In addition, I found no research on the factors influencing self-care practice among people affected by leprosy in Nigeria. These observations prompted this research as I believe if these factors are understood, interventions can be targeted to maximise self-care benefits.

1.5 Study Overview

This section provides the study overview. It includes a brief description of the methodological and theoretical approaches adopted in this study and the structure of the thesis.

1.5.1 Theoretical Positioning

This study adapted constructs from SPT (Shove et al., 2012) to understand self-care practices among people affected by leprosy. The SPT moves away from applying behavioural and rational choice as the driver of human action and elevates the dynamic interaction of three core elements – 'competences,' 'meanings,' and 'materials' as central to the initiation and sustenance of practices. Thus, this study viewed self-care as a health practice rather than behaviour by applying SPT. This approach enabled profound insights into how leprosy self-care practice can be sustained. SPT is explored in more detail in Chapter 2.

1.5.2 Methodological Approach

This qualitative exploratory research sought an in-depth account of how people affected by leprosy practice self-care. It applies hermeneutic phenomenology to explore how people affected by leprosy experience self-care and the factors that influence their practice (Armour et al., 2009). This research moves away from the dominant behavioural paradigm and adopts SPT, as Shove et al. (2012) proposed.

1.5.3 Thesis Structure

- Chapter One articulates the study background and justifies the research. It presents the structure of the study and contains a brief synopsis of each Chapter.
- Chapter Two provides an overview of practice theories and distinguishes between behaviour and practice theories. It highlights the choice of SPT and how it relates to leprosy self-care practice. It proceeds to describe the following concepts of SPT: core elements, the interconnectedness of practices, and the influence of time and space on practices. The Chapter ends by discussing approaches to designing policy initiatives using SPT.
- Chapter Three reviews the literature on leprosy self-care and attempts to organise and discuss the various themes identified around the three core elements of SPT as follows: 'Meanings' (level of adherence to self-care of people affected by leprosy; self-efficacy and perceived importance of self-care; social support, including family and peer support); 'Materials' (availability of self-care materials); and 'competences' (knowledge, training

and skills in self-care; and health care provider support). Finally, the Chapter ends by identifying the theoretical gaps in this study.

- The fourth Chapter introduces hermeneutic phenomenology and its application in the research. It addresses research ethics concerning the study and the data collection methods adopted (semi-structured interviews). The Chapter also discusses the steps applied in the thematic analysis process and elaborates on the approaches adopted to ensure research trustworthiness and rigour.
- Chapter Five presents the findings of the data analysis. It begins by identifying factors that influence leprosy self-care and attempts to structure them under the three core elements of SPT, 'competence,' 'meanings,' and 'materials' (Shove et al., 2012). The factors include self-care knowledge and skills, health system (competence); belief; self-efficacy; prioritisation of self-care; social support; perceived importance of self-care (meanings), and resources (materials). It then identifies other practices that could compete with self-care (e.g., begging) and those that facilitate it (e.g., ablution).
- Chapter Six discusses and synthesises the results of this research in relation to the literature. The Chapter reveals that the factors that influence leprosy self-care interact at various levels and occur in a continuum, explaining the interplay in daily routines and evolution in leprosy self-care practice.

- Finally, Chapter Seven summarises how the study aims and objectives were achieved. Next, it discusses the reflexive considerations for this study. Next, it revisits the empirical contributions of the research to knowledge and its implications for practice and policy in the domain of leprosy self-care. Finally, it highlights the study's limitations and proposes recommendations for further research.

1.6 Chapter Summary

Leprosy-related disabilities and their attendant stigma and discrimination continue to pose a significant public health challenge globally, and in Nigeria, to address this challenge, leprosy self-care is required (Wilder-Smith and van Brakel, 2008). However, evidence from the literature shows that although proper implementation of leprosy self-care practices has several beneficial effects, its implementation and uptake at the country level, including Nigeria, has remained sub-optimal and unsustainable. Also, the factors influencing leprosy self-care practice are not clearly understood. This is the first time a study exploring these factors through SPT will be conducted in Nigeria. Applying an SPT lens envisaged that the knowledge of factors influencing leprosy self-care practice would be deepened. Also, inconsistencies in the practice of leprosy self-care among people affected by leprosy would be better explained; new approaches and policies encouraging uptake, scale-up, and sustainability of leprosy self-care practice would be developed.

CHAPTER 2

Social Practice Theory

2.1 Introduction

This Chapter introduces SPT as the theoretical underpinning of this study. It demonstrates its utility for exploring leprosy self-care practice by considering its three core elements ('meanings', 'competences', and 'materials') and how their interaction and interconnectedness could produce and sustain leprosy self-care practice. SPT has never been used in leprosy research. As such, its application in this study is novel. It provides an opportunity to radically reconceptualise how the ongoing leprosy self-care programme is organised and implemented across Nigeria and globally.

2.2 Practice Theories – 'Beyond Behaviour'

This thesis explores SPT's role in providing new insight and practical application to improving policy and practice in self-care, particularly leprosy self-care. Practice theories have been successfully applied in other fields, for example, in education (Kemmis et al., 2004), transport (Spurling and McMeeking, 2015; Spotswood et al., 2015), and organisational studies (Gherardi, 2000). They have also been very influential in sustainable consumption and have contributed significantly to the debates around climate change (Welch, 2016; Hargreaves, 2011). In principle, practice theories could be applied in any field of interest and, in recent times, have been used in public health policy (Blue et al., 2016).

In the last few decades, most public health and research interventions, including leprosy self-care, concentrated on convincing individuals to modify their behaviour to minimise their chances

of developing these 'lifestyle' conditions. On the face of it, this approach would seem appropriate since the underlying cause of these 'lifestyle' diseases is related to what people do and the details of how they live daily. However, while remote behaviours are easily understood and accepted ways of life, routines and habits are difficult to change. Achieving behaviour change has been particularly challenging and has triggered a deluge of propositions, arguments, and a series of evaluations, experiments, tools, approaches, and methods.

Theory of Planned Behaviour (Ajzen, 2011); The health belief model (Becker, 1974; Sharma and Romas, 2012); Social cognitive theory (Bandura, 1986); Information Motivation and Behavior theory (Fisher and Fisher, 1992); and The Transtheoretical Model (Prochaska, 1983; Prochaska et al., 1992) are some of the most widely cited and applied behaviour change theories in leprosy self-care. Although varied in their philosophies, most behaviour change theories assume that individuals can make rational choices based on available information. Consequently, their health and well-being are primarily determined by their actions, preferences, and decisions. This position has been critiqued by Thompson and Kumar (2011); and Ioannou (2005), who argue that behaviour theories often fail to consider contextual factors. The Nudge theory has also been heavily critiqued, asserting that individuals usually respond automatically to their environments and are only partially calculators and rational assessors of information (Marteau et al., 2011).

Other criticisms of behavioural approaches include their inconsistency in replicating the effects of interventions (Johnson et al., 2010); their inability to take into consideration the scope of the impact across a wide range of outcomes, and their lack of anticipation of unintended results or

unanticipated consequences (Moore et al., 2015; Thomson et al., 2014). Besides the limitations of behavioural approaches as a predictive framework, behavioural approaches suggest that ill health is often based on individuals' flawed decision-making. Despite these limitations, it is interesting that some scholars still call for using behavioural theories to design and implement leprosy self-care interventions (Choudhury et al., 2021).

Self-care for leprosy is lifelong; hence, it requires carrying out specific daily activities to prevent leprosy-related disabilities and manage them where they occur (Netherlands Leprosy Relief, 2007). This thesis highlights the practical and potential importance of a substitute social theoretical model. SPT identifies the modelling of everyday life (and related impact on health) as a consequence of the synchronisation and coordination of social practices that continue over time and space and are transformed and reproduced by individuals who 'carry' them (Reckwitz, 2002; Schatzki, 2002). This thesis argues that self-care policies would better emphasise the 'lives' of social practices, making social practices sites of intervention and analysis topics. Also, this thesis's basic assumption is that individuals' well-being and health patterns are informed and influenced by the practices they carry out. This proposition is with the understanding that practices are not synonymous with individual behaviour.

While this is the first study to apply SPT in leprosy self-care, other examples exist in public health where SPT has been used in other lifestyle studies. For instance, it has been applied to critique food safety practices (Meah, 2014) and food waste (Milne, 2011; Evans, 2011). In these empirical studies, associated risks were viewed as the responsibility of the individual consumer.

Other scholars have made similar points that emphasise the importance of Bourdieu's concepts of practice and habitus for well-being and health or highlight Giddens' structuration theory's relevance in appreciating and addressing the difference between agency and structure. This thesis's distinctive contribution is applying SPT (Shove et al., 2012) in the self-care domain, particularly leprosy self-care while exploring the factors that influence its practice. As this thesis shows, emphasis on the dynamics of social practices unearthed relationships and processes may not be apparent when approached from behavioural theories and models or the perspective of macro phenomena (e.g., social determinants of health or structures of inequality). In adopting a social practice approach, this thesis asks for a radical reconceptualisation of how leprosy self-care is currently organised and implemented in Nigeria and globally.

2.3 Social Practice Theory

Some early proponents of practice theories include Marx, Wittgenstein, Foucault, Bourdieu, and Giddens (Reckwitz, 2002). Although practice theories differ in ambition and orientation, they share a common theme: they are regarded as the site for social change and order. Consequently, analysis and interest are focused on the contemporary characteristics and history of daily practices – common examples include smoking, watching television, swimming, commuting, or eating dinner. Researchers interested in analysing and understanding the core of practices emphasise several related features. "*By nature, practices are social as they are always shared. They persist across time and space*" (Giddens 1984, p.2) and are never completely static. Practices materialise, sustain, transform and vanish. They interrelate and could combine to form more complex bundles (Schatzki, 1996). These central notions give rise to more specific suggestions that help frame how practices are constituted and evolve.

In deciding which model of Social Practice theory to adopt for this study, consideration was given to the model described by the social theorist Pierre Bourdieu. Bourdieu's model comprises three conceptual elements, field, habitus, and capital, which interact to determine the action of a person (Bourdieu, 1977). The field represents the space within which practices occur; habitus relates to the individual's skills, social tendencies, and disposition, while capital describes the individual's cultural or economic resources (Bourdieu, 1977). Unfortunately, Bourdieu's model was not applied because it was considered a bit old and not commonly applied in health.

The other consideration was the model described by Reckwitz, which comprised seven elements of practice. These include agent, structure, language, knowledge, things, mind, and body (Reckwitz, 2002). Reckwitz (2002) defined the SPT approach as an alternative concept that places 'practices' as the focus of analysis, as a *"form of bodily activities, mental activities, 'things' and their use, a background knowledge in the form of understanding, know-how, states of emotion and motivational knowledge"* (Reckwitz 2002, p. 250). Consequently, a practice is a *"pattern which can be filled out by a multitude of single and often unique actions reproducing that practice"* (Reckwitz 2002, p. 250). A practice was demonstrated by Reckwitz (2002) using the example of consumption, which results from several actions and activities that are carried out daily. Thus, SPT seeks to understand what people do every day, i.e., their actions and behaviour and *"how a certain nexus or interconnection of these actions, behaviours, and routines – practices – affects the way a social activity is undertaken in a specific place and time"* (Reckwitz 2002, p. 258). Although more recent than Bourdieu's model, Reckwitz's model was not applied in this study because it was cumbersome and complicated.

Table 2.1: Comparison of Social Practice Elements

Brief Explanation	SPT Elements (Reckwitz, 2002)	SPT Elements (Shove et al., 2012)	Brief Explanation
Ways of wanting, feeling, avoiding unwanted things; motivational knowledge	Knowledge	Meanings	Symbolic and social participation at any one moment
Social relations between body, mind, and objects	Things		
Mental activities (desiring something, understanding the world, knowing what to do)	Mind	Materials	Objects, infrastructure, tools, and the body itself
Bodily performances and emotional activities	Body		
Carriers of practice depending on past experiences; use of know-how as	Agent	Competences	Multiple forms of knowledgeability; knowing in the sense of having the skills

motivational knowledge			required to perform (deliberately cultivated skills)
A structured set of routines (temporality, repetition, and social reproduction)	Structure/process		
It exists only in its routinised use.	Language/discourse		

(Source: Shove et al. 2012; and Reckwitz 2002)

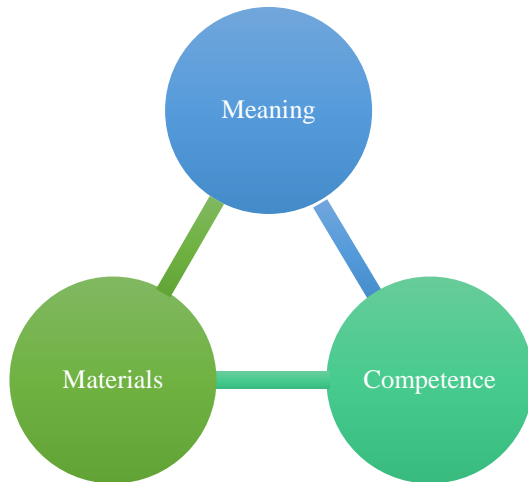
Although they share similar ontological and epistemological perspectives, Shove et al.'s (2012) reconceptualisation of SPT theory differs from that of Reckwitz concerning categorising the core elements. First, Shove et al. view practices through three core elements: 'meanings,' 'materials,' and 'competences' to appreciate why people act in specific ways every day. Secondly, to understand how social practices change or sustain, Shove et al. (2012) argue that ongoing practices should be examined concerning co-occurring practices. Since Shove et al.'s (2012) reframing of SPT is more recent and heavily influenced by the work of Reckwitz, it is chosen as the theoretical framework for this study. Shove et al.'s approach is practical, concise, empirically sound, and less complicated and is most helpful when exploring behaviour change issues (Maller and Strengers 2013, Spurling et al. 2013). Shove et al.'s (2012) approach has been applied in this thesis to examine leprosy self-care practice elements to improve its implementation, scale-up, and sustainability.

According to Shove et al. (2012), social practices interrelate; in certain circumstances, they compete for resources, including energy and time. However, they can also sustain and support each other (e.g., eating and cooking) and consequently form complex bundles or systems that take on a life of their own. Furthermore, Shove et al. (2012) argue that the persistence and survival of practices depend on recruiting and retaining people ('practitioners') who sustain and ensure the practice's ongoing transformation. Certain practices find it easy to recruit 'practitioners'; others struggle and lose out. Leprosy self-care could belong to the latter category as its scale-up has been suboptimal, hence the need for this study. Finally, Shove et al.'s (2012) approach argues that people are vital to the initiation, recruitment, and ongoing transformation of practices. This point is essential to mention as critiques of SPT often argue that focusing on practices as the unit of analysis means people are likely to be relegated to the background. However, it is not the case as people are integral to practices, and if people do not re-enact a practice, it will not be sustained.

2.3.1 Core Elements of Social Practice Theory

According to Shove et al. (2012), practices result from an ongoing, dynamic integration of three core elements, 'meaning,' 'materials', and 'competences.' In the context of leprosy self-care, 'materials' are taken as tools, objects, and things required for self-care. 'Competences' relates to having the requisite skills needed to carry out self-care activities, and 'meanings' is construed through aspiration, ideas or visions of the importance of participating in self-care activities and the value placed on self-care. These core elements of SPT and their significance in this research are described briefly in the following sections.

Figure 2.1: Social Practice Theory



Meanings: symbolic meanings, ideas, and aspirations.

Materials: including things, technologies, tangible physical entities, and the stuff of which objects are made.

Competences: which encompass skill, know-how, and technique.

(Source: Shove et al., 2012, p.14)

2.3.1.1 Meanings

Meanings are socially shared ideas or concepts associated with the practice that gives meaning to it; reasons to engage in it. Reckwitz (2002) posited that motivational knowledge, emotion, and mental activities could portray the meaning of practices through the symbolic and social significance of the practice at every given time. The theorisation of future and past of meaning, motivation, and emotion by Schatzki (1996) was condensed by Shove et al. (2012) by adding "*symbolic meanings, ideas and aspirations*" clustered as meaning (Shove et al., 2012, p.14). To understand these terms, Schatzki (1996) applied the term 'teleoaffective structures,' which includes tasks, beliefs, purposes, moods, and emotions as critical considerations to planning, situating, and implementing social practices within a designated setting or 'time-space.' This relatively new concept of 'teleoaffective structures' is further elaborated by Shove et al. (2012) by

arguing that practices usually have a history or previous account and a context or setting. The authors draw from the term *time-space*, advanced by Shatzki (1996), which brings to the fore the significance of history and setting as practices are enacted. In this study, the importance of 'meanings' as an element of leprosy self-care practice is to explore why self-care practice is not normalised, valued or sustained by people affected by leprosy.

2.3.1.2 Materials

One of the processes in SPT is to explore the linkages between the core elements of practice. Materials refer to tangible and physical components used in practice. Understanding how people relate to materials or objects is directly connected to the role of 'things' (Knorr-Cetina et al., 2000). Taking this idea forward, Gherardi (2009) argues that 'materialised knowledge' represents objects and materiality related to people and even probes them. According to Røpke (2009), it is generally agreed among practice scholars and theorists that objects and things are part of the core elements of practice. These are explored in this research. The materials used in leprosy self-care include water and soap for washing and soaking hands and feet; lubricants and oils for lubricating affected limbs; and all kinds of assistive and protective devices to aid mobility and function; including the physical space used for carrying out self-care practice.

2.3.1.3 Competences

Shove *et al.*'s (2012) idea of skills represents competences, know-how, and techniques required for the practice. It is a sense of understanding and knowing, being conscious of one's abilities and skills necessary for participation in the practice, for example, through the skills needed to implement leprosy self-care. This study includes knowing when, where, and how to carry out

leprosy self-care practice. For example, learning to carry out blinking exercises moistens and protects the cornea (Kim et al., 2021).

In summary, SPT envisages that practices are connoted by interdependent relationships and linkage between respective core elements –meaning, material, and competence/skills. Also, SPT argues that the sustainability of practices is partly dependent on how much these elements and their interaction is understood and ensured. Other vital concepts associated with social practices are discussed in the following sections. These include 'carriers' of practices, inter-connectedness of practices, practices as entities and performances, and the relationship between time, space, and practices.

2.4 Individuals as Carriers of Practices

A key feature of practices is their ability to persist, reproduce, and even transform over time. Furthermore, this depends on how they can attract and retain cohorts of people, also known as 'practitioners' or 'carriers,' who carry out such a practice (Shove et al., 2012). According to Reckwitz (2002. p. 250), a practitioner is *"a carrier of practice who carries certain routinised ways of understanding, knowing-how and desiring, as well as many different practices which need to be coordinated with one another."* While some practices easily attract new adherents, carriers, and practitioners, others find it challenging to retain their recruits.

According to Shove et al. (2012), practitioners are individuals who participate in practices irrespective of their power, competence, or skill. Individuals' participation in practices plays a role in how practitioners as carriers avoid, want, desire, know and understand practices.

Consequently, the level of involvement in a given practice is a valuable indicator of the meaning a practitioner attaches to a particular practice. For example, this study's relevance relates to the level of implementation and adherence to self-care practice. The symbolic and social importance of practices, i.e., '*meanings*,' greatly determines the impact of practices in the lives of people (Shove et al., 2012).

Expectedly, participation relates to the various opportunities available for people to engage or not to engage in a practice; hence, past experiences with a practice are critical in addressing issues relating to access and participation in a practice. Furthermore, the uptake and discontinuation of practices are continually occurring in the lives of individuals. Therefore, a fundamental assumption in SPT is that practitioners' role as carriers greatly determines where practices are produced, the consistency with which they are produced, and how they are sustained because people have agency. Also, through the enactment of the practice, the practice itself evolves and is therefore defined (Shove et al., 2012). Bear in mind that the focus of SPT is not on individual behaviour, as its enactment could be related to self-efficacy. In essence, human agents are the practitioners that implement practices; practices are shaped by their personal beliefs, values, and contexts, influencing how practices are carried out, sustained, or discontinued. Hence, this study seeks to answer some critical questions: How do people affected by leprosy become carriers of self-care practice? Why and how do some people affected by leprosy discontinue self-care practice? What are the factors that influence self-care practice?

2.5 Interconnectedness of Practices

Shove et al. (2012) further argue that a continuous relationship and interconnection exist among different social practices. Hence, practices do not exist in isolation. Sometimes they sustain and support each other (e.g., dancing depends on playing music), and in other instances, they compete for resources (e.g., materials, energy, and time). These interactions between practices lead to complex systems that grow into a life of their own.

To understand how practices are interlinked and influence each other, Shove et al. (2012) highlighted three scenarios: the first scenario is one in which existing practices are not integrated, mainly because their elements do not compete, e.g., leprosy self-care and watching television. People use different skills in watching television from those required for their self-care. In the second scenario, practices are interlinked, depend on, or facilitated. Hence, there could be interdependence or co-occurrence because they share common materials, e.g., the practice of bathing and swimming. After all, both practices cannot be accomplished without water availability. In the third scenario, there is a broken relationship between practices. Such practices are threatened and unsustainable, e.g., using electric cars instead of those powered by fossil fuel. The connection between practices might appear obvious because we live in a co-dependent world. Shove et al. (2012, p. 84) observe that practices "*can and do coexist and co-depend in ways their practitioner-carrier barely recognises.*"

According to Shove et al. (2012), they become connected when practices share certain elements. However, when they compete for specific elements, their connection is broken, and they could cease to exist. The notion that the enactment of practices depends on another practice's existence

underpins this. Hence, some practices produce elements that other practices require. This interaction implies dependence and further collaboration. In essence, practices can become so connected that they create new groups or bundles of practices (Schatzki, 2002). According to Schatzki (2002), these connections could be harmonious or conflicting. In other words, some practices can be so intricately linked and interdependent while others might be incompatible. Given this, critically observing how new groups or bundles of practices co-evolve could provide an opportunity for intervening by weakening or strengthening the links between them.

2.6 Practices as Entities and Practices as Performances

In applying practice theories, the change process could occur at two points. The first point is when practices (e.g., cooking) are considered entities, and the second is when they are considered performances. According to Reckwitz (2002), practice as entities is informed by the many interrelated elements that make up the practice (e.g., practical cooking skills, utensils, food items and a kitchen). These elements' configuration determines how practices are recognised and how they are conducted. Practices also exist as performances: A practice is only meaningful through its enactment, reproduction, or modification. In this context, leprosy self-care as an entity is only meaningful through its 'doing.' It is only through its enactment or performance that it 'lives'. This notion of 'doing' practices lends further credence to this research's relevance, which seeks to identify factors that inhibit leprosy self-care practices' uptake and sustainability. This repetitive interface (between entity and performance) is where the dynamics of change and reproduction exist. Hence, in considering practices as entities or performances, interventions can be viewed as 'macro', 'meso,' or 'micro-level concepts Reckwitz, (2002). Actions at the 'macro-level involve changes to policies, systems, and structures. Activities at the 'meso' level involve

changes at the family or group level, while actions at the 'micro' level include changes at the individual level. In discussing the findings and highlighting the implications of this study, in Chapters Six and Seven, reference is made to these three levels of interventions.

Alternatively, change can occur when re-arranging the elements that constitute a practice: a shift in how these elements are ordered could lead to a change in how practices are carried out. Alternatively, the reproduction of practices (as recognisable entities) depends on practitioners' continuous enactment or 'doing' of the practice in specific ways and weaving together the different elements that constitute the practice as they live daily. For instance: *"[i]n washing clothes every day, people keep a specific formulation of laundering alive [...] Daily laundering becomes normal, but only so long as sufficient numbers of carriers continue to reproduce it in this fashion."* (Shove 2010, p. 1279). As such, practitioners can be regarded as the 'carriers' of the practice. However, while practices are often carried out faithfully and consistently (habitually and routinely) across time and space (and so reproduced), practitioners may *"adapt, improvise and experiment" with ways of doing and, therefore, the performance of practices also 'contains the seeds of constant change'* (Warde 2005, p. 141). Through 'doings' (performances), practices as entities are altered, reproduced and improved.

2.7 Time, Space, and Practices

Social practices also change over time. Shove et al. (2012) depict this change by describing the trajectories of change to explain how certain practices have evolved with time, particularly in response to changes in materials and how society has equally adjusted in line with this trajectory. The usefulness of analysis of the trajectories of practices lies in the lesson history has in store.

Lessons can be learned from why the meaning of practice has changed over time and the new skills and competencies required to carry out the practice. Consequently, how the practice has changed and sustained over time or discontinued is essential in understanding its history and evolution.

Spaces influence relations between practices in different ways. According to Shove *et al.* (2012), spaces such as homes and self-care meeting venues can lead to "*emergent consequences for the trajectories of individual practices and, hence for the collection of practices that are, and that are not, enacted in such environments*" (p.85). The relevance of space is reflected in exploring how leprosy self-care practices differ at home or in self-care groups or how self-care venues' location and nature impact self-care practice.

2.8 Approaches to Designing Policy Initiatives using Social Practice Theory

The core elements of SPT, 'competences,' 'meanings,' and materials (Shove et al., 2012) inspired Spurling et al. (2013) to propose three approaches to designing policy initiatives using social practice. These include: 'recrafting practices', 'substituting practices', and 'changing how practices interlock.' These approaches are proposed as alternatives to behaviour theory model approaches. Concerning 'recrafting practices,' one or more of the components of the core elements of SPT are changed. For example, when conducting training to improve competences such as leprosy self-care training, implementing health education or social marketing that seeks to address meanings. According to Spurling et al. (2013), this approach's innovation relates to how the beginning of such initiatives links to the dynamic interconnectedness of the meanings, competencies, and materials that make up the practice.

The second approach relates to promoting more sustainable alternatives to a practice, replacing them with new practices, or minimising competing practices. This approach tasks policymakers to reflect on how different practices can achieve the same purpose as the initial practice and how other practices could compete for resources, space, and time, including how practices that are dependent on each other might develop together in a particular path or trajectory (Spurling et al., 2013). A good example is driving and cycling, which compete for the same resources, including budgetary allocations for infrastructure, space on the road and commitment of commuters (Watson, 2012). So, for more people to commute by cycling, a social practice approach could mean changing the meanings associated with cycling (e.g., from associations of poverty to fitness), ensuring more people know how to cycle and access bicycles.

The third model is based on the interconnectedness of practices and the identification of how this can be explored. According to Spurling et al. (2015, p. 5), this depends mainly on aiming for *"change in the complex interaction between practices."* Practices intersect and interconnect in temporal, spatial, material (infrastructural), and institutional dimensions. Also, Spurling et al. (2013) identify how practices intersect through synchronisation and sequencing. An example of sequential ordering is food provision, which might take the following sequence: shopping, storing, cooking, and eating. On the other hand, synchronisation might involve mealtimes when people eat together. Research shows how changes in mealtime patterns resulted in changes in entire household working schedules (Southerton et al., 2011).

Finally, Spurling et al. (2013) argue that interventions are highly likely to stimulate a ripple effect through interlinked elements and practices because social practices are generally interconnected. Thus, practice theorist argues that a social practice perspective typically facilitates a more robust understanding of these effects and outcomes than approaches based on behaviour theories. Hence, it may offer new insights and provide a more holistic experience of conventional behaviour initiatives' effectiveness than those found in the 'portfolio' model of behaviour theories. The notion of interconnected practices is crucial for this research because applying SPT would ensure that people affected by leprosy have the requisite skills/competence for self-care. It will also ensure uninterrupted access to all materials required for self-care; and that people affected by leprosy are adequately motivated to implement self-care. Also, it provides consideration to identify which other practices could inhibit or facilitate self-care and ways to either promote or address these.

2.9 Chapter Summary

The Chapter aims to advance the central ideas and thoughts within SPT described by Shove et al. (2012) and how it relates to leprosy self-care. The research is novel as it moves away from the dominant behavioural paradigm that influences most public health research and adopts SPT to explore self-care practices among people affected by leprosy. Accordingly, this research suggests a shift from self-care as a behaviour to viewing it as a social practice. It is envisaged that the application of SPT would generate new insights about leprosy self-care practice; clarify inconsistencies in the practice of leprosy self-care; and encourage uptake, scale-up, and sustainability of leprosy self-care.

CHAPTER 3

Literature Review

3.1 Introduction

This Chapter examines relevant literature on self-care practice among people affected by leprosy. It explores and synthesises the evidence and knowledge base currently available on leprosy self-care and organises the emerging themes to align with the core elements of the SPT perspective. An integrative review was conducted and identified themes were organised around three core elements of SPT: 'Meanings' (level of adherence to self-care of people affected by leprosy; self-efficacy and perceived importance of self-care; social support, including family and peer support); 'Materials' (availability of self-care materials); and 'competences' (knowledge, training and skills in self-care; and health care provider support). In addition, although a scoping review on leprosy self-care was recently conducted (Ilozumba and Lilford, 2021), no systematic reviews and randomised control trials were found. Also, most studies were conducted from a behavioural theory perspective, and no study on leprosy self-care was conducted from an SPT perspective. The Chapter ends by summarising the conclusions of the literature review on leprosy self-care.

3.2 Literature search strategies

This integrative literature review aimed to synthesise the available research evidence on the engagement of people affected by leprosy in their self-care practice. The review focused on people affected by leprosy's perspectives and experiences concerning self-care and factors influencing their self-care practice. The studies included in this review were systematically reviewed and examined to highlight knowledge gaps in this area of interest.

3.2.1 Literature Review Question

- What are the facilitators and barriers influencing self-care practice among people affected by leprosy?

3.3 Design

An integrative review was conducted. Integrative reviews adopt a transparent and rigorous approach that allows researchers to critically study existing literature to identify actual results and learnings, which are then published. Also, it identifies gaps in extant literature (Arksey and O' Malley, 2005).

According to Russell (2005), an integrative review summarises past empirical and theoretical literature and comprehensively explains a health care problem or phenomenon. Integrative reviews allow for the literature of diverse methodologies to be included. Hence, in integrative review, experimental and non-experimental studies are included. It also applies data from empirical and theoretical literature (Evans and Pearson, 2001). When well-conducted, integrative reviews have direct applicability to policy and practice and contribute to theory review and development, the definition of concepts, and the analysis of methodological problems of a phenomenon (Russell, 2005).

The integrative review approach applied in this research is based on the method developed by Cooper (1982) and expounded by Whittemore and Knafl (2005). In line with this framework, the integrative literature review process comprises five stages: problem formulation; data collection; data evaluation; data analysis, data verification; and conclusion drawing based on the data analysed (Whittemore and Knafl, 2005).

3.3.1 Problem Formulation Stage.

Identifying the problem and outlining the variable of interest is necessary for successfully conducting an integrative review (Whittemore and Knafl, 2005). Here, specifying a research problem facilitates the easy and accurate operationalisation of variables and the extraction of appropriate data from primary studies. Besides, it provides clear outlines and limits for the review process (Whittemore and Knafl, 2005). This integrative review focused on the factors influencing self-care practices among persons affected by leprosy. Factors (enablers and barriers) influencing the engagement (involvement and participation) of people affected by leprosy in self-care practice and their experiences adapting to self-care were examined as outcomes of interest.

3.3.2 Data Collection.

Well-defined literature search strategies enhance rigour in integrative reviews (Cooper, 1982). Thus, a narrow and incomplete literature search will result in inaccurate results. Therefore, the researcher followed processes to mitigate this: developing and applying inclusion and exclusion criteria, conducting a literature search, and gathering the data set.

3.3.3 Literature Search

Electronic databases relevant to self-care in chronic conditions were searched: British Nursing Index (BNI); CINAHL; EMBASE; Web of Science; Medline; PsychINFO; and SCOPUS. The search strategy used the MeSH terms 'Leprosy', 'Hansen's Disease', linked to 'self-care', 'self-management'; 'self-treatment', 'home-care; 'self-care group', 'self-care practice' to identify the relevant articles on the experience and factors that influence the practices of self-care among

people affected by leprosy in terms of disability management. Each search category's results were subsequently combined using Boolean terms 'AND' and 'OR' to refine the search results.

The strategy adopted for the literature search and the key terms used are detailed in Appendix 1. A hand search of the reference and citation lists of all the included studies was also carried out. The hand search aimed to identify additional references relevant to the study. The database of other leprosy-focused journals such as Leprosy Review; Indian Journal of Leprosy, Asia Pacific Disability Rehabilitation Journal; and the International Journal of Leprosy and Other Mycobacterial Diseases were also searched.

3.3.4 Selection and Screening Process

3.3.4.1 Inclusion and Exclusion Criteria

Table 3.1: Inclusion and Exclusion Criteria

Criteria Type	Criteria Description
Inclusion criteria	<ul style="list-style-type: none"> • Studies describing self-care practice among people affected by leprosy at home or in self-care groups. • Studies reporting self-care of people affected by leprosy in adults whose ages were ≥ 18 years of age. • Studies published between 1988 - 2020. • Studies published in the English language. • Academic theses hand searched or retrieved via electronic databases.
Exclusion criteria	<ul style="list-style-type: none"> • Studies carried out that investigated the self-care of people affected by leprosy aged <18 years old.

- Studies in other languages, other than the English language.
- Papers published before 1988.
- Studies which did not include a research methodology.
- Non- academic theses grey literature.

(Source: Author)

Studies were included if they described self-care practice among people affected by leprosy at home or in self-care groups. Besides this study not being focused on children, FCT Ethical approval on research involving children is often bureaucratic and time consuming. Hence, only studies that report self-care of people affected by leprosy aged ≥ 18 years were included. Due to translation costs and time limitations, the review only included studies written and published in English. Because this is an integrative review, no limits were applied to the study design. The literature search was limited to a timeframe of 1988–2020. This timeframe was used because WHO recommended the implementation of self-care in leprosy by the year 1988, making it the official inception of self-care, by limiting the search to this period will help to maximise search results (World Health Organisation, 1988) fully. In order to enrich the study and minimise publication bias, some grey literature was included. However, only academic theses obtained from electronic databases or hand searching were included. Other grey literature was excluded.

Mendeley TM (a reference management system) was applied to screen, and selected articles and duplicate sources were removed. All titles and abstracts retrieved were screened, and all potentially relevant reports were selected to assess their eligibility. Full texts of all studies considered to be potentially relevant were retrieved. Titles and abstracts with insufficient

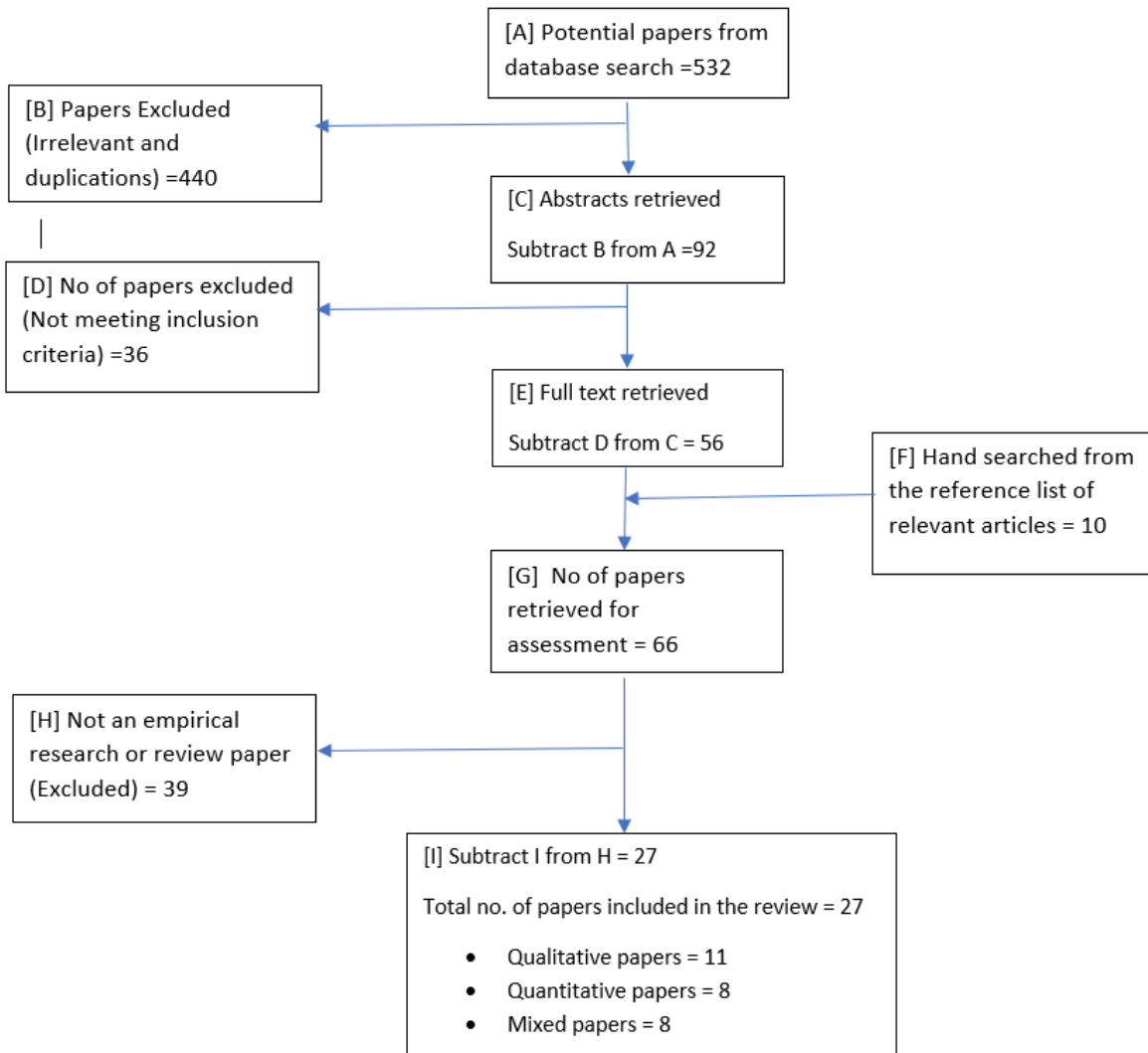
information had their full texts retrieved to ascertain their relevance or otherwise. The inclusion and exclusion criteria were applied to examine if the reports selected were eligible for inclusion in the review. Studies reporting on similar subjects were considered one study with their results stated under the primary reference. Only studies whose full text could be accessed were included.

The researcher conducted the selection and screening process alone, which could lead to a lack of consistency and poor error checking (Haddaway et al., 2015). However, this concern was mitigated by applying a validated framework for conducting integrative reviews developed by Whitemore and Knafl (2005). The provisions of this framework were religiously adhered to for each stage of the review thus ensuring comprehensiveness, procedural objectivity, and transparency of the review process. As part of the audit trail, the framework has been described in detail in this thesis. Finally, throughout the process, I was very reflexive and constantly referred to the purpose and objectives of the review.

3.4 Findings from the search

The flow diagram (Fig. 3.1) adapted from PRISMA (Moher et al., 2009) illustrates the search results.

Figure 3.1: PRISMA Flow Chart of Retrieved Studies



(Source: Author)

The search of the databases yielded 532 articles relevant to the research. Ninety-two abstracts were retrieved after 440 articles were removed due to duplications and irrelevance to the review.

After that, the abstracts were assessed, and 36 papers were dropped because they did not meet the inclusion criteria. Finally, the full text of 56 articles was retrieved, including ten additional articles identified from the relevant articles' reference lists, bringing the total articles assessed to 66. Out of the 66 articles considered, 39 studies which were neither empirical nor review papers were excluded. At the end of the process, 27 studies, including 11 quantitative, eight qualitative, and eight mixed-method studies, were included in this review.

3.5 Data Analysis Process

3.5.1 Appraisal of Data

The methodological quality of all papers selected in this study was assessed using the universal appraisal tool developed by Hawker et al. (2002). A universal appraisal tool ensures consistency and rigour in assessing papers in integrative reviews. However, Armijo-Olivo et al. (2015) argue that research findings and recommendations are likely to be inconsistent when diverse quality scoring systems and tools are applied for measuring methodological quality during an integrative review. Moreover, scholars have argued that evidence to support the reliability and validity of using tools of varying methodological quality for assessing studies in integrative reviews is ambivalent (Crowe and Sheppard, 2011).

The universal appraisal tool advanced by Hawker et al. (2002) assesses the quality of papers with mixed methodologies (qualitative, mixed-method, and quantitative). It considers studies across nine areas: (abstract and title; introduction and aims; method and data; sampling; data analysis; ethics; findings; transferability; and implication of the study). Each domain has four points and a minimum of one point. Four points mean very good, and one point means very poor. Thus,

according to Hawker's appraisal tool, the total score for a paper's quality is 36. A study was rated as high quality (A) if it had a total score of 30 and above; medium quality (B), 24–29 points; and low quality (C), 9–23 points (See Appendix 2 for Hawker's Assessment tool and the details of the output of the assessment in Appendix 3).

3.5.2 Data Reduction and Comparison

This literature review analysed the included articles in an evidence table (Appendix 4) under the following sections: author and year of publication, study aim and purpose; sample; study methods; and essential findings. Such an evidence table enhanced the visual presentation of relationships within and across data sources (Whittemore and Knafl, 2005). Also, constant evaluation of the similarities and differences between findings was done to clarify and define overlapping attributes and determine the relationships between themes. This continuous evaluation also facilitated concluding findings within the included studies and how these relate to other results (Sandelowski and Barroso, 2007). Data analysis in an integrative review requires ordering, categorising, and summarising data from primary sources, facilitating an integrated and cohesive conclusion on the research problem (Cooper, 1998).

3.5.3 Drawing Conclusions

Drawing conclusions is the last stage of the data analysis process. During this stage, the data analysis progresses from describing relationships and patterns to producing a concise, coherent argument backed with empirical evidence that addresses the review questions (Whittemore and Knafl, 2005). In this study, the information summarised the synthesis of the existing knowledge

about the factors that influence self-care among persons affected by leprosy presented from an SPT perspective.

3.6 Results/Findings

3.6.1 Extent and Quality of the Literature Base

Hawker's appraisal tool (Hawker et al., 2002) was used to assess the methodological quality of the 27 papers included in this study. Hawker's appraisal tool was applied in this study because it enables a variety of study designs to be reviewed (Hawker et al., 2002). Following the assessment, 16 were of good methodological quality (scored 30 or more points); eight were of medium quality (scored between 24 and 29 points) and three were of low quality (scored less than 23 points). Many papers had a good background with clearly stated research aims, objectives, and questions. The fact that assessing the overall quality of the studies showed varied methodological quality could affect the results' validity and credibility. However, the limited word space for published papers was noted.

Regarding methodological variation of the 27 studies, there were 11 quantitative, eight qualitative, and eight mixed-methods studies. Inclusive in the 27 studies were three research theses. No systematic reviews and randomised control trials were found. Also, most studies were conducted from a behavioural theory perspective, and no study on leprosy self-care was conducted from an SPT perspective.

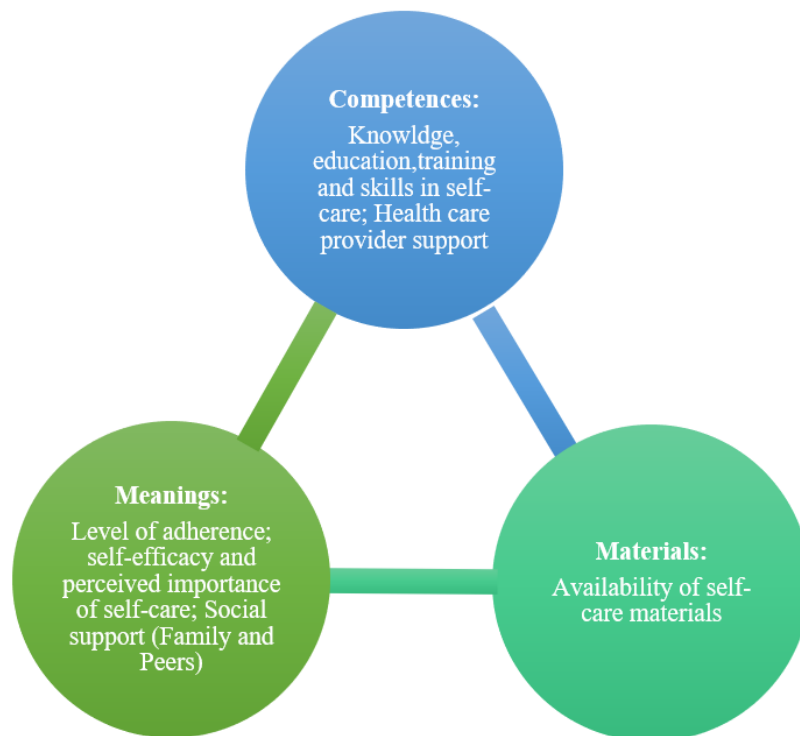
Concerning context, the papers included in this review were carried out in various countries. The countries are detailed in Appendix 5. Of the 27 studies included in this review, 18 were carried

out in Asia, three in South America, and six in Africa. Six were conducted in South Asia (four from India and two from Nepal); seven were in Southeast Asia (four from Indonesia and three from Myanmar); five were in East Asia (all from China). Three studies were conducted in South America (all from Brazil), and six were conducted in Africa (one from Mozambique, three from Ethiopia, and two from Nigeria). However, no research was found explicitly addressing factors (facilitators and barriers) influencing self-care practice among people affected by leprosy in Nigeria. This finding is another gap in the body of literature and further highlights the need for understanding the factors that influence leprosy self-care in Nigeria.

3.7 Synthesis of study findings

Six themes emerged from the data that influenced leprosy self-care practice. These themes include adherence to leprosy self-care, self-efficacy and perceived importance of self-care. The others include social support (family members; peers), availability of self-care materials, knowledge, training, and self-care skills, and healthcare provider support. From the review, the novelty of the application of the SPT to identify factors that influence leprosy self-care practices in this study presented themes around the three core elements of SPT as follows: 'Competence' [knowledge, education, training and skills in self-care; and Health care provider support]; 'Meanings' [level of adherence to self-care of people affected by leprosy; self-efficacy and perceived importance of self-care; social support (family members; peers)]; and 'Materials' [availability of self-care materials]. (See figure 3.2 for details). These themes and how they could be linked to the three core elements of SPT are discussed in the following sections.

Figure 3.2: Summary of Literature Review Findings



(Source: Author)

3.7.1 Competences

'Knowledge, education, training and skill in self-care and 'health care worker support' were two themes related to competences identified by this review. Each of them is discussed in the following sections.

3.7.1.1 *Knowledge, Education, Training, and Skills in Self-Care.*

Twelve studies identified knowledge, education, training, and leprosy self-care skills as essential factors in promoting leprosy self-care practice among people affected by leprosy. The studies

also identified inspection of the hands and feet, soaking, oiling, scrapping, essential exercise, and using protective wear as some of the competencies required for the performance of self-care practice (Arief 2008; Baker et al., 2016; Cross and Newcombe, 2001; D'Azevedo et al., 2018; Gautham et al., 2011; Sathiaraj et al., 2010; Girma et al., 2019; Lay et al., 2007; Li et al., 2008; Smith et al., 1995; Souza et al., 2014; Susanto et al., 2017). In the qualitative study by Souza et al. (2014), which focused on understanding the perception of self-care by people affected by leprosy conducted in Brazil, the author reported inadequate self-care knowledge as a barrier to leprosy self-care. Souza et al. (2014) also reported self-care education as a recognised primary prevention method that actively modifies behaviours by empowering and motivating individuals to engage in self-care practices.

Cross and Newcombe (2001) reported that an intensive 14-day Self-Care Training Programme at Lalgadh Leprosy Services Centre in Nepal reduced hospital admission rates after three months for those who participated in the training programme. However, only 12% of those who participated were admitted to the hospital. Furthermore, in a study in Tamil Nadu, 50 leprosy patients with grade-1 disability and grade-2 disability who received self-care education over eight years were compared with a control group with similar disabilities who had no self-care education (Sathiaraj et al., 2010). Adequate knowledge of inspection of the hands and feet in the self-care versus the control group was (84.3% vs 0%) and (91.3% vs 8.9%) respectively (Sathiaraj et al., 2010). Also, compliance with the practice of various techniques (soaking, oiling, scrapping, essential exercise, and using protective wear) of preventing wounds in the self-care group ranged from 93.9% – 100%, compared with an average of 30.3% in the control group (Sathiaraj et al., 2010). In another study in the same city, Madhavan et al. (2007) recruited 1,232

people affected by leprosy (who were cured of leprosy but with a disability) and taught them self-care for one year. Follow-up assessments indicated that 86% were practising self-care regularly.

From the studies included in this review, while there is consistency in the positive role self-care education and training play in promoting leprosy self-care, there is heterogeneity in the duration of the training provided. Retrieved studies showed that training duration varied considerably, three months (Cross and Newcombe, 2001), one year (Madhavan et al., 2007), and over eight years (Sathiaraj et al., 2010). The reasons for this significant variation in the duration of self-care training were not explained. One of the studies conducted by Smith et al. (1995) reported that leprosy self-care is a lifelong practice that is not quickly adopted and, as such, requires repetitive training over a long period. In addition to the inconsistency observed in the duration of self-care training provided, none of the studies reviewed mentioned the content of self-care education or training delivery mode. However, most studies said health care workers offered them.

3.7.1.2 Healthcare Provider Support

Evidence from other chronic conditions found that a positive patient/ healthcare provider relationship is critical for a successful self-care programme (Coulter, 1997; Holman and Lorig, 2002). Similar results are found in this study, as four studies reported healthcare provider support and communication as an essential predictor of leprosy self-care practices (Lay et al., 2007; Madhavan, 2007; Smith et al., 1995; Win et al., 2010). For example, Lay et al. (2007) identified poor supervision and inadequate communication between healthcare providers and people affected by leprosy as self-care barriers. Similarly, the study conducted in India by Madhavan

(2007) focused on the sustainability of disability care within an integrated leprosy control programme and reported adequate support of self-care groups by government staff as a positive contributor to motivating people affected by leprosy to practice self-care. This finding is further corroborated by Smith et al. (1995) in their quantitative study, which assessed the effectiveness of the collaborative Prevention and Management of Disability Programme in China. The authors reported that healthcare provider support is essential in promoting self-care. Health care workers provided information on how to conduct self-care and provided hands-on solutions to challenges members faced, particularly regarding patients who already had physical disabilities.

There is sufficient evidence that supportive supervision from healthcare providers and a positive patient/ healthcare provider relationship improve self-care compliance. Despite this evidence, none of the studies in this review discussed how to ensure healthcare providers make their engagement and consultation with people affected by leprosy more participatory and empowering. Patient empowerment requires that people affected by leprosy are involved in their self-care decision-making process. It is essential because the traditional biomedical model of care is typically patriarchal and places the locus of power for decision-making on the health care provider (Livengood, 2004). In addition, the biomedical model makes the patient a passive recipient of care and treatment and only expects patients to 'cooperate' with their treatment. According to Stewart et al. (1995), for a positive patient/healthcare provider relationship, there is a need for a paradigm shift for health care providers from a biomedical model of care that is mostly 'doctor-centred' to being 'patient-centred in their engagements and consultation with patients.

3.7.2 Meanings

Here, the SPT elements of meanings include the level of adherence to self-care among people affected by leprosy, self-efficacy and the perceived importance of self-care, and social support. Each of these factors is discussed in the following sections.

3.7.2.1 Level of Adherence to Leprosy Self-care

The review identified five studies that reported on the level of adherence to self-care among people affected by leprosy (Madhavan et al., 2007; Li et al., 2008a; Gautham et al., 2011; Baker et al., 2016; Cross et al., 2017). Adherence is the degree to which a person's actions or behaviour aligns or complies with healthcare providers' agreed recommendations (Grey et al., 2006; Riegel et al., 2012). Based on this definition, the level of adherence to self-care practices reported by these five studies is generally good, which means most people affected by leprosy in these studies carried out the recommended self-care practices. For example, Baker et al. (2016) explored compliance with using disability aids among 71 leprosy patients in Karnataka, India, and found that the compliance rate ranged from 60% to 100%. Furthermore, a study by Madhavan et al. (2007) conducted in Tamil Nadu, India, among 1,232 people affected by leprosy, found that 86% practised self-care daily at home and weekly self-care groups two years after the commencement of the programme.

This high adherence to self-care practices noted among people affected by leprosy in India was also observed in studies conducted in China. For example, Smith et al. (1995) enrolled 3571 patients from six provinces in China on a collaborative prevention programme that included self-care. After two years of the programme, 238 (76.0%) of 313 patients with lagophthalmos were

adherent to self-care; 730 (72.0%) of patients with hand impairments were adherent to self-care, and 745 (68.0%) of 1094 patients that participated in foot self-care were adherent to it.

No study investigated the level of adherence to self-care practice among people affected by leprosy in Africa. Benbow and Tamiru (2001) did not directly assess self-care adherence among people affected by leprosy in Ethiopia's 72 self-care groups (SCGs). However, they found that 90% of the entire group at any one time had well-hydrated skin, and 85% had well-trimmed and clean wounds. Benbow and Tamiru (2001) also reported that 80% of the wounds were dressed. Finally, they found that 95% of people affected by leprosy used footwear, which afforded some protection despite the various wear stages. The high level of adherence to leprosy self-care reported in this study suggests that people affected by leprosy value self-care benefits and are motivated to comply with recommended self-care practices. However, none of the included studies addressed the symbolic meaning of why people affected by leprosy participate in self-care. Neither did they examine the social significance and underlying meanings people affected by leprosy associated with self-care. Also, no study in this review directly focused on measuring the predictors of leprosy self-care adherence.

Some factors that have been reported to influence the level of adherence to leprosy self-care include patients' knowledge about leprosy, level of leprosy self-care education, and self-efficacy (Abera and Lemma, 2003; Pakasi, 2007; Sathiaraj et al., 2010).

3.7.2.2 *Self-efficacy and Perceived Importance of self-care*

Self-efficacy is “*people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives*” (Bandura, 1994, p. 71).

Bandura (1994) further argues that self-efficacy provides the foundation for human motivation, personal accomplishment, and well-being. Therefore, it could be argued to relate to the 'meaning' of SPT, representing the social significance and motivation of why people perform certain practices (Shove et al., 2012). In this review, six studies identified high self-efficacy as a facilitator of self-care among people affected by leprosy (Pakasi, 2007; Lay et al. 2007; Li et al. 2008; Beise, 2012; Baker et al. 2016; Cross et al., 2017). However, while all these studies identified self-efficacy as a factor that influences leprosy self-care, they failed to mention the factors that increase or reduce self-efficacy in people affected by leprosy.

For example, in a mixed-methods study conducted among 495 people affected by leprosy in Nepal, Cross et al. (2017) identified high self-efficacy as a positive factor for the initiation and maintenance of self-care practice among people affected by leprosy. Similarly, a qualitative study in Indonesia found that low self-efficacy, self-esteem, self-neglect, and low self-worth were barriers to initiating and sustaining self-care. Another study by D’Azevedo et al. (2018) studied people affected by leprosy in Brazil and reported that depression is a crucial inhibitor to self-care. Although the authors did not mention how depression demotivated people affected by leprosy from carrying out self-care, similar studies conducted among diabetic patients found that depression reduces self-efficacy, leading to low compliance with self-care (Lin et al., 2004; Pouwer, 2009).

Another factor reported to reduce self-efficacy among people affected by leprosy is internalised stigma or self-stigma (Heijnders, 2004; van Brakel, 2003). Similar findings have been reported among mental health patients. For example, in a study conducted by Pasmatzi et al. (2016), the authors found that self-stigma was associated with low self-efficacy and self-esteem among people with mental health issues, adversely affecting their commitment to care for themselves. For further discussion on leprosy-related stigma, see section 1.2.4.2.

3.7.2.3 Social Support (Family Support and Peer Support)

The benefits of social support in the care of patients with chronic conditions are generally well accepted and documented (Cohen and Wills, 1985; Kessler et al. 1985; Thoits, 1982; Turner, 1981; Turner et al., 1983). Given this, several authors advocate that chronically ill patients should receive social support from friends, peers, relatives, neighbours, and colleagues in the process of 'shared care' as this links to better outcomes (Riegel and Dickson, 2008; Grey et al. 2006; Riegel et al., 2012). Social support is a significant psychosocial factor in motivating patients and promoting compliance and adherence to self-care in chronic conditions. It is a psychological sense of acceptance, belonging, and assistance that increases people's ability to cope better with demanding conditions (Cohen et al., 2000). It can be argued that social support, particularly from peers, helps participants find 'meaning' and motivation to engage in and sustain self-care practices. In this review, two kinds of social support influencing self-care practice were identified, family support and peer support. Both are discussed in the following sections.

3.7.2.3.1 Family Support

Six studies identified family support as a facilitator for leprosy self-care. These studies include: (Arief, 2008; Lay et al., 2007; Li et al., 2008b; Madhavan, 2007; Sussanto et al., 2017; Win et al., 2013). For example, in the study by Arief et al. (2008), conducted in Indonesia, the authors found that family members' involvement and support promoted self-care adoption and maintenance. Specifically, family members helped remind and assist their siblings and spouses in self-care at home and provided psychological support to continue self-care. In addition, a qualitative study conducted by Win et al. (2013) sought to assess factors influencing the care of plantar ulcers among people affected by leprosy in Mon-Ywa Township in Myanmar and found that support from family members encouraged people affected by leprosy to continue self-care. In this study, family members helped remind their relatives about their daily self-care routines, accompanied them when they attended self-care group meetings, and directly assisted with caring for their plantar ulcers.

A similar result was reported by Li et al. (2008b), who found that people affected by leprosy in China who reportedly received family support were 15.8 times more likely to adhere to self-care practices compared with those who did not receive family support (Li et al., 2008b). In this review, other positive actions from a family member that were found to facilitate self-care among people affected by leprosy include: helping with daily routines for their family member affected by leprosy, so time could be freed up to engage in self-care activities; providing money to procure ulcer care materials; and helping to source for self-care materials, for example fetching of water (Lay et al. 2007; Win et al., 2013). Family support contributes to the 'material' element and the 'meaning' element of leprosy self-care practice.

Despite its usefulness, lessons from self-care in other chronic conditions show that family support is not always a positive experience. For example, studies from patients with type 2 diabetes show that when family members try to support patients, they could sometimes feel nagged, criticised, or guilty about receiving such help and so refuse the help (Carter-Edwards et al., 2004; Trief et al., 2003). Also, family members can be a barrier to self-care (Jones et al., 2008; Gallant, 2007). For example, family members may place competing demands on the patient's time for self-care or cause patients to feel embarrassed about their self-care (Jones et al., 2008). In addition, such barriers may affect younger patients who try to juggle other family roles (e.g., parent, Spouse) (Anderson et al. 1998; Samuel-Hodge et al., 2000). Despite these insights, little is known about the frequency with which these barriers occur or how they affect patients' self-care. Family members may sometimes be willing to support patients but may not have the requisite knowledge and self-care skills. Thus, they are eager to help but do not know how to go about helping. This lack of self-care knowledge among family members has been reported among heart failure patients requiring self-care (Clark et al., 2007).

3.7.2.3.2 Peer Support

Nine studies reported peer support through membership in self-care groups as a critical motivator to carry out self-care (Benbow and Tamiru, 2001; Cross and Newcombe, 2001; Cross et al., 2017; Deepak et al., 2013; Ebenso et al., 2009; Gidado et al., 2010; Pakasi, 2007; Sussanto et al., 2017; D'Azevedo et al., 2018). For example, Benbow and Tamiru (2001), conducted in Ethiopia, found that membership in self-care groups positively impacted its members' continuous self-care practice, primarily driven by peer support, peer challenge, and peer encouragement. Furthermore, the authors reported that participation in self-care groups improved group members' self-esteem

and social participation, which helped them continue self-care at home or during group self-care activities (Benbow and Tamiru, 2001). Similarly, in a study conducted in Mozambique, Deepak et al. (2013) reported that self-care group membership was a positive factor for self-care. The authors noted that people affected by leprosy were quite happy to join self-care groups because of the encouragement they received from their peers. Peer support diminishes dependence on professionals and is characterised by equality and mutuality, allowing for receiving and giving social support.

Furthermore, Aberra and Lemma (2003) reported that peer support activities, e.g., peer assessment of wounds, helped people affected by leprosy learn from the experiences of others who had similar problems in the past, which motivated them to continue self-care at home. Similarly, in a study conducted in Nigeria, Gidado et al. (2010) found that peer support through positive deviants was instrumental in promoting and sustaining self-care. Although they face similar problems and resource constraints as their peers, positive deviants are people who identify solutions within their environment and succeed by adopting a positive behaviour, attitude, and disposition to their problem (Lawton et al., 2014).

The solutions adopted by positive deviants are usually considered feasible, acceptable, and sustainable because solutions and resources are internally generated within the environment (Lawton et al., 2014). Positive deviants have been applied in other areas of health care. For example, they were promoting adherence to guidelines in the management of heart disease (Bradley et al., 2009), improving pregnancy outcomes (Ahrari et al., 2002), and promoting childhood nutrition (Marsh et al., 2002). Given their findings, Gidado et al. (2010) concluded

that positive deviants provide a unique opportunity to strengthen and sustain leprosy self-care groups and advocated for self-care programmes to identify and work with them to promote the sustainability of self-care interventions. However, the authors did not describe the process of identifying positive deviants. Indeed, the current understanding of how positive deviants can be identified remains unclear and problematic, as deviants are currently identified using various methods that seem to lack validity or reliability (Griffith et al., 2013).

Several reasons contribute to the effectiveness of peer support in promoting self-care in chronic conditions. One of the reasons is the reciprocal and non-hierarchical relationship among peers due to shared experiences (Dennis, 2003). This non-threatening relationship promotes an understanding of self-care behaviour, gives meaning to self-care, and improves chronic conditions. Also, since the social gradient among peers is slight, people may learn better when their peers teach them and provide self-care support from people they easily relate to and share everyday experiences with (Dennis, 2003). Where there are more similar peers in social, demographic, disease, and disability status, support will likely lead to mutual help, empathy, and understanding (Dennis, 2003).

While peer support has several benefits, some negative consequences have been reported in self-care for other chronic conditions. These include criticism, conflict, and stress which result from over-involvement, a diminished feeling of self-efficacy and reinforcement of poor behaviours (Heller et al., 1991; Illich, 1981; Marshal et al., 1990; Rook, 1984; Stewart and Tilden, 1995).

Although the level of adherence to leprosy self-care, self-efficacy, perceived importance of self-care, and social support (family and peer) all appear to link to the core element 'meaning', they do not directly address the symbolic meaning of self-care. According to Shove et al. (2012), 'Meanings' also refer to the symbolic and social significance of engagement and participation in a practice. However, this aspect of meaning has not been addressed. Some of the questions needing answers include: What meaning do people affected by leprosy associate with self-care engagement? Why do people affected by leprosy practice self-care? What is the social significance of leprosy self-care? Adopting a social practice approach for this study provides an opportunity to answer these questions.

3.7.3 Materials

3.7.3.1 Availability of Self-Care Materials

Five studies reported self-care materials' availability as a positive factor for carrying out leprosy self-care (Abera and Lemma, 2003; Arief, 2008; Deepak et al., 2016; Madhavan, 2007; Win et al., 2013). These materials include water, basin, soap, oils, footwear, pumice stones and dressing materials like bandages. In their study to assess the effectiveness of self-care support groups in Ethiopia, Abera and Lemma (2003) reported that dressing materials' availability and protective footwear were essential factors in initiating and sustaining self-care. Similarly, in a study conducted by Arief (2008) to assess self-care groups' situation in Indonesia, adequate self-care materials were found to promote compliance with self-care practice. Arief (2008) reported that materials and equipment like a basin, pumice stones, and oils were available in 95% of self-care groups. The availability of self-care materials was highlighted as a significant reason for participation in self-care group meetings. While all the above studies mentioned the importance

of self-care materials, none explored the factors influencing their availability or how they are sourced. Besides, none of the studies explored how leprosy self-care had changed over time in response to self-care material changes. Self-care materials changes are critical as they relate to the trajectory of social practices (Shove et al. 2012), representing how practices evolve in response to changes in the availability and quality of materials. Given this, a study of how leprosy self-care practice has evolved due to changes in the availability or quality of self-care materials will be explored.

3.7.4 Interconnectedness of Practices

Another critical characteristic of practices is their interconnectedness (Shove et al., 2012). The argument is based on the notion that the enactment of practices depends on the existence of another practice, and other practices produce elements on which certain practices depend. Therefore, practices can co-occur, facilitate, or compete for time and other resources (Shove et al., 2012). No previous research has been identified comparing and addressing leprosy self-care practices' interconnectedness with other practices. Thus, this study provides, for the first time, an opportunity to explore what other practices could facilitate or compete with leprosy self-care.

3.8 Limitations of the Literature Review

A scoping review, narrative review and systematic review were considered for this study. However, leprosy and leprosy self-care are under-researched areas, indicating an integrative review.

Despite its appropriateness in this study, there are some limitations in adopting an integrative review for this study. First, the varied methodological quality of included studies may have limited the credibility and validity of the findings of this review. Hence, this has been acknowledged and made explicit in this thesis so that the reader can consider this. Second, while efforts have been made to carry out a comprehensive review of the literature, there is some possibility that not all available literature was found and included. This possibility exists because of publication bias and inconsistencies in a search term (Whittemore and Knafl 2005). Third, relevant literature could have been missed despite strict adherence to the literature review protocol. In dealing with this, a wide range of databases was searched, and reference lists of included papers were hand-searched.

Fourth, papers published in languages other than the English language were excluded. Hence other experiences, perceptions, and perspectives of non-English speaking countries on leprosy self-care may have been missed. Also, studies published before 1988 were not included. Hence important information from previous studies may have been missed in this study. Also, this literature review yielded a limited number of papers that focused on self-care practices among people affected by leprosy. This limited evidence could be because of the dearth of research on leprosy and leprosy self-care.

Finally, since the review was conducted alone, the personal experiences and biases of the author may have affected the publications selected, how data was interpreted and analysed, and the conclusions are drawn. However, different approaches were adopted to address this risk. First, the framework by Whittemore and Knafl (2005) was strictly adhered to and applied to develop a

full protocol which guided the literature review. In addition, the author's continuous reflexive posture throughout the review ensured that his experiences and biases did not impact the process and outcome of the review.

3.9 Chapter Summary/Conclusion

This Chapter explored factors that influence self-care practice among people affected by leprosy. The integrative literature moved away from the dominant behavioural paradigm and adopted an SPT lens to explore factors influencing leprosy self-care. Concerning the review question, six factors influencing leprosy self-care practice were identified. These include the level of adherence to leprosy self-care, self-efficacy and perceived importance of self-care. The others include social support (family members; peers), availability of self-care materials, knowledge, training, and self-care skills, and healthcare provider support.

Analysing the data from a social practice theory perspective revealed the following gaps in our current understanding of leprosy self-care:

- No study has examined factors that influence leprosy self-care from an SPT perspective.
- No study has explored the symbolic meaning of self-care and how this shapes self-care practice among people affected by leprosy.

- The required duration to optimise self-care education/training is a gap in our current understanding. Also, there is a gap in which mode of training delivery was most effective, considering the low educational level of most people affected by leprosy.
- No study has examined how leprosy self-care practices evolve in response to changes in the nature and availability of self-care materials over time (Blue et al., 2014).
- No study has identified other practices that might compete with or complement leprosy self-care and how leprosy self-care relates to these practices.
- No study has explored how factors influencing leprosy self-care interconnect and shape each other (Shove et al., 2012).

These gaps formed critical lines of inquiry in this study.

Finally, the review revealed that no study specifically addressing factors influencing leprosy self-care practices has been conducted in Nigeria. Therefore, adopting an SPT approach provides an opportunity to improve leprosy self-care research, policy, and practice in Nigeria and elsewhere. The research and data collection methods adopted in this study are described in the next Chapter.

CHAPTER 4

Methodology and Methods

4.1 Introduction

The Chapter presents the study's aim, objectives, and questions; and gives an overview of the methodology adopted in the research. The researcher's ontological and epistemological position is outlined to locate the study within the paradigm of interpretivism. The qualitative research approach adopted and the hermeneutic phenomenology study design were justified. The fieldwork process is described, highlighting the practicalities of the data collection method adopted and the data analysis approach while explaining how data trustworthiness was ensured in the study. Further, ethical challenges faced, including the role of reflexivity and the Chapter summary, are provided.

4.2 Research Aims and Objectives

4.2.1 Research Aim

The study explored self-care practice among people affected by leprosy in Nigeria and the factors influencing their engagement in self-care practice.

4.2.2 Research Question

What factors influence the initiation and sustaining of leprosy self-care practices in Nigeria?

4.2.3 Research Objectives

- To explore the value of Social Practice Theory in understanding leprosy self-care practices in Nigeria.
- To explore the experiences, perspectives, perceptions, and practices of people affected by leprosy on self-care.
- To identify facilitators and barriers for self-care practice among people affected by leprosy at home and in a self-care group.

4.3 Philosophical Position and Epistemological assumptions

According to Saunders et al. (2012), research philosophy is constructed in two significant ways: Ontology and epistemology. Each defines and describes critical understandings and influences how undertaking research can be implemented (Saunders et al., 2012).

4.3.1 Ontology

In this study, subjectivism is the ontological perspective adopted, and the aim is to explore how leprosy self-care is constructed from a social practice perspective. Ontology's central focus is understanding reality's nature (Saunders et al., 2012; Ormston et al., 2014). Thus, ontology facilitates an understanding of how the world operates and can be described from two points of view: objectivism and subjectivism. In objectivism, reality is independent of and external to the social actors (Snape and Spencer 2003; Saunders et al. 2012). In subjectivism, social actors' actions and perceptions inform how reality is constructed and understood. Hence, understanding a phenomenon from the social actor's perspective is particularly important because social actors continually seek new ways to improve their health. They also strive to find new and meaningful

roles within their family, friends, and community (Saunders et al., 2012). This concept of a social actor is relevant in this study as some of the critical goals of self-care are to build a better body image and facilitate social inclusion.

4.3.2 Epistemology

The researcher identifies with the epistemological position of interpretivism. The central tenet of epistemology focuses on how researchers consider what makes up acceptable knowledge. Interpretivists view acceptable knowledge as fluid and subjective social phenomena (Saunders et al., 2012; Goertz and Mahoney, 2012). Interpretivism promotes the need for researchers to appreciate humans as social actors whose actions are characterised by seeking out details of a social phenomenon or situation and are motivated to unravel the reality underpinning these details and their subjective meanings (Saunders et al., 2012; Goertz and Mahoney, 2012). Over a decade of experience in leprosy interventions and early reading influenced my questions and research interest. As a hands-on front-line health worker, I witnessed several unsuccessful efforts to scale up the intervention, and where self-care interventions were commenced, they could not be sustained. Also, research on leprosy self-care was conducted outside Nigeria and primarily based on behavioural models. These spurred an interest in exploring the possible reasons for this low uptake of leprosy self-care practice from the perspective of other theories. Hence, my decision to apply SPT, which, in turn, influenced my literature review, thus ensuring alignment with my ontology and epistemology.

4.4 Methodology

4.4.1 Qualitative Research

Within social sciences, qualitative approaches have become accepted and established forms of research (Silverman, 2011; Creswell, 2007; Guba and Lincoln, 2005). Therefore, this section justifies why the qualitative approach was chosen instead of comparing qualitative and quantitative methods. According to Creswell (2007), qualitative research helps explore issues that are not well-researched. For example, factors influencing leprosy self-care practice are not well-researched (van Brakel et al., 2010). Several thought schools argue that the nature of research questions should inform a qualitative approach (Creswell, 2007; Denzin and Lincoln, 2005; Patton, 2002). Qualitative research helps explore 'how' and 'why' questions and provides “*answers to questions that stress how social experience is created and given meaning*” (Denzin and Lincoln, 2005, p.4). Qualitative approaches are also suitable for an in-depth understanding of complex phenomena, which relates to this study's aim to explore how leprosy self-care is practised (Creswell, 2007). Given deep involvement in the research process, qualitative inquiry facilitates the production of thick descriptions of each participant's meaning and process (Guba and Lincoln, 2005). It applies thick descriptions to explore their lived experiences (Creswell, 2007).

4.4.2 Justification for the Qualitative Research Approach Adopted

The study's overall purpose was critical in determining the choice of qualitative research adopted. The study was not focused on understanding the self-care experience of an individual affected by leprosy; as such narrative research was not chosen (Clandinin and Connelly, 2000). Furthermore, although persons affected by leprosy could be described as a culture-sharing group

due to their disease, this research was not focused on understanding how this shared culture influenced their self-care practice, so ethnography was not chosen (Wolcott, 2010). Also, a case study was considered suitable for this study. It offers the opportunity to collect data from multiple sources (Simons, 2009), such as healthcare workers and family members of people affected by leprosy. However, it was not applied in this study mainly due to the constraint of time and financial resources to execute proper data collection from these multiple sources. Likewise, grounded theory was not chosen as the research was not focused on testing or developing a theory (Corbin and Strauss, 2014).

Following these considerations, a phenomenological methodology was adopted for the research because it enables researchers to develop new knowledge and an in-depth understanding of people's lived experiences by providing a thick description of such experiences (Langdrige, 2007). Hence, it enabled exploring how people affected by leprosy made meaning of their lived experiences of their self-care practices. Also, phenomenology encourages the full exploration of the structures which formed those experiences. Phenomenology is within a humanistic paradigm and is considered a philosophy and method (Dowling, 2007). In the sections that follow, the different approaches to phenomenology are discussed. Also, the rationale for the phenomenological approach adopted for this study was provided.

4.4.3 Descriptive Phenomenology

A German philosopher, Husserl is acclaimed to be the founding father of phenomenology (Rapport, 2005). At the core of Husserl's phenomenological approach was the drive for the experience to be viewed as it occurred, with minimal or no interference. It involved examining

human experience in a careful manner (Smith et al., 2009). Husserl argued that our consciousness demonstrates how we interact with the world. The importance placed on consciousness shows that phenomenologists are concerned about how things are perceived. Consciousness is reflected in the word phenomenology, Greek origin, *phaenesthai*, and means 'to appear', 'show itself' (Moustakas, 1994). In a nutshell, Husserl argues that phenomenology requires ignoring our natural attitude and daily experience to examine a phenomenon. Ignoring our natural attitude anticipates that the researcher will put on a 'phenomenological attitude' (Smith et al., 2009), which refers to turning attention from external objects and concentrating on one's inward self to understand the object.

4.4.3.1 Epoché

According to Racher and Robinson (2003), Husserl considered experiences as the source of knowledge; phenomenology aimed to study things in an unbiased and accurate way based on human experience and consciousness devoid of interpretation (Valle et al., 1989). Husserl further opined that lived experience was instant without resorting to our reflective self (Dilthey, 1985). For this 'phenomenological attitude' to be achieved, Husserl advocated that the researcher's subjective viewpoint should be withheld. Withholding the researcher's subjective viewpoint is known as epoché or 'bracketing' (Racher and Robinson, 2003). Epoché entails the researcher suspending their biases and prejudices towards the investigated subject (Spinelli, 2005). Among phenomenologists, epoché has been and remains a controversial issue. The controversy is primarily due to the researcher's engagement with the social world (Langdrige, 2007). Criticism and controversies surrounding 'epoché' underpinned much of the further developments in phenomenology.

4.4.5 Hermeneutic Phenomenology

Although the move toward hermeneutic phenomenology is generally attributed to Heidegger, two other researchers, Gadamer (1900 – 2002) and Ricoeur (1913 – 2005) are also acknowledged for their significant contributions to advancing hermeneutic phenomenology (Vagle, 2018). The emphasis of Gadamer was on the influence of culture and history in promoting understanding (Langdridge, 2007). In line with Heidegger's thinking, Gadamer advocated the centrality of knowledge to all aspects of human endeavour and existence; and argued that language was the vehicle through which the understanding of the world can be advanced (Vagle, 2018). He further argued that conversation promotes shared understanding and revelation (Langdridge, 2007). Thus, shared understanding facilitates what is revealed; in other words, understanding occurs when researchers accept other people's experiences while at the same time acknowledging their position and experiences (Langdridge, 2007).

4.4.5.1 Fusion of Horizons

Gadamer argued that epoché was unachievable as it was not possible to bracket one's judgments concerning understanding a phenomenon (Vagle, 2018). Instead, he emphasised that before a researcher can understand others, they first must understand themselves. Understanding themselves requires researchers to develop an awareness of their biases and prejudices determined by history and culture. Rapport (2005) suggested that researchers should approach understanding a phenomenon through their lens and perspective.

Regarding the research process, respondents' meanings could be merged with the researcher's perspective; a process termed a 'fusion of horizons' by Gadamer (Vagle, 2018). Gadamer

believes this ‘fusion of horizons’ occurs in an iterative process defined as the ‘hermeneutic circle’ and allows the researcher to understand the subject and the researcher's fused (Vagle, 2018). In this process, the researcher moves iteratively and at various levels and stages in the data to infer new meaning rather than in a sequential approach. The interpretation occurs in a cyclical movement continuum (Rapport, 2005).

4.4.6 Justification for Adopting Hermeneutic Phenomenology

In this study, I held that it was impossible to fully understand the experiences of persons affected by leprosy related to their self-care practice without considering the historical and social contexts that influenced their experiences. Therefore, it was needful to explore their self-care experiences and practices because of their previous, current, and future experiences to fully understand and appreciate the phenomenon. Also, as Heidegger argued, I believe it was impossible to clear my mind of my clinical, managerial, and work experiences in leprosy and leprosy self-care, which prompted me to investigate the phenomenon in the first place. Given this, I conceded that the process of achieving epoché was not possible. Consequent to these, a hermeneutic phenomenological approach was adopted throughout the study.

4.5 Methods

4.5.1 Data Collection

The data collection team comprised a research assistant responsible for the logistical arrangements necessary for recruiting and interviewing research participants. The team also included a professional interpreter, who was recruited from the local university in Abuja and was responsible for the translation of all data, and the Principal Investigator (PI), who was primarily

responsible for collecting and analysing all data and the overall coordination of the research process.

4.5.1.1 Study Setting

In order to meet the aims and objectives of this study within the time and resources available, this study was conducted in only one leprosy village, the Alheri village, located in Yangoji, Kwali Area Council of the Federal Capital Territory (FCT) of Nigeria. The Government of FCT set up Alheri village in 2007 to resettle homeless people within the FCT; these were mainly leprosy-affected persons engaged in street begging in Abuja. The community is predominantly Islamic and has around 851 people (including 372 children, 278 women and 201 men) (The Leprosy Mission-Nigeria, 2019). Alheri village was selected because it is easily accessible and has many people affected by leprosy who practice self-care; hence recruiting participants for this study did not pose any serious challenge.

Alheri village was visited on a designated day, and village members were briefed about the research's purpose. Handbills (Appendix 6), Expression of Interest Form (Appendix 7); Participant Information Sheets (Appendix 8); and Consent Forms (Appendix 9); were distributed to participants. Participants were given two weeks within which to sign the consent forms. After two weeks, Alheri village was revisited to retrieve the signed consent forms.

4.5.1.2 Sampling Technique

As a qualitative phenomenological study, purposive sampling was employed to identify the study participants. Purposive sampling is a non-probability sampling technique that ensures

participants are deliberately chosen based on their attributes and characteristics to reflect the sample population which will be adopted (Ritchie and Lewis, 2003).

In determining the sample size, an iterative data collection approach was utilised. Data was collected from batches of five people and analysed until 20 people (ten women and ten men) were interviewed. By the time the fourth batch of five participants was interviewed, saturation had been reached. Saturation occurs in qualitative research when no new codes, themes, or data emerge during data collection (Guest et al., 2006).

4.5.1.3 Interviews

Most interviews were conducted in participants' homes or any venue within the leprosy village they preferred. With permission from the participants, all of the interviews were audio recorded. Also, detailed field notes were made after each interview.

All interviews were conducted in the Hausa language. However, the interviews were translated into English by a translator hired from the local university for data analysis. Data were first transcribed verbatim into Hausa and then translated into English. Temple and Young (2004) argue that participants' language usually projects their values, assumptions, thoughts and feelings, which may not be picked by someone who only reads a text without participating in data collection. Hence, biases could be introduced into the data (Squires, 2008). In order to ensure translations were as accurate as possible, the following steps were taken: 1) the translator was provided with all relevant information about the research; and his role in data collection was clarified and agreed upon before collecting data (Murray and Wynne, 2001); 2) the translator

was briefed to remain as close to the words and meaning in participants statements as much as possible, to avoid modifying participants' accounts to what he thought the researcher wanted to hear (Baker, 1981); 3) for consistency, this study utilised only one professional translator (from the local university) (Twinn, 1997); 4) the translator was not involved in data analysis and was made to sign a confidentiality agreement; 5) a random selection of six of the translated texts was back-translated and reconciled to verify the accuracy of the first translations (Dept et al., 2017). Back translation was done by a different translator. After the back translation was completed, the researcher reviewed the text before being finalised. The review indicated a satisfactory equivalence between the target and source language versions.

Interviews were conducted using a one-page topic guide describing key issues. For example, participants were asked to describe how they practised self-care. They were also asked to mention those things that made it easy or difficult to carry out self-care. Twenty semi-structured interviews were conducted for six months (July to December 2019). Each interview lasted between 30 to 50 minutes. This study adopted a responsive interviewing approach because it advocates for trust between the interviewer and interviewee (Rubin and Rubin, 2012). In addition, it suited my epistemological and ontological perspective as it expects both the participants and researcher to be involved in a "*joint process of discovery*" (Rubin and Rubin, 2012, p.36). Finally, central to responsive interviewing is the belief that participants' experiences are natural to them, and through sharing them, they invite a researcher to understand their experiences (Rubin and Rubin, 2012).

4.5.1.4 Observations and Field Notes

While interviews were the principal data collection method in this research, I also conducted non-participant observations (Baker, 2006) and collected field notes. The community has one male and one female self-care groups and a self-care clinic, all were observed. The observational activities were guided by an observation schedule developed before the fieldwork (See appendix 10). The observation schedule helped to maintain the focus of the observation and ensure that every element observed was in line with the research aims, objectives and questions.

Observations were conducted weekly over six months, from July to December 2019. Each observation took 30 to 60 minutes, depending on the self-care clinic or self-care group session. Again, the observation schedule helped maintain the observation's focus and ensured that every element observed aligned with the research aims, objectives, and questions. The observation focused on the interaction between healthcare workers and patients concerning how self-care is supported, encouraged, and explained and the reaction of people affected by leprosy to these. Also, verbal and non-verbal responses, including body language, facial expressions and physical interactions, were observed. It was envisaged that patients' understanding of self-care could be understood by collecting such information.

The observations of the SCG and clinics were mutually agreed upon by the patients and the Healthcare workers involved. To avoid distracting them and to minimise intrusion, where the participants may struggle to act naturally, the researcher avoided eye contact as much as possible (DeWalt and DeWalt, 2011). While intrusion may not be wholly mitigated, considerations of how the researcher's presence may have influenced participants' behaviour were recorded in the

field notes (Walshe et al., 2011). Also, data from the observation, including the clinic setting, activities during the self-care sessions (the expressions, responses, interactions, issues that arose and conversations), and participants' responses, including a reflexive account of the researcher, were recorded in the field notes.

4.5.2 Data Analysis

4.5.2.1 *Thematic Analysis*

Thematic analysis, as propounded by Braun and Clarke (2006), was selected as the method of choice to analyse the findings in this study. It allowed the exploration of how identified themes interconnected with the theoretical underpinning of this study, SPT. Hence, in the results Chapter, an attempt was made to organise the study results using SPT. Although several computer applications facilitate the sorting and organising of data in qualitative research, they are not very helpful in providing the conceptual and intellectual processes needed to make judgments and transform data (King, 2004). Given this, data analysis was conducted with pen and paper. It was a recursive and iterative process.

Irrespective of the data analysis process, credibility is optimised if more than one person is involved in data analysis (Lincoln and Guba, 1985). Although this could not be achieved in this study, other means to assure credibility adopted include constantly checking interpretations and preliminary results against the raw data. In addition, this study further enhanced credibility by triangulating data from interviews against data from observations. Finally, credibility was optimised through participants' feedback to check the interpretations and results (Lincoln and Guba, 1985).

Step 1 - Data Familiarisation

After data transcription and translation, it was read and re-read honestly, considering the overarching theory guiding the research, and my pre-existing beliefs, thoughts, and perspectives (Starks and Trinidad, 2007). I developed a coding chart to help identify excerpts that seemed immediately relevant to the study. The coding chart included the participant's code (Age, sex, and interview sequence number), the excerpt, and the observation or meaning noted. As I read through and immersed myself in the data, I made notes of my theoretical and reflective thoughts, including growing insights about the research topic, interests, and values (Lincoln and Guba, 1985). All raw data records were archived to enable an audit trail and benchmark against which future data interpretation and analysis can be compared for adequacy (Halpren, 1983; Lincoln and Guba, 1985).

Step 2: Generating Initial Codes

Coding was carried out inductively (Miles and Huberman, 1994). Hence, codes were generated directly from reading, thinking about the data and re-reading. The entire process was iterative and recursive. Based on Miles and Huberman's (1994) classification, the codes identified in this study were primarily descriptive, i.e., they required little or no interpretation. In determining the descriptive codes, I used words and phrases based on participants' testimonies (level one). Also, I continuously referred to concepts within leprosy, self-care, and SPT to identify codes. This continuous reference to theory facilitated a better understanding of participants' subjective reality and contextualised the phenomenon under review. Throughout this process, I ensured I remained conscious of my experiences and presumptions. Also, codes and interview excerpts were continuously checked against the study objectives to provide a systematic classification of the

information generated (table 4.1). In practical terms, I began by applying specific words and phrases based on participants' testimonies (Level One). Then, after repeated readings, I attempted to establish connections and links with ideas based on theory and literature (Level two) (Table 4.2).

Table 4.1: Example of initial coding chart

Research Objective	Codes (Level one)	Excerpts of Testimonies
To identify the factors that make it easy (facilitators) or difficult (barriers) for self-care practice among people affected by leprosy at home and in a self-care group.	<ul style="list-style-type: none"> • Trained on self-care by healthcare workers. • Training was useful. • Duration of training. 	<p><i>“The health workers give us training from time to time on how we should take care of our bodies. This has been very helpful. We received over 12 sessions of training. One session per week.”</i> (PT 10: Male, 30).</p>
	<ul style="list-style-type: none"> • Positive problem-solving orientation. 	<p><i>“Even if I face problems doing self-care, I really don’t worry because I know I can solve them, Problems don’t bother me. Whether it is lack of water or bandages. I know what to do”</i> (P06: Female, 24)</p>

(Source: Author)

Step 3: Searching for Themes

Themes were derived in an inductive-deductive manner (Braun and Clarke, 2006). The following steps were followed:

- The codes developed in phase two were read iteratively, ensuring that the identified data elements were accurate.
- The relationship between codes and the interview excerpts was continuously assessed concerning their relevance to the study objectives and underlying theories, particularly SPT. Afterwards, the coded information was grouped with sequences of words or concepts in line with patterns or similarities to identify themes.
- The identified themes were reviewed and further categorised into overarching themes and subthemes. Finally, the material was continuously read to identify any relationships between the themes.

At the end of the process, a thematic matrix was created, which indicated the relationships between codes, subthemes, themes, and relevant social practice core elements and captured the relationships identified within the dataset and the ordered complexity of the patterns that emerged (Table 4.2). In addition, a column identifying the study objectives was included in the matrix to enable an easy and accessible reference to connect the data's relevance to the study's overall goal. The details of the final thematic matrix (with exemplar quotes) applied in this study are shown in Appendix 12.

Table 4.2: Example of initial thematic matrix

COMPETENCE			
Research Objective	Theme (Level two)	Sub-Theme	Codes (level two adjusted)
To identify the factors that make it easy (facilitators) or difficult (barriers) for self-care practice among people affected by leprosy at home and in a self-care group.	Skills and competence in Self-care	Self-care empowerment and education	<ul style="list-style-type: none"> • Organisation of training • Patient confident to carry out self-care • Positive impact of training on motivation for self-care

(Source: Author)

Table 4.3: Example of the final thematic matrix (without exemplar quotes)

COMPETENCE		
Theme	Sub-Theme	Codes
Self-care Knowledge and Skills	Self-care training and personal Skills	<ul style="list-style-type: none"> • Patient Empowerment through self-care training. • Organisation, duration and scope of training • Positive impact of training on motivation for self-care • Problem-solving skills and Decision making

(Source: Author)

Step 4: Reviewing the Themes

The detailed review of the matrix was done continuously and led to some adjustments. Some adjustments included changing the titles, labels, and relative positions of themes and codes, as necessary. Subthemes and themes were out rightly deleted in some instances because they were considered irrelevant to the research question. Some themes deemed inaccurate, unclear, or disconnected from identified codes were renamed on other occasions. For example, a subtheme initially identified as '*Spousal Support*' was adjusted to '*Family Support*'.

The analysis took place over 20 weeks (January to June 2020). Previous analysis phases were revisited within this period, making the process recursive and iterative. Throughout the process, an element of reflexivity was maintained to continually raise awareness of how my prejudices, experiences, and biases impacted the study. To remain reflexive, Bott (2010, p.160) stated the need for “...researchers to constantly locate and relocate themselves within their work, and to remain in dialogue with research practice, participants and methodologies.”

Step 5: Defining and Naming Themes

This step comprised two key stages: stage one was revising the subthemes and themes. The matrix was thoroughly analysed to assess hierarchical relationships and reconfirm if the meanings attributed at this level accurately represented the codes. In stage two, the names given to themes were repeatedly revised until there was clarity and no ambiguity regarding their accuracy. The conceptual definitions for the subthemes and themes were developed in this stage. In doing this, I made exclusive reference to relevant documents on leprosy, self-care, and disabilities.

Step 6: Presenting and Discussing Results

According to Braun and Clarke (2006), this final step commences once the themes have been fully established and the researcher is ready to write the report. Vivid extract examples related to the themes, literature, and research questions were used to build a concise, coherent argument. It was also backed up with empirical evidence that addressed the research question and was guided by the overarching theory, SPT. Given this, the results were categorised under the core elements of 'competences', 'meanings', and 'materials' (Shove et al., 2012). The results are detailed in Chapter five.

4.6 Ensuring Data Quality

4.6.1 Ethical Considerations

Informed consent was obtained from all participants in this study, and participants were assured of their anonymity and confidentiality. Illiteracy and physical disabilities were challenges encountered while obtaining informed consent. In addressing literacy issues, all communication materials were translated into the source language, *Hausa*, to improve understanding before signing. For participants affected by leprosy who had physical disabilities, some could not hold a pen due to clawed fingers, loss of some or loss of all fingers. Thus, participants with clawed fingers or losing some fingers were asked to fingerprint on documents, including the consent form. Two participants who had lost all their fingers volunteered their spouses to sign on their behalf. It was ensured that these family members attended all the briefing meetings.

As the CEO of TLM-Nigeria, responsible for coordinating the FCT self-care programme, I was hugely aware of the power differential between the participants and myself. In dealing with this

power differential, some practical steps were taken before, during, and after data collection. Before the data collection, I committed to presenting the study findings openly, concisely, and straightforwardly to participants (Bravo-Moreno, 2003). The research goals and reasons were thoroughly explained to participants while assuring privacy and anonymity. Furthermore, a continuous attempt was made at different stages of the research to clarify the rights, roles, and responsibilities of participants and the researcher (Bravo-Moreno, 2003). Hence, on a few occasions, when participants presented individual or community needs, I took the opportunity to remind them that I was engaging with them at that point as a PhD student and not the CEO of TLM-Nigeria and referred them to the appropriate department of TLM-Nigeria.

During data collection, I made every attempt to be conscious and aware of the power gradient. I provided open communication that allowed participants to ask questions about the research process, its purpose, and the method (Bravo-Moreno, 2003). Furthermore, I ensured participants were continuously informed about their right to raise objections and even opt out of the research process whenever they felt uncomfortable (Brinkmann and Kvale, 2005). Also, periodic reminders about the study's nature and how the findings will be applied were given, particularly during the interview's sensitive aspects (Brinkmann and Kvale, 2005). Finally, the summary findings of this research were shared with six participants to confirm how I understood the data collected and accurately captured their thoughts and experiences (Enosh and Buchbinder, 2005).

After data collection, I ensured my obligations to the participants were kept. I ensured I did not misrepresent the significance of participants' voices, avoided representing only my voice (Marcus and Fischer, 1986), and was clear on which voice was being projected, always

protecting the anonymity of participants. Also, in writing the thesis, I employed several participants' quotes. This was important to ensure participants' voices and meanings were accurately conveyed and respected. Forbat and Henderson (2005, p. 1125) opined, “*Your methodology of quoting at length from the statements and perceptions of individuals is very successful at bringing out the revolutionary underlying principle of respecting them and taking them seriously*”. Finally, I included a detailed description of my reflexive considerations to be accountable and transparent for the methodologies adopted in this study and their limitations. I stated clearly how my values, experiences, and institutional pressures influenced the research journey, including their role in data interpretation and presentation (see section 7.5.2 on reflexivity) (Malacrida, 2007).

4.6.2 Issues of Rigour

As a qualitative study, the concept of trustworthiness was employed to ensure the study's rigour (Guba and Lincoln, 1989). According to Polit and Beck (2011), the concept of trustworthiness includes credibility (truth), transferability (applicability), dependability (consistency), confirmability (neutrality), and authenticity. A description of how these elements were applied in this research is given below:

4.6.2.1 *Credibility*

Credibility relates to believable and truthful findings (Tobin and Begley, 2004). During data collection, the researcher spent six months in Alheri village to understand the research context, enhance the understanding of participants' perspectives, and hopefully offset researcher bias. The researcher kept field notes to capture personal reflections and identified and dealt with

trustworthiness issues. Also, participants' feedback was sought to ensure the interpretations given to the data resonated with the participants.

4.6.2.2 Transferability

This element seeks to establish if research findings are comparable. The goal of a qualitative study is not to produce generalisable results. However, the intention is to produce results other researchers can apply in similar settings. It also means using the research design for similar purposes (Trochim, 2006).

Transferability in this study was enhanced by using 'thick descriptions'. 'Thick description' comprises the researcher's field notes, including explicit descriptions and extensive detail when recording conversations and interpretations during data collection (Lincoln and Guba, 1985).

In addition, all interviews in this study were limited to 30 to 50 minutes per person, and no interview could go more than the stipulated time. Also, the researcher applied probes and prompts during interviews to generate rich data.

4.6.2.3 Dependability

Dependability relates to the stability and consistency of the research process and findings (Riege, 2003). Also, it relates to the extent to which readers can be satisfied that the findings and conclusions of the study are because of a rigorous research process (Ritchie and Lewis, 2003). To increase dependability, concrete codes, which are descriptive and based on participants' dialogue, were applied (Guest et al., 2012).

In addition, a deliberate effort was made to ensure that the entire research process, including study design and research question, was consistent with the overarching research epistemology. For example, a hermeneutic phenomenological approach was adopted, and thematic analysis was applied for data analysis. A clear description and audit trail of the process used in data collection, analysis, and conclusion were provided (Silverman, 2011).

4.6.2.4 Confirmability

Confirmability relates to the accuracy of the findings of the study. It explores other ways results could be corroborated. This is to help generate confidence in the results and reflect the truthfulness of the participants' perspectives.

Regarding ensuring confirmability: two approaches were employed 1) the use of audit trails; 2) reflexivity.

(1) Audit trails: All the research data, transcripts, and field notes were kept. During coding, the researcher continued maintaining a reflexive note of my impressions of the meaning of the data and how they related to each other (Morse and Richards, 2002; Starks and Trinidad, 2007). I did this because I believed these reflexive notes were a part of my audit trail for this research (Lincoln and Guba, 1985). Also, care was taken to describe this study's limitations and recommendations for future studies. Also, I included my perspective on how well the research process worked.

(2) Reflexivity: This is briefly introduced in section 4.6.2.2 below and more extensively discussed in the conclusion Chapter.

4.6.2.5 Authenticity

This element focuses on the research's usefulness, intended value and contextual purpose (Polit and Beck, 2011). It seeks to identify the study's benefit to participants and explores if the research has considered all the realities represented such that research findings have meaning. In order to achieve this, all the recommendations were carefully thought through and discussed with key stakeholders to ensure they were valuable and practical.

4.7 Chapter Summary

Methodological decisions supporting this research were introduced, described, and discussed. The study explores how leprosy self-care is practised and the factors influencing it. The research objectives will be answered through a hermeneutic phenomenological study and in-depth interviews of 20 people affected by leprosy. The Chapter also describes the research methods adopted, including the thematic analysis processes for data interpretation and analysis. A reflective account of the ethical considerations of this research and how research trustworthiness was ensured was presented. The research findings and results are presented and described in detail in the following Chapter.

CHAPTER 5

Findings

5.1 Introduction

This Chapter presents data analysis from findings through a social practice lens and categorises them under the three core elements of SPT; 'competence', 'meanings', and 'materials' (Shove et al., 2012). The analysis identified support from healthcare workers, self-care knowledge and skills (competence), social support, belief, inclusion, competing and complementary practices (meanings), and resources (materials) as factors that influence the self-care practices of people affected by leprosy in Nigeria. Data analysis also revealed other practices competing with or complementing leprosy self-care, such as begging and Ablution.

5.2 Demographic Profile of Research Participants

The mean age of the 20 participants was at 47 years. Most participants worked in low-paying jobs, with seven (35%) unemployed and living entirely off begging. However, even those with low-paying jobs still augmented their income through begging. The participants' demographics (Appendix 13) generally reflect the demographics of people affected by leprosy globally (Lockwood, 2004) and could further explain some factors that influence self-care in leprosy identified in this study.

5.3 Factors Influencing Leprosy Self-Care Practice in Nigeria

Seven main themes described the factors influencing self-care in Nigeria: healthcare worker support, self-care knowledge and skills; social support; belief; inclusion, competing and

complementary practices; and resources. This Chapter provides a narrative of the research findings under the three core elements of SPT –competences, meanings, and materials (Shove et al., 2012).

Figure 5.1: Factors affecting leprosy self-care



(Source: Author)

5.4 Competences

Two themes, health care worker support and self-care knowledge and skills, emerged under this core element (Table 5.1). Each is discussed in the next section.

Table 5.1: Themes and categories describing leprosy self-care under ‘competences.’

COMPETENCES	
Theme	Category
Healthcare Worker Support	Healthcare Worker-Patient Relationship and Communication
Self-care Knowledge and Skills	Self-care Knowledge
	Self-care training and personal skills

(Source: Author)

5.4.1 Healthcare Worker Support

This theme relates to the degree to which leprosy patients felt cared for and valued by healthcare workers, with the subtheme - healthcare worker-patient relationship and communication.

5.4.1.1 Healthcare Worker-Patient Relationship and Communication

The data reveals that several participants developed a sense of responsibility for caring for themselves and achieved a reasonably good level of understanding of how to go about their self-care routines:

In terms of how I practice it, every day, I soak my feet for at least 30 minutes as recommended and apply oil to them, and I make sure I wear my sandals to protect my feet anytime I am going out of the house, especially when going to the farm. I do these activities because I know they help me to prevent the common complications of ulcers and loss of limbs. (PT 14: Male, 45)

Participants generally perceived that healthcare workers had the requisite qualifications to make recommendations and instructions about preventing and managing leprosy disabilities and complications. In addition, they found their advice relevant and meaningful. Hence, several participants perceived it essential to adhere to the instructions of healthcare workers if they were to have good outcomes for their condition. While the ultimate goal is for patients to own self-care processes, the balance is to ensure there is no dependence or over-reliance on healthcare workers:

'I trust the nurse at the ulcer clinic because I believe going there to discuss with them is very useful. From my own experience, each time I visit the clinic, I felt cared for because she is qualified and trained to attend to my issues.' (PT 05: Female, 35)

However, it appears that some participants were reluctant towards regular engagement with healthcare workers due to the fear of receiving harsh feedback if they could not achieve expected self-care outcomes. Thus, the participants' primary purpose of adherence to reminders and instructions from healthcare workers appeared to be hinged on avoiding being rebuked rather than the perceived importance of self-care.

Based on the interviews, participants felt they were meant to adhere to healthcare workers' instructions and achieve desired self-care outcomes, regardless of the challenges of everyday life they might be facing as people affected by leprosy. Also, there appears to be a significant power disparity between healthcare workers and patients, as evidenced by their tendency to rebuke patients whenever they perceive patients were not adhering to self-care instructions. This

patient's rebuke also reflects what appears to be a hierarchical relationship between healthcare workers and leprosy patients. Contrarily, the situation seems to be different from the staff of the NGO, whom participants felt were more approachable:

'All that nurse knows how to do is to scold you. He continued to ask me why my ulcer was always infected. Every time I visited the clinic, the nurse always asks the same questions: "Why is your ulcer infected? Why is it not healing?" Each time he asks, I usually don't have a response. I just keep quiet. The good thing is that we have the TLM staff... She is much more understanding, and I am more comfortable with her.' (PT 01: Female, 50)

It was also clear that healthcare worker-patient communication was restricted, largely one-directional from healthcare workers to participants, threatening and focused mainly on self-care activity instructions. As mentioned by participants, the intimidation and rebukes of healthcare workers further reduced participants' confidence and willingness to discuss the other personal and social challenges they were experiencing, which negatively affected their self-care practice and outcomes. Opportunities to discuss these challenges were limited, as healthcare workers rarely asked about such things:

'When you attend these ulcer clinics, the instructions provided ... are always all about how we are to prevent ulcers, protect our skin, eyes, hands and feet. Rarely do they ask about other challenges we are confronted with at home that make us not to be able to adhere to our self-care routines.' (PT 04: Female, 45)

The use of threatening communication by healthcare workers is illustrated by this extract from the researcher's field note:

Figure 5.2: Extract from Researcher's Field Notes

Field Notes taken during a Self-care Group Meeting between Self-Care Group Coordinator (SCGC) and Mr A.

The SCGC asked Mr A whether he adhered strictly with the self-care requirements at home. Mr A replied that he did not do soaking and oiling as he should. That he missed a few sessions because he had to go source for income to take care of his daily needs. Mr A was told to soak his hands and feet for 30 minutes every day and always put on protective gear like shoes, glasses and gloves. Mr A did not respond and listened to the SCGC's explanation. Also, a picture of a bad foot ulcer and amputated hand was shown to Mr A, and he was cautioned about the possibility of developing the same complications if he did not improve his adherence to self-care instructions. Mr A appeared quite concerned and said, 'this is exactly my biggest fear and worry.' (Field notes – September 2019)

(Source: author)

It was apparent from the field note that the healthcare practitioner used threatening communication or 'scare tactics' to challenge the patient to be more adherent. Threatening communication seemed to increase the level of fear of the participant towards the threats of leprosy complications.

Poor listening and communication appeared to be at the centre of some participants' experience of unhelpful support and care from healthcare workers. This poor listening and communication seem driven by the power gradient between healthcare workers and patients. However, they may not be unconnected to the top-down nature of the medical model:

'They only want to speak without listening to your complaints. There was a day I visited the clinic to discuss the discomfort I was having with my leg stump, and the nurse wouldn't even listen; she said she knew what could be wrong and referred me to the centre in Chanchaga.' (PT 16: Male, 57)

5.4.2 Self-care Knowledge and Skills

This theme refers to the level of knowledge and skills for leprosy and self-care among people affected by leprosy. Several patients alluded to the importance of understanding self-care and having the required skills to practice it. Therefore, the categories under this theme include self-care knowledge, training, and personal skills. Each category is described in detail in the subsequent sections.

5.4.2.1 *Self-care Knowledge*

Knowledge about leprosy, self-care practice, and self-care skills was crucial in improving self-care adherence, promoting better outcomes, and preventing complications. Additionally, an understanding of the physiological links between leprosy, disabilities and self-care appears to help participants appreciate the need to adhere to self-care expectations:

'The self-care training, I received has been very helpful. They taught us about leprosy, how it can cause disabilities and how to care for our eyes, hands and feet.' (PT 12: Male, 50)

Six participants reported receiving health education and self-care training at the clinics. Another five participants recalled being given brief, primarily prescriptive advice from the healthcare worker on self-care tips. At the same time, seven reported receiving sparsely written material (either as an information sheet or pamphlet). These seem to suggest that the health information provision for people affected by leprosy attending clinics may be inconsistent or unsystematic. The researcher also observed a general lack of information, communication, and educational materials on leprosy self-care while visiting a leprosy clinic in the Alheri village in Yangoji on the 18th of September and another visit to the self-care group session, which took place on the 20th of September. On both visits, the only materials sighted were posters with information on the causes, signs, symptoms, and treatment of leprosy, and another on the eyes, hands, and feet complications of leprosy.

When there is inadequate information, education, and communication from healthcare workers and little effort to understand existing levels of patients' knowledge or beliefs about their conditions, it allows room for myths and misconceptions about leprosy. For example, a participant believed leprosy was caused by witchcraft:

'I didn't know the cause of this disease or how it got into my body. I got it when I was a teenager, and at the time, my mother told me it (leprosy) could be a sign that bad people (Witches or Wizards) from my village cast a spell on me, and I somehow believe it because the way it started was very strange.' (PT 15: Male, 43)

5.4.2.2. Self-care Training and Personal Skills

Aside from knowledge acquisition, people affected by leprosy also require specific skills to implement self-care. Some of these skills include oiling eyes, soaking, scraping hands and feet, and appropriate use of protective devices. Analysis of the data revealed that training provided by healthcare workers was fundamental for the acquisition of skills required for implementing leprosy self-care:

'At the hospital in Chanchaga and even here in Yangoji, we have received several self-care trainings. We were taught how to care for our eyes and hands...They informed us that because of the nerve damage from leprosy, we were prone to have a problem even after being cured of the disease, and only proper self-care can help us.' (PT 07: Male, 50)

While several participants mentioned the critical contribution of self-care education and training, few talked about the quality, duration, and training scope. This lack of clarity about the quality, duration and content of training suggests that self-care training may not be well organised and may lack a structured approach. As it was only one participant who mentioned the duration of training received. Even at that, the narrative was not specific:

'The health workers give us training from time to time on how we should take care of our bodies... We received over 12 sessions of training. One session per week.' (PT 10: Male, 30)

In addition, during a visit to observe a self-care group training session on the 3rd of October, the researcher observed a nurse conducting the training, which lasted for about 40 minutes, was conducted in *the Hausa* language and was not guided using a training manual. The extent to which patients understood the training could not be ascertained because no pre and post-training test was conducted.

Although training on self-care has been indicated to be a positive motivator for leprosy self-care practice, self-care knowledge and training do not necessarily lead to compliance. Some respondents still demonstrated poor adherence to self-care despite training. This contradiction highlights the limitations of training to change attitudes and further questions the quality of self-care training received by people affected by leprosy. Also, it raises questions about the impact of negative attitudes and beliefs on self-care training and self-care practice:

'It's true; we were taught to soak our hands and feet in soapy water for at least 30 minutes every day and apply oil on them. Well, I don't soak and oil them (hands feet) every day (...) maybe once every 3 days (...) But I do put cream on them every day because I believe it will still work (effective) to protect my skin.' (PT 15: Male, 43)

In addition to acquiring knowledge about leprosy and competence to carry out self-care, this study suggests that patients also require personal skills to maximise self-care benefits. Personal skills include problem-solving, planning, goal setting, and decision-making skills (Bodenheimer et al., 2002; Omisakin and Ncama, 2011). For example, in several accounts, participants narrated how they were faced with a shortage of water supply due to a malfunction of the community borehole. Although this shortage in water supply affected their self-care practice, rather than

being discouraged, some participants sought alternative water sources to ensure continuity of their self-care routine:

'There was a time we did not have water in this community for more than three months. The only borehole has issues. Many people couldn't even have their baths let alone do soaking and oiling. At the time, we advised members of the self-care groups to get water from the closest stream, which is like five kilometres away, but only those who could walk long distances or had family members who helped get water. We knew it was not a very good idea because we know the pressure it could put on the feet of those with ulcers. At some point, the self-care group tried to organise the youths to bring water to the ulcer shed it worked for a while and stopped.' (PT 14: Male, 45)

While effective healthcare worker-patient relationship and communication are critical for achieving a positive leprosy self-care outcome, it is sometimes inadequate, with a power lopsidedness skewed towards healthcare workers. In some instances, healthcare workers used threatening communication. Also, while self-care training and education are essential for implementing leprosy self-care practice, it appears that self-care training and education are unsystematic, disorganised and may not focus on providing personal skills.

5.5 Meanings

This section discusses three themes of 'meanings' emerged in this study. These themes include social support, belief and inclusion (Table 5.2).

Table 5.2: Themes and categories describing leprosy self-care under ‘meanings’

MEANINGS	
Theme	Categories
Social Support	Family Support
Belief	Religious Belief
Inclusion	Stigma, Discrimination and Social Inclusion
Fear	Fear of Complications

(Source: Author)

5.5.1 Social Support

5.5.1.1 *Family Support*

Participants recounted feeling appreciative of being reminded by family members to carry out their self-care routine. Such reminders were seen to be quite helpful as they sometimes forgot their routines due to the busyness of life:

‘My husband reminds me if I forget to do my daily self-care activities. It’s like he is the in-house doctor (Laughs). I like it because it has really helped me to take care of my body. For example, if I forget to inspect my hands and feet, he will remind me. He goes as far as making sure I get necessary materials.’ (PT 17: Female, 30)

Participants also received emotional and psychological support from their spouses. Participants who were married felt privileged for having an empathetic spouse who shared in their burden

and provided an avenue to air their concerns regarding the issues they faced in managing their condition:

'My wife ensures I do every necessary self-care activity as prescribed. She sometimes even joins me to soak her feet just to encourage me... Before I go out to any place, she gets my sandals ready; if she finds me walking about the house without my sandals (protective shoes), she would not be happy.' (PT 12: Male, 50)

Also, participants reported stories about tangible support they received from family members, such as the provision of self-care materials and resources:

'My son takes care of me. He gets me water, bandages, eye ointment and other self-care materials.' (PT 18, Male: 63)

Many participants reported receiving care and support from their spouses and other family members. However, a few reported non-supportive behaviours and actions from family members, particularly spouses, whose actions or dispositions did not encourage participants' adherence to self-care practice. It would appear that a lack of understanding about leprosy and the effectiveness of self-care practice; and stigma contributed to the non-supportive behaviour of this husband toward his wife:

'Honestly, I don't know why my husband is so worried about my looks. While I really don't mind about how people feel about whether I have had leprosy or not, he on the other hand, doesn't want people to know I have leprosy. So, because of him, I don't wear

the Kano shoes, which are very soft and protect my feet...He has threatened me with divorce before. So, I am careful. It is for the same reason that I used to avoid attending self-care groups meetings. He didn't want me to associate with them.' (PT 01: Female, 50)

5.5.2 Belief

5.5.2.1 *Religious belief*

All participants in this research were Muslims. When asked how they accepted leprosy, several stated they regarded leprosy as a test from God and positively accepted it. Several participants expressed confidence that Allah, who created everything, including human beings and permitted them to have the disease, could likewise cure them. This perception suggested that participants used religious beliefs as a coping mechanism to accept the leprosy diagnosis and face its consequences. Participants' awareness of and motivation for self-care did not diminish because they accepted their leprosy diagnosis and confidence in Allah's power. On the contrary, their motivation appeared to increase due to their belief that as they kept praying for forgiveness, mercy and a cure from Allah, they were required to continue to care for their bodies:

'At a point, I stopped worrying because I believe my condition (leprosy) is from Allah. He is the one that allowed me to have leprosy, and I know he will also heal me. This is why I always ask for help from him (Allah). Although I have this confidence and trust in the ability and power of Allah to take life, give life and heal me, I know I still have to care for myself because Allah asks us to always strive to make our bodies better.' (PT 16: Male, 57)

For some participants, psychological relief appeared connected to how they made sense of their relationship with God, which is reflected through submission to Allah's will and remembrance of his promises. Despite the positive impact of religious belief on leprosy self-care, findings differed on how religious practices influenced self-care. While some practices were found to be facilitators of self-care, others were reported as inhibitors. For example, some participants mentioned prayer as a positive contributor to increasing their confidence to practice self-care:

'But anytime I am not able to carry out self-care, I always get strength after prayer to continue. Prayer reminds me of God's sovereign ability to heal me completely while I play my part to care for myself.' (PT 19: Female, 50)

On the contrary, fasting was reported as an inhibitor of leprosy self-care. Some participants considered it a severe hindrance to self-care, as expected, particularly during Ramadan. Ramadan is observed once every year, and practising Muslims the world over are expected to abstain from food:

'Another time I struggle is during the Ramadan fasting. As a Muslim, you fast for about 1 month every year. You know fasting makes you a bit weak. So truly, I don't do everything I am meant to do during fasting. Honestly speaking, I don't use the pumice stone to scrape my feet; it takes too much effort. I only soak and oil my feet and just not do much during this period.' (PT 01: Female, 50)

5.5.3 Inclusion

5.5.3.1 *Stigma, Discrimination, and Social Inclusion*

Discrimination, rejection, changes in self-worth and self-stigma were reported to influence self-care practice negatively. These appear to be propelled by developing a negative view of illness and feelings of unworthiness, which diminished their self-esteem and self-worth. Consequently, their interest and confidence in continuing with self-care were negatively impacted:

'... when I remember how I have been treated badly by some people because I have leprosy, I feel very sad. It gets to me. I had a man who wanted to marry me after some time he just changed. Someone told him I had leprosy. Instead of asking me himself, he just stopped coming to visit me. Honestly, when I remember, I just feel so bad that I lose interest in everything, including doing self-care, because really, what's the point.' (PT 02: Female, 43)

However, in some cases, reduced stigma, as indicated by an increased social acceptance; and a desire to be healthy and ulcer-free; appeared to be critical drivers to increase self-efficacy and motivate continuation and adherence to self-care practice:

'My ulcers have healed, and my general appearance has really improved, and people want to associate with me more... This is what is encouraging me to continue this self-care programme because I don't want my condition to reverse.' (PT 13: Male, 50)

For some participants, self-care represented a desire for unhindered family life involvement to have an active voice in family decision-making. Furthermore, for others, it represented a quest for participation in community life and an opportunity to fulfil their yearning for acceptance, belonging, and social inclusion:

'I do it because if you do not take care of your body, you will not enjoy your health, and people will shy away from you. Someone even said to me, 'how can someone who cannot care for himself be taken seriously? I will never forget that statement. I remember when I had a bad smelly foot ulcer, they would not even involve me when discussing serious issues in the community; even within my family, I was often left out of some decisions. I am happy; those days are gone. Self-care helps me stay clean and as healthy as possible, and this brings respect from my family and other members of this community in this Yangoji.' (PT 16: Male, 57)

Support from family members and religious beliefs are crucial to leprosy self-care practice. Family members provide physical, emotional, and economic support, while belief in God's sovereign power enables leprosy patients to accept and cope with their condition. However, family support is not always positive, as some were reported to inhibit self-care due to stigma-related issues. Similarly, certain religious practices like fasting could act as inhibitors. Finally, while a desire for family and community inclusion facilitates leprosy self-care, stigma and discrimination were potent barriers.

5.5.4 Fear

5.5.4.1 *Fear of complications*

Understanding the consequences of leprosy seemed to inform patients' resolve to practice self-care. Many participants described leprosy as a devastating condition that destroys the body and limits functionality. In addition, the chances of developing complications were of grave concern to many participants. Many of the participants claimed this was the most common aspect highlighted by healthcare workers when they were diagnosed with leprosy or during a visit to self-care clinics:

'I spoke with the nurse. She told me that my condition is very serious - that I can lose my sight, because it can damage my eyes, I will have ulcers that do not heal and many people have lost their hands and legs' (PT 02: Female, 43)

Another participant expressed a similar understanding of leprosy:

'When I was told I had leprosy, I had no idea that was what I was dealing with. The doctor informed me that leprosy was a skin and nerve disease'. They [healthcare workers] also showed me images of people without legs because of leprosy. That made me afraid. I knew leprosy was a dangerous disease' (PT 12: Male, 50)

It would appear the use of scare tactics increased the feelings of fear towards the threatening consequences of leprosy, and this was applied by healthcare workers in this study to increase the awareness of patients to adhere to their self-care routines:

'I know that because I have leprosy, I may develop complications. This is because of what we have been told by the nurses. I believe them because I have seen other people who had leprosy and their legs were cut off. I am afraid that the same things may happen to me. So, I think I need to care for myself before things will get worse.' (PT 7: Male, 50)

The above quote shows the patient's fear of complications and awareness of the need to adhere to self-care routines to prevent complications. Aside from being reminded by the healthcare workers, personal experience or the observation of how others developed complications also increased the patients' awareness and adherence to self-care routines:

'I developed a wound on my right leg, and it took a long time for it to heal. When that happened, I then realised the effect of leprosy on my body, and it made me realise the importance of self-care. Actually, you can prevent damage to your body if you have knowledge about it.' (PT 06: Female 42)

From the data presented above, awareness and understanding of complications appeared to facilitate engagement in leprosy self-care. However, it seems the motivation for self-care gained from fear of complications may not be sustainable as fear of complications appears to overwhelm some patients and incite a feeling of hopelessness and stress:

'After realising I had leprosy, a lot of negative feelings came into my mind. I was afraid of what would happen to me in the future. Who will like to marry someone like

me...Someone told me I might go blind, lose my fingers or lose both my legs if I am not careful. I was so worried that I did not know what to do anymore' (PT 08: Female 58)

Participants' contrasting views about the perception of complications suggest that scare tactics may not be effective for all patients. Also, the difference in perceptions and understanding of leprosy and its complications by participants is apparent. These perceptions of leprosy and its complications were influenced by several factors, including information received, the experience of complications or lay understanding by friends or relatives. Hence, using scare tactics to encourage patients to adhere to self-care routines without considering the patients' psychosocial state may produce different outcomes in different patients. While it may motivate some, it could demotivate others.

5.6 Materials

One theme, resources, emerged under this core element (Table 5.3).

Table 5.3: Themes and subthemes/categories describing self-care under 'materials.'

MATERIALS	
Theme	Subtheme
Resources	Availability of self-care materials
	Affordability of self-care materials
	Acceptability of self-care materials
	Accessibility of self-care materials

(Source: Author)

5.6.1 Resources

This theme is related to the availability, affordability, acceptability, and accessibility of materials required for self-care. Each of these categories is discussed below.

5.6.1.1 Availability of Self-care Materials

Participants indicated the importance of the availability of materials such as bandages, eye ointment, eye shields, protective sandals, pumice stones for scraping off dead skin, water, soaking bowls, soaps, and oils for lubrication. These materials were also vital to self-care practice:

'I said it before, from time to time, we run short of things like eye ointment, bandage or cotton wool, and this makes self-care very difficult. Once materials are available, self-care is very easy to do.' (PT 11: Male, 35)

5.6.1.2 Acceptability of Self-care Materials

Participants raised issues concerning the effectiveness and appropriateness of alternative or home-based self-care material. The use of home-based substitutes was driven by the need to address concerns about self-care sustainability as materials were initially provided free of charge. The new policy that mandated people affected by leprosy to source self-care materials from home evoked concerns about the acceptability of such alternative materials due to cultural biases as some participants raised concerns about applying 'food' to their bodies:

'Some of my friends say they use cooking oil. But honestly, how can you apply food on your wounds? It doesn't sit well with me, so I don't do it. Anytime I have Vaseline, I use it; when it finishes, I try olive oil; if it's not available, I wait until I can buy any of them.'
(PT 03: Female, 48)

Interestingly, patients who refused to apply 'food' on themselves would be happy to use olive oil, which in Nigeria is used as an emollient for skin and hair and a holy anointing oil rather than a food product. However, others have been reluctant to apply alternative self-care materials due to doubts about their effectiveness:

'Now you have to get everything by yourself and even apply substitutes like home oils. I really don't believe they are effective. So, I don't apply it. Although we were told it is okay...' (PT 01: Female, 50)

Despite the concerns, the use of alternative materials appeared to have been embraced and accepted by other participants. Their acceptance of alternative materials seemed to be driven by trust in medical expertise rather than personal experience of their effectiveness:

'We were informed during one of the training sessions that we should use old clothes instead of bandages for covering our ulcers. They said it was now very expensive to continue to provide these things free of charge. Initially, I was very reluctant, but after we were told it was okay to do so, I was happy to do it.' (PT 12: Male, 50)

Another dimension to the acceptability of self-care materials is the role of stigma. Some self-care materials, in this instance, protective shoes, were perceived as stigmatising by some participants, who refused to use them. Hence, they preferred to conceal their condition by refusing to use materials they perceived could connect them to the disease:

'For example, I don't wear the sandals provided by the programme because it's like a label and a negative one for that matter. I have advised the Mission staff that the style should be changed to look like the normal sandal you can buy in Wuse market so we would not be viewed and treated differently. Everybody knows that shoe is for leprosy people. I cannot wear it because of my work.' (PT 17: Female, 30)

5.6.1.3 Affordability of self-care materials

The change in policy from the free provision of self-care materials to individuals taking personal responsibility for sourcing their self-care materials introduced a financial burden on individuals and posed a barrier to self-care. This policy change is particularly significant as many of the participants were either unemployed or under-employed:

'Many of my colleagues suffer because they can't buy some of these items—especially items like eye ointment, eye shield, gloves. For the rest, you can easily have substitutes, but for these ones, it is difficult. I can tell you that many more people used to practice self-care when these items were provided free of cost by the Missionaries. Now we have to source for them ourselves.' (PT 14: Male, 45)

The acceptability and affordability of self-care materials raised another concern about the feasibility of implementing this policy. Data from this study revealed two kinds of materials applied in leprosy self-care - 'replaceable' and 'irreplaceable' materials. Examples of replaceable materials include bandages and petroleum jelly, which can be substituted with old or used rags and home-based cooking oils. Irreplaceable materials include water and eye ointment. The high poverty rate among people affected by leprosy poses a severe challenge to sustaining self-care:

'I understand if they say we should use substitutes for oiling our legs and use old rags for dressing our wounds, but we can't afford to put just any kind of medication on our eyes. I am already blind in one eye, so I am very careful.' (PT 11: Male, 35)

5.6.1.4 Accessibility of self-care materials

Another critical 'material' consideration for leprosy self-care is water, an 'irreplaceable' material. Access to water was a significant finding as 14 of the 20 respondents in this research mentioned that inadequate access to water was a significant inhibitor of their leprosy self-care practice:

'Aside from this, the other is lack of water. Sometimes when our borehole does not have water, it (self-care) is difficult to do...' (PT 20: Female, 42)

Self-care resources are crucial for practices to be enacted and sustained. However, beyond their availability, it is critical for self-care resources to be affordable, culturally and contextually appropriate and accessible. In addressing these issues and with due consideration for the socio-

economic status of people affected by leprosy, self-care programmes must deliberately differentiate between replaceable and irreplaceable materials.

5.7 Competing and Complementary Practices

In line with SPT, practices can complement or compete with each other (Shove et al., 2012).

5.7.1 Competing Practices

Competing demands relate to the impact of conflicting priorities and goals on adherence to a self-care routine. Many of these conflicting priorities appeared to be driven by the socio-economic status of people affected by leprosy, who generally belong to society's lower quartile due to the disabilities and stigma associated with the disease (Rodrigues and Lockwood, 2011; Bowers et al., 2014). Street begging, work demands, and economic hardship were reported as competitors for self-care.

5.7.1.1 Begging

Street begging, defined as soliciting financial favours in a public place (Lynch, 2002), appeared to be a significant inhibitor to leprosy self-care. Several participants interviewed reported prioritising begging over self-care. These participants leveraged that Islam promotes almsgiving and often targeted religious gatherings to beg. Also, begging seemed to be driven by old age, financial needs, and sustenance:

‘Although it is not every day that I go out to beg, but I usually don’t miss Fridays...To be honest, Fridays are the worst days for self-care because I have to leave home early to

ensure I have a good spot where I can be seen by those entering and leaving the mosque so I can get enough money.’ (PT 20: Female, 42)

Due to the need to draw pity from their targets, some participants reported they tended to ignore their self-care practices so that their targets could quickly notice their worsened physical condition. This set of participants seemed to believe that the more unkempt and severe their disability was, the more they drew sympathy and the more money they would get. Unfortunately, this belief made them consciously ignore caring for their bodies:

‘Begging sometimes gets in the way because you have to make people have mercy on you by showing your problems...’ (PT 12: Male, 50)

5.7.1.2 Work Demands

Some participants reported that striving to meet work demands did not allow them enough time to practice self-care as expected. Besides from this, the challenge of physical exhaustion was another factor that impeded on self-care routine:

‘As I said, the major issue that sometimes affects my self-care is that I have to go to work very early...And after I come home, I am sometimes too tired to do all the self-care procedures, so I do some like covering eyes before I sleep. And like I already mentioned, I don’t soak and oil every day.’ (PT 17: Female, 30)

5.7.1.3 Economic Hardship

People affected by leprosy's lack of financial resources were clearly expressed across the data corpus. This lack of financial resources is not surprising, as seven of the 20 participants in this study were unemployed. Furthermore, out of the other 13, nine participants were petty traders and subsistence farmers with low incomes, while the remaining four had jobs in the formal sector. It is interwoven across many themes and sub-themes emerging from data analysis; for example, several participants were forced into begging due to their low economic status, which competed for self-care. Here, it is referred to as a barrier to leprosy self-care, and participants reported they had difficulty in procuring and providing self-care materials:

'The major challenge I sometimes face is the lack of self-care materials. Especially the expensive ones like eye ointments. I apply it when it is available, but when it finishes I cannot...' (PT 11: Male, 35)

5.7.2 Complementary Practices

In this study, two complementary practices were identified by participants as facilitators of self-care practice. The first is Ablution and the other bathing.

5.7.2.1 Ablution

All participants were Muslims; carrying out Ablution five times a day is mandatory. For several participants, Ablution created an opportunity to reflect on the condition of their bodies. In addition, Ablution provided a constant and powerful reminder of the need to adhere to self-care routines:

'You know, I am a Muslim, and we have to pray at least five times a day. And each time, before we pray, we must do Ablution. Anytime I am doing Ablution, it reminds me of the need to also take care of my hands and leg.' (PT 11: Male, 35)

5.7.2.2_Bathing

Similarly, participants reported that bathing was an excellent reminder to carry out self-care. Also, linking self-care practice to bathing made it easier to comply with self-care expectations:

I told myself that after I bathed in the morning, I would do my self-care. The same thing is what I do in the evening after I take my bath before I sleep, and I have done this now for over three years. Each time I take my bath, it reminds me of the need for self-care (PT 13: Male, 50).

5.8 Chapter Summary

This Chapter presents the findings of the study. The results identified the factors that influence the engagement of people affected by leprosy in self-care practice. Data analysis was conducted through the lens of SPT and enabled the findings to be structured around its three core elements—competences, meanings, and materials. Results associated with competences included healthcare worker support and self-care knowledge and skills. Factors related to meanings included: social support, belief, inclusion, and fear of complications. Also, findings associated with materials included resources (availability, affordability, accessibility, and acceptability of self-care resources). Finally, the Chapter also identified practices that compete with and complement leprosy self-care practices.

CHAPTER 6

Discussion

6.1 Introduction

This Chapter aims to synthesise the findings from the data analysis of this phenomenological study. Also, it attempts to integrate the results into the existing literature on leprosy self-care. First, individual factors influencing leprosy self-care, including self-care knowledge and skills, family support; availability; affordability; acceptability; and accessibility of resources, are discussed. After that, the Chapter identifies and discusses other practices that could compete with and complement leprosy self-care practices. Next, it outlines how factors influencing leprosy self-care practice interact and how they could be conceptualised as the Leprosy Self-Care Continuum. Following this, the Chapter considers the contributions of SPT to leprosy self-care practice and research and concludes with a summary.

6.2 Healthcare Worker – Patient Relationship and Communication

Findings from this study highlighted the importance of effective healthcare worker-patient relationship and communication in improving leprosy self-care outcomes. In this study, several participants highlighted poor healthcare worker-patient interpersonal relationships, poor feedback, and inadequate attention to their views on some challenges they faced while interacting with healthcare workers. These negative interactions also appear responsible for patients' reluctance to share some of their problems during attending self-care clinics and non-compliance with self-care plans and routines. Therefore, it often amounts to negative consequences for their self-care outcomes.

For effective implementation of self-care for chronic conditions, research indicates that understanding and addressing the social context of people living with a chronic condition is critical for success. Healthcare workers, with the traditional role of diagnosis and treatment of disease conditions, are increasingly tasked to provide an avenue for patients to get involved in managing their conditions. In addition, they are expected to deliberately look out for and address patients' needs, values, and preferences (Epstein and Street, 2011). Hence, in addition to offering clinical management underpinned by evidence-based practice (Elissen et al., 2013), healthcare workers are encouraged to appreciate how patients experience ill health and to consider how these experiences are influenced by the availability of resources, physical environment, customs, and cultural norms.

Despite that, research on the healthcare worker-patient relationship shows that a person-centred approach is still to be achieved, especially for people from marginalised groups (Sointu, 2017; Chang et al., 2016). Similar to results in this study, Franklin et al. (2019a), reported that self-care engagements were less collaborative and person-centred for socially disadvantaged, stigmatised or more marginalised groups. In these instances, engagements were reported to be more formal and top-down. In addition, other reports highlight that people from stigmatised, marginalised, or disadvantaged groups are less likely to challenge or interrogate healthcare workers' professional advice, tend to ask fewer questions, receive less information and time, and are subjected to more negative evaluations by healthcare workers (Protheroe et al., 2013; Dubbin et al., 2013; Chang et al., 2017). For these reasons, more attention must be given to how structural and social factors influence healthcare worker-patient relationships and communication in leprosy self-care.

In adopting a social practice approach, this thesis highlights the need to acknowledge other essential factors in the self-care domain. These other factors include healthcare workers-patient engagement, the context in which this engagement takes place (e.g., clinic), the larger healthcare institutional setting (e.g., policies, self-care training/education programmes), and available resources (Franklin et al., 2009b). This notion of a self-care domain helps explain why achieving the desired person-centred goal of self-care, which involves equality in the healthcare worker-patient relationship, seems elusive in reality. Within the self-care domain, healthcare workers have the edge over patients. They have more power, control, and authority in the healthcare worker-patient relationship and over what is considered valuable or correct knowledge. This power disparity could explain why the knowledge of healthcare workers and the goals they set for patients continue to be valued in self-care policy, practice, and research. In this domain, patients' knowledge tends to be considered illogical or subjective compared to healthcare workers, who are seen as rational or practical (Kennedy et al., 2013). Patients are therefore viewed as passive recipients of care and knowledge in the care process (Pilnick and Dingwall, 2011; Nimmon and Stenfors-Hayes, 2016; Mudge et al., 2015). This study could explain why self-care training is not structured and organised and why patients could not understand the reasons behind some decisions—for example, the reluctance of some participants to apply cooking oil as a substitute for Vaseline.

For a better healthcare worker-patient relationship, patients are considered more equal partners, where their voices are heard, and their expectations, opinions, values, and wishes are given due attention. To achieve this, healthcare workers must work in ways that directly challenge or disrupt their deep-rooted assumptions and authority (Mol, 2008). While this may be the goal of

person-centred care, studies have shown that many healthcare workers are less willing to allow individual patient opinions and values and wish to override their professional knowledge and experience (Mudge et al., 2015; Ellis et al., 2017). Given this, a person-centred approach to self-care that recognises and integrates the patient's values, goals and wishes require a fundamental change in the rules underpinning self-care; and a reconfiguration of the normative values which determine what effective self-care entails.

6.3 Leprosy Self-care Knowledge and Self-care training

This study revealed that knowledge about leprosy and leprosy self-care is essential for a positive self-care outcome. In addition, this study revealed that current leprosy self-care training is uncoordinated, generic, and not tailored to the individual patient's needs.

Self-care training assists patients in understanding their disease condition, making decisions about self-care care needs, and informing changes in their lifestyle, actions, choices and behaviour to improve self-care. While the result is consistent with evidence from the literature on leprosy self-care (D'Azevedo et al., 2018; Gautham et al., 2011; Girma et al., 2019; Sathiaraj et al., 2010), this study amplifies the need to ensure that leprosy self-care education is coordinated and organised. Therefore, the results suggest that providing a generic template or framework for leprosy self-care practice would be inappropriate. Rather, a more appropriate approach would be to tailor interventions to the context and individual needs of the leprosy patient and any changes in their situation over time. Adopting such an approach will enable practitioners and policymakers to make more informed decisions about how leprosy self-care training will be initiated, sustained, and tailored to the specific needs of individual leprosy patients.

Considering the above finding, leprosy self-care training and education programmes should ensure that (i) educational content is tailored to the individual needs of the patient, (ii) the patient and the care-providing team agree on shared goals, (iii) training approaches or methods consider the learning style preferences, culture, and educational status of patients (Lagger et al., 2010). Therefore, the ultimate objective of leprosy self-care training and education programmes is to transform training/teaching into an individualised education programme, address observed skill gaps, mitigate inhibitors to self-care practice and improve self-care outcomes (Golay et al., 2008). Hopefully, this approach facilitates beneficial exchanges between an activated, informed patient and a proactive, prepared healthcare team (Kourakos, 2017).

However, irrespective of the gaps identified, three essential components must be included in the self-care training programme for all leprosy patients to ensure effective and sustainable outcomes. The first component should relate to medical management. For example, soaking hands and feet, scraping off dead skin tissue and callus, oiling hands and feet and ulcer management. The second component should relate to creating a new lifestyle, changing competing practices, or maintaining complementary practices. For example, emphasising consistent use of assistive and protective devices like footwear. The third component should include managing the negative emotional consequences of leprosy, such as depression, frustration, fear, and anger (Shahsavari et al., 2015). These negative emotions could be a barrier to sustaining leprosy self-care practices as they have been shown to reduce self-efficacy (Lin et al., 2004; Pouwer, 2009). Next, the self-care training programme should be tailored to the specific expectations of leprosy patients based on identified gaps and needs. This approach would enable co-constructing the education needs and adapting the training approach to suit the

patient and self-care objectives. Also, a periodic evaluation of the efficacy and outcome of the leprosy self-care training programme should be carried out to ensure sustainability.

A significant challenge capable of negatively impacting leprosy self-care training programmes is the limited or diminishing leprosy capacity or knowledge. According to the World Health Organisation, almost all endemic countries are currently affected by this dwindling leprosy capacity issue (WHO, 2021). Furthermore, this diminishing expertise affects the health workforce at all levels, as well as all facets of leprosy prevention, screening, diagnosis, treatment, and programme case management, including self-care (WHO, 2021). Hence, for these leprosy and self-care education and training programmes to be successful, this challenge must be kept in view and measures put in place to ensure continuous training and re-training of healthcare workers in leprosy and self-care.

6.4 Family Support

Beyond leprosy and self-care knowledge, this study also showed that family support positively facilitates leprosy self-care practice. As an integral component within the self-care context (Trief et al., 2003) in this study, ‘family members’ and ‘families’ are defined as two or more people related emotionally, legally, or biologically (Institute for Patient and Family Centred Care, 2009). Data analysis from this study highlighted that close involvement of family members leads to a variety of support for members who require self-care. For example, families were reported to provide tangible support like self-care materials (E.g., water, dressing materials). At other times family members offered emotional and psychological support, motivation, and encouragement, including self-care reminders to people affected by leprosy. This finding is in line with evidence

that suggests that patients have better self-care compliance and outcomes when they have increased family support (Boateng et al., 2018; Mendenhall and Norris, 2015; Abrahams et al., 2019).

In addition, the current study extends previous knowledge on leprosy self-care practice by highlighting that support from family members evokes a desire for belongingness and inclusion. It rouses the desire within people affected by leprosy to reciprocate the positive support they received from family members by carrying out self-care. This positive influence of family support on self-care could be partially explained by decreased depressive symptoms among patients with higher levels of family support, increased illness management, self-efficacy, and better self-management behaviour (Gallant 2003). Furthermore, family support has been reported to improve a patient's general health by lowering stress hormones and less blood pressure variation (Uchino 2006).

Despite these benefits, family involvement in leprosy self-care has not always been found to be positive. Also, results from this study reveal that family involvement in leprosy self-care is not systematic. While attempts are made to provide information on the general cause and symptoms of leprosy and the patient's role in managing their illness, the role of family members is often not addressed directly. Additionally, it was found in this study that family members could be non-supportive due to stigma. For example, a husband did not allow his wife to participate in self-care group meetings because he wanted her condition concealed due to stigma. According to De Stigter et al. (2000), leprosy negatively impacts the entire family. Family members of people affected by leprosy often face prejudice, stigma and discrimination, including violation of their

rights. For example, children have been reported to face discrimination in school, while spouses have been reported to lose their jobs. These negative experiences force many family members of people affected by leprosy to adopt various coping mechanisms such as concealment and dissociation (De Stigter et al., 2000). In recognising this challenge of stigma, discrimination and violation of human rights faced by family members of people affected by leprosy, the United Nations Human Rights Council adopted Resolution 29/5. This Resolution seeks to eliminate discrimination against persons affected by leprosy and their family members (United Nations Human Rights Council, 2015). Consequently, a United Nations Human Rights Council Special Rapporteur for the elimination of all forms of discrimination against persons affected by leprosy and their family members was appointed in November 2017 to champion this cause.

Furthermore, participation of family members in the self-care of their members have been reported to cause stress and friction between family members and persons needing self-care in instances of adhering to their self-care routines and staying healthy (Boateng et al., 2018; Mendenhall and Norris, 2015; Abrahams et al., 2019). Family members can make it harder or easier for patients to achieve their self-care goals by creating the emotional, social, and practical context for self-care (Whitehead et al., 2018).

Given family members' critical role in self-care and the stigma and discrimination they often face, mechanisms should be put in place to ensure they are adequately equipped to provide proper support. Such mechanisms would enhance their effectiveness, minimise caregiver burnout and assist them in coping effectively with stigma and discrimination.

Preventing caregiver burnout is particularly important in settings like Northern Nigeria, where women caregivers may not be open to communicating their challenges because of cultural expectations to care for their family members (Okeke, 2017). The situation worsens as women's roles in Northern Nigeria are expanding. Many more women are getting educated and employed (i.e., taking up more roles outside the home) to complement family income. This changing role increases their overall workload, whereby they must support a family member who requires self-care (Okeke, 2017). Because of this, the following specific actions are recommended for leprosy self-care programmes involving family members:

- Assess the influences and roles of family members in individual leprosy patients' self-care practice and apply this information to tailor self-care advice.
- Train family members in the following critical roles aimed at enhancing their engagement in leprosy self-care practices: a) 'doing' tasks (e.g., provision of self-care materials), b) facilitating, reminding, motivating, and partnering in self-care practice, c) participating in decision making and problem-solving, d) helping patients cope with symptoms and stress, e) helping patients connect to information and community resources required for self-care, f) supporting patients to integrate self-care into existing life roles, g) assisting in tracking clinically-related data, that may influence referral decisions, h) managing clinical appointments, and i) supporting patient-healthcare provider communication.
- Support family members to learn advocacy, communication techniques and skills that will equip them to deal with the stigma and discrimination they might face and make them more effective at assisting patients.

6.5 Impact of Stigma, Discrimination and Social Inclusion

Another study result indicated that the desire for family/community participation and social inclusion are critical drivers in encouraging leprosy patients to practise self-care. Several participants in this study reported that they engaged in self-care because their physical condition improved their social inclusion and community participation. In addition, participants enhanced body image helped to reduce stigma and discrimination against them. Although these findings are consistent with previous studies (Cross and Choudhary, 2005; Hofstraat and van Brakel, 2016), this study deepens previous knowledge on the impact of stigma on self-care by revealing that self-stigma negatively influences self-care practice. Self-stigma is believed to inhibit self-care by decreasing self-efficacy (Link et al., 2001; Corrigan et al., 2006); and triggering the concealment of the disease and disabilities (Heijnders, 2004).

Concealment occurs when an individual consciously diminishes functional limitations (Pachankis, 2007). These practical limitations could be social, cognitive, psychological, or physical, as in leprosy. Concealment may occur in a variety of ways. For example, it may happen by minimising the impact of the condition by diminishing its visibility or playing down the limitations it causes, or it may be by denying the existence of the limitation to other people. According to Heijnders (2004), concealment could occur before, during, or after leprosy treatment. In this study, people affected by leprosy concealed their condition due to self-stigma. For example, many people affected by leprosy preferred to hide their conditions by refusing to use protective shoes supplied by the self-care programme. Instead, they chose to use everyday shoes (which may not offer enough protection for their feet) than risk being identified as having leprosy. Similar behaviour has been observed among visually impaired young people who are

reluctant to use white canes due to the stigma of carrying one (Worth, 2013). Similarly, this behaviour has been reported among diabetic patients who conceal their ulcers (Kato et al., 2015). Such concealment by persons affected by leprosy could also be linked to the acceptability of materials discussed in section 6.5 of this Chapter.

To minimise concealment and its negative impact on leprosy self-care outcomes, providers should ensure beneficiaries are involved in designing and developing these materials, particularly assistive or protective devices. Their involvement would hopefully ensure that finished products are acceptable to people affected by leprosy. For example, in a study assessing the development of assistive technology for visually impaired and blind people, Bradley and Dunlop (2008) established the need for users to be involved in the design process of such devices. Their involvement improved user-friendliness and the effectiveness of devices. In addition, it enhanced physical functioning and supported psychological and social independence.

Another approach to mitigating concealment is through peer support, which is effective in mental health (Masuda and Boone, 2011) and HIV/AIDS (Chime et al., 2019). In the context of leprosy self-care, receiving peer support through belonging to a self-care group has been reported to minimise concealment by increasing the self-confidence of people affected by leprosy (Benbow and Tamiru, 2001; Ebenso et al., 2009; Darlong, 2021). Therefore, more effort is needed to improve peer support through the effective implementation of self-care groups. Furthermore, concealment can be minimised by integrating interventions that promote social inclusion in self-care programmes.

Concealment is not always a negative phenomenon as it has some benefits (Pasek et al., 2017). For example, concealment has been reported as a protective mechanism for those prone to being socially anxious (Cole et al., 1997). Furthermore, successful concealment has also been reported to aid professional advancement and other self-relevant goals requiring external acceptance by preventing prejudice (Gupta and Jürges, 2012). In addition, Individuals have referred to concealment as protective, citing concerns about disclosure, such as worries about being bullied, losing relationships, and being viewed as different (Freeborn et al., 2013). Finally, the flexibility to choose if, when, and how to disclose provides a sense of personal control, highlighted as an intrinsic and essential social need (Fiske, 2004).

6.6 Fear of Complications

In this study, healthcare workers apply fear appeals to encourage and entuse patients to adhere to their leprosy self-care routines. This approach seems to have worked with some patients who described being afraid of developing complications as their motivation for implementing self-care. However, in some instances, persistent fear seems to inhibit learning and effective self-care practice. Similar results were reported in research carried out in China, which showed that worries and fear about complications were the significant concerns and preoccupations of patients with type 1 and 2 diabetes (Shiu and Wong, 2002). Furthermore, according to Jeon et al. (2010), fear can emanate from a feeling of loss of control and powerlessness. Fear was reported to limit self-care behaviour (Brundisni et al., 2015), which increased the possibility of complications.

Scare tactics and seemingly demeaning communication approaches by healthcare workers in this study appear to raise some critical practice and ethical dilemmas. A key issue is training healthcare workers to identify practical alternatives to scare tactics. However, if scare tactics must be applied, Witte and Allen (2000, pp. 605) posit:

Fear appeals motivate attitude, intention, and behaviour changes—especially fear appeals accompanied by high-efficacy messages. Therefore, they can be pretty valuable for practitioners. However, fear appeals should be used cautiously since they may backfire if target audiences do not believe they can avert a threat effectively.

An ethical dilemma would be if self-care programmes will be happy to promote scare tactics if it leads to sustainable practices without negative psychological consequences or impact. While ample evidence supports the effective use of scare tactics in some public health interventions, for example, smoking cessation programmes (Tannenbaum et al., 2015), confirmation for its successful application in promoting adherence to self-care in chronic conditions is limited (Harvey and Lawson, 2009). Thus, this study highlights the need for research into the benefits or otherwise of scare tactics in leprosy self-care practice in Nigeria. In addition, a deeper understanding of patients' beliefs about their condition and the meanings and motivations for self-care could influence or moderate the use of scare tactics and promote a more patient-centred approach (McCormack and McCance 2016).

6.7 Availability, Affordability, Accessibility, and Acceptability of self-care Materials

A key contribution of this study is that self-care materials' availability, affordability, accessibility, and acceptability are essential for an effective leprosy self-care regimen. Also, they are critical factors for 'initiating', 'retaining' and sustaining leprosy self-care practice. For instance, findings from this study highlighted the affordability of these materials and leprosy patients' financial capacity to provide for themselves. However, the availability of self-care materials is complicated by a policy that discontinued the free supply of self-care materials to leprosy patients and placed the responsibility of sourcing self-care materials on leprosy patients (The Leprosy Mission-Nigeria, 2008). This policy was driven by the need to ensure the sustainability of self-care interventions in the face of dwindling donor funds. However, it appears its implementation may not have been well planned, as findings from this study showed that many leprosy patients struggled to meet the resource requirements for self-care.

This study suggests that uninterrupted access to leprosy self-care materials is required to sustain the practice. Given this, there is a need for self-care programmes to appreciate the financial capacity of leprosy patients, their access to and acceptability of substitute self-care materials and adapt care accordingly. This finding, therefore, reinforces the need for tailored self-care interventions. Furthermore, it is clear from this study that the policy expectation that people affected by leprosy should source for all their self-care materials is not practicable as many persons affected by leprosy cannot do so sustainably. Thus, this study suggests that special attention should be paid to sustainability elements like the availability and affordability of self-care materials for better leprosy self-care outcomes.

Addressing issues relating to the availability and affordability of self-care materials has profound implications for leprosy self-care policy and practice. Ensuring the availability and affordability of self-care materials is especially important in low-income settings like Nigeria, where the general poverty in the society, coupled with the prevalence of stigma and discrimination, worsens the socio-economic outlook for people affected by leprosy (Ebenso et al., 2007). Therefore, the practical implication is that self-care programmes must find creative ways to integrate financial empowerment programmes within self-care interventions to improve sustainability. An example is Nepal, where self-help activities are integrated into self-care programmes. While self-care assuages the bio-medical consequences of leprosy, the emphasis on self-help is on the socio-economic impact of the disease. Therefore, self-help interventions often include training in income generation activities and the provision of start-up funds (Shrestha et al., 2021).

6.7.1 Replaceable' and 'Irreplaceable' Materials

The affordability of leprosy self-care materials also spotlights another key and novel finding in this study: the concept of 'replaceable' and 'irreplaceable' materials, which also affects the sustainability of leprosy self-care practice. Replaceable materials are self-care materials that could be substituted, e.g., bandages and lubricants, which could be substituted with old rags and home cooking oils. On the other hand, irreplaceable materials are those self-care materials that cannot be substituted, e.g., water and eye ointment. Since there are no alternatives to irreplaceable materials, patients are left with no choice but to buy such materials to sustain their lifelong self-care routines. Moreover, many leprosy patients live below the poverty line, which burdens their already meagre resources. Thus, this categorisation of self-care materials reiterates

the need for self-care providers to assess people affected by leprosy's financial capacity during the design of self-care interventions. Furthermore, assessing leprosy patients' finances will help identify patients who can afford the irreplaceable materials and those who cannot. Thus, arrangements can be made for those who cannot afford irreplaceable materials to ensure the uninterrupted supply of such materials.

However, for replaceable materials, a modification of practices due to evolution and change in these materials and its impact on the sustainability of practices is a unique aspect of SPT that requires further exploration. Such material changes have been reported to improve, disrupt, or terminate self-care practice (Blue et al., 2016).

Benbow and Tamiru (2001) reported similar findings while studying leprosy self-care group members in Ethiopia. The authors found that many people affected by leprosy in Ethiopia were reluctant to practice self-care when the self-care programme stopped supplying bandages and petroleum jelly and encouraged them to source locally available, low-cost alternatives. Their reluctance was due to an erroneous belief that petroleum jelly was medicinal even though it was recommended solely for its lubricant properties. Given the potential of such misconceptions and their negative impact on the acceptance of alternative self-care materials, providers need to ensure systematic leprosy self-care education to clarify each self-care material's role and mechanism of action. Integrating such topics in self-care training programmes will assist in providing the correct information and dispelling myths and misconceptions surrounding self-care materials and their mechanism of action.

6.7.2 Centrality of Water to Leprosy Self-Care

Additionally, the study's findings revealed that accessibility to water was a significant influencer for leprosy self-care practice. As part of their self-care protocol, persons affected by leprosy must soak their hands and feet in water for at least 30 minutes daily (Netherlands Leprosy Relief, 2007). In addition, regular bathing, laundry, washing, and disinfecting surfaces are other water-related activities that could indirectly impact the outcome of leprosy self-care. These personal and environmental hygiene practices improve self-care by reducing the risk of secondary or opportunistic infections, complicating self-care. Moreover, bathing has been identified as a complementary practice for self-care (This is described in detail in section 6.8.2). Other benefits of water in self-care include optimising self-care outcomes. For example, drinking enough water ensures individuals remain adequately hydrated, thus promoting wound healing (Ousey et al., 2016). Water also assists in promoting the management of chronic pain and infections, for example, swallowing antibiotics with water to treat infections and antipyretics and analgesics to reduce fever and pain (International Federation of Anti-Leprosy Associations, 2006).

Hence, it is essential for leprosy self-care programmes to deliberately analyse and address the technical and social barriers to accessing water to ensure uninterrupted access to water. Technical barriers are usually structural and include not being able to collect water alone, carrying water over long distances, and finding water taps and well walls too high (Tesfu and Magrath, 2006; Pradhan and Jones, 2008). Furthermore, even where they can carry water, they may face difficulty moving the amount they need (Kendra, 2008). On the other hand, social barriers, including stigma and discrimination from other people when using public and household water sources, may hamper access. Similarly, fears that people with disabilities would

contaminate water sources have been reported to make community members deny them access (Pradhan and Jones, 2008). Given that water has been identified as an irreplaceable leprosy self-care material and coupled with the challenges often faced by people affected by leprosy in accessing water, more effort is needed to ensure an uninterrupted supply of water to people and communities affected by leprosy.

6.8 Competing and Complementary Practices

Another significant finding in this study is the ability of complementary practices to facilitate leprosy self-care and competing practices to inhibit it. Thus, this study deepens previous knowledge on leprosy self-care by identifying the need for healthcare workers supporting leprosy self-care programmes to deliberately assess and seek practices that may complement or compete with leprosy self-care. Hence, to sustain leprosy self-care outcomes, self-care programmes must find creative and practical ways to identify and promote complementary practices while discouraging competing ones.

6.8.1 Religious Practices and Belief

In this study, the religious practice of fasting or the annual Ramadan observed by Muslims was revealed as a significant barrier and competing with self-care practice. Considering that the act of fasting is energy-consuming, several participants in this study, who are all Muslims, said they were left with little or no energy to carry out self-care after fasting. This finding is also interesting because, in Islam, sick persons during Ramadan are exempted from fasting (Pinar, 2002). However, once they recover, they are obligated to fast for the missed days, pay some money, or feed the poor (Pinar, 2002). For leprosy patients, paying some money or feeding the

poor may be complicated due to their low financial status. Furthermore, fasting to make up for the missed days may also prove problematic, considering that leprosy self-care is a lifelong practice.

On the other hand, data analysis identified Ablution as a critical facilitator that complemented leprosy self-care practice. Ablution is a congruent Islamic religious ritual that requires regular washing of the hand and feet. Some of the participants in this study stated that regular Ablution was a facilitator for self-care because it acted as a reminder to undertake self-care. This finding is consistent with results from a previous study on leprosy self-care in northern Nigeria which also showed that Ablution was a positive facilitator of self-care practice among people affected by leprosy (Gidado et al., 2010).

However, despite its impact on health, religious belief and practices are often not considered by clinicians and biomedical researchers (Balboni et al. 2007; Koenig 2002). The relative lack of interest in this field is attributed to insufficient evidence for the relationship between religion and health (Koenig, 2012). Also, the general view that faith is personal tends to be an additional bottleneck to consider in clinical care (Koenig, 2012). One exception might be palliative care, where pastoral care is a common approach in many clinical settings, especially when dealing with end-stage conditions. Another domain where religious beliefs and practices have gained attention is mental health. It has been reported as a positive facilitator in maintaining mental health and overall well-being (Polzer et al., 2007). A study looking at the relationship between religion and mental health found that the way individuals understand the connection between appraisal, attention, and beliefs in preventing emotional disorders is mediated or influenced by

religious belief. Also, studies among individuals suffering from other chronic conditions such as systemic sclerosis and rheumatoid arthritis revealed people's belief that despite their effort to promote their health, God still had sovereign control over such efforts (Keonig, 2012).

Given the significant influence religious practices could have in promoting and sustaining leprosy self-care practice, it is recommended that the spiritual history of all new people affected by leprosy attending self-care clinics should be documented. The aim is to learn a) the religious background of the patients, b) the extent to which religious beliefs or practices act as a coping mechanism or as a source of distress, and c) religious beliefs or practices that may compete with or promote self-care, d) any spiritual needs that might need to be addressed (Bayhakki and Thaniwatthananon, 2019; Baoteng and Evans, 2018; Permana et al., 2019). All religious and spiritual beliefs and practices revealed during this spiritual history-taking must be respected. Healthcare workers are expected to take neutral positions and not challenge (at least not initially) those beliefs, even if the beliefs seem pathological or bizarre or even conflict with expected self-care routines. Where beliefs are complementary and healthy, actively supporting them would be necessary. Challenging beliefs of patients are most likely to be resisted by the patients and could lead to non-compliance. Healthcare workers should consult appropriate spiritual leaders, e.g., Chaplains and, in this case, Imams, to address these.

Furthermore, healthcare workers should receive proper training to collect patients' religious and Spiritual history (Bayhakki and Thaniwatthananon, 2019; Baoteng and Evans, 2018; Permana et al., 2019). Hence, appreciating the critical role religion and belief can play in the failure or success of self-care and the importance of integrating spirituality into self-care programmes and

protocols may contribute to a culturally competent and holistic approach to self-care. However, further research may be needed to explore how healthcare workers may integrate spirituality and religion into self-care support programmes in Nigeria and how religious leaders and institutions can support leprosy self-care.

Equally, involving religious leaders and institutions in leprosy self-care needs to be carefully planned. Their involvement is critical because they need to be trained to address some of the teachings and stories in their holy books that continue to reinforce the myths, misconceptions and prejudices surrounding leprosy. For example, in Islam, a very popular Hadith admonished people to run away from leprosy patients as they would from a lion (Al-asqalani, et al., 1993 cited in Hasnain et al., 2020). Similarly, specific Bible texts seem to suggest that leprosy is a result of sin, punishment or the will of God (New International Version Bible, 2011, 2 Kings 5: 20 – 27). On the other hand, some religious texts seem to have a favourable view of leprosy. For example, in another Islamic Hadith, the Prophet Muhammad was reported to share a meal with a person affected by leprosy (Al-Tabari and Jarir, 1995 cited in Hasnain et al., 2020). Furthermore, Bible stories such as Christ's touching and publicly healing a leprosy patient project an attitude of love and acceptance towards persons affected by leprosy (New International Version Bible, 2011, Matt 8: 3).

Leprosy is intricately connected with many of the world's great religions. Aspects of leprosy covered in the texts of some of the world's religions are indicated in table 6.1.

Table 6.1: Items Relating to Leprosy found in Religious Texts

Items relating to leprosy found in religious texts	Christianity	Islam	Hinduism	Sikhism	Buddhism
Signs, symptoms and diagnosis of leprosy	Yes	No	Yes	Yes	No
Treatment and confirmation of cure	Yes	Yes	Yes	Yes	No
Restriction to participate in places of worship	Yes (Old Testament) No (New Testament)	No	Yes	Yes	No
Laws relating to leprosy in religious texts	Yes	No	Yes	No	No
Treating persons affected by leprosy as unclean due to ulcers and deformities	Yes	Yes	Yes	No	No
Ostracising or keeping away of leprosy patients	Yes	Yes	Yes	Yes	No

(Source: Raju et al., 2020)

Given these strong and sometimes contradictory teachings and their role in perpetuating the myths, misconceptions and stigma surrounding leprosy, religious leaders and institutions must be trained on the appropriate knowledge and response to leprosy and leprosy self-care. This training would ensure their involvement leads to meaningful, effective and sustainable outcomes.

6.8.2 Bathing

Like Ablution, bathing was revealed as a critical facilitator of leprosy self-care practice. Bathing is critical because it shares many materials applied in leprosy self-care. These include water, soap, sponge (like the pumice stones), and body creams or oils. Several participants mentioned bathing regularly was a potent reminder to carry out their self-care routine. The striking similarity between materials applied to leprosy self-care and bathing appears to inform the basis for this reminder. In addition, others mentioned that leprosy self-care became less of a burden when they aligned it with their regular body washing and bathing.

In essence, the morning routine of waking up, getting out of bed, and showering or bathing is an example of one nexus of social practices that provides a powerful stimulus for leprosy self-care. At the micro-level, this knowledge informs self-care programme managers to integrate personal hygiene promotion as part of their leprosy self-care programme. Thus, improving personal hygiene literacy and practices among people affected by leprosy may help improve leprosy self-care practices. Furthermore, bathing as a facilitator for leprosy self-care underscores the importance of ensuring access to an uninterrupted water supply in leprosy communities. The availability of water and challenges faced by persons affected by leprosy in accessing water is discussed earlier in section 6.7.2.

6.8.3 Street Begging

This study also revealed street begging as a practice that could inhibit leprosy self-care practice. This is because several participants in this study reported using their worsened disability to attract sympathy to enhance the receipt of alms while begging. As a result, they stopped

practising self-care to prevent improvements in their physical impairments and disability to maximise their income from begging. Begging was also found to compete for self-care practice time. Many participants reported they would rather choose to go begging than implement self-care if they thought they would miss an opportunity to make money. These findings were consistent with a previous study from India, which revealed that leprosy patients' financial problems were a significant impediment to self-care practice as they would often choose to beg rather than care for themselves (Chakraborty et al., 2006).

According to Lynch (2002), street begging is voluntarily soliciting a unilateral gift in a public place. Although it is prevalent in developing countries, it is a global phenomenon and is understood to emanate from multiple reasons which have taken place over time. In this study, 12 of the 20 participants admitted to begging. Out of the 12, seven (35%) were full-time beggars, all of whom were unemployed, and begging was their only income source. These findings are consistent with the literature, which showed that 60% to 100% of people affected by leprosy undertake to beg for alms as a means of economic sustenance (Kaur and Van Brakel, 2002). While economic reasons were identified as the leading cause of begging in this study, its prevalence has been attributed to several other causes such as gambling, alcohol and drug addiction, social security inadequacies, mental illness, and physical disabilities (Ripley, 2010; Ogunkan and Fawole, 2009; and Fawole et al., 2010). Also, Cook (2010) argues that a common challenge is that people could become so accustomed to begging that they prefer not to work. Many believe they could make more money from begging than from working.

This study also indicated that begging could be driven by self-stigma. Self-stigma reduces people's feelings of self-worth, undermines self-esteem, diminishes optimism, and extinguishes hope (Corrigan et al., 2006; Livingston et al., 2011; Watson et al., 2007). Over time, the impact of self-stigma stimulates a sense of learned helplessness, and low productivity becomes ingrained in their minds. Thus, they accept these roles society constructs for them; and choose to go begging instead of striving to look for employment opportunities (Lockwood, 2004). Building on the argument that an individual tends to beg due to their prevailing circumstances, it is noted that begging is perceived as a better option for satisfying immediate needs than resorting to criminal activities such as prostitution, drug dealing or theft (Lynch, 2002).

Additionally, religious and cultural attitudes towards begging may also contribute. Many participants in this study appeared to leverage the fact that Islam encourages almsgiving, thus indulging in begging. This is because where religious practices encourage people to give to the poor and needy, it seems to beg may be more tolerated. The encouragement to give to the needy and less privileged is not peculiar to Islam, as other religions, such as Christianity and Judaism, also encourage almsgiving (Levenson, 2018).

Given the negative impact of street begging on leprosy self-care and the myriad reasons behind its practice, self-care programme managers must be aware of these and identify individuals who engage in street begging to co-construct a solution (Jelili, 2009). The need to co-construct a solution further strengthens a central argument of this thesis that self-care interventions need to be tailored and individualised. Therefore, people affected by leprosy needing self-care should be assessed to ascertain their disposition towards begging, and practitioners must work with

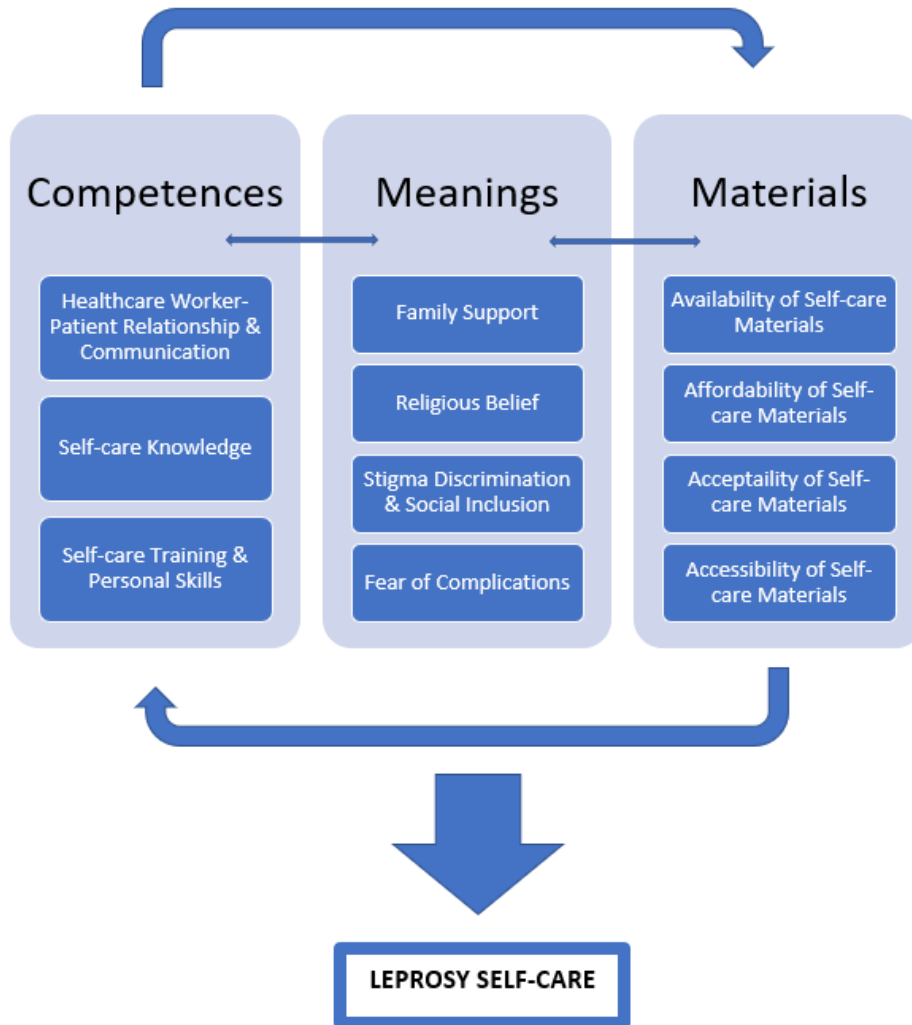
individuals to outline measures to address these. Otherwise, efforts at sustaining self-care practice may be compromised. Interventions and approaches that will effectively address the challenges of begging will be multi-dimensional and likely to go beyond the mandate of local self-care programmes. These might include 1) socio-economic interventions and poverty reduction programmes, 2) religious, psychological, and mental well-being interventions, including counselling, 3) physical planning measures, and 4) policy and legal interventions (Jelili, 2009), for example, implementing the provisions of the Discrimination Against Persons with Disabilities [Prohibition] Act (2018) which prohibits begging based on disability.

6.9 Factors Influencing Leprosy Self-care Practice may Interact

This study's original contribution to leprosy self-care practice knowledge is that factors influencing leprosy self-care practice may interact. These interactions could affect an individual's interest, drive, motivation, disposition, and ability to initiate, sustain and effectively carry out leprosy self-care practice. These interactions could occur across or within the three core elements of SPT – meanings, materials, and competences (Fig 6.1). For example, under 'Meanings', a high level of family support could help reduce stigma and improve social inclusion. Under 'Competences', poor healthcare worker-patient relationships could lead to ineffective communication and poor self-care knowledge and skills among people affected by leprosy.

Furthermore, under 'Materials, unaffordability of self-care materials could limit the accessibility of leprosy patients to basic self-care materials. Across core elements, a high level of family support (Meaning) could suggest that families were happy to provide self-care resources to support the self-care of their family members (Materials). This, in turn, enhances an individual's desire, drive, and disposition to learn and implement self-care practice (Competences).

Figure 6.1 Factors Influencing Leprosy Self-Care Interact



(Source: Author)

The interaction of factors could affect the quality of leprosy self-care practice. It also could affect the ability and motivation of individual leprosy patients' adherence to their self-care routines. This understanding could aid self-care planners in identifying a 'factor portfolio' that will assist in determining the self-care support required by individual leprosy patients.

In addition, this study revealed that factors that influence leprosy self-care practice could be categorised across three levels - micro, meso and macro-levels. Such categorisation would enable interventions to be simultaneously targeted at each of these levels to maximise the impact of leprosy self-care programmes. Factors at the 'macro-level relate to changing policies, systems, and structures. Factors at meso-level involve making changes at the family or community level, while factors at the 'micro-level relate to changes at the individual level. For example, interventions aimed at addressing self-stigma could be considered micro-level interventions. However, interventions addressing family and community inclusion could be considered meso-level interventions, while healthcare worker relations and communication could be viewed as macro-level interventions.

Similarly, interventions to improve the self-care skills of individual leprosy patients could be considered micro-level interventions when seeking to address competences required for leprosy self-care. In contrast, interventions aimed at improving family members' skills and competences to support their self-care could be considered meso-level interventions. Similarly, interventions addressing competencies required by healthcare workers to provide effective self-care support could be viewed as macro-level interventions. This understanding can inform self-care planners and programme managers to articulate a rigorous but complex labyrinth of interconnected and interrelated interventions that can create the basis for a robust multi-level leprosy self-care strategy. Such an approach will likely ensure that self-care interventions are comprehensive and practical, facilitate positive and sustainable patient outcomes, and avoid fragmentation of leprosy self-care services.

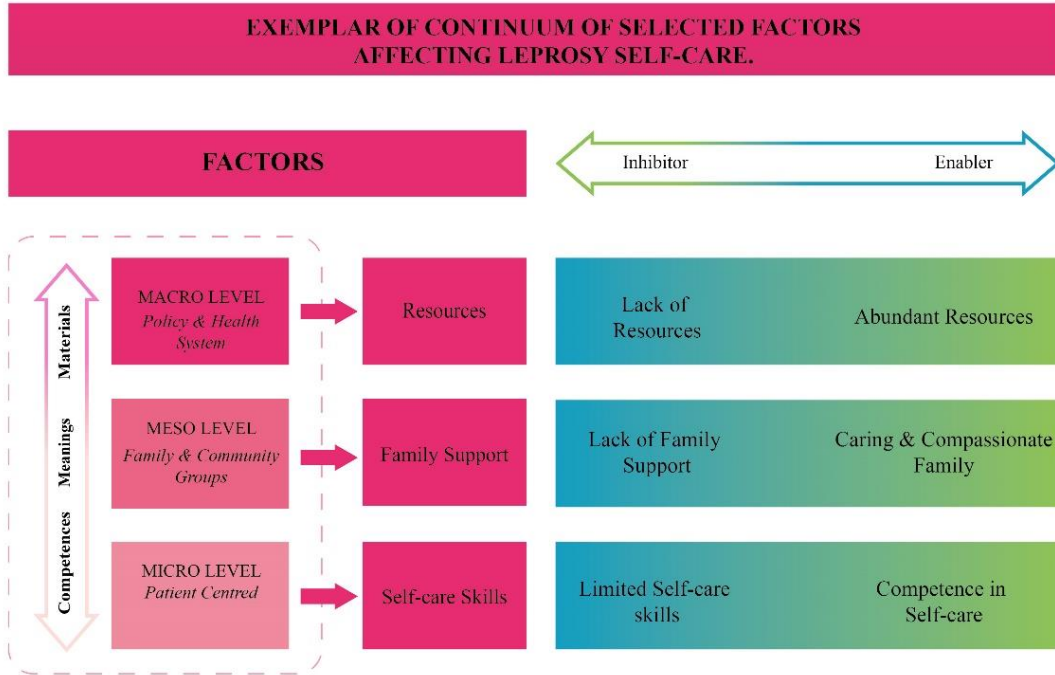
6.10 Factors Influencing Leprosy Self-care Practice may occur in a Continuum.

Another novel contribution this study makes to leprosy self-care practice knowledge: factors affecting leprosy self-care occur in a continuum. This notion is conceptualised as the leprosy self-care continuum (LSCC). Primarily, the LSCC suggests no absolute presence or absence of factors affecting leprosy self-care practice. Instead, it indicates various degrees of positive (enabler) or negative (inhibitor) influence depending on the location of the individual along the continuum (Fig 6). For example, involving family members in the self-care of their relatives may be a positive factor (enabler). For example, they show care and compassion by providing support (e.g., reminding family members of self-care routines or helping with self-care resources such as fetching water).

On the other hand, family involvement could also be a negative factor (inhibitor). For example, when the family is not supportive (e.g., preventing one's spouse from using protective shoes due to stigma concerns), or somewhere in the middle, when actions that are indeed beneficial may be construed as bothering and pesky. Also, leprosy patients may not have the self-care materials they require (inhibitor), may have some, and may have all they need (enabler). Moreover, under 'Competences', patients may have limited self-care skills (inhibitor) and may be competent in self-care (enabler) or may lie somewhere between poles, where they lack specific skills. A similar finding is reported by Schulman-Green et al (2016), who conducted a meta-synthesis describing factors affecting self-management in chronic conditions. The meta-synthesis showed that factors affecting self-management of adults with chronic conditions may interact and may also exist on a continuum of positive (enabler) to negative (inhibitor).

The left panes of the schematic (Fig. 6) describe the factors influencing leprosy self-care practice. This part of the schematic relates to the three core elements of SPT ('competences': 'meanings' and 'materials) and the three levels of leprosy self-care interventions (micro, meso, macro). On the other hand, the right pane describes the two poles of the continuum as factors ranging from inhibitors to enablers. As a continuum, the framework suggests that an individual can move bi-directionally along the continuum, contingent upon changes. This potential for bi-directional movement along the LSCC highlights the need to understand individual patients' personal and contextual circumstances before and during leprosy self-care implementation. Understanding the patient's personal and contextual circumstances helps to inform tailored and individualised interventions. Also, conceptualising factors influencing leprosy self-care as being on a continuum ranging from negative (inhibitors) to positive (enablers) suggests that self-care interventions aim to assist individuals in moving towards the positive end.

Figure 6.2: Leprosy Self-Care Continuum (LSCC) - Exemplar factors affecting leprosy self-care practice



(Source: Author)

The availability of a specific conceptual framework could facilitate the development of suitable and sustainable leprosy self-care interventions. Furthermore, it could improve the understanding of leprosy self-care and promote pragmatic field-based research.

Thus, this thesis advances a comprehensive and practical framework that attempts to conceptualise leprosy self-care in its totality and can be applied by all stakeholders. Furthermore, the proposed Leprosy Self-Care Continuum heralds a new way of conceiving leprosy self-care

that could influence the initiation, implementation, monitoring and evaluation of leprosy self-care interventions.

The LSCC represents a consolidation of various interactions among factors that influence leprosy self-care. Leprosy self-care consists of several individual-level activities such as daily inspection of their eyes, hands and feet and soaking. Leprosy self-care also requires family and healthcare system-level interventions. While these activities are interrelated, they are sometimes approached as separate activities. Therefore, LSCC provides a comprehensive, multi-level framework addressing significant leprosy self-care aspects. Also, it allows a logical linkage between them and provides a model on which metrics for measurements can be developed and based. Thus, the LSCC offers real-life conditions and a model that allows all stakeholders to understand the different factors influencing leprosy self-care and their interconnectedness.

A particular strength of the LSCC is that it highlights the inter-relationship between the three elements of SPT and how this impacts leprosy self-care. This inter-relationship can assist leprosy self-care planners in identifying the various distinct factors affecting leprosy self-care capabilities and capacities across different scenarios and settings. In addition, since the LSCC is underpinned by research, it enables stakeholders to apply an evidence-based approach to determine the initiation and deployment of suitable leprosy self-care interventions. On the other hand, a limitation of the LSCC is that it is based on a single case study. However, it has resulted from natural data gleaned from the meanings, experiences and perspectives of people affected by leprosy. As such, it could be adapted to other Neglected Tropical Diseases (NTDs) of the skin, which share similar characteristics as leprosy and require self-care. For example, it could be

applied to facilitate integrated morbidity management of neglected tropical diseases, such as combined self-care groups for leprosy, lymphatic filariasis and buruli ulcer (Mieras et al., 2016)

The LSCC provides a model for the study and creation of relevant policy instruments for leprosy self-care, facilitating a collective approach to leprosy self-care interventions. Therefore, the LSCC could be applied as a suitable framework for evaluating leprosy self-care interventions as it ensures that the different components of leprosy self-care across the three levels and elements of SPT are considered. Furthermore, an objective evaluation of leprosy self-care interventions using the LSCC could help engender a culture of evidence-based conception for leprosy self-care interventions.

Furthermore, the LSCC suggests self-care goals must be understood as socially constructed, complex phenomena instead of outcomes of distinct individual action produced by increasing individual self-efficacy or patient knowledge as emphasised by behavioural models. Given this, individuals affected by leprosy requiring self-care should first be assessed (Table 6.1) to locate them on the LSCC to establish the personal and contextual factors that may affect their self-care practice. Taking such an approach is radically different from the current practice, where leprosy self-care is offered as a generic intervention without considering other contextual requirements that may impact individual leprosy self-care practices.

Table 6.2: Assessment Criteria for Planning Leprosy Self-care Interventions

Level	Focus	Exemplar Assessment Criteria
Macro	Policy and	<u>Meanings:</u>

	Healthcare System	<ul style="list-style-type: none"> • Level of integration into other complementary interventions (WASH, NTDs., etc.) • Impact of begging. • Impact of public stigma and discrimination. • Level of involvement of religious institution. <p><u>Materials:</u></p> <ul style="list-style-type: none"> • Accessibility to self-care materials, particularly ‘irreplaceable’ materials (Water, eye ointment). • Access to assistive and protective devices. • Access to self-care clinics. • Access to referral services. <p><u>Competences:</u></p> <ul style="list-style-type: none"> • Policy on leprosy Self-care (Referral, Self-care Groups). • Implementation guidelines and frameworks for leprosy self-care. • No. of healthcare workers involved in leprosy self-care. • Healthcare workers' skills, knowledge and attitude (Leprosy, self-care, communication). • Availability and quality of leprosy self-education programme.
Meso	Family and Community Groups	<p><u>Meanings:</u></p> <ul style="list-style-type: none"> • Level of participation and inclusion in family life.

		<ul style="list-style-type: none"> • Level of participation and inclusion in community life • Membership in self-care groups. <p><u>Materials:</u></p> <ul style="list-style-type: none"> • Nature and level of tangible support from family members. (Financial, material, emotional). <p><u>Competences:</u></p> <ul style="list-style-type: none"> • Family members' skills, knowledge, and attitude (Leprosy, self-care, communication). • Level of the functionality of self-care groups.
Micro	Patient-centred	<p><u>Meanings:</u></p> <ul style="list-style-type: none"> • Meanings and motivations for self-care. • Self-efficacy. • Impact of self-stigma. • Religious beliefs and practices. • Patient's demographic information (age, sex, education, socio-economic status). <p><u>Materials:</u></p> <ul style="list-style-type: none"> • Availability, acceptability, affordability and accessibility of self-care resources. <p><u>Competences:</u></p> <ul style="list-style-type: none"> • Skills, knowledge and attitude of people affected by leprosy (Leprosy, self-care).

(Source: Author)

In sum, the LSCC allows addressing aspects of daily living in the lives of people affected by leprosy beyond achieving wound healing. For example, facilitating participation in family and community activities rather than only focusing on issues related to the medical consequences of the disease. The LSCC thus aligns with the arguments of Richardson et al. (2014), who postulate that self-care should empower and motivate patients to take responsibility for their chronic conditions in their real-life context. In addition, Richardson et al. (2014) suggest that the goal of self-care should move from purely focusing on medical needs to broader biopsychosocial needs.

6.11 Contributions of Social Practice Theory to Leprosy Self-care Practice

Adopting SPT as the theoretical framework for this study demonstrates how it can facilitate a better understanding of leprosy self-care practice. Instead of focusing on leprosy patients' behaviour toward self-care, an SPT approach scrutinises the practice as the phenomenon of interest. Given this, it provides a broader and deeper basis for change. For instance, data analysis indicates that interventions might seek to address: healthcare worker-patient relationship and communication challenges; the need to promote self-care knowledge and skills among people affected by leprosy; the necessity of having family members play a role in supporting leprosy self-care; the benefit of identifying religious beliefs and practices that could facilitate or inhibit leprosy self-care; the vital role stigma, discrimination and desire for social inclusion could play in leprosy self-care; fear of complications; and ensuring the availability, affordability, acceptability of self-care materials and accessibility of self-care materials.

Thus, a critical question is how an SPT perspective can inform leprosy self-care interventions. Existing leprosy self-care interventions often focus on individuals and their self-care routines. They rarely focused on social practices of leprosy self-care, how it is performed, what elements of practice are involved in theory performance, and how leprosy self-care practices are carried, transformed, and shaped. Leprosy self-care is generally considered a single concept of behaviour, dependent on general laws, leading to standard approaches for promoting its implementation, policy and practice. However, research does not give enough consideration to the possibly essential differences in how leprosy self-care practices may be organised and why and how they might differ. This thesis, therefore, argues that leprosy self-care policy should be reconceptualised from changing individual leprosy patient behaviour to modifying broader practices of leprosy self-care.

This approach entails a redefinition of the research field and understanding that carrying leprosy self-care is not simply driven by the choices, beliefs, values and personalities of people affected by leprosy. Instead, researchers would be encouraged to concentrate on how leprosy self-care practices are initiated. In addition, researchers would be interested in how policies or practices promoting leprosy self-care could be applied in reframing the landscape in which leprosy self-care practices are sustained or not sustained. A holistic and comprehensive leprosy self-care intervention that adopts an SPT approach may instead emphasise recognising and changing the form, availability, and interaction between all the elements of leprosy self-care practice.

Furthermore, the enhanced value of SPT resides in the interconnections; it helps to elucidate between factors and elements. Examples from this study could include the possible relationship

between effective family support and improved social inclusion, the link between poor healthcare worker-patient relationships and poor self-care knowledge and skills among people affected, and the link between the affordability of self-care material and accessibility of leprosy patients to basic self-care materials. This type of analysis could assist self-care programme managers in putting together an intricate but accurate labyrinth of interconnected factors which may inform the development of a multi-level self-care strategy.

Also, adopting an SPT perspective enables a more explicit understanding beyond individual practices of the interconnectedness among groups of practices that occur in specific areas of daily living (Warde, 2005). Individuals are thus mainly “unique crossing points” (Reckwitz 2002, p. 256) of several interconnected practices, either in loose bundles or tight complexes. It can be seen, for example, how intimately linked the practice of leprosy self-care is to bathing. The other practice could be affected if changes are made to the links between elements of any practice. In this study, for example, it could be seen that bathing is considered part of regular daily activity while leprosy self-care is viewed as imposed by the illness and difficult.

Further research could examine the interplay between making water available for bathing and personal hygiene and its possible impact on leprosy self-care. Also, the level of implementation of the Discrimination against Persons with Disabilities (Prohibition) Act, 2018, which prohibits street begging in Nigeria, may be explored for its impact on leprosy self-care practice. Such an approach, which examines the interplay between social structures (e.g., legislation and policy) and human action, could provide alternatives to current leprosy self-care research largely underpinned by behaviour theories (Michie et al., 2014). An SPT approach could assist in

reversing the limited success of such behavioural approaches. Hence, the notion that leprosy self-care actions are ingrained and the results of meanings reproduced by the nature of the practice and how it is carried out (performance) indicate that simple persuasive interventions focused on the individual is not likely to change such understandings significantly.

Another contribution of SPT in exploring leprosy self-care is that it facilitates multi-level and multi-sectoral thinking, often required when behaviour change issues need actions beyond the individual (Marsden et al., 2014). SPT provides a practical framework to analyse the issue (the low uptake of leprosy self-care practice), which is comprehensive enough to provide "a broad range of opportunities for change" (Rettie et al., 2012. p. 425). This wide range of opportunities is informed by the notion that changing a practice demands challenging or breaking the connections between several interconnected elements (Shove and Pantzar, 2005). Given this, an array of links between interconnected meanings, materials and competences would need to be addressed to achieve sustainable change. Hence, a variety of coordinated policy, individual, family, community and healthcare system interventions may be necessary for reframing the practice of leprosy self-care as an interdisciplinary initiative. Adopting an interdisciplinary approach to behaviour change has been proposed in several policy domains (Butland et al., 2007; Teasley and Wolinsky, 2001) and among academicians (Michie et al., 2008; Abraham and Mitchie, 2008; West, 2006; Nash et al., 2003). This proposal is based on the assumption that similar approaches would enable interventionists to become "more adept at reassembling the unity of knowledge and coping with problems that are too large for any discipline to tackle alone" (Robertson et al., 2003, p. 24). Considering that a multi-level approach to health problems

such as leprosy disabilities is difficult to deal with, SPT may provide a valuable framework to conceptualise it.

Preferably, these actions to reframe and re-organise the elements that influence leprosy self-care could lead to a holistic and coherent strategy to facilitate and promote leprosy self-care. Practices are generally influenced by numerous factors outside the individual, such as family, community, and the healthcare system. Promoting leprosy self-care would require a shift towards more comprehensive and holistic policymaking and interventions that address these factors and consider why leprosy self-care practices interact with other daily life practices.

A final contribution of SPT to leprosy self-care practice is how it enables self-care programme managers and researchers to avoid the pitfall of victim-blaming. Hence when leprosy patients prefer to go begging rather than care for themselves, programme managers can look beyond the individual action and attempt to address the overarching structural problem contributing to the individual's actions and choices. Taking such an approach is possible because SPT facilitates an abstract conceptualisation of practices (Shove et al., 2012; Hargreaves, 2011; Wilson and Chatterton, 2011) and does not frame actions and choices from the perspective of individuals but instead advocates for multi-level, comprehensive, whole-system approaches.

6.12 Chapter Summary

The Chapter identified and discussed some critical factors that influence leprosy self-care practice. These include 1) the Healthcare worker-patient relationship and communication. 2) Leprosy self-care knowledge and self-care training. 3) Family involvement and participation in

leprosy self-care practice 4) The impact of stigma and discrimination on leprosy self-care practices 5) Availability, affordability, accessibility, and acceptability of leprosy self-care materials. Also, the Chapter identified practices that could compete with or complement leprosy self-care practices and advocates for self-care programmes to deliberately look out for creative and practical ways to identify and promote complementary practices while discouraging competing ones.

Furthermore, this Chapter highlighted that factors influencing leprosy self-care practices could interact and occur in a continuum. This notion is conceptualised as the leprosy self-care continuum (LSCC). The LSCC argues that factors influencing leprosy self-care could be enablers or inhibitors depending on where an individual lies along the LSCC. Thus, individuals affected by leprosy must first be assessed to identify their location along the LSCC before commencing self-care interventions. Finally, the Chapter demonstrates how adopting SPT as the theoretical framework for this study can facilitate a better understanding of leprosy self-care practice.

CHAPTER 7

Conclusion

7.1 Introduction

This final Chapter overviews the study and presents the research's empirical and theoretical contributions. Next, the dissemination process of the findings is outlined. Next, the role of reflexivity in qualitative research and its application throughout this research is presented. After that, the Chapter acknowledges the limitations of the research and the study's recommendations for leprosy self-care practice and policy; and future research is discussed.

7.2 Overview of the study

This study was motivated by the low uptake and adherence to self-care practices among people affected by leprosy despite its proven effectiveness and recommendations to country programmes by WHO and ILEP. Findings from the literature review showed that despite the abundance of literature on self-care for other chronic conditions like diabetes, very few studies focused on self-care among people affected by leprosy. Worse still, fewer studies focused on Nigeria. Similarly, most leprosy self-care studies were underpinned by behavioural theories, and none had been conducted from an SPT perspective. Therefore, this study extends work on how leprosy self-care is constructed by considering it a practice rather than a behaviour. The overall purpose is to understand the experiences of people affected by leprosy in carrying out self-care as part of their daily routines. The current study draws on an interpretivist ontology and applies a hermeneutic phenomenological design. A phenomenological study was selected to facilitate an in-depth understanding of the lived experiences and self-care issues faced by people affected by

leprosy in the Nigerian context. This study is the first phenomenological research applied to explore factors influencing leprosy self-care practice in this context.

The significance of self-care from the perspective of 20 people affected by leprosy was elicited through comprehensive, in-depth interviews. Using open-ended questions facilitated an understanding of the participants' reactions, perceptions, and experiences of leprosy self-care practice. The justification of the appropriateness of using a phenomenological approach is reflected in the success of this study in answering the research questions and achieving its study objectives to explore factors influencing self-care among people affected by leprosy in Nigeria.

Detailed data analysis was underpinned by SPT and carried out using the thematic analysis approach described by Braun and Clarke (2019). Findings from this research challenge current evidence relating to the factors that influence leprosy self-care. The data in this study strongly suggest that the low uptake and compliance to self-care in leprosy are not only due to factors relating to the individual in question but include the dynamic interaction of materials required for self-care. Likewise, it includes the meanings and significance attached to the practice of self-care and the skills and competencies needed to initiate and sustain self-care practice. Other social and contextual factors could complement and encourage self-care or compete for time and resources for leprosy self-care practice.

7.3 Research Aim and Objectives

This thesis's overarching research question is: What factors influence the initiation and sustaining of leprosy self-care practices in Nigeria? To answer this question, three research objectives were formulated:

- To explore the value of SPT in understanding leprosy self-care practices in Nigeria
- To explore the experiences, perspectives, perceptions, and practices of people affected by leprosy on self-care.
- To identify facilitators and barriers for self-care practice among people affected by leprosy at home and in a self-care group.

7.4 Contributions of the study

The research objectives have been achieved as the findings provided an understanding of people affected by leprosy's perceptions and self-care practice experiences. Also, the analysis of the perspectives of people affected by leprosy enabled the exploration of the factors that influence leprosy self-care. As earlier stated, Chapter Three presented how previous studies on leprosy self-care focused on it as a behaviour. However, by exploring the experiences of people affected by leprosy's self-care practice from a social practice lens, this study has revealed numerous enablers and inhibitors of self-care practice. Furthermore, several inhibitors and enablers revealed have not been previously considered, thereby making a novel contribution to present knowledge.

7.4.1 Contribution to the theory of Leprosy self-care

This thesis's original contribution is to extend the theory of self-care practice underpinned by SPT (Shove et al., 2012; Reckwitz, 2002) to explore the daily experiences of people affected by leprosy practising self-care. By drawing on SPT (Shove et al., 2012), this thesis advances the following contributions to the theory of leprosy self-care practice:

- 1) This thesis makes a novel contribution to leprosy self-care practice by identifying that several factors affecting leprosy self-care interact and could occur in a continuum. This notion is conceptualised as the leprosy self-care continuum (LSCC), which suggests there is no absolute presence or absence of factors. Instead, it indicates various degrees of positive (enabler) or negative (inhibitor) influence. Thus, the goal of self-care interventions should be to move people towards the positive pole of the continuum and retain them there.
- 2) This study deepens current knowledge on leprosy self-care practice by highlighting the need to ensure that self-care materials are available, affordable, appropriate, and culturally acceptable to people affected by leprosy. Furthermore, this study adds a novel contribution that leprosy self-care materials could be subdivided into two broad categories, 'replaceable' and 'irreplaceable' materials. This understanding could help policymakers review current expectations regarding advocating for home-based alternatives for self-care materials.

- 3) Another novel contribution of this study is that some practices could complement or even compete with leprosy self-care. Thus, self-care interventions should implement mechanisms to identify these to encourage the former while discouraging the latter. For example, fasting and begging were identified as competing practices to leprosy self-care, while this study identified bathing and ablution as complementary practices to self-care.

- 4) This study has successfully demonstrated the utility of SPT as a suitable theoretical framework for understanding the factors that influence leprosy self-care. Methodologically, it has laid a framework upon which future research on leprosy self-care practice can build. Additionally, understanding the factors that influence leprosy self-care may improve self-care practice assessment among people affected by leprosy, inform personalised interventions to meet their needs, and improve self-care outcomes and overall health and well-being.

- 5) This study presents an evidence-based contribution to the under-researched field of leprosy (Odia and Omofonmwan, 2013) by expanding current thinking on how leprosy self-care is carried out. Current literature in the field of leprosy called for further research on “Identifying effective and feasible strategies for self-care programmes in low endemic areas” (Khazai et al., 2019, p. 17). This qualitative phenomenological study explored self-care practice in a leprosy village in Nigeria. Moreover, scant literature on leprosy and behaviour theories has underpinned the little research conducted in this area. There has been no research on leprosy self-care conducted through an SPT lens. By drawing on Shove’s approach (2012) to explore how self-care was practised in the leprosy field, this

research adds depth to the little researched field of leprosy self-care. The thesis deepens existing knowledge on how leprosy self-care is constructed by moving away from viewing leprosy self-care as behaviour and considering it as a practice.

7.5 Reflexivity

Throughout the various stages of this study, reflexive considerations were made. The following sections have presented these to show my values and promote transparency and openness.

7.5.1 Reflexive Considerations before the Commencement of the Study

Chapter One outlined my position toward the research participants, my experience of the phenomenon, and my professional background. Chapter Four discussed the reasons for considering phenomenology as an appropriate methodology to explore the perceptions and factors influencing leprosy self-care as experienced by the participants. Descriptive phenomenology was acknowledged as unsuitable to meet the purpose of the research. I also stated the difficulty I would have if I attempted to 'bracket' my assumptions and values concerning the phenomenon because of my professional experience, having worked in the field of leprosy for almost two decades. Therefore an interpretivist paradigm was adopted, and the study focused on the interaction between the participants and the context.

According to Woolgar (1988, p. 20), "*representation and object are not distinct, they are intimately interconnected*". In essence, objects and subjects within the world are connected and inseparable. As the Principal Investigator, I connected with the participants to explore how they interacted within their world and attempted to understand how they made sense of their

experience of leprosy self-care from my perspective. My reflexive approach to the research was demonstrated through being open and honest and acknowledging my values and assumptions before commencing the study.

7.5.2 Considerations for Reflexivity during the Research

I received extensive and regular support from two supervisors throughout this study. My supervisors held varied experiences in qualitative research. Regular debriefing sessions during supervision enabled me to frequently step back and reflect on my choices.

During data collection, I found field notes quite helpful as they facilitated capturing non-verbal actions, thoughts, and emotions. Concerning data collection, one example of reflexivity occurred during an interview with a single mother, which I found challenging. Although the interview served its purpose, it seemed the participant used the opportunity to let go of her emotional burden. In my notes, I described how I had struggled to keep her on track with the interview. Reflecting on this experience, I realised the need to rethink how I engaged with her and the rest of the study participants. Through my reflections, I became aware of doubts about my interviewing skills because rather than attempt to bring the interview back to focus, I allowed the participant to express the issues she was facing. Unexpectedly, I felt some guilt that I had not made any attempt to make any contributions. At the same time, she shared her problems because I constantly reminded myself that I was there as a researcher and not as the CEO of a Non-Governmental Organisation that provided support for leprosy patients. So I was applying non-verbal cues like nodding. Although I was emotional about some of the challenges she shared, I

did not show it. Reflecting on this experience, I was reminded of my position and could successfully guard my emotions in subsequent interactions with participants.

Field notes contribute to an audit trail of a research process as thoughts and ideas are recorded to show the study's progress (Kosh, 1994). In addition, using field notes facilitated a revisit of my approach to the research, including my values and assumptions. An example of how my field notes enabled reflexivity was when I took several weeks off the study due to a robbery incident I suffered at home. Making field notes helped refresh my thinking and assumptions for the research and facilitated recognition of how I changed interpretations throughout the research process. For example, after the robbery incident, I realised that I could appreciate the patients' experiences of struggling to live with inadequate finances and how they had to prioritise spending.

In hermeneutic phenomenology, participant feedback is recommended (Lincoln and Guba, 1985). Several reasons are adduced within phenomenology for the application of participant feedback. The key reason is that it promotes research credibility (Lincoln and Guba, 1985). Furthermore, according to Bradbury-Jones et al. (2010), it helps to compliment the hermeneutic circle by negotiating the mean between researchers and participants (Doyle, 2007; Bradbury-Jones et al., 2010).

The use of participants' feedback is not without its antagonists due to potential issues with its implementation (McConnell-Henry et al., 2011; King and Horrocks, 2010; Langdrige, 2007; Barbour, 2001; Ashworth, 1993). For example, according to Barbour (2001, p. 115), participant

feedback merely forms a prescriptive 'checklist' and does not necessarily guarantee rigour. Also, participants may reject the interpretation's accuracy, may not give honest feedback (Langdrige, 2007), or agree with an account they know is inaccurate due to the power relations between them and the researcher (King and Horrocks, 2010). According to King and Horrocks (2010), such behaviour might stem from participants' attempts to protect themselves concerning the so-called '*socially represented self*' (Ashworth, 1993, p.10).

Although I recognise the arguments against participant feedback, I subscribe to the thinking of (Lincoln and Guba, 1985), so I shared the summary findings of this thesis with six participants (three males and three females) who participated in the research for their feedback. I was pleased to note that the summary of findings resonated with the feedback I received. Also, their feedback helped me identify where I needed to lay more emphasis on my findings.

7.5.3 Considerations for Reflexivity after Completion of the Study

After completing this research, a reflexive approach will continue to encourage openness and honesty in the study. Openness and honesty will be ensured by giving a detailed account of the results, particularly when disseminating the results to a broader audience. Consequently, a sense of reflexivity during conference presentations might inspire others to challenge my interpretations. Hence, I need to be ready and prepared to welcome any different views or assumptions my audience might have.

7.6 Reflection on the Research Journey

My experience of this research journey has been positive. I have acquired new knowledge, and my understanding of research processes, mainly qualitative research processes, has deepened. My knowledge of the factors that influence leprosy self-care deepened, particularly concerning how these interact and how they could occur in a continuum. It has been a fascinating journey and has presented an excellent learning opportunity. It has expanded views regarding leprosy self-care and self-care in other chronic conditions, which have immensely helped my professional role. TLM-Nigeria just started a new Research and Learning Department, which helps me apply the new insights and knowledge I have acquired of both the subject and research process. My confidence has increased, and my writing ability has improved significantly.

7.7 Limitations of the Study

Although this study demonstrates the factors that influence leprosy self-care by exploring people affected by leprosy experiences, it has not been without limitations. These are acknowledged in this section.

7.7.1 Personal Limitations

This study represents participants' experiences captured at a particular point through interviews of people affected by leprosy. Given my position as CEO of a leprosy organisation that supports intervention in the study site, it could be implied that some participants could discuss what they believed I should hear. Another issue during data collection was my position when I always needed to inform participants that this was research and not a needs analysis. In overcoming this

challenge, I ensured the research purpose was read to the participants restating the difference before starting my interviews.

I have identified some of the changes I could have made in hindsight if I were to go over this exercise, particularly regarding data collection. For example, I would use more probing questions during the interviews. Due to my limited interview skills, I was concerned that using many probes could lead the participant. However, as I conducted more interviews, my confidence in noticing participants' points and probing them further grew. Also, mid-way through interviewing, a significant issue was raised by one of the participants regarding the role of self-stigma in influencing self-care. This made me ask further questions about this issue during the rest of the interviews. However, because the other interviews had been completed, I could not go back and get previous participants' views on that subject. I may have missed information that could have enriched this study by not going back.

Finally, despite my best efforts to be aware of my biases, my experiences as a leprosy worker possibly created a bias that placed limitations on my analysis (Charmaz, 2014).

7.7.2 Methodological Limitations

This study was limited to one leprosy village in Northern Nigeria, a predominantly Muslim part of the country. Hence, due to the participants' relative religious and regional homogeneity, the transferability of the findings to other regions or religious groups of Nigeria should be treated with caution. However, this approach follows a strong phenomenological study tradition in the discipline of public health research and across the qualitative social sciences (Dowling, 2007). Its

benefits include providing a complete and rich description of human experiences and meanings. In addition, it provides a window to appreciate people's actions and motivations, challenges conventional assumptions, facilitates changes in practices and policies, and contributes to developing new conceptual frameworks, such as the LSCC.

This study is based on the perspectives and experiences of people affected by leprosy who were purposively chosen and living in a leprosy village. Because of the selection criteria for the study, leprosy patients who are still actively undergoing treatment or those who reside in other leprosy settlements were excluded. In addition, persons affected by leprosy who were 18 or younger at the time of the interviews were not included due to the FCT ethical requirements. The results may have been enriched by including these groups in the sample.

It is acknowledged that for effective SPT research, a combination of interviewing and other data collection techniques such as document analysis could have enhanced this study's richness by promoting triangulation (Martens, 2012). Also, adopting an entirely different research methodology, such as a case study, could have allowed data collection from multiple data sources, such as healthcare workers and family members of people affected by leprosy involved in the self-care programme (Flyvbjerg, 2011; Merriam, 2009). Their inclusion in the research could have allowed an exploration of the phenomenon from different perspectives, which leaves room for further research.

7.8 Dissemination of Findings

In 2019, I presented findings from my literature review at the 20th International Leprosy Congress, which took place from the 10th to the 13th of September in Manila, Philippines. Although the presentation was based on my literature review, it generated a lot of debate and interest among the delegates and organisers.

Regarding how findings will be disseminated in the future, I intend to share the results locally, nationally, and internationally. In addition, I will share the findings through conferences and various online platforms created by the NTBLCP at the local level. In targeting national and international audiences, I intend to publish the study results in relevant peer-reviewed journals. Specifically, three papers will be published in *Leprosy Review*. The first is on the Factors Influencing Leprosy Self-Care, the second is on the Policy and Practice Implications of the Leprosy Self-care Continuum, and the third will be on the Impact of Religion on Leprosy Self-care Practices. In addition, a paper on the Utility of the Leprosy Self-Care Continuum in Facilitating Integrated Self-Care for Neglected Tropical Diseases will be published in the *International Journal of Leprosy and Other Mycobacterial Diseases*. I also intend to share the results of this study at national and international conferences on Neglected Tropical Diseases, particularly the Coalition for Operational Research on Neglected Tropical diseases (COR-NTD) Conference.

7.9 Implications for Policy and Practice

7.9.1 Revising healthcare worker-patient Relationship and communication

This research highlighted an overarching challenge concerning the relationship and communication between healthcare workers and leprosy patients, which were perceived as top-down, unfriendly, disempowering, and ineffective. It is therefore imperative to put in place mechanisms and policies that ensure healthcare worker-patient engagements are more collaborative and respectful of patient's wishes, values and goals. However, despite its usefulness, practice gaps exist in implementing patient-centred approaches (Mudge et al., 2015; Ellis et al., 2017). As such, patient-centred care (PCC) needs to be integrated into leprosy self-care training programmes, so that patients, their families, and all healthcare workers supporting leprosy self-care interventions are trained and re-trained in patient-centred care.

Evidence suggests that integrating PCC into the healthcare curriculum does not always translate into practice (WHO, 2007). Given this, the framework created by Santana et al. (2017) will be used to guide PCC implementation. The framework is laid out like a road map, showing how PCC should be implemented in practice, starting with the structural domains at the health systems level. The structural changes include developing and integrating structures to support health information technology, providing a supportive and accommodating PCC environment, supporting a workforce committed to PCC, co-designing the development and implementation of educational and training programs, and measuring and monitoring PCC. In addition, there will be ongoing leadership development and training through mentors and role models to impact a lasting culture change.

7.9.2 Developing a systematic and organised leprosy self-care education programme

This study revealed leprosy self-care training as unsystematic and unorganised. Also, this study highlighted that training alone might be insufficient to sustain self-care practice. Therefore, the National Tuberculosis and Leprosy Control Programme (NTBLCP) needs to implement a systematic and organised leprosy self-care training and support programme. Such a programme will enable healthcare workers to provide supportive, tailored interventions and education to enhance the confidence and skills of people affected by leprosy to manage their health, including problem-solving support, goal setting, and regular assessment of progress and problems. In addition, such training will consider the skills gaps identified in the individualised self-care plans. There is ample evidence that suggests that similar self-care training and support programmes are adequate for the self-management of other chronic conditions, for example, Therapeutic Patient Education (Norris et al., 2001; Weingarten et al., 2002; Norris et al., 2002; Warsi et al. 2004; Chodosh et al. 2005; Guevara et al. 2003).

7.9.3 Facilitating multi-level planning and implementation for leprosy self-care practice

The application of an SPT approach in this study and the conceptualisation of the leprosy self-care continuum (LSCC) suggest a radical departure from the current 'vertical' approach adopted in planning and implementing leprosy self-care interventions. Instead, the LSCC enables a comprehensive assessment and planning for making changes at multiple and interconnected levels, including 1) – patient-centred (micro-level), 2) -family and community groups (meso-level), and 3) policy and healthcare system (Macro-level). Hence, the LSCC highlights the need for comprehensive leprosy self-care practice requirements and enables the development of changes tailored to individuals' specific needs and resources and the peculiarity of their context.

7.9.4 Enabling wholistic monitoring and evaluation of leprosy self-care practices

The LSCC could promote and facilitate a culture of structured evaluation of self-care intervention in the leprosy domain as it provides a framework for assessing people's self-care practices. Furthermore, the LSCC is based on the consideration that numerous factors interact with people affected by leprosy practising self-care. Therefore, all these factors must be considered for a proper multi-level assessment of self-care needs (see table 7.1). Thus, the LSCC could provide a helpful tool and guided approach to collecting reliable and comprehensive data on the self-care practices of people affected by leprosy, as such can be applied to facilitate the evaluation of leprosy self-care interventions or programmes.

7.9.5 Involving Religious Institutions

There might be a need to consider involving religious institutions in leprosy self-care by training religious leaders on issues of stigma reduction, leprosy, begging, and self-care. Due to its influence on leprosy self-care, it is recommended that healthcare workers make it a routine to document the spiritual history of all new people affected by leprosy attending self-care clinics. Furthermore, healthcare workers should be trained to collect patients' religious and Spiritual history. Finally, adjustments might need to be made to the NTBLCP patient self-care recording and reporting tools to capture these new expectations. In collaboration with the National Leprosy Technical Working Group, the National Tuberculosis and Leprosy Training Centre and religious leaders, the leprosy self-care training curriculum will be revised to include sections on the role of religious institutions in leprosy self-care. Religious institutions own many leprosy referral hospitals where self-care is implemented, and these will be a natural place to commence this training.

7.9.6 Optimising the involvement of family members in leprosy self-care practice

Family support was highlighted by this study as a critical enabler for leprosy self-care practice. Given this, the NTBLCP is urged to consider developing a separate training curriculum for family members of people affected by leprosy to optimise the benefits of their involvement. Although most interventions highlighting the role of families in the self-care of chronic conditions have focused on increasing family support, it is probably equally important to assist people affected by leprosy in dealing with family barriers. For example, interventions to increase family use of support techniques that minimise avoidance, control, criticism, or nagging could be considered. Future research could also focus on teaching people affected by leprosy ways to navigate barriers created by others to avoid adverse family effects on their motivation and self-efficacy for self-care.

7.9.7 Delineating replaceable and irreplaceable materials

The results of this study show that leprosy self-care materials could be subdivided into two broad categories, 'replaceable' and 'irreplaceable' materials. Based on this finding, ILEP is urged to consider reversing the policy that places the responsibility of sourcing self-care materials solely on leprosy patients. While leprosy patients could focus on sourcing replaceable materials, ILEP and the NTBLCP should take responsibility for providing irreplaceable materials, particularly eye ointments. This step can go a long way in addressing the challenges faced by leprosy patients when asked to source their self-care materials themselves. Also, self-care programmes are to ensure they incorporate socio-economic interventions to address issues related to economic hardships. Such socio-economic interventions could include livelihood interventions and the deliberate support to self-care groups to mature and transform into self-help groups, which could

later become registered as Cooperatives to access available financial facilities from public financial institutions. Access to public financial institutions would hopefully empower people affected by leprosy financially to meet this obligation of ensuring uninterrupted availability of 'replaceable' self-care materials.

Furthermore, the current study established water as a critical 'irreplaceable' self-care material. Thus, access to water is integral in ensuring successful leprosy self-care practice and outcomes. Given this, the NTBLCP and its development partners are urged to take advantage of leprosy's recent integration into the neglected tropical diseases (NTDs) programme to ensure improved access to adequate water for leprosy self-care activities. Furthermore, improved access to water could be achieved if the NTBLCP collaborates with the NTD programme to advocate for leprosy's inclusion on the agenda of national and international institutions responsible for water, sanitation, and hygiene (WASH) in Nigeria.

7.9.8 Identifying competing and complementary practices

This study identified practices that could complement or even compete with leprosy self-care. In light of this, self-care interventions should put in place mechanisms to identify such practices so that leprosy self-care programmes and support can be considered during the planning, implementation and evaluation of self-care interventions.

7.10 Implications for Future Research

1. Many factors affecting leprosy self-care appear to be on a continuum where there is no absolute presence or absence of factors. This notion implies that factors are not

necessarily static and challenges the traditional thinking and notion that assumes that factors influencing self-care occur in a dichotomy. Several personal, environmental, structural or policy reasons could shift an individual from one end of the spectrum to another, with attendant consequences on self-care practices' quality and outcome. Further research is required to explore how and why individuals could gravitate towards the negative pole of the continuum and what factors could tilt them more towards the positive pole of the continuum and retain them there.

2. About 35% of respondents in this research beg as their only means of livelihood, a practice that was found to compete for self-care time and negatively impacted self-care outcomes. To improve adherence to self-care practice, it is, therefore, crucial that begging is systematically addressed. Over the years, TLM-Nigeria has implemented programmes for people affected by leprosy to improve their socio-economic situation. These include vocational and skills development, education; livelihood programmes; and various income generation projects, for example, farming and petty trading. However, begging among people affected by leprosy continues to thrive despite these interventions, raising several unanswered questions requiring research. Some questions include: how effective are these interventions in meeting people affected by leprosy's needs? Are there alternative forms of employment for people affected by leprosy? How do women affected by leprosy fare given the significant disadvantages they face compared to men who have leprosy? What do people affected by leprosy think about begging, and how do they view the lives they lead? Finally, how can cultural, social, and individual attitudes be changed such that begging is no longer seen as an appropriate role for people affected by leprosy?

Answers to these questions will hopefully curtail the negative influence of begging on leprosy self-care practice.

3. Considerations for religion provide unique opportunities to improve leprosy self-care services. However, they raise an important question about the role religious leaders and institutions could play in promoting leprosy self-care. Further research is required to answer this fundamental question.

4. Nine out of the 20 people interviewed in this study were women. However, exploring the gender dimensions in the data could not be done due to time and word limit constraints. Gender-specific data analysis will be conducted in the future to evaluate the facilitators and barriers that influence leprosy self-care practice among women affected by leprosy.

7.11 Summary

This study extends current knowledge on factors influencing leprosy self-care practice in Nigeria. It is the first-time leprosy self-care has been explored through an SPT lens. As such, leprosy self-care is viewed as a practice and not a behaviour (Shove et al., 2012). Furthermore, the lucidness of vision afforded by SPT goes beyond a single practice to the interconnections between bundles of practices that occur in specific areas of daily life and the core elements - competences, material and meanings that reproduce them (Warde 2005). Thus, this thesis argues that leprosy self-care practice results from the dynamic interaction and interconnectedness of these core elements, reproduced by the nature of the practice and how it is performed. Therefore,

the implication is that simple persuasive behavioural-based approaches aimed at the individual are not likely to sustain leprosy self-care practice.

The study makes an original contribution to leprosy self-care theory by revealing that factors affecting the self-care of people affected by leprosy are dynamic, interact and may occur in a continuum – conceptualised as the leprosy self-care continuum (LSCC). The LSCC suggests no absolute presence or absence of factors but indicates various degrees of positive (enabler) or negative (inhibitor) influence. Thus, self-care interventions should be individualised and aim to nudge people affected by leprosy towards the positive end of the continuum. In applying SPT, this study revealed that leprosy self-care practice could be improved when the competencies of people affected by leprosy, healthcare workers and family members are optimised. In addition, the availability and accessibility of self-care materials (Water, pumice stones, lubricants) should be tailored to the individual needs of people affected by leprosy in ways which empower them to apply the meanings associated with self-care.

Finally, acknowledging the existence of competing and complementary practices to leprosy self-care practice requires deliberate action from leprosy self-care programmes to discourage competing practices while encouraging complementary ones if leprosy self-care practice is to be sustained.

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Appendices

Appendix 1: Literature search strategy and the key terms used.

S/No	Database	Search strategy	Number of articles retrieved
1	MEDLINE	1. leprosy.mp. or exp Leprosy/ 2. Hansen's disease.mp. 3 'self-care'OR self-management OR 'self-treatment' OR 'home-care OR 'self-care group' OR 'self-care practice' #1 AND #2 AND 3	116
2	EMBASE	1. leprosy.mp. or exp Leprosy/ 2. Hansen's disease.mp. 3 'self-care'OR self-management OR 'self-treatment' OR 'home-care OR 'self-care group' OR 'self-care practice' #1 AND #2 AND 3	21
3	WEB of SCIENCE	Self care* AND leprosy	64
4	SCOPUS	Self care* AND leprosy	95
5	CINAHL	1. leprosy.mp. or exp Leprosy/ 2. Hansen's disease.mp. 3 'self-care'OR self-management OR 'self-treatment' OR 'home-care OR 'self-care group' OR 'self-care practice' #1 AND #2 AND 3	28
6	PsychINFO	1. leprosy.mp. or exp Leprosy/ 2. Hansen's disease.mp. 3 'self-care'OR self-management OR 'self-treatment' OR 'home-care OR 'self-care group' OR 'self-care practice' #1 AND #2 AND	14

7	British Nursing Index (BNI)	'self-care'OR self-management OR 'self-treatment' OR 'home-care OR 'self-care group' OR 'self-care practice AND leprosy OR Hansen's disease	23
8	Leprosy Review	Self-care* AND leprosy	36
9	Indian Journal of Leprosy	Self-care* AND leprosy	23
10	International Journal of Leprosy and Other Mycobacterial Diseases	Self-care* AND leprosy	97
11	Asia Pacific Disability Rehabilitation Journal	Self-care* AND leprosy	15
TOTAL ARTICLES RETRIEVED			532

Appendix 2: Hawker's Assessment Tool

Hawker's Assessment tool

This tool has 9 domains. Each domain has a maximum of 4 points and a minimum of 1 point. 4 points means very good and 1 point means very poor. Thus, the total score for the quality of a paper according to Hawker's appraisal tool is 36. A study is rated as high quality (A) if it has a total score of 30 and above; medium quality (B), 24 - 29 points; and low quality (C), 9 - 23 points

Table 1: Description of Hawker's Tool

S/N	Domain	Assessment Criteria
1	Abstract and title: Did they provide a clear description of the study?	(4) Good: Structured abstract with full information and clear title (3) Fair: Abstract with most of the information (2) Poor: Inadequate abstract (1) Very poor: No abstract
2	Introduction and aims: Was there a good background and clear statement of the aims of the research?	(4) Good: Full concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge. Clear statement of aims and objectives, including the research questions. (3) Fair: Some background and literature review. Research question outlined. (2) Poor: Some background but no aim/objectives/questions, OR aims/objectives but inadequate background. (1) Very poor: No mention of aims and objectives. No background or literature review
3	Method and data: Is the method appropriate and clearly explained?	(4) Good: Method is appropriate and described clearly (e.g., questionnaires included). Clear detail on data collection and the recording process. (3) Fair: Method appropriate, description could be better. Data described. (2) Poor: Questionable whether method is appropriate. Method described adequately. Little description is given on data. (1) Very poor: No mention of method, AND/OR method inappropriate, AND/OR no details of data.

4	Sampling: Was the sampling strategy appropriate to address the aims?	<p>(4) Good: Details (age, gender, race, context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates is shown and explained.</p> <p>(3) Fair: Sample size justified. Most information given, but some is missing.</p> <p>(2) Poor: Sampling mentioned but few descriptive details.</p> <p>(1) Very poor: No details of sample.</p>
5	Data analysis: Was the description of the data analysis sufficiently rigorous?	<p>(4) Good: Clear description on how analysis was done.</p> <ul style="list-style-type: none"> • Qualitative studies: Description of how themes derived/respondent validation or triangulation. • Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed. <p>(3) Fair:</p> <ul style="list-style-type: none"> • Qualitative: descriptive discussion of analysis. • Quantitative: The process of data analysis <p>(2) Poor: Minimal details about analysis</p> <p>(1) Very poor: No discussion of analysis.</p>
6	Ethics and bias: have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?	<p>(4) Good: Ethics – where necessary issues of confidentiality, sensitivity and consent were address. Bias – Researcher were reflexive and/or aware of own bias.</p> <p>(3) Fair: Lip service was paid to above (i.e., these issues were acknowledged).</p> <p>(2) Poor: Brief mention of issues.</p> <p>(1) Very poor: No mention of issues.</p>
7	Results: Is there a clear statement of the findings?	<p>(4) Good: Findings explicit, easy to understand, and in logical progression. Tables if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.</p> <p>(3) Fair: Findings mentioned but more explanation could be given. Data presented relate directly to results.</p> <p>(2) Poor: Findings presented haphazardly, not explained, and do not progress logically from results.</p> <p>(1) Very poor: Findings not mentioned or do not relate to aims.</p>

8	Transferability or generalisability: Are the findings of this study transferable (generalisability) to a wider population?	<p>(4) Good: Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).</p> <p>(3) Fair: Some context and setting described, but more needed to replicate or compare the study with others, plus fair score of higher score in Question 4.</p> <p>(2) Poor: Minimal description of context/setting.</p> <p>(1) Very poor: No description of context/setting</p>
9	Implication and usefulness: How important are these findings to policy and practice?	<p>(4) Good: Contribute something new and/or different in terms of understanding/insight or perspectives.</p> <p>(3) Fair: Two of the above (state what is missing in comments).</p> <p>(2) Poor: Only one of the above.</p> <p>(1) Very poor: None of the above.</p>

Appendix 3: Output of Assessment of Included Studies using Hawker's Tool

S/N	Article	Abstract & Title	Introduction & Aims	Data Collection	Sampling	Analysis	Ethics/Bias	Results	Generalisability	Implications	Total	Grade
1	Abera and Lemma (2003)	4	4	4	3	4	1	3	4	3	30	A
2	Arief (2008)	4	4	4	4	4	4	4	4	4	36	A
3	Baker et al., (2016)	1	2	3	4	1	1	4	3	4	23	C
4	Beisi (2012)	4	4	4	4	4	4	4	4	4	36	A
5	Benbow & Tamiru (2001)	4	2	1	1	1	1	4	4	4	22	C
6	Cross & New Combe (2001)	4	4	4	4	2	1	3	4	4	30	A
7	Cross et al (2017)	4	2	4	4	2	2	4	4	4	30	A
8	D'Azevedo (2018)	4	4	3	3	3	1	4	4	4	30	A
9	Deepak et al (2013)	4	3	3	3	3	3	3	4	4	30	A
10	De souza (2017)	4	2	4	2	2	2	4	3	3	26	B
11	Ebenso et al (2009)	4	4	4	4	4	4	4	3	3	34	A
12	Gautham (2011)	4	2	4	2	4	4	4	3	3	30	A
13	Gidado et al (2010)	4	2	3	2	2	1	4	3	3	24	B
14	Girma et al (2019)	4	3	3	3	4	4	4	4	3	32	A

15	Lay et al (2007)	4	4	3	3	3	1	4	4	4	30	A
16	Li et al (2008a)	4	2	2	3	2	1	4	3	3	24	B
17	Li et al (2008b)	4	3	2	4	2	1	3	3	4	26	B
18	Madhavan et al. (2007)	3	4	3	2	2	4	4	4	4	30	A
19	Maia (2016)	4	3	3	4	2	4	4	3	3	30	A
20	Pakasi (2007)	4	4	4	4	4	4	4	4	4	36	A
21	Sathiaraj et al. (2010)	3	3	2	3	2	1	4	3	3	24	B
22	Shumin et al., (2003a)	3	2	1	1	1	1	4	4	4	21	C
23	Shumin et al. (2003a)	3	2	4	1	3	1	4	4	4	26	B
24	Smith et al. (1995)	1	2	2	4	3	2	4	3	4	25	B
25	Sussanto et al. (2017)	1	3	4	4	4	4	4	3	3	30	A
26	Win et al. (2010)	1	4	4	3	3	1	4	3	3	26	B
27	Win et al. (2013)	3	4	4	4	3	1	4	3	4	30	A

Appendix 4: Evidence Table

No.	Reference	Study aim/Purpose	Sample	Methods	Findings
1	Abera and Lemma (2003)	An evaluation of the cost-effectiveness and psychological changes brought about by the self-care programme, in the management and prevention of ulcers	n= 85	Mixed methods - Survey and Interview	<ul style="list-style-type: none"> • Self-care is effective in managing leprosy disabilities. • The practice of self-care is contingent on the person's desire to see change. • Perceived importance of self-care is important to promote self-care practice. • The availability of self-care materials is an important motivation to initiate and sustain self-care practice.
2	Arief (2008)	Description and analysis of implementation of self-care group	n = 219	Mixed methods - Survey, observation and Interview	<ul style="list-style-type: none"> • Availability of self-care materials played a key role in the adoption of self-care practices. • Involvement and support of family members is a facilitator of self-care. • Discomfort, pain and slow wound healing are inhibitors to self-care • Work related needs and livelihood competes for time with self-care • Ignorance and inadequate knowledge and skills about self-care are inhibitors to self-care practice.
3	Baker et al. (2016)	Compliance with use of disability aid and materials	n = 70	Mixed methods- Survey, Interviews	<ul style="list-style-type: none"> • Self-care is significantly better in people affected by leprosy who received self-care education. • Lack of self-motivation is a barrier to self-care
4	Beise (2012)	Perceptions of people affected by leprosy about their membership of SHGs	n = 20	Qualitative – Interviews and Focus Group Discussions	<ul style="list-style-type: none"> • Genuine desire, interest to participate and self-determination are drivers for practicing self-care. • Low Self-esteem, low self-efficacy, self-neglect, low self-worth are barriers to self-care

5	Benbow & Tamiru (2001)	Experiences of people affected by leprosy in self-care groups.	n = 72	Mixed methods – Survey and interviews	<ul style="list-style-type: none"> • Self-Care groups were effective in improving wounds. • Active membership of self-care groups encouraged persons affected leprosy to take responsibility for the management of their wounds/disabilities
6	Cross and Newcombe (2001)	Impact of self-care training programme on leprosy disability management	n = 254	Quantitative - survey	<ul style="list-style-type: none"> • Training on self-care reduced admission rates for complicated ulcers. • Active participation in a self-care group is a positive influence on self-care
7	Cross et al (2017)	Impact of stigma elimination on poverty reduction among people affected by leprosy. (Evaluation)	n = 495	Mixed method – Survey, Focus group	<ul style="list-style-type: none"> • Active participation in a self-care group is a positive influence on self-care. • Self-efficacy is a positive influence to commence and sustain self-care behaviour and self-care also improves self-efficacy.
8	D’Azevedo (2018)	Perception of people affected by leprosy on self-care support groups	n = 11	Qualitative study - interviews	<ul style="list-style-type: none"> • There is better adherence to self-care when Self-care Groups receiving support from family members of people affected by leprosy and health workers. • Health education of people affected by leprosy is a facilitator for self-care • Depression is a key inhibitor to self-care
9	Deepak et al (2013)	Perceptions of people with leprosy regarding the benefits and challenges of participating in the Self-care Groups	n = 22	Qualitative - Interview	<ul style="list-style-type: none"> • Being a member of a self-care group promotes self-care through peer support. • Availability of materials such as protective/assistive footwear was an encouragement to carryout self-care • Attendance at SCG meetings were facilitated by: proximity of self-care group meetings venues, training of self-care group members by health workers; and availability of self-care materials.
10	De Souza (2014)	Perception of self-care by people	n = 15	Qualitative - interview	<ul style="list-style-type: none"> • Limited knowledge about leprosy and its consequences hinders participation in self-care

		affected by leprosy			
11	Ebenso et al. (2009)	Assessment of self-care on ulcer management	n = 24	Mixed study – Survey, interview, key informants, focus group	<ul style="list-style-type: none"> • Active membership of self-care group promoted self-care practice.
12	Gautham et al. (2011)	An assessment of the medical, disability prevention and rehabilitation and psychosocial needs of leprosy patients	n = 259	Quantitative - Survey	<ul style="list-style-type: none"> • Lack of education on self-care was a limiting factor to self-care practice. • Lack of required materials inhibited the practice of self-care • Lack of belief in self-care inhibits self-care
13	Gidado et al. (2010)	Impact of positive deviants on self-care practice	n = 26	Quantitative -	<ul style="list-style-type: none"> • Group support was effective to promote self-care at home. • Patients who did not belong to self-care groups abandoned self-care • Positive Deviants challenged and encouraged self-care among group members
14	Girma et al. (2018)	Knowledge and self-care practice of leprosy patients	n = 424	Quantitative	<ul style="list-style-type: none"> • As people affected by leprosy get older, their commitment to self-care reduced. • Good knowledge about leprosy and its consequences is a positive factor for self-care. • The higher the level of formal education, the likely patients would practice self-care • As income increases, self-care practice increases.
15	Lay et al. (2007)	Investigation of level of compliance with home-based self-care	n = 324	Mixed methods – Survey Interview	<ul style="list-style-type: none"> • Knowledge of the benefits and consequences of leprosy and self-care are key factors for compliance with self-care. • Family support, encouragement and assistance contributed to high compliance to self-care. • Belief that self-care is effective served as a motivation continue

					<p>with the practice.</p> <ul style="list-style-type: none"> • Poor supervision and little support from health staff negatively impacted on self-care. • Low self-efficacy is a barrier to self-care. • Low economic status, time constraint due to competing daily activities, no family support and poor supervision from health workers were barriers to self-care.
16	Li et al. (2008a)	The role of Government health workers in prevention of leprosy disabilities.	n = 1215	Quantitative - Survey	<ul style="list-style-type: none"> • Basic understanding of leprosy and self-care procedures positively influenced self-care practice. • Improvement in disability (healed ulcers), increased confidence, was a motivating factor for self-care. • Increased self-efficacy increased compliance to self-care. • Perceived stigma reduced the participation of people affected by leprosy in self-care. • Competing daily activities, time of going to work and farming reduced engagement in self-care by competing with time for self-care. • Supportive family member was a positive influence on self-care
17	Li et al., 2008b	Sustainability of Self-Care	n = 81	Quantitative	<ul style="list-style-type: none"> • Self-Care is effective • Active support from family members promoted self-care practice.
18	Madhavan (2007)	Sustaining leprosy disability care within an integrated leprosy control programme	n = 1232	Quantitative	<ul style="list-style-type: none"> • Effective supervision by Government health staff contributed to sustainability of self-care practice. • The use of locally available materials for self-care positively influenced practice of self-care. • Family support is key to compliance to self-care • People affected by leprosy who received Self-care education
19	Maia et al. (2016)	Role of assistive technologies in role of care	n = 8	Qualitative - interview	<ul style="list-style-type: none"> • Availability of assistive technology enabled, and motivated people affected by leprosy to conduct self-care by increasing their self-esteem and ability to do things for one's self. i.e. ability to care for one

20	Pakasi (2007)	Experiences of people affected by leprosy who were members of self-care groups	n = 15	Qualitative – observation, interviews	<ul style="list-style-type: none"> • People affected by leprosy who participated in self-care had high self confidence and self-esteem. • A functional self-care group is pre-requisite to sustaining self-care
21	Sathiaraj et al. (2010)	Impact of self-care knowledge on self-care practice.	n = 100	Quantitative - Survey	<ul style="list-style-type: none"> • Self-care education resulted in very high level of knowledge and practice of self-care.(knowledge on inspection for predisposing factors for wound development; knowledge on external causes for ulcers; knowledge on self-care practice techniques i.e. skills for self-care).
22	Shumin et al, (2003a)	The study focused on the past, current and future role of leprosy	n = 643	Quantitative	<ul style="list-style-type: none"> • Self-care was effective
23	Shumin et al, (2003b)	The study analysed the disability status and socio-economic situation of people affected by leprosy in Shandong Province	n = 14,193	Quantitative	<ul style="list-style-type: none"> • Adherence to leprosy Self-care was high.
24	Smith et al. (1995)	Assessment of a collaborative prevention of disability programme	n = 3571	Quantitative - Survey	<ul style="list-style-type: none"> • Self-care was enhanced by training in self-care methods. Training was aimed at people affected by leprosy and health workers.
25	Sussanto et al. (2017)	Experiences of people affected by leprosy in a self-care programme	n = 17	Qualitative – Focus group	<ul style="list-style-type: none"> • Active participation in Self-care groups helped to sustain and reinforce self-care practice among people affected by leprosy. • Self-care training is a positive factor for self-care practice. • Support from family members is a motivating factor for self-care practice

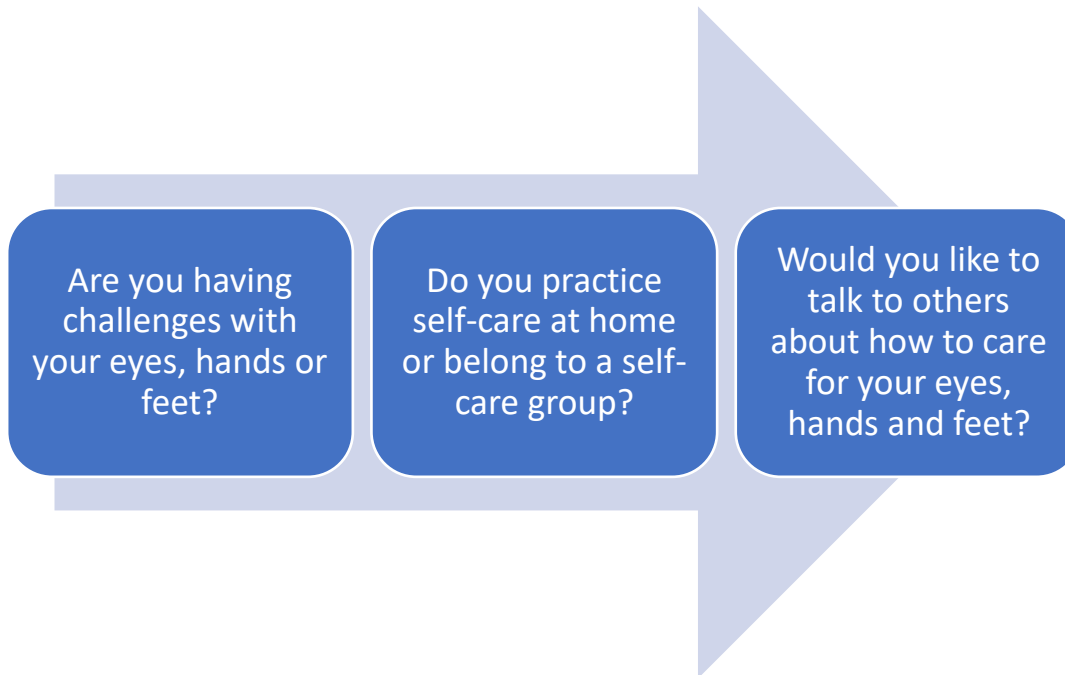
					<ul style="list-style-type: none"> Continued coaching, guidance and mentorship support is required for people affected by leprosy to develop self-agency and efficacy to continue self-care practice
26	Win et al. (2010)	Why people affected by leprosy neglected their plantar ulcer.	n = 101	Mixed methods – Survey, Focus Group	<ul style="list-style-type: none"> The following were hindrances to self-care: (a) Lack of knowledge on what to do and how to do self-care; (b) physical disabilities such as blindness or limited use of hands (clawed hand or shortened hands) (c) Poor relationship with family members.
27	Win et al. (2013)	Factors that promoted self-care of plantar ulcers	n = 31	Qualitative - interviews	<ul style="list-style-type: none"> Erroneous belief that leprosy ulcers are caused by environmental factors Availability of care materials (bandages, oil, soap etc.) promoted self-care. Family support is a motivating factor for self-care

Appendix 5: List of Studies Included In the Review and Country of Study

Primary Study (n = 24)		Thesis (n=3)	
Studies	Country of the Study	Studies	Country of the Study
Abera and Lemma (2003)	Ethiopia	Arief (2008)	Indonesia
Baker et al (2016)	India	Beissi (2012)	Indonesia
Benbow and Tamiru (2001)	Ethiopia	Pakasi (2007)	Indonesia
Cross and Newcombe (2001)	Nepal		
Cross et al. (2017)	Nepal		
D'Azevedo et al. (2018)	Brazil		
Deepak et al. (2013)	Mozambique		
Ebenso et al. (2009)	Nigeria		
Gautham et al. (2011)	India		
Gidado et al. (2010)	Nigeria		
Girma et al. (2018)	Ethiopia		
Lay et al. (2007)	Myanmar		
Li et al. (2008a)	China		
Li et al. (2008b)	China		

Madhavan et al. (2007)	India		
Maia et al. (2016)	Brazil		
Sathiaraj et al. (2010)	India		
Shumin et al. (2003a)	China		
Shumin et al. (2003b)	China		
Smith et al. (1995)	China		
Souza et al. (2014)	Brazil		
Susanto et al. (2017)	Indonesia		
Win et al. (2010)	Myanmar		
Win et al. (2013)	Myanmar		

Appendix 6: Research Information Handbill



If you answered YES to these questions, you are invited to join a research study!

This activity will involve you participating in an interview and the researcher will join your self-care group to observe how you care for yourself if you belong to a self-care group

If interested please inform your village head and you will receive further information on how to participate.

Appendix 7: Expression of Interest Form

Project: An exploration of self-care practice and the factors that influence self-care among people affected by leprosy in Nigeria

The 'Participant Information Sheet' has been explained to me and I understand what I am expected to do.

I am interested in taking part in this research because:

- I am a person affected by leprosy and I belong to a self-care group.

- I am a person affected by leprosy and I practice self-care at home.

Please return this form to the researcher. The researcher will be in contact with you to discuss the project, answer any questions you may have about the research and whether you would like to take part in it.

Please complete the following but only provide contact details that you are happy to share (*To be filled on behalf of the participant by a chosen family member*):

Name: _____

Mobile phone: _____

Email: _____

Work phone: _____

Postal address: _____

Researcher contact details:

Name: Sunday Odihiri Udo
The Leprosy Mission-Nigeria
12/14 King's Drive, Forte-Royal Estate,
Lugbe,
FCT-Abuja
Email: sundayu@tlmnigeria.org
Tel: +2348090850600

Appendix 8: Participant Information Sheet

Topic: An exploration of self-care practice and the factors that influence self-care among people affected by leprosy in Nigeria.

This research is being conducted as part of requirements for the award of a PhD degree from the Lancaster University in the UK. The research is led by Sunday Odihiri Udo, with 3 research assistants.

What is the study about?

The purpose of this study is to understand the practice of self-care among people affected by leprosy and the factors influencing their engagement in self-care practice.

Why have I been approached?

You have been approached because you are currently taking part in self-care practice at home or with a group and we are inviting you to share your experience of self-care practice.

Do I have to take part?

No. It's completely up to you to decide whether or not you would participate or not.

What will I be asked to do if I take part?

If you decide to take part, with your permission the researcher will ask for some introductory details about you and your involvement in self-care.

The researcher will conduct an interview with you in your home or at another convenient location of your choice and will take between 30 to 60 minutes to complete. Not everyone who agrees to take part may be interviewed; it will depend on the number of people we recruit. The Interview session will be recorded on an audio device so that the research staff may review your comments after the session is over. These audio recordings will not identify who you are. The audio recordings will be reviewed only by qualified research staff.

During the interview you will be asked a series of questions about a variety of topics including problems you have faced in managing your eyes, hands and feet since being diagnosed with leprosy. You will be interviewed alone. If you feel uncomfortable and need to interrupt or stop the interview, you are able to do so at any time.

Do I have the right to Withdraw from this study after I commence?

You have the right to withdraw completely from this research, before, during, or up to four weeks after data collection; additionally, you have the right to request that your data should not be used in the study.

Will my data be confidential?

All information you will provide will be treated as confidential and will be used only for research purposes.

Also, all the information you will provide in this study, whether in electronic formats or in hard copies, will be stored in a secure manner according to the policies of Lancaster University. All electronic data will be transcribed, analysed and reported. Then they will be stored in a password encrypted device for about 10 years before being deleted. The hard copies will be locked up in a secure cabinet. The Laptop where data will be analysed will be password protected and the individual files (audio, and text) on the computer will be encrypted, this means only those permitted to access them can do so.

For this research, only the researchers and the Lancaster University Ethics Review Committee may inspect study records. The Lancaster University Ethics Review Committee is the group that monitors research to make sure that they are safe for participants. After typing your interview, all details that might identify you will be removed, including your name. Even if we are using your quotations, your name will not be mentioned.

Sometimes, confidentiality may have to be broken: if for some reason we think what is said in the interview might place you or someone else under significant risk of harm, we may have to break confidentiality and speak to another member of the research team about the issue. If possible, we will let you know if this situation arises.

What will happen to the results?

This proposal is part of fulfillment of requirement for a PhD degree from Lancaster University. As such, it will be written up as a PhD thesis and submitted to the University of Lancaster. A summary report of the main findings will be written and shared with all participants including relevant Government agencies. Also, the findings will be disseminated through relevant peer reviewed journals. It will also be presented at national and international conferences.

Are there any risks?

There are no risks anticipated with participating in this study. However, discussions around challenges inherent in managing yourself as a person affected by leprosy may make you uncomfortable. Because you will be interviewed alone, the possible risk that the information you provide may be revealed outside the group is very minimal.

You do not need to talk about anything that makes you uncomfortable. Should any distress be observed in the course of the research you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

There will be no direct benefit to you from taking part in this study. However, by taking part, you will provide us with the information on the experience of people affected by leprosy practicing self-care in their daily life. The information that you provide will help us and the healthcare professionals to understand the experiences that people affected by leprosy may have in looking after their conditions. In addition, your participation will give us the information which enable us to identify ways the healthcare professionals could provide in meeting the needs of people affected by leprosy in helping them to manage their own

conditions. Apart from that, we will be informed of people affected by leprosy's opinions regarding whether the support given by the healthcare professionals met the needs of people affected by leprosy in managing their conditions. The finding of this study hopefully will improve practices and enhance the quality of care in the management of people affected by leprosy by providing the assistance and support depending on the patients' needs

Who has reviewed the project?

This study has been reviewed and approved by the University Research Ethics Committee at Lancaster University, UK.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the researcher:

Name: Sunday Odihiri Udo.
Division of Health Research
Faculty of Health and Medicine
Furness College
Lancaster University
Lancaster LA1 4YG
Email: sundayu@tlmnigeria.org
Tel: +2348090850600

Thank you for taking the time to read this information sheet.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact any of the following:

Professor Roger Pickup
Tel: +44-1524-593746
Email: r.pickup@lancaster.ac.uk
Chair FHMREC Research,
Faculty of Health and Medicine,
Division of Biomedical and Life
Sciences
Lancaster University, Lancaster LA1 4YD

Professor Bruce Hollingsworth
Tel: +44-1524-594154
Email: b.hollingsworth@lancaster.ac.uk
Head of Department
Faculty of Health and Medicine,
Health Research
Lancaster University, Lancaster LA1 4YD

Resources in the event of distress

Should you feel distressed either as a result of taking part in this project, or in the future, the following resources may be of assistance:

- Contact your Local Government TBL Supervisor or call +2348090850600.

Appendix 9: Consent Form

Study Title: An exploration of self-care practice and the factors that influence self-care among people affected by leprosy in Nigeria.

The purpose of this study is to understand the practice of self-care among people affected by leprosy and the factors influencing their engagement in self-care practice. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials (or finger-print) if you agree. If you have any questions or queries before signing the consent form please speak to the researcher.

Please initial or finger-print box after each statement

1. I confirm that I have read the participant information sheet and fully understand what is expected of me within this study	
2. I confirm that I have had the opportunity to ask any questions and to have them answered.	
3. I understand that my interviews and group observations with the researcher will be audio recorded and then made into an anonymised written transcript stored securely at Lancaster University.	
4. I understand that audio recordings will be kept for 10 years after PhD is awarded.	
5. I understand that I am not obliged to take part in this study and can withdraw my participation before, during, or up to four weeks after the interviews.	
6. I understand that the information from the interviews will be pooled with other participants' responses, anonymised and may be published.	
7. I consent to information and quotations from the interviews being used in reports, conferences and training events.	
8. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others: in which case the researcher may need to share this information with the research team.	
9. I consent to Lancaster University archiving audio and written transcriptions of the interviews and group observations after the study has finished.	
10. I consent to take part in the above study.	

Date:

Name of participant: _____ Signature: _____

Name of researcher: _____ Signature: _____

Appendix 10: Demographic Questionnaire

Thank you for coming today. We are interested in finding out what people know or have been advised to do about self-care. We ultimately want to understand what kind of information or help you could best use to manage your chronic conditions.

We have a few background questions before we start with the focus group. Please answer the following questions about yourself:

1. What is your age? _____
2. Gender: M _____ F _____
3. State of Origin: _____ I would rather not say _____
4. When were you diagnosed with Leprosy? _____ (MM/YYYY)

Indicate the classification: PB leprosy or MB Leprosy

5. When did you begin multi drug therapy (MDT)? _____ (MM/YYYY)
6. What MDT medications are you currently taking? _____
7. What visible deformities do you have? _____
8. Where do you stay? _____
9. What do you do for a living and how much do you earn in a day?-

Appendix 11: Full thematic matrix

STUDY OBJECTIVE: To identify the factors that make it easy (facilitators) or difficult (barriers) for self-care practice among people affected by leprosy at home and in a self-care group			
COMPETENCE			
Typical Quotes	Codes	Subtheme	THEME
<i>...but they could not put themselves in my shoes to understand and show empathy. They just kept asking questions and trying to find fault with my self-care routine... (PT 09: Male, 65)</i>	Lack of empathy	Healthcare Worker-Patient Relationship and Communication	Health Care Worker Support
<i>... he knows me very well and we understood each other. He is a good listener and pays attention to the things I say to him. (PT 13: Male, 50)</i>	Effective communication between patient and health worker		
<i>I want to tell the self-care facilitator supporting our group currently to learn to listen to patients when they are speaking to her. I also want her to know that its beyond how our wounds are healing, but also how feel. (PT 04: Female, 45);</i>	Ineffective communication between patient and health worker		
<i>'All that nurse knows how to do is to scold you. He continued to ask me why my ulcer was always infected. Every time I visited the clinic, the nurse always asks the same questions: "Why is your ulcer infected? Why is it not healing? "Each time he asks, I usually don't have a response. I just keep quiet. The good thing is that we have the TLM staff, Titi. She is much more understanding and I am more comfortable with her.' (PT 01: Female, 50); 'They only want to speak without listening to your complaints. There was a day I visited the clinic to discuss the discomfort I was having with my leg stump, and the nurse wouldn't even listen, she said she knew what could be wrong and referred me to the center in Chanchaga.'(PT 16: Male, 57)</i>	Unprofessional and Threatening communication		
<i>There is this other one, I don't even want to mention her name, see, no matter how many times you tell her the way you feel, she will say "you cannot be feeling like that". I don't understand how she could talk that way. As if she is sharing your body with you. She does that especially when she is about to close. It's her own way of avoiding responsibility' (PT 05: Female, 35)</i>	Insensitive/dismissive of patient concern		
<i>She wasn't nice in how she said it. It was obvious the conversation was over. She was informing me she did not hear my view and thought. She is the health worker and what she says is final. She didn't even care to know why I couldn't do it every day as she prescribed. (PT 17: Female, 30); Honestly, I did not want her to see me again. I prefer health workers who would be more like partners with me in my leprosy-self-care who would listen to why I do things the way I do them. Afterall, it's my body and I want to get well. So, some are not ready to understand how you feel what struggles you might be facing in trying to comply to their instructions. (PT 17: Female, 30)</i>	Inclusion/Non-inclusion of patients in decision making		
<i>They only want to speak without listening to your complaints. There was a day I visited the clinic to</i>	Patriarchal (Top down medical		

<i>discuss the discomfort I was having with my leg stump, and the nurse wouldn't even listen, she said she knew what could be wrong and referred me to the center in Chanchaga.'(PT 16: Male, 57)</i>	model)		
<i>I didn't know the cause of this disease or how it got into my body. I got it when I was a teenager and at the time my mother told me it (leprosy) could be a sign that bad people (Witches or Wizards) from my village cast a spell on me, and I somehow believe it, because the way it started was very strange.' (PT 15: Male, 43)</i>	Knowledge about leprosy	Self-care training and personal Skills	Self-care Knowledge and Skills
<i>The self-care training, I received has been very helpful. They taught us about leprosy, how it can cause disabilities and how to care for our eyes, hands and feet. (PT 12: Male, 50)</i>	Knowledge and understanding about self-care		
<i>It's true, we were taught to soak our hands and feet in soapy water for at least 30 minutes every day and apply oil on them. Well, I don't soak and oil them (hands feet) every day (...) maybe once every 3 days (...) But I do put cream on them every day because I believe it will still work (effective) to protect my skin. (PT 15: Male, 43)</i>	Self-care knowledge not necessarily leading to compliance		
<i>The health workers give us training from time to time on how we should take care of our bodies. This has been very helpful. We received over 12 sessions of training. One session per week. (PT 10: Male, 30)</i>	Duration of training		
<i>The self-care training, I received has been very helpful. They taught us about leprosy, how it can cause disabilities and how to care for our eyes, hands and feet. (PT 12: Male, 50)</i>	Scope of training		
<i>I did not choose it. This is how we were taught. We received many trainings from the health staff. The training was practical. They brought all the materials and showed us directly how to do it (self-care). The trainings made me realise what I need to do and how I should care for myself. (PT 10: Male, 30)</i>	Organisation of training		
<i>Those lessons (self-care training) have stayed with me and make me want to care for myself. At least I know what to do. (PT 12: Male, 50)</i>	Patient Empowerment through self-care training.		
<i>Those lessons (self-care training) have stayed with me and make me want to care for myself. At least I know what to do. (PT 12: Male, 50)</i>	Positive impact of training on motivation for self-care		
<i>Another problem is that we sometimes don't have water and self-care is difficult. There was a time we did not have water in this community for more than 3 months. The only borehole has issues. Many people couldn't not even have their baths let alone do soaking and oiling. At the time we advised members of the self-care groups to go get water from the closest stream, which is like 5 kilometers away but only those who could walk long distances or had family member who helped got water. We knew it was not a very good idea because we know the pressure it could put on the feet of those with ulcers At some point the self-care group tried to organize the youths to bring water to the ulcer shed it worked for a while and stopped.' (PT 14: Male, 45).</i>	Positive Problem-solving orientation/ Decision making		
MEANING			

Typical Quotes	Codes	Subtheme	THEME
<p>My husband reminds me if I forget to do my daily self-care activities. It's like he is the in-house doctor (Laughs). I like it because, it has really helped me to take care of my body. For example, if I forget to inspect my hands and feet, he will remind me. He goes as far as making sure get necessary materials. There was a time we did not have water; he went out of his way to get me water from the nearby stream just to make sure I did not miss that day's (self-care) activities. (PT 17: Female, 30)</p>	Family (siblings and children) support (provision of self-care materials – water, bandages)	Family Support	Social Support
<p>My wife ensures I do every necessary self-care activity as prescribed. She sometimes even joins me to soak her feet just to encourage me. I don't think I could have been more consistent in carrying out some of the activities without her support... Before I go out to any place, she gets my sandals ready, if she finds me walking about the house without my sandals (protective shoes) she would not be happy.' (PT 12: Male, 50).</p>	Practicing self-care so as not to disappoint family members.		
<p>My family are giving me all the required support I need. Especially my wife who is always assisting me in running my daily activities, like fetching water for me to bath, she helps me to wash my clothes and supports me when I run out of money to buy self-care materials. For example, this current soaking bowl I am using was bought for me by my wife. She has been very good to me. I don't know how to pay her.' (PT 15: Male, 43)</p>	Tangible support from family members		
<p>Honestly, I don't know why my husband is so worried about my looks. While I really don't mind about how people feel about whether I have had leprosy or not, he on the other hand, doesn't want people to know I have leprosy. So, because of him, I don't wear the Kano shoes, which are very soft and protect my feet...He has threatened me with divorce before. So, I am careful. It is for the same reason that I used to avoid attending self-care groups meetings. He didn't want me to associate with them. (PT 01: Female, 50).</p>	Non-supportive family member due to stigma		
<p>You know, I am a Muslin and we have to pray at least five times a day. And each time, before we pray, we must do ablution. Anytime I am doing ablution, it reminds me of the need to also take care of my hands and leg. (PT 11: Male, 35)</p>	Ablution as a reminder to do self-care		
<p>But anytime I am not able to carry out self-care, I always get strength after prayer to continue. Prayer reminds me of God's sovereign ability to heal me completely, while I play my part to care for myself. (PT 19: Female, 50)</p>	Spirituality (Prayer) as coping mechanism and motivator.		
<p>As a matter of fact, I felt bad as a result of this ailment. However, because of my strong faith in Allah, I am not too worried because I know he allowed me to have this disease. Not that I am thinking, I know it is a test from Allah. So, for me getting leprosy is just how Allah decided to test me. We all have to be tested one way or the other. For me it is leprosy. Although it is a test which I have accepted, I know I still have to play my part by caring for my body and in so doing Allah will have mercy on me</p>	Test of Faith		

<i>and heal me completely. (PT 11: Male, 35</i>			
<i>Another time I struggle is during the Ramadan fasting. As a muslim, you fast for about 1 month every year. You know fasting makes a you a bit weak. So truly I don't do everything I am meant to do during fasting. Honestly speaking, I don't use the pumice stone to scrape my feet, it takes too much effort. I only soak and oil my feet and just not do much during this period. (PT 01: Female, 50)</i>	Religious practices as inhibitor (Fasting)		
<i>My ulcers have healed, and my general appearance has really improved, and people want to associate with me more ... This is what is encouraging me to continue this self-care programme because I don't want my condition to reverse. (PT 13: Male, 50</i>	Positive impact of self-care on stigma	Stigma and Discrimination	Inclusion
<i>Everybody knows this Kano sandal is only for us who have leprosy. I have complained that its design should be changed to look like ordinary sandal, so that people will not label us because of it, but they refused and still supply them. Honestly, I stopped wearing them because it makes people run away from me. (PT 14: Male, 45)</i>	Stigma associated with self-care materials		
<i>What else can they do? They beg for money, food, clothes anything that can make their lives better. This is one of the major problems in this country. The level of stigma and discrimination you face from leprosy is still very high. (PT 17: Female, 30)</i>	Negative impact of stigma and discrimination		
<i>I do it because if you don't take care for your body you will not enjoy your health, and people shy away from you. Someone even said to me, 'how can someone who cannot care for himself be taken seriously'. I will never forget that statement. I remember when I had a bad smelly foot ulcer, they would not even involve me when discussing serious issues in the community, even within my family I was often left out of some decisions. I am happy, those days are gone. Self-care helps me stay clean and as healthy as possible and this brings respect from my family and other members of this community in this Yangoji.' (PT 16: Male, 57)</i>	Social inclusion/participation		
<i>For example, when I remember how I have been treated badly by some people because I have leprosy, I feel very sad. It gets to me. I had a man who wanted to marry me after some time he just changed. Someone told him I had leprosy. Instead of asking me himself, he just stopped coming to visit me. Honestly when I remember I just feel so bad that I lose interest in everything, including doing self-care, because really what's the point. And then I look at my children I pick up courage to continue. (PT 02: Female, 43)</i>	Diminished self-esteem and self-worth		
<i>Also, through self-care, I am developing a relationship with myself and knowing myself better and this helps me to develop a good relationship with my family and others, especially the community and my colleagues. (PT 10: Male, 30)</i>	Respect (family, community)		

<p><i>There is really nothing except I have this pain on my amputated leg. The pain was there before the amputation. I thought after the amputation it would go away, but it hasn't. It only relives me for a while and starts again. I don't understand because they said leprosy doesn't cause pain. I don't know why my own is so different. The pain keeps coming back and it's been there for a long time. It (pain) makes me feel very sad and drains my energy. How can I care for myself when this pain makes me feel sad and does not allow me care for myself? I sleep little because of this pain. (PT 09: Male, 65)</i></p>	Chronic Pain inhibits self-care	Neuropathic Pain	Health Status
<p><i>I get serious pains on my amputated leg. It's a burning pain that lasts for hours and when it starts, I can't even do anything for myself. (PT 15: Male, 43)</i></p>	Physical pain inhibits self-care		
<p><i>You know, I am a Muslin and we have to pray at least five times a day. And each time, before we pray, we must do ablution. Anytime I am doing ablution, it reminds me of the need to also take care of my hands and leg. (PT 11: Male, 35)</i></p>	Ablution facilitates self-care	Complimentary Practices	Competing and Complimentary Practices
<p><i>It (self-care) is a bit easy for me because I have taken it to be part of my life. I told myself that after I bath in the morning, I will do my self-care. The same thing is what I do in the evening after I take my bath before I sleep, and I have done this now for over three years. Each time I take my bath, it reminds me of the need for self-care (PT 13: Male, 50).</i></p>	Bathing serves as self-care reminder		
<p><i>Is there anybody who likes to beg. It's the condition we have found ourselves. I am even ashamed to say this, I really don't like begging, but I have to beg to be able to survive. I have no job and I have only limited land to farm. Like I said, I am even ashamed to beg this is why I sometimes go very far away from my settlement to another part of town to beg so people will not recognize me. (PT 15: Male, 43)</i></p>	Unemployment in an inhibitor of self-care	Economic Hardship	
<p><i>There is no regular income. I believe if Allah has mercy on you, you get enough to get by for two to three days... (PT 16: Male, 57)</i></p>	Low level of financial resources		
<p><i>Although it is not every day that I go out to beg, but I usually don't miss Fridays. Because we usually get a lot of money from people after praying (Moslems).To be honest, Fridays are the worst days for self-care because I have to leave home early to ensure I have a good spot where I can be seen by those entering and leaving the mosque to I can get enough money. So, to be honest, I don't do much of self-care on Fridays.' (PT 20: Female, 42)</i></p>	Begging competes with self-care	Competing Demands	
<p><i>Begging sometimes gets in the way because you have to make people have mercy on you by showing your problems. Sometimes you have to go early to beg and will not be able to do self-care. Don't get me wrong it's not all the time I beg. But some days when I beg, I don't have time for self-care. I just have to tell you the truth...' (PT 12: Male, 50)</i></p>	Begging (using disease condition to beg)		

<p>As I said, the major issue that sometimes affects my self-care is that I have to go to work very early. I am a receptionist in an office. I am the one that opens the office doors and organize the cleaners. So, I have to be there very early. The distance between my house and the office is very far and I don't have my one transportation. And after I come home, I am sometimes too tired to do all the self-care procedures, so I do some like covering eyes before I sleep. And like I already mentioned, I don't soak and oil every day. (PT 17: Female, 30)</p>	<p>Work demands competes with self-care</p>		
<p>I spoke with the nurse. She told me that my condition is very serious - that I can lose my sight, because it can damage my eyes, I will have ulcers that do not heal and many people have lost their hands and legs (PT 02: Female, 43)</p>	<p>Concern of developing complications</p>	<p>Fear of complications</p>	<p>Fear</p>
<p>When I was told I had leprosy, I had no idea that was what I was dealing with. The doctor informed me that leprosy was a skin and nerve disease'. They [healthcare workers] also showed me images of people without legs because of leprosy. That made me afraid. I knew leprosy was a dangerous disease (PT 12: Male, 50)</p>	<p>Fear of complications</p>		
<p>I know that because I have leprosy, I may develop complications. This is because of what we have been told by the nurses. I believe them because I have seen other people who had leprosy and their legs were cut off. I am afraid that the same things may happen to me. So, I think I need to care for myself before things will get worse. (PT 7: Male, 50)</p>	<p>Scare tactics and use of threatening communication</p>		
<p>I developed a wound on my right leg, and it took a long time for it to heal. When that happened, I then realised the effect of leprosy on my body, and it made me realise the importance of self-care. Actually, you can prevent damage to your body if you have knowledge about it. (PT 06: Female 42)</p>	<p>Personal experience of complications</p>		
<p>After realising I had leprosy, a lot of negative feelings came into my mind. I was afraid of what would happen to me in the future. Who will like to marry someone like me...Someone told me I might go blind, lose my fingers or lose both my legs if I am not careful. I was so worried that I did not know what to do anymore' (PT 08: Female 58)</p>	<p>Feeling of hopelessness and stress</p>		
MATERIALS			
<p>Typical Quotes</p>	<p>Codes</p>	<p>Subtheme</p>	<p>THEME</p>
<p>That was the good old days, now they say we should provide these materials by ourselves and it is not everybody who can do so. (PT 10: Male, 30)</p>	<p>Change in policy for supply of self-care materials</p>	<p>Availability of materials</p>	<p>Resources</p>
<p>I said it before, from time to time, we run short of things like eye ointment, bandage or cotton wool and this makes self-care very difficult. Once materials are available, self-care is very easy to do.' (PT 11: Male, 35)</p>	<p>Availability/Unavailability of self-care materials (E.g Water)</p>		

<i>Some of my friends say they use cooking oil. But honestly how can you apply food on your wounds? It doesn't sit well with me, so I don't do it. Anytime I have Vaseline I use it, when it finishes, I try olive oil, if it's not available, I wait until I can buy any of them.' (PT 03: Female, 48).</i>	Motivation to innovate and use alternatives		
<i>One thing I can tell you straight up is lack of materials. Many of my colleagues suffer because they can't buy some of these items. Especially items like eye ointment, eye shield, gloves. For these rest, you can easily have substitutes but for these ones, it is difficult. I can tell you that many more people used to practice self-care when these items were provided free of cost by the Missionaries. Now we have to source for them ourselves. (PT 14: Male, 45)</i>	High cost of materials	Affordability of materials	
<i>I used to apply eye ointment every night before going to bed. But now, I only apply it about three times a week. This is because I cannot even afford to apply it every day as expected because it will finish on time and it is expensive for me to procure. (PT 11: Male, 36)</i>	Lack of financial resources		
<i>Although we were told it is ok, I still struggle with putting cooking oil on myself. See, sometimes we don't even have the cooking oil to apply. (PT 01: Female, 50)</i>	Rejection of alternatives	Acceptability of materials	
<i>Some of my friends say they use cooking oil. But honestly how can you apply food on your wounds? It doesn't sit well with me, so I don't do it. Anytime I have Vaseline I use it, when it finishes, I try olive oil, if it's not available, I wait until I can buy any of them.' (PT 03: Female, 48).</i>	Negative perception of using substitute materials (e.g cooking oil)		
<i>They say we can use old rags, cooking oil to apply on our legs and hands. Honestly, I don't do it because I don't think it is right. Can you put cooking oil on your hands and feet? So, I buy my Vaseline and when it is finished, I wait until I can buy another. (PT 10: Male, 30)</i>	Lack of understanding of mechanism of action of self-care materials		
<i>Now you have to get everything by yourself and even apply substitutes like home oils. I really don't believe they are effective. So, I don't apply it. Although we were told it is ok... (PT 01: Female, 50)</i>	Doubts about effectiveness of alternatives		
<i>For example, I don't wear the sandals provided by the programme because it's like a label and a negative one for that matter. I have advised the Mission staff that the style should be changed to look like the normal sandal you can buy in Wuse market so we would not be viewed and treated differently. Everybody knows that shoe is for leprosy people. I cannot wear it because of my work. (PT 17: Female, 30)</i>	Stigma associated with self-care materials (e.g Protective shoes)		
<i>Aside from this, the other is lack of water. Sometimes when our borehole does not have water, it (self-care) is difficult to do... (PT 20: Female, 42)</i>	Difficult/limited access to alternatives (e.g fetching water from stream)	Accessibility of Materials	

Appendix 12: Demographics of Participants

Participant ID	Age (Mean: 46.5)	Gender	Occupation	Duration since Diagnosis (Years)	Type of Leprosy
PT 01	50	F	Fish Farmer	> 10	MB
PT 02	43	F	Unemployed	> 10	MB
PT 03	48	F	Petty Trader	> 10	MB
PT 04	45	F	Petty Trader	> 10	MB
PT 05	35	F	Fuel Pump Attendant	< 5	MB
PT 06	42	F	Unemployed	> 10	PB
PT 07	50	M	Unemployed	> 5 ≤ 10	MB
PT 08	58	M	Cleaner	> 5 ≤ 10	MB
PT 09	65	M	Unemployed	> 10	MB
PT 10	30	M	Teacher	< 5	MB
PT 11	35	M	Petty Trader	< 5	MB
PT 12	50	M	Farmer	> 10	MB
PT 13	50	M	Farmer	> 5 ≤ 10	PB
PT 14	45	M	Farmer	> 5 ≤ 10	MB
PT 15	43	M	Farmer	> 10	MB
PT 16	57	M	Unemployed	> 10	PB
PT 17	30	F	Receptionist	> 10	MB
PT 18	63	M	Unemployed	> 10	MB
PT 19	50	F	Petty Trader	> 10	PB
PT 20	42	F	Unemployed	> 10	PB

Appendix 13: FCT Health Research Ethics Committee Approval



FEDERAL CAPITAL TERRITORY *Health Research Ethics Committee*

Research Unit, Room 10, Block A Annex, HHSS, FCTA Secretariat,
No. 1 Kapital Street 11, Garki, Abuja-Abuja.

Notice of Expedited Review and Approval of Research

Approval Number: FHREC/2018/01/79/09-07-18

Study Title: An Exploration of Self-Care Practice and Factors that Influence Self-Care among People Affected by Leprosy in Nigeria.

Principal Investigator: Dr. Udo Sunday Odihiri

Address of Principal Investigator: No 32 Ayim Pius Street, CBS Estate, Along VON Road, Lugbe, Abuja.

Date of receipt of valid application: 19/06/2018

This is to confirm that the FCT Health Research Ethics Committee (FCT HREC) has given expedited approval to the research described in the above stated protocol. The FCT HREC has determined that this research qualifies for expedited review pursuant to the National Code of Health Research Ethics; Section E (f - 1a);

- Study does not involve more than minimal risk.

Note that no activity related to this research may be conducted outside of these dates. Only the FCT HREC approved informed consent forms may be used when written informed consent is required. They must carry FCT HREC assigned protocol approval number and duration of approval of the study. The FCT HREC reserves the right to conduct compliance visit to your research site without prior notification.


The National Code of Health Research Ethics requires the investigator to comply with all institutional guidelines, rules and regulations regarding health research, and with the tenets of the code. **Modifications:** Subsequent changes are not permitted in this research without prior approval by the FCT HREC.

Problems: All adverse events or unexpected side effects arising from this project must be reported promptly to FCT HREC.

Renewal: This approval is valid until the expiration date. If this project is to proceed beyond the expiration date, an annual report should be submitted to FCT HREC early in order to request for a renewal of this approval.

Closure of Study: At the end of the project, a copy of the final report of the research should be forwarded to FCT HREC for record purposes, and to enable us close the project.

For queries and further information contact FCT HREC office. I wish you best of luck with your research.


Desmond Emeonyeokwe
Ag. Secretary, FCT HREC
July 09, 2018.



Appendix 14: Lancaster University Research Ethics Approval



Applicant: Sunday Udo
Supervisor: Mark Limmer & Katherine Froggatt
Department: Health Research
FHMREC Reference: FHMREC17113

30 July 2018

Dear Sunday

Re: An exploration of self-care practice and factors that influence self-care among people affected by leprosy in Nigeria

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "Becky Case".

Becky Case
Research Ethics Officer, Secretary to FHMREC.