



UNIVERSITEIT VAN PRETORIA
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**A MIXED METHODS STUDY TO DEVELOP A SELF-CARE MANAGEMENT TOOL FOR
BOTH PEOPLE LIVING WITH DIABETES AND THEIR FAMILIES**

By

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DECLARATION

DECLARATION

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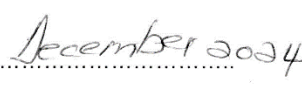
I, Jennifer Denise Jumat, hereby declare that the thesis:

**A MIXED METHODS STUDY TO DEVELOP A SELF-CARE MANAGEMENT TOOL FOR
PEOPLE LIVING WITH DIABETES AND THEIR FAMILIES**

is my original work. It has not been submitted to any other institution before for any degree or examination. All the sources used and quoted were acknowledged by means of complete references in the text and bibliography.


.....

Jennifer Denise Jumat


.....

Date

DEDICATION

DEDICATION

This study is dedicated to:

I dedicate this work to all people diagnosed with diabetes and their support systems. Without my husband, who encouraged me throughout every challenge and served as my inspiration for this research, this study would have remained a dream.


.....

Jennifer Denise Jumat


.....

Date

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ABSTRACT

A MIXED METHODS STUDY TO DEVELOP A SELF-CARE MANAGEMENT TOOL FOR BOTH PEOPLE LIVING WITH DIABETES AND THEIR FAMILIES

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DEGREE: PhD Nursing Science

Introduction and background: The progressive nature of Diabetes Mellitus requires lifelong self-care, which refers to the deliberate decisions and practices of the people living with diabetes (PLWD) and supporting family. The essence of self-care is to prevent risks and complications, but health education programs are lacking, and support for care is weak.

Aim and objective: To create a self-care tool that will support and improve self-care habits, it was necessary to investigate how PLWD perceive self-care and how the family is involved.

Research design and methods: This Mixed methods study followed a qualitatively driven, descriptive and explanatory approach. In Phase 1, 104 individuals living with diabetes provided data using the DSSQ-Fv. Phase 1 reliability analysis revealed that the five constructs obtained high Cronbach Alpha values, ranging from 0.803 to 0.989, and had a good discriminating power. Phase 2 Stage 1 data collection involved conducting fifteen telephone interviews after a focus group with four individuals. Phase 2 Stage 2 data collection involved four family members in a focus group, and eight telephone interviews were conducted afterwards. Coding, categorisation, and theming were used in the analysis process. Phase 3 involved the Delphi consensus-building process being used to collect information from ten experts.

Results: The general self-care regimen was deemed inadequate. Most PLWD concentrate primarily on the diet, paying little attention to medication or exercise as a means of controlling blood sugar levels. An easy-to-use self-care tool was developed.

Conclusion: The study revealed inadequate self-care behaviours and a weakness in DSME/S. Developing a daily self-care regimen is necessary to enhance self-care practices.

Keywords: Diabetes Mellitus, Diabetes self-care management tool, Orem's Theory, Mixed-methods, Family support, Person-centeredness, Coding, Thematic analysis, Delphi technique.

ABBREVIATIONS AND ACRONYMS

BALD	Baker Able Leaflet Design
Bn	Billion
CAQDAS	Computer-Aided Qualitative Data Analysis Software
CCS	Country Capacity Survey
α	Cronbach alpha
CHWs	Community health workers
COVID-19	Coronavirus disease of 2019
CRD	Chronic renal disease
CVD	Cardiovascular disease
DSME	Diabetes self-management education
DSME/S	Diabetes self-management education and support
DSSQ-Fv	Diabetes Social Support Questionnaire Family version
HCPs	Health care professionals
IDF	International Diabetes Federation
JEMDSA	Journal of Endocrinology Metabolism and Diabetes of South Africa
NCD	Non-communicable diseases
NHI	National Health Insurance
PHC	Primary Health Care
PIL	Patient Information Leaflet
PLWD	People living with diabetes
QUAL	Qualitative
Quan	Quantitative
SA	South Africa
SEMDSA	Society for Endocrinology, Metabolism and Diabetes of SA
SGDs	Sustainable Development Goals
Sms	Short message service
Std Dev	Standard deviation
UN GA	United Nations General Assembly
UP	University of Pretoria
VGTs	Voluntary Global Target
WHA	World Health Assembly
WH GA	World Health General Assembly
WHO	World Health Organisation

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This chapter provides a brief overview of the research study and indicates the layout of the thesis. This study focused on self-care of Diabetes Mellitus (DM) types 1 and 2 and introduces the reader to diabetes self-care management. The presumption is that people who are diagnosed with diabetes take care of themselves; however, the effectiveness and level of self-care practices vary. It therefore explores how they are taking care of themselves and how the family is involved in diabetes self-care management. It is therefore necessary to ask how people who are diagnosed with diabetes and their families can be helped to improve family support and diabetes self-care management education (DSME). Diabetes Alliance South Africa (2012:3-4) and American Diabetes Association (2025:56) explain the effect of diabetes language, stating “They also affect how individuals and society view people living with, or at risk of, diabetes.” Therefore, to help reduce the stigma attached to the diabetes language, this study used the term people living with diabetes (PLWD). The purpose of this project was to create a tool that would improve diabetes self-management and education (DSME) and family support systems for both PLWD and their families in Tshwane, South Africa.

1.2 BACKGROUND OF DIABETES SELF-CARE MANAGEMENT

Allie, Van Wyk, Coetzee and Van Wyk (2017:23) promote a patient-centred approach for the management of diabetes. In this study and in consideration of the stigma attached to diabetes language, a patient-centred approach might be appropriate when PLWD are admitted to receive care in hospital, the term patient-centred(ness) is interchangeably used with person-centredness. In order to support a person-centred approach, Allie et al. (2017:23) offered advice to health care professionals (HCPs) in diabetes management. Knowing how a PLWD or family is impacted in day-to-day living and attending to their concerns would be part of this strategy to improve diabetes self-care.

The World Health Organisation (WHO, 2016a:4) acknowledged DM as one of the four priority non-communicable diseases (NCDs). Luan et al. (2017:1172) regard diabetes as a chronic NCD. World Health Organisation (2016a:11) classifies this disease as type 1 diabetes, type 2 diabetes, gestational diabetes, impaired glucose tolerance (IGT), and impaired fasting glycaemia (IFG). The non-production of insulin characterises type 1 diabetes due to Beta-cell (β cell) destruction, subsequently leading to insulin dependence. Type 2 diabetes, on the other hand, occurs when there

is β -cell dysfunction, relative insulin deficiency and some level of insulin resistance. The pancreas makes insufficient insulin, or the body fails to use the insulin which is being produced effectively. In this case, insulin is not required for the survival of PLWD type 2 diabetes (WHO, 2019:15). People diagnosed with IGT or IFG diabetes types might be vulnerable to increased cardiovascular diseases (CVD), like strokes. This illness might progress to type 2 diabetes over a prolonged timeframe. Hyperglycaemia, a condition in which blood glucose levels are above normal but below the threshold required to diagnose diabetes, is the primary indicator of gestational diabetes, which typically only manifests during pregnancy. Thus, pregnant women are at a higher risk of potential problems during their pregnancy and delivery (Diabetes (who. int). (2023/11/22 online), 5 April 2023. This research introduces the reader to Type 1 and Type 2 diabetes self-care management and explores how PLWD are taking care of themselves and how the family is involved with diabetes care.

Diabetes is a progressive disease, and as such, life-long self-care management is inevitable (Luan et al., 2017:1172; WHO, 2016a:4). Diabetes self-care management could be instituted as outlined by Allie et al.(2017:23). They recommended that HCPs ensure a person-centred approach, which includes knowing how the PLWD or family is affected in their daily life, ensuring to solve uncertainties or addressing questions asked, attending to concerns about living with diabetes and how PLWD or family can be assisted to improve self-care. These authors imply that PLWD and their families must make decisions about self-care. It is, therefore, regarded that support must be receptive to individual needs and values.

Van Der Heide, Snoeijs, Boerma, Schellevis and Rijken (2017:7,9-10) view patient/person-centredness as coordinated health care, simultaneously emphasising individual needs, preferences and value systems that are essential for quality care. In addition to the above authors' opinions, Kaakinen and Denham (2015:237-244) identified that micro-, macro-, and meso-level strategies enable balanced person-centred care to include everyone who is involved in diabetes self-care management. Within the context of a coordinated and person-centred approach to health care, the significance of families was emphasised in various diabetes self-care management research studies. Some authors observed families inherently part of dealing with chronic disease management and encouraged family inclusion over and above multi-disciplinary health teams (Baig, Benitez, Burnet & Quinn, 2015:89-90; Van Der Heide et al., 2017:9-10; Allie et al., 2017:23; Wichit, Courtney, Mnatzaganian, Schulz & Johnson, 2017:44). However, Kaakinen and Denham (2015:237-244) argued that there is a need to learn how diabetes self-care management can be managed in a family context. They emphasised that frequent unexpected changes make the roles and responsibilities of families unpredictable. Peñarrieta, Flores-Barrios, Gutiérrez-Gómez, Piñones-Martínez, Resendiz-Gonzalez, and Quintero-Valle (2015:78) noted the complexity of diabetes self-care management. Chlebowy (2021:287) summarised the complexities of diabetes self-care management as for PLWD

to adhere to a complex diet, take medicine, do physical activities and monitor the blood glucose, stating that these actions are complicated by financial constraints, poor self-control, not motivated or a lack of knowledge and skills. It is thus argued that self-care of diabetes can affect both PLWD and their families. World Health Organisation (2016a:8) proposed that strategies for the management of diabetes must be developed and implemented at the primary care level. Subsequently, for this study, a self-care management tool was developed for both PLWD and their families in Tshwane, in order to increase diabetes self-management education and support (DSME/S). Therefore, individual perceptions and preferences of both groups during DSME/S need to be considered.

According to WHO (2016a:6,21) the 1st Global Report on Diabetes showed that the prevalence of PLWD had increased from 108 million (4.7%) in 1980 to 422 million (8.5%) in 2014. Moreover, Baig et al. (2015:89) and Chasens and Luyster (2016:1) argued that people with long-term diabetes were prone to risks. Besides the statistics reported in the only global report so far, statistics in 2010 showed that retinopathy amongst PLWD caused 1.9% visual impairment and 2.6% of blindness, as well as other complications (WHO, 2016a:30). Data from 54 countries indicated that comorbidities such as hypertension and diabetes were diagnosed in 80% of all people diagnosed with diabetes, with end-stage renal disease. Internationally, diabetes was rated as the 8th leading cause of death in both genders. According to WHO (2015:11), 6% of the total South African population (54 490 000 at that time of the said report) were living with diabetes, and findings posit a mortality rate for males at 0.071% (38 580) and females at 0.093% (50 810). World Health Organisation (2016a:4,6) declared diabetes an emerging global health challenge. In 2015, WHO (2015:11) had already suggested that health services must be integrated to encourage health promotion, to prevent, diagnose, treat, manage, and put in place rehabilitation and palliative care services that would meet individual needs when dealing with diabetes self-care management.

However, diabetes self-care management and support require different perspectives. From a self-care perspective, PLWD and individual family members have specific needs (Ogunbayo, Schafheutle, Cutts & Noyce, 2017:434). Luan et al. (2017:1172) assessed the impact of diabetes self-management education and support (DSME/S) after the implementation of comprehensive health education programmes in China. Findings posit that effective and feasible self-care contributed to a decline in acute and chronic complications and medical costs. Wichit et al. (2017:44) found that improved cooperation amongst families with strong relationships holds more advantages. They suggested that families must be included in training programmes that focus on self-care management. Ansari, Hosseinzadeh, Harris and Zwar (2017:69,71) explored the factors which influenced type 2 diabetes self-care management in middle-aged people in rural Pakistan. These authors developed a conceptual model to enhance self-care management for people diagnosed with type 2 diabetes. They also emphasised the significance of the family in self-care management.

Another study of self-care management came from Peñarrieta et al. (2015), who employed a cross-sectional correlational design to investigate the relationship between self-care management and families in Mexico. They also identified how Mexican families could be involved, as well as the value of the family, but concluded that families required more knowledge. Diabetes self-care management could thus be enhanced by considering these viewpoints of family support. Kaakinen and Denham (2015:238) further argued that the family should identify all the available resources and use them to their full potential despite limitations.

These authors further argued that PLWD with comorbidities have more demands, which complicates self-care management. Allie et al. (2017:22-23) and American Diabetes Association (2025:56) stated that the families of PLWD should be placed at the centre of care and receive education and support to manage diabetes self-care management effectively. In addition, JEMDSA (2017:20-21) define diabetes self-management education (DSME) as “an ongoing process of facilitating knowledge, skills, ability and motivation for diabetes self-care management that involves active participation of the PLWD”.

Dube et al. (2015a:3) audited type 2 DSME programmes in some of the developing countries, which included South Africa (SA). Their systematic review focussed on cultural sensitivity and low literacy amongst patients with chronic diseases. Despite DSME interventions by HCPs and how PLWD perceived these training programmes, the authors did not include families in their study. According to the country profile report (WHO, 2016b:1), SA responded positively to the availability and implementation of diabetes policies. However, a diabetes registry has not yet been implemented. Dube, Van den Broucke, Dhoore, Kalweit and Housiaux (2015b:176-179) also investigated auditing DSME programmes; and reviewed policies and DSME implementation in SA. They employed semi-structured interviews to collect data from service providers and experts (health professionals in public and private health settings). Regrettably, families of PLWD were excluded. Dube et al. (2017:24) explored how people with chronic diseases were experiencing self-management to determine their needs and explore perspectives about patient self-management from key informants (health professionals).

These authors developed a self-management support tool for patients with chronic diseases in SA. This study also excluded the family. From a South African perspective, the studies mentioned above show the significant role of families in self-care management, which strengthens the reasons why self-care management with the family should be investigated.

1.3 PROBLEM STATEMENT

Without effective diabetes self-care management, the prevalence and mortality rates of diabetes are likely to escalate (Luan et al., 2017:1173). Murphy, Chuma, Mathews, Steyn and Levitt (2015:2) noted that some PLWD were unable to take care of themselves. The 2017 SEMDSA Guideline for the Management of Type 2 Diabetes were updated and released in mid-2017 (JEMDSA 2017). Chapter 5 of 2017 SEMDSA Guideline for the Management of Type 2 Diabetes is dedicated to DSME/S, which provides six recommendations for diabetes self-care management. Consequently, one of the recommendations related to “diabetes self-management and education and support (DSME/S) that should be patient-centred, respectful and receptive to individual needs and values and non-discriminatory towards cultural, ethnic language, socio-economic and educational differences” (Allie et al., 2017:22). This recommendation was therefore contextualised to support easy-to-understand and straightforward implementation of self-care management practices for both PLWD and their families in Tshwane. This recommendation became the focus of this research project. Patient/person-centredness, individual values and needs are key factors and the need for a solid, established family support system are necessary to enhance self-care management practices for both PLWD and their families in Tshwane.

Individuals diagnosed with diabetes must make informed daily decisions regarding the self-management of this complex and challenging condition. Diabetes self-care management education and support provides a foundation to assist all PLWD in confidently navigating their daily self-care routines, resulting in improved outcomes. Diabetes self-care management education and support addresses the comprehensive integration of clinical, educational, psychosocial, and behavioural aspects of care essential for effective daily self-management. Notwithstanding the Standards of Medical Care in Diabetes (2018), or the Revised Standards of Care in Diabetes (2025) which has provided extensive clinical details on how to manage diabetes, uncertainty remains on how to involve the family during self-care management (Fort, Castro, Peña Hernández, Camacho, Ramírez-Zea & Martínez, 2015:2,6). Murphy et al. (2015:1-2) noted that families who were adequately empowered responded positively to self-care management. The 2017 SEMDSA Guideline for the Management of Type 2 Diabetes have been adopted in SA at national health level. No published studies to investigate person-centred diabetes self-care management with the involvement of families in Tshwane have been found. These 2017 SEMDSA 2017 guidelines focused on self-care management for type 2 diabetes (JEMDSA, 2017:1-196), and consequently, self-care management for type 1 diabetes was thus not addressed. Neither could SA guidelines for the management of type 1 diabetes be found (Diabetes Charter, 2021). The researcher perceived this as a gap for knowledge regarding total diabetes care. Therefore, this gap will be addressed by including people diagnosed with type 1 diabetes in this study.

Although Dube et al. (2015a; 2015b and 2017) conducted three investigations from a SA perspective, no considerations were given to involve the families of PLWD. Therefore, the researcher perceived the exclusion of families as another gap in diabetes self-care management. By excluding families in diabetes self-care management it can be assumed that there appears to be a lack of support from the family or support groups which include appropriate aspects of DSME/S pertaining to diabetes self-care management. Therefore, as family members might lack education or understanding of the diagnosis, appropriate diabetes self-care management practices and support for PLWD might be compromised. Hence, an increased awareness for diabetes self-care management amongst both PLWD and their families in Tshwane, including HCPs is supported (Diabetes Alliance South Africa, 2021:12). These arguments motivated as to why both PLWD and families should be placed at the centre of diabetes self-care management.

The focus of the problem is thus the lack or absence of a patient/person-centred approach when dealing with diabetes self-care, a solid family support system and DSME/S. It is maintained that the intricacy of managing diabetes self-care affects PLWD daily lives, so it is critical that these people and their families be equipped with the fundamental knowledge necessary to manage diabetes in specific circumstances. Developing a self-care management tool for individuals living with diabetes is crucial for especially the following reason, Empowerment and Education. Such tools provide individuals with the knowledge and skills needed to manage their condition effectively. From this perspective, the prevalence and death rates of diabetes in SA can be reduced by involving the family in diabetes self-care management.

1.3.1 Aim

The aim of this study is two-fold, first to describe the perceptions of PLWD, and to explain the experiences of both PLWD and their families in order to enhance their diabetes self-care management education and family support system. Secondly, to develop a diabetes self-care management tool for PLWD and their families to enhance their self-care management practices.

1.3.2 Research questions

The following three research questions guided this research:

- What are PLWD perceptions of family support related to their diabetes self-care management
- What are the experiences of PLWD and their families in practising diabetes self-care management?
- How can PLWD and their families be supported to increase/enhance their diabetes self-care management education and family support systems

1.3.3 Objectives

The following objectives guided the study:

- Phase 1: To describe PLWD perceptions of family support related to diabetes self-care management.
- Phase 2: To explore self-care management experiences of PLWD and their families in diabetes self-care management.
- Phase 3: To develop a self-care management tool for both PLWD and their families in order to enhance their diabetes self-care management education and family support system.

1.4 CONCEPT CLARIFICATIONS

The applicable concepts used in the study were:

Diabetes is a chronic NCD. Type 1 diabetes is characterised as non-production of insulin due to β -cells destruction, and the person becomes insulin dependent. Type 2 diabetes occurs when the body fails to effectively use the insulin which is being produced (WHO, 2016a:11).

Family refers to blood relatives, kinship, or friends (Bennich, Røder, Overgaard et al., 2017:2). In this study, the family was an extension of support for PLWD (Mitchell, Laurens, Weigel, Hirschman, Scott, Nguyen, Howard, Laird, Levine, Davis, Gass, Shaid, Li, Williams & Jack, 2018:228). The concept “family” in this study was applicable to any person who was supporting a PLWD with self-care management.

Health care professionals (HCPs) refer to persons who have obtained a health-related degree and complied with specific standards of competence as prescribed by the different health regulatory councils in SA. It included but is not limited to the Health Care Professions Council of SA (2008:i). In this study, HCPs included medical practitioners, podiatrists, dieticians, psychologists, physiotherapists, biokineticist, occupational therapists, pharmacists and social workers who were providing diabetes care to PLWD and their families within their respective scope of practices. HCPs also include professional nurses who were registered with the South African Nursing Council.

Patient-centeredness is the coordinated health care by different role-players, emphasising individual needs, preferences, and value systems to provide quality care (Van Der Heide et al., 2017:7,9-10).

People living with diabetes. In this study people living with diabetes (PLWD) meant those people who were diagnosed with type 1 or type 2 diabetes with or without comorbidities.

Self-care is the “self-initiated and self-directed actions of persons to know their current and future requirements and to regulate their own functioning and development, also to exercise their choice of how they want to meet such requirements to sustain life and to promote health and well-being” (McLaughlin Renpenning & Taylor, 2003:217). In this study, self-care referred to the deliberate decisions and actions of PLWD, supported by the family, taking responsibility for their diets, physical activities, adherence to medicine and medical prescriptions, physical, mental and emotional well-being, etc. (Alligood, 2014; JEMDSA, 2017; Omisakin & Ncama, 2011). The decisions of diabetes self-care management were based on the knowledge levels, attitudes and activities of both PLWD and their families. This study, therefore, used the concept of diabetes self-care management.

1.5 CONTEXT

The study took place at two health care settings, which were selected to secure an adequate number of volunteers to enable power analysis for phase 1. It is geographically located south-west of the Tshwane metropolitan (City of Tshwane, 2019). One setting was the Lyttleton Clinic, a primary health care clinic which operated between 08h00 and 17h00 during the week but closed over weekends and public holidays. This clinic provides community-oriented programmes such as facilitating support groups for tuberculosis and Human immunodeficiency virus once per month; as well as basic nutrition; antenatal services; and counselling to survivors of rape and abuse. Community health workers (CHWs) provided home-based care for the sick and needy and conducted health assessments. Patient referrals were made to tertiary healthcare facilities for mental health problems and expert services for chronic diseases, which included diabetes.

The second setting was the Laudium Community Health Centre that provided a 24-hour service and was open over weekends and public holidays. Their functions were slightly more expanded than the Lyttleton Clinic. Recruitment and data collection for phase 2 took place at the Laudium Community Health Centre, where focus group sessions for stages 1 and 2 were held. The Laudium Community Health Centre was selected due to the availability of and convenience of space over a weekend as a place where participants gathered for focus group sessions without interfering with the normal functions of the health care setting.

1.6 RESEARCH FRAMEWORK

Diabetes mellitus self-care management takes place within a family context (Van Der Heide et al., 2017:7,9-10; Wichit et al., 2017:44). This opinion is supported by Allie et al. (2017:22), who further argued that PLWD, caregivers and families should be skilled in various activities to effectively self-manage diabetes. This study is about how the families assisted PLWD with diabetes self-care management and perceived skilling as a development for PLWD and their families within the context

of a person-centred approach and DSME. Information about self-care management aspects was discovered during data collection. It included what both PLWD and their families are doing, how they were performing, how it could be done better and if their efforts could be sustained due to frequent lifestyle modifications (Kaakinen & Denham, 2015:244).

Allie et al. (2017:22) proposed the Chronic Care Model (CCM) for the management of type 2 diabetes. This model supports quality care to improve effective outcomes through a systems approach (Werfalli et al., 2017:1). The CCM comprise the following six elements, which can be used in any sequence, individually or combined: (1) community resources, (2) health care organisations, (3) delivery systems, (4) self-management support, (5) decision support, and (6) clinical information systems (Bodenheimer, Wagner & Grumbach, 2002:1776; Strickland, Hudson, Piasecki, Hahn, Cohen, Orzano, Parchman & Crabtree, 2010:295). Allie et al. (2017:22) emphasised DSME/S, which is nested in the CCM element, self-management support. The researcher associated self-management support with PLWD who are living for years with a chronic disease like diabetes and who require self-care education and family collaboration to manage diabetes. Even though the six elements are broad and flexible; the opinion is that it lacks a proposed plan for application or implementation. Even though this model was implemented in SA, evidence of how PLWD and families were managing self-care could not be determined.

The research framework is based on Orem's works, which conceptualised self-care in 1956. Orem's works supported the theoretical focus area for this study. Orem's theory provided specific concepts with clear guidelines, which were applied during data collection to find out what was known about person-centred self-care management perspectives of PLWD and their families, to discover how they interacted and what their perceptions and needs were, and to identify how lifestyles were adjusted to accommodate all individuals involved in self-care management. Orem's Model comprises the following three central theories: (1) Theory of Self-Care, (2) Theory of Self-Care Deficit and (3) Theory of Nursing System (Berbiglia, 2014:223). Two models were used, and to demonstrate the integration, the researcher extracted the self-management support element from the CCM to adjoin with Orem's Self-Care Model. This study wanted to improve diabetes self-care management, which could easily be performed and sustained to improve quality of life; therefore, Orem's Self-Care Model provided the framework for this research. The research findings determined the utilisation of the other two theories. Chapter 3, discuss the study framework.

1.7 PARADIGM AND PHILOSOPHICAL ASSUMPTIONS

The paradigmatic worldview or set of shared beliefs provided the structure for this study (Lewis, 2015:19-20). Both traditional quantitative and qualitative methodologies were utilised in this study. Consequently, the researcher employed a pragmatic approach to examine the complexities

associated with diabetes self-care management (Chilisa & Kawulich, 2012:9; Fiorini, Griffiths & Houdmont, 2016:37; Shannon-Baker, 2016:321-322; Schoonenboom & Johnson, 2017:108,110-111; Feilzer, 2010:7-8). According to Shannon-Baker (2016:321-322), pragmatism is an inquiry that is philosophically grounded when both traditional approaches are integrated into one research study, stating further that it can take place in a philosophical context or theoretical framework to specify data collection and analysis. Pragmatism emphasises practical outcomes and solutions, addressing real world problems. The researcher focused on what works best for PLWD and for their families as support systems rather than adhering strictly to theoretical aspects.

In Mixed methods design, quantitative data can confirm and test the results of qualitative data, and qualitative data can add meaning to the quantitative data (Brierley, 2017:6). According to Fiorini et al. (2016:40), pragmatism encourages objectivism and subjectivism, providing it focuses on what will work best when real problems such as diabetes self-care management are investigated. Philosophically, pragmatism exerted significance in this topic; it indicated the entire research process interpretation of the findings and influenced the norms, standards, and language (Guetterman, Fetter & Creswell, 2015:554; Kivunja & Kuyini, 2017:26; Rahi, 2017:1). The philosophical assumptions for this study are outlined below.

1.7.1 The ontological assumption

This assumption supported the researcher's belief about the nature of being, what makes sense, what is real and what the nature of diabetes self-care management entailed (Kivunja & Kuyini, 2017:27). The quantitative component gathered objective information and single realities. The qualitative components engaged in dialogue to explore subjective meanings with multiple realities. Diabetes is a chronic condition, and high blood glucose levels lead to the development of long-term complications. The importance, therefore, was to describe the perceptions and experiences of PLWD and their families in dealing with the complexities of diabetes self-care management and how to enhance their performances. These reasons prompted this research undertaking in order to enhance their diabetes self-care management education and family support system.

1.7.2 The epistemological assumption

This assumption supports the nature of knowing in this study. It includes quantitative and qualitative perspectives, which helped to describe how researchers know what they know, how they acquired knowledge, how to deepen and expand the study and to have a more comprehensive understanding of diabetes self-care management (Kivunja & Kuyini, 2017:27, Schoonenboom & Johnson, 2017:110-111). Hesse-Biber (2010:184) added that a qualitative-driven Mixed methods approach increases the validity of qualitative findings; therefore, the researcher was seeking first to gain

perspectives about self-care management through a quantitative approach and to lay the foundation for in-depth data exploration in the qualitative approach through focus groups, interviews and consensus.

1.7.3 Methodological assumption

According to Kivunja and Kuyini (2017:28), this assumption influences methods and procedures as to how to collect and analyse data. Both quantitative and qualitative data collection instruments and data analysis methods were applicable. This study was undertaken as a Mixed methods explanatory sequential design in three phases. Results from one component informed the other sequential components; therefore, perspectives about self-care management in the quantitative component helped to explore rich data in the qualitative component through focus groups, interviews and consensus. Schoonenboom and Johnson (2017:119-120) provided the various typologies to design the Mixed methods study. The research methodology is presented in Chapter 3.

1.7.4 Axiological assumptions

The axiological assumptions were based on works from authors who highlighted the importance of values and emphasised ethical norms and standards when human beings participate in research studies (Fouché & Chubb, 2017; Kivunja & Kuyini, 2017; Vollman & Winau, 1996; Cassell, 2000). This design used quantitative and qualitative data collection strategies.

1.8 SIGNIFICANCE OF SELF-CARE

This study added value to diabetes self-care management practices by identifying Orem's self-care concepts of requisites and deficits of self-care management among PLWD and their families. The study included diabetes self-care management related issues that needed to be addressed in order to enhance their diabetes self-care management education and family support system.

1.8.1 Nursing Education

This study is significant because it confirms what we already know about the self-care behaviours of PLWD. Self-care can be difficult for a variety of reasons, namely: (1) a lack of commitment to oneself and support from others; (2) inadequate DSME/S programmes that result in a lack of knowledge and skills; (3) incorrect diets because of socioeconomic issues; (4) a lack of physical activities; (5) psychological obstacles due to stressful events; and (6) improper lifestyles because of behaviour, cultural differences, and socioeconomic issues. These reasons prompted this research undertaking in order to enhance their diabetes self-care management education and family support system.

1.8.2 Nursing research

It was noted that most of the diabetes research comprises clinical and pharmacological studies, suggesting that there is little support for both PLWD and their families for self-care practices. This study has the potential to determine how PLWD and their families can be up-skilled to enhance diabetes self-care management by expanding their existing knowledge base and current practices of diabetes self-care management. This study increased the likelihood of PLWD and their families to eventually enjoy a better quality of life through self-applied non-clinical self-care management. Even though PLWD accept responsibility for their own well-being and choose how to practise it with the support of their families and health support networks, this study suggested that self-care is generally weak. Still, with further research into the above topics, self-care might improve.

1.8.3 Nursing management and policy

This study promoted intensified diabetes self-care management, which reduced the pressure on primary healthcare clinics, hospitals, and the national health budget. A person's health could be improved, and the gaps mentioned above could be filled with appropriate self-care practices. This study has the potential to enhance knowledge. Therefore, it is hoped that the South African Nursing Council, in collaboration with relevant institutions, will create a new, nationally recognised qualification expressly for diabetes educators. By taking these actions, PLWD and their family may also be able to effectively manage diabetes-related issues and better take care of themselves, which should eventually reduce the financial burden of medical expenses on the state and PLWD. It may even lower fatality rates in addition to improving the ability of medical personnel to provide appropriate diabetes care and support.

1.9 DELINEATION OF THE STUDY

The study focused on the discovery of self-care practices and problems associated with diabetes self-care management, which the PLWD in Tshwane, Gauteng Province, SA, encountered and to have insights into self-care practices, aiming to assist with self-care improvement. Participants in this study comprise PLWD who were diagnosed with diabetes, family members who support them with day-to-day self-care and HCP experts who helped for more than six months. The latter through their expert opinions to reach a consensus on information to create a self-care tool. The study included diabetes self-care management related issues that needed to be addressed in order to enhance their diabetes self-care management education and family support system

1.10 OVERVIEW OF THE RESEARCH DESIGN AND METHODS

Schoonenboom and Johnson (2017:119) cited prominent scholars of Mixed methods typologies and identified, amongst others, Morse and Niehaus, Johnson, Christensen and Onwuegbuzie, Teddlie and Tashakkori. This study was designed according to the Morse notation system and labelled as quan → QUAL→ QUAL, and it expressed a qualitatively driven, inductive, explanatory sequential design of which the typology is explained under paragraph 3.5 in Chapter 3. Usually accepted in Mixed methods studies, data collection, analysis, and inferences for all three phases were done separately and sequentially (Schoonenboom & Johnson, 2017:119; Teddlie & Tashakkori, 2006:21-22).

Phase 1: This quantitative design was significant for the quantitative component of the study and was used to describe PLWD perceived support from the family. A total number of 104 or more participants provided power analysis. For this supplementary component (Phase 1), PLWD completed the existing Diabetes Social Support Questionnaire Family version (DSSQ-Fv), which was developed by La Greca and Bearman (2002) to describe their perception of family support pertaining to diabetes self-care management. Based on Orem's Model of Self-Care Theory, the Theory of Self-care concepts were identified as aspects to determine the level of diabetes self-care management amongst PLWD and their families, which is regarded as the performance indicators for both approaches to data collection in this study.

Phase 2: This qualitative design was conducted based on the results of Phase 1 and presenting two dominant components referred to as focus groups and interviews in Phase 2. This phase was divided into two stages and focussed on the self-care management experiences of PLWD in Stage 1, and their families participated in Stage 2. This phase had its intention to conduct multiple dialogue sessions with focus groups with 8 to 12 different participants at one time. However, due to data collection difficulties, interviews were added to ensure adequate data collection.

Phase 3 referred to the Delphi consensus-building technique in order to develop a self-care management tool with the help of HCPs, aiming to enhance self-care practises. The third phase of the study focussed on the findings of the entire study where HCPs helped with the development of a self-care management tool for both PLWD and their families. This tool is non-clinical or pharmaceutical-invasive and safe to use at home without supervision. This study took place in Tshwane and included people diagnosed with diabetes for more than six months and HCPs who provided a service to PLWD. The research design phases and methods are presented in Chapter 3.

1.11 ETHICAL CONSIDERATIONS

Ethical approval for this research was granted by the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria (710/2019) and by the Department of Health Tshwane Regional Research Ethics Committee (14/2020) to undertake the research at the identified two health facilities with NHRD reference GP_202002_029. The following principles, amongst others, were applied:

1.11.1 Principle of beneficence

Beneficiaries in this study included PLWD, families and HCPs. In this study, potential harm was minimised, and their benefits were maximised to secure the well-being of the participants throughout the research. Acceptable international norms and standards were applied (Belmont Report, 1979:14).

1.11.2 Principle of respect for human dignity

Participation was voluntary, anonymous, and autonomous, and written informed consent was asked in Phase 2 for the focus groups in Stages 1 and 2 (Annexures 9-A and 9-B), and for the interviews (Annexures 10-A, 10-B and 10-C), including Phase 3 (Annexures 11-A, 11-B, 11-C and 11-D). The identity of the participants was protected through pseudonyms (Belmont Report, 1979:13; Rothwell et al., 2016:3).

1.11.3 Principle of justice

Differential treatment was communicated and justified. Reimbursement for travel expenses was considered when the participants were participating in focus group discussions or education development activities if they were outside their normal follow-up appointments and was confirmed against their scheduled appointment cards. Refreshments were provided if activities continued around lunchtime. Participants were informed that they could withdraw at any time without prejudice, and no unjustifiable pressure or coercion was exercised. Participants were guaranteed that they were entitled to full health care service despite withdrawal (Belmont Report, 1979:15,18). Due to multiple spoken languages in SA, participants could use a preferred language, and translations were available.

1.12 LAYOUT OF THE CHAPTERS

- This study is divided into the following eight chapters:

- Chapter 1 introduces the readers to the study and outlines the background and justification for why this study is important. It further provides the research questions and objectives and outlines the purpose and significance of this study, including an overview of the research methodology.
- Chapter 2 reviews the literature and discusses the nature of diabetes self-care management, propositions from the United Nations and WHO including the disposition of SA regarding diabetes self-care management. This chapter further provides an overview of related research studies.
- Chapter 3 describes the research design and methodology and how the study was conducted in Phase 1, Phase 2 and Phase 3.
- Chapter 4 discusses the findings of phase 1 to present the perceptions and experiences of PLWD and the emotions of the supporting family, including the reliability of the quantitative data collection instrument.
- Chapter 5 discusses the findings of Phase 2, Stage 1, focussing on the perceptions and experiences of PLWD.
- Chapter 6 discusses the findings of Phase 2, Stage 2, focussing on the experiences and emotions of a family member of the PLWD.
- Chapter 7 describes the research methodology for Phase 3, including the development of a self-care development tool through the Delphi consensus technique.
- Chapter 8 provides the summary, conclusions, and recommendations and future research.

1.13 CONCLUSION

This chapter introduces the reader to the study about diabetes self-care management by both PLWD and their families at the Laudium Health Centre and Lyttleton Clinic in Tshwane, Gauteng Province, SA. It did not measure self-care practises, training courses or organisational practices of HCPs. It focuses on how PLWD perceives and experiences the support from the family, how the family is affected and what measures can be put in place to manage self-care better. It further provided an overview of diabetes types 1 and 2 and the problem statement. The WHO regards diabetes as an emerging health challenge internationally; therefore, a proactive approach is necessary that could enhance the quality of life, not only for PLWD but also for their families. A positive approach towards diabetes self-care management can relieve the pressure on primary healthcare facilities and personnel, including a decline in health budgets. It can slow down morbidities and prevent premature deaths. However, diabetes self-care management is complex, and the main reasons for not dealing with self-care and related challenges are ascribed to a lack of information, resources and motivation. An overview of diabetes is provided to broaden the understanding of why self-care and inclusion of the family bears significance. The foundation for the questions and objectives were set, and based on 2017 SEMDSA guidelines, the internationally proposed CCM for the management of diabetes and Orem's works, which conceptualised self-care already as far back as 1956. The significance of

this investigation is to enhance the self-care performance of PLWD and their families by applying non-clinical self-care management. Apart from quantitative and qualitative data collection, sufficient and relevant accredited literature was available to support this investigation.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides an overview of the literature that is relevant to diabetes self-care management. It also provided context for the aspects of self-care related to the current research questions. Due to the ever-rising diabetes prevalence and mortalities, the WHO (2016a:4,6) regarded this NCD as an emerging global health challenge. Consequently, decisions from the United Nations (UN) and guidelines from the WHO are international guidelines on how this disease should be managed. The disposition of SA as a Member State of both organisations is therefore reflected. Several studies describe diabetes as a multidimensional, progressive disease that requires lifelong self-care and management (Iloh & Collins, 2017:30; Luan et al., 2017:1172; WHO, 2016a:4). Self-care is associated with certain activities which PLWD perform daily to manage diabetes (McLaughlin Renpenning & Taylor, 2003:217). Self-care can only be effectively implemented if PLWD comprehend its significance and its influence on their daily interactions with family members for the prevention of further complications. Therefore, robust family support systems and DSME can play a crucial role in minimising the complications associated with diabetes self-care management.

Self-care can be cumbersome; therefore, Murphy et al. (2015:2) argued that there are still some PLWD who are unable to care for themselves. Consistent with Illoh and Collins (2017:30), who referred to the complexity of self-care, Ahmed and Yeasmeen (2016:104) argued that social support of diabetes self-care is a characteristic that is the least studied. In this context, it is assumed that PLWD needs some level of family support to manage to live with diabetes (Theory Based Nursing Practice, 2014:2). Albeit the smallest unit in society to provide significant diabetes self-care management support for adult PLWD, the family is regarded as being part of social support. Diabetes self-care management practises can be improved and supported at home, and this makes it important to up-skill the knowledge of PLWD and their family members. Home-based diabetes self-care management could enable self-applied non-clinical practices to enhance the quality of life. This could be instituted as outlined in the South African Journal of the Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA, 2017:1-196). Allie et al. (2017:23) promoted patient-centredness to manage diabetes. Self-care is viewed in the context of the individual and relates to Van Der Heide et al. (2017:7,9-10) viewpoint of patient-centredness. This by itself is

understood as coordinated health care, which considers individual needs, preferences, and value systems.

2.2 SOURCES OF THE LITERATURE

The literature was reviewed in the context of diabetes as an NCD and self-care management from a nursing and social perspective. The information comes from scholarly sources, textbooks and peer-reviewed journal articles involving diabetes self-care management in the health fraternity, particularly those that emphasise self-care of PLWD and their families. Searched terms included diabetes, self-care management, Orem's theory, Mixed methods, family support and person-centeredness.

The Google search engine covers information across world research databases with numerous open-source electronic academic research repositories and includes, but is not limited to, PubMed, Science, ScienceDirect, JSTOR, PsychINFO, Weblin, WorldWideScience and many more. Although the norm is to use articles of 5 years and less, it was necessary to include older articles as those provided educational insight and original works, for example, into Orem's theoretical framework, which supports this current research. As a result, articles ranged between 1963 to 2025. Although information about diabetes research is wide-ranging, the search for information about diabetes self-care management in SA appeared below expectations. The researcher sought to amplify the significance of the family during self-care management. This chapter discussed the literature review pertaining to self-care management, particularly the effect of family support.

2.3 OVERVIEW OF DIABETES

The World Health Organisation (WHO) acknowledged diabetes as one of the four priority non-communicable diseases. It is a progressive disease, and as such, lifelong self-care management is inevitable and regard diabetes as a chronic non-communicable disease (Luan et al., 17:1172; WHO 2016a:4). The WHO (2016a:11) classifies this disease as type 1 diabetes, type 2 diabetes, gestational diabetes, impaired glucose tolerance (IGT), and impaired fasting glycaemia (IFG). The non-production of insulin characterises type 1 diabetes due to Beta-cell (β cell) destruction, subsequently leading to insulin-dependence. Type 2 diabetes, on the other hand, occurs when there is β -cell dysfunction, relative insulin deficiency and some level of insulin resistance. If the pancreas makes insufficient insulin, or the body fails to effectively use the insulin which is being produced (WHO, 2019:15). People diagnosed with IGT or IFG diabetes types might be vulnerable to increased cardiovascular problems like

strokes, this illness might progress to type 2 diabetes over a prolonged timeframe. Gestational diabetes usually occurs only during pregnancy and is recognised due to hyperglycaemia (the blood glucose values are above normal values but below the level to confirm diabetes). Pregnant women are thus affected with an increased risk of possible complications during pregnancy and birth (who.int_2023/11/22 online, 5 April 2023).

2.4 THE GLOBAL IMPACT OF DIABETES ON SOCIETY

It is a well-known fact that the WHO, as part of the UN system, is primarily responsible for giving guidance to countries and coordinating health issues to achieve health objectives through policies and strategies. Data for the first Global Report on Diabetes was collected in 2010 and released in 2016 and emphasised the magnitude of diabetes around the world (WHO, 2016:8). The WHO addressed NCDs through the Sustainable Development Goals (SDGs), the UN Political Declaration on NCDs, and the WHO NCD Global Action Plan (WHO, 2016:8) which is briefly explained in the next sections. so as to increase coherence and justification for this research project. Diabetes has a cumulative impact on public health systems, PLWD and their families. This disease is affecting all ages, societies, and economies. Uncontrolled diabetes and high blood glucose levels cause serious health complications and premature deaths (Saeedi et al., 2019: 4, 9). Diabetes further imposes a substantial economic burden on health facilities and national budgets. Estimates of the national budget for Type 2 PLWD in 2018 were about ZAR 2.7 billion (bn) and ZAR 21.8 bn for diagnosed and undiagnosed people. However, estimates for 2030 for type 2 diabetes is about ZAR 35.1 bn (Erzse, Stacey, Chola, Tugendhaft, Freeman & Hofman, 2019:1).

In view of (Erzse et al., 2019:2), this study can concur that self-care is a relevant contributor in helping decrease costs associated with diabetes; it can also have a significant impact on the quality of care. Knowing the basics about the illness allows PLWD to modify their self-care practices for better health, potentially preventing uncontrolled blood sugar and delaying dangers and problems.

Luan et al. (2017:1172) assessed the impact of DSME/S after the implementation of comprehensive health education programmes in China. Findings posit that effective and feasible self-care reduces acute and chronic complications and medical costs. Several studies in the selected literature emphasised different dimensions of self-care. The latest figures at the international level showed that the prevalence of diabetes has doubled from 108 million (4.7%) in 1980 to a staggering 422 million (8.5%) in 2014.

WHO (2016b: 4,6,13) reports an increasing prevalence and high mortalities in low- and middle-income countries. This organisation released statistics for 2012, showing 3.7 million deaths were due to diabetes-related illnesses, 1.5 million were directly diabetes-related, and 2.2 million deaths were due to complications and adverse effects. According to SEMDSA (2017), the International Diabetes Federation (2015) predicted a potential increase of 55% in adult PLWD by 2040. Even though separate statistics for type 1 and type 2 diabetes could not be found, the majority of cases fell under the type 2 diabetes category. The prevalence of type 2 diabetes in 2010 was estimated at 4.5%. According to Piotie, Webb and Rheeder (2024:37) there is an increase of PLWD Type 2 in SA, for one in four older than 45 years). They cited estimates from IDF 2021 of 4.2 million (1.7-4.6).

Saeedi, Petersohn, Salpea, Malanda, Karuranga, Unwin, Colagiuri, Guariguata, Motala, Ogurtsova, Shaw, Bright, and Williams (2019:1-2,4) provided new estimates for global projections for 2030 and 2045 which came from data provided by 138 countries. Globally, the 2019 prevalence was estimated at 9.3% (463 million people), with an increase to 10.2% (578 million) by 2030 and 10.9% (700 million) by 2045. These authors concluded a higher prevalence in urban (10.8%) than rural (7.2%). They hold further that prevalence in high-income countries is at 10.4% in comparison to low-income countries at 4.0%. They conclude that about one in two (50.1%) PLWD is unaware they have diabetes, and half a billion people are living with diabetes, and projected that it can increase by 25% in 2030 and 51% by 2045. The above statistics are evidence of dramatic increases. Subsequently, this study will support to decrease the above aspects and the development of a self-care management tool for PLWD, and enhancing support from their families, are hoped to positively influence these statistics.

2.5 INTERNATIONAL INFLUENCES ON DIABETES MELLITUS

2.5.1 The 2030 Agenda for Sustainable Development

The 2030 Agenda for Sustainable Development accepted that NCDs are a major challenge in sustaining the development of health. To affirm the leadership and coordinating role of the WHO that aims to promote and monitor global actions against the mounting NCDs, specific targets were set during 2011 and 2014 at High-level Meetings of the UN General Assembly (GA) for NCDs. As the main policy-making structure of the UN, the GA convened a 3rd High-level Meeting on NCDs in 2018 to review the progress and forged an agreement for the period 2018-2030. In the 2030 Agenda for Sustainable Development, Heads of State and Member States agreed to develop national responses by 2030 to reduce by one-third the premature

mortalities caused by NCDs, SDGs target 3.4. hence, interventions are required to achieve this global target of a 25% relative reduction in the risk of premature diabetes mortalities by 2025.

2.5.2 Resolutions (United Nations World Health Assembly 66.10)

Resolutions of the UN World Health Assembly (WHA) 66.10 (United Nations, 2013) was a follow-up of the political declaration of the WHGA high-level meeting to prevent and control NCDs. Already during 2008, 48% of cardiovascular diseases (CVD), 21% of cancer, 12% of chronic respiratory diseases (CRD) and 3.5% of diabetes were identified as the four major NCDs, which accounted for about 63% (36 million out of 57 million) deaths. These four NCDs were identified because they share four behavioural risk factors such as use of tobacco, unhealthy diet, physical inactivity, and harmful use of alcohol. Further, it is noted that children died from type 1 diabetes, which can be treated. It was proposed that the burden of NCDs can be reduced by providing preventative and curative actions, including implementation of interventions to prevent and control NCDs (WHA, 2013:8). The GA gathered for a follow-up to the political declaration of the high-level meeting to prevent and control NCDs, this is where a decision was taken that those nine voluntary global targets (VGT) must be achieved by 2025. This target is related to a relative diabetes mortality reduction of 25% for CVD, cancer and CRD. These four NCDs are responsible for premature deaths between the age group 30-70 (WHA, 2013:3). Member States were urged to develop monitoring frameworks that include 25 indicators and the 9VGT (WHA, 2013:4), of which the seventh VGT is to halt the rise in diabetes and obesity (WHA, 2013:7).

2.5.3 World Health Organisation Global Action Plan 2013-2020

The WHA, in resolution WHA 64.11, developed a global action plan to prevent and control NCDs from 2013-2020 (WHA, 2013:8). The vision of this plan was a world free of the avoidable burden of NCDs (WHO, 2013). However, based on a lack of statistics, the researcher could not confirm that it has been realised. The action plan provides a roadmap and policy options for Member States to reduce 25% of premature mortalities in the four major NCDs. Other NCDs, such as mental disorders and disabilities, are associated with and influence these four major NCDs (WHA, 2013:9). The action plan is based on six objectives and not specifically on diabetes; objective 2 proposes ten policy options for Member States (WHA, 2013:18-19).

2.5.4 Non-communicable Disease Country Capacity Survey

As part of the four main NCDs, diabetes is a threat to the health of the country. In order to assess national capacity for NCD prevention and control and to collect information on how to respond to NCDs to collect data from countries regarding their current capacity for NCD infrastructure, policy action, surveillance, and health-systems response to monitor progress and achievements in expanding capacities to respond to the epidemic of NCDs. WHO (2015:9) conducted the 1st NCD country capacity survey (CCS) in 2001 with periodic follow-up assessments during 2005, 2010, and then biennially from 2013. The 5th assessment was in 2015. Results revealed areas that needed increased attention and assistance and identified poor multisectoral coordination and insufficient finance for crucial initiatives that can assist those in need or stop people from acquiring NCDs. 75% of countries reported having diabetes guidelines in place, 73% reported having a diabetes referral criterion from PHC to higher levels, and only 14% of nations had a population-based diabetes registry (WHO, 2015:11). The latest survey was done in 2021.

2.6 A SOUTH AFRICAN PERSPECTIVE ON DIABETES

Global diabetes policies guide Member States of the WHO. Like other countries, the SA government prioritised the management of NCDs. Resolution WHA74.42 calls Member States to prioritise diabetes prevention, diagnosis, and control, including risk factors relating to NCDs. In cooperation with the National Department of Health for NCDs, this guideline prompted the creation of the Diabetes Charter for South Africa and is in line with the National Strategic Plan. The goal is to focus on the increasing threat posed by NCDs between 2021 and 2026. As a result of the international influence, the Diabetes Charter is aligned with the WHO Global Diabetes Compact. The primary goal of the Diabetes Charter is to address the nation's diabetes-related issues (Diabetes Alliance SA, 2021:2-3).

South Africa confirmed the availability and implementation of protocols in health facilities. Still, despite this positive response, a diabetes registry was not implemented (Piotie, Webb & Rheeder, 2014:37). In addition, the WHO (2016b:1) showed that 6% of the total SA population (54 490 000) is living with diabetes. Findings posit that the mortality rate is at 0.056% (30,400) for males and 0.045% (24,430) for females. The International Diabetes Federation (IDF) (2015) estimated that 3.85 million (7%) South Africans in the age group 21 to 79 years are living with diabetes and has the highest population of adult PLWD (2.3 million) compared to the Democratic Republic of Congo (1.8 million), Nigeria (1.6 million), and 1.3 million in Ethiopia (JEMDSA, 2017:S8). On a global scale for 2021, 10.5% of adults aged between 20 and 79

have diabetes, however nearly half are not aware that they have the disease (IDF Diabetes Atlas, 2021). Piotie, Webb and Rheeder (2024:37) estimated the diabetes prevalence for 2019 in SA around 2.4 million, while the IDF estimates for adult diabetes prevalence could be 11.3% in 2021. Generally, the HbA1C differs according to the individual condition. To prevent micro- and macro-vascular complications, 2017 SEMDSA Guideline for the Management of Type 2 Diabetes recommend an HbA1c target of <7 % for the majority Type 2 diabetes individuals or lower (SEMDSA, 2017:35; Piotie, Webb & Rheeder, 2024:38). Diabetes is a chronic metabolic disease affecting Type 1 and Type 2 diabetes. Type 1 diabetes is caused by the destruction of β cells, making the person insulin dependent. Type 2 diabetes occurs when the pancreas produces insufficient insulin or fails to use it effectively, leading to uncontrolled blood glucose. Uncontrolled blood glucose can lead to heart disease, stroke, visual impairment, amputations, kidney problems, and other complications. To manage diabetes, individuals should establish a daily routine, be active, and maintain a random reading between 7 and 8.6 mmol/L. Regular exercise, balancing calories and carbohydrates with prescribed medicine, and making healthy food choices are essential.

2.6.1 Society for Endocrinology, Metabolism and Diabetes of SA (SEMDSA) Guideline

The 2017 SEMDSA Guideline for the Management of Type 2 Diabetes is a comprehensive document comprising twenty-nine sections to provide broad guidelines on how type 2 diabetes should be managed (JEMDSA, 2017:1-196). The latest version was issued around mid-2017. The 2017 SEMDSA Guideline for the Management of Type 2 Diabetes Expert Committee for Chapter 5 deals with diabetes self-management education and support (DSME/S) and suggests that education must be provided and managed by accredited HCPs and trained CWHs. It further provided six recommendations. This research study focuses on the recommendation, which reads, “Diabetes self-management education and support (DSME/S) should be patient-centred, respectful and receptive to individual needs and values; and non-discriminatory towards cultural, ethnic language, socio-economic and educational differences” (Allie et al., 2017:22).

This recommend PLWD and their families should be placed at the centre of care (interpreted as person-centredness) and should receive relevant education and support to effectively self-manage diabetes (Allie et al., 2017:22-23; American Diabetes Association, 2025:56). This recommendation was contextualised in terms of diabetes self-care management and management, which aimed to create a general understanding of how PLWD and their families can implement effective, safe, and easy, non-supervisory self-care at home. WHO (2016:7)

foresees an improvement in outcomes without specifying the type of diabetes. To implement the abovementioned recommendation, this research followed an integrated way by including the family and also people diagnosed with type 1 diabetes.

2.6.2 Person-centredness in diabetes self-care management

Allie et al. (2017:22) advocated for a person-centred approach that identifies and considers individual needs during self-care. Their findings indicate that robust family support systems are crucial for enhancing self-care management practices for both PLWD and their families in Tshwane. However, there was uncertainty around involving the family in self-care management (Ansari et al., 2017:69,71; Fort et al., 2015:2,6). Peñarrieta et al. (2015:78) used a cross-sectional correlational design to examine the relationship between self-care management and family involvement in Mexico, highlighting the importance of the family but noted that families required more knowledge. These authors emphasized that the complexity of diabetes self-care management affects both PLWD and their families and suggested considering the perceptions and preferences of both groups during self-care management and support.

This argument reinforces the concept of person-centredness and relates to the recommendation on which this research is based. Diversity influences the outcomes of diabetes self-care; therefore, diversity aspects should always be considered when addressing health issues in SA. This includes inequalities in access to health facilities, race, socioeconomics, language, culture, value systems, and other preferences. From a SA perspective, diversity can influence the ability to perform self-care activities, hence the need for a person-centred approach to awareness and education (Diabetes Alliance SA, 2021:7).

Different experiences and opinions were anticipated, emphasising the complexity of diversity in person-centredness consistent with Iloh and Collins (2017:34), who noted that self-care issues could differ from person to person. These authors too recommended a patient-centred assessment, indicating that individual empowerment should be considered. It is anticipated that this study will contribute towards effective and sustainable diabetes self-care management practices.

The 2017 SEMDSA guidelines align with other literature addressing DSME/S (Diabetes Care, 2018; Powers et al., 2017:40). According to Allie et al. (2017:22), DSME/S reduces costs, lowers hospital admissions, and extends the lifespan of PLWD. Powers et al. (2017:40) stated that self-management education and support form the basis for activities and decisions to

improve health. These authors argued that DSME positively affects clinical, psychosocial, and behavioural aspects (Powers et al., 2016:40,42). According to Powers et al. (2017:40), DSME facilitates the acquisition of self-care knowledge, skills, and abilities. The programs address health beliefs, cultural needs, current knowledge, physical limitations, emotional concerns, and family support. They also consider socio-economic status, medical history, health literacy, numeracy, and other factors influencing individuals' abilities to manage challenges during self-management and their families play a crucial role in self-care and adherence to treatment plans. PLWD can have a better quality of life if there are changes in eating patterns, physical activity, and stress coping mechanisms. However, HCPs need advice to overcome difficulties and barriers and enable day-to-day self-care.

In the context of this research, aspects such as empowerment, training, education, skills, and knowledge are closely related. The selected literature showed similarities in training aspects, but it is unclear how it should be provided. For example, PLWD or a family member can receive information/training on administering insulin or taking prescribed oral medication. Anecdotal evidence suggests that different pharmaceutical companies providing original or generic products can confuse patients due to differing packaging and designs. This argument links to medicine adherence, where pharmacists play a vital role. Similarly, psychologists could provide emotional support to adjust behaviour patterns influencing actions and reactions in dealing with lifelong disease management and life transitions. Additionally, dieticians must render nutritional information and dietary services. Some authors (Peyrot, 2017; Dube et al. 2015; Dube et al., 2017; Motta et al., 2017; Murphy et al., 2015; Sahin & Naylor, 2017) share similar concerns about diabetes self-care management education, training programmes, level of training and knowledge, group interventions, and empowerment. Iloh and Collins (2017:30,34) noted a lack of adequate education for PLWD and their families when medications are changed and found that PLWD and their families are sometimes unable to react to a hypoglycaemic episode. They recommend equipping them with knowledge about symptoms, causes, and appropriate lifesaving self-management actions. It is anticipated that other related challenges are managed similarly. Tools must be provided for PLWD and their families to manage the complexities of diabetes, provided that a multi-professional group offers clear guidelines and advice. Motta et al. (2017:3) noted that health workers and nurses were trained and received a certificate under a web-based ACE training programme following a competency assessment, developed by Flinders University in Australia. It is an issue that most training focuses on healthcare workers while very few studies include PLWD and their families. Additionally, the SA National Department of Health has not developed a programme for diabetes self-care management for PLWD and their families. The significance of this is to

encourage cooperation and understand the different dimensions of diabetes self-care management.

It is argued that PLWD can only change the prevalence and mortality rate if they are adequately empowered to make their own decisions instead of health facilities enforcing a treatment plan by empowering individuals to care for themselves and those who provide care. The 2017 SEMDSA guidelines, Chapter 5 recommends that DSME/S should be provided and managed by accredited HCPs and trained community health workers (CWHs) (Allie et al., 2017:22-23). It is assumed that some SA healthcare professionals have obtained different accredited levels of diabetes care training. However, training in diabetes care for nurses is not listed as a (specialised) qualification with the South African Nursing Council; therefore, statistics were unavailable. In SA, diabetes care training focuses on healthcare professionals instead of PLWD and families. Despite the rising prevalence and mortalities, including some PLWD and their families who cannot take care of themselves, the SA National Department of Health has not implemented a standardised diabetes self-care management programme for PLWD and their families.

Similarly, in Thailand, a family-oriented educational program for type 2 diabetes has never been conducted (Wichit et al., 2017:39). As a result, these authors undertook a single-blinded randomised controlled clinical trial to evaluate a family-oriented intervention to determine improved self-management outcomes in individuals diagnosed with type 2 diabetes. Wichit et al. (2017:39) noted the strong relationships among Thai families and provided physical, mental, and economic support. Families also exerted a profound influence on PLWD to self-manage diabetes. However, they admitted that knowledge about health conditions was limited. Findings suggest that a theoretically derived education programme for families is significant because it further strengthens cooperation. They agreed that families must be included in self-care management education programmes and that self-efficacy and self-care behaviours are critical to reducing diabetes-related complications. These authors confirmed that Thai nurses play a key role in diabetes education and suggested that nurses should deliver DSME (Wichit et al., 2017:44-46).

Dube et al.(2015a:3) conducted a systematic review to audit type 2 DSME programmes in developing countries, focusing on cultural sensitivity and low literacy among patients with chronic diseases in SA. Although there are some considerations by healthcare professionals for DSME interventions and how PLWD perceived the training programmes, families were not considered to participate in the study. In another investigation, Dube et al. (2015b:176-179)

conducted a systematic review to audit DSME to determine the nature of primary health care in SA. These authors employed semi-structured interviews to collect data from service providers and expert health professionals in the public and private health settings to review the policies and DSME implementation in the country. They employed purposive, convenience, and snowball sampling with content analysis. Findings suggest that no policies or guidelines exist for diabetes education for PLWD, and their families have diverse needs. However, they realised this limitation, and evidence of practice is inadequate. Regrettably, families of PLWD were also not included in this investigation. Dube et al. (2017:24) conducted another study to explore how people with chronic diseases experience self-management, determine their needs, and explore the perspectives of key informants (health professionals) about patient self-management. A self-management support tool was developed for patients with chronic diseases in SA. This study also excluded the family.

2.7 SUPPORTING FRAMEWORK

Regardless of the variety of theories available to study family involvement and diabetes self-care management, Orem's Theory of Self-care is based on three interrelated theories and was selected because the concepts are clear and related to the research questions. It further helped to identify challenges that needed to be addressed. This study was carried out within the framework of diabetes self-care management. Although Allie et al. (2017:23) proposed the well-known Chronic Care Model (CCM), Orem's Model of Self-care Theory was integrated, which is discussed in Chapter 3.

2.8 PROPOSED STRATEGIES FOR DIABETES SELF-CARE MANAGEMENT

Due to the impact of diabetes and the lack of effective policies in some formal health settings, evidence-based and multi-sector interventions should guide the implementation of standardised protocols. It is thus appropriate to recommend early detection, screening and treatment for diabetes (WHO, 2016a:8; WHO, 2016b:4,6-7,9,15,21,47). To alleviate the burden on healthcare settings, it is expected that health facilities implement a primary health approach to enable a family structure to deal with self-care. In line with guidance from the WHO, the Global Conference on Primary Health Care was hosted on 25 and 26 October 2018 in Astana, Kazakhstan, to introduce the declarations to move from Alma-Ata towards universal health coverage and the SGDs. Heads of State, governments and other representatives who were present at that meeting reaffirmed their commitments. They envisaged primary health care (PHC). Services that are safe, of quality, integrated, accessible, available, and affordable (Astana Declaration, 2018:3). Of significance is the commitment to empower individuals and

families, amongst others, to enable participation and implementation of clear plans that support health literacy, knowledge, skills, health promotion and resources that impact on health including accepting ownership (Astana Declaration, 2018:10)

2.8.1 The role of primary health care in South Africa

The SA Government held a National Summit in 2011 to develop and implement strategies to prevent and control NCDs through health promotion, curative care, rehabilitation, and palliative services (Dube, Van den Broucke, Dhoore, Kalweit & Housiaux, 2015b:176). The country supports universal health coverage through the National Health Insurance (NHI), which includes PHC services. According to Moosa, Derese and Peersma (2017:2), this government decided to reform public health service delivery through NHI and aimed to address public-private inequity. This approach is consistent with Motta, Shephard, Brink, Lawson and Rheeder (2017) and aligned with the declaration of Astana (Astana Declaration, 2018:5) to move away from inequalities in healthcare.

According to Moosa et al. (2017:2), the PHC concept allows the expansion of healthcare services but only if CHWs are included. Moosa et al. (2017:3) undertook a qualitative study to understand the opinions of district health managers in Johannesburg for implementing PHC outreach teams. As part of these teams, CHWs were responsible for 250 families in a defined population to augment interactions between the population and the health care facility; however, some government officials hold different opinions, such as that those CHWs were poorly coordinated with randomly distributed tasks, inadequate training, and supervision. From this viewpoint, the standard scope of practice was lacking. Moosa et al. (2017:4) argued that an influx of patients would decrease over time provided prevention and promotion efforts improved but also noted that CHWs are the first contact between the patient and the health system. In view of this, it is argued that the basic level of self-care should thus start at home with PLWD and their families, followed by CHWs that link up with health facilities. The opinions were inconsistent. Moosa et al. (2017:6) proposed to redefine the concept of re-engineering to allow strategic and organisational planning of district health systems in SA and to avoid losing the patients in the health system. Interesting to note is the suggestion that person-centredness should be organised around an integrated service.

It is argued that diabetes management might be deemed unsuccessful if PLWD and their families are excluded and not considered in making decisions about their health. Strategies to control diabetes self-care management by PLWD with the support of the family and significant others can prevent premature deaths associated with diabetes. From a clinical perspective,

Motta et al. (2017) conducted a study in SA to determine if point-of-care testing can improve diabetes management at the PHC level. The aim was HbA1c testing in PLWD to promote changes in clinical practice. Point-of-care testing, also referred to as on-site pathology testing, has the potential to provide innovative and practical opportunities to improve pathology services in disadvantaged health settings and to narrow the gap of health inequalities. This strategy is extensively available in primary care facilities in developed and developing countries (Motta et al., 2017:2-3).

2.8.2 Self-management education and support

The 2017 SEMDSA guidelines are well in line with other literature that addresses DSME/S (Diabetes Care, 2018; Powers et al., 2017: 40). DSME/S reduces costs, lower hospital admissions, and expands the life span of PLWD. In support of these views, PLWD and the family play a crucial role in self-care and adherence to aspects of a treatment plan. They can have a better quality of life if there are changes in eating patterns, physical activity, and stress coping mechanisms. But to overcome difficulties and barriers and to enable day-to-day self-care, HCPs need to give advice. In the context of this current research, aspects such as empowerment, training, education, skills, and knowledge are closely related. The selected literature showed similarities in training aspects, but it is questionable how it must be provided. For example, a PLWD or a family member can receive information/training on how to administer insulin, or how to take oral medication as prescribed. Anecdotal evidence is the different pharmaceutical companies that provide original or generic products to the market, which is confusing for some PLWD due to different packaging and designs. This argument is linked to medication adherence where pharmacists play an extremely essential role. Similarly, psychologists could provide emotional support to adjust behaviour patterns that influence action and reaction in dealing with life-long disease management and life transitions while treating; additionally, nutritional information and dietary services must be rendered by dieticians.

Byrne, Davies, Willaing, IHolt, Carey, Daly, Skovlund and Peyrot (2015); Sahin and Naylor (2017) share similar concerns about diabetes self-care management education, training programmes, level of training and knowledge, group interventions and empowerment. Iloh and Collins (2017:30,34) noted a lack of adequate education for PLWD and their family when medications are changed and found that PLWD and their family are sometimes unable to react to a hypoglycaemic episode and recommend equipping them with knowledge about symptoms

and causes and appropriate lifesaving self-management actions. It is anticipated that other related challenges are managed in the same way.

From this viewpoint, education and knowledge are regarded as tools for PLWD and the family to manage the complexities of diabetes, providing a multi-professional group give clear guidelines and advice. Flinders University in Australia developed this programme. It is disappointing to note that most training is focussed on files and ranks of health (care) workers, while very few studies included PLWD and the family. To this end, it was also a concern that the SA National Department of Health had not developed a programme for diabetes self-care management for PLWD and the family. The significance of this is to encourage cooperation and to understand the different dimensions of diabetes self-care management. It is argued that the prevalence and mortality rate can only be changed by these two groups if they are adequately empowered to make their own decisions instead of the health facilities enforcing a treatment plan.

Narasimhan and Kapila (2019:76) stated that the Global Conference on Primary Health Care emphasised the empowerment of individuals to care for themselves and to empower those who provide care. It is assumed that some SA HCPs have obtained different accredited levels of diabetes care training. However, training in diabetes care for nurses is not enlisted as a (specialised) qualification with the South African Nursing Council; therefore, statistics were not available. In SA, diabetes care training focuses on HCPs instead of PLWD and families. Despite the rising prevalence and mortalities, including some PLWD and their families who were unable to take care of themselves, the SA National Department of Health has not implemented a standardised diabetes self-care management programme for PLWD and their families.

Dube et al. (2015a:3) conducted a systematic review to audit type 2 DSME programmes in developing countries and focussed on cultural sensitivity and low literacy amongst patients with chronic diseases in SA. Although some considerations by HCPs to DSME interventions and how PLWD perceived the training programmes, families were not considered to participate in the study. They employed purposive, convenience and snowball sampling with content analysis. Findings posit that there were no policies and guidelines for diabetes education for PLWD, and their families required diverse needs. However, they realised this limitation and evidence of practice was inadequate. This study, too, excluded the family.

2.9 KNOWN AND UNKNOWN OF DIABETES SELF-CARE MANAGEMENT

This section focussed on what is known and not known about safe diabetes self-care management without direct clinical supervision, successes, and inconsistencies. Ontology deals with the nature of the content of what is known and consistent with the opinions of others. It was also important to identify challenges, and poor practices which facilitate risk factors (Kivunja & Kuyini, 2017:27). From an epistemology point of view, experiences and perceptions of how PLWD and their families were dealing with self-care management were equally important (Kivunja & Kuyini, 2017:27, Schoonenboom & Johnson, 2017:110-111). It is not known to what extent the family plays a role in reducing risk factors or facilitating modifications; therefore, how to engage the family must still be learnt.

2.10 RELATED STUDIES

There is a notable trend in research social perspectives which influence diabetes self-care management. As discussed in the above section, some authors provided evidence that treatment protocols, education programmes, resources, costs, modifications to diets, and self-care are not limited to clinical and pathology areas. Instead, it investigated adherence to lifestyle changes, medication, follow-up appointments, behavioural changes, knowledge, skills, diets, obesity, weight, physical activities and blood glucose monitoring (Tanenbaum, Breland, Yu, Walker & Gonzalez, 2016; Iloh et al., 2017; Adegbola et al., 2016; Coughlin & Smith, 2017).

2.11 DIABETES TYPES 1 AND 2 SELF-CARE PRACTICES

In the absence of family support systems, the abilities and commitment of life-long self-care towards dietary adjustments, physical activities, self-monitoring blood glucose, use of medication, insulin therapy, foot care and eye care are questioned. Quantitative-qualitative approaches, variations of randomised control studies that address the stabilisation and slow-down of type 2 diabetes were addressed. Still, they showed a lack of information in the type 1 diabetes category. It is worthy to note the increased focus towards socio-economic perspectives and co-responsibilities of family support systems in type 1 and type 2 diabetes. Living with diabetes is cumbersome, and complications further aggravate the situation of self-care. Because the normal life of PLWD and their families is lived most of the time out of the hospital, additional influences that impact workable adherence must be minimised to ascertain life-long commitment. Very few studies have investigated diabetes self-care management in the workplace, and self-care management at work is non-negotiable for PLWD. It proposed

that their health condition should be disclosed at the managerial level. The reason why self-care in the workplace is important is the ability to take care of oneself because some are working irregular hours or the work requires physical demands, influences their quality of life, and affects their glucose levels. Therefore, the employer and PLWD employees could adjust the working environment. Hakkarainen, Moilanen, Hänninen, Räsänen and Munir (2017:3-5) conducted a cross-sectional study in Finland aiming to determine self-management and psychosocial work factors that were associated with disclosing their diagnosis as type 1 diabetes person in the workplace. This study showed that PLWD spent about 60% of their time at work. Findings posit that certain actions and mealtimes will be better understood and will gain support from colleagues and managers where it is required (Hakkarainen et al., 2017:8-9). Even though the research study focussed on type 1 diabetes working individuals, the same holds true for type 2 diabetes individuals. These factors gave a distinct perspective of active working PLWD who can live a normal life and continue diabetes self-care management if employed.

Hilli, Lööf, Malmberg, and Hess (2018:36) stated that the prevalence of type 1 diabetes in children and adolescents was high in Europe when investigating what motivated self-care practises and how to minimise the risks and complications such as nerve damage, kidney damage and changes in the fundus oculi of glycaemic control, regular medical check-ups and education while still maintaining life qualities. These authors found that type 1 diabetes young individuals have specific and demanding needs. There was a need for frequent follow-up visits with HCPs (Hilli et al., 2018:37). However, this, too, is consistent for older adults diagnosed with type 1 and type 2 diabetes. Hilli et al. (2018:37) acknowledged that younger adolescents make transitions (“emerging adulthood”) and observed anxiety, selfishness, conflicts, disappointments, and emotional crises. It is viewed that the turning point period for this group is the challenges of normal development, anticipated and increased responsibility to care for themselves during the transition. Continuity and regular follow-up visits were important in promoting self-care; this age group also needed a lot of emotional support. This study showed consistencies in self-care for PLWD type 2 and adult type 1.

Riddell, Gallen, Smart, Taplin, Adolfsson, Lumb, Kowalski, Rabasa-Lhoret, McCrimmon, Hume, Annan, Fournier, Graham, Bode, Galassetti, Jones, Millán, Heise, Peters, Petz and Laffel (2018:1) reviewed exercise management of individuals diagnosed with type 1 diabetes, and confirm that this group are facing challenges of physiological and behavioural issues in self-care. The importance of regular exercise was disclosed, but there were concerns that physical activities could present difficulties for PLWD and HCPs. A specific barrier to activities

was the distress for hypoglycaemia due to insufficient knowledge as to how to manage and control glucose levels during physical activities. Riddell et al. (2018:2,4) reached a consensus that those strategies were recommended targets set to consider when PLWD are exercising regularly or for those who participate in sports and competitions.

2.12 MODIFICATIONS OF VARIOUS SELF-CARE PRACTICE BEHAVIOURS

According to the literature, PLWD needed to take steps to improve their health, which can be identified as better controlled blood sugar levels, better foot care, healthy diet and meal plans, acceptable weight, acceptable blood pressure, improved behaviour towards smoking and alcohol consumption, taking of medicine and insulin, etc. These steps are linked with adherence and modifications. In a qualitative study in Paraná, Brazil, Teston, Sales, and Marcon (2017:2) used Orem's Theory of Self-Care to investigate the self-care perceptions of individuals diagnosed with type 2 diabetes. Findings posit that nurses, in particular, “need to recognise self-care actions as a key tool for promoting better living conditions, despite the disease”. These authors argued that nurses should approach PLWD through dialogue, emphasise daily activities and argue that self-care must be strengthened with family support and adherence.

In Jordan, Alefishat, Abu Farha and Al-Debei (2017:158) employed a cross-sectional study design to evaluate knowledge and attitudes which impede adherence to those who were at risk of developing a metabolic syndrome. These authors used the term “adherence” to define the extent to which patients complied with the recommendations or treatment by HCPs and were consistent with Teston et al. (2017:2). Findings posit that older people better adhered to medication but noted that they found it difficult to change their lifestyles. According to Alefishat et al. (2017:161-162), higher levels of education help to improve adherence if the attitude is positive. Non-compliance gave rise as to why the family was significant during self-care. Tanenbaum et al. (2016:4) employed a face-to-face, in-depth, semi-structured interview to investigate self-monitoring blood glucose in type 2 diabetes individuals in the United States of America. Findings posit that effective implementation of self-monitoring of blood glucose was a powerful tool for non-insulin dependent individuals.

The Common-Sense Model of Self-Regulation was used to promote routine and to receive immediate feedback. This allowed PLWD to monitor the outcomes and to change behaviour accordingly (Tanenbaum et al., 2016:6). This points to personal responsibility and was associated with concepts of Orem's Theory of Self-care. Even though Tanenbaum et al. (2016:6) expected PLWD to develop a sense of self-monitoring, the latter developed over time

for them to become confident in practising self-care on a day-to-day basis. Consistent with others, Ahmed and Yeasmeen (2016:104) viewed PLWD as part of a family and family support as inherently part of daily living. However, the involvement of families in self-care remained vague.

An appropriate diet is an important step to control blood sugar levels. Owing to public belief that PLWD should avoid eating carbohydrates, Iloh and Colins (2017:33-34) undertook a cross-sectional descriptive study in Nigeria due to concerns about poor medication education and low societal health literacy of diet management. These authors emphasised the societal belief that carbohydrates should be avoided. They argued it is an erroneous disposition that can result in hypoglycaemia, especially when PLWD is adhering to prescribed medication.

None of the selected literature highlighted this important view, which was believed to create a wrong impression of the diet with subsequent changes to the treatment plan. Accurate information sharing and continuous professional development for dieticians were thus important when providing individualised nutritional plans, as proposed by Ceronio and Mbhenyane (2017:6-8). Findings posit that recommended diets, other lifestyle measures, and medication adherence should be patient-centred (Iloh & Colins, 2017:33-34).

In another related SA study, Adegbola et al. (2016:1-2,5) conducted a cross-sectional study amongst people diagnosed with type 2 diabetes at an outpatient department of Matlala District Hospital in Limpopo to investigate medicine adherence by type 2 diabetes individuals. Findings posit poor medicine adherence and unhealthy lifestyles; however, the recommendation focused on organisational support. It was noted that type 1 diabetes individuals and their families were excluded. Dedefo, Ejeta, Wakjira, Mekonen, and Labata (2019:1-2) conducted a study in West Ethiopia and used factors such as diet, exercise, foot care and blood glucose testing to assess self-care practices, including those related factors that affected PLWD. Findings posit that poor self-care practices were ascribed to older people, males, a lack of family support, lack of education and knowledge, complications, unemployment, poor adherence and lack of a glucometer, non-adherence to diet and lack of exercise. Dedefo et al. (2019:1) stated that a (self-care) management plan should consider DSME/S as integral components of care.

2.13 THE SIGNIFICANCE OF FAMILY SUPPORT

Empirical findings. The importance of self-care management should be viewed in the context of family support and the community in which self-care is taking place. A few studies have

investigated the role of the family. Some authors have a shared view of “family” as blood relatives, kinship, or friends (Bennich et al., 2017:2). Others (Mitchell et al., 2018:228) view the family as an extension of support to PLWD. Ahmed and Yeasmeen (2016:104) referred to the complexity of diabetes self-care management and argued that social support in diabetes self-care management was also the least studied. However, family members provided significant support for self-care to adult PLWD. According to predictions by Murphy et al. (2015:1-2) families who are adequately empowered will respond positively.

Theoretical perspectives. Kaakinen and Denham (2015:237-244) argued that there is a need to learn how to manage diabetes in a family context while they highlight frequent unexpected changes. Consequently, the roles and responsibilities of families were unpredictable. The essence of family support to PLWD is to understand the implications of non-adherence. Adherence will facilitate difficulties with modifications of diets, encouragement of physical exercise, adherence to medication, attending appointments and blood glucose monitoring. These authors identified that micro-, meso- and macro-level strategies enable balanced person-centred care, which refers to everyone who is involved in diabetes self-care management. Kaakinen and Denham (2015:238) identified that the family have a responsibility to identify all the available resources and use them to their full potential. They argued that PLWD with comorbidities has more demands, which complicate self-care management even more, but support from the family can alleviate the difficulties. On the contrary, Wichit et al. (2017:39) are of the opinion that PLWD with severe complications and comorbidities should be excluded as they hinder participation in clinical trials. In the context of a coordinated and person-centred approach, the significance of PLWD and families was documented in various diabetes self-care management research studies.

Ansari et al. (2017:69,71) explored the factors which influenced type 2 diabetes self-care management in middle-aged people in the rural part of Pakistan. They have developed a conceptual model to enhance self-care management for people diagnosed with type 2 diabetes. The individual or group concepts of this conceptual model were consistent with other studies, but the role of the family remained unclear. If the family bear significance in self-care, as this research anticipates, the role and responsibilities of the family need to be explored.

Kaakinen and Denham (2015:237-244) provided an extensive explanation of the micro- and meso-levels strategy, which could help to manage unexpected changes and further highlighted the role and responsibilities of families. Kaakinen and Denham (2015:226) referred to an individual when they discussed the micro-level strategy. The microsystem describes the

physiological systems of individuals, the development and psychological aspects and memory. Therefore, the microsystem is the basis of knowledge which was linked to DSME. Kaakinen and Denham (2015:326) also explained the Developmental Trauma Theory and described how individuals learn coping mechanisms. The Bio-ecological Theory concluded that nurses needed to assess the microsystem. The Meso-level strategy, on the other hand, enhanced understanding of the Ecological Model, where it impacted significantly on individuals but was influenced by the community. The community is referred to as the macro system (Kaakinen & Denham, 2015:323,325). In the context of this current research study, the three levels of strategy are referred to as PLWD (microsystem), family support (mesosystem) and the community (macrosystem).

2.14 ENGAGING THE FAMILY IN DIABETES SELF-CARE MANAGEMENT

Policy perspective. The problem statement highlighted inadequate family support; however, the literature provides evidence of the uncertainties regarding how to engage the family. Branch, Deak, Hiner, and Holzwart (2016:127) supported diabetes self-care management for both patients and families. This gap can thus be addressed by including the families of PLWD. Other studies have observed families as an important part of managing chronic disease and encourage the inclusion of the family and multi-disciplinary health teams (Baig et al., 2015:89-90; Van Der Heide et al., 2017:9-10; Allie et al., 2017:23; Wichit et al., 2017:44).

Theoretical perspective. Narasimhan and Kapila (2019:76) viewed self-care interventions as promising and an exciting novel approach to promoting health. They confirmed the working definition of self-care by the World Health Organization (WHO) as “the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health-care provider.” This statement validated Orem’s view of self-care and Kaakinen and Denham’s point on family support. Narasimhan and Kapila (2019:76) viewed improved self-care as individual autonomy and respect and argued that PLWD will access healthcare if a person-centred approach is followed.

This perspective also supports the recommendation that has been contextualized and selected for this current research study. PLWD and their families are the custodians of their health and should thus be considered to actively participate and make their own decisions, which hold benefits for research outcomes. This implies that decisions and activities are not enforced but willingly adhered to and should decrease the costs of national health budgets where PLWD is dependent on free public health services.

Practice perspective. Some PLWD are residing far from health facilities and find it strenuous to adhere to scheduled medical appointments. Improving self-care will prevent them from attending unscheduled appointments as they will be able to manage their condition at home. Knowledge and improved self-care can thus prevent complications their families

According to some, the intricacy of managing diabetes self-care affects PLWD daily lives, thus it's critical that they and their family have a foundational understanding of how to manage their condition in certain circumstances. In order to improve the diabetes self-care management education and family support system for PLWD and their families, the researcher set out to create a self-care management tool. Therefore, a self-care management tool that would help PLWD and their families deal with uncertainty in diabetes self-care management. According to this perspective, diabetes can decrease mortality and prevalence rates in South Africa. SA can be reduced by involving the family in diabetes self-care management.

Regrettably, studies investigating self-care with the involvement of families to ensure diabetes self-care management in Tshwane have not been found. This current research intends to describe how both PLWD and their families in Tshwane should be involved in self-care management when a family member is diagnosed with diabetes, subsequently developing a self-care management tool. According to Teston et al. (2017:4), PLWD individuals must be allowed to make their own decisions. It is argued that the complexity of diabetes self-care management impacts the ordinary life of PLWD, and it is therefore important that these individuals and their families be capacitated with basic knowledge of how to deal with diabetes in certain situations.

According to Teston et al. (2017:5-6), PLWD are subjected to difficulties and stressful situations, for example, diet management in the workplace as outlined by Hakkarainen et al. (2017:3-5). Another example is meal preparation at home, as referenced by Teston et al. (2017:7). It is argued that it is important for the family to have adequate knowledge of diabetes, understand the associated risks and potential complications of non-adherence and apply the appropriate skills necessary for self-care. As documented by Teston et al. (2017:7), therapeutic plans are imposed instead of deliberated, which jeopardises cooperation between PLWD and their families. These authors also noted the poor collaboration and attitude of the family. Meals were a catalyst to enhance family social cohesion, but it posed challenges if PLWD had different meals or ate separately or at different times. In view of this example, engaging the family was critical to plan and prevent incidents like these. Meal planning, and preparation should be adjusted to accommodate the whole family at one time.

Ahmed and Yeasmeen (2016:104-5) provided a clearer picture of how families can be actively engaged in diabetes self-care management and recommended that the roles and responsibilities were to mitigate stressors. Considering this point, emotional support could enable better adherence to self-care. These authors also found that older people needed attention and support to perform routine day-to-day chores. Consistent with Powers et al. (2016:40-42), the family could have provided support if they were knowledgeable about certain aspects of self-care, which would permit appropriate care and advice. Ahmed and Yeasmeen (2016:104-105) suggested some clear roles and responsibilities for the family, which include, amongst others, grocery shopping to mitigate stressors of how to get to a grocery store or to buy the appropriate food, arranging regular follow-up medical appointments, emphasised good family ties with low conflict levels and good organisation. There might be a need to renegotiate family roles, reorganise responsibilities and modify daily or certain elements of self-care routine.

Although PLWD is responsible for self-care, the family and HCPs are instrumental in supporting adherence to diet, exercise, medication, management of physician appointments and blood glucose monitoring. As documented, the most frequent problem is irritability when blood glucose level rises, but Asian families are tolerant, supportive and responsible for PLWD irrespective of the hardship. Ahmed and Yeasmeen (2016:106) also showed that 12% of PLWD were suffering from major depression, which influenced adherence to treatment but emphasised the importance of keeping on track rather than not taking care of oneself. Iloh and Colins (2017:33-34) stated that PLWD should avoid eating carbohydrates due to hypoglycaemia incidents, whereas Ahmed and Yeasmeen (2016:106) focused on diets and stated that modification is a tough challenge. They also found that carbohydrate-rich foods (rice, wheat, etc.) were responsible for obesity in relatively poorer countries where adequate food was not ensured. Consistent with cultural beliefs in Bangladesh, a family member prepares meals for the family and PLWD according to dietary guidelines but found that PLWD showed lower triglycerides, cholesterol, and HbA1c. The family can also assist with self-care of diabetes foot.

2.15 INVOLVEMENT OF HEALTHCARE PROFESSIONALS IN SELF-CARE

Some authors stated that family involvement and support from multi-disciplinary health teams was inherently part of how to address self-care (Baig et al., 2015:89-90; Van Der Heide et al., 2017:9-10; Allie et al., 2017:23; Wichit et al., 2017:44). Based on the above viewpoints and noted in the study by Dube et al. (2015b:176-179), HCPs were regarded as experts in their

respective fields. They were expected to identify deficits and requisites through the concept of self-care agency. Subsequently for this investigation, HCPs will help to develop a self-care management tool for PLWD and the family.

2.16 ASSOCIATED RISKS AND COMPLICATIONS

Type 1 diabetes: WHO (2016a:30) statistics of 2010 showed that global diabetes retinopathy caused 1.9% visual impairment and 2.6% blindness. Data from 54 countries showed that hypertension and diabetes accounted for 80% of end-stage renal disease. Overall, diabetes is rated as the 8th leading cause of death in males in the world (WHO, 2016b:6,12-13,21). Chasens and Luyster (2016:1) argued that people with long-term diabetes were prone to risks and listed complications such as retinopathy, nephropathy, neuropathy, cardiovascular disease, and amputations that were affecting the quality of life and causing premature deaths in PLWD.

Type 2 diabetes: WHO (2016b:4,6,13) indicate complications as CVD, chronic kidney disease and tuberculosis, amputations of the lower limbs, damage to nerves and diabetes retinopathy. This organisation also recognised diabetes as an international emerging health challenge and noted an increase in physical and cognitive impairments as well as some cancer types linked to diabetes.

Some people are unaware of having diabetes, and they risk developing complications. When PLWD are aware of the effects of diabetes, they will be able to take care of themselves and, at the same time prevent further complications. Recent studies showed that poor glucose control was responsible for obesity, high blood pressure and kidney disease, amongst others. From this point, self-care could avert acute illness and reduce the risk of long-term complications. According to WHO (2016b:35), risk factors such as genetics, ethnicity and age cannot change. Still, it is a concern how traditional risk factors like unhealthy diets, physical inactivity, smoking, and poor life quality can be reduced. Reid, Walsh, Raubenheimer, Bradshaw, Pienaar, Hassan, Nyoni and Le Roux (2018:122) stated that risks have the potential to increase morbidity and mortalities if it is not addressed. According to the IDF Diabetes Atlas (2021), 10.5% of adults aged 20 to 79 globally have diabetes, and nearly half are not aware that they have the disease. Overweight is rated at 51.9%, obesity at 25.6% and physical inactivity at 47.1%. Other serious complications included retinopathy, nephropathy and neuropathy (Patino, Torres, Landgrave, Contreras, Patiño & Martinez, 2017; Pinchevsky, Butkow, Chirwa & Raal 2017:2). Majority of the risks in the literature are common among

people with type 1 and type 2 diabetes. Hilli et al. (2018:36) discuss how to minimise nerve and kidney damage and changes in the fundus oculi in children and adolescents with type 1 diabetes. However, similar complications can also occur in adults. WHO (2016b:6,21; 2017) recommends a comprehensive multi-sector approach.

2.17 CONCLUSION

This chapter summarised the current state of knowledge and self-care concerning family support to PLWD. The literature showed the impact diabetes has on society and provided a broad insight into the social aspects that affect self-care. Due to the consistencies of risks and complications, including the ever-rising prevalence and mortalities, the WHO influenced the management thereof through policy guidelines. It further provided aspects of current knowledge and strengthened the reasons for research into family support for diabetes self-care management. From a South African perspective, the guiding document for SA is well aligned with other guidelines but criticised for the gaps, as highlighted in the problem statement. The supporting framework has been outlined for clear understanding and will be introduced in the appropriate chapters. Adherence was found to be consistent in the literature, but it is noted that an integrated approach to risks, complications and modifications was required. Although the role and responsibilities of the family were not clear in how they could be engaged, the pinnacle is the support that they can provide during self-care. The gaps were identified in 2017 SEMDSA guidelines, which excluded the management of type 1 diabetes, family support and the lack of addressing the dimension of nursing in diabetes self-care management, diabetes self-management education and support for nurses and the family. A standardised programme for PLWD and the family was regarded as the initial point for self-care; therefore, this current research aims to develop a self-care management tool for PLWD and the family, further reinforcing this research. The next chapter discusses the research methodology. The development of a self-care management tool specifically tailored for both PLWD and their families holds significant promise in advancing diabetes care. By addressing the gaps identified in the 2017 SEMDSA guidelines, this research not only bridges the existing deficiencies but also introduces a holistic approach that encompasses familial dimensions of diabetes management. This self-care management tool is designed to provide comprehensive guidance on managing the everyday uncertainties associated with diabetes. For PLWD, the tool offers structured support that enhances their ability to self-manage their condition, promoting better health outcomes and greater independence. By empowering individuals with practical strategies and resources, the tool helps in mitigating the psychosocial burdens often experienced in diabetes management. For families, the tool serves as a vital resource for

understanding and supporting their loved ones with diabetes. It educates family members about the complexities of diabetes care, fostering a supportive environment that is crucial for the emotional and physical well-being of PLWD. The inclusion of family support in diabetes self-care management ensures that families are equipped to provide the necessary assistance, thereby improving the overall quality of care and reducing the risk of burnout among caregivers.

In essence, this research project contributes to the field of diabetes care by creating a standardized program that addresses the needs of both PLWD and their families. It underscores the importance of a collaborative approach to self-care management, where the roles and contributions of both groups are recognized and valued. By synthesizing the insights from previous research and situating them within the context of this project, the study justifies its significance and highlights its potential to make a meaningful impact on the lives of those affected by diabetes.

It is said that because PLWD everyday lives are impacted by the complexity of managing diabetes self-care, it is essential that they and their family have the basic information needed to manage diabetes under certain conditions. Therefore, the researcher set out to develop a self-care management tool for PLWD and their families in order to enhance diabetes self-care management education and family support. PLWD and their families can benefit from a self-care management tool to assist them cope with the uncertainties that come up in diabetes self-care management scenarios. According to this viewpoint, family involvement in diabetes self-care management can lower the prevalence and mortality rates of diabetes in South Africa.

The next chapter discusses the research methodology.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter describes the research methodology for the study. This Mixed methods approach is qualitative driven and applied in three phases. Philosophically, pragmatism exerted significance for diabetes self-care management and indicated the entire research processes (data collection, analysis, and inferences) for each of the three phases and considered norms, standards, and language (Guetterman, Fetter & Creswell, 2015:554; Kivunja & Kuyini, 2017:26; Rahi, 2017:1).

3.2 THE FRAMEWORK

Due to the multicultural lifestyle in SA, the recommendation in question that refers to the aspects of patient-centredness is supported (Allie et al., 2017:22-23). This study also considered the philosophical assumptions which are integrated with the theoretical framework identified as the Chronic Care Model (CCM). This model was created as a multidimensional solution for complex problems like chronic diseases. The conceptual and theoretical frameworks represent an integrated understanding of diabetes self-care management and support this specific research problem. The study is carried out within the framework of chronic diseases and self-care management. According to Shannon-Baker (2016:321-322), the inquiry can also take place by using a theoretical framework to specify data collection and analysis. The essence of the framework exerted significance as it indicated the performance indicators which supported the type of data that is collected and to discover how well or poorly they have performed during self-care management. The performance is determined by using specific self-care concepts as identified by Orem's Model.

3.2.1 Chronic Care Model

The CCM is widely used for the management of NCDs and was developed for primary care to improve chronic illnesses in patients (Bodenheimer, Wagner & Grumbach, 2002:1775-1776). See the diagram depicted in Figure 3-1 below.

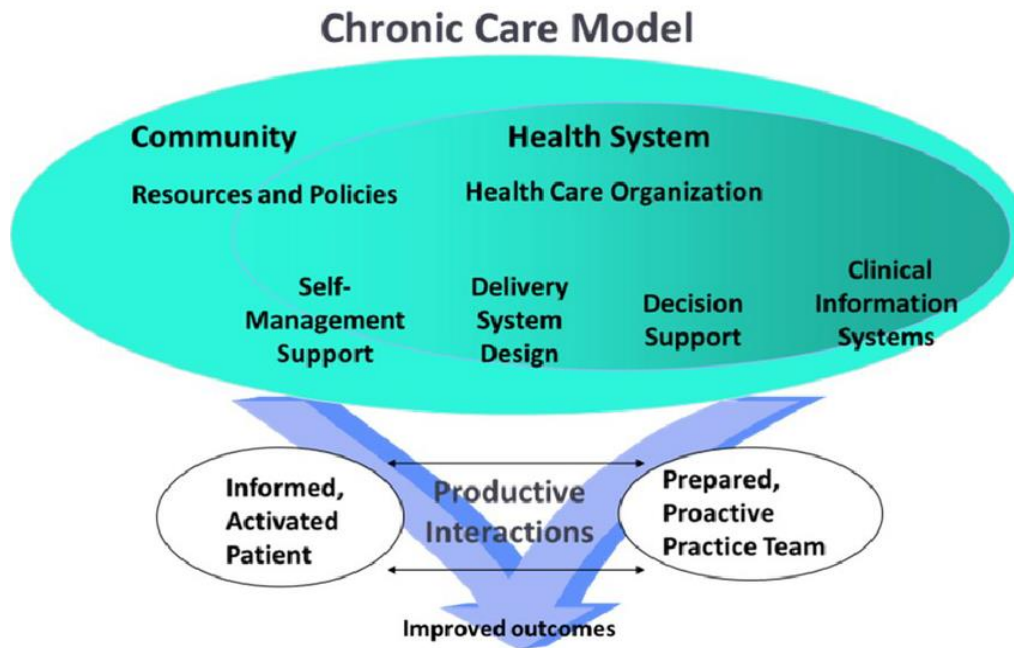


Figure 3-1. Chronic Care Model

Developed by the MacColl Institute, © ACP-JSIM Journals and Books, reprinted with permission from ACP-ASIM Journals and Books.

The CCM comprise the following six core elements as explained below. It can be used individually, combined and in any sequence (Bodenheimer, Wagner & Grumbach, 2002:1776; Strickland, Hudson, Piasecki, Hahn, Cohen, Orzano, Parchma & Crabtree, 2010:295):

- **Community resources.** This element refers to basic self-help groups, home-based care, education and exercise programmes that are linked to the health setting to improve chronic care management.
- **Health care organisations.** This element refers to the values and organisational structure and further suggests setting organisational goals, leadership, and values in prioritising chronic care.
- **Delivery systems.** This element indicates that the organisational structure must make the necessary changes to accommodate patients. Physicians are responsible for treating acute and stubborn diseases and should provide training to the health team (e.g. learn how to do foot care and other tasks to support self-management). This element further suggests that visits to the health facility must be planned.
- **Decision support:** This element refers to leadership, which must implement evidence-based practices, follow the standards of care, and integrate daily practice.
- **Clinical information systems:** This element refers to computerised systems and addresses three aspects: (1) reminders that assist the health team in complying with practice standards, (2)

feedback to the physician to indicate how the health team is performing care, (3) for use as a registry to plan individual care.

- Self-management support: For families living with long-term chronic diseases. Requires collaboration with patients and families, suggests diabetes self-management education and support (DSME/S) to take care of them.

The 2017 SEMDSA Guideline for the Management of Type 2 Diabetes proposed this model to enable health systems which can provide quality care and improve outcomes when managing diabetes (Allie et al., 2017:22). Further, Allie et al. (2017:22-23) support a patient-centred approach to achieve DSME, which is nested in the element of self-management support. Patient-centredness relates to coordinated healthcare responses that emphasise individual needs, preferences, and value systems to offer quality care (Van Der Heide et al., 2017:7,9-10). Based on this explanation, the term person-centredness was selected as it included individual people and family members. The element of self-management support can be used individually for families supporting people living with people with long-term chronic diseases such as diabetes. Still, they will require DSME and acceptance and cooperation from the affected individuals. As such, the recommendation was contextualised to consider an individual, albeit a PLWD or a family member(s) who is providing support. By focussing on PLWD and family, an individual approach was thus followed; it can be argued that PLWD depends on family support to care for themselves and others. World Health Organisation (2016:4) indicated that there is a need for civil society and PLWD to prevent and manage diabetes; this points to self-care and can be achieved through Orem's Model of Self-care Theory.

3.2.2 Orem's Model of Self-care Theory

Orem and colleagues developed the self-care concept around 1956, aiming to respond to "man's need for self-care action and the provision and management of it on a continuous basis in order to sustain life and health, recover from disease or injury, and cope with their effects", and "overcoming human limitations" (Berbiglia, 2014:222). Orem's model is based on three interrelated central theories, which are summarised as follows (Theory Based Nursing Practice, 2014:3):

- **Theory of Self-Care Deficit:** This is associated with the inability to perform self-care due to certain limitations. Therefore, nursing interventions such as education and support might be required.
- **Theory of Nursing:** This is the process where nurses help individuals meet self-care requisites to expand self-care capabilities.
- **Theory of Self-Care:** This refers to actions performed which can enhance life qualities.

It is noted that Orem's theories concentrate on nursing care in particular. Still, since self-care is an integrated process, it is argued that other HCPs could be included. Other research studies portrayed

the model in a variety of ways; this study adds a modified version of Orem's Model of Self-care Theory to the existing variations and is shown in Figure 3-2.

Theoretical/conceptual framework

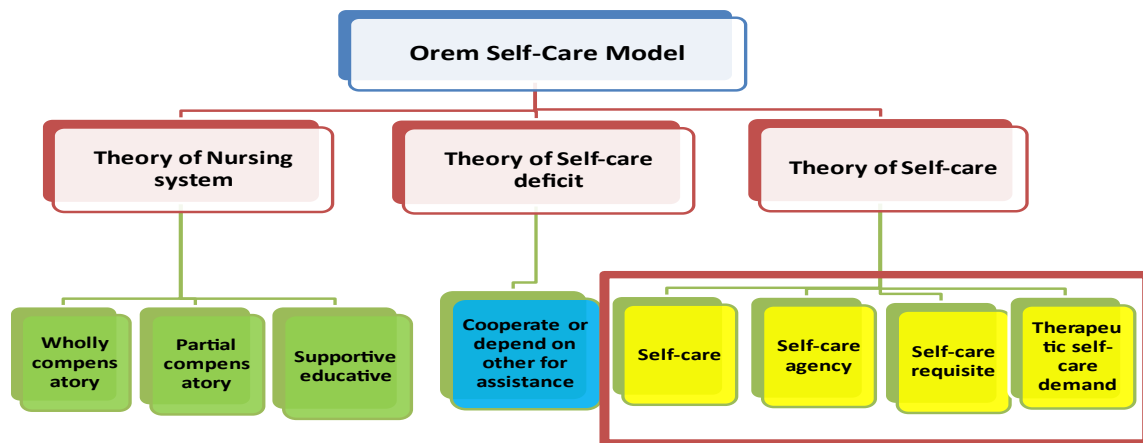


Figure 3-2. Modified version of Orem's Model of Self-care Theory

The term “chronic illnesses” describes a health condition that lasts longer than six months, is not easily resolved, and is rarely cured by a surgical procedure or short-term medical therapy (Kaakinen & Denham, 237). People living with diabetes needs to take care of themselves with the support of others. In conjunction with the CCM, Orem's Model formed the basis of the theoretical framework because it supported the Theory of Self-care, which is one of the three interrelated central theories and singled out to employ in this investigation due to its four identifiable and specific abstracts but relevant concepts. This study thus presented a modified conceptual model to show how the CCM and Orem's Theory of Self-care were integrated. Figure 3-3 shows the extraction of the Self-management support element from the CCM and how it is adjoint with Orem's Theory of Self-care.

Adjoining two frameworks

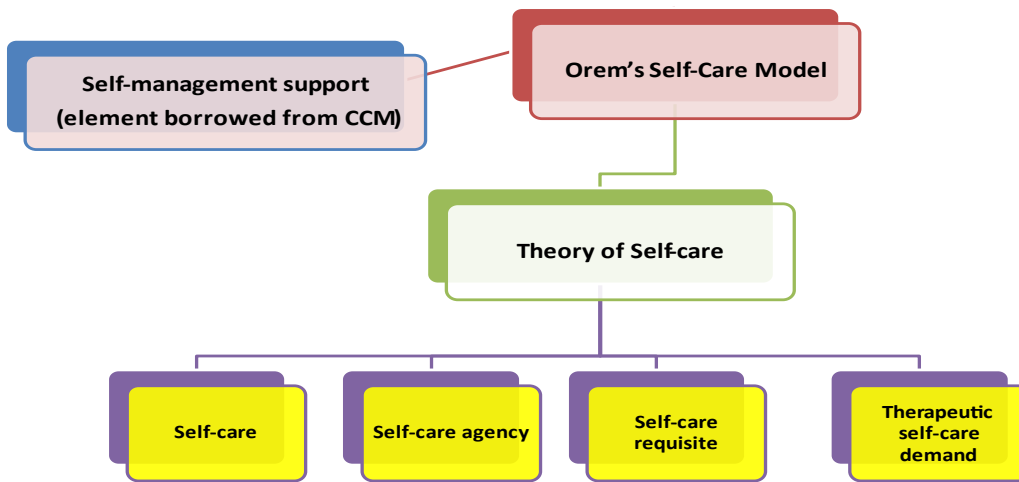


Figure 3-3. Adjoining two supporting frameworks

This diagram shows the extraction of the Self-management support element from the CCM adjoint with Orem's Theory of Self-care concepts (Self-developed modification).

Generally, PLWDs are, for the greatest part of their life, living outside a hospital environment, expected to take care of themselves. From an ontology point of view, diabetes cannot be eradicated but can be managed effectively if realistic self-care is practised. The importance of effective self-care is to prevent further complications and to enable people diagnosed with type 1 and type 2 diabetes to live a healthy lifestyle to enhance life quality. The ability to reduce hospitalisation frequency and minimise the load on primary and tertiary healthcare institutions as well as the individual is a benefit of self-care management. Based on the problem statement and research questions, the key concepts stem from Orem's Theory of Self-care, which are explained below to indicate how they were operationalised and to indicate the relevance of Orem's theory to the aim and objectives. Although the concepts were integrated during implementation, it is important to describe them individually for better understanding. A key factor of the Theory of Self-care is the ability to uncover the PLWD perceptions of family support related to their diabetes self-care management and to uncover the experiences of PLWD and their families when practicing diabetes self-care management

The significance of Orem's Theory of Self-care concepts was integrated and clarified according to the concepts which are explained below:

Table 3-1. Orem's concepts of Theory of Self-care

Orem's concepts of Theory of Self-care	Description of concepts
Self-care	This concept focuses on PLWD and their families to perform certain activities at home such as blood glucose testing, administering the correct dosage and correct insulin, taking the correct dosage of pills and at the prescribed times, following and adjusting meal plans, participating in physical activities, etc. According to Orem (Theory Based Nursing Practice, 2014:2-7), nurses provide support when PLWD are unable to care for themselves. Since PLWD needs family support due to their inability to self-care, this gap was narrowed by including the family in self-care and the guidelines from other HCPs.
Self-care requisites	This concept is associated with the health care needs of a patient who requires care and assistance (Theory Based Nursing Practice, 2014:3). To highlight this concept, Murphy et al. (2015:2) state that not all PLWD have the knowledge or skills to perform some of the actions that are required, for example, a blood glucose test or knowledge how to operate the blood glucose machine, how to administer the correct dosage of insulin, etc. PLWD requires assistance, and these activities must be deliberately taught and learned. This is a tedious and timely process (Theory Based Nursing Practice, 2014:2-7; Berbiglia, 2014:223). This concept is viewed to embrace DSME. Self-care requisites relate to a person-centric approach to what they always do, usually do, what they neglect to do, or special adjustments they must make (McLaughlin Renpenning & Taylor, 2003:164). The learned abilities must be integrated with culture and traditions, language, knowledge base, educational level and socio-economic status to enable PLWD and the family to make certain decisions and adjustments as to how they practise self-care (Alligood, 2014:446). The information enabled insight into how to empower them to improve their abilities and continuously practise self-care.
Self-care agency	This concept refers to the ability of PLWD to perform certain actions that they need to care for themselves. To meet these requirements, they must be taught. However, achieving these abilities will develop over time. The abilities also include aspects such as knowledge to make certain decisions and if they can remember what they must do and how to do things if they are motivated to practise self-care to augment the treatment plan (Theory Based Nursing Practice, 2014:15-17). Berbiglia (2014:223,226-229) also emphasised the importance of decision-making, suggested a practical approach to self-care, and supported Orem's idea of cooperation to determine self-care. Therefore, PLWD and their families should be allowed and able to make decisions as to how they want to take care of themselves (McLaughlin Renpenning & Taylor, 2003:217).

Orem's concepts of Theory of Self-care	Description of concepts
Therapeutic self-care demand	This concept summarises the actions that are performed to regulate life functioning, which is indispensable for life-long self-care when living with diabetes. Besides the preservation of life, it is important to prevent further complications. This concept is associated with the requirements they need and the ability to achieve it (McLaughlin Renpenning & Taylor 2003:214; Theory Based Nursing Practice, 2014:15-17).

3.3 DIABETES SOCIAL SUPPORT QUESTIONNAIRE FAMILY VERSION

La Greca and Bearman (2002:666) developed the Diabetes Social Support Questionnaire Family version (DSSQ-Fv) (Annexure 5-A) related to primarily measure how the family perceived and supported diabetes care within families of paediatric and adolescent patients. The instrument had been previously utilised in a similar study, making it suitable for the current research despite differing age groups. No modifications were necessary, thereby ensuring data validity minimising errors. Permission was obtained to employ the questionnaire (Annexure 3-A and 3-B). Even though a variety of data collection instruments were available to measure self-care, the DSSQ-Fv was appropriate for Phase 1 of this study as it aimed to determine the level of perceptions and experiences by PLWD and the level of family support in a SA context. The DSSQ-Fv questionnaire proved suitable to describe PLWDs perceptions of family support and diabetes self-care management. Relevant information and specific problems that participants had experienced during diabetes self-care management were identified. In this current study, the purpose of employing the questionnaire was to measure the PLWD perceptions and the support by the family during diabetes self-care management.

The constructs of this instrument relate to Orem's Model of Self-care Theory within the Theory of Self-care concepts (self-care, self-care agency, self-care requisites and therapeutic self-care demand. Construct validity is the measure of how meaningful an instrument is when in practical use, it was achieved through the Known-group validity. Content validity is regarded the degree to which the five constructs of the DSSQ Fv fully measure perceptions and experiences of PLWD diabetes self-care management. Despite the relevance of the questionnaire, the part to establish the socio-demographic profile of the study population was missing and in this study, Part 1 was developed to collect the participants' characteristics such as age, marital status, where they live, etc. The DSSQ-Fv questionnaire proved suitable for describing PLWDs perceptions of family support and diabetes self-care management.

This instrument contained five constructs with a total of 58 questions (10 items for insulin injections, 14 items for blood testing, 20 items for meal plans, 9 items for exercise, and 5 items for general aspects). There were two questions for each component, therefore 116 questions were addressed. The first set of 58 items measured perceptions and experiences, whereas the second set of 58 items measured feelings or emotions. Welch, Shepherd, Dirks, Tan and Coad (2019:2) view the semantic differential tool useful as a quantitative method to analyse experiential factors even if it cannot represent an objective or absolute measurement. From this basis, and although the semantic differential tool was not the yardstick in this current study, it was argued that this questionnaire has an affinity with a semantic differential tool because two types of rating scales were measured. Relevant information was identified and specific problems that participants had experienced during diabetes self-care management were identified.

3.4 RATIONALE TO PILOT THE DSSQ Fv QUESTIONNAIRE

Based on items of behaviour and emotion in the DSSQ-Fv questionnaire, instrument development appears from a psychological perspective to measure how the family perceived and supported diabetes care in paediatrics and adolescents elsewhere in the United States of America. In this current study, the questionnaire was employed to measure the perceptions of adult PLWD and family support during diabetes self-care management in SA, viewed from a nursing-social and psychological perspective. In Phase 1, the pilot study was conducted preliminary to determine the feasibility of the DSSQ FV to identify shortfalls and deviations, to establish the complexity and appropriateness, to clarify wording and sentence phrasing, to confirm the order of the questions and to establish if the layout of the instrument posed any challenges. Essentially, to collect relevant information from PLWD about perceptions and experiences during self-care, and to understand how they feel about family support (Van Teijlingen & Hundley, 2001:1; Van Teijlingen & Hundley, 2005:220).

It was significant to determine if the questions addressed any concerns pertaining to self-care. South Africa acknowledged multiple official languages (Lehohla, 2012:23). Translations during the pilot test would most probably enhance understanding of what was being asked while yielding the same understanding in a SA context, as would be for the American population. Language barriers can negatively influence understanding and compromise data collection, which had to be ruled out, and participants had to establish if they would need the original DSSQ-Fv questionnaire to be translated into some of the local SA languages. This would then determine if the participants clearly understood all the questions asked to enable the appropriate collection of information. It was anticipated that translations could become time-consuming during data collection, it was necessary to establish a time period to complete the DSSQ-Fv questionnaire in its original format and language.

3.5 OUTLINE OF THE RESEARCH DESIGN

PLWD are mainly living their lives outside a hospital environment, which implies their primary responsibility for diabetes self-care management as part of their individual treatment care plan. Based on the selected recommendation as per Chapter 5 of 2017 SEMDSA guidelines (Allie et al., 2017:22), concepts were contextualised in terms of dependent variables (patient-centredness, respectfulness, receptiveness, needs, values, non-discrimination of culture, non-discrimination of ethnic language and non-discrimination of socio-economic circumstances). Independent variables were selected concepts from the CCM and Orem's theoretical model to allow a Mixed methods investigation. Participants were able to express their thoughts, feelings, and experiences regarding diabetes self-care management outside of the hospital setting by filling out questionnaires in Phase 1, taking part in focus groups and phone interviews in Phase 2, and reaching a consensus in Phase 3. This mixed methods research design formalised the application of two sequential strands using quantitative and qualitative approaches. The pragmatist approach supports Mixed methods designs to answer the research questions (Onwuegbuzie & Leech, 2006:475). Schoonenboom and Johnson (2017:119-120) regard Morse and Niehaus (2009), Johnson et al. (2007) and Teddlie and Tashakkori (2009), amongst others, as prominent scholars of Mixed methods typologies. There is a variety of Mixed methods typologies and each design manifests differently. Schoonenboom and Johnson (2017:117-118) record that an exploratory sequential design comprises qualitative data collection and analysis, and quantitative data collection and analysis is used to test or generalise qualitative results. Ordinarily, with an exploratory sequential design, qualitative data collection and analysis are done first, and the findings then inform the quantitative component. On the other hand, an explanatory sequential design requires that the quantitative data collection and analysis is done first (Fetters et al., 2013:2136).

The design for this study is based on the Morse notation system and constructed in three phases, labelled as quan → QUAL → QUAL, indicating that the quantitative component precedes the qualitative components (Schoonenboom & Johnson, 2017:114). By following the Morse notation system, the lower-case term "quan" implies that the quantitative component has a supportive role. The capitalised term "QUAL" denotes dominance or primacy to the qualitative component of the study during the qualitative approach (Hesse-Biber, 2010:64; Schoonenboom & Johnson, 2017:112). The dominance of the qualitative component reveals that more weight is attached to the data coming from those core qualitative components. The arrows indicate a sequential implementation of the three phases.

However, by simply using quantitative and qualitative data collection methods in a single research study does not necessarily imply that it can be labelled as a Mixed methods study. Fetters et al. (2013:2135-2136) record that the principles and practices of Mixed methods involve the integration

or linkage of two strands of the data at the design level, methods level, or interpretation level. These authors confirmed that integration or linkage can take place during the investigation by connecting, building, merging, or embedding when explaining the design level. Mixing occurs at multiple levels where qualitative and quantitative data are analysed and integrated to answer the same research question(s).

Therefore, based on the explanation by Fetters et al. (2013:2140), the plan was developed during the design phase to collect quantitative and qualitative data that can be merged. It is common for researchers to first do interviews to gather a wealth of narrative information to develop a quantitative instrument to conduct large-scale research studies (Hesse-Biber, 2010:3; Van Teijlingen & Hundley, 2001:3). However, due to the availability of an existing data collection instrument, the DSSQ-Fv, and based on the above views, the development of a large-scale quantitative data instrument was pointless and followed the reversed approach to first administered the structured existing questionnaire during Phase 1 with a series of scales to collect data which could measure the perceptions of PLWD regarding diabetes self-care management quantitatively. According to the opinions of the above authors, quantitative data can assist qualitative researchers by providing them with a broader context within which to place their qualitative data and quantitatively sample in identifying representative cases for their in-depth research. Subsequently, the salient findings formed the basis to collect qualitative data during Phase 2 (Hesse-Biber, 2010:5). Irrespective of whichever component is done first, quantitative data can confirm and test the results of qualitative data; alternatively, qualitative data can add meaning to quantitative data (Brierley, 2017:6).

Fetters et al. (2013:2136, 2139) also emphasised integration during Mixed methods and further held the view that integration at the methods level happens through different approaches. In addition, Fetters et al. (2013:2140) maintained that building happens when results from one data collection procedure inform the data collection approach of the following procedure. During this investigation, data was connected and linked from Phase 1 (quantitative or supportive component) to Phase 2 (qualitative components) Stages 1 and 2. Participants were lobbied already during Phase 1 to participate in Phase 2, Stage 1. The salient findings emanating from Phase 1 thus helped to shape probing questions to explore rich data in the sequential qualitative components. The collected data were useful to establish the generalisability of the qualitative results (Hesse-Biber, 2010:3-5). Data collection, analysis and inferences for each phase were conducted separately before moving on to the next phase. The inferences from Phases 1 and 2 were analysed and merged to build meta-inference for Phase 3. The meta-data results were organised in Figures, Tables, matrices, or graphs before it was disseminated to those who participated in Phase 3, where the consensus/decision-making process through the Delphi consensus technique took place (Fetters et al., 2013:2143).

Based on the label for this typology, the qualitative (core or primary) components were complimented by the quantitative (supplemental or secondary) component. The quantitative design was done first, and the findings of the quantitative data were analysed to inform two sequential qualitative designs (Boehmer, Kyriacou, Behnken, Branda & Montor, 2018:2). This study design thus used a Mixed methods explanatory sequential design in three phases with different methodology strategies to enable an investigation into diabetes self-care management, viewed from three different perspectives. Figure 3-5 therefore presents Phase 1 as the 1st perspective of the research design.

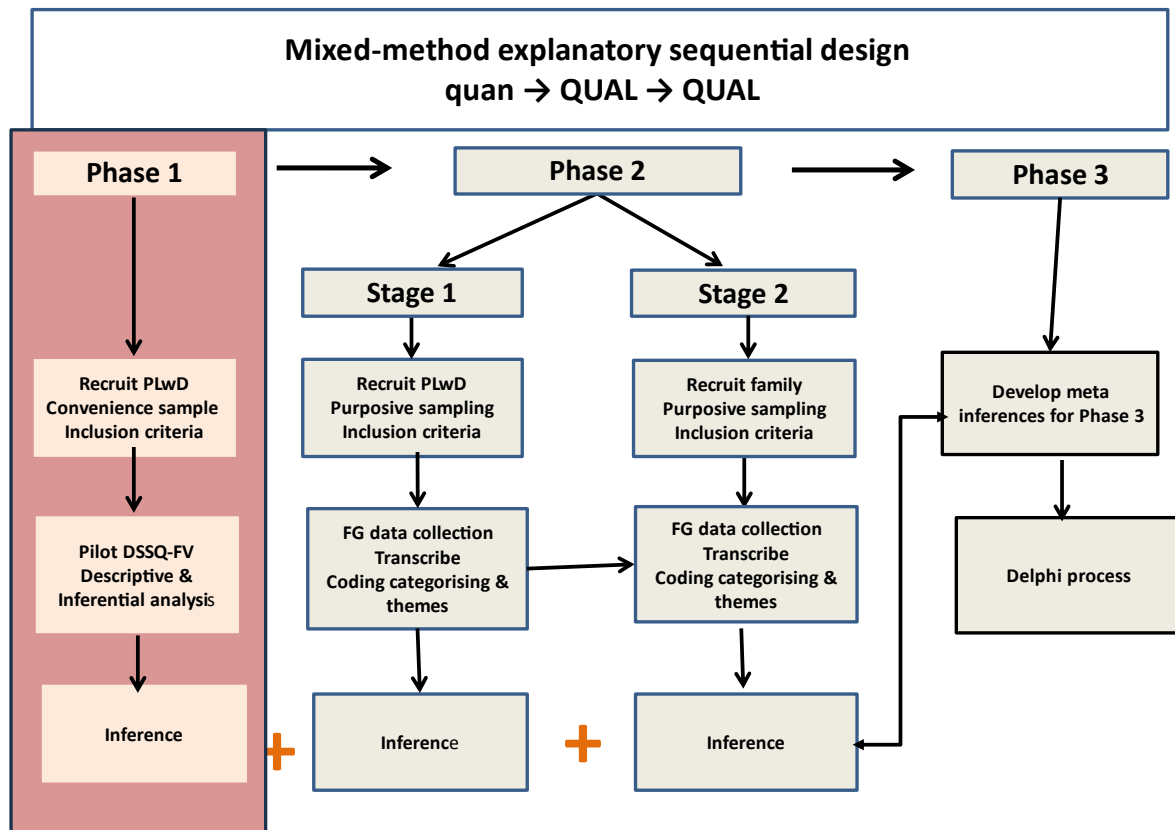


Figure 3-4. Mixed Methods research process (Phase 1)

3.6 PHASE 1 (quan)

Figure 3-4 shows the demarcation Phase 1 which is guided by Objective 1: To describe PLWD perceptions of family support related to diabetes self-care management. This phase of the study is quantitative and was conducted at two selected health facilities in the Tshwane region, Gauteng Province of South Africa.

3.6.1 Conducting the pilot study

Ten PLWD were chosen at random to fill out the Sociodemographic (Annexure 6-A) and DSSQ-Fv questionnaires in order to assess the study's viability. Participants consisted of five respondents (one male and four females), two were recruited at Clinic 1 on 23 October 2020, and an additional three were recruited on 2 November 2020. An additional five participants were recruited at Clinic 2, consisting of two males and three females on 26 October 2020. Since the pilot participants had to establish the time, they were allowed to ask questions and seek clarity on questions asked, ample time was thus allowed to read the questionnaire before completion. Afterwards, they had to complete the self-developed questionnaire (see Figure 3-5), which consisted of 7 questions to rate the DSSQ-Fv questionnaire for which the pilot test sought feedback.

Question	Item	Rating scale		
		1	2	3
1	Rate the understanding of the questions	easy to understand	difficult to understand	very difficult
2	The sequence of the questions are easy to follow	acceptable	difficult	confusing
3	Rate the layout of the questionnaire	easy	difficult	complex
4	Would you prefer that the English questions should be translated to a language of choice?	Yes	No	Uncertain
5	Consider translations from English and indicate the time to complete the questionnaire	less than 1 hour	1 hour and more	
6	Do you require translation from English during completion of the questionnaire?	Yes	No	
7	How long did it take you to complete the questionnaire	Hours Minutes.....		

Figure 3-5. Pilot questions to rate DSSQ FV questionnaire

3.6.2 Pilot feasibility analysis and conclusions

The frequencies of variables (V1, V2, V3, V4, V5, V6, V7a and V7b) came from ten pilot participants ratings of DSSQ-Fv questionnaire. Questions (Q) 1 to 4 provided a three-rating scale. Q1 indicated that nine out of ten easily understood the questions, and one experienced some difficulties. Q2 indicated that ten found the questions acceptable. Q3 showed that nine rated the layout as easy, and one found the layout complex. Q4 asked if the respondents would prefer translations to a language of their choice and could select yes, no, or uncertain. Only two out of ten preferred

translations. Q5 asked the respondents to consider translations from English and to indicate the time to complete the DSSQ-Fv questionnaire by rating it as less than 1 hour or an hour or more.

Nine respondents completed the questionnaire in less than an hour. One required an hour and more. Q6 asked if the respondents required translation from English during the completion of the DSSQ-Fv questionnaire and could choose the option between yes and no. Seven did not require translation from English while they were completing the DSSQ-Fv questionnaire. Three needed translations of some of the questions or specific words. Q7 asked about the time to complete the DSSQ-Fv questionnaire. Nine responded to the question. The average time to complete the questionnaire ranged between 10 minutes to 1 hour. Two respondents completed in 10 minutes, one took 12 minutes, four took 15 minutes, one took 17 minutes, and one took 30 minutes. The time to complete the DSSQ-Fv questionnaire had been set as 18 minutes.

At face value and prior to the pilot, the layout of the DSSQ-Fv questionnaire appeared to be complex, but after a thorough explanation, it was easy to complete. The need for translation was ascribed to the differentiation in literacy levels. As the majority did not require changes to questions 1 to 6, no amendments were made. Only PLWD were selected to complete and to reflect on how they have experienced the DSSQ-Fv questionnaire, whilst the main reason was to find out how the respondents rated the DSSQ-Fv questionnaire instead of focussing on the data gathered. Based on the above findings, Phase 1 could proceed.

3.6.3 Conducting the main quantitative study.

Sampling method and sample size. The section justifies the sample size. Determination of the sample size posed a challenge. Information about the study population could not have been disclosed at the initial stage of the design, which affected the ability to conduct a power analysis to determine the sample size. Following ethics approval from the University of Pretoria (UP), it was hoped that more information about the study population would come to the fore to enable power analysis subsequently. Power analysis could not be performed due to unavailability of the information about the study population, influenced by the POPI Act, medical confidentiality and the non-functional manner how registration and administration were conducted.

In order to proceed with the study, complying with timelines and circumvent the obstacles of time, hard to reach participants, the uncertainty of the size of the study population, an accurate number could thus not be determined, but the rationale for the selected sample size of 100 was influenced by the statistician inability to perform power analysis and the sampling process ended when a sample size of 100 was obtained. Due to the inability to recruit a larger sample, convenience sampling under the pragmatic approach was appropriate. Convenience sampling was selected due to the advantage it holds during the Covid-19 period of ease of access, cost-effectiveness and

anticipated not be time-consuming. This method was a limitation. Despite this method be easy to access participants, they were hard to reach. Probability sampling would have been resulted in fewer participants.

Credibility was enforced by excluding those who participated in the pilot study, and this action helped to rule out them giving different answers to the same questions to which they were exposed already. Due to a lack of resources, time, accessibility, geographical proximity, and availability of participants at any given time, convenience sampling was applied during the recruitment and selection of the target population (Hesse-Biber, 2010:65). Unlike what was anticipated, the clinics did not accommodate “diabetes clinics” on selected days. Patients for all types of chronic care follow-up appointments were individually scheduled on any day and the dates on the appointment cards were not helpful at all to identify PLWD. Over and above this challenge, the clinic appointment schedules did not indicate the number of patients scheduled for a specific day, neither their personal details nor the type of chronic care clinic that they would attend. Subsequently, the health facility was unable to determine the number of follow-up appointments or visits PLWD per day, per week or month. Dates for follow-up appointments depended on their health status and progress of the last visits and ranged between two weeks, once a month, two monthly, quarterly, or even six monthly for PLWD between the two health facilities. These aspects made recruitment very tedious and hard.

Recruitment and population. Participants were recruited in the waiting areas of the respective clinics on the days of the follow-up medical appointments. Those who showed interest received an information sheet about the study, which addressed, amongst other, the rules to participate or opt out of the study. Even though there was no foreseeable physical discomfort or risks involved, they could decide not to answer sensitive questions. The questionnaire was administered to 105 type 1 and PLWD type 2 at both clinics to determine their knowledge and understanding, which helped to gain better insights into how PLWD practised self-care and how the family provided support in managing this health condition (Hesse-Biber, 2010:65).

Inclusion criteria. Study participants were included if they met the following inclusion criteria:

- Diagnosed with type 1 or type 2 diabetes, with or without comorbidities
- Diagnosed for a minimum period of 6 months
- Exposure to self-care
- 18 years or older
- Both genders
- Did not participate in the pilot study

3.6.4 Data collection process

Participants were recruited in the waiting areas of the respective clinics on the days of the follow-up medical appointments. Those who showed interest received an information sheet about the study, which addressed, amongst other, the rules to participate or opt out of the study. Even though there was no foreseeable physical discomfort or risks involved, they could decide not to answer sensitive questions. The questionnaire was administered to 105 PLWD Type 1 and 2 at both clinics to determine their knowledge and understanding, which helped to gain better insights into how they practised self-care and how the family provided support in managing this health condition (Hesse-Biber, 2010:65).

The data was collected with the Socio-demographic questionnaire and DSSQ-Fv questionnaire. Participants were explained how to complete the two instruments. Each participant received a sequentially numbered “participant package” consisting of Part 1: Socio-demographic questionnaire, Part 2: the original English version of the DSSQ-Fv questionnaire and a pen. Adequate time was allotted to read the questionnaires before answering the questions. At that point, they could decide whether they still wanted to participate or withdraw. To confirm anonymity, they were informed not to write any form of identification on any of the questionnaires. By voluntarily completing the questionnaires anonymously, written informed consent was thus not required. Arrangements were made for those who wished to complete the questionnaire in privacy. Despite careful consideration and planning, challenges were experienced during recruitment, which impacted data collection (see Chapter 8 for clarification).

3.6.5 Data analysis

Thabane, Ma, Chu, Cheng, Ismaila, Rios, Robson, Thabane, Giangregorio and Goldsmith (2010:5) refrained from including pilot participants; therefore, the main study excluded them. One hundred and fourteen PLWD in total were recruited for Phase 1 at the selected two clinics in Tshwane. A 99% response rate was attained. Based on the manual for the DSSQ-Fv questionnaire, scores were calculated for the sub-scales. Data analysis was done with the help of the program SPSS IBM® SPSS® software statistics version 27 to calculate single frequencies. Data was analysed through interval and ratio scales to measure the accuracy of the instrument and provided statistical analysis through descriptive and inferential analysis, mean, standard deviation, percentages, mean and frequency count (Breimaier et al., 2015:2).

The perceptions and experiences were summarised for the 1st set to show the corrected item-total correlations and Cronbach’s α if items were deleted. Each construct had a different number of items, and the corrected item-total correlation coefficients showed that each item contributed to the reliability of the DSSQ-Fv questionnaire with the exception of Q1a, with an α value of 0.846 if the

item was deleted. The corrected item-total correlation would decrease significantly to 0.102, and Q6a had a value of 0.835. If the item were deleted, the corrected item-total correlation would also decrease significantly to 0.29. Both items were retained to increase the α . Cristobal, Flavián and Guinalíu (2007:327) used item-total correlation with a minimum of 0.3 to improve Cronbach's α . The 1st set of items with a six-point rating scale attained α value of 0.692 to 0.932 if Cronbach's α if item was deleted. The corrected item-total correlations attained α value of 0.102 to 0.903. Some items (Q3a, Q4a, Q10a, Q54a, and Q56a) reached α value between 0.724 and 0.798 as the second lowest.

According to the Cronbach Alpha reliabilities, 15 items (Q1a, Q2a, Q5a, Q6a, Q7a, Q8a, Q9a, Q45a, Q46a, Q47a, Q48a, Q49a, Q50a, Q55a, Q58a) reached α value ranged between 0.84 and 0.888, the remaining 45 items scored α values between 0.807 and 0.932. The items per construct demonstrated that it fits well within Orem's Theory of Self-care and can thus be recommended for studies investigating self-care. It is worthwhile for HCPs to support self-care of medicine adherence, foot care, and weight management. The "Cronbach's α if item deleted" column values ranged between 0.692 questionable ($0.7 > \alpha \geq 0.6$) and 0.932 excellent internal consistency. Based on the α value, the "Corrected Item-Total Correlation" was positive (acceptable, $0.8 > \alpha \geq 0.7$), which supported high internal consistency, except for Q57a, which encourages PLWD to enhance diabetes self-care management and scored 0.692 as the column corrected item-total correlation indicated. If this item had been excluded from the questionnaire, α value would have increased slightly to 0.79, but the small escalation of Cronbach's α did not warrant the question to be excluded. Some items (Q2a, Q9a, Q13a, and Q18a) focussed on nagging. The findings are discussed in Chapter 4. The next section presents the qualitative phase of the study.

3.7 PHASE 2 (QUAL)

Phase 2 is guided by Objective 2: To explore self-care management experiences of PLWD and their families in diabetes self-care management. This phase of the study is qualitative and designed in two, to represent Stage 1 which comprised of PLWD and Stage 2 comprised of family support. The research process is similar except for the differentiation of the population. Prior to starting Phase 2, a pilot study was conducted in both stages to ensure the feasibility of data collection methods through a series of focus groups and to determine the way forward. Fetters et al. (2013:2136, 2140) emphasised the importance of data integration during Mixed methods studies and maintained that integration at the methods level happened through different approaches. Figure 3-6 presents Phase 2 as the 2nd perspective of the research design.

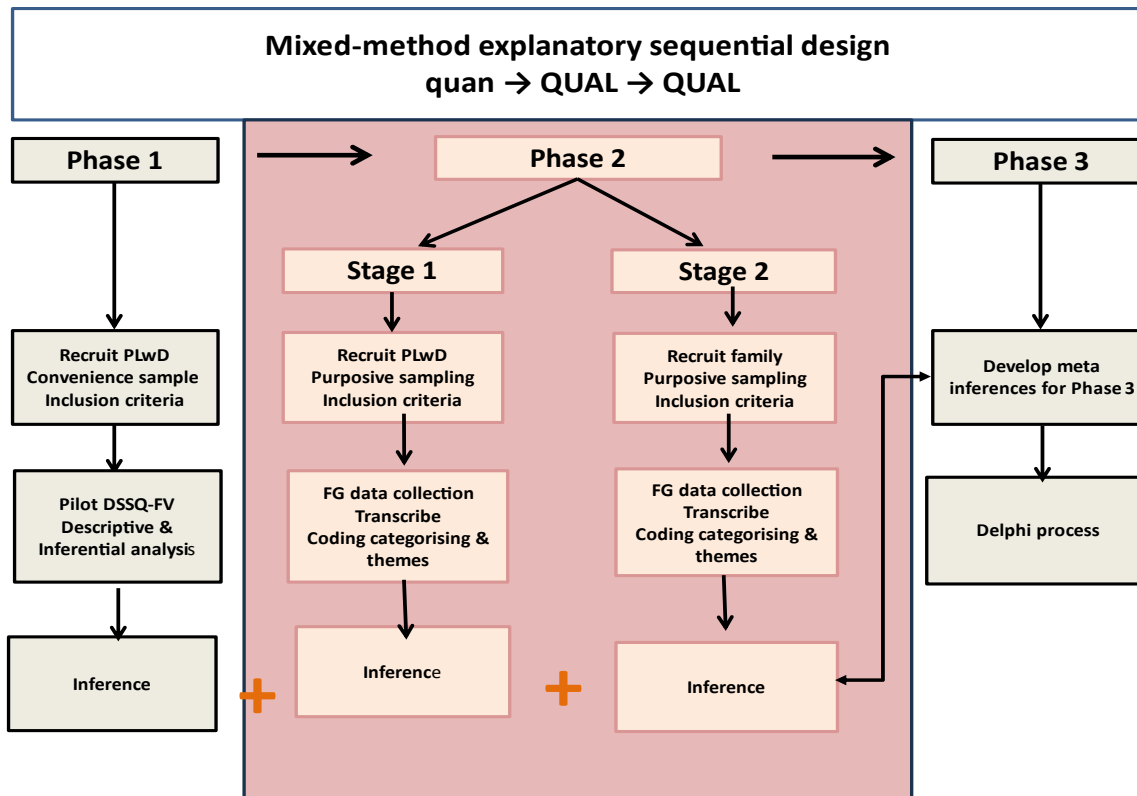


Figure 3-6. Mixed Methods research process (Phase 2)

3.7.1 Rationale to conduct a pilot study

Apart from a focus group being a common qualitative data collection method, Rothwell, Anderson, Botkin et al. (2016:3) view that focus groups are effective ways to gather rich data about complex health issues like diabetes self-care management. Therefore, due to the complexity of diabetes self-care management, it was significant to gain first-hand information through a dynamic conversation. Bloor et al. (2002:9) maintain that focus groups may be done early in a study to explore and inform the development of later stages, which were applicable to Phase 2. Rothwell, Anderson, Botkin et al. (2016:3) added that focus groups are effective ways to gather rich data about complex health issues like diabetes self-care management. In view of this current investigation, rich data was interpreted as to obtain pertinent information through a variety of individual viewpoints, attitudes, and experiences rather than as having a large amount of created data. This perception also reflected different value systems and their understanding of the social and health phenomenon of diabetes self-care management. Moreover, to express their emotions when their family encouraged them and recognised the global influence on every facet of this health issue.

Due to the complexity of diabetes self-care management, it was significant to gain first-hand information through a dynamic conversation with the small group and to delve into the factors that either influence or require self-care to have insights into the everyday life and practices of how PLWD

experienced self-care in the absence of clinical management (Cyr, 2015:2; Rothwell et al., 2016:2). To identify individual needs and to generate quality data, Orem's Theory of Self-care concepts and the DSSQ-Fv constructs were related. It guided the focus group discussions (Theory Based Nursing Practice, 2014:2-7). A better understanding of non-clinical or non-pharmaceutical interventions could be discovered (Cyr, 2015:2). Another aspect was to determine the general knowledge and self-care management practices for PLWD and their families in Tshwane at an individual level. These factors were intended later as inputs to Phase 3 (Krueger & Casey, 2015:507).

Allie et al. (2017:22) outline one of the recommendations which focussed on patient-centredness of diabetes self-care management. Doria, Condran, Boulos et al. (2018:2) support patient-centredness and argue that patient-oriented research is not a research method but rather a process that involves patients. In view of these arguments, the researcher wanted to understand different behaviours, attitudes and experiences of self-care. Therefore, acknowledgement of different value systems, socio-economic aspects, and educational differences played a significant role.

Another aspect was to consider the different spoken languages in the country (Lehohla, 2012:23). Van Teijlingen and Hundley (2001:2-3) documented that language barriers could negatively affect data quality. In support, Bloor et al. (2002:9) argued that focus groups helped to access everyday languages as a first step into the taxonomy of vernacular terms. Nyumba et al. (2018:29) added that skilled facilitators can guide dialogue to enhance discussions. Multilingualism was thus a strategy to circumvent this potential weakness. The moderator/study assistant was conversant with most of the local languages and posed the questions or topics for discussion in a language, which most could understand. In the context of language barriers, "language-switching" enhanced the extrapolation of rich data (Cyr, 2015:3; Rothwell et al., 2016:1-3). The focus group pilot study was conducted to establish how smooth and sound dialogue would ensue in multiple or Mixed languages, to test and check the audio-recording device for voice and data quality, to establish a time limit for a focus group session and to determine feasibility for this data collection method.

Thabane et al. (2010:5) suggested not to include results from a focus group pilot study. They argued that due to previous exposure to the questions, participants might respond differently to the same questions in follow-up sessions than those who had not yet participated. According to Van Teijlingen and Hundley (2001:1,3), there is no need to conduct a focus group pilot study but acknowledged the progressiveness of qualitative pilots. Unlike Thabane et al. (2010:5), they were not very concerned about data contamination. They argued that the data could be included by stating, "it is simply not possible to exclude these focus group pilot study participants because to do so would result in a too small a sample in the main study". In view of this statement, the spill-over effect of the emerging data collection challenges during Phase 1, impacted negatively on Phase 2 and onwards. Therefore, despite the small number of participants, the decision was taken to include the data from the focus

group pilot study as a means to increase the database. In contrast with these authors, Van Teijlingen and Hundley (2001:1-3) argued that the focus group pilot study can improve the internal validity of the questionnaire. In order to conduct the focus group, general focus group characteristics had to be complied with, a conducive environment had to be created, ground rules had to be set, and the research team had to know their responsibilities. The next sections discussed these aspects.

3.7.2 General focus group characteristics

This section provides a concise review of different approaches of size vs data saturation, which include the number of focus groups and duration. These elements indicate the influence that these common characteristics had on this study's focus group. There are various types of focus groups. A participant pool of two to five people who were difficult to reach formed a small focus group (Nyumba et al., 2018:24). A group like this would be regarded as "experts" because these individuals can manage their health condition through self-care practices. Therefore, it is assumed that they would be better informed and adequately skilled to participate in the focus group to impart personal experience.

3.7.3 Creating a conducive environment for dialogue

Krueger and Casey (2018:510) emphasised the importance of conducive research environments when conducting focus groups. Nyumba et al. (2018:29) argued that a conducive environment aids in rapport-building, and a comfortable environment enhances good relationships. A conducive environment was created by selecting a secluded outdoor space on the premises of Clinic 2. It was more spacious than the other. To minimise potential distractors, the selected space for the focus group activity leveraged separation from the normal clinic activities and minimised noise and movements to an extent. During this time, attention was given to specific regulations related to the COVID-19 pandemic, where space was a key factor for distance. Anecdotally, some of the COVID-19 pandemic regulations influenced data collection. Participants had to maintain a specific distance from each other. They were obliged to wear face masks, which influenced sound and audio recording and thus affected voice quality.

Notwithstanding long-term visits to the familiar location of the clinic, the separate space created a sense of privacy where participants could speak freely, share experiences and raise their different viewpoints. The selection of the venue was an important aspect because the majority of the participants used one or the other form of public transport, and familiarity with the venue and travel route reduced unnecessary strain and movement. It further minimised financial expenses because different travel routes to unfamiliar locations could have increased the travelling costs, considering that some were unemployed and had to borrow travelling fares to attend the focus group.

The agreement was that any participant first had to attend the focus group before reimbursing travel fees at the end of the session. As an “icebreaker,” an informal “meeting and greeting” took place before the session started. This helped them to feel more at ease with each other during the dialogue sessions. Participants were registered by signing the travel reimbursement sheet and selected a number ranging from 1 to 12 to indicate the placement at corresponding numbered seats. The half-circular seating arrangement enhanced group interaction. Language freedom created a stress-free environment and maximised participation. Refreshments were served during a 15-minute break to create socialisation and refresh.

3.7.4 Ground rules for the focus group

Krueger and Casey (2015:510) provided thoughtful information for the focus group. Ground rules were set in advance, and even when the participants were invited to add or change some of the rules, they remained unchanged, as presented below:

- No cell phone disturbances: Participants had to switch off their cell phones or use the silent mode function but could respond to a call and exit the group quietly at any time but were required to re-join as soon as possible.
- Respecting different opinions: Due to individual backgrounds, it was anticipated that they might have different experiences and opinions, and they could speak freely. There were no right or wrong answers and participants were allowed to agree or disagree on condition that they respect the views of others.
- Freedom of speech: Multilingualism was encouraged during information sharing. It helped to increase participation, for those individuals who were timid or less confident to share information. In cases where some did not fully comprehend the spoken language, the moderator translated the statements and questions into a language better understood by most.
- Enhancing recording: One person at a time was allowed to speak. It helped immensely with the audibility during recording.
- Reimbursement: None of the participants were remunerated to participate in the study but a fixed individual travel expense was reimbursed against a signature at the end of each session (Bosma et al., 2020:2-3).

3.7.5 Responsibilities of the research team

The research team consisted of the researcher, moderator/study assistant and note-taker. All had individual qualities and assisted the researcher during the focus group. The group met a day prior to the focus group to discuss the activity and to know their individual roles and responsibilities. This strategy helped to streamline the dialogue during the focus group session.

3.7.5.1 *Researcher*

The researcher welcomed the participants on arrival at the designated location and briefed them on how the focus group would be conducted and what needed to be achieved, including the ground rules. Krueger and Casey (2015:511-512, 522) proposed that the researcher only sits and listens to the discussions and monitors the interactions. Sutton and Austin (2015:226) believed the researcher must attempt to assess what the participants were thinking and how they felt. Despite being present throughout Stage 1, the researcher did not interfere with the data collection/generation process but rather took a peripheral role during the focus groups and merely provided advice to the moderator/study assistant and note-taker where it was required. This strategy enhanced the trustworthiness of the study (Nyumba et al., 2018:21). The researcher took responsibility for the audio recording (Moore & Llompert, 2017:410). She was also responsible for debriefing the team at the end of the focus group to confirm the accuracy of the recordings and to determine if any adjustments were required.

3.7.5.2 *Moderator / study assistant*

Nyumba et al. (2018:29), citing a few authors (Berg 1989; Morgan 1996; Litosseliti 2004), suggested that facilitators should have some skills and techniques to enhance and guide dialogue during focus groups, they further suggested that the flow of discussions should be flexible; remain open to change and must be adjusted according to the participants' requirements. Given the diverse SA population, the researcher anticipated diversity pertaining to cultural differences, value systems and multiple spoken languages to emerge. Language was the most important aspect. Given SA diversity, the preferred language helped to express their experiences and feelings better (Lehohla, 2012:23). Nyumba et al. (2018:29) emphasised that facilitators must have good communication skills and knowledge of the topic to enable probing different answers for more in-depth discussions. The moderator/study assistant, being a polyglot, extrapolated rich data, which added value during the discussions.

The moderator/study assistant was a statutory professional qualified dietician. Based on her academic qualifications, knowledge, and professional attributes, she clearly understood the importance of glycaemic index control. These attributes were quite significant in discovering how PLWD fared with dietary concepts during self-care. The lesson learned was that the right person for a job must be considered. Those participants who gave one-word responses were encouraged to describe their experiences. She ensured that all participants had an opportunity to share information with controlled dominant speakers while simultaneously encouraging timid participants. Even though Bosma et al. (2020:3) reported on a focus group study held in The Netherlands, which was conducted in Dutch as the first language and later translated to English, they did not provide the reasons for the language preference. Krueger and Casey (2015:507) also held focus groups in different languages.

3.7.5.3 *Note-taker*

Qualitative studies are about the emic perspective. Therefore, over and above the availability and use of audio-recording devices, the note-taker was responsible for capturing information and gestures (Sutton & Austin, 2015:228). Note-taking is perceived as a task given to the most junior person on the team (Nyumba et al., 2018:29). Further, this author maintains that one should have the ability to remain impartial and must have good observation skills, need to pay attention to body language or behaviour during the dialogue sessions. The note-taker was a professional registered nurse with more than 40 years of experience; she understood the importance of diabetes self-care management and noted physical behaviour and activities. The note-taker provided comprehensive hand-written notes, which completed the information for transcribing. Nonetheless, her vast knowledge and skills in nursing care captured the conversations and most important interactions, such as body language and facial expressions, which could not be audio-recorded (Elo et al., 2017:2-3; Sutton & Austin, 2015:229).

3.7.6 Obtaining informed consent for focus group discussions

Information about the study and informed consent was explained during recruitment. Those who indicated interest received a written information sheet, which included a single page to give informed consent (see Annexures 9-A and 9-B). Participants have read and understood the study details before signing the written consent. Written informed consent was obtained to 1) participate in the focus groups and 2) to audio-record the conversations on a recording device to ensure that no information is missed during transcribing and translation (Rothwell et al., 2016:3; Babbie and Mouton 2014:168,174). They were informed that there were no medical risks associated with the study and no clinical procedures would be done. Nobody was subjected to physical or emotional discomfort. Participants understood that they were not compelled to share sensitive information, and they could opt-out at any stage without prior notification and for any reason. Some subsequently withdrew. More importantly, they were guaranteed that no punitive actions would be taken and that future treatment would not be affected. Participants were informed that sharing information about experiences would benefit other PLWDs because self-care management would be better understood by those who were struggling with self-care practices.

Psychological support and counselling were arranged for those who wished to use the service, and follow-up visits were arranged in consultation with the relevant clinics if participants agreed. Anonymous participation strengthened confidentiality and protected their identity. However, they had to sign a travel reimbursement sheet for control purposes. As suggested by Rees-Punia et al. (2020:2), numerical pseudonyms were allocated. Krueger and Casey (2015:510) suggested that data contamination is minimised when participants do not divulge the discussion content with others

outside the focus group, and even if this was emphasised, there was no guarantee that participants had complied.

3.7.7 Conducting the focus group pilot study

3.7.7.1 *Recruitment and population*

Two different population groups participated in the focus group session to gather rich information. Stage 1 data collection was conducted with PLWD, and to corroborate the information, a family member of a PLWD participated in Stage 2. This current study anticipated to conduct a pilot with six additional focus groups per Stage 1 and 2 of Phase 2. The reluctance to participate and hard-to-reach participants is ascribed to the consequences of the Covid-19 safety protocols. Guest, Namey and McKenna (2017:4) could not discover any empirical evidence to suggest a sufficient sample size when determining data saturation. Nonetheless, the researcher argues that data saturation was reached. Data saturation was accomplished by applying an operational method to quantify the number of codes, which were reduced by overlapping and merging those with similar meanings and resulted in the creation of themes (see explanation in the coding process). Focus group and interview data were combined. It revealed that eight broad concepts in Open coding. The 1st level of Line-by-line coding created 650 preliminary descriptive codes. The high number of codes is ascribed to the frequency of some codes. During the 2nd level, codes that appeared multiple times were aggregated, and those that had similar meanings were merged, the codes were thus reduced to 520 second-order descriptive codes and created 14 emerging categories. These numbers provide evidence that data saturation was achieved.

The transcribing method and process of the focus group pilot study and individual telephone interviews were conducted separately but combined to code integrated as one data set. Four family members who had supported a PLWD participated in the focus group. Due to cultural diversity, participants' rights to communicate in different languages and with respect to associated diabetes challenges and complexities, participants were encouraged to speak in a language of their choice (Lehohla, 2012:23). It helped the participants to express themselves better. One participant was able to translate or summarise the information if it was shared in a language that the rest of the group had not understood; this strategy aided with recording purposes (Cyr, 2015:3; Rothwell et al., 2016:1-3). The structured pre-developed opening questions for the focus group were authorised by the Faculty of Health Sciences Research Ethics Committee, Ethics reference number 710/2019. The discussions started with a central leading question with the following open-ended questions: "How do you experience caring for and supporting a family member who is living with diabetes?" The questions were compiled to guide the discussions and written out, followed with probing questions: "What adjustments have you had to make in order to care for and support a family member living with diabetes?" and "How can HCPs better support you in caring for and supporting a family member

living with diabetes?” (Annexure 9-B). The focus areas for probing included the experiences of the family, which were identified with the first open coding, and Orem’s concepts (Berman, 2017:5; McIntosh & Morse, 2015:2).

The population sample for Phase 2 Stage 2 comprised of family members of a person who had been diagnosed with type 1 or type 2 diabetes, with or without complications or comorbidities (Hesse-Biber, 2010:64). Purposive sampling was applied for the pilot study to ensure a representative population, the process was similar as for Stage 1 and already conducted during 2021. In the clinic waiting room, the researcher selected participants at random who met the inclusion criteria. Potential participants were invited, and the researcher provided her contact information to no avail. Only four family members volunteered to participate, despite the fact that recruitment for potential participants had already started during Stage 1. This focus group was regarded as the pilot study, and further recruitment showed hard-to-reach and reluctant participants. The challenge to arrange more focus groups was unsuccessful; it stalled, and the research process of sampling and method had changed to snowball sampling and telephone interviews, similar to Stage 1 (Hesse-Biber, 2010:64). Snowball sampling was applied for the interview based on the inclusion and exclusion criteria to explore how the family support and care for a person diagnosed with diabetes (Hesse-Biber, 2010:64).

Recruitment started during the Stage 1 focus group on 12 April 2021. The researcher lobbied amongst the participants from the focus group pilot study for Stage 1 to persuade a family member or from their existing network to participate in a focus group on 15 April 2021 (Bloor et al., 2002:31). In consideration of the Protection of Personal Information Act 1 July 2020, participants were advised to ask if the volunteers agreed to share their contact details with the researcher who will contact them about the research. Contact details of potential participants were received on 13 April 2021. They were contacted, and all agreed to participate in the focus group. Two male and two female family members participated in the focus groups; all were residing in Gauteng Province. The same recruitment method was followed for the telephone interviews with four female participants. They were included if they had exposure for a minimum period of six months in caring for and supporting a family member who had been diagnosed with diabetes, irrespective of whether they lived in the same household. A period of six months enabled them to share their experiences as to how they cared for and supported the needs of the PLWD, and it enabled them to give insights into the adjustments they, as a family, had to make. All participants were older than 18 years. The age group enabled voluntary informed consent to participate in the interviews. All were able to engage in the interview by telephone. There was no reason to consider exclusion. One participant resided in KwaZulu Natal, two in Gauteng, and one in the Eastern Cape Provinces. Even though these four participants were residing in different provinces, it did not pose a challenge as the interview depended on the telephone at an arranged time and date. As a reminder, they were contacted via e-mail, WhatsApp, and sms to explain the study and to confirm the interview appointment. Besides a

verbal request for consent, and a letter with the study information, including the consent form with instructions on how to give consent, only two sent written consent. The remaining two agreed to the interview pledge of written consent but failed to do so. Nonetheless, by granting the interview, consent was assumed.

Diabetes self-care management and its complexities were given much consideration, while Orem's Theory of Self-care concepts supported the foundation of how discussion sessions were structured to generate quality data (Rothwell et al., 2016:2; Theory Based Nursing Practice, 2014:3-7). For these reasons, the concepts employed in this current investigation were intentionally selected to conduct the pilot focus group. Four questions were linked to concepts of Orem's Theory of Self-care and integrated with the five constructs of the DSSQ-FV (Theory Based Nursing Practice, 2014:15-17; La Greca & Bearman, 2002). Different participants shared the "how" and "what" information. Saldaña (2013:61) advocated those ontological questions like "What is the nature of ...?" "What are the lived experiences of ...?" and "What is it like being ...?" addressed the nature of realities, explored individual experiences, and made it possible to make inferences. The observed nuances, intonation, gaps, etc., in participant responses enabled the note-taker to give an accurate account of the discussions.

From an epistemological view, Stage 1 engaged with one male and two female PLWDs through dialogue on 12 April 2021. The UP-Ethics Committee authorised the structured pre-developed opening questions intended to answer the research questions. The leading question asked was: "How do you experience caring for yourself in managing and living with diabetes?" Further probing questions asked were: "With regards to diabetes, how do you experience the involvement of your family in managing and caring for you? How can your family better care and support you in your living with diabetes?" and "How can health care professionals better care and support you in living with diabetes?" Participants shared their perceptions, attitudes, experiences, complexities, and beliefs about self-care. To ensure that the group remained focused on the questions, the questions were written down on a whiteboard. The moderator facilitated the focus group. Even though most dialogue was conducted in English, participants could respond in a preferred language. One of the participants conversed with some of the local languages. Because it was important to understand each other, the group agreed that the participants could summarise or repeat the dialogue in English. Even though it was time-consuming, this strategy achieved a translation that was as true to the original response.

Inclusion criteria for the focus group pilot study. Inclusive criteria were set for all participants to be 18 years and older. This age would permit written informed consent and allow them to share information and experiences about diabetes self-care management. Participants had to be diagnosed with type 1 or type 2 diabetes with or without comorbidities for a minimum period of 6

months. The importance of the duration would ensure adequate exposure and would enable them to provide relevant information on their individual experiences. Those who did not meet the criteria were excluded (Hesse-Biber, 2010:65; Krueger & Casey, 2015:511).

Sampling method. Despite the challenges of recruitment for data collection and based on the availability and willingness to participate in the focus group, purposive sampling was employed. The location for the focus groups was scheduled at Clinic 2. However, participants from both clinics were participating. Krueger and Casey (2015:506) recommend that focus groups should be planned well in advance, subsequently, verbal information about the focus group was shared with eligible participants already during Phase 1. Those who showed interest voluntarily provided their contact details for recruitment and invitation at the appropriate time. Advanced recruitment also helped the potential participants to arrange their availability for the focus group discussions.

Sample size versus data saturation. Bloor et al. (2002:28) highlight the unpredictable makeup of a focus group due to the possibility that some volunteers who had confirmed participation might not attend and encouraged over-recruitment. Unpredictability was experienced during this study. During the planning and recruitment of the focus group, the intention was to include a pool of eight or more participants per focus group. Thirty-seven potential participants expressed interest, but at the time of invitation, only 12 confirmed their participation. Unfortunately, only three people attended the focus group pilot study (Bloor et al., 2002:28; Bosma, Boot, Schaafsma, & Anema, 2020:2-3). The remaining nine did not attend. However, as stated in the information pamphlet regarding participation and informed consent, they had the option to withdraw at any time. Despite the unsettlingly low number, to continue with the focus group pilot study was given serious consideration to either cancel or continue.

However, Nyumba et al. (2017:23) supported the viability of small groups, they cautioned that data collecting could be constrained. These authors regarded costs and other difficulties as potential weaknesses for focus groups. Nevertheless, it was decided to proceed with the small number of participants because of the inconvenience with travelling arrangements and difficulties in gathering a group at the same period. Bloor et al. (2002:26) recommend a pool ranging between six to eight but have conducted mini-focus groups at various times with a small number of two to four participants. Small-scale focus groups are thus not unusual. Cortini, Galanti and Fantinelli (2019:30) researched group numerosity and cited some of the focus group pioneers, Osborn (1953), Slater (1958), Bouchard and Hare (1970), and Bouchard, Barsaloux and Drauden (1974) recommendations that a group between five and 10 participants. Krueger and Casey (2015:511) discussed different numbers for a focus group. In their report on studies with small groups, Bloor et al. (2002:27) cited Quine and Cameron (1995) about older individuals with disabilities and Thomas's (1999) research into holiday romance.

Due to practical limitations, several authors also reported on smaller focus groups. Three to 14 individuals participated in each group. Very few people attended the focus group for numerous unidentified reasons; they were categorised as being difficult to contact. To organise and conduct the focus group, it was crucial to consider the number of participants, the length of the focus group, and the number of sessions. However, Guest, Namey and McKenna (2017:4) could not discover any empirical evidence to suggest a sufficient sample size when determining data saturation. To streamline pharmaceutical care intervention programs, Jarab, Mukattash, Al-Azayzih and Khmour (2018:301) conducted an exploratory study in Jordan with six focus groups, each with a pool of six participants, to examine opinions on the management of type 2 diabetes.

On the other hand, Bloor et al. (2002:27–28) contend that a group with a considerable number of participants becomes challenging to manage if they are under time pressure when exchanging experiences and viewpoints. It was determined as a result that bigger groups might produce less information in the allotted period. These examples illustrated various arguments about the size of focus groups and demonstrated that smaller focus groups of three to six people were workable. Based on these premises, size is deemed unimportant. With respect to the different opinions, the size of focus group participants is thus inconsistent, and therefore, this study unintentionally had to conduct a small focus group.

Duration and number of focus groups. A qualitative design with a semi-structured focus group was employed. It was planned to have one pilot and six additional focus groups, with a total of 28 participants. Still, due to the challenges with recruitment and subsequent data collection, this target was not achieved. Some authors (Krueger & Casey, 2018:511; Rees-Punia et al., 2020:1) posit that a minimum of three to four focus group sessions is usually sufficient to explore rich data. However, they caution about the duration and believe that extensive sessions cause fatigue. Bosma et al. (2020:3) undertook a study in The Netherlands and reported that one session lasted approximately two hours. Boger, Demain and Latter (2015:3) suggested 45 to 90 minutes. This current focus group pilot study lasted about 60 minutes with a 15-minute break halfway.

It was discovered that the small group allowed optimal time to explore information. It allowed an individual to discuss their experiences without haste extensively. Follow-up questions could be explored instead of generating larger volumes of data with shallow information. From this premise, it is believed that a larger group might produce volumes of information within the same period. However, rich-quality data might be compromised. In this context, quality refers to exploring relevant questions such as Who, What, Why, Where, When, and How.

3.7.8 Data analysis

DSSQ-Fv questionnaire, scores were calculated for the sub-scales. Data analysis was done with the help of the program SPSS IBM® SPSS® software statistics version 27 to calculate single frequencies. Data was analysed through interval and ratio scales to measure the accuracy of the instrument provided statistical analysis through descriptive and inferential analysis, mean, standard deviation, percentages, mean and frequency count (Breimaier et al., 2015:2). The mean scores were calculated for the subscales. Inferential statistics include the Cronbach Alphas to gauge internal reliability of the DQQS Fv. The mean scores for the subscales were compared across the demographic variables by performing independent t-test or ANOVAs if the data came from normal distribution. If the data was not normally distributed, nonparametric statistical test were performed to compare the median scores of the subscales.

3.7.8.1 *Audio recordings of focus groups Stages 1 and 2*

Audio recordings for both phases were made using the Philips VoiceTracer DVT 2810 with Dragon speech recognition software for automatic transcription in order to guarantee that all information is recorded and to minimise recording-related issues. As an extra recording device, the LG G8XThinQ smartphone with the HD audio recorder app was fully charged in anticipation of any power disruptions. The note-taker supplemented the audio with handwritten notes (Moore & Llompert, 2017:413). For qualitative research, a variety of resources can be employed, according to Azevedo, Carvalho, Fernandes-Costa et al. (2017:160). Despite the use of a high-quality recording transcription device, linguistic difficulties were encountered. The device was considered poor in transcribing audio recordings from one of the SA languages to any other language because it did not support the SA languages. Mobile phones become a popular denominator for recording interviews, according to McMullin (2021:143). Owing to subpar audio recordings, the researcher read the script aloud while repeatedly listening and typing to record the conversation using an LG G8XThinQ mobile phone. Phase 2, Stages 1 and 2 focus group pilot study was held on 15 April 2021 in two sessions with a 15-minute refreshment break. The discussion was recorded to ensure a true reflection of what was discussed. Because non-gestures could not be recorded, the note-taker kept handwritten notes as the discussions proceeded. An overview of the audio recordings is given in Table 3-2 to present a summary of the participant characteristics, serial reference, data volume, and duration of the focus group recordings and Table 3-3 present their characteristics, which were made using an LG G8XThinQ are displayed in the accompanying tables.

Table 3-2. Summary of focus group pilot study for Phase 1 (Stages 1 and 2)

Phases and Stages	Session	Serial reference	Data volume and duration
Phase 2 Stage 1	1	102855	17.70MB / 24:01
Phase 2 Stage 1	2	113623	30.93MB / 41:26
Phase 2 Stage 1	2	105711	6.98MB / 09:08
Phase 2 Stage 2	1	103203	39.53 MB / 53:06
Phase 2 Stage 2	2	115157	15.58 MB / 18:17

Table note: P2/S1 (Phase 1 Stage 1), P2/S2 (Phase 2 Stage 2)

Table 3-3. Participant characteristics for focus group pilot study for Phase 2 Stages 1 and 2

Race and gender (Age)	Duration of self-care and support to PLWD	Relationship to PLWD
BM (39)	10 + years	Self
BF (U)	Longer than 6 months	Self
BM (U)	Longer than 6 months	Self
BM (39)	10 + years	Son
BM (29)	2 + years	Brother
BF (41)	4 + years	Friend
WF (62)	15 + years	Wife

Table note: BM (Black male), BF (Black female), WF (White female), Not disclosing age (U)

3.7.8.2 Transcribing the focus group discussions Stages 1 and 2

Data analysis started with the transcribing process (Moore & Llompert, 2017:404; McMullin, 2021:141). Transcribing is the process of converting the original audio recordings to written text to facilitate analysis better (Sutton & Austin, 2015:227; Jarab et al., 2018:301; Da Silva Nascimento & Steinbruch, 2019:414). According to Barbour (2005:747), data analysis of focus groups and other qualitative studies follows a similar process; they advised that utilisation of opportunities for comparison and exceptions are significant. Transcribing was done with Microsoft 365 on a mic-enabled device powered by Microsoft Speech services on the Microsoft Word (MS Word) program. The dictation icon on the MS Word programme allowed to use of speech to text, but like the Philips VoiceTracer, this program, too, did not support SA languages. The first round of Afrikaans transcriptions was done by selecting the Dutch language on the MS Word program. The second effort was to translate the Dutch version to English, also on the MS Word program. However, when

the Afrikaans audio recordings were compared with the English text, the Dutch version showed many bizarre errors, and the transcripts were discarded. The third attempt was to listen to the Afrikaans audio-recorded version and then monotonously type the documents in Afrikaans.

The back-and-forth process of making corrections to typing errors and ensuring accuracy required repetitive listening, typing, and pausing. This process was extremely time-consuming. After the relevant transcripts were completed in Afrikaans, including certain Afrikaans sections where a Mixed of both languages was spoken, it was translated with Google Translate to English, after that, it was compared with the Afrikaans version. Even though this process was easier and only needed the audio-recordings stored on the LG G8XThinQ Mobile Phone and in MS Word on the computer, and an internet connection, it was extremely overwhelming. This process of transcription was much better than transcribing with the Philips VoiceTracer DVT 2810 Dragon speech software recognition or directly with the MS Word program.

Restricted resources inhibit professional transcribing services. Subsequently, the researcher conducted the translation and transcribing and ensured that the conversion from audio to text was an accurate record of the focus group discussion (McMullin, 2021:143). The importance was to determine the dialogue essence from the transcript. Moore and Llompert (2017:414) advised about problems with multilingualism data, however, except for during transcription, language did not pose any challenges. Many authors suggested verbatim transcriptions to establish the reliability, dependability, and trustworthiness of the transcripts. McMullin (2021:141) stated that there are no rules on how to transcribe audio recordings to text. The denaturalised transcript process was applied. According to Sutton and Austin (2015:227), an experienced researcher or transcriber might take up to 8 hours to transcribe a 45-minute audio-recorded interview to generate about 20–30 written pages. In this current study, it took more than 8 hours to transcribe a 40-minute focus group session. Despite the limited data, the duration for both sessions was approximately 65.27 minutes. Quality transcriptions depend on noise limitation. The focus group was held in a distant location to limit noise interference for better audible recording. However, background noise impeded recording, and the fact that participants were compelled to wear face masks during the COVID-19 pandemic, clear and clean recordings were compromised and created a barrier to audio and voice quality

3.8 DIVERTING FROM FOCUS GROUPS TO INTERVIEWS

The epistemological assumption affirmed that pragmatism allowed for more than one method and was applied during Phase 2. By understanding and interpreting the philosophical assumptions, axiology, norms, and standards related to the regulations which the SA government issued as to how citizens had to conduct themselves during the COVID-19 lockdown periods, it is the belief that the pragmatic approach exerted significance over the data collection during this study of diabetes self-care management (Guetterman et al., 2015:554; Kivunja & Kuyini, 2017:26; Rahi, 2017:1). Stage 1

data consisted of audio-to-text transcripts that came from three participants, and Stage 2 data came from four participants, including the handwritten notes (Braun & Clarke, 2006:78). Due to the small number of attendees, limited information was gathered during the pilot focus group, but to move forward with Phase 2, there was a need to make modifications to the data collection method made possible by the pragmatic approach.

Kivunja and Kuyini (2017:28) and Shannon-Baker (2016:321-322) pointed out that the methodological assumption influences the methods and procedures of how data is collected and analysed. Whilst still amid the pandemic, it was anticipated that the recruitment challenges would continue. They further argued that a qualitative inquiry can take place in a philosophical or theoretical framework. Therefore, the decision to divert from focus groups to interviews was considered on recruitment and data collection challenges experienced during this study. Telephone interviews replaced focus groups. Nevertheless, Van Teijlingen and Hundley (2001:1,3) are of the opinion that there is no need for a focus group pilot study and recognise the progressiveness of qualitative pilots. Although Nyumba et al. (2017:23) supported the viability of small groups, they cautioned that data collecting could be constrained

As a result, to increase the data, the focus group data was included and created data building for later use in Phase 3. Data building occurs when findings from one data collecting method inform the data gathering strategy of the following, which supported the diversion from focus group to telephone interviews (Fetters et al., 2013:2136, 2140). Pragmatism encourages objectivism and subjectivism and focuses on what worked best in an investigation of real issues such as diabetes self-care management (Fiorini et al., 2016:40). Guest et al. (2017:693) recorded, "Other researchers posit that individual interviews produce more detail than focus groups, and offer more insight into a respondent's personal thoughts, feelings, and world view".

The objective for this phase was to explore the self-care management experiences of PLWD and their families in diabetes self-care management. Data collection and single realities of the perceptions and experiences of PLWD during Phase 1 gave rise to further exploring subjective meanings with multiple realities during Phase 2. They shaped the dialogue for a qualitative study. Data was collected through dialogue to investigate how PLWD and the families fared during diabetes self-care management outside a hospital environment. The COVID-19 pandemic was an existential threat this world has ever experienced, and similar to other countries, the national regulations in SA were the most unprecedented of all times. Anecdotally, no person could predict how long the pandemic would last. Based on this extraordinary event, extraordinary measures had to be employed to mitigate the challenges of recruitment, and to proceed with this study. Even if it was unplanned, people were hard-to-reach, and some were reluctant to participate, which also occurred during the focus group pilot study. These circumstances were beyond the control of this study. Subsequently,

unforeseen period pauses were experienced. However, standing true to the interpretation of pragmatism as to what works well, the best option was to amend the recruitment and data collection method (Fiorini et al., 2016:40). Reasons that justified telephone interviews varied but were mainly ascribed to inadequate data collection, compliance with the health and safety regulations amidst the COVID-19 pandemic and consideration of strict safety protocols such as lockdown periods and social distancing. Face-to-face interviews were considered but compromised due to hard-to-reach and reluctant participants, including geographical distance. Online focus groups were an option but compromised due to the current situation of energy supply in the country. This factor affected the stability and availability of power supply at the time and affected online communication. Although Skype telecommunications application and Zoom Video Communication platforms were considered to conduct interviews, some of the participants did not have a smart phone, laptop, or internet connection. Few had Wi-Fi connections, but the power supply was intermittent. Appointments could not be scheduled for the same time and the viable option was to schedule individual telephone interviews.

3.8 .1 AMENDMENT TO THE RESEARCH DESIGN FOR PHASE 2

Data analysis of Phase 2 revealed that data collection was inadequate and participant groups too small, including hard-to-reach which could compromise the study. Phase 2 was amended to ensure continuation of the study, emphasising trustworthiness. Figure 4.7 present the amendments to both Stages of Phase 2.

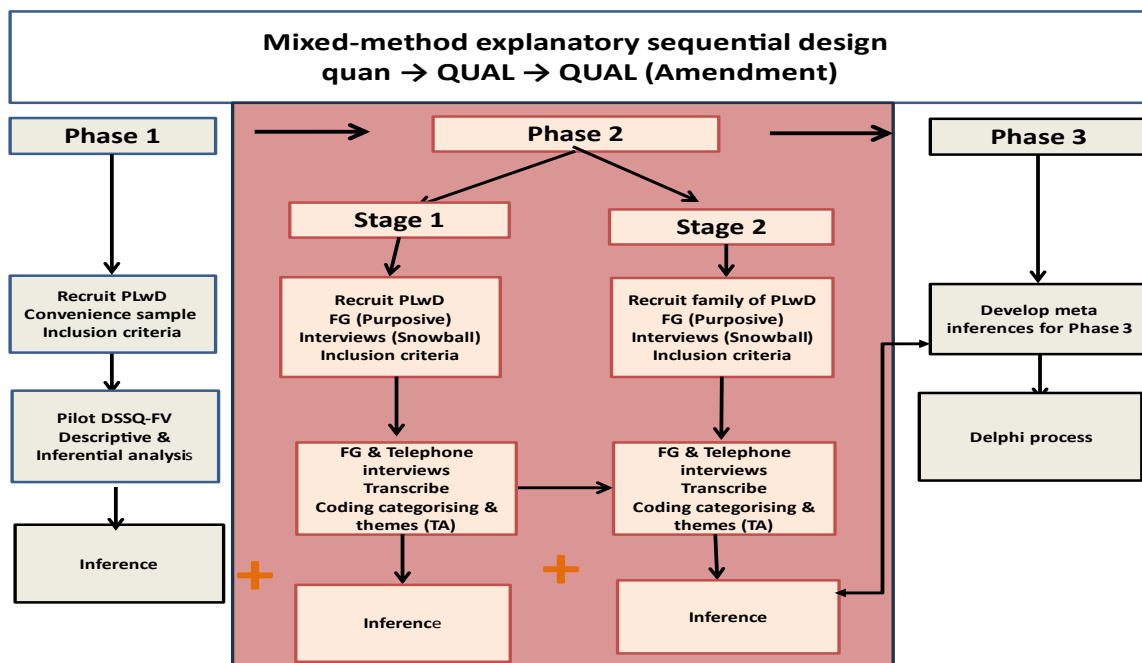


Figure 3-7. Mixed Methods research process AMENDMENT (Phase 2, Stages 1 and 2)

Due to the change of data collection method, the research design required amendments to recruitment and data collection method and informed consent.

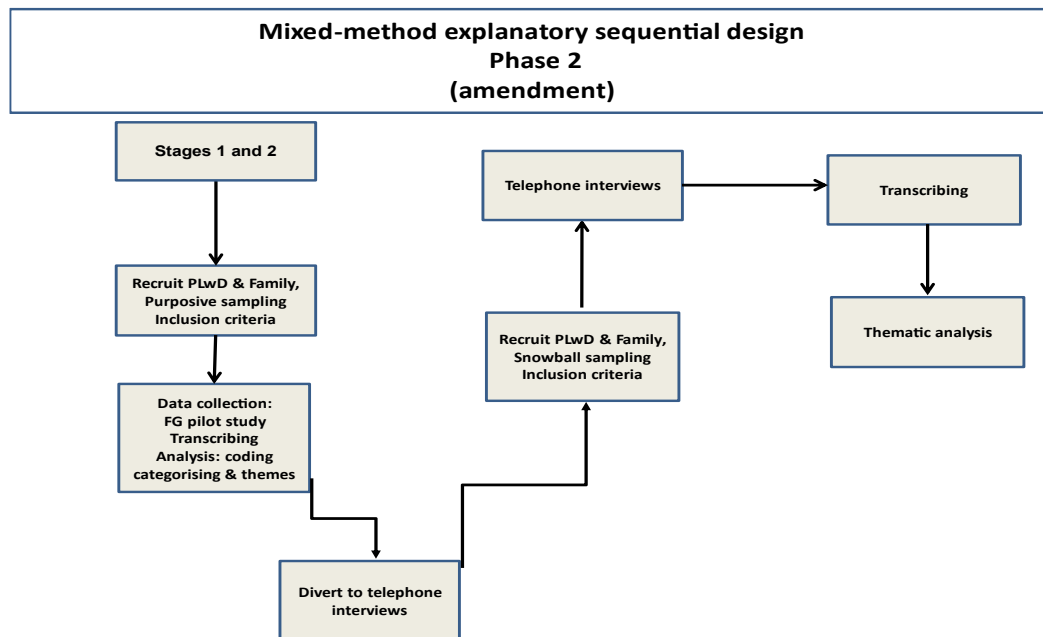


Figure 3-8. Mixed Methods research process (extraction of Phase 2)

Data collection, analysis and inferences for each phase were conducted separately before moving on to the next phase. The inferences from Phases 1 and 2 were analysed and merged to build meta-inference for Phase 3. The meta-data results were organised in Figures, Tables, matrices, or graphs before it was disseminated to those who participated in Phase 3, where the consensus/decision-making process through the Delphi consensus technique took place (Fetters et al., 2013:2143).

3.9 TELEPHONE INFORMED CONSENT

Even though recent literature documented informed consent within the realm of the COVID-19 pandemic, this information is equally applicable for telephone interviews under circumstances as explained above. Garg and Khanna (2021:10) conducted research on hard-to-reach participants pertaining to dilemmas researchers faced in obtaining consent during the COVID-19 pandemic. They further stated that due to modifications over the past couple of years, the content of informed consent must be explained in detail. Garg and Khanna (2021:12) reported that the Indian Council of Medical Research provided guidelines for research during the COVID-19 pandemic and stated that the ethics committee in India approved a waiver of consent. These same authors believed that telephone interviews carried greater weight during the pandemic and enabled electronic or telephone informed consent. These authors emphasised that explanations to the prospective participants must be detailed and that informed consent was valid if the conversation with participants was recorded for

later record keeping. They proposed a step-by-step guideline approach for telephonic informed consent.

De Vries, Burgess, Blockman et al. (2020:1) stated that informed consent is a key pillar of ethical research and mentioned the development of international guidelines to obtain informed consent for research during exceptional circumstances. They, too, referred to the COVID-19 pandemic. From a SA perspective and research context, these authors suggested combined an individual consent, albeit delayed and proxy consent for those that might experience challenges such as safety protocols, which included “physical distancing requirements, risk of exposure and infection to research staff”. In regard to these views, this study encountered similar real challenges for both the researcher and participants when considering safety protocols during the pandemic.

Different suggestions to obtain informed consent during the pandemic emerged. Although Kulkarni et al. (2022:839) argued that physical and face to face interviews were a better option to collect data, it was discouraged during the pandemic. The use of mobile telephone interviews was recommended as a safer option. Garg and Khanna (2021:12) suggested modifications and individualised consent proformas according to patient and participant needs. The Food and Drug Administration recommended that participants put their signature and date on a blank paper with a written statement to indicate agreement to voluntarily participation (De Vries et al., 2020:2). These authors proposed telephone consent under a blended approach while focussing on informed consent during the COVID-19 pandemic. This blended approach embodied focus groups with the ordinary informed consent process for Phase 2 in both stages.

3.9.1 Obtaining informed consent for telephone interviews

Considerations to obtain informed consent for the telephone interviews during this stage were practical. The notion of the pragmatic approach was to apply what worked best (Fiorini et al., 2016:40). Guided by the above-mentioned arguments, in this study, a single page was designed and required particulars of the participant and researcher, the study title, identification of the institution and authority reference. Basic guidelines were given on how to give informed consent. Participants had to print and fill out the page (Annexures 10-A and 10-B), then use their cell phone to take a picture of the completed consent form and re-send via WhatsApp. Regrettably, not all had the means to print, or send the page via WhatsApp, neither did they considered other social media platforms.

An alternative was to re-write the consent form by hand on an ordinary piece of paper and follow the same as above. Some did not inform about their decision not to complete the consent form but still agreed to the interview which was recorded. While some did not provide written consent, some also did not give verbal consent, but merely allowing the interview was regarded as informed consent. This was followed amid the pandemic and might be applicable under exceptional circumstances as

well. Even though the interview was conducted, only a few forwarded a completed informed consent form. A strength was that those who did not reside within proximity could be interviewed (Thunberg & Arnell, 2022:2).

3.10 DATA COLLECTION WITH TELEPHONE INTERVIEWS (STAGES 1 AND 2)

Telephone interviews were conducted at a convenient time with fifteen PLWD in Stage 1 and four family members in Stage 2. In both Stages they reported on aspects of diabetes self-care management that related to the five constructs of the DSSQ Fv. Interviews were recorded with the Microsoft Speech Services and G8XThinQ Mobile Phone. The central question was: “How do you experience caring for yourself in managing and living with diabetes?”, and probing questions were: “With regards to diabetes, how do you experience the involvement of your family in managing and caring for you?” “How can your family better care and support you in your living with diabetes?”. “How can health care professionals better care and support you in living with diabetes?” The telephone interviews were individually conducted on days and at times as agreed with fifteen PLWD in Stage 1 and four individual family members in Stage 2.

3.11 ANALYSIS OF THE TELEPHONE INTERVIEWS FOR STAGES 1 AND 2

3.11.1 Transcribing of interview data

The transcribing followed a similar process as for the focus groups.

3.11.1.1 *Audio recordings of telephone interviews Stages 1 and 2*

Table 3-4 provides a summary of the interview recordings, shows the serial reference, data volume and duration of the recordings with an LG G8XThinQ cell phone.

Table 3-4. Recording data of telephone interviews Phase 2 Stages 1 and 2

Date	Pseudonym	Serial	Interview mode	Duration
19-Mar-23	INTP2/S1-P 1	172900	LG G8XThinQ Cell	25.23 MB / 33:42
22-May-22	INTP2/S1-P 2	Summary by moderator	LG G8XThinQ Cell	
24-May-22	INTP2/S1-P 3	133305	LG G8XThinQ Cell	17.38 MB / 23:34
16-Aug-22	INTP2/S1-P 4	111348	LG G8XThinQ Cell	34.60 MB / 46:26
17-Aug-22	INTP2/S1-P 5	Int 004.m4a	Samsung & Galaxy 9 Cell	136 MB / 1:13:28
16-Aug-22	INTP2/S1-P 6	191054	LG G8XThinQ Cell	70.55 MB / 01:35:15
23-May-23	INTP2/S1-P 7	Summary by moderator	LG G8XThinQ Cell	
19-Mar-23	INTP2/S1-P 8	162232	LG G8XThinQ Cell	17.58 MB / 23:51

Date	Pseudonym	Serial	Interview mode	Duration
30-May-22	INTP2/S1-P 9	174849	LG G8XThinQ Cell	607 MB / 13:50:58
24-May-22	INTP2/S1-P 10	Summary	WhatsApp voice notes with LG G8XThinQ Cell	
01-Jun-22	INTP2/S1-P 11	135908	LG G8XThinQ Cell	49.53 MB / 01:06:42
19-Mar-23	INTP2/S1-P 12	183127	LG G8XThinQ Cell	35.22 MB / 47:16
26-Feb-22	INTP2/S1-P 13	WhatsApp voice notes	LG G8XThinQ Cell	
31-May-22	INTP2/S1-P 14	Summary by moderator	LG G8XThinQ Cell	
29-May-22	INTP2/S1-P 15	Summary by moderator	LG G8XThinQ Cell	
31-May-22	INTP2/S2-P1	Summary by moderator	LG G8XThinQ Cell	20 minutes
16-Aug-22	INTP2/S2-P2	121050	LG G8XThinQ Cell	25.75MB / 34:09
	INTP2/S2-P2 cont.	124510	LG G8XThinQ Cell	38.46 MB / 51:40
29-Sep-22	INTP2/S2-P3	112100	LG G8XThinQ Cell	44.86MB / 01:00:21
19-Mar-23	INTP2/S2-P4	170410	LG G8XThinQ Cell	9.28MB / 12:19

Table Note: IntP2/S2-P2 identify interview participant Phase 2/Stage 2, participant number. Summary by moderator (where the interview took place in the preferred indigenous SA mother tongue and summarised in English by the moderator).

3.11.1.2 Participant characteristics of telephone interviews Stages 1 and 2

Table 3-5. Participant characteristics of Phase 2 Stage 1 (PLWD)

Race/Gender (Age)	Duration of diagnosed (Diabetes Type)	Have a glucometer	Using oral medication or insulin	Current complications & comorbidities	Type of health service used
C?F (73)	10 yrs (2)	Yes	Oral meds	Hypertension Cholesterol	Private
A/F (62)	7 yrs (2)	Yes	Oral meds	Arthritis	Private
C/F (63)	27 yrs (1)	Yes	Oral meds & insulin	Diabetes, Neuropathy Retinopathy	DHS
W/M (62)	14 yrs (2)	Yes	Oral meds & insulin	Cholesterol Hypertension Asthma	DHS
C/M (56)	8 yrs (2)	Yes	Oral meds & insulin	Hypertension Cholesterol	DHS

Race/Gender (Age)	Duration of diagnosed (Diabetes Type)	Have a glucometer	Using oral medication or insulin	Current complications & comorbidities	Type of health service used
C/M (46)	16 yrs (2)	Yes	Oral meds & insulin	Obesity, Gout	DHS
A/F (67)	12 yrs (2)	Yes	Oral meds & insulin	Diabetes Amputation	Private
C/F (68)	18 yrs (2)	Yes	Oral meds	Hypertension Cholesterol	Private
C/M (59)	11 yrs (2)	Yes	Oral meds & insulin	Cardiovascular Disease, Hypertension Cholesterol	DHS
W/F (50)	6 yrs (2)	Yes	Oral meds & insulin	None	DHS
C/M (63)	4+ yrs (2)	Yes	Oral meds & insulin	Arthritis, Cholesterol, Hypertension	DHS
C/M (71)	30 yrs (2)	Yes	Oral meds & insulin	Cardiovascular Disease, Hypertension, Cholesterol, Diabetes Neuropathy	Private
W/F (53)	2yrs (2)	Yes	Oral meds & insulin	Diabetes Neuropathy, Asthma	DHS
A/M (50+)	1 year (2)	Yes	Herbal self-treatment	None	Private
A/M (42)	13 months (2)	Yes	Oral meds & insulin	None	Private

Table Note: Race and gender (C/M, A/M, W/F is an abbreviation for Coloured, African, or White male or female. DHS is the abbreviation for a public service for a designated group. Yrs (years).

Table 3-6. Participant characteristics of Phase 2 Stage 2 telephone interviews with family members

Race and gender (Age)	Duration of support to PLWD	Relationship to PLWD
B/F (52)	Several years	Carer
W/F (61)	15 yrs	Wife
C/F (65)	4 yrs	Wife
C/F (68)	30 yrs	Wife

Table Note: Race and gender (C/M, A/M, W/F is an abbreviation for Coloured, African, or White male or female. DHS is the abbreviation for a public service for a designated group. Yrs (years).

3.12 CODING OF TRANSCRIPTS

Text data are thick and a tedious process to make sense of the data;. To enable coding, the data were divided into sizeable segments with a label assigned to the text (Elliot, 2018:2851). Coding is central to qualitative data analysis. Saldaña (2013:3) recorded, “A code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data”. Braun and Clarke (2012:61) have a similar view and record: “Codes identify and provide a label for a feature of the data that is potentially relevant to the research question.”

Charmaz and Thornberg (2021:307) and Linneberg and Korsgaard (2019:261) stated that most grounded theory studies are based on interviews. Charmaz and Thornberg (2021:305-307) describe grounded theory as a systematic method to conduct research which structures data collection and analysis. These authors posit that data analysis, which emerges during the research process, is more important than what was discovered through the interviews. They advised line-by-line coding to be done in consideration of the research question to explore the experiences of PLWD and their families during self-care. Saldaña (2013:1-2, 23, 64) described 32 coding profiles. Through the inherent iterative nature of the coding process in this grounded theory study to explore the self-care experiences of PLWD, coding was done in two cycles (Saldaña, 2013:1-2, 23, 64; Nyumba et al., 2018:23).

A manual coding process and thematic analysis were utilised in the qualitative study. Section 3.12 details the two-cycle coding process, while section 3.13 outlines Braun and Clarke's 6-phase thematic analysis process (2006, 2012). These methods were applied in Chapters 5 and 6. To reduce researcher bias, interviews and focus groups were used for data collection. Questions aligned with objectives. Bias was minimised by taking a peripheral role during focus group activities. The coding, and data interpretation enhanced credibility of the research.

3.12.1 First Cycle coding (informant centric)

The First Cycle of coding consisted of Open coding, Line-by-line coding with Descriptive codes and In Vivo coding.

Initial or Open coding. Data came from the interview transcripts. Prior to starting Initial or Open Coding, data were separated into smaller segments. Open Coding is a spontaneous process with no specific formulas or guidelines, and assigned codes were subjected to change (Saldaña, 2013:100). Through this coding process, eight broad concepts related to self-care, treatment, diet, risks, knowledge, health care professionals, activities, and support, were identified and regarded as common themes in the everyday life of diabetes self-care management.

Line-by-line coding using descriptive codes. To make sense of the data, every sentence of the transcripts was coded to understand the experience and perspective of diabetes self-care management (Charmaz & Thornberg, 2021:307). Through line-by-line coding, an initial descriptive code list was created and subjected to change through an iterative process. Saldaña (2013:88) recorded that descriptive coding is applied in transcript interviews to label the topic of what is talked about or written about without interpretation. This coding method involved repetitive text reading to identify challenges to establish data accuracy and to make meaning of the coding in order to create emerging categories (Saldaña, 2013:64). The 1st level of Line-by-line coding created 650 preliminary descriptive codes. The high number of codes is ascribed to the frequency of some codes. During the 2nd level, codes that appeared multiple times were aggregated, and those that had similar meanings were merged, the codes were thus reduced to 520 second-order descriptive codes and created 14 emerging categories. The eight initial emerging concepts, which came from the Open coding process, were linked or integrated with the emerging 14 categories, creating 18 categories. With the 3rd level of Line-by-line coding, the data categories with similar meanings were analysed for similarities and dissimilarities and refined through literature.

In Vivo coding. The next method, profile coding, was conducted by In Vivo coding to develop the meaning of the data (Saldaña, 2013:61). Guided by Saldaña (2013:91), the codes were taken directly from the transcripts to record the exact words as to how the participants used them to capture the emic perspective where verbatim transcribing was imperative (Saldaña, 2013:64; Rees-Punia et al., 2020:2).

3.12.2 Second Cycle coding (researcher centric)

3.12.2.1 *Pattern coding*

Theme analysis was employed to identify and report patterns/ themes that related to the data coming from the codes of the focus groups and telephone interviews (Braun & Clarke, 2006:79, 82). Three themes are reported in Chapter 5 with PLWD, and one main theme with four sub-themes in Chapter 6 with the family.

Table 3-7: Themes, sub-themes and sub subthemes

Main theme	Sub-themes	Sub-sub-themes
Essence of family support	HCP influence on family in supporting a PLWD.	Relationship of family during support
	Psychological influences on family,	Behaviour and emotions Adjustments Compliance and non-compliance Risk and complications
	Health system improvement and support	Knowledge and information Activities

Main theme	Sub-themes	Sub-sub-themes
		Self-reliant Community outreach
	Glycaemic control	Diet and weight

3.13 THE 6-PHASE THEMATIC ANALYSIS PROCESS

Saldaña's (2013) guidance on coding is particularly distinguished for this qualitative inquiry. Saldaña's guidelines are detailed and provide a clear understanding of coding. This information supports the novice researcher or student during the coding process. Braun and Clarke (2012:57) developed a 6-step process for thematic analysis, affirming that it is an analysis method and not a methodology and highlighting that accessibility and flexibility make this method popular to analyse qualitative data. Due to the systematic identification, organisation, and insights it provided into the themes, reflexive thematic analysis was thus applied to analyse the data from the focus group pilot study and telephone interviews combined and reported on in an integrated style. The inductive (bottom-up) approach was employed, which indicates that the codes and themes came from the data (Braun & Clarke 2012:58). This study drew on the concept of diabetes self-care management within the conceptual frameworks of the CCM and Orem's model of care (Theory Based Nursing Practice 2014:3-7). The aim was to have insights into how PLWD experience daily self-care, and the care provided with support from others.

Phase 1: Familiarisation with the data. Overall, insight into the data was done during this phase through audio recordings and transcribing (Braun & Clarke, 2006:88; Braun & Clarke, 2012:60). The data revealed how the family perceived care and support given to a person diagnosed with diabetes, adjustments they had to make, and how they viewed the HCPs supported them in caring for a PLWD. The data revealed eight initial areas of common interest to the participants identified as (1) support, (2) adjustments, (3) behaviour, (4) diet, (5) dissatisfaction with HCPs, (6) information, (7) complications and risks and (8) glycaemic control (Braun & Clarke, 2006:88).

Phase 2: Generating initial codes. Coding is the foundation of qualitative data analysis (Braun & Clarke, 2012:61). Transcript data were separated into smaller segments to enable better systematic coding through a spontaneous process. Initial Coding, also known as the Open Coding process, has no specific formulas or guidelines, but it allows recording and code modification (Saldaña, 2013:100; Maguire & Delahunt, 2017:3355; Braun & Clarke, 2012:63). An iterative process of reading enabled coding. The researcher concurred that the coding process was faster and easier (Braun & Clarke, 2012:60). While Charmaz and Thornberg (2021:307-308) supported line-by-line coding as the initial coding process, Braun and Clarke (2012:62) regard coding of every line unnecessary. They maintain that a data segment can have multiple codes but is subject to change. An MS Excel sheet was created to indicate some of the excerpts, labelled with an appropriate code that related to the topic

or question. Initially, two hundred and seventeen codes were created and similar or overlapping codes were brought together and reduced to twenty-nine codes. This was reorganised into seventeen overarching codes to develop four preliminary themes.

Phase 3: Generating themes. The first theme (1) Care and support by a family member to a person diagnosed with diabetes, was developed with the codes of family support, Support from HCPs, Health facility service support and Relationship with HCPs. The second theme (2) Psychological influence was developed with the codes of behaviour and emotions, adjustment, compliance, and non-compliance. The third theme (3) Knowledge and information was developed with the codes activities, risks and complications and glucose control. The theme (4) Miscellaneous was developed with the codes community outreach, education, and weight (Braun & Clarke, 2006:63).

Phase 4: Reviewing Potential Themes. A quality check was done on the four candidate themes to confirm the relatedness and re-clustering. where they fit better under another theme and unrelated themes were discarded (Braun & Clarke, 2012:66). Braun and Clarke (2012:62, 65) posit that during the early stage of analysis, the themes are potential because their relevance is unknown. A recursive process was followed, and the themes were checked against the excerpts to develop the themes. The codes were rearranged. The potential themes were reviewed in two levels, as outlined in this section, to confirm that each theme related to the data (Byrne, 2020:1404). Levels one and two reviews demonstrated that the excerpts with associated codes were logic and captured important or the most relevant elements of the data and confirmed that themes can appropriately be linked as one central theme can underpin all themes (Braun & Clarke, 2012:65-66). Four candidate themes were identified (1) Influences on the family, (2) Psychological influences, (3) Health support system and (4) Significance of knowledge and all showed a relationship. The codes that were similar or overlapped were clustered to reflect a pattern that related to the question and codes linked to diet, blood glucose control, public perception of diabetes diet, and support (Braun & Clarke, 2012:63). Participants raised their concerns that the public had a distorted opinion about a diabetes diet, which pointed to uninformed people in the community. It was noted that the group frequently reverted to the diet when they discussed family support. The theme “miscellaneous” was created to accommodate some codes that did not properly fit anywhere (Braun & Clarke, 2012:65).

Phase 5: Defining and Naming Themes. The uniqueness of this focus group was the intense focus on the diet. The themes linked to the data excerpts and highlighted aspects of the diet, indicating that each theme was built on the other but in no sequence. Thematic analysis of data coming from PLWD and developed five themes: (1) The essence of a patient support system, (2) Role of therapeutic strategies to improve self-care, (3) Aspects to improve self-care, (4) Impact and effect of psychological aspects and (5) The value of knowledge and information in self-care. These themes were condensed to finally provide three themes (1) Strategies to improve a patient support system

with the sub-theme Patient support system and include few categories (Support, HCPs, Hospital care, Treatment, Disease profile and Diet). The second theme (2) Impact and effect of self-care aspects on the psyche with sub-theme Aspects of self-care related to the categories of Self-care, Self-care activities, Lifestyle, behavioural conduct and challenges, Blood glucose monitoring and Reminders. The third theme (3) The value of knowledge and information in self-care with sub-theme Enhance general knowledge has one category, Knowledge and information. Thematic analysis of data coming from the family developed one main theme: Essence of family support, with four sub-themes (1) HCP influence on family in supporting a PLWD with the category Relationship of family during support (2) Psychological influences on family with categories behaviour and emotions, Adjustments, Compliance and non-compliance and Risks and complications, (3) Health system improvement and support with categories Knowledge and information, Self-reliant and Community outreach and (4) Glycaemic control with the category Diet and Weight. Each of the four sub-themes consist of between 1 to 4 categories and are presented with the corresponding four sub-themes.

Phase 6: Producing the Reports. Stages 1 and 2 data analysis was based on the data extracts from the focus group dialogue to explain how the participants viewed diabetes self-care management. The uniqueness of the group was the emphasis on dietary concerns and subsequent blood glucose control. This finding explored issues about healthy eating plans, (un)affordable dietary items, and community misconceptions of the diabetes diet. Despite lengthy discussions, it was difficult to determine if the correct diabetes diet was followed. In Stage 1, the three themes were interconnected, the findings are reported in Chapter 5 and for Stage 2, the main theme” Essence of family support” is presented in Chapter 6.

3.14 PHASE 3 (QUAL)

Figure 3-9 presents the 3rd sequential qualitative component, which entails material development to build a collective agreement process through the Delphi technique. Works from Kern, Priddy, Ellis and McDowell (2017:293) distinguished between inductive and deductive decision paths which are normally employed to develop materials. Health care professionals reached consensus through a highly structured process where individual interactions were required according to the Delphi technique (Adebisi et al., 2018; Msibi, Mogale, De Waal & Ngcobo, 2018; Mukerji, Halperin, Hunter, Segal, Wolf, Bevan, Jeff & Goguen, 2018; McMillan, King & Tully 2016:658-259). The Delphi method is carried out in Stages, with each stage building on the outcomes of the previous stages (McKenna, 1994:1221). In Stage 1, the preparation is presented in three steps; in Stage 2, a schematic presentation is made to build consensus in three Rounds; and in Stage 3, the three steps taken to develop the educational material are demonstrated. The Delphi technique is presented in Chapter 7.

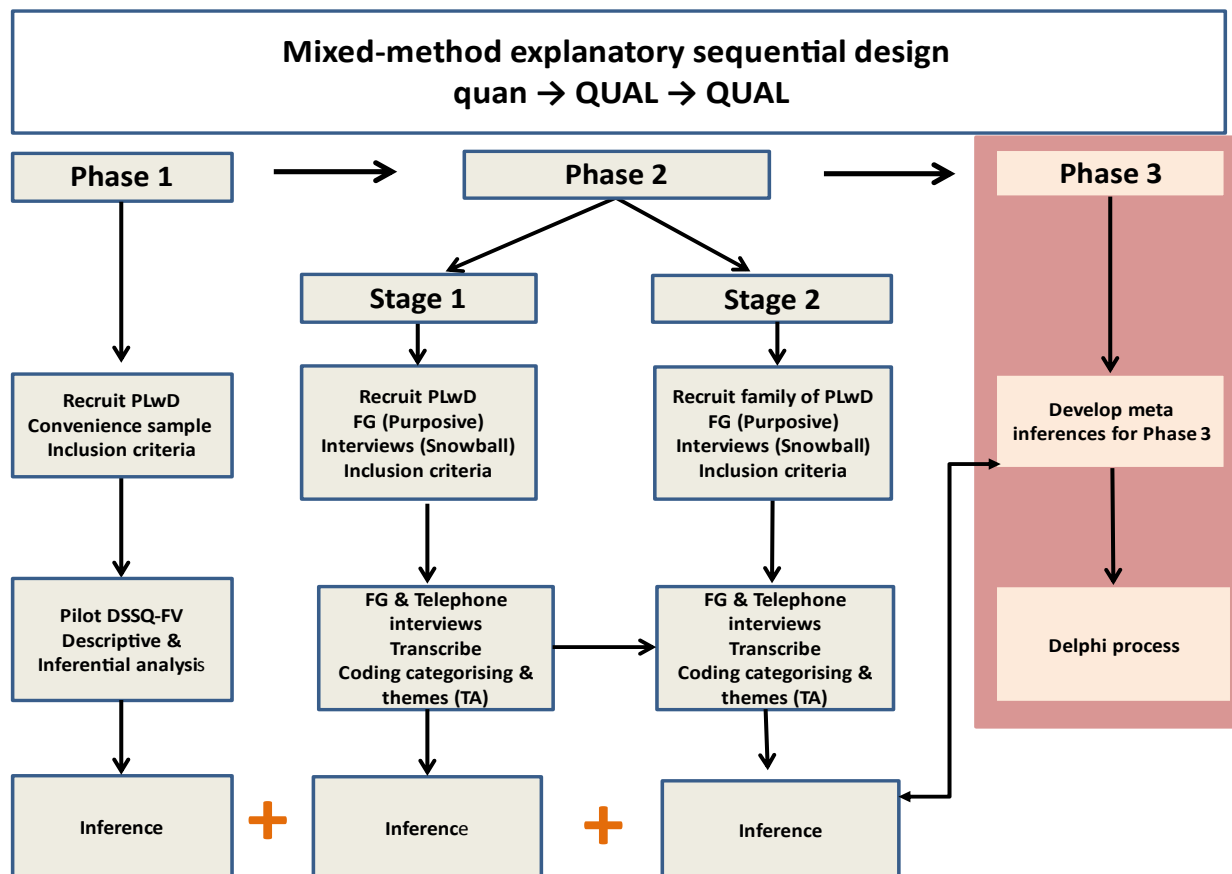


Figure 3-9. Mixed Methods research process (Phase 3)

3.15 DATA MANAGEMENT

The primary research data included the results of three different questionnaires in Phase 1, the documents were stored in a data file. It also included the audio recordings of the focus groups and telephone interviews, electronic transcripts and handwritten notes taken by the note-taker. The data analysis sets further included rough and raw MS Excel sheets. Both data sets were stored on an LG G8XThinQ cell phone and USB flash drive. As a backup, the information was imported on a personal laptop. For both sets, the data were marked according to the appropriate pseudonym for easy reference and audit purposes or further studies. The audio recordings are dated and have an automated serial number with a date stamp for easy reference

All data was electronically captured in MS Excel spreadsheets. Two questionnaires (Part 1 Socio-demographic questionnaire and the DSSQ-FV) formed part of Phase 1. The file with DSSQ-Fv questionnaires was transferred to the statistician for analysis. Data management is an integral part of the research process and any research conducted under the University of Pretoria must comply with its policy. The research data management policy (UP, 2017:3) requires that general research data must be stored for a minimum of ten (10) years after completing the study.

The DSSQ-Fv questionnaires were sequentially numbered. The DSSQ-Fv questionnaires from the pilot study and quantitative study were clearly marked with a permanent ink stamp which indicated the UP-authority number, identification of the appropriate Phase and the clinic where the data was collected. They indicated the date when the data was collected and therefore reflected a unique number, for example, “Pilot C1-3”, whereby Pilot indicated the DSSQ-Fv questionnaire came from the pilot group, C1 presented clinic 1, followed with a sequential number ranging from 1 to 5 per clinic (in the case of pilot study). Phase 1 was similarly marked as the pilot study but reflected as Phase 1–C1 or C2 with sequential numbering per clinic, totalling 114 for both clinics. The completed DSSQ-Fv questionnaires were filed in numerical order according to the date and kept safe in an Arch Lever file, which was divided into different sections (Pilot, Clinic 1 and Clinic 2). The files were kept in secure external storage (OneDrive-Personal, Cloud) for future access if it is required for audit purposes (Krefting, 1991:221). A variety of Computer-Aided Qualitative Data Analysis Software (CAQDAS) is available to code data. Manual coding was used during this study but instead of using printed transcripts, pencil and paper, information was captured electronically. Manual coding in this study refers to an electronic device, but capturing was done by hand and not automated by a software program. The data is stored electronically.

In Phase 2, data was collected from three participants for the focus group in Stage 1 with PLWD and four participants for the focus group in Stage 2 with the family members. Additionally, data collection was made possible in both stages through telephone interviews and the same process was employed in both stages of Phase 2. The focus group was conducted at clinic 2 and the telephone interviews at the preferred location to their convenience, resulting in a separate data management process (Berman, 2017:1).

The transcribed data was managed according to pseudo-identification for transcribing, translating, and reporting to establish the accuracy of the content and for confidentiality purposes (Krueger & Casey, 2018:511-512). The data transcripts are equally marked. For example, the pseudonym FGP2/S2-P4 reflects the focus group data from participant 4 for Stage 2, and the pseudonym INTP2/S2-P4 reflects the telephone interview with participant number 4 for Stage 2. The data collection and analysis of Phase 1 were conducted separately (Berman, 2017:1), resulting in a separate data management process. Two research sites were used during Phase 1. To maintain confidentiality, only appropriate people will have access to the information. The data is kept safe in the possession of the researcher and will be transferred and kept at the repository of UP.

The data collection and analysis of Phase 1 were conducted separately (Berman, 2017:1), resulting in a separate data management process. Two research sites were used during Phase 1; therefore, data management was integrally part of the research process. The research data management policy (UP, 2017:3) requires that general research data should be stored for a minimum of ten (10)

years after the completion of the study. The primary research data included the results of three different questionnaires completed by 105 respondents; the documents were stored in a data file.

The related statistical results were marked accordingly and stored on a USB flash drive. To maintain confidentiality and as a measurement to ensure that only the appropriate people have access to the information. The completed DSSQ-Fv questionnaires were completed anonymously and individually collected, although provision was made to deposit the DSSQ-Fv questionnaires in a container before leaving the venue. While the data collection was in process, the completed DSSQ-Fv questionnaires were kept safe in the possession of the principal researcher until the sample size was reached. The DSSQ-Fv questionnaires from the pilot study and quantitative study were clearly marked with a permanent ink stamp which indicated the University of Pretoria authority number, identification of the appropriate Phase and the clinic where the data was collected.

3.16 QUALITY ASSURANCE

Quality assurance was measured through validity and reliability, which the PLWD assessed after they had completed the DSSQ-Fv (Rick, Rowe, Hann, Sibbald, Reeves, Roland & Bower, 2012:1). Qualitative content analysis is subjective. Although Cyr (2015:18) asserts that focus groups assess measurement validity, this study did not employ focus groups to interpretation as a measure. Intercoder reliability gauge validity. The focus group questions were in line with Orem's ideas of the Theory of Self-Care (activities taken that can improve life quality, see Figure 3.2) and the constructs of the DSSQ-FV. The constructs and concepts by implication were performance indicators. The purpose of this was deemed unnecessary due to the small data set, it was manageable by a single coder through manual coding to learn how PLWD and their families perceived support and management of self-care.

Validity. Validity refers to the integrity of the study (Elo et al., 2014:4). Content and construct validity were visible in the existing questionnaire (Noble & Smith, 2015:5). Validity is portrayed through the extent where the existing questionnaire was measured accurately (Heale & Twycross, 2015:1). Cyr (2015:18) stated that focus groups evaluate measurement validity. This was attained through the performance indicators identified as Orem's concepts of the Theory of Self-Care, which measured self-care management and support by PLWD and their families; this was aligned to the existing questionnaire and focus group questions.

Reliability. Reliability refers to the accuracy of the data collection instrument; it describes the consistency (Heale & Twycross, 2015:1; Noble & Smith, 2015:5). The DSSQ-Fv measured the perceptions of PLWD about support by the family (La Greca & Bearman). Cronbach alpha indices, corrected item-total correlations, and item correlations are used to examine the internal consistency

and item reliability of the DSSQ FV. The high Cronbach alpha scores of internal consistency findings available in Chapter 4.

3.17 ESTABLISHING RIGOUR

Trustworthiness is associated with qualitative research, and is linked to credibility, dependability, confirmability, and transferability in qualitative studies (Elo et al., 2014:2-3; Gabarre et al., 2016:1073; Sutton & Austin, 2015:229; Wium & Louw, 2018:8). Forero et al. (2018:1) refer to these concepts as “the Four-Dimensions Criteria”. This section presents the rigour of diabetes self-care management and in family support for PLWD.

3.17.1 Credibility

In qualitative studies credibility corresponds with internal validity in quantitative studies. The research team consisted of the researcher, moderator, and note-taker and interacted with the participants during the focus group. The participants received a package that consisted of the information about the study and a form to give written informed consent. They had to sign a register to confirm their presence and to be reimbursed travel fare at the end of the session. In part of a conducive environment, a “meet and greet” was introduced for all to get acquainted with the research team and fellow participants to ease tension during the discussion. Their inputs were invited to complete the ground rules when the focus group was in process which portrayed credibility to the participants.

The research team gathered one day prior to acquaint themselves with expectations, individual responsibilities, and timings during the focus group. The researcher did not interfere with the data collection/generation process but rather took a peripheral role during the focus groups and merely provided advice to the moderator/study assistant and note-taker where it was required. This strategy enhanced the trustworthiness of the study (Nyumba et al., 2018:21). The researcher took responsibility for the audio recording.

Questions were sent via e-mail and discussed with the moderator to become familiar with the facilitation of the focus group. Even though the attendance was very low and did not compromise the study amidst the challenges of getting a group together, the researcher decided to continue. To cancel at the last minute would have risked the credibility of the study. The researcher conducted the English and Afrikaans telephone interviews, and the moderator undertook the interviews in a language other than English but provided an English summary. The recording device did not support those languages. The interviews had several probing questions to allow the participant to expand on the response where it was required. The researcher did not influence the findings. The respondents shaped it.

There was no interference with the data collection/generation process, the researcher took a peripheral role during the focus groups and merely provided advice to the moderator/study assistant and note-taker where it was required. This strategy enhanced the trustworthiness of the study (Nyumba et al., 2018:21). The researcher took responsibility for the audio recording (Moore & Llompert, 2017:410). She was also responsible for debriefing the team at the end of the focus group to confirm the accuracy of the recordings and to determine if any adjustments were required.

A significant element of the Delphi technique is anonymity. Rigour was established through anonymity, which secured confidentiality and safeguarded the identity of the participants against their respective professional councils and employers. Anonymity allowed them the freedom to voice negative opinions, which imparted rigour in the study. Another significant element of the Delphi is controlled feedback.

3.17.2 Confirmability

Confirmability corresponds to objectivity. Morrow (2005:252) stated that research is not objective. The findings must be presented according to the research (data collection) instead of researcher bias. In support of this viewpoint, the findings came from the focus group and telephone interviews as what and how the participants had disclosed. Through the data analysis processes for both methods, the researcher was responsible for transcribing to confirm that the audio recording correlated with the text. The coding process led to the development of themes according to reflexive thematic analysis. Morrow further questioned if those involved in the research were “true” knowers, citing Sparkes (1998) who stated that member checking is not validation but must be viewed for the detail on emerging findings and treated as data (Moore & Llompert, 2017:410). The researcher was also responsible for debriefing the team at the end of the focus group to confirm the accuracy of the recordings and to determine if any adjustments were required.

The researcher cross-confirmed the transcribed dialogue for quality and accuracy. Member checking was done through a pragmatic approach. The use of different languages did not restrict confirmation of what was discussed in a language that not all understood. By speaking in a preferred language helped the participants to express themselves better, confirming all could follow the discussion. One participant was reasonably able to communicate in a few languages and volunteered to translate or summarise the information in the presence of the speaking participant. Where the “translating” participant accidentally omitted information, the moderator added on, hence confirming the information. From this view, member checking was done, and if the information was wrong, the speaking participant could and would have made corrections. Member-checking was therefore done during data gathering, and data accuracy was confirmed during transcribing. Multiple realities were confirmed by participants giving similar information. When obstacles occurred during participant

recruitment for the focus group, the researcher relied on the pragmatic approach and diverted to interviews to explore subjective meanings with multiple realities as data collection for the qualitative stage of the study.

In Phase 3, twelve experts completed an online questionnaire. They received an online Qualtrics link with information about the study and had to give written informed consent. One participant completed the questionnaire but did not consent, and another completed only 47% of the questionnaire. These two participants were not considered for participation and those inputs were discarded. Due to the data collection method, interference with the data collection process was impossible and enhanced the trustworthiness of the study (Nyumba et al., 2018:21). The statistician conducted the statistical analysis, and the researcher was responsible for interpretation and controlled feedback to the participants (Moore & Llompert, 2017:410). A significant element of the Delphi technique is anonymity. Rigour was established through anonymity, which secured confidentiality and safeguarded the identity of the participants against their respective professional councils and employers. Anonymity allowed them the freedom to voice negative opinions, which imparted rigour in the study. Another significant element of the Delphi is controlled feedback. These actions made the study credible.

Researchers have collected real data in the field and interpreted the authentic data accurately to provide assurance that reliable research has credible attributes (internal validity) (Miles et al., 2014). In order to achieve credible research at the stage of the data collection and data analysis process, a focus group discussion was conducted, of which the members consisted of researchers and experts in the field of psychology. Focus group discussions aim to get input and suggestions in data analysis. In addition, to increase credibility, the results of the analysis were compared with the findings of previous experts

This element relates to objectivity and reflects on the integrity of the results and the meaning of experiences (Elo et al., 2014:2-3; Sutton & Austin, 2015:229). The integrity of subjective information was based on the results and inferences from Phases 1 and 2, following coding, categorising and theming. The database of Phase 3 helped with the development of questionnaires for the Delphi consensus building and the development of a self-care management tool. Transcribed dialogue of the focus groups and interviews was cross confirmed for quality and accuracy through text vs audio-recordings comparison. The researcher was responsible for developing the questionnaire and presented to the statistician and two professional HCPs to rule out ambiguity.

3.17.3 Dependability

In qualitative studies, dependability is associated with reliability in quantitative studies. According to Brierley (2017:6), qualitative data adds meaning to quantitative data. The focus group questions and

interviews were related to previous and follow-up sessions, and its dependability showed in the collected data and analysis which implied that the findings from the pilot focus group and interviews were consistent. Questions for the interviews were repeated to other interviewees, and the information was consistent. The salient results from this one focus group pilot study built on the interviews to further explore data until saturation. The participants had to respond to similar questions, and the information was comparable (Elo et al., 2014:2; Sutton & Austin, 2015:229).

A code list was created in MS Excel for modification during the coding process. The mind map for thematic analysis described the process of how themes were developed. The term "auditable" is used by Krefting (1991:221) to characterise a situation where a different researcher may easily trace the decision trail that the study's investigator utilised. Performing a code-recode technique on the data during the analysis phase of the study is another way the researcher can improve the study's dependability. Based on this argument, the study dependability can be confirmed during the iterative coding process leading to theme creation. Data management is a tool to depend on for future research, hence files were kept in secure external storage (OneDrive-Personal, Cloud) for future access if it is required for audit purposes (Krefting, 1991:221).

According to Elo et al. (2014:2) and Sutton and Austin (2015:229), salient results from one focus group discussion built on the following to augment exploring rich data until saturation is reached which enhanced dependability. This was evident as most of the responses did not add significant differences to their experiences of self-care. The quantitative study also increased the validity and reliability of the results in the qualitative study. It was helpful during meta-inferences to elaborate, clarify results, to make comparisons and contrasts in Phase 3 (Hesse-Biber, 2010:66). In Phase 3, items were developed from the findings of Phase 2 of the study. Dependability showed in the collected data and analysis which implied that the findings from Phase 2 were consistent with Phase 3, Stage 2. The participants had to respond to related questions, and the information was comparable (Elo et al., 2014:2; Sutton & Austin, 2015:229).

The items were developed from the findings of Phase 2 of the study. Dependability showed in the collected data and analysis which implied that the findings from Phase 2 were consistent with Phase 3, Stage 2. The participants had to respond to related questions, and the information was comparable (Elo et al., 2014:2; Sutton & Austin, 2015:229).

3.17.4 Transferability

This criterion corresponds with external validity or generalisability. It is linked to the extent to which the researcher generalises the study findings, linking the research question to her own context and generalising the findings (Morrow, 2005:252). This author posits that a small sample finding cannot be generalised. The literature is inconsistent regarding sample size, data collection was conducted

with small groups in Phases 2 and 3. Ten experts participated. The provided sufficient information about self-care, and despite different health disciplines, there were no significantly different opinions about self-care amongst the experts, the findings were not generalised. Transferability is associated with the applicability of the results in qualitative contexts. The significance was the transfer of the findings of Phase 2 (Stages 1 and 2) to Phase 3, and in Phase 3, Stage 1 to Stage 2, to develop the tool in Stage 3.

Coding and theme development is described in sect 3.12.1. The 6-phase thematic analysis process by Braun and Clarke (2006, 2012) is detailed in sect 3.13.6 and applied in Chapters 5 and 6. The data from the focus group pilot study and telephone interviews underwent an iterative inductive coding process based on Saldanha (2013). Themes were created following the 6-phase process outlined by Braun and Clarke (2012). To ensure the robustness of the study, transferability is linked to the applicability of the results in qualitative contexts. The literature provided sufficient information about self-care, and despite different health disciplines, there were no significantly different opinions about self-care among the experts. However, the sample size was small, and Morrow (2005:252) suggests that findings from a small sample cannot be generalised. The significance was the transfer of the findings of Phase 2 (Stages 1 and 2) to Phase 3, and in Phase 3, Stage 1 to Stage 2, to develop the tool in Stage 3. Additionally, the findings from the focus group pilot study indicated the way forward for Stage 2, and it revealed that a focus group was not ideal given the time frame and attendance.

3.18 CONCLUSION

This chapter described the research methodologies for Phase 1 and the planned Phase 2, including the amendments to Phase 2 of how the study proceeded when it became clear that the focus groups did not yield sufficient data. The data analysis and findings of Phases 1 and 2 are presented in the respective proceeding chapters. The philosophical assumptions provided an overview and foundation for this investigation and supported the changes in the research methodology. Diabetes self-care management forms the framework for the study. Even though 2017 SEMDSA guidelines proposed the CCM, only one of the six elements was extracted with an explanation of how it fits into Orem's Model of Self-care Theory. The rationale for the DSSQ-Fv questionnaire pilot study and focus group during the investigation of the phases is outlined.

CHAPTER 4

FINDINGS OF THE PERCEPTIONS AND EMOTIONS OF DIABETES SELF-CARE MANAGEMENT

4.1 INTRODUCTION

Chapter 3 provided a comprehensive explanation and description of the research methodology about the perceptions, experience and emotions of diabetes self-care management for Phase 1 in the conduct of this Mixed methods study. This chapter discusses the findings emanating from Phase 1, which involves the use of a number of scales to gather information and quantify PLWD's perceptions and emotions of diabetes self-care management

As recorded previously, some authors believe that quantitative data can help qualitative researchers by giving them a more comprehensive framework to situate their qualitative data and by using quantitative sampling to find representative cases for their in-depth analysis. The key findings then served as the foundation for Phase 2 qualitative data collection. Chapter 4 will discuss the findings of the perceptions and emotions how PLWD experienced self-care.

4.2 DESCRIPTION OF PARTICIPANTS CHARACTERISTICS

According to the DSSQ-Fv findings of a previous study by La Greca and Bearman (2002:666), they documented that there is not much knowledge about the specifics of how families can support PLWD. Still, they argued that those findings were useful to make relevant recommendations. To establish the applicability of the DSSQ-Fv questionnaire for this study, a pilot study was conducted (Annexure 4-A). Part 1 Socio-demographics results were provided through nominal scales by measuring nominal/categorical data (Hole, 2000:1). Frequency and percentages of the participants' characteristics of Phase 1 are shown in Table 4-1.

Table 4-1. Participant characteristics of Phase 1

Demographics (N)	Variables	Frequency (%)
Age distribution (104)	Mean	54.02
	Median	55
	Std Dev	12.033
	Range	53
	Minimum	26

Demographics (N)	Variables	Frequency (%)
	Maximum	79
Diabetes type (104)	Type 1	33 (32)
	Type 2	71 (68)
Gender (105)	Male	40 (38)
	Female	46 (62)
Marital status (104)	Married or living with a partner,	46 (44)
	Single,	34(32)
	Widow or widower	17(16)
	Divorced	8 (8)
Education (104)	University graduates	9 (8.6)
	Vocational skills	5 (4.5)
	Primary school	20 (19)
	High school	58 (55.2)
	No formal education	13 (12.4)
Employment status (99)	Employed	51(48.6)
	Self-employed	29 (1.9)
	Unemployed	31 (29.5)
Duration of diagnosis with diabetes (99)	6mnths to 5 years	41 (39)
	6 to 10 years	24 (22.9)
	10 years and more	34 (32.4)
Support for diabetes (104)	Family support to find a family/support	73 (69.5)
	Not support	32 (30.5)
	Prefer to be referred	18 (17.1)
	Prefer to find own support	6 (5.7)

4.3 FREQUENCY AND PERCENTAGE DISTRIBUTION

This section provides a summary of the data to determine any trends and patterns (Hole, 2000:1). Patterns were identified as assistance, support and motivation. According to Hole (2000:2), frequency distribution provides insight into the trends (low and high scores and per item). Annexure 5 provide the individual responses of sets 1 and 2 as per construct.

4.3.1 Frequencies distribution of perceptions and experience

The following table showed the percentages of the item frequencies for the five constructs of the 1st set, where data was collected about perceptions and experience of PLWD. Table 4.2 report on the frequency percentages of perceptions and experiences by PLWD which was measured in five response scales. Each of the 58 questions started with “How often does a family member.... for which a 6-point rating scale was allocated as “Never (0), Less Twice a month (1), Twice a month (2), Once a week (3) Several times a week (4) or At least once a day (5)”. The scales were rearranged as “Frequent” (Several times a week, At least once a day), “ Less frequent” (Less than 2 x a month, Twice a month and Once a week) and “Never”. The results aided in understanding how often family members supported, assisted and motivated PLWD with self-care.

Table 4-2. Frequency of perceptions and emotions (set 1)

Patterns	Questions numbers	Frequent	Less frequent	Never
Support	2, 5, 6, 8, 9,12, 13, 14, 16, 17, 23, 26, 27, 30, 31, 33, 34, 35, 40, 43, 48, 50, 54, 55, 58	1 – 49.5	1 – 18.1	28.6 – 89.5
Motivate	3, 4, 6, 10, 18, 20, 25, 38, 39, 41, 45, 47, 49, 51, 52, 53, 57	1 - 50.5	1.1 - 14.3	2.1 – 95.2
Assist	1, 5, 7, 11, 15, 19, 22, 24, 28, 29, 32, 36, 37, 42, 44, 46, 56	28.6 – 88.6	1 – 16.2	1 – 49.5

Table Note: Frequent (Several times a week, At least once a day) / Less frequent (Less than 2x month, Twice a month, Once a week /Constructs (Insulin injections, Blood test, Meal plan, Exercise, General)

The missing data did not bear significance. The findings show patterns of (1) Support (2) Motivation and (3) Assistance, including trends:

Support. According to Qs 2, 5, 6, 8, 9,12, 13, 14, 16, 17, 21, 23, 26, 27, 30, 31, 33, 34, 35, 40, 43, 48, 50, 54, 55, 58 the percentages for support scored between 1 – 49.5% for Frequent, Less frequent scored between 1 – 18.1% and Never scored between 28.6 – 89.5%. From these scores it can be deducted that PLWD perceived and experienced family support below expectations. The significance was the assigned family support responsibilities (by themselves or PLWD), which were measured on the responses and were interpreted as if some family members did not or provided very little support with self-care throughout the five constructs. High scores were allocated to the option “Never” as pointed out in the above questions. Nonetheless, it can be inferred that high or low scores did not necessarily imply non-involvement from the family. From a different perspective, instead, it could mean that

PLWD were more than capable of taking personal responsibility and showed strong intentions to increase self-care practices and behaviour. Based on this inference, PLWD became, therefore, less dependent on the family with a subsequent lesser need for family support or involvement. Poor support thus creates the void in self-care and might be filled through motivation.

Motivation. Stressing goal-setting, family problem-solving, and self-management support can all help to motivate people. Besides the option “Frequent” it also implies increased support in that Q4a and Q10a boost morale and encouraged self-care whilst Q3a and Q8a showed increased support with reduced stress, it was thus concluded that blood sugar levels were monitored and better controlled. As for the ratings of Qs 3, 4, 6, 10, 18, 20, 25, 38, 39, 41, 45, 47, 49, 51, 52, 53, 57 with a rating scale of Frequent (1 - 50.5), Less frequent (1.1 - 14.3) and Never (2.1 – 95.5), it is deducted that PLWD may be encouraged to take care of themselves by exercising regularly, eating a healthy diet to control their blood sugar levels, and decreasing weight in order to prevent and lessen related consequences. They can be promoted if the pharmacological treatment is adhered to. The rating scale showed that Q51a, which asked about encouragement to join an organised sports activity, was rated “Less frequent” (3.8%) and “Frequent” rated (1.9%). Q52a also rated low (1.9%) when asked if the family buy sports equipment. The option “Never” received the highest scores for all items, and it is inferred that buying a membership at a gym is a luxury as most are expensive. A gym was not within a reasonable distance and, therefore, inaccessible for most. Physical activities do not imply that they have to visit a formal gym, even if it is affordable. Free, easy, and accessible type of activities include gardening, such as lawn mowing, raking, and trimming small plants on the lawns, taking walks in the neighbourhood, and walking to shops if it is within appropriate distance. Swimming and ball games in the park or yard are part of physical activities. However, care should be taken not to go overboard with the activities which might result in hypoglycaemia.

There is a very slight difference between those who never had someone to speak with about their fears of diabetes in relation to those who communicated daily, those who were encouraged to take care of diabetes and to inform them how they are doing with self-care (Q56a, Q54a, Q57a). Higher scores were achieved for never understanding when they fault or not receiving reading material about the disease. Although the scores for most questions were low, PLWD and the family communicated with each other on general things related to diabetes. Hence, a motivated individual requires continuous support and motivation through assisting them with tasks, knowledge and advice.

Assist. Although self-care is an individual responsibility that PLWD can take autonomously, they might fare better with assistance from the family and other. Qs 1, 5, 7, 11, 15, 19, 22, 24, 28, 29, 32, 36, 37, 42, 44, 46, 56 achieved scorings of 28.6 – 88.6 for Frequent, 1 – 16.2 Less frequent and 1 – 49.5 for Never. The significance of family support with allocated or chosen responsibilities to provide self-care support with blood testing and related activities indicated that some family members did not provide assistance and support according to the scores. It further showed that the scoring for the option “Never” for assisting with blood testing was individually remarkably high, (89.5%), with the lowest score of 49.5%. Although the frequency on average was 104, it was not confirmed if each participant had a blood glucometer to do the blood tests at home, viewed in the light that the focus was on self-care at home without clinical supervision, or if their responses were based on clinic appointments.

Diabetes has a cumulative impact on public health systems, PLWD and their families. This disease is affecting all ages, societies, and economies. Uncontrolled diabetes and high blood glucose levels cause serious health complications and premature deaths. Diabetes further imposes a substantial economic burden on health facilities and national budgets. This research focused on those PLWD in SA who were dependent on public health care. Estimates of the national budget for PLWD type 2 in 2018 were about ZAR 2.7 billion (bn) and ZAR 21.8 bn for diagnosed and undiagnosed people. However, estimates for 2030 for type 2 diabetes is about ZAR 35.1 bn (Erzse et al., 2019:1). Inferences were drawn that the family was not involved, and blood glucose was either not or poorly monitored. The majority of PLWD did not have a glucometer, and therefore, most did not test their blood or could not be assisted at home but had to make follow-up visits at the PHC clinic. Few who selected the responses fitting under “Frequent” and “Less frequent” obtained a glucometer at their own cost (because the clinics did not provide glucometers). The majority were on a fixed dose of insulin at any time. However, given a low-income community and related financial situation and (un)employment status, participants raised their concerns about the exorbitant prices for test strips at private pharmacies and barely being able to afford a glucometer. Those who had a glucometer were only tested when they did not feel well or had to make unscheduled walk-in visits. The fact that some (those diagnosed with type 1 diabetes) did not have a glucometer was of great concern, as they needed to know the glucose levels. Despite possible budgetary constraints at a national or regional level, blood glucose monitoring is important. Being it is too high or too low, it is recommended that the diverse levels of the health department reconsider issuing glucometers and test strips to all PLWD, to those who are insulin-dependent and need to test their blood glucose levels at regular intervals. If policies are to be the obstacle, they should be revisited and adjusted.

The scoring for “Frequent” was skew. In consideration of the items “Buy special foods that you can eat (2.9%), Avoid tempting you with food or drinks that you shouldn't have (6.7%), it is assumed that the low scorings were related to buy tests strips, (17.1%) were pensioners, (29.5%) were unemployed and dependent on other sources to make a living. Even the item “Get on your case after you ate something that you shouldn't”, which received a rating of (4.8%), was also debatable; the same argument of low income did not really allow for treats. The response “Less frequent” was rated (44.8%), which was extremely high in comparison to the rest of the items under the same rating scale. “Never” was rated 26.7% on “Do the grocery shopping for your meals” and “Avoid tempting you with food or drinks that shouldn't have” on Q34a” to affordability. The participants came from a low-income community (less than R2000.00 per month as indicated in Chapter 1) and planned meals and ate according to what was available at home or affordable. The response to “Choose restaurants that serve food you can eat” was low (2.9%), which correlates with affordability. Since they hardly can afford the basics, it would be difficult and senseless to have restaurant meals, take-outs and luxury treats, bearing in mind that most could not afford an essential glucometer or test strips.

4.3.2 Frequencies distribution of emotions

Similar as with the preceding, the following table showed the percentages of the 2nd set of five constructs where data was collected about emotions and feelings of PLWD. It is anticipated that emotional stable individuals should feel at ease, have better quality of life and satisfied with family support. Table 4.3 report on the frequency percentages of emotions and feelings by PLWD which too was measured in five response scales. All items started with “How does this make you feel or how would you feel? The items had a 5-point rating scale as “Unhelpful or not supportive (-1), Neutral (0), A little Helpful/supportive (1), Helpful/Supportive (2), Very Supportive (3)”. These scales are slightly different arranged as “Frequent” (A little Helpful/supportive, Helpful/Supportive, Very Supportive”, “Less frequent” (Unhelpful or not supportive) and “Neutral”. The results aided in understanding the feelings and emotions of PLWD when family members supported, motivated and assisted with self-care.

Table 4-3. Frequency of feeling and emotions (set 2)

Patterns	Questions numbers	Frequent	Less frequent	Never
Support	2, 3, 5, 9, 11, 13, 14, 16, 17, 26, 27, 30, 33, 34, 35, 38, 44, 46, 48, 50, 54, 58	1.1 – 72.4	1.1 – 4.8	13.3 – 55.2
Motivate	4, 10, 18, 25, 31, 32, 39, 47, 49, 51, 57	1.1 – 74.3	1.1 – 4.8	13.3 – 46.7

Patterns	Questions numbers	Frequent	Less frequent	Never
Assist	1, 5, 7, 8, 12, 15, 19, 24, 23, 22, 21, 28, 36, 37, 40, 41, 42, 43, 44, 45, 52, 53, 55, 56	1 – 77.1	1.1 – 25.7	12.4 - 55.2

Even though different concepts were measured, most of the scorings for the 2nd set of questions and rating scales were comparable to set 1.

Support. Within the same range of the different constructs, Qs 2, 3, 5, 9, 11, 13, 14, 16, 17, 26, 27, 30, 33, 34, 35, 38, 44, 46, 48, 50, 54, 58 revealed a rating for Frequent (1.1 – 72.4), Less frequent (1.1 – 4.8) and Neutral (13.3 – 55.2). The ratings for Frequent were reasonably high and indicated emotional stability. Those who selected Neutral could have been anxious and wanted to avoid conflict. Hence, they chose to tolerate negative comments and actions in pursuit of good family relationships. It is assumed that anxiety could instil fear, and they would have wanted to stay away from the fear of failing in the attempts of self-care.

Respondents remained neutral on questions about exercise, which were in a comparing range between 28.6% and 39% but rated about 50% less than felt the family were very helpful with ratings between 58.1% and 65.7%. They rated their feelings low towards the family as Frequent and Less frequent. Respondents remained Neutral on general questions about their feelings towards communication and understanding; there were no significant lower or higher ratings. However, according to the scores for very helpful it can be concluded that more than half of those who took a neutral stance felt that the family was very helpful with support. Participants were informed that they did not have to answer questions, which made them feel uncomfortable. Hence, it is deduced that the neutral response was selected where they thought a response to those questions could have been favourable or unfavourable or a bit too sensitive, for which they opted not to share such information out of self-pity or embarrassment that the family did not support them.

Motivate. Generally, the family plays a significant role in the lives of PLWD and it is thus expected that the family motivates them through advise of general aspects of self-care and daily activities. Whilst most activities could be of no of little interest, regular support may activate an increased motivation to success with establishing a daily routine to effect life quality. Motivated individuals might be more receptive to change and might regard daily blood testing an important activity or responsibility to have better control over the blood glucose, following a diet to control glycaemic spikes, exercise regularly within boundaries of blood glucose levels and eager to obtain the necessary knowledge and skills. Motivation could be a

driver to initiate assistance from other. The ratings for motivation and support are within similar ranges and percentage comparisons can be drawn, for Frequent 1.1 – 74.3, Less frequent 1.1 – 4.8 and Neutral 13.3 – 46.7. The ratings relate to QS 4, 10, 18, 25, 31, 32, 39, 47, 49, 51, 57. Healthy relationships are borne out of trust; however, it does not imply that the PLWD must trust the family members who support them. Essentially, PLWD should be autonomous in decision making which is possible through assistance by the family which can be achieved through healthy interpersonal relationships.

Assist. Living with diabetes is complex and requires emotional stability, effective self-care practices and frequent motivation. Emotional care can easily be overlooked, it is therefore anticipated that PLWD is skilled, have relevant knowledge and surrounded with healthy and relevant family support. The 2nd set measured the emotions and feelings of PLWD which points to psychological well-being. Emotions can relate to poor self-care, unhealthy diets, poor life quality. Qs 1, 5, 7, 8, 12, 15, 19, 24, 23, 22, 21, 28, 36, 37, 40, 41, 42, 43, 44, 45, 52, 53, 55 and 56 relates to feelings and emotions. Frequent rated 1 – 77.1%, Less frequent 1.1 – 25.7% and Neutral 12.4 – 55.2%. Important items Qs 8, 12 relate to assistance which imply the monitoring of the blood glucose values after testing to ensure the correct insulin and dosage is administered. Q 54 relates to the availability of family members to listen to concerns and act as soundboard even if they do not have the correct answers or advice.

Reliability and internal consistency were used interchangeably in this study. In this current study, the DSSQ-Fv questionnaire was administered to PLWD to determine validity and reliability, which were fundamental in the evaluation of the instrument (McCowan & McCowan, 1999:3; Tavakol & Dennick, 2011:53). It is the most critical dimension of test development. The ratings indicated the level of how PLWD with family support performed diabetes self-care management. Measures for internal consistency of a test/scale are expressed as a number between 0 and 1 and coined Cronbach's Alpha (α). It was developed in 1951 by an American psychologist, Lee Cronbach (Cronbach, 1951). Tavakol and Dennick (2011:53) stated that α is the most widely used statistic to measure reliability and preferred to measure multiple-item constructs. Reliability measured the measurement errors in the DSSQ-Fv questionnaire. Tavakol and Dennick (2011:53) stated that internal consistency described the extent to which all the items in a test measured the same concept/construct and are connected to inter-relatedness; in addition, the items provided insight into how PLWD experienced self-care and family support. The results also related to understanding the applicability of Orem's theory of self-care concepts. Cronbach's Alpha (α) was used in this phase to determine the estimates of internal consistency.

4.4 DESCRIPTORS AND VALUES OF CRONBACH VALUES

Literature showed variations of α values and descriptors. Bland and Altman (1997:572) argued that if groups were to be compared, α values of 0.7 to 0.8 were satisfactory but expected higher α values in clinical application. A minimum of 0.90, and 0.95, were desirable. According to these authors α values were “excellent (0.93–0.94), strong (0.91–0.93), reliable (0.84–0.90), robust (0.81), fairly high (0.76–0.95), high (0.73–0.95), good (0.71–0.91), relatively high (0.70–0.77), slightly low (0.68), reasonable (0.67–0.87), adequate (0.64–0.85), moderate (0.61–0.65), satisfactory (0.58–0.97), acceptable (0.45–0.98), sufficient (0.45–0.96), not satisfactory (0.4–0.55) and low (0.11)”. Taber (2017:1278) described α values similar to what Bland and Altman (1997:572) suggested. By contrast, (Statistics How to 2021) determined α values and descriptors as excellent ($\alpha > 0.9$), good ($0.9 > \alpha \geq 0.8$), acceptable ($0.8 > \alpha \geq 0.7$), questionable ($0.7 > \alpha \geq 0.6$), poor ($0.6 > \alpha \geq 0.5$) and unacceptable ($0.5 > \alpha$). The above description indicated that different values and descriptors can be utilised. These descriptors and values were used to determine the internal consistency of this current study. According to the Cronbach’s α descriptors, a minimum value of 0.7 was thus considered.

4.5 RELIABILITY STATISTICS

Tuan, Chin and Shield (2005) reported on a study “to develop a questionnaire to measure students’ motivation toward science learning”. This questionnaire included items of six distinct scales of self-efficacy, active learning strategies, science learning value, performance goal, achievement goal and learning environment stimulation, and motivational factors were considered. These authors used Cronbach’s α coefficient to measure the internal consistency of the six scales to measure the different constructs. Taber (2017:1281) noted other authors who have provided high α values for multi-construct scales and cited Eilam and Reiter (2014) for the calculations of α for a full scale to conduct a study of the Learning and Study Strategies Inventory to explore emotions (enjoyment, hope, pride, anger, anxiety, and shame) where a 76-item instrument comprised of 10 scales was employed. Both these studies related to this current study, where a lengthy $58 \times 2 = 116$ item instrument was employed and comprised a six-point rating scale for the 1st set of 58 items (perceptions and experiences) and a five-point rating scale for the 2nd set of items (emotions). As both sets comprised the same five constructs and according to Welch et al. (2019:2) explanation, this instrument can be compared with the semantic differential tool.

Table 4-4. Subscales and measures related to diabetes self-care management (Support)

SUPPORT				
Scale (Number of items)	Cronbach's α	Std Dev	Cronbach's α	Std Dev
Insulin injections (10)	0.832	18.523	0.984	15.746
Blood testing (14)	0.93	20.893	0.985	21.292
Meal plan (20)	0.931	40.453	0.986	28.439
Exercise (9)	0.901	14.657	0.989	13.101
General items (5)	0.803	9.264	0.946	7.173

Reliability or high internal consistency was determined by α value achievement. Reliability analysis showed that the five constructs had good discriminating power and obtained high α values, between 0.803 and 0.989 (good to excellent). Amongst the five constructs, General items had the lowest value for frequency ($\alpha = .803$) and supportiveness ($\alpha = .946$) but were still acceptable ($0.8 > \alpha \geq 0.7$) and therefore achieved high internal consistency. The remaining four constructs for frequency were α values between 0.832 and 0.931. The 2nd set revealed that the lowest α value for supportiveness was achieved between 0.984 and 0.989, which was high. Overall, the DSSQ-Fv questionnaire did not show α values that were Questionable = $0.7 > \alpha \geq 0.6$. Consequently, it was concluded that this current study showed high internal consistency across 58 items in both 1st and 2nd sets of items as can be seen in table 4.12 and given its high reliability, this study can be replicated. McCowan and McCowan (1999:10) argued that higher scores indicated variations in responses if the items are too easy or too difficult when it is poorly phrased, it could lead to misunderstanding, errors in the scoring where there are environmental interferences (noise, temperature, etc.), technical interference (apparatus functioning) or the length of the test. McCowan and McCowan (1999:10) further argued that reliabilities as low as .50 were satisfactory for short tests of about 10 to 15 items, but those with 50 items and more should be .80 and higher. Based on these authors' viewpoints and Cronbach's α values and descriptors, scores lower than acceptable ($0.8 > \alpha \geq 0.7$) were anticipated for this study. On the other hand, Tavakol and Dennick (2011:53) stated that when items in a test correlate with another, the α value increases, but a high α coefficient does not imply high internal consistency.

4.6 ITEM STATISTICS OF PERCEPTIONS AND EXPERIENCE

In the construct of Insulin injections, the mean values of 41 responses showed Q1a ($M = 37$, $Std\ Dev = 1.24$), Q2a ($M = 0.71$, $Std\ Dev = 1.736$), Q6a ($M = 0.24$, $Std\ Dev = 1.09$) and Q9a ($M = 0.54$, $Std\ Dev = 1.416$). The mean for these items was significantly lower than <1 , bearing in mind that few were insulin-dependent and did not need family support with insulin injections. It was concluded that the minority PLWD were not insulin dependent. Out of 96 responses, the scores for Q11a ($M = 1.52$, $Std\ Dev = 1.989$), Q18a ($M = 1.07$, $Std\ Dev = 1.921$) and Q20a ($M = 1$, $Std\ Dev = 1.881$) were >1 in comparison to the other items in this construct. On average, it was concluded that some PLWD did not have a blood glucose test machine or test strips or were unable to test the blood glucose due to their inability but depended on follow-up clinic visits. Ninety-seven scored the Meal plan for this construct. They showed that Q27a ($M = 0.98$, $Std\ Dev = 1.831$), Q33a ($M = 0.61$, $Std\ Dev = 1.374$), Q34a ($M = 0.59$, $Std\ Dev = 1.463$), Q37a ($M = 0.56$, $Std\ Dev = 1.172$) and Q43a ($M = 0.54$, $Std\ Dev = 1.128$) were <1 in comparison to the remaining items which were between >1 to $2+$. These questions related to consideration in terms of accessibility and affordability besides temptation and what is not allowed. On the other hand, it also directly impacts the commitment to withstand temptation, which must be respected. The scores came from one hundred and three respondents, which achieved on Q48a ($M = 0.89$, $Std\ Dev = 1.726$), Q51a ($M = 0.26$, $Std\ Dev = 1.029$), and Q52a ($M = 0.08$, $Std\ Dev = 0.436$) were <1 in comparison to the other items. The general perception was that the family should encourage physical activities that are inexpensive. Out of 104 respondents Q55a ($M = 0.63$, $Std\ Dev = 1.27$) and Q58a ($M = 0.88$, $Std\ Dev = 1.433$) were <1 . On average, it is concluded that PLWD has a need for information about caring for them and are not always able to take care of themselves and need some form of support.

Table 4-5. Mean and Std Dev of perception and experience

Construct	N	Number of items	Min	Max	Std Dev	Variance
Insulin injections	41	10	0.37	2.46	1.09-2.399	1.309
Blood testing	96	14	1.52	1.07	1.102-1.989	0.887
Meal plan	97	20	0.54	2.93	1.128-2.24	1.112
Exercise	103	9	0.08	1.84	0.436-2.067	1.631
General items	104	5	0.63	2.6	1.27-2.223	0.953

4.6.1 Discussion of the perceptions and experiences

The primary objective was to measure perceptions, experiences, and emotions to determine the performance levels of self-care management, which eventually disclosed the impact on the life of PLWD. The DSSQ-Family was useful for this non-clinical investigation and showed

the associated challenges PLWD experienced in their daily lives. Orem's concepts of (self-care, self-care agency, self-care requisites and therapeutic demands) were helpful in drawing inferences (Berman, 2017:1). Family support should be highlighted for the management of self-care activities. It is recommended to include other factors that relate to risks and complications (foot care, weight management, dietary advice). Four indicated that a family member sometimes gives the insulin injections, and it can be inferred that some PLWD type 1 were not confident enough to administer the insulin themselves, unfamiliar with the procedure or more dependent on family support. Although it was not indicated, complications and risks of eyesight problems could prevent them from preparing and administering the correct dosage, which required assistance from the family. Obesity and uncontrolled weight must be monitored and depend on eating habits.

Blood glucose monitoring and meal planning are important aspects of self-care. According to Mottalib, Kasetty, Mar, Elseaidy, Ashrafzadeh and Hamdy (2017:2), people diagnosed with type 1 diabetes were thought to have a lower body mass index (BMI), but recent research showed that obesity in this group was fast increasing. Further, these authors noted that insulin therapy is a factor that increases weight. They suggested increased physical activity but also observed that PLWD were reluctant to participate in physical activities fearing hypoglycaemia, which impact on the psyche of PLWD. In the absence of a biokineticist, physical activity could be done easily and free if the health status allowed. Family support also strengthens relationships and leads to improved emotional life.

On the other hand, if the family fails to provide support, PLWD could experience stress-related anxiety and depression with subsequent poor diabetes control. This could aggravate psychological health. It can be concluded that weight management in type 1 diabetes should include proper advice on nutrition and well-coordinated, low-impact activities. HCPs can influence this part of self-care management. The importance of involvement of HCPs is extremely important, they could aid in increased family support. It is also argued that self-care is a critical component of diabetes control despite socio-economic standing and psychological aspects. The crux would be to engage with PLWD for their different inputs to enable tacit agreements if they have a clear understanding of the impact on their daily life.

Poor self-care or non-compliance impacts the quality of life for both PLWD and the family. If self-care is below expectancy, or if there is evidence of non-compliance, poor glycaemic monitoring and control can be expected, which subsequently could develop into long-term complications (retinopathy, neuropathy, renal disease, etc.). Poor self-care could increase

medical costs for healthcare departments and PLWD and their families. It also is a denominator for unnecessary stress, which negatively impacts on overall quality of health.

The trajectory to self-care management is self-confidence, compliance, and commitment. By interpreting the perceptions, experiences and emotions, self-care compliance plays a major part in lifestyle adjustments for PLWD with or without family support. Some of the results were helpful in drawing inferences on some aspects of social life, psychological well-being, and physical health. It is not uncommon for people diagnosed with type 1 diabetes to carry a glucometer, test strips and insulin/oral medication if attending social activities, but by doing so, exposing unwillingly their health condition. This affects psychological well-being and causes continuous and unnecessary stressors if it was intended to keep their health condition confidential and private. Hakkarainen et al. (2017:3-5) found that PLWD spent about 60% of their time at work, and if the health condition is not disclosed, self-care is jeopardised, leading to psychological stress.

Life quality is also influenced by stressors (affordability and accessibility). Affordability in this context refers to equipment and supplies to monitor blood glucose (blood glucose machine and test strips). Some food items are unaffordable and influence healthy eating patterns. Travel costs might be unaffordable, and PLWD (or other patients in general) might be unable to attend follow-up clinic appointments, especially where a health facility is not within reasonable reach. This makes healthcare inaccessible. According to the results of the employment status in this current study, (48.6%) were employed and lived a normal life. Lifestyle changes bring about various restrictions for PLWD and the family; therefore, follow-up clinic visits are highly encouraged and should take place at least once per month, according to staff numbers and resources from the Department of Health, to ensure continuous support. Educational sessions for groups are highly recommended as is informal/formal group interaction. One of the questions in the socio-demographics questionnaire asked if the PLWD would like to belong to a support group. This is an important aspect because a bigger group of people with the same concerns can create a sense of belonging, and it further can create opportunities where PLWD can share information and learn from one another instead of having a false sense of feeling isolated. It is recommended that HCPs create such groups. PLWD should feel free to ask for help. Language barriers in clinical settings also influence self-care management.

4.7 ITEM STATISTICS OF EMOTIONS

In the construct of Insulin injections, the mean values of 42 responses showed Q2b (M = 1.31, Std Dev = 1.554) and Q7b (M = 1.37, Std Dev = 1.575), while the remaining items had M =

1.5 to 1.71, which were not of concern. The deviation was between 1.554 and 1.588 and all were in range. Out of 101 responses, the overall $M = 1.13$ to 2. The deviation was all in close range except for Q11b, which asked about the emotions if a family member wants to know about the blood results, for which the $M =$ was the highest and had the lowest Std Dev = 1.442, which was in range with the other items where the highest showed 1.552. Ninety-eight scored the Meal plan showed $M = 0.53$ and 2.35, Std Dev between 1.123 and 2.439. Q43 asked how they would feel if a family member bought special foods that they could eat and had a low $M = 53$ with Std Dev = 1.123. This item showed that affordability and temptation were of concern. One hundred and three responses were given to the construct of the exercise. Q52b, which asked about how they feel if the family bought sports equipment and attained $M = 1.74$, Std Dev 1.488, there were no significant differences with the other items on the same construct. One hundred and three responses were given to the construct of general items on item Q54b, where they indicated their feelings about the availability of the family to listen to their concerns or worries about self-care. Five items were answered with $M = 1.93$ to 2.16 (206) and Std Dev between 1.396 and 1.508. There was no significance in the results.

Table 4-6. Means and Std Dev of emotions

Construct	N	Number of items	Min	Max	Std Dev	Variance
Insulin injections	42	10	1.36	1.71	1.554 - 1.588	0.034
Blood testing	101	14	1.13	2	1.442 - 1.552	0.11
Meal plan	98	20	1.77	2.35	1.244 - 1.491	0.247
Exercise	103	9	1.74	2.01	1.424 - 1.49	0.066
General items	103	5	1.93	2.16	1.393 - 1.508	0.115

4.7.1 Item-Total statistics of perceptions, experience and emotions

Tavakol and Dennick (2011:53) and McCowan and McCowan (1999:3) argued that it would not be senseless to report α for an entire test with multiple constructs because large numbers of items inflate α values and affect lengthy tests. The DSSQ-FV was a lengthy test; it had two sets of questions. According to the pilot results (see question 7 of the pilot study), additional time was added to complete the questionnaire. Consideration was given to the somewhat complex layout at face value, two sets of questions, and the unknown level of education, including a diversity of spoken languages. Due to multiple constructs and the lengthy questionnaire, results are presented per item per construct (Tavakol & Dennick, 2011:53). Cronbach's α was used during Item-Total statistics: corrected item-total correlations and

Cronbach's α if item deleted is visible in Tables 4.7 and 4.8. According to the literature item-total correlation was for the purpose of instrument development. There was no intention to develop further the DSSQ-Fv other than to measure perceptions, experiences, and feelings/emotions. From this viewpoint, none of the questions were deleted as this instrument was administered in the SA context for this study to gain a better understanding of how PLWD in the participating clinics of Tshwane, SA, practice diabetes self-care management.

Table 4-7. Item-Total statistics of perception and experience

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q1a	Give you injections	10.61	140.094	0.102	0.846
Q2a	Nag you about your injections	10.27	123.101	0.481	0.821
Q3a	Remind you to take your insulin	9.68	108.622	0.692	0.798
Q4a	Praise you for giving yourself injections correctly or on time	8.93	105.57	0.692	0.798
Q5a	Help out when you give yourself insulin	10.02	122.274	0.427	0.827
Q6a	Wake you up so you can take your morning injection on time	10.73	136.051	0.29	0.835
Q7a	Change their own schedule to get an early start, too, when you give yourself a morning injection	10.05	114.048	0.652	0.804
Q8a	Check after you've taken your insulin to make sure you've done it	9.54	112.105	0.585	0.811
Q9a	Get on your case about taking your insulin after you were late or forgot	10.44	127.702	0.466	0.823
Q10a	Let you know they appreciate how difficult it is to take insulin injections	8.51	103.706	0.72	0.794
Q11a	Ask you about the results of your blood tests	7.83	191.151	0.762	0.922

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q12a	Watch you test your blood sugars to see what the values are	8.56	198.754	0.746	0.922
Q13a	Nag you until you do your testing	9.01	220.684	0.462	0.93
Q14a	Remind you to test urine for ketones	9.01	214.305	0.63	0.926
Q15a	Test your blood sugar for you	9.02	217.473	0.564	0.928
Q16a	Remind you to test your blood sugar	8.77	203.715	0.755	0.922
Q17a	Make sure you have the materials needed for blood testing	8.63	199.521	0.77	0.921
Q18a	Let you know they appreciate how hard it is to test blood sugars every day	8.28	189.362	0.832	0.919
Q19a	Set up the materials you need for testing your blood sugar	8.95	212.618	0.635	0.926
Q201	Praise you for testing your blood sugar on your own	8.35	191.41	0.809	0.92
Q21a	Help out when you test your blood sugar	8.99	213.358	0.63	0.926
Q22a	Keep track of testing results for you	8.81	206.407	0.677	0.924
Q23a	Watch you for signs that your blood sugar is low	8.61	205.271	0.598	0.927
Q24a	Help out when you might be having a reaction	8.77	212.768	0.544	0.928
Q25a	Encourage you to eat the right foods	32.91	656.543	0.661	0.926
Q26a	Let you know they understand how important it is for you to eat right	32.95	645.029	0.762	0.924
Q27a	Ask if certain foods are okay for you to eat before serving them	34.76	694.37	0.478	0.93

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q28a	Do the grocery shopping for your meals	34.47	715.564	0.376	0.931
Q29a	Schedule meals at the times you need to eat	32.82	658.396	0.655	0.927
Q30a	Remind you about sticking to your meal plan	33.97	659.259	0.673	0.926
Q31a	Suggest foods you can eat on your meal plan	34.28	671.14	0.62	0.927
Q32a	Join you in eating the same foods as you	33.05	666.237	0.574	0.928
Q33a	Get on your case after you ate something that you shouldn't	35.13	705.117	0.505	0.929
Q34a	Avoid tempting you with food or drinks that you shouldn't have	35.15	703.299	0.495	0.929
Q35a	Watch what you eat to make sure that you eat the right foods	33.76	641.308	0.795	0.923
Q36a	Cook meals for you that fit your meal plan	33.41	661.932	0.623	0.927
Q37a	Choose restaurants that serve food you can eat	35.19	716.507	0.413	0.931
Q38a	Eat at the same time you do	32.81	662.34	0.615	0.927
Q39a	Praise you for following your diet	33.42	644.163	0.782	0.924
Q40a	Tell you when you've eaten too much or too little	34.49	683.232	0.558	0.928
Q41a	Show they're pleased when you've eaten right	33.26	639.339	0.824	0.923
Q42a	Keep track of your meal plan for you	33.41	639.078	0.801	0.923
Q43a	Buy special foods that you can eat	35.21	724.478	0.298	0.932
Q44a	Tell you not to eat something you shouldn't	34.63	687.527	0.548	0.929

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q45a	Suggest ways you can get exercise	7.2	95.262	0.79	0.88
Q46a	Remind you to exercise	7.34	92.501	0.903	0.869
Q47a	Invite you to join in exercising with them	7.39	98.299	0.763	0.882
Q48a	Get on your case when you haven't exercised	7.79	103.13	0.721	0.885
Q49a	Congratulate or praise you for exercising regularly	7.43	101.129	0.713	0.886
Q50a	Bug you about exercising	7.68	102.357	0.688	0.888
Q51a	Encourage you to join an organised sports activity	8.42	121.089	0.409	0.906
Q52a	Buy sports equipment for you	8.6	128.164	0.308	0.911
Q53a	Exercise with you	7.59	104.048	0.683	0.888
Q54a	How often is a family member available to listen to concerns or worries about your diabetes care	6.46	30.115	0.652	0.745
Q55a	Give you things to read on diabetes care	8.23	41.577	0.441	0.807
Q56a	Tell you how well you've been doing with your diabetes care	6.51	29.184	0.708	0.724
Q57a	Encourage you to do a good job of taking care of your diabetes	6.27	27.17	0.79	0.692
Q58a	Understand when you sometimes make mistakes in taking care of your diabetes	7.99	41.194	0.39	0.817

On the other side, items Q4a, Q10a, Q18a and Q20a were repetitive and addressed appreciation and praise. Although none of these items were deleted, related questions were tested. Q43a achieved a high score, PLWD had to indicate how often the family buys special foods that they could eat, and if this item were deleted, the α value would have decreased to 0.298 (see column "Corrected Item-Total Correlation"), but according to the Cronbach's descriptors, this value would have been unacceptable ($0.5 > \alpha$) and was not worth to consider deleting this item.

4.8 SCALE MEAN IF ITEM DELETED (PERCEPTIONS AND EXPERIENCE)

The 1st set is depicted per item M, and Std Dev showed the mean range of twenty-seven items was low (< 1.0), from $M = 0.08$ to 0.98 . To make the questionnaire more reliable, out of 31 variables, 17 items (Q3a, Q8a, Q11a, Q18a, Q28a, Q29a, Q30a, Q31a, Q35a, Q40a, Q44a, Q45a, Q46a, Q47a, Q49a, Q50a, Q53a) had a much higher $M = 1$ to 1.98 , and 14 items (Q4a, Q10a, Q25a, Q26a, Q29a, Q32a, Q36a, Q38a, Q39a, Q41a, Q42a, Q54a, Q56a, Q57a) had a $M = 2.05$ to 2.93 . Although it appeared that the “Scale Mean if Item Deleted” were skew, the scale mean if items were deleted was individually analysed within the context of the constructs. It was found the mean was within a reasonable range and did not show significance. According to the results in Table 4.15, the scale mean showed values for Insulin injections = $7.83 - 10.73$, Blood testing = $7.83 - 8.77$, Meal plan = $32.91 - 34.63$, Exercise = $7.2 - 7.59$ and General items = $6.46 - 7.99$. There are no significant outliers that need to be reported between the construct's minimum and maximum itemised scale means.

Table 4-8. Item-Total statistics of emotions

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q1b	Give you injections	13.86	175.345	0.931	0.982
Q2b	Nag you about your injections	14.26	179.954	0.816	0.985
Q3b	Remind you to take your insulin	13.9	173.844	0.967	0.981
Q4b	Praise you for giving yourself injections correctly or on time	14	174.341	0.948	0.981
Q5b	Help out when you give yourself insulin	13.93	173.531	0.974	0.98
Q6b	Wake you up so you can take your morning injection on time	14.07	175.287	0.922	0.982
Q7b	Change their own schedule to get an early start, too, when you give yourself a morning injection	14.21	178.611	0.839	0.984
Q8b	Check after you've taken your insulin to make sure you've done it	13.93	173.531	0.974	0.98
Q9b	Get on your case about taking your insulin after you were late or forgot	14.07	175.287	0.922	0.982

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q10b	Let you know they appreciate how difficult it is to take insulin injections	13.9	176.235	0.893	0.983
Q11b	Ask you about the results of your blood tests	16.84	342.535	0.678	0.987
Q12b	Watch you test your blood sugars to see what the values are	17.43	328.187	0.906	0.984
Q13b	Nag you until you do your testing	17.59	330.164	0.888	0.984
Q14b	Remind you to test urine for ketones	17.71	331.247	0.861	0.985
Q15b	Test your blood sugar for you	17.56	326.588	0.942	0.984
Q16b	Remind you to test your blood sugar	17.54	327.77	0.93	0.984
Q17b	Make sure you have the materials needed for blood testing	17.53	326.211	0.947	0.984
Q18b	Let you know they appreciate how hard it is to test blood sugars every day	17.5	327.012	0.924	0.984
Q19b	Set up the materials you need for testing your blood sugar	17.63	326.034	0.961	0.983
Q201	Praise you for testing your blood sugar on your own	17.53	325.951	0.947	0.983
Q21b	Help out when you test your blood sugar	17.63	325.574	0.961	0.983
Q22b	Keep track of testing results for you	17.45	329.25	0.874	0.985
Q23b	Watch you for signs that your blood sugar is low	17.49	326.392	0.935	0.984
Q24b	Help out when you might be having a reaction	17.5	329.012	0.877	0.985
Q25b	Encourage you to eat the right foods	38.71	579.649	0.865	0.986
Q26b	Let you know they understand how important it is for you to eat right	38.74	579.594	0.863	0.986
Q27b	Ask if certain foods are okay for you to eat before serving them	38.74	579.326	0.881	0.986
Q28b	Do the grocery shopping for your meals	38.39	590.178	0.844	0.986

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q29b	Schedule meals at the times you need to eat	38.47	584.85	0.879	0.986
Q30b	Remind you about sticking to your meal plan	38.62	578.382	0.933	0.985
Q31b	Suggest foods you can eat on your meal plan	38.68	577.084	0.92	0.985
Q32b	Join you in eating the same foods as you	38.56	582.043	0.88	0.986
Q33b	Get on your case after you ate something that you shouldn't	38.97	581.762	0.817	0.986
Q34b	Avoid tempting you with food or drinks that you shouldn't have	38.87	580.157	0.854	0.986
Q35b	Watch what you eat to make sure that you eat the right foods	38.71	575.464	0.927	0.985
Q36b	Cook meals for you that fit your meal plan	38.59	581.048	0.885	0.986
Q37b	Choose restaurants that serve food you can eat	38.81	584.158	0.822	0.986
Q38b	Eat at the same time you do	38.6	583.005	0.852	0.986
Q39b	Praise you for following your diet	38.71	574.598	0.96	0.985
Q40b	Tell you when you've eaten too much or too little	38.68	576.899	0.943	0.985
Q41b	Show they're pleased when you've eaten right	38.67	574.944	0.956	0.985
Q42b	Keep track of your meal plan for you	38.67	577.665	0.924	0.985
Q43b	Buy special foods that you can eat	38.92	588.488	0.732	0.987
Q44b	Tell you not to eat something you shouldn't	38.82	580.77	0.849	0.986
Q45b	Suggest ways you can get exercise	15.23	124.729	0.96	0.987
Q46b	Remind you to exercise	15.25	124.563	0.966	0.987
Q47b	Invite you to join in exercising with them	15.36	123.585	0.956	0.987
Q48b	Get on your case when you haven't exercised	15.32	123.769	0.977	0.986
Q49b	Congratulate or praise you for exercising regularly	15.26	124.901	0.942	0.987

Item number	How often does a family member ...	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's A if Item Deleted
Q50b	Bug you about exercising	15.27	124.514	0.973	0.986
Q51b	Encourage you to join an organised sports activity	15.45	125.053	0.915	0.988
Q52b	Buy sports equipment for you	15.5	126.586	0.856	0.991
Q53b	Exercise with you	15.29	123.738	0.975	0.986
Q54b	How often is a family member available to listen to concerns or worries about your diabetes care	8.17	28.263	0.815	0.939
Q55b	Give you things to read on diabetes care	8.34	26.795	0.849	0.934
Q56b	Tell you how well you've been doing with your diabetes care	8.21	26.817	0.94	0.918
Q57b	Encourage you to do a good job of taking care of your diabetes	8.17	27.041	0.893	0.926
Q58b	Understand when you sometimes make mistakes in taking care of your diabetes	8.39	28.338	0.769	0.948

Reliability analysis was carried out on the perceived task values per construct, which comprised $58 \times 2 = 116$ items, to determine how the self-care performance could be sharpened. The 2nd set of items with a five-point rating scale attained α value of 0.918 to 0.991 Cronbach's α if an item was deleted. The corrected item-total correlations attained α value of 0.678 to 0.0977. The column Cronbach's α if item deleted provided the lowest α value of 0.918 for Q56b, which asked about the feelings when a family member told them that they were doing well with self-care. The column corrected item-total correlation showed the α value would have slightly increased to 0.94 if this item were deleted from the scale to make the items more reliable. Still, as alluded to previously, none of the questions were deleted as it measured emotions instead of developing a data collection instrument.

Cronbach's α if item deleted showed the highest score of 0.991 for Q52b, which asked about how PLWD felt if the family bought sports equipment and showed in the corrected item-total correlation an insignificant decrease in the α value to 0.856 if this question was deleted. Nevertheless, the threshold for Cronbach's values and descriptors selected for this study still showed overall high internal consistency (acceptable = $0.8 > \alpha \geq 0.7$) to (good = $0.9 > \alpha \geq 0.8$). Yet, Q11b asked about feelings if the family were asking about blood results; this question achieved an α value of 0.987, and if this item were deleted, the real α value would decrease

to 0.678 which was questionable ($0.7 > \alpha \geq 0.6$) and thus considered to delete. All the items were retained as they did not have a notable change in the overall α values, even if the few as mentioned were to be deleted.

4.9 SCALE MEANS IF AN ITEM IS DELETED (EMOTIONS)

Although it appeared that the “Scale Mean if Item Deleted” were extremely skewed, the scale mean if items were deleted was individually analysed in context as per construct per item, and it was concluded that the mean was still within range and did not show significance. As per construct in table 4.16, the scale mean showed values for Insulin injections = 13.86 - 14.26 (14.013), Blood testing = 16.84 - 17.5 (17.495), Meal plan = 38.39 – 38.97 (38.6965), Exercise = 15.23 – 15.5 (15.325) and General items = 8.17 - 8.39 (8.256). There are no significant outliers that need to be reported between the construct's minimum and maximum itemised scale means. The 2nd set showed 40 items had $M = 1.13$ to 1.99 . Some variables (Q25b, Q28b, Q29b, Q30b, Q31b, Q32b, Q35b, Q36b, Q38b, Q39b, Q40b, Q41b, Q42b, Q45b, Q54b, Q56b, Q57b) had > 2.0 average score with $M = 2.0$ to 2.35 , these items could have been excluded from the questionnaire to make the questionnaire more reliable.

Tavakol and Dennick (2011:53) suggested that too high scores implied that some items were redundant as they might test the same question from different angles. Such items could represent different content areas (for example, where a collective meaning was ascribed). In this study, encouragement, inspiration, and motivation collectively hold the same intent) to make PLWD feel good. If those types of items were deleted in instrument development, or as in this current study, excluded and not formed part of the questionnaire, the questionnaire's reliability would have increased. The mean indicated per item was too high and preferred to be deleted according to the scores.

4.10 INFERENCE

4.10.1 Participant characteristics

This study focussed on adults and showed that diabetes was also prevalent amongst younger people which showed that diabetes can develop at any age. It is important to make lifestyle changes, such as practising healthy eating habits at an early age. The findings indicate a larger proportion of females which was not surprising. It is assumed that females traditionally play a key role in the decision-making of meal planning and preparation. Still, with the higher percentage of diabetes in gender, it is unsure if they consume healthy diets. This is regarded as a critical factor and far outweighs the males, considering that females are in the best position to influence healthy eating behaviours in the family. Even though males constituted a

lesser percentage in gender distribution, a lower number does not imply that diabetes was less prevalent amongst males. In the SA context, it would not be unusual for both genders to work as migrant workers away from home. It was assumed that some males were migrant workers, and it would make sense for them to visit clinics closer to where they were employed and lived, however, if a higher proportion of males participated, it could have revealed different statistics. The results of marital status could be interpreted that being married or living with a partner must consider others in the family in contrast where single, widow or divorcee only take care of themselves, implying that they can better practise healthy lifestyles.

Educational status indicates the level of interaction and communication and how to address, communicate and approach the participants. The researcher perceived that there is a general tendency to believe that people with higher cognitive levels would grasp complex matters better and would turn to self-education. On the other side, people with a lower cognitive or educational level could be more dependent, especially in reading-related pieces or by understanding why certain actions should happen. It also gave an idea of the level and how communication should take place if aiming to enhance self-care performance. The essence of employment status was to determine financial viability to provide the basic needs, which also help with independency and affordable care. It is uncertain if those who were unemployed received any financial assistance and if they had the means of self-sustainment. In terms of the preferred or necessary diabetes dietary products, it is perceived that those who are employed/self-employed have the means to purchase products within their budget.

The sample represented PLWD with a wide language diversity (Afrikaans, English, IsiNdebele, IsiXhosa, IsiZulu, Xhitsonga, Sepedi, Sesotho, Setswana, Siswati, Tshivenda, and other (Gujarati, French and Somali). Although the majority were Sepedi speaking, and despite the variation of languages, a large group could understand and speak English. It would be better if PLWD were addressed in their mother tongue to understand the impact of diabetes on their livelihood. The importance of language is about a clear understanding of information. The researcher believes that clear communication aids in understanding information. The link between language and self-care is the ability to have a clear understanding of the information that is communicated. Clarity enables effective communication that will increase knowledge, effective skills application and a level of self-confidence to make informed decisions during self-care activities. Effective communication enables improved self-care with better health outcomes.

The responses to the question regarding support for people living with diabetes, revealed that the family supports 73 (69.5 %) PLWD, and almost half (32, 30.5%) were not supported.

Eighteen (17.1%) out of 24 indicated that they would like to be referred to a support group, while 6 (5.7%) preferred to find a family/support group by themselves. The majority preferred to belong to a support group, but despite social, dietary, and psychological services, support groups for PLWD were not yet established. Such support groups could make a stark difference for those PLWD where family support failed, and it is thus recommended that support groups are established.

4.11 CONCLUSION

The literature revealed numerous studies were conducted on diabetes care. However, the majority were from a clinical perspective, and few addressed the involvement of the family. From an SA perspective, the SEMDA guidelines were adopted for the management of diabetes but did not focus on the family. This study attempted to determine the level of self-care by measuring the perceptions, experiences, and feelings of PLWD in relation to support received from the family. Secondly, to gain insight into the level of support provided by the family. The primary objective of this study was (1) to describe PLWD perceptions of family support related to diabetes self-care management in Phase 1. This chapter discussed the pilot study, provided the context of the Phase 1 process and indicated data collection for the quantitative component, which was essential to describe individual perceptions of how PLWDs take care of themselves and view the support they receive from the family. Still, it was also expected that family support would be associated with better self-care adherence. In summary, diabetes can have a serious psychological impact and can affect self-management as well as the individual's quality of life. The impact of stress related to diabetes can have significant psychological consequences and may affect self-care management and the individual's quality of life. Intervention strategies should focus on achieving positive outcomes in the dimensions of psychological well-being. This study allowed the researcher to investigate how the family could be more involved. The measures were evaluated to compare a normative and individualised approach according to the scores. The frequency distribution showed a strong family relationship despite other forms of group support. According to the responses of PLWD of family support, the frequency rates is 69.5 %. The 2nd set of 58 items revealed high alpha values for five constructs, despite the lowest alpha measure for supportiveness being 0.984. It showed high internal consistency according to the scoring and presentation of α values. It is hoped that the results would be useful to sharpen the ability of PLWD and to enable better family involvement. Within this framework of self-care, the research showed areas where self-care can be improved and how the family can assist. The appointment scheduling was concerning and could be revisited. In addition, it showed the importance of cooperation with

HCPs. A significant factor was little diabetes-related information and a shortage of resources, in particular, equipment to test blood glucose at home.

CHAPTER 5

FINDINGS OF SELF-CARE MANAGEMENT EXPERIENCES OF PLWD

(PHASE 2, STAGE 1)

5.1 INTRODUCTION AND BACKGROUND

Across the world, people are diagnosed with diabetes, and due to this worldwide health condition, PLWD is expected to take care of themselves. Self-care is the activities that PLWD practices to obtain better health outcomes, leading to better life qualities. These self-care practices can include behavioural adjustments such as healthy eating patterns, being physically active, monitoring blood sugar, adhering to prescribed medication to better cope with problems and deciding how they want to deal with specific challenges. It also contributes to reducing risks and delaying the progression of the disease (Hilli, et al., 2018:36; Reid, et al. 2018:122). Therefore, to gain insight into how they practise these activities, the participants were invited to engage in dialogue, to uncover problem areas and to offer relevant solutions. Chapter 3 provided the research approach used to obtain data from focus groups and telephone interviews with PLWD. This chapter presents the findings of Phase 2 Stage 1.

5.2 DESCRIPTION OF PARTICIPANTS

The participants of Phase 2, Stages 1 and 2 have been presented and discussed in Chapter 3, sub section 3.13.9.2 and Table 3-3 for the focus groups and sub section 3. 3.19.3, Tables 3.5 and 3.6 for the telephone interviews.

5.3 TRANSCRIBING OF DATA

The same transcribing process was followed for the focus group pilot study and telephone interviews as described in Chapter 3.

5.4 THEMATIC ANALYSIS

The process is explained in Chapter 3.

5.5 CATEGORIES

5.5.1 Emerging categories

Categorising happened when similarly coded data was organised and grouped (Charmaz & Thornberg, 2021:308; Ravindran, 2019:43; Saldaña, 2013:9). Inductive reasoning is used for the focus groups and interviews (themes) in the qualitative phases of data processing. Through the process of Open coding and Line-by-line coding, 14 sub-categories were identified and the percentage sum of frequency reveals where they were most and least frequently clustered as: Support (15,34%), Blood glucose monitoring (13,75%), Treatment (11,95%), HCPs (11,35%), Hospital (2,99%), Psychological (2,39%), Disease profile (59%), Reminders (0,40%), Diet (0,56%), Knowledge (9,96%), Self-care (7,77%), Lifestyle (4,58%), Challenges (3,98%), Self-care activities (3,39%).

5.5.2 Merging and refining the themes

The sub-themes as identified in the above section were clustered according to comparable codes and was applicable to more than one theme (Saldaña, 2013:9). Frequency count of similar codes which showed relations with others were grouped and fifteen themes/sub-themes were developed and refined into five themes identified as (1) Patient support system (Support, HCPs, Hospital care, Diet), (2) Therapeutic strategies (Treatment, HCPs, Diet, Hospital), (3) Aspects of self-care (Self-care, Blood glucose monitoring, Self-care activities, Reminders), (4) Psychological aspects (Lifestyle, Disease profile, Challenge, Behavioural conduct, Diet), and (5) Enhancing general knowledge (Knowledge and information).

5.6 DEVELOPING THE THEMES

The themes were developed by grouping the codes in a meaningful way to present the findings for this study (Sutton & Austin, 2015:229). Latent content analysis involved coding and theming to identify patterns and themes that were found in the data transcripts (Ravindran, 2019:42). Table 5-1 shows the development of five themes.

Table 5-1. Development of themes

<i>Themes</i>	<i>Sub-themes</i>
The essence of a patient support system	Patient support system
Role of therapeutic strategies to improve self-care	Therapeutic strategies
Aspects to improve self-care	Aspects of self-care
Impact and effect of psychological aspects	Psychological aspects
The value of knowledge and information in self-care	Enhancing general knowledge

Table note: The repetitive occurrence of codes, words and phrases was substantial and indicated commonalities. Therefore, codes overlap if they are related to the topic and research questions. Some codes were related and

overlapping during theme development, they were revisited and condensed to three final themes, as presented below.

Table 5-4 provides a summary to condensed three themes and sub-themes that emerged from the sub-themes link to participants' responses.

Table 5-2. Condensing the themes

Themes	Sub-themes
Strategies to improve a patient support system	Patient support system: • Support • HCPs • Hospital care • Treatment • Disease profile • Diet
Impact and effect of self-care aspects on the psyche	Aspects of self-care: • Self-care • Self-care activities • Lifestyle • behavioural conduct and challenges • Blood glucose monitoring • Reminders
The value of knowledge and information in self-care	Enhance general knowledge: • Knowledge and information

Theme analysis is a method to identify, analyse and report patterns or themes and confirm that themes capture the data that relates to the research question (Braun & Clarke, 2006:79, 82). The following section provides researcher-based questions. While the sub-themes overlapped and related to the themes, it was complicated to provide participants with responses on single codes. Therefore, responses were integrated.

5.7 FINDINGS AND LITERATURE CONTROL

Five themes provided a conceptual and theoretical level insight into the experiences of PLWD. Information was categorised into themes and sub-themes based on the questions that came

from the focus groups and telephone interviews. The five themes were condensed to three main themes and is discussed as (1) Strategies to improve a patient support system, (2) Impact and effect of self-care aspects on the psyche and (3) The value of knowledge and information. The responses are displayed as verbatim quotes from the participants.

5.8 PHASE 6 OF THEMATIC ANALYSIS: PRODUCING THE REPORT

5.8.1 Theme 1: Strategies to improve a patient support system

An effective strategy to improve a patient support system is to described strategies associated with the sub-themes Support, HCPs, Hospital care, Treatment, Disease profile and Diet. The sub-theme was consistently significant when participants described their experience of self-care.

5.8.1.1 Sub-theme 1: Patient support system

This sub-theme is presented integrated within the sub-sub-themes of (1) Support and HCPs, (2) Support, HCPs, Hospital care, Treatment and (3) Disease profile and Diet. In this study, a patient support system for PLWD is viewed in the context of the inter-related codes or sub-themes. To understand the essence of an effective patient support system, it was necessary to know the participants' viewpoints. This section provides extracts related to the questions about support from family and health care professionals, the commitment to follow a treatment plan, how PLWD were taken care of during hospitalisation, compliance with the diet and the management of the disease profile (diabetes). Insights into PLWD view on self-care and implementing the needs of a person-centred service might help to create a better patient support system. Participants experiences and views on questions are presented under different or integrated themes. Within the sub-theme of Patient support system, the sub-sub-themes Support and HCPs are addressed. The following quotes reflect on the participants responses.

The question asked: "How can a healthcare professional better care and support you?".

"I had an excellent dietitian at the hospital maybe for the first year. And all of a sudden, when I went there in January again, she was not there. Now I got somebody else, and I had to establish a new relationship, maybe the first two visits. When I go there again, she's gone, so that is the weak point for me" (INTP2/S1-P5).

"Ek was by die dieetkundige. maar die dieetkundige was meer gepla oor my lengte, ek is te dik en oorgewig en ons moet eerder dit reg kry, en hy was meer geïnteresseerd in, oor nie soseer oor die diabetes nie, oor die dieet vir die suiker nie, maar omdat ek 'n dieet moes gekry het omdat my lyf te veel suur in het",

[translated: "I was at the dietitian but the dietitian was more concerned about my height, am I too fat and overweight and we should rather get it right and he was more interested in, not so much about the diabetes, about the diet for the sugar but because I should have been given a diet because my body has too much acid in it."] (INTP2/S1-P10).

The question asked: "Do you think it's important that the HCPs should always listen to what you say?"

"Hulle, elke keer as jy daar kom dan sien jy iemand anders, jy het nie iemand met wie jy n vertroue kan opbou wat jou ken nie. elke keer is dit iemand nuut dit is vir my n probleem daai". [translated: "...every time you come there you see someone else; you don't have someone you can build trust with who knows you. every time it's someone new; that's a problem for me.] (INTP2/S1-P4).

"Ek dink hulle gee nie genoeg aandag aan die mense nie, hulle sien jou vinnig, skryf die bloed toetse voor en daar gaan jy. Dit gaan nie regtig oor die klient nie, hulle bespreek dit nie" translate: *"I think they don't pay enough attention to the people; they see you quickly, prescribe the blood tests and there you go. It's not really about the client, they don't discuss it", "Die laaste keer toe ek dokter toe gegaan het, het gelyk of sy nie geluister het na wat jy sê nie"* [translated: *"The last time I went to the doctor she didn't seem to listen to what you were saying"*] (INTP2/S1-P4).

The following responses was to the question "Did you see a dietitian before?"

"Yes, I saw at the ...hospital, it was on three occasions, and where I was this cholesterol. "...to be honest with you is that I'm an undisciplined person 'cause I know I'm not supposed to eat white bread..." (INTP2/S1-P5).

"Ek is n diabeet, ek moet n ander dieet kry as die ander mense. Maar daai het nie gebeur nie. Ek het dieselfde kos as die ander. Die volgende oggend het ek bietjie pap gekry met melk end it is dit. My Sondag middag ete was almal dieselfde gekry was n groot stuk steam bread met n klein stukkies vleis." [translated: *I am a diabetic; I must get a different diet, get a different diet than the other people. But that didn't happen. I have the same food as the others. The next morning, I got some porridge with milk, and that was it. My Sunday lunch, lunch was a large piece of steamed bread with a small flat piece of meat.*] (INTP2/S1-P4).

"I don't follow a rigid or stringent diet plan. I feel like I sometimes eat more than my portion size, but it's like I have a big meal now, and that's it. I prefer to do that because it works for me rather than, I feel if I eat small portions every then I start snacking..." (INTP2/S1-P6).

The above responses revealed dissatisfaction. The response imply that the respondents want better support in terms of continuity and to address the reason for the visit. Their unspoken words suggested that HCPs should change their attitude and rather concentrate on what

cause participant dissatisfaction. Negative feelings were projected towards the dietitian. The responses implied that the relationship between some of the HCPs and PLWD could improve, implying that when there is a strong relationship, PLWD will openly discuss their concerns and seek information. HCPs play a vital role in follow-up consultations. Still, some PLWD indicated their disappointment with poor to no relationship with different HCPs and required the service to change. It was expected that the health facility would implement a better support system. Due to dissatisfaction with HCPs, they prefer family support. The participant described how he had drawn from the behaviour of his sister and brother-in-law and got indirect support pertaining to diet and exercise. Related to negative opinions and their experiences during follow-up visits.

In the sub-theme Support, HCPs, Hospital care and Treatment., the question was, “From 2015 until last year, when the blood sugar was a bit out of control, what do you think was the cause of it?”.

“OK it was my behaviour, my personal behaviour, not to follow strict, to follow a strict diet process. The bad behaviour of me eating sweet stuff but I'm not supposed to eating what do you call this what do you call this thing now, rice and starch, that was my main problem, bread, those three things”. “They say I must eat bananas. Still, then the dietitian said no, I must stop eating bananas, so I am a bit confused” (INTP2/S1-P5).

“I don't test every day; I test maybe every three or four days” (INTP2/S1-P12)).

“One day I forget to drink it, maybe I will hurry and then I forget to drink it on the specific time I am supposed to drink” (INTP2/S1-P5).

“My pills are collected monthly, so I drink every day” but indicated further that “No pharmacist says anything, he doesn't ask questions, doesn't say anything, just issues my pills and that's it, there I go”.

“The pills are the most difficult for me, I think for anybody that has diabetes, every day you've got to take your medicine, it is a burden”(INTP2/S1-P14).

In the sub-theme: Disease profile and Diet., the question was, “From 2015 until last year, when the blood sugar was a bit out of control, what do you think was the cause of it?”.

“In the beginning, in 2001, when I had slight angina or the cause of that was the cholesterol, so from that time onwards, I know what I supposed to eat or not to eat” (INTP2/S1-P5).

“I've been a diabetic now for technically speaking 2008 this will be 12-14, no 15-16 years” (INTP2/S1-P6).

a) *Implications and effects of a patient support system*

Luan et al. (2017:1172) and WHO (2016a:4) confirmed that diabetes is progressive and requires lifelong self-care management. This disease is frequently associated with complications and comorbidities. Some participants reported weight issues, hypertension, other cardiovascular problems, cholesterol, gout and arthritis, asthma, diabetes neuropathy, and retinopathy. These complications and comorbidities influence their physical, social, and psychological well-being. Even though clinical management of diabetes focuses on physical health and glycaemic control primarily while out of hospital, individuals must concentrate and commit to self-care. The emphasis of satisfactory blood glucose control is an individual responsibility which contributes to quality of life if it is done correctly. However, some PLWD or the family have limited abilities and barriers. A lack of a glucometer and test strips are barriers that prevent regular blood glucose monitoring. Some individuals obtain their resources via a private medical scheme or designated health service, while public hospitals are unable to issue these resources. Regular blood glucose monitoring supports positive behaviour that might reduce stress. A sound patient support system is viewed as not only a means to assist when PLWD experiences difficult or uncertain times but should serve as an enabler for self-care if a patient support system is improved.

The responses suggested that despite recommendations or medicine adherence strategies from the pharmacist, there was a level of compliance to medicine treatment. Different pharmaceutical companies provide original or generic products to the market, which is confusing for some patients due to different packaging and designs. This argument is linked to medicine adherence where pharmacists play an extremely essential role. INTP2/S1-P14 was diagnosed just over three years ago showed negative responses towards medicine treatment and disclosed that he stopped the insulin after three months and is using African herbs for blood glucose control, stating *"I also use some herbs but I do not go to a traditional healer."*

Some of the participants had different views on dietetic service and support and inconsistency in dietary requirements were observed. Blood glucose monitoring was inconsistent. The responses revealed that some knew the importance of and how to control the blood glucose with diet but did not follow through. Some mentioned that they were on treatment for complications and comorbidities such as hypertension, high cholesterol, arthritis, etc. One male participant mentioned that diabetes medication has side effects and deliberated extensively on erection problems by diabetes males, presuming it is a worldwide problem. However, he complied with the treatment but suggested that research on this sensitive matter could be helpful.

5.8.2 Theme 2: Impact and effects of self-care aspects on the psyche

The aspects of self-care were integrated in various sub-themes for this study. Diabetes self-care management is complex and must be viewed in an integrated way to gain insights into the impact and effects self-care aspects have on the psyche. The sub-theme describes the aspects of self-care according to participants experiences and is presented with quotations in their own words. To understand the impact of diabetes and the effect on PLWD, sub-sub-themes of self-care, self-care activities, lifestyle, behavioural conduct and challenges, blood glucose monitoring and reminders were identified.

5.8.2.1 Sub-theme 1: Aspects of self-care.

This sub-theme is presented integrated within the categories of (1) Support and HCPs, (2) Support, HCPs, Hospital care and Treatment and (3) Disease profile and Diet. In the categories of Support and HCPs. Self-care and Self-care activities, Lifestyle and Behavioural conduct and challenges, self-care is the deliberate decisions and actions of PLWD to take responsibility for their diets consciously, physical activities, adherence to medicine and medical prescriptions, and psychological well-being (JEMDSA, 2017; Omisakin & Ncama, 2011:1734). Diabetes self-care management is demanding and requires commitment from the PLWD but with support from family, friends, and HCPs within available resources. The ability to meet self-care demands is imperative. Peñarrieta et al. (2015:78) investigated the relationship between self-care management and families. To reflect the experiences of self-care as a PLWD to care for themselves.

The question asked: “How do you, as a diabetic, experience and care for yourself in living with diabetes?”

“I then took a conscious decision to stop drinking, so yeah, I've stop drinking for the past 12-13 years”; “I can honestly say that it's a mental shift that has taken in”. “I'm trying to get into a better physical condition because any problem, that if you're physically better, exercise more, and diabetes becomes controlled” (INTP2/S1-P6).

“It's an adjustment to be a diabetic because you have a whole lifestyle change, so it took a little while to adjust, but once you're in it, you know what to do”. “So the most important thing is you have to look after yourself, you have to adjust your meals correctly” (INTP2/S1-P3).

The question asked: “Speak about what physical activities you are doing”

“Currently, I'm not active in any physical activities due to certain reasons. My workload, the only time I get is over weekends. During the week is very difficult for me because I leave home very early in the morning, 5:00 o'clock

in the morning, and then I come home late, around about 5:30 or past five or the latest, 5:30 and then you are tired. You don't want to take the walk as recommended by the medical professionals. So it is only on weekends, at work yes, you get an opportunity to take part, but for my situation, I can only take part in physical activities on medical supervision because I have this heart problems" (INTP2/S1-P5).

"changed lifestyle by not taking a local taxi to the taxi rank, walks to the taxi rank. It is safe because there are many of them walking at that time" (INTP2/S1-P15).

"... it is also unsafe to walk, especially in your old age. You don't take a walk; you don't know what can happen. And also, how do you carry the stuff back that you bought" (INTP2/S1-P12").

In the categories of Self-care activities, Reminders, Behavioural conduct and challenges, the question asked: "Speak about what physical activities you are doing".

"I have it on my phone" and "I've got my pill box that I pack every day"(INTP2/S1-P1)

"I've got alarms set to remind me, and I think that's important thing is that if you got a busy schedule is to set reminders, set alarms so now we have long meetings, also ensure there is a snack available, and the medication is close by" (INTP2/S1-P6).

The fact that they set reminders to take the medication was their way to ensure they took the medications at the prescribed times and showed commitment and responsibility. This is a positive step towards positive behaviour and lifestyle changes. In the category of Blood glucose monitoring, the question asked: "Do you understand how the machine works?"

"I understand properly with the help sometimes of my wife and my sisters. Both of my sisters are also in the medical profession. They are nurses and, on many occasions, when I don't understand the readings and so on. I called them and ask, and then they will guide me on what it means and what the desired results are to keep my sugar levels intact" (INTP2/S1-P5). "I also test my blood myself every morning as soon as I get up, then I write it down in a book" (INTP2/S1-P13).

"I was still drinking excessive alcohol, drinking energy drinks, soft drinks and it happened in 2008 that I actually end up in high care hospital in the hospital cause my sugar levels were uncontrollable. It went to the extent that it actually went over the 28-29 mark. I spent about a week in the hospital" (INTP2/S1-P6).

"testing every morning and evening," "I have a pattern in the morning of when I wake up, immediately test my sugar," "before I go to eat that I always test my sugar, 30 minutes before I eat it is now for morning and for evening. And then at 22h00. I test my sugar again before I go to bed." (INTP2/S1-P13)

"My high sugar is 16 or 17 but then it is also what did you eat that the sugar is so high. And then, if the sugar is high, then I will inject myself with the dose for the evening." This showed that the person attempted to keep the blood glucose at satisfactory levels. Another response was, "... stick to the 5:00 o'clock, but I always make sure that I do take insulin before I go sleep." (INTP2/S1-P13)

The question asked: "What is your normal pattern, how you eat"

"OK, it was my behaviour, my personal behaviour not to follow strict... to follow a strict diet process. The bad behaviour of me eating sweet stuff but I'm not supposed to, eating what do you call this, what do you call this thing now, rice and starch, that was my main problem, bread those three things", "It's not as the dietitian said to me, that is not desired way, I carry on..." (INTP2/S1-P5

"my wife's Indian so it was a bit of a challenge in terms of the dietary applications"((INTP2/S1-P6).

a) The self-care attributes impacting on the effects and aspects of the psyche

The person admitted that his behaviour and lifestyle played a role in poorly controlled blood glucose. Based on the Patterns identified, it is evident that there were some differences in when and how they checked their blood glucose. McLaughlin Renpenning and Taylor (2003:217) describe self-care as the actions of a person who acknowledges self-needs and decides how and what they want to do in taking care of themselves. Effective diabetes self-care management is viewed as the behaviours and activities or tasks which are performed daily to manage the condition and to avoid or delay complications (Hilli et al., 2018:36; Reid et al., 2018:122). In view of the category Behavioural conduct and challenges, emotional well-being is an important aspect of self-care practises. Positive feelings and good health influence self-care. Negative feelings and thoughts influence behaviour and affect how people practice self-care. It is expected that PLWD must follow complex aspects like positive lifestyle adjustments, which define how they behave during self-care.

The findings revealed that self-care aspects include an active, healthy lifestyle, dietary advice, blood glucose monitoring, compliance with treatment, adherence to consultations and advice, follow-up visits and a sound self-care routine and if not followed, it might delay or prevent complications. During follow-up consultations, insulin dosage or medicine treatment is prone to change. Therefore, the PLWD must know how to administer the insulin and the medication. Foot care and advice by a podiatrist can prevent diabetes neuropathy, just as annual or bi-annual eye tests might prevent diabetes retinopathy.

For the same reason, adherence to dietary advice might help with weight issues and keeping blood glucose at acceptable levels. PLWD can significantly reduce the risks to develop complications, that is, by improving their activities, however, some need support, knowledge, and encouragement. To understand if they were able to operate the glucometer to monitor the blood sugar and have an understanding that the glycaemic readings must be maintained at acceptable levels, The essence of blood glucose monitoring is the information or glucose reading that is obtained which allows for the HCPs to assess the readings and adjust the therapy. Blood glucose testing was a routine, unlike those who tested when feeling unwell, and it indicated that some were more cautious about glucose control than others To gain insights if they follow a suitable diabetes diet, they had to responding eating patterns. Some PLWDs endure problems with self-care; these are referred to as barriers, and they must be removed. Based on employment status and discussions during focus groups and telephone interviews, participants highlighted the unaffordable diabetes products, hence, from a socio-economic perspective, services and products must be affordable, assessable, and accessible. Not all PLWD can afford expensive private medical insurance but must rely on free or less expensive state resources.

PLWD usually approaches HCP for guidance. Some of the participants complained that HCPs do not spend time giving guidance or doing proper health evaluations to discuss their concerns and perceptions. The importance of this is that the PLWD are depending on HCPs for recommendations for self-care activities, it was noted that most participants consult Google. They might misinterpret information from this online platform, even if the information is accurate. The risk of following online information might be totally misunderstood. They might need clinical interventions and are not in a position to make assessments.

5.8.3 Theme 3: The value of knowledge and information in self-care

Knowledge is a key aspect of self-care. Alemayehu, Dagne and Dagnaw (2020:1) wanted to determine the knowledge and associated factors of diabetes. Their perception was that diabetes can enable diabetes complications. Further, an insight into the general knowledge base and associated factors of PLWD the category of seeking information and knowledge were identified. It was anticipated that these aspects would translate to actions of the knowledge to self-care.

5.8.3.1 Sub-theme 1: Enhance general knowledge.

This sub-theme is presented integrated within the category of Knowledge and information and showed consistent significance when participants shared their experiences of diabetes self-

care management. The values of knowledge and information to gain first-hand information how the PLWD can enhance their general knowledge. The sub-theme is identified as to Enhance general knowledge under the category Knowledge and information. This category is described through the lens of participant experiences in their own words. In the category of Knowledge and information, participants must have acquired a level of information and knowledge about diabetes self-care management.

The questions asked: “Tell me how informed you are about diabetes.” and “Where do you get your information from?”

“I’m not 100% informed, yes, but I read magazines going social media, Google and yeah... I’m in conversation with different groups members of the community who also suffer from this thing of diabetes”, “they (the family) don’t understand it because they are not aware of it, they are not exposed to it, yet it’s only myself who told them the dangers of PLWD” (INTP2/S1-P5).

“Okay, I suppose apart from the leaflets and stuff I read, sometimes they’ll tell me to attend a seminar or something in connexion with diabetes or so and my doctor will also say at such and such a time there will be a discussion on diabetes whatever and please try to attend”, “the day when I was discharged I got a booklet that deals with PLWD I still have it, it’s in my shelf I’m reading from time to time”, “I was also googling”(INTP2/S1-P9).

“Because I like to read, I read a lot so I go to Google about diabetes” (INTP2/S1-P13).

a) The value of knowledge in diabetes self-care management

Knowledge and information are essential in gaining understanding of diabetes self-care management practices, such as behavioural changes, healthy eating habits, physical activity, blood sugar monitoring, taking prescribed medication as directed to better manage diabetes related issues, and choosing how to handle particular challenges, is the main goal of knowledge and information. Gaining knowledge about these factors may help lower risk and slow disease progression (Hilli et al., 2018:36; Reid et al., 2018:122). Therefore, it was necessary to determine their level of expertise in order to understand how they practise these activities.

Diabetes education is imperative (Allie et al., 2017:22-23). The findings revealed that any form of education was lacking. Participants approached Google to find answers to general questions about their health condition. While this action was not absolutely rejected, it was disappointing that the health facilities, for various reasons, was unable to provide relevant informational sessions. It is expected that PLWD practice effective self-care, in this context,

effectiveness extent to the limits of the PLWD. Participants did not divulge significant information about family support, but it was noted that implementation of self-care management practices for PLWD in Tshwane needs the family to support them. They verbalised mixed viewpoints towards HCPs, which need to be addressed. It would be ideal for HCPs to take adequate time during consultations and discuss the concerns of the PLWD, which will enable the person to make informed decisions and cooperate. The notion was that the participants were uncertain about the HCPs' position and, therefore, did not foster a trustworthy relationship or ask for guidance. A sound support system need not be formalised, it must be available. Formal educational sessions are not required. Education, training and information must be provided at the organisational level where the individual and the family gain knowledge. If this matter is not addressed, PLWD will continue to approach Google, and they are not in a position to make informed decisions about clinical or pharmaceutical interventions. Much more is thus expected from the health facilities and staff to capacitate PLWD with relevant knowledge and skills..

5.9 CONCLUSION

Chapter 5 presented the findings of Phase 2 Stage 1, where data were collected from PLWD through a focus group and telephone interviews. The data from both methods were analysed through coding and thematic analysis. This study focussed on one of the recommendations of Chapter 5 of 2017 SEMDSA guidelines, which is dedicated to DSME/S, which implied that care should be “patient-centred, respectful and receptive to individual needs and values; and non-discriminatory towards cultural, ethnic language, socio-economic and educational differences” (Allie et al., 2017:22). From this recommendation, it was clear that patient/person-centredness, individual values and needs are key therefore individual account of their experiences were important. With a sound family support system assisted by HCPs, self-care practices might enhance on condition that PLWD receives adequate information through education and information sessions.

In spite of the fact that focus groups and interviews are highly regarded as qualitative data collection methods, this study discovered that establishing a focus group was particularly challenging for several reasons as mentioned in sections 3.7.7, 3.8, 8.6.4 and 8.6.9. It is suggested that researchers rethink the data collection method if there are factors of language barriers or if there is a need to alter the data collection method during the research. The researcher was confronted with the obstacles of hard-to-reach participants with subsequent compromises. The COVID-19 period changed the academic landscape. Lessons learnt during

this research study is the significance to employ pragmatism in future similar situations, with reference to research methos and informed consent..

CHAPTER 6

FINDINGS OF SELF-CARE MANAGEMENT EXPERIENCES BY THE FAMILY (PHASE 2, STAGE 2)

6.1 INTRODUCTION

This chapter investigate how the family cares for and support a person who has been diagnosed with diabetes. The objective which guided Phase 2 Stage 2 was to explore self-care management experiences of the family members of PLWD in diabetes self-care management.

6.2 SELF-CARE EXPERIENCES BY THE FAMILY

Diabetes is a progressive disease, and as such, life-long self-care management is inevitable (Luan et al., 2017:1172; WHO, 2016a:4). The corresponding excerpts undoubtedly revealed that family support is essential. Wichit et al. (2016:38) reported about the crucial role a family plays in the care and support of a PLWD. However, he reported on inconsistent family-oriented healthcare programs which should assist the family in taking care of the PLWD. This author recorded his findings and disclosed that family interventions were for Type 1 PLWDs. Like Wichit et al. (2016:38), care and support include medicine adherence, health diets, skin and foot care and physical activities and confirmed that DSME (diabetes self-care management and education) had not been standardised and a multidisciplinary team approach lacked, this study report on the same.

6.3 THEME 1: ESSENCE OF FAMILY SUPPORT

The four sub-themes can stand alone but when integrated can form one main theme (Essence of family care and support). Each of the four themes had a singular focus and even though the codes were not repetitive, the themes showed a relatedness to the questions. As illustrated in figure 6-1, the main theme consists of four sub-themes, (1) HCP influence on family in supporting a PLWD (2) Psychological influences on family, (3) Health system improvement and support and (4) Glycaemic control.

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oriented healthcare programs which should assist the family in taking care of the PLWD. This author recorded his findings and disclosed that family interventions were for Type 1 PLWD. Like Wichit et al. (2016:38), care and support include medicine adherence, health diets, skin and foot care and physical activities and confirmed that DSME (diabetes self-care management and education) had not been standardised and a multidisciplinary team approach lacked, this study report on the same.

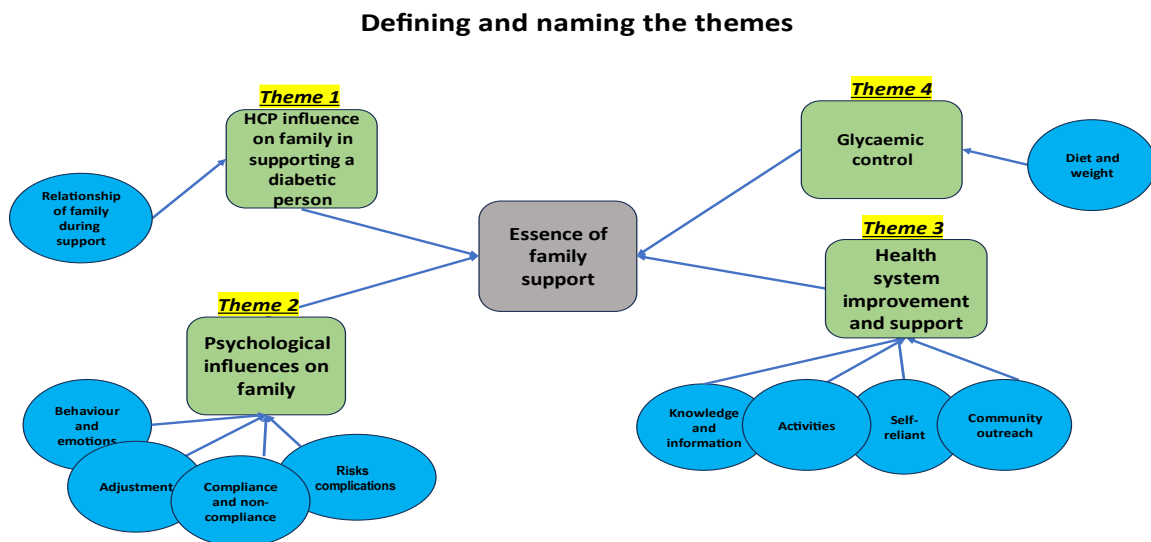


Figure 6-1. Integrating the candidate themes into one main theme

The following verbatim responses of all themes came from the focus groups and telephone interviews. To understand the Essence of family support their experiences and support were explored as aligned with the Phase 2 objective. The question asked: “How do you experience caring for and supporting a family member who is living with diabetes?”.

“It is really an ongoing challenge” (FGP2/S2-P6).

“Sometimes it ends up, you know, in having to have harsh conversations, not always with the effect that you would like to have” (INTP2/S2-P2).

“I can assist him and teaching him and then, but sometimes it's like, you know, a horse, taking the horse to the water, but you can't make him drink” (INTP2/S2-P2).

On the question asked, “What adjustments have you had to make to care for and support a family member living with diabetes?”

“we also had to adjust the way of eating, looking up salt and sugar and making better choices (FGP2/S2-P7).

"it's a sacrifice that I had to make. I spoke with my wife, and I said, this is what I want to do. Therefore, there is no price to it" (FGP2/S2-P9).

"We had to accept the diet of a person with diabetes because they prepare food in a way that is still for a person with diabetes but the salt and all, that type of thing. So for them, it became a challenge to accept such a diet because then it becomes tasteless," and "they starting adapting to the diet and also eating the same diet now as a diabetic and slowly getting used to it"; "they used to cook some separate diet for the mother and themselves. It becomes cumbersome, so let's just all eat what she eats"(FGP2/S2-P6).

"There's not much communication with the patient in terms of, you know, have you thought of this, have do that in terms of your diet. Thinking maybe I should refer this person again to the dietitian. I took him again to the dietitian so that she could again explain to him in front of me now that I'm almost also on pension, I will go with him to his medical appointments to ask questions" (FGP2/S2-P7).

"It started running because it could not just be abandoned because there were clients that needed service, which irrespective of him lying in bed. So, it was quite a challenge for me having to stay a whole year just to take care of business (FGP2/S2-P9).

a) Support from Health Care Professionals(HCP)

The question asked was, "How can HCPs better support you in caring for and supporting a family member living with diabetes?".

"Then came Covid, which I fully understand, but suddenly, the only illness that was "available" for anybody was Covid. Nobody worried about heart conditions, about diabetes, or the diabetic or hypertensive patient that had to follow up. So the doctor used to write the script, and you collected the script whether it will be that I just give you the script, it's fine" (INTP2/S2-P2).

"a new guide that she (dietitian) gave"; "in the hospital he got the wrong diet so even though the dietitian was involved, they put him on a sliding scale because his sugar was 23, 24 which very fluctuated a lot" (INTP2/S2-P2)

"That really just went down the drain, maybe with shortage of personnel I cannot find the real reason for that"; if there's a doctor they don't listen to your heart they don't listen, to you know they don't do the blood pressure themselves and they don't really ask you any questions" (INTP2/S2-P2).

"we don't belong to any group or organisation that relates to diabetes, no, not at all" (INTP2/S2-P3)

“normally when you go to a clinic, even if you got to the sick bay, especially if there's a doctor, they don't listen to your heart, they don't listen to you, they don't do the blood pressure themselves, and they don't really ask you any questions”.

“like a wors machine going, that they can tackle the next patient only by her and that can also be because she's in a hurry. That can also affect into maybe have less empathy with the patients or maybe this not really taking the personal needs to heart” (INTP2/S2-P2).

While this pandemic created havoc, the PLWD was extremely vulnerable, and the family experienced dissatisfaction with some services, had negative emotions and anxiety. The findings revealed that even though the family complied with the guidance on diet and meal planning suitable for the PLWD, the HCPs in the hospital ignored the guidelines. The family voiced concerns that HCPs neglected other diseases during the Covid-19 pandemic. The participant further opines that healthcare was deteriorating, The participant anticipated that to ensure adherence truly, PLWD must fully comprehend their condition, the short and long-term effects of their condition, how their prescribed medication will resolve their condition, how to take their medication, their medication's potential side effects, how to prevent or address side effects.

While it involved factors such as refilling and collecting new chronic pharmaceutical prescriptions, the pharmacists failed to advise on medicine adherence. In view of this, it is anticipated that medicine adherence failed because neither the PLWD nor the family understood how to take the treatment regime. The family was dissatisfied with how the PLWD were managed during consultations. Some excerpts revealed that the doctor did not really care about the patient and just wanted to get quickly to the next patient. While some perceived poor service it cannot be generalised across all health facilities. However, there was a staff shortage for the day, and the doctor-patient ratio was non-aligned. Despite the skewed picture of staff ratio, it is expected that family support must be exceptional.

Participant INTP2/S2-P2 expressed that she was at times impatient and had arguments with the PLWD for not following through on the correct things. Despite continuing to support the spouse, her efforts were in vain because he did not comply to the extent that she wished him to do, which initiated these harsh conversations and arguments. She continues to express her discord. Drawing on these excerpts, the responses revealed that care and support for the PLWD was not easy, and it influenced them psychologically.

The excerpts for Theme 1 reveal the essence of family support and how the family perceived and experienced support from the health facilities and HCPs by showing dissatisfaction with

the support implied that HCPs neglected other diseases during the Covid-19 pandemic. It is a concern that participants implied poor or non-existing interaction between themselves and HCPs and subject it skews staff-patient ratio. Family members must make adjustments as disclosed by FGP2/S2-P9 that he was a technical expert and had to quit his full-time employment to relocate to his parental home to care for and support the father and the business. Being a technical expert to develop a new or temporary skill was a challenge which also align with the excerpt *"It is really an ongoing challenge"* (FGP2/S2-P6).

This statement augments the opinion of another participant who explained that her family lived in the Eastern Cape, and whenever she wanted to visit them, she first thought of the person she was supporting. She elaborated on her feelings and said that it was an adjustment, and it became a bit difficult because she was anxious that something might happen to the PLWD in her absence. According to her response, she disclosed a level of anxiety which was ascribed to previous experiences where she lost two family members and is still blaming herself for their deaths. It indeed had a psychological impact on her psyche.

Even though the 2017 SEMDSA guidelines had been adopted for the management of diabetes, none of the participants reported on a formalised program that could ease their knowledge and skills in dealing with the hardships to care for PLWD. They expressed their dissatisfaction with the service provided by HCPs in general. According to Wichit et al. (2016:40,45), families in Thai society are informal carers and relatives who support their parents, siblings, or spouses. Another finding was that the Thai families focused on dietary support. This was accepted as a true reflection of what the participants in this current study had disclosed. It is thus confirmed that the findings of this study discovered that the support given to the PLWD in Thailand correspond with some activities in SA. The next section presents the four sub-themes in relation to the respective sub sub-themes as pointed out in the main theme, Essence of family support.

6.3.1 Sub-theme 1: HCP influence on family in supporting PLWD

This sub-theme is integrated within the single category of relationship of the family during support. The question asked, "How can HCPs better support you in caring for and supporting a family member living with diabetes?"

"I do get the regular stuff to read from the medical aid, I think I'm about informed about that, I do also read what they send me via e-mail or messages, I do read" (INTP2/S1-P8).

"I'm reading books and pamphlets about diabetes to better my knowledge. My mother had Type 2 diabetes as well, and I researched the management of diabetes to assist my mother" (INTP2/S1-P10).

a) The influence of HCPs on the family who support a PLWD

This study examines the influence HCPs can exercise over the family that support PLWD. Understanding the participants' perspectives was essential to comprehending the fundamentals of a successful support system for the family. The participants data highlight the importance of family support and how the family viewed and experienced assistance from medical facilities and healthcare professionals. The family's discontent with the help suggested that medical professionals overlooked other illnesses during the COVID-19 pandemic. Concerns have been raised about participants' inferred poor or non-existent interactions with HCPs and the resulting unbalanced staff-patient ratio. Self-care is defined by McLaughlin Renpenning and Taylor (2003:217) as the acts of an individual who recognises their own needs and chooses how and what to do to take care of themselves. This is relevant to PLWD, but self-needs are applicable to families when they acknowledge family assistance.

6.3.2 Sub-theme 2: Psychological influences on family

This sub-theme is integrated within four identified sub sub-themes of Behaviour and emotions, Adjustment, Compliance and non-compliance and Risks and complications. The question asked, "How do you experience caring for and supporting a family member who is living with diabetes?".

"Sometimes I get cross. And that seems also not to bother him (FGP2/S2-P6).

"She said she did go for counselling, and she came right with it, but at times, she recall the incident, and then it still pain her a bit to know that had she'd known what to do, then it could have been avoided cause all that she did was she couldn't test the blood glucose because she did not know how to use the machine and therefore she went on to give the injection without knowing so she always think bad about it because maybe she might have caused the death (FGP2/S2-P5).

It's a sacrifice that I had to make. I spoke with my wife, and I said, this is what I want to do. Therefor there is no price to it (FGP2/S2-P9).

a) The psychological influences on the family when supporting PLWD

Self-care includes using a glucometer to measure blood sugar levels, ensuring that medications are taken as prescribed and that a healthy diet is followed to control the glycaemic

levels. Even though it was anticipated that PLWD would be able to take care of themselves outside of a hospital setting, the findings revealed that they required support from the family, community, and HCPs to carry out some of these functions. However, because support for PLWD comes in large part from the family members, the family needs knowledge and skills to enable adequate support. Kaakinen and Denham (2015:237-244) claimed that families must learn how to manage a PLWD and emphasised the different roles and obligations due to frequent unanticipated changes.

Drawing conclusions about various facets of social life, wellbeing, and physical health was made easier by some of the findings. The family too take responsibility for self-care and ensure PLWD carry a glucometer, test strips, and insulin or oral medication when they attend social events, doing so unintentionally exposes their illness. If it was meant to keep their health condition discreet and confidential, this has an impact on psychological well-being and creates ongoing, needless pressures. The family should be available and skilful to deal with concerns of psychological issues, however, they too are under stress if they do not know how to intervene.

According to Hakkarainen et al. (2017:3-5) PLWD spent over 60% of their time at work which may increase stress with a spill over to the family. If the health condition is not reported, self-care is compromised, which results in psychological stress. It is important for the family to observe the person closely and suggest professional help.

Some of the findings were useful for making deductions about various facets of social life, mental health, and physical health. When attending social events, persons with type 1 diabetes frequently bring a glucometer, test strips, and insulin or oral medication; however, this unintentionally reveals their health condition. This impacts mental health and creates ongoing, needless pressures if the goal was to keep their medical condition hidden and confidential.

6.3.3 Sub-theme 3. Health system improvement and support

This sub-theme is integrated within the four identified sub sub-themes of Knowledge and Information, Activities, Self-reliant and Community outreach. The question asked, “How can HCPs better support you in caring for and supporting a family member living with diabetes?

“I do share with him (information), not the negative, but the general things I share”; “My husband will follow the rules and all the information that he has very strictly, and he will get the results”; “He knows what he should and

should not do”; his mother also had diabetes, and he also knows you know, what the complications and risks were when she was not adhering to a diet. You know, she landed up in hospital in a coma” (INTP2/S2-P2).

“if there are new developments, I will definitely share with him. Yeah, that I can say about reading material, something that got in now, the Internet, to see if you need any info. He likes reading on the Internet” (INTP2/S2-P3).

“We had instances where he woke up with the sugar very low. Say like below 2. Because then they did not understand when he goes to bed what really it has to be. Now, he is starting to wake up, and his sugar level is stabilised. So, when he goes to sleep, he checks that he has eaten enough, and they gave him a snack before bed” (FGP2/S2-P9).

“...like how to test the person’s blood, the course for machine. The vital signs for, and this is the machine. Basically, how to respond to the diabetic. She knows a little bit but should like to learn more” (FGP2/S2-P5).

“My sister has also mentioned that she struggles with operating the machine as well. I tried and educate my mother just to know how to deal with the situation. Learning how to inject him and just getting used to the medication that he takes. As well as just understanding what Type of food does what for his diabetes” (FGP2/S2-P9).

“Clinics are full people are standing before from early morning, five o’clock, 4:00 o’clock, etc. because there is no time or they ignore time OK to do all those services, but those services are available, and they are there to support at significant others” (INTP2/S2-P3).

“will be great advantage for the community. It’s a very good point he is raising. It could be a nice thing if the health facility can be brought to the communities. Something like because diabetes is that it doesn’t have the age. It now affects everyone. This is what they can do for PLWD and those who have it can start to get the proper medication before it gets complicated. And they may sometimes postpone to start come to the clinic or hospital” (FGP2/S2-P9)

“like the doctors and the nurses can actually have a service like we are having now to educate us as supporters to PLWD” (FGP2/S2-P6)..

“it was COVID, the outreaches to the community it is something like this, it can be done, and we don’t only have to do it for HIV or for TB because, yes, it is reality diabetes is one of the worst and most in numbers, relevant illness in the community and in the population all over” (FGP2/S2-P7)..

“I think that doctors must be more caring and must see the broader picture and not just diabetes, yeah I mean, nobody’s ever asking take off your shoes, said it I can see your toes” (INTP2/S2-P2).

a) Employing knowledge and information to contribute to health system improvement

The importance of this theme reveals the family must have knowledge and information to care for and support a family member diagnosed with diabetes. Powers et al. (2017:40,42) posit that DSME/S form the basis for self-activities and decisions to improve health. From this viewpoint, it was anticipated that HCPs and health facilities must provide some level of relevant educational programs, to the family in dealing with support to PLWD. Such programs will facilitate skills and knowledge which will alleviate psycho-social and behavioural aspects. However, the findings revealed that the HCPs or the health facility did not capacitate the family with skills, knowledge, or information. One participant confirmed that she knows a little bit but should like to learn more. This statement implied that knowledge sharing of certain activities for supporters was lacking. These activities referred to a blood glucose test to understand the glucose reading and other vital signs.

According to Powers et al. (2017:40), DSME facilitates knowledge, skills and abilities, and the programs must be designed inclusive of health beliefs, cultural needs, current knowledge, physical limitations, emotional concerns, and how the family can support the PLWD. Some self-acquired knowledge and information although they did not attend educational or informal informative sessions at the health facility. In view of these excerpts, DSME was lacking, and it was anticipated that it must be addressed

b) *The importance for the health system to promote self-care activities*

The findings revealed that the participants want doctors to be caring and to provide a holistic service that include diabetes related illness, and not only to concentrate on the glucose levels during a consultation. They found that HCPs hardly do a foot inspection. Even though it is strongly advised to participate in physical exercises, none confirmed their involvement with physical activities or referrals to biokinetics to suggest an exercise program. Meal planning and blood glucose monitoring are crucial components of self-care. It was previously believed that individuals with type 1 diabetes had a lower body mass index (BMI), but new research revealed that obesity rates in this population were rapidly rising (Mottalib et al., 2017:2). These scientists also pointed out that insulin treatment contributes to weight gain. Weight and glucose can be managed through activities. They recommended more physical activity, but they also noted that people with PLWD were hesitant to engage in physical activities because they were cautious of hypoglycaemia, which had an effect on their mental health. If one's health permitted it, physical exercise might be done freely and simply without a biokineticist.

c) Self-reliance with diabetes self-care management

Some of the PLWDs were self-reliant but the family confirmed that they oversee certain activities. Self-reliance and cooperation confirmed that there is good understanding between the family and PLWD, their independence is acknowledged, and they took responsibility for their illness. Another mentioned that they had changed the diet to accommodate the PLWD because preparing separate meals was cumbersome, however, they noted the food was tasteless but adjusted later.

Support to a PLWD can be emotionally and psychologically challenging and might impact relationships. PLWD who were self-reliant were still supported psychologically and emotionally. Their family listened to them and gave advice, although they did not always follow through. The family could discuss issues that bothered both and remind them and check if the medication was taken, if the blood test was done, search for information and adjust food items. That showed support and encouragement instead of making the PLWD solely reliant on the family. It is worth noting that even if the family did “nothing”, they were emotionally supporting the PLWD.

d) Community outreach to support of PLWD

A Community-based outreach health facility may enhance follow-up visits due to accessibility. These programs might expand service and extend to remote and disparate areas. These initiatives are focused on protecting and promoting health. The majority of patients get to a health facility early in the morning and leave in the late afternoon to return home. The findings suggested the establishment of community outreach programs for health services. Due to the unaffordability and accessibility, such programs might support accessible services for the community.

6.3.4 Sub-theme 4: Glycaemic control.

This sub-theme is integrated within the sub sub-themes of Diet and Weight. The participants had their own ideas on how they stabilised the blood glucose. This was a worrying factor as the findings revealed that most PLWD follow up at the clinic between 3 and 6 months and majority did not have a glucometer, implying that there is a poor history record of glycaemic control. Other participants said that they prepared a peanut butter sandwich and fruit juices to elevate hypoglycaemia quickly and confirmed effectiveness for this home remedy

“But there are ways when my husband was still working, we could help him to pack his lunchbox and have the right things there and maybe have extra peanut butter sandwich, so if he thought or feel he was going low that the rather could eat that” (FG-P2/S1-P7)..

“...maybe take a whole bottle of juice because it can make it difficult to for him and then also to help him” (FG-P2/S1-P9).

A family member mentioned previously that she had harsh conversations and got angry if the PLWD did not comply with regular blood testing. This statement revealed that the glucose fluctuations did not bother the individual, nor was he concerned about his well-being. However, the statements by the family member revealed that she was more than often agitated by the poor behaviour. Therefore, she insisted on accompanying the PLWD to the dietitian for dietary advice and to the doctor to ask the relevant questions which can be implemented at home

In the discussion of glycaemic control (Hilli et al., 2018:36) found that nerve and kidney damage and changes in the fundus oculi were common complications, and it was important to minimise risks and complications if the glucose was controlled. This sub-theme is integrated presented within the sub sub-themes of Diet and Weight.

The question asks, “How do you experience caring for and supporting a family member who is living with diabetes?”

“It feels OK having to look after a person who is diabetic, and to support them and at the same time having this worrisome feeling in he has to go somewhere else and does not see someone else that can be supportive, I'm always try to be there for the diabetic person, I'm generally very happy that I'm there for them” (FG-P2/S1-P9).

“My experience in managing diabetes is uhm, the difficulty of uhm, affordability of healthy living. If you actually think, uhm looked at the prices of normal food, healthy living is unaffordable”. He made an example of “a normal [non-diabetic] slab [chocolate] will cost you about R10 or R15, but if you go for half the size of that, it is sugar-free, it is trice the cost”; “...the losses that we had over the past, especially during the COVID, makes it a bit difficult for us actually to afford health living, especially for diabetes” (FG-P2/S1-P7).

“I agree with him. Yes, it is better than the normal food, it is expensive, it's too much more expensive than the normal food, yes.” (FG-P2/S1-P2).

“At times, I've had the situations where in the family gatherings it would look, I say abnormal when you carry your own lunchbox when everybody having a function, So you find that the communities are not very acceptable of the idea because its, its uh somewhat look like you trying to make yourself better all the time” (FGP2/S2-P9).

“My sister has also mentioned that she struggles with operating the machine as well. I tried and educate my mother just to know how to deal with the situation, learning how to inject him and just getting used to the medication that he takes. As well as just understanding what Type of food does what for his diabetes (FGP2/S2-P9).

“he just finished his script, and you know. The thing is, I would also say they must tell the patient do your blood sugar and even write it down or bring their machine along. I can also check, but because I rely on and think over a period, you don't really know during which the patient is going through a crisis”; “many moons ago, and he's having a little problem at the moment. Is it please also ask the doctor if he can't send you for a sonar for abdominal sonar, to check your liver and to check your gall bladder, maybe your pancreas” (INTP2/S2-P2).

a) *Aspects of glycaemic control*

Diet and weight influenced the glycaemic index and were a concern. Except for one participant, all of them prepared meals suitable for a person with diabetes, and they shared the same meals, though not always at the same time. Another said that they were concerned about the sudden weight loss. The exception was one participant who said the person with diabetes took full responsibility for the grocery shopping and meal preparation, which helped a lot as she was full time employed. According to the excerpts, the HCPs had an influence on the family in their efforts to support the PLWD. It was anticipated that the family's role is essential in supporting a PLWD. However, they disclosed that the relationship between the family and PLWD and experienced that the relationship between the HCPs and family and PLWD was dissatisfactory. This influenced how they interacted with the HCPs, which impacted the family.

It is seldom that they do a finger prick at the clinic, they won't tell and say, your sugar is a little bit high, drink two glasses of water to make sure that you drink enough water because you know it does influence your blood sugar. Her perception was that doctors should give guidelines and tell the PLWD what to do. It is concluded that doctors do not really understand the needs of a PLWD. This family member wants the HCPs to provide a better service and said, if the family member had an interactive relationship with any of the HCPs, she would have drawn attention to the things that she feels they should do.

INTP2/S2-P2 mentioned that they shared the responsibility for grocery shopping and bought appropriate items for the PLWD, Due to the ease of practicality and her work schedule, the husband prepared the meals and ensured that they ate at scheduled times to accommodate the times for the medication or insulin. He did the grocery shopping and prepared the meals. This PLWD was preparing the family meals prior to being diagnosed, and he continued to do

that. He adjusted the food items to what was appropriate for a person with diabetes but had a strong craving for bread. INTP2/S2-P3 tried to reduce carbohydrates and introduced low GI bread. This statement confirmed there is an understanding and cooperation between them because she could explain the risks and complications of hyperglycaemia and he tried to follow her advice.

HCPs should be available even if it is “just to listen” to concerns verbalised by the family. They need support to care for the PLWD where it is required. The unanswered concerns impact the emotions and behaviour of HCPs, families, and PLWD. Therefore, cooperation is necessary to build better relationships and to adjust, which suits all in the process of supporting PLWDs. The lack of healthy relationships with all might influence actions, and the lack of proper actions and skills might cause risks and complications for PLWD. Good relationships can establish a positive attitude toward the treatment plan and imply thus that the family and PLWD will comply. The aim is to establish a life quality, and better relationships with HCPs could help.

Health system improvement and support are the basis for diabetes self-care management, management, and support. In this Phase, the family experienced a lack of knowledge and skills and needed assistance from HCPs. If there is better cooperation between the family and PLWD, it might change their perceptions and could enhance their attitude towards medicine adherence, Glycaemic control, and communication. Medicine adherence is a dual responsibility. People living with diabetes are responsible for adhering to the medical treatment plan, which can be accomplished through cooperation, knowledge, and information if they fully understand the extent of the treatment schedule. They must know how to take the medicine dosage, the reason for taking the specific medicine and the importance thereof. It is suggested that the pharmacist is responsible for explaining medicine adherence when new packages are issued. Adherence and knowledge provision must be easily understandable and to the point on the level that the PLWD or family would understand. One would assume that knowledgeable people are more compliant in adhering to medication. However, to do that, PLWD and the family must be informed about their health condition and know what they must do, why they must do certain things and how to do it. Education level should not be a stumbling block. Formal education programmes could be cumbersome, information should reach the level of the audience. It is suggested that informational sessions linked to DSME for the family and PLWD must be informal. The health facility must support the family with information via sms, appointment and DSME.

Participants expressed their opinions that health systems should better support them, saying:

“will actually make reminders to the patient even to her as the supporter say on a certain day, you need to be coming here to collect your medication, they also don't know when she's supposed to go” (P2S2FG-5).

“where he is attending there is never any support groups for the patients in a group or for the family. They can explain what signs and symptoms to look at, what extra to do, what to do in an emergency, who to phone in an emergency” (P2S2FG-9).

like the doctors and the nurses can actually have a service like we are having now to educate us as supporters to PLWD” (P2S2FG-6).

In view of the central or main theme Essence of family support, which is supported by the four sub-themes, Kaakinen and Denham (2015:323,326) give an account of five levels: (1) the intimate microsystem that includes friends and family as well as what community organisations offer, (2) the mesosystem that fosters interactions among various microsystems and (3) the exosystem that includes workplaces and institutions, (4) macrosystem that is shaped by social and cultural values, and (5) chronosystem that encompasses the dimension of time supportive environments can encourage, foster, and sustain family engagement with PLWD. In view of the diverse levels, it is summarised as the engagement with the family to care for and support the PLWD in his or her daily environment in living with diabetes, and the family that is dependent on the health care system and HCPs to provide effective care.

6.4 CONCLUSION

This study focussed on patient/person-centredness, individual values and needs of the family when giving care and support to a PLWD. As a leading chronic metabolic disorder that affects PLWD they expected care and support by the family, it was anticipated that the family also need to provide effective support to PLWD. However, scarce resources compromised family support. Self-management programs are but one of the key elements to assist PLWD. The families, too, required assistance. This must be provided by HCPs, which include knowledge, information and support from the health care system. It was noticed that the family can assist, but there is a need to put in place strategies on how to provide effective care and support to improve life quality of PLWD. The findings revealed that strategies were inconsistent, and that the family were not included in education sessions, or it was not available. Participants approached Google to search for general answers to their questions and be it not absolutely rejected; it was disappointing that the health facilities lacked in this area.

The family verbalised mixed viewpoints of the support by HCPs and did not have a good, professional trustworthy relationship with them. In reference to HCPs or the health system, a

sound support system need not be formalised; it must be available, and educational sessions could be informal. Support from the HCPs and health system did not meet the family's expectations. In spite of the fact that focus groups and interviews are highly regarded as qualitative data collection methods, this study discovered that establishing a focus group was particularly challenging for several reasons. It is suggested that researchers rethink the data collection method if there are factors of language barriers or if there is a need to change the data collection method during the research.

The international pandemic caused havoc in all domains of society, and the study experienced obstacles. Still, the philosophical foundation selected for this qualitative study and the pragmatic approach are recommended for future similar situations. The COVID-19 period changed the academic landscape, and lessons were noted. Results from this Stages 1 and 2 are transferred to Phase 3 to inform the data in developing a diabetes self-care management tool.

CHAPTER 7

DEVELOPING A SELF-CARE MANAGEMENT TOOL

(PHASE 3)

7.1 INTRODUCTION

The complexities of self-care and support from others require determination and commitment. For that, PLWD, and those who support them need relevant knowledge and appropriate skills to make informed decisions to practise self-care confidently (Powers et al., 2020:1637). Whilst emphasising effectiveness, ineffective self-care stems from inadequate knowledge and skills, which may result in inappropriate care that may lead to associated risks and complications such as obesity, elevated cholesterol, hypertension, CVD, gout, arthritis, asthma, kidney failure, diabetes neuropathy, and retinopathy (Hilli et al., 2018:36; Reid et al., 2018:122). These risks and complications might profoundly influence the psyche of PLWD or their families, which compromises life quality (Omisakin & Ncama, 2011:1734).

The significance of self-care is to enhance quality of life and to create a level of independency. If a recommended treatment plan is followed to maintain physical and psychological well-being, life quality may improve (Omisakin & Ncama, 2011:1734). In addition to controlling the warning signs and symptoms of potential risks and complications, most variables related to dietary requirements, which may control glycaemic levels, would be considered aspects of life quality. Allie et al. (2017:23) advocate a patient-centred approach. This method is predicated on the idea that a PLWD and their family have unique needs, and that each person should be treated accordingly. In collaboration with families, HCPs can play a crucial role in addressing these issues. The researcher suggests that even minimal interventions can substantially improve self-care practices. Through structured training programs, healthcare workers develop the necessary skills to manage chronic illnesses and impart relevant knowledge to PLWD and their families. One can therefore anticipate that they would teach PLWD and the family the relevant information and skills to enhance self-care routines. These initiatives may potentially contribute to delaying the progression of diseases.

Conversely, HCPs who are required to provide formal or informal educational programmes are referred to in this study as formal networks and could aid in diabetes care. Standardised self-care practices are expected to be challenging to apply because of the complexities; nevertheless, through dialogue in Phase 2 it is anticipated that HCPs can help to bridge that gap by assisting PLWD and their families to improve practices, knowledge, and

abilities. Phase 3 outlines the three-stage Delphi process (Figure 7-1), results, diabetes self-care management tool, and details on how PLWD might create a personal daily routine.

7.2 RESEARCH DESIGN, METHOD, AND MATERIALS

The objective for Phase 3 was to develop a self-care management tool for PLWD, useful for the family who support them, but also relevant for HCPs. De Bont et al. (2015:1) emphasised the significance of evidence-based information. Subsequently, relevant excerpts were selected from the focus groups and telephone interviews conducted in Phase 2, to create a database for Phase 3. The Delphi was employed to reach consensus on which material to include to develop a diabetes self-care management tool. Refer to the research design as explained in Chapter 3 paragraph 3.14, Figure 3-9.

7.3 PHILOSOPHICAL APPLICATION OF THE PARADIGM

PLWD and family members shared similar beliefs about diabetes self-care management, these beliefs provided data from Phases 1 and 2 to inform a data base for Phase 3 (Lewis, 2015:19-20). This data creates the basis to develop a diabetes self-care management tool. It is anticipated that a tool could ease the functioning of an individual with complexities associated with self-care management (Chilisa & Kawulich, 2012:9; Feilzer, 2010:7-8; Fiorini et al., 2016:37; Shannon-Baker, 2016:321-322; Schoonenboom & Johnson, 2017:108,110-111). Pragmatism is philosophically grounded in this study design and encourages objectivism and subjectivism and allowed for alternative qualitative methods as better options for emerging problems (Fiorini et al., 2016:40). Based on this view, the Delphi consensus-building technique was employed to inform that relevant information is selected for the development of the diabetes self-care management tool (Hesse-Biber, 2010:56).

From an axiological assumption, ethical clearance was obtained, and values, ethical norms and standards were observed (Cassell, 2000; Fouché & Chubb, 2017; Kivunja & Kuyini, 2017; Vollman & Winau, 1996). The significant elements of the Delphi are aligned with the axiology of the Delphi consensus-building technique, subsequently referred to as the Delphi. One of the key elements is to prioritise anonymity (Gordon, 1994:1,3; Linestone & Turoff, 2002:22). To strengthen anonymity, participants were not asked to provide personal particulars or information about their respective employers. Anonymity preserved individual identities, except for the researcher; nobody knew who else was participating, and therefore, participant responses had equal weight to individual responses (Bowling, 2000:425). Anonymity was ensured in an individual information letter to the participants, and anonymity and individualism were exercised during the data collection process. Participants had to indicate their

professional status as an HCP and years of experience in dealing with diabetes care. All communication between researcher and HCPs took place via individual e-mails, WhatsApp voice notes or messages and telephone calls.

Another irreducible axiological element is controlled feedback (Gordon, 1994:1,3; Linestone & Turoff, 2002:22). This is a structured process where three rounds of questionnaires in Stage 3 were distributed to collect information, leading to group consensus (Bowling, 2002:425). Nasa, Jain and Juneja (2021:117) believe that the Delphi technique is employed to generate a consensus opinion amongst the experts through an iterative process of questionnaires with controlled feedback.

7.4 OVERVIEW AND RATIONALE FOR THE DELPHI APPROACH

The Delphi is a group facilitation technique used to generate ideas, determine priorities, and solve problems. It is a structured method that seeks consensus on experts' opinions through structured questionnaires. The Delphi has been used in various studies to reach consensus. This study aimed to develop educational material for a self-care management tool for diabetes, focusing on managing glycaemic control, day-to-day activities, knowledge, skills, medication adherence, eye care, physical activities, and psychological influences during self-care.

7.5 DESIGN OF THE DELPHI PROCESS

This modified Delphi was designed in three stages as seen in Figure 7-1 to present application in the study.

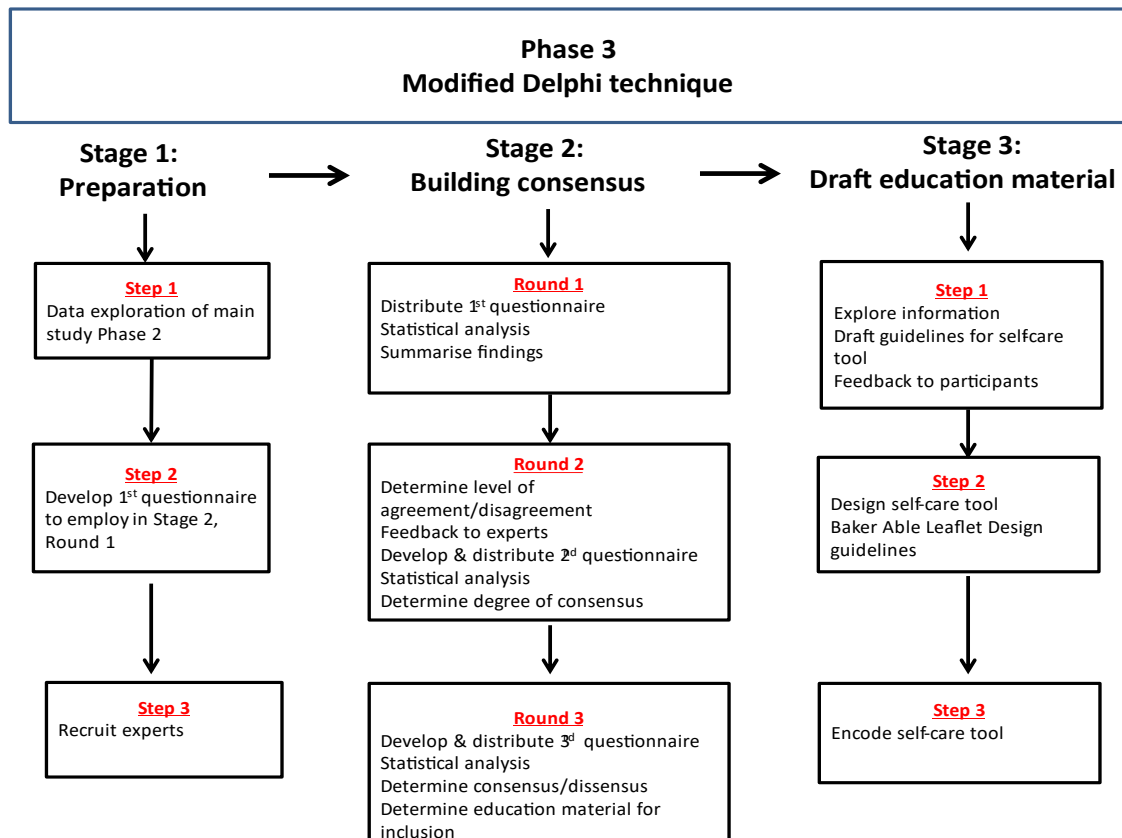


Figure 7-1. Delphi process in three Stages

Each stage built on the other to reach consensus on how participants viewed and responded to the items listed in the questionnaires (O'Hara et al., 2000:63). The Delphi technique is conducted in multiple stages, and each stage is built on the results of the preceding stages (McKenna, 1994:1221). Stage 1 presents the preparation in 3 steps, Stage 2 is a schematic presentation to build consensus in 3 Rounds, and Stage 3 shows the three steps to develop the education material.

7.5.1 Stage 1: Preparation

This stage is comprised of three steps, which briefly explain data exploration in the preceding phase to develop the 1st questionnaire and to recruit the experts for participation in Stage 2.

a) Step 1: Data exploration from meta-inferences of the main study

Data integration gives readers more confidence in the results and the conclusions drawn from a study (McKim, 2017:203). As can be observed in Figure 7.1, meta-inference in Phase 3 was the integration of data from Phase 2, Stages 1 and 2, elaborating and clarifying the results and comparisons and contrasts (Feilzer, 2010:9; Berman, 2017:1,6-7; Teddlie & Tashakkori,

2006:53-54). Phase 3 data enabled the development of the Round 1 Delphi questionnaire, as presented in Figure 7-1

Powers et al. (2020:1636) believe that diabetes care is often not accessible through DSME. The latter concept is viewed as knowledge and skills, which are regarded as essential elements for self-care practises. This knowledge and skills can be acquired through informal and formal activities, which include one-on-one sessions during consultations, information sharing in support groups, self-reading, etc. Even though SA adopted the 2017 SEMDSA Guideline for the Management of Type 2 Diabetes, training programs for HCPs, training opportunities for PLWD and the family, including relevant training for home-based caregivers, was not discovered during data collection, neither recorded in literature studies in the country. When interacting with PLWD or their families, it is crucial to consider the principles and conditions of person/patient-centeredness.

A patient-centred approach amidst diversities could be challenging, and therefore, a modified Delphi was conducted with an expert panellist to identify relevant items on which consensus could be reached. The focus areas were the (mis)perceptions that the family and PLWD had about how HCPs assisted them in managing their diabetes. Hence it became necessary to ask HCPs for their advice on how to support self-care best. Following that, excerpts with an inductive foundation pertaining to the perspectives and opinions of the participants demonstrated the ways in which PLWD and their families attempted to practise self-care. This provided an understanding of self-care behaviours even in the absence of empowerment via DSME. A literature review was conducted to confirm the issues which must be addressed (Belton, 2019:4).

b) Step 2: Development of the 1st questionnaire

Mateti et al. (2015:622) noted the significance of informative material as an internationally accepted tool to guide and educate service users about knowledge, behaviour, and practices in chronic disease management. In support of Powers et al. (2020:1636) argument that DSME produces knowledge, and if skills may be added, these elements were regarded as relevant attributes to improve self-care. It is anticipated that knowledgeable people behave in a certain way and practise self-care differently than those with limited knowledge and skills.

Afshari (2019:178) pointed out that the importance of a Delphi study is to discover the information which panellists contribute, over and above what the researcher provides. In the preceding phase, PLWD and the supporting family participated in focus groups or interviews and shared individual perspectives of self-care. The main task was to transform the verbatim

excerpts into an itemised list to develop a questionnaire for Round 1. Gordon (1994:8) explained that question phrasing is important because subtle changes might influence the responses. Data from Phase 2 (Stages 1 and 2) were combined, of which 210 relevant verbatim excerpts were selected, 81 from Stage 1, and 129 from Stage 2 and created the database for Phase 3 (McMillan et al., 2016:658). The initial excerpts that showed a relationship were grouped in no specific order as (1) physician-related matters, (2) pharmaceutical concerns, (3) services rendered by HCPs, (4) knowledge and skills, (5) ophthalmological issues, (6) activities, (7) general issues related to trust and relationships, (8) footcare and (9) dietary guidelines.

An iterative process of reading, interpretation, and item/statement/question formulation was conducted to identify weaknesses linked to diabetes support and care. These items were reduced to 68. To ensure statistical analysis, the questionnaire was discussed with the statistician and item grouping was re-established as (1) physician behaviour and care, (2) patient-centred care, (3) medication and treatment concerns, (4) healthcare system challenges, (5) foot care and complications, (6) eye-care and complications, and (7) other, the items were reduced to 61. Through the 3rd iteration process, some items showed similar interpretations, and after refinement, the items were reduced to 58. The 4th iteration process was repeated for quality purposes, and the items were reduced to 54.

Some authors (Gordon, 1994:8; Belton, 2017:5; Holey et al., 2007:2; Shang, 2023:4) suggested instrument testing. The 1st draft questionnaire was shared with two non-participating professionals and the statistician for input and to rule out ambiguity. Following three iterative rounds, all items were rephrased and re-selected, and only those deemed not important for a self-care tool were omitted to reduce the final item list to 37. The questionnaire was divided into two sections, of which section A addressed participant demographics and section B enquired about domains of self-care. For each of the items, the question was asked: "Should the following information be included to..." The response options were "Yes", "No", and "Not applicable to my health discipline". Linstone and Turoff (2002:6) stated that one of the failures of a Delphi is not to allow participants to contribute related information. Therefore, the participants were encouraged to provide suggestions for self-care improvement, and they could provide an opinion even if the item or question were not applicable to their specific health discipline.

c) Step 3: Recruitment and inclusion of panel experts

Gordon (1994:3-34) stated, "Because the number of respondents is usually small, Delphis do not (and are not intended to) produce statistically significant results; in other words, the results

provided by any panel do not predict the response of a larger population or even a different Delphi panel. They represent the synthesis of opinion of the group, no more, no less". Zartha-Sossa, Montes-Hincapié, Toro-Jaramillo et al. (2017:109) added that there is no evidence that a large panel size will improve accuracy. Dalkey and Helmer (1963:460) confirmed that the first Delphi study was conducted with seven experts. Variations of the Delphi were conducted on small numbers, ranging from as low as 3, 4, 5 and 7 to thousands (Bloor et al., 2015:62; Dalkey & Helmer, 1963:460; Msibi et al., 2018:5). Others suggested a range between 8 and 23 (Shang, 2023:4; Powers et al., 2020:1637; Msibi et al., 2018:2; Petrosyan et al., 2018:3; De Vet et al., 2005:198; Hsu & Sandford, 2007:3-4). From the above references, the literature was deemed inconsistent in sample sizes.

Delphi studies do not necessitate large sample sizes, as the reliability and validity of achieving consensus are generally not impacted by sample size (Seery et al., 2022:2596). This particular Delphi study commenced with the recruitment of 37 participants of which 21 indicated their willingness to participate. However, 12 participants completed the questionnaire of which 2 were discarded. One participant completed the questionnaire in full but omitted the written consent, the other questionnaire was partially completed. Although the sample later on dropped to 10 and then 9 participants in later rounds raises concerns, the specific health fields were still represented. It revealed a reluctance amongst the HCPs to participate which resulted in data loss. Ideally, having multiple HCPs from each discipline participating would have increased the sample size and provided more comprehensive data. Consequently, this phase lacked sufficient data from various domains on self-care. Expert dropout was an issue, and frequent reminders about the response deadline were necessary; late responses were not included. To maintain a low attrition rate, participants needed to be fully engaged for three rounds and were reminded via email and WhatsApp messages. The researcher had to ensure participants remained engaged once recruited, which was a challenge of conducting an online three-round Delphi survey. Although challenging, these methods were effective.

Terminology for the participants in a Delphi study varies. Some preferred the labels to be participants, experts, panellists, consensus groups, etc. (Shang, 2023:4; Gordon, 1994:7; Holey et al., 2007:2). The appropriate label preferred for this study is participants.

Although the Delphi study depends on participant selection, the literature provides inconsistent guidelines. Hallowell and Gambatese (2010:102), cited Rogers and Lopez (2002) about specifications to participate. Shang (2023:4), on the other hand, stated, "The choice of participants is also open to debate". Due to the variations and the lack of specific guidelines, deviations were thus admissible. Delphi uses non-random sampling and attempts to obtain

expert opinions over a brief period (Shang, 2023:3). Accordingly, Gordon (1994:4) argues that it is essential to include participants who are knowledgeable to contribute valuable ideas. In this study, participant selection was influenced by the data from Phase 3. A heterogeneous sample of expert HCPs was purposefully composed because it was anticipated that much could be learnt from those who were well informed, involved with, and applying their knowledge and skills to problems associated with diabetes care. All HCPs had to be statutory qualified, registered in their respective disciplines with the different regulatory bodies in the country, and had to provide a service for six months or more to PLWD (Santos et al., 2017:2; Hesse-Biber, 2010:64).

The participants consisted of HCPs specialising in various domains who were involved with the complexities of diabetes care, including individuals who identified themselves as PLWD. They were regarded as experts through personal experience in living with diabetes and based on their perceptions and lived experiences, allowing them to voice their priorities. They could also refer to as service-users. Service users were included to give them the opportunity to provide additional suggestions about treatments and advice on what they deemed work best to inform self-care decisions (Bourne et al., 2022:2; Seery et al., 2022:2595; Barrington et al., 2021:5; Hall et al., 2018 22; Grant et al., 2021:1746; Holly et al., 2000:6). This involvement aimed to inform self-care and healthcare decisions through their insights on effective treatments. Their participation provided unique information that is often overlooked. Their inclusion was based on their experiences, wants, and needs, and their responses were consistent with those of medically qualified experts. The involvement of people living with diabetes (PLWD) was essential to present their knowledge and experience. While their insights might differ from scientific perspectives, the differences stem from varied experiences and opinions. Therefore, these differences are significant. In general, participants can assist in nominating and prioritising topics they consider important (Bourne et al., 2022:2; Seery et al., 2022:2595; Barrington et al., 2021:5; Hall et al., 2018:22; Grant et al., 2021:1746; Holly et al., 2000:6).

For these reasons, a modified Delphi is instituted. Recruitment was conducted between 11 August and 19 October 2023. Gordon (1994:6) posits that when the selection of participants is confirmed, they should be contacted individually and receive individual letters of invitation which describe the research, aspects of anonymity and consent. Thirty-one expert HCPs were individually recruited by telephone, WhatsApp messages, and e-mail with information about the study, and to invite them to participate, 21 people confirmed interest in participating and provided contact details.

7.5.2 Stage 2: Building consensus

This stage comprises three Rounds (questionnaires) to generate ideas and opinions from the participants, to identify the level of agreement with the contributing information and to address those questions in disagreement to pursue consensus building. In the 3rd Round, consensus is confirmed, and information is utilised to develop the self-care tool in Stage 3. Like others, Nasa, Jain and Juneja (2021:117) believe Delphi methods are a structured technique to facilitate a group communication process to deal with a complex issue, in this case, diabetes self-care management. Reaching consensus is a much-debated aspect of the Delphi process, yet standard guidelines are lacking. Literature showed discrepancies in consensus definitions, measures, and methods. The most widely used definition of consensus is the proportion of agreement based on central tendency and a predetermined cut-off, or both. Whilst some researchers argue that consensus is reached when a certain percentage of the responses falls within a prescribed range, Nasa et al. (2021:120) propose that the agreement percentage is chosen at random and ranges significantly from 50% to 97%. McKenna (1994:1222), on the other hand, suggests that consensus should be equated with 51% agreement among respondents and cites Sumsion (1998), who recommends 70% and Green et al. (1999), suggesting 80%. The cut-off point in this study for Round 3 was thus set at 60%, as per consensus.

According to Adebisi et al. (2018:6) the Delphi experts use two or more Rounds to answer the questions, hence, in this study, three Rounds were conducted, and the responses were monitored for stability. Alternatively to provide information on the collective judgments of the respondents, the main statistics used in Delphi studies are measures of central tendency, mean, median, mode and degree of dispersion, standard deviation, and interquartile range (Jones & Hunter 1995; Bowling 2002). According to Jones and Hunter (1995:377, 379), consensus approaches are used when unanimity is lacking. They contend that this approach aims to address disagreements by either measuring the degree of agreement or developing consensus. These authors go on to say that the consensus approach is helpful in creating training programmes, and it could meet a specific client group's long-term care demand. In this context, the study's self-care management tool and the complexities of diabetes self-care management are applicable.

a) Round 1: Generation of ideas and opinions from the experts

In agreement with Gordon (1994:10), the Delphi process is time-consuming. This author records that one round can require a turnaround time of three weeks, or three Rounds could take at least three to four months, considering preparation and analysis. Dalkey and Helmer

(1963:460) had one-week intervals. Due to time constraints, the turnaround time allowed for this study in Round 1 was ten days, excluding months for preparation and analysis. None of the participants met each other prior to the process.

To generate ideas and opinions anonymously, participants received an open-ended questionnaire (Annexure 11-B) (Hsu & Sandford, 2007:2-3). This link included instructions on how to complete the questionnaire, including contact details for assistance in case participants might experience difficulties. Participants were encouraged to provide an opinion even if it was not applicable to their specific health discipline, and they could provide suggestions for self-care improvement. They had to respond to 60 items across 37 domains ((Annexure 11-C). An e-mail distribution took place via an online Qualtrics link on 16 November 2023, and the closing date was 24 November 2023. Gordon (1994:7) suggested a response rate between 40 to 75%.

According to the Qualtrics survey, the response rate was 41%. But after two closing date reminders on 21 and 23 November 2023, the responses increased to 86%. This section provides an overall view of the choices and opinions of the participants in the descriptive statistics. The questionnaire was already well structured and did not need much data cleaning or preprocessing. This section provides an overall view of the choices and opinions of the participants in the descriptive statistics. The questionnaire was already well structured and did not need much data cleaning or preprocessing. Out of the 12 who completed the questionnaire, one individual completed the survey but did not give consent. Another participant completed only 47% of the questions. Consequently, both questionnaires were discarded, and the participants were removed from the study and consecutive rounds. Subsequently, only ten individuals participated. The frequency (count frequencies for each category/response are calculated) and proportions (obtained from the frequencies of each category/response) were calculated across all categorical variables in the data set. Descriptive statistics of the frequencies and percentages were used to analyse the baseline characteristics of the participants.

Summary of participant descriptive data (n=10). The metrics and descriptive data for Round 1, n=10, who consented to participate in this survey, were equally divided as 50% each for both genders. There were 30% in the age groups of 31 – 40, 20% in the age groups 41 – 50 years, 30% in the age group of 51 - 60 years and 60 years and older comprised of 20%. The field of expertise was multi-disciplinary and were 10% per clinical psychology, dentistry, PLWD 30%, diabetes psychosocial care (10%), diabetes specialist nurse (10%), military practitioner (10%), paediatric nursing and nursing administration (10%), periodontology and oral medicine (10%), social sciences 10%, team leader in IT training and diabetes advocacy

the lived experience (10%). Their years of experience with diabetes care or living with the condition are observed in Table 7-1.

Table 7-1. Participant characteristics

Demographics (N)	Variables	Frequency (%)
	Missing	0
	Minimum	8
	Maximum	41
	Median (IQR)	18.50 (11.50, 28.75)
	Mean (SD)	20.7 ± 10.74
	Mean (95% CI)	20.7 (95% CI: 13.02, 28.38)
Years of experience as a PLWD	Missing Values	4 (40)
	16	1 (10)
	33	1 (10)
	41	1 (10)
	Not living with diabetes.	1 (10)
	Because of the long-term diabetes, it resulted in kidney failure and being on APD Dialysis since 2017.	1 (10)
	Neuropathy- and amputee Not applicable	1 (10)

Participants had to indicate their overall experience in years of being a PLWD prior to participation. Two of them reported complications identifying peripheral arterial disease, kidney problems, hypertension, neuropathy- and amputee, chronic kidney failure and on automated peritoneal dialysis (APD), with deterioration of eyesight.

The use of a categorical scale in Round 1 allowed the identification of questions based on the percentage who responded to “Yes”, “No”, and “Not applicable to my health discipline”. The purpose of the qualitative analyses in Round 1 was to provide preliminary individual feedback against the overall group results. The purpose of the qualitative analyses in Round 1 was to determine which of the item's preliminary agreements was reached that led to consensus. With the majority of items, consensus was reached, but as noted in the five questions, some individuals did not select “Yes” or “No”, and those responses were questionable and reviewed. Subsequently, Q18, Q20, Q25, Q28, Q40 and Q55 were analysed but consensus was not determined.

Mixed responses emerged for Qs18 and 25 regarding a sudden onset of hypoglycaemia and keeping a diabetes log during self-care. These two questions have been rephrased for

reassessment in Round 2. Qs 25, 40 and Q55 was not explored as it was overlapping with other questions that focussed and reported on dietary planning and regular diabetes education, referred to as lifestyle management. Regular dental visits were recommended for PLWD, with dentists determining necessary work and appointments based on availability (American Association of Diabetes, 2015:57). Individual consultations are crucial for problem resolution. The integrated approach to psychological well-being addressed issues surrounding the psyche of PLWD, ensuring comprehensive behaviour responses to prevent negative behavioural outcomes. The Hotline centre's potential to provide a toll-free National Diabetes Hotline was met with negative responses due a majority scepticism, indicating that a hotline was not currently opportune and Q 28 should be discarded for Round 2

If all the above were treated as “No Consensus met” due to the non-selection of a yes/no option, there is a $31/37 = 83.78\%$ consensus rate. For those treated as “Met consensus”, there were few individuals who selected “Not applicable to my health discipline”. Consensus for the 31 questions was met for those applicable to that question. If consensus is met by the “Might be met” questions, there would have been a $35/37 = 94.59\%$ consensus rate, which is regarded as excellent. While Gordon (1994:8) suggested displaying data in several ways, the analysis shows metrics were calculated across all categorical variables in the data set, which comprised of the frequency (count frequencies for each category/response were calculated, and proportions (proportions were obtained from the frequencies of each category/response).

b) Round 2: Level of agreement or disagreement leading to building consensus

Due to the disagreement of some questions in Round 1 that did not achieve consensus, three were reconstructed for Round 2. Table 7-2 indicated the rephrasing of questions for Round 2. Only those participants who completed Round 1 received feedback and were included in Round 2 (Slade et al., 2014:3). The questionnaire (Annexure 11-C) was distributed via individual e-mail as an online Qualtrics link on 13 December 2023 to the 10 participants to reassess their responses. The closing date of 20 December 2023 was set.

Table 7-2. Rephrasing questions to repeat in Round 2

Initial question in Round 1	Question rephrased for Round 2
A peanut butter sandwich and a cup of tea can be given for the sudden onset of hypoglycaemia during self-care	How should the PLWD or family manage a sudden onset of low blood sugar at home if the PLWD: (1) unable to chew or swallow? (2) able to swallow and chew?

Initial question in Round 1	Question rephrased for Round 2
To keep a journal/diabetic log to record glucose testing and reading, diet consumption (Types of food), weight, medicine taken and reminders for follow-up consultations.	Can a diabetic log/journal be kept as a daily monitoring tool to record self-care activities?

It was noted that there was a decrease of two respondents from Round 1 (n=10) to Round 2 (n=8) because ten participants received the questionnaire, nine started with the questionnaire, but only eight responded with a completion rate of 89%. Furthermore, it was noted consensus has been met for Q15 and Q17 (as numbered in Round 2). For Q16, two individuals did not select yes or no (in the “no” selection columns), which was problematic but provides a summary of the consensus of responses, as can be seen in Table 7-3, the number assigned in this section. Descriptive analysis was performed using R Software (version 4.2.1; <http://www.r-project.org/>)

Table 7-3. Summary of responses to Round 2 questions

Question number	Question	Yes (Prop. of yes)	No (Prop. of No)	# of not applicable (Prop. Not applicable)	# of No for selection) No of prop. For No selection)
15	How should the PLWD or family manage a sudden onset of low blood sugar at home if the PLWD is able to swallow and chew?	6 (75.0)	0 (0.0)	0 (0.0)	2 (25.0)
16	Can a diabetic log/journal be kept as a daily monitoring tool to record self-care activities?	7 (87.5)	0 (0.0)	0 (0.0)	1 (12.5)
17	How should the PLWD or family manage a sudden onset of low blood sugar at home if the PLWD is unable to swallow and chew?	4 (50)	1 (12.5)	1 (12.5)	2 (25.0)

c) Round 3: Reaching consensus with a Likert scale instrument

Likert scales are a useful tool to obtain different opinions in surveys. A 5-point Likert scale questionnaire (Annexure 11-D) was developed to gauge the opinions of the respondents to determine how they feel about the inclusion of the statements for the self-care tool. A preliminary reminder as encouragement was sent to individual participants on 26 February 2024. The number of response options for this survey were structured as “strongly agree”, “agree”, “neither agree nor disagree”, “disagree”, and “strongly disagree”. Participants had to respond to 78 questions in 17 domains. The 5-point Likert scale questionnaire was distributed individually to 10 participants as an e-mail with an online Qualtrics link on 1 March 2024, with the closing date as 10 March 2024. Due to the slow response, two reminders were circulated on 5 and 7 March 2024, followed by WhatsApp messages on 9 March 2024 to encourage completion. Analysis of the 5-Point Likert scale measured the opinions, perceptions, and attitudes of the experts towards a range of items to which they could give one of five responses from “strongly disagree” to “strongly agree” (Bowling, 2014:426). Their responses helped to facilitate the interpretation of the results. In this Delphi study, the aim was to establish the measurement of consensus of the items to be included for a diabetes self-care management tool.

Summary of participant descriptive data (n=9). The metrics and descriptive data for Round 3, n=9, who consented to participate in this survey, include a gender of 44.44% female and 55.56% males. There were 33.33% in the age group of 31 - 40 years old and 22.22% in each of the age groups 41 - 50 years old, 51 - 60 years old, and 60 and older. The fields of expertise refer to the same multi-disciplinary group who participated in the previous Round and were 11.11% per clinical psychology, dentistry, PLWD, dietitian, diabetes educator, nutrition support for people with diabetes, paediatric nursing and administration and social sciences. Their years of experience with diabetes care or living with the condition are observed in Table 7-4.

Table 7-4. Years of experience in caring or living with diabetes

METRICS	DESCRIPTIVE STATISTICS (N=9)
Missing	1
Minimum	9
Maximum	42
Median (IQR)	19.00 (13.25, 33.75)
Mean (SD)	23.38 ± 13.39
Mean (95% CI)	23.38 (95% CI: 12.18, 34.57)

Summary of responses of options selected “strongly disagree and disagree”. Twenty-two percent strongly disagree with Q16, Q21 and 11% strongly disagree with Q43, Q47 and Q61.

- Q16: To prevent risks and complications, Type 2 PLWDs can manage their blood glucose by ensuring a reading not higher than 13mmol/L (random), or as suggested by the physician.
- Q43: In the absence of a physical support group, a WhatsApp group can give access to telephonic conversations and questions, and it can be used as an online meeting platform.
- Q47: List the food items which contain carbohydrates and how to eat them responsibly.
- Q54: To prevent mistakes during medication intake, the pharmacist is responsible for providing advice and must check for drug interactions and potential allergic reactions.
- Q61: Needles should not be buried, burnt, or toilet flushed, nor throw used or unused needles loose in the dustbin

Summary of responses of options selected “neither agree nor disagree”. The following section revealed responses to “neither agree nor disagree” (NAND). This selected option is important because it could be interpreted of not having an opinion or interest due to a difference in expertise and multidisciplinary field of health or found the item irrelevant or for the same reason did not have sufficient information to make an informed option, or it is irrelevant to self-care. Alternatively, it could also reflect that diabetes care is fragmented. This, by itself, could be argued for a more integrated HCP self-care approach. For better visibility, the questions and Figures are illustrated below. Except for Q92, which rated NAND (22%), 11% responded to the following questions:

- Q16: Always take the glucometer with you and have a healthy snack at hand.
- Q18: If the blood glucose is too high, a Type 2 PLWD can exercise, eat less carbohydrates and drink plenty of water.
- Q21: Do not exercise alone. If necessary, exercise under the supervision of a biokineticist.
- Q22: To maintain an acceptable blood glucose level, do not consume a heavy meal prior to exercise, but also do not exercise on an empty stomach. Monitor blood glucose levels before, during and after exercise.
- Q24: The diabetes amputee can do cycling with a prosthetic, swimming, walking with aid, etc.
- Q27: To record the weekly blood glucose readings prior to the next consultation or during times when PLWDs make significant changes to their routine or are struggling with blood glucose control.

- Q40: Psychology sessions must include family therapy, cognitive behavioural therapy and general psychoeducation.
- Q42: Members of the support group should meet on a regular basis
- Q57: Physicians or pharmacists should inform and explain when medicine prescriptions are changed
- Q61: Needles should not be buried, burnt, or toilet flushed, nor throw used or unused needles loose in the dustbin.
- Q68: Report any problems such as bleeding or painful gums timeously to the HCP.
- Q72: Wash the feet with lukewarm, soapy water and dry feet properly between the toes.
- Q92: Avoid painful exercise as the pain might increase glucose levels and blood pressure.
- Q99: Consult the dietitian for an improved diet to reduce blood glucose levels, which may improve blood flow and circulation.

Summary of responses of options selected “agree or strongly agree”. Most/all selected the option “agree or strongly agree”, ranging from 67% to 100%, showing consensus which is based on the questionnaire stability and a frequency of 60% or more. Consensus was predetermined at 60% for Round 3.

Prevalent responses across the entire questionnaire. An interesting graphic to include for Likert Scale responses is the Likert Plot which is grouped into themes based on the original questionnaire. (Annexure 11-E). They provide a good visual summary of what the spread of the responses was.

To obtain the most reliable consensus (opinions by experts), including the descriptive statistics, the internal consistency was measured through Cronbach Alpha calculations. Values closer to 1 indicate excellent internal consistency and values closer to zero indicate poor consistency. The entire questionnaire resulted in a Cronbach Alpha score of 0.989, which indicates excellent internal consistency (values and descriptors are available in Chapter 4).

7.5.3 Stage 3: Information to develop a self-care tool

This stage comprises three steps which include the proposed guidelines from the experts in Round 3 to include in the development of the self-care management tool, the design of the tool, and text information to read.

- a. Step 1: Feedback on which guidelines to include for self-care tool

This section identifies the themes to consider for inclusion in the self-care tool. These themes are described in the encoded text document:

- Manage the blood glucose during self-care
- Recommended exercises for a PLWD with physical restrictions
- The value of a diabetes log
- Establish a daily routine
- Ensuring effective insulin storage when travelling by road, air or abroad
- Recommended DSME provided by HCPs
- The value of a support group for the PLWD or family
- Relevant dietary information to ensure healthy diets
- Prevent errors with medicine or insulin
- Disposal of used insulin needles
- Dental care of the PLWD
- Footcare to prevent complications
- Eyecare to prevent diabetes eye disease
- Coping skills and managing risk-reduction behaviours

b. Step 2: Designing the self-care tool

This diabetes self-care management tool serves a similar purpose as a Patient Information Leaflet (PIL). Baker (1997:12) found that PILs become problematic when it is produced by well educated people who read a lot, while the product might be used by less educated (in that field) who do not read that much. Subsequently, the standard Baker Able Leaflet Design (BALD) was used as a baseline to design the self-care management tool, including layout and readability of text.

Sufficient information must be provided for better understanding, which enables the user to exercise autonomy in making informed decisions about self-care. Just as leaflets allow consumers to internalise information at their own pace, and serve as a point of reference, so is the intention with this self-care tool. Although Mathew, Rajiah and Sharma (2013:2800) maintain that printed education materials are used to augment verbal information from a healthcare professional, this proposed tool is available for a QR code, easily available at their convenience to use at home during self-care. The layout of the design is orientated in the landscape for better visuals.

c. Step 3: Diabetes self-care management tool with encoded information

The schematic of a proposed diabetes self-care management tool and text is presented in the following diagrams in Figures 7-2 to 7-6 and Annexure 12-A). The proposed tool is designed for use by both individuals living with diabetes (PLWD) and their families.

This study acknowledges the complexity of diabetes self-care management, the autonomy of PLWD, and the interactive dynamics within the family. It is advisable for both parties to mutually agree on when and how support and assistance should be provided. Therefore, this tool does not emphasize family dynamics or set specific boundaries but rather anticipates that diabetes self-care management will be approached seamlessly. Consequently, no specific responsibilities are assigned to any individual. PLWD are receptive, and family members are willing to assist. This approach aims to foster strong relationships and an effective family support system.

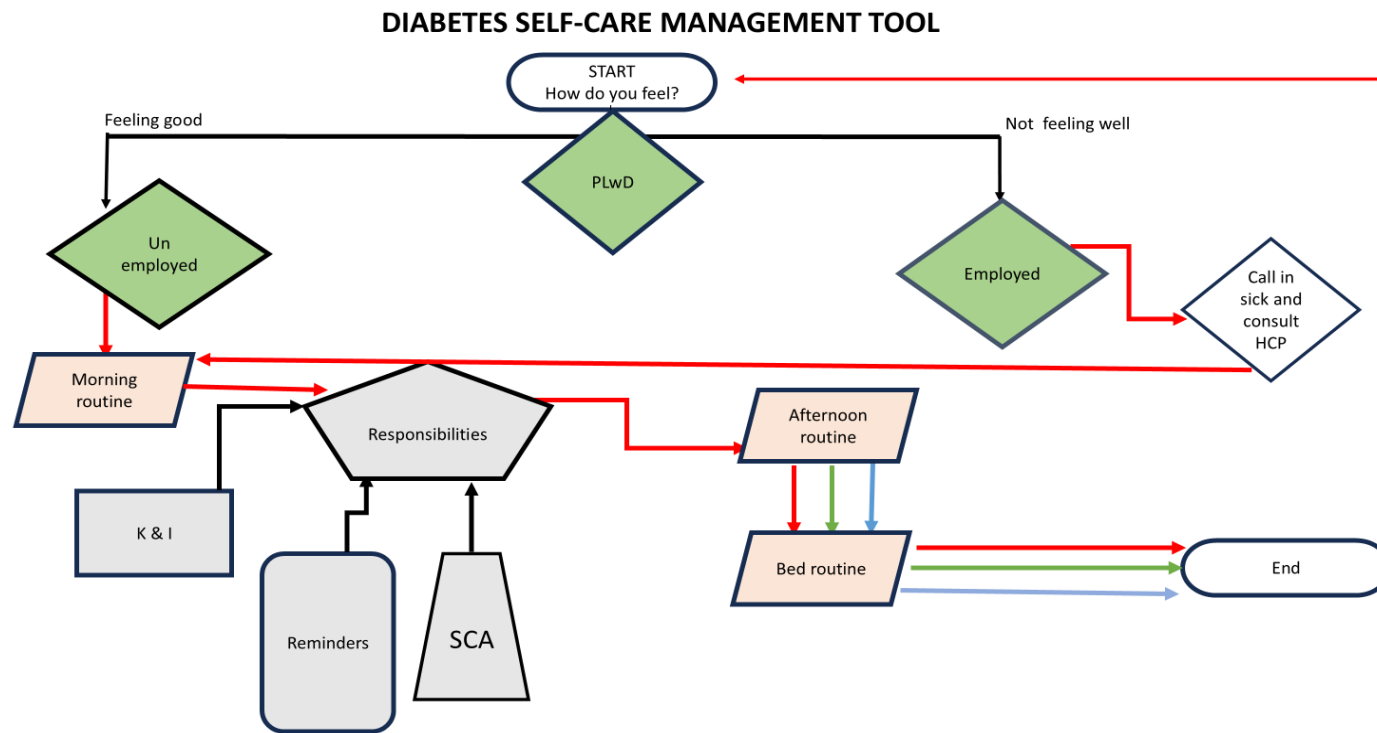


Figure 7-2. Diabetes self-care management tool (link)

Knowledge & Information

What you should know about DSCM

Managing the blood glucose

Maintain a stable blood glucose level during physical exercises

Recording the blood glucose reading and other information

The value of a diabetic log

Reminders to follow through with activities and a routine

Suggestions for education by different health domains

Managing stress with health coping skills to reduce risk behaviour

Join a support group

Healthcare support to the diabetic person and family

Adjusting a therapeutic diet for financially constraint families

Preventing mistakes in drug events and medicine adherence

Insulin storage when travelling

Administering of insulin

Disposal of used insulin needles

Disposal of used insulin needles

Dental/Foot/Eye care/sexual dysfunction

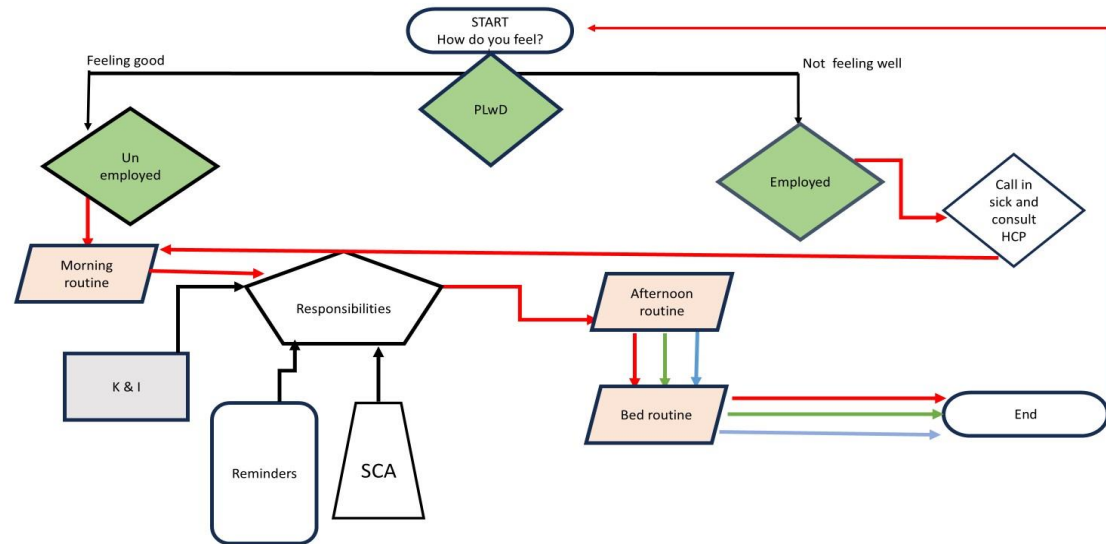


Figure 7-3. Diabetes self-care management K & I

K & I: Knowledge and information to manage diabetes self-care

Reminders

Keep a record of blood glucose and discuss with HCP at follow up visit
Comply with dates for follow-up visit
Join a support group
Schedule and attend the annual eye examination
Schedule an appointment and attend the podiatry clinic at least every 6 months
Schedule 6 monthly Dental appointments or more often if necessary

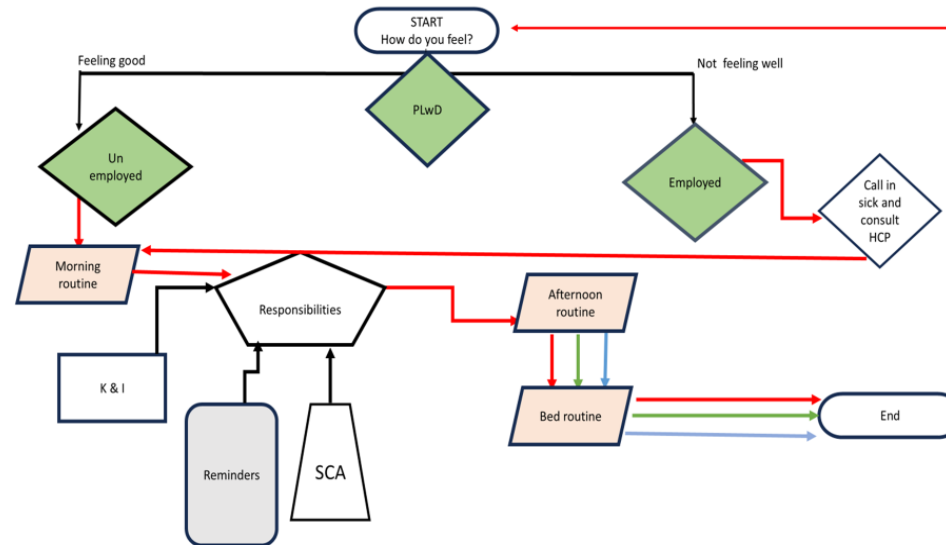


Figure 7-4. Diabetes self-care management tool for reminders

Reminders to manage diabetes self-care

Self-care activities

Blood glucose testing
Record keeping
Reminders
Diet planning
Medicine/Insulin therapy
Join support group
Physical exercise
Foot care
Dental care
Needles disposal
Eye care

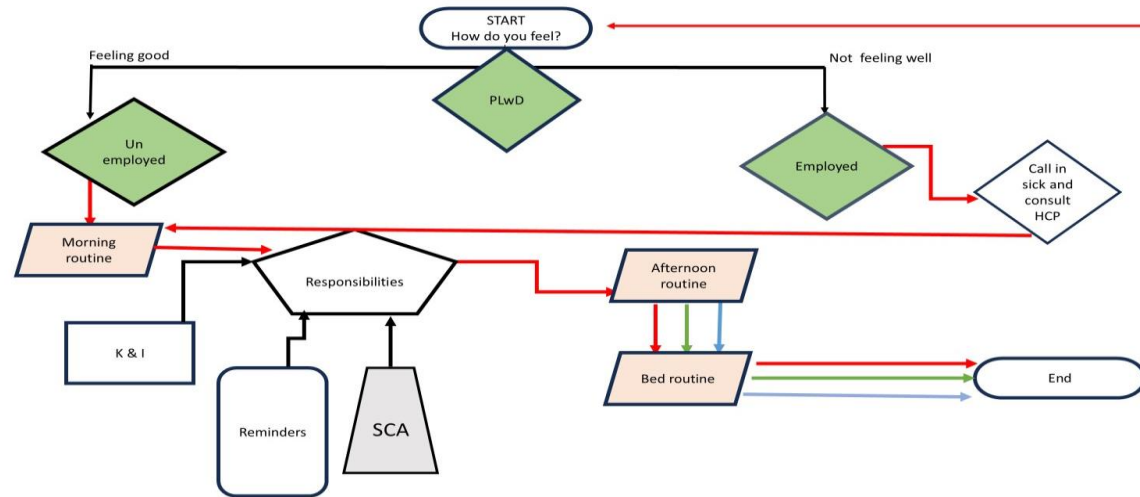


Figure 7-5. Diabetes self-care management tool for SCA

SCA: Self-care activities to manage diabetes self-care

Responsibilities

Regularly manage the blood glucose
Always maintain a stable blood glucose level during physical exercises
Recording the blood glucose reading and other information
Managing stress with health coping skills to reduce risk behaviour
Join a support group
Adjusting and comply with therapeutic diet
Preventing mistakes in drug events and medicine adherence
Insulin storage when travelling
Administering of insulin
Disposal of used insulin needles
Dental care/footcare/eye care

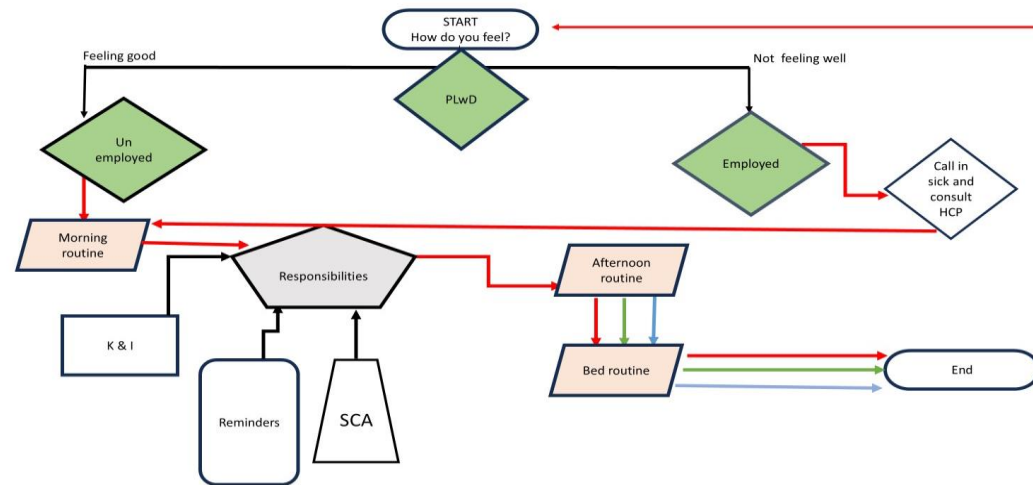


Figure 7-6. Diabetes self-care management tool indicating responsibilities

Responsibilities to manage diabetes self-care

7.6 CONCLUSION

Anonymity, iteration, controlled feedback, and statistical stability of agreement are all crucial components of the Delphi process, yet there are differences in the literature on these points. Modified Delphi has been utilised in published studies, and information on techniques such as expert panels, consensus, and closing criteria is not made clear. Diabetes self-care management is complex and affects all domains. Therefore, this tool does not claim to be authoritative or a complete routine for diabetes self-care management. The structure intends to merely propose how PLWDs and their families can structure a routine and decide how they want to practice self-care.

CHAPTER 8

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

8.1 INTRODUCTION

Diabetes is a chronic metabolic condition and is characterised by uncontrolled blood glucose levels. As a result, self-care is required to control blood glucose. In the absence of relevant self-care practices, a person's health condition may deteriorate due to related risks and the development of long-term complications. The significance was to understand their daily living with diabetes; therefore, it was important to understand how PLWD practise self-care, the difficulties that they encountered and how they were supported. The management of diabetes care at home is complex and could influence self-care performance. One of the prominent problem areas was identified as dietary-related issues, which lead to uncontrolled blood glucose. This chapter discuss the conclusions, limitations and recommendations of the study.

8.2 STUDY DESIGN, AIM AND OBJECTIVES

This Mixed methods study was designed in three phases and conducted sequentially according to the Morse notation system, labelled as quan → QUAL→ QUAL, of which the typology expressed a qualitatively driven, inductive, explanatory sequential Mixed method design (Schoonenboom & Johnson, 2017:119; Teddlie & Tashakkori, 2006:21-22). The study aimed to develop a diabetes self-care management tool for PLWD and their families in Tshwane, Gauteng Province, South Africa. The intention for this tool is to be used during diabetes self-care management at home. To achieve this, the research was guided by three objectives:

- Phase 1 (quan): represented the supplementary component with the objective: To describe PLWD perceptions of family support related to diabetes self-care management. People diagnosed with diabetes completed an existing questionnaire.
- Phase 2 (QUAL): represented two dominant components (Stages 1 and 2) with the objective: To explore self-care management experiences of both PLWD and their families in diabetes self-care management. In both Stages, experiences were discovered through focus groups and telephone interviews; to understand and describe the experiences of the PLWD in Stage 1 and their families in Stage 2 in diabetes self-care management.

- Phase 3 (QUAL) represented another qualitative phase where experts participated in the Delphi consensus-building technique with the objective: To develop a self-care management tool for both PLWD and their families to enhance self-care management practises for PLWD and their families, It further wanted to discover material relevant to create the self-care tool, which both PLWD and their families can use to enhance self-care management practises.

8.3 SUMMARY OF THE MAIN FINDINGS

Phase 1. The study explores the role of family support in diabetes self-care management for PLWD in South Africa's Tshwane region. It found that diabetes is prevalent among adults and younger people, with a majority of the participants being females. The study aimed to improve family involvement in diabetes management, finding strong family bonds. The study suggests that a proactive approach is needed to enhance individual self-care performance without reducing dependency on family support. Factors like motivation, goal-setting, and physical activities can help control blood sugar levels. Challenges included scheduling appointments, collaboration with healthcare professionals, and lack of knowledge about diabetes. Emphasis should be placed on self-care practices and education.

Phase 2. In Stage 1, three themes were developed (1) Strategies for improving patient support systems, (2) The impact of self-care on the psyche, and (3) Knowledge value. Diabetes is a progressive condition that impacts physical, social, and psychological well-being. People living with diabetes often struggle with self-care due to barriers such as unaffordable products and services, and lack of knowledge about essential activities like blood glucose tests. The study also emphasises the importance of seeking information from HCPs to help individuals make informed decisions about their health and diabetes self-care management. It suggests the establishment of community outreach programs to improve follow-up visits and accessibility to health services which might lead to better glycaemic control.

Family support is essential for managing the condition, but inconsistent family-oriented healthcare programs have been reported. During the Covid-19 pandemic, PLWD were extremely vulnerable, leading to dissatisfaction with some services, negative emotions, and anxiety. Hospital-based healthcare providers ignored diet and meal planning guidelines, and PLWD expressed concerns about healthcare deterioration. In Thailand, informal carers and relatives supported their parents, siblings, or spouses. There is correlation between the Thai and SA population of family support in terms of diabetes self-care management

The COVID-19 pandemic has led to a shift in the way researchers obtain informed consent, particularly in telephone interviews. Guidelines for telephonic informed consent have been proposed, and mobile telephone interviews have been suggested as a safer option. A pragmatic approach was used, with participants filling out a single page and sending it via the WhatsApp platform.

Phase 3. Diabetes is a chronic metabolic disease affecting Type 1 and Type 2 diabetes. Type 1 diabetes is caused by the destruction of β cells, making the person insulin dependent. Type 2 diabetes occurs when the pancreas produces insufficient insulin or fails to use it effectively, leading to uncontrolled blood glucose. Uncontrolled blood glucose can lead to heart disease, stroke, visual impairment, amputations, kidney problems, and other complications. To manage diabetes, individuals should establish a daily routine, be active, and maintain a reading between 7 and 8.6 mmol/L or as specified by the HCP. Regular exercise, balancing calories and carbohydrates with prescribed medicine, and making healthy food choices are essential.

8.4 GAPS IDENTIFIED IN THE LITERATURE

The following gaps were identified:

1. Guidelines: 2017 SEMDSA Guidelines focus on the management of type 2 diabetes and overlooked type 1 diabetes. The guidelines are strongly leaning towards physicians, dietitians etc, and it is disappointing to note that nursing health services were inadequately addressed.
2. Diabetes self-management education and support: An undisclosed number of nurses in SA obtained diverse levels of accredited diabetes care training. However, it is a concern that the training is not standardised. The available courses are not enlisted as a qualification with the South African Nursing Council. It is suggested that this matter be addressed by the SA National Department of Health, the Department of Education, and the different statutory and regulatory bodies, particularly the South African Nursing Council.
3. Primary health care: Despite the concerns of rising prevalence and mortalities, including the inability of some PLWD and their families who are unable to take care of themselves, the South African National Department of Health has not yet instituted the NHI, and PHC remains fragmented.
4. Family support: The role and responsibilities of families remained a grey area. Some literature documented the unpredictability of family support. The role and responsibilities of PLWD and the family could be discovered during this study. This further strengthened why self-care management with the family should be investigated. Since diabetes management is

a worldwide challenge, appropriate self-care programmes for PLWD and their families are still not available.

8.5 CHALLENGES DURING DATA COLLECTION

Recruitment of participants was planned to start in April 2020 but was delayed by almost a year. The initiation of Phase 1 coincided with the COVID-19 pandemic outbreak. In SA, national guidelines and regulations with strict health security protocols were issued and enforced around April 2020, and data collection of Phase 1 was only completed on 11 April 2021. In the research setting, office space was arranged but allowed only one participant at a time in order to adhere to the stipulated COVID-19 guidelines and safety regulations. As a result, data collection was very time-consuming and due to this time constraint, some participants who volunteered to participate left earlier due to other commitments before they could complete the questionnaire.

Even though a notification was displayed in advance to increase the visibility of the research and to draw as many participants as possible (Elo et al., 2014:1), potential participants were hard-to-reach or hidden due to national health issues and appointment scheduling, which is discussed below. The mentioned challenges reduced the potential participant numbers and negatively delayed recruitment and data collection in Phase 1 with but to ensure a good response rate, the questionnaires were completed on-site and immediately collected to ensure a good response.

8.5.1 National health issues

The worldwide COVID-19 pandemic and the national lockdown in the country limited movement and consequently affected recruitment. Like many other countries, the SA government issued timeframes which were aligned with the national regulations of COVID-19 alert levels. This was an extremely risky period, and to prevent unnecessary exposure to the virus for all citizens and for people with chronic illnesses such as diabetes who were at heightened risk of contracting the disease, it was crucial to comply with the lockdown regulations.

As such, the duration for recruitment and data collection for this study was extended to 8 months or longer. The delay did not only affect the pilot study and Phase 1 but had a ripple effect throughout, as it was very hard to find participants. The first attempt at data collection was planned for April 2020, but due to the unforeseen and extended lockdown regulations,

the national lockdown was extended with further data collection delays. Data collection was only allowed during the lowest COVID-19 alert level (level 1). Phase 1 started on 2 November 2020 at clinic 1 and 4 November 2020 at clinic 2 with intervals of one day per week for both clinics. Recruitment and data collection continued until December 2020, when most people in the country usually take a holiday break. The recruitment and data collection were below expectations.

The next period for data collection was planned for the middle of January 2021. Still, due to another extremely risky 2nd serious COVID-19 surge, which was riskier than the previous, the SA government announced yet again another national lockdown from alert level 1 back to alert adjusted level 3 with effect from 28 December 2020. The regulations were revised on 15 February 2021, anecdotally. This jeopardised the January recruitment; a second attempt to recruit and collect data for Phase 1 re-started only at the beginning of March 2021. Due to time constraints and hidden participants, recruitment was increased to four days per week at alternate clinics. The unforeseen and uncontrollable national issues had a profound effect on recruitment and data collection and subsequently delayed the entire study.

8.5.2 Appointment system functioning

Another reason is ascribed to how the follow-up appointments were scheduled. Additionally, the slow and low recruitment to data collection was ascribed to low clinic attendance due to the fact that some patients from Clinic 1 collected their medications from large supermarkets and pharmaceutical retail stores closer to their work or enroute home. The medicine collection point was a contractual arrangement between the provincial Department of Health and the retailer outlets and was implemented if the patients' health condition was under control.

For this purpose, the clinic issued an endorsed letter to the PLWD to collect their medication as per arrangement and to minimise their time away from work for convenience and not to spend long waiting hours at the clinic. This function relieved the work pressure on already limited clinic staff. However, those PLWD who posed health challenges, returned to the clinic for follow-up of their health condition. Regrettably, this information was not initially shared and impacted recruitment.

8.6 LIMITATIONS

Limitations of this study contribute to its credibility. While this study has limitations, it may affect the generalizability of the results, they also provide a foundation to generate opportunities for future studies.

Participant selection and availability. The Delphi study recruited 37 participants, but only 12 completed the questionnaire, resulting in data loss. This was due to reluctance among healthcare professionals to participate, resulting in a lack of data on self-care. Expert dropout was a problem, and participants were reminded about response deadlines to keep attrition low. Consequently, the low number of participants reflected inadequate data collection.

2017 SEMDSA Guidelines and DSME. In this study, findings reveal a limitation in self-care guidelines and DSME. The implication of the lack of a diabetes register restricts experts and HCPs from fully guiding diabetes self-care management and would encourage more research to modify methods to stabilise or aid in managing the illness.

While the 2017 SEMDSA focused on guidelines for Type 2 diabetes, there is a lack of guidelines for PLWD and their families and regarded as a weakness but this issue should not be generalised. Findings revealed that Diabetes Mellitus is increasingly becoming a global public health concern with a growing prevalence worldwide as reported elsewhere in the thesis. It is thus argued that poor or the lack of proper diabetes self-care management can exponentially increase, resulting in an increase in mortalities and in healthcare costs, largely due to its complications. Research show that PLWD face various challenges in adhering to self-care practices. Self-care is crucial for individuals with diabetes to promote health, maintain autonomous control, reduce risks, delay complications, and improve quality of life.

The 2017 SEMDSA guidelines give a lot of preference to doctors, dietitians, and other HCPs. It is disappointing to learn that nurse health services were not given enough consideration. As the first point of contact for both short-term and long-term care, the nursing fraternity is acknowledged for its relevance. It was expected that comprehensive guidelines would have been created to enhance nursing care. Levitt and Dave (2017:S21) define a diabetes educator as "any healthcare worker who has completed, with competence, a SANC or SEMDSA-approved diabetes educators course". That there is no standardised training is alarming. However, the exact number of SA nurses who have studied diabetes treatment abroad to varied degrees is unknown.

Communication. Mixed languages and communication have benefits as well as drawbacks. Due to the multiple spoken languages in the country, some of the participants at the Laudium Community Centre and Lyttleton Clinic in the Tshwane region of the Gauteng Province, were unable to understand each other's language, therefore one participant who were conversant with most of the spoken languages offered to summarise and translate the conversation in English in the presence of the respondent. This gave readers an inside look at the person's sharing, and more people might join in. The fact that the study was conducted in multiple spoken languages, however, was also advantageous because it allowed participants who spoke a language other than English to express their thoughts, feelings, and experiences more easily. Phase 2 was a qualitative study and by allowing Multilingualism, rich data as experienced by the participants were extrapolated and contextualized.

Multilingualism among participants opens eyes to new cultural nuances and permits in-depth data inference and can be generalised for future studies. Multilingualism was used as a strategy to overcome potential weaknesses in language barriers. The first language challenge was experienced during translations of the transcriptions and managed as explained in section 3.7.1. The second challenge was experienced in Phase 2 Stages 1 and 2 during data collection through the focus groups and interviews with PLWD and their family members and managed as explained in sections 3.7.8.1 and 3.7.8.2. Participants were encouraged to speak in a language of their choice. The moderator's good communication skills and knowledge of the topic were an advantage. Because she is familiar with most local languages she could comfortably posed questions in a language most understood which attributed to extrapolating rich data from in-depth discussions..

Impact of the Covid-19 pandemic. In April 2020, the world witnessed an outbreak of the COVID-19 pandemic, which prompted the SA government to issue guidelines and regulations with stringent health security standards which created limitations for the study. The restrictions on travel and movement jeopardised recruitment with a spillover effect of timings and data collection throughout the investigation. The initial process of recruitment and data collection in the respective health settings in Tshwane region of the Gauteng Province, started more than eight months later for Phase 1 and finished on April 11, 2021. This situation delayed the data collection process even further. which impacted the time frame for the study with a subsequent spillover effect to Phase 1, which required alternative planning.

The intermittent lockdown and social distancing, including other safety protocols, potential participants for Phase 2 were hard-to-reach and recruitment for the focus groups created

enormous challenges to put a focus group together at the Laudium Community Centre and Lyttleton Clinic. Even though people confirmed to participate, very few attended, and data was lost due to the small sample and absence of other non-attendees. This caused a change in recruitment and data collection. The pragmatic mindset of "what works best in a given situation" was embraced, and the data collection method diverted to interviews, which created other challenges.

The unprecedented pandemic with national regulations also affected recruitment and data collection. The government was clear about health security protocols, and due to limited office space, only one participant at a time was allowed inside the room due to social distancing, which resulted in a loss of participants who had to leave due to extended waiting periods. Sample size in Phases 2 and 3 was too small and a larger size could have different results. The sampling and sample size should not be generalised, it might impact statistical calculations and affect validity and reliability.

One of the regulations required people to wear face masks and restricted social distancing, which affected audio recordings during the focus groups with subsequent poor voice recording quality or inaudibility. This impacted transcribing. Transcribing was exceedingly difficult, time-consuming, and tedious as the audio-recording devices could not support the local languages of South Africa. The audio-to-text transition was more challenging even after repeated reading and listening. Regrettably, these events are unintended and in order not to derail research projects, it requires researchers/students to be flexible.

Sample size and hard-to-reach participants. A larger study population could have provided better statistically significant results regrettably, the study population was initially hard-to-reach, and challenges incurred during recruitment significantly affected the sample size. The system approach of appointment scheduling impacted recruitment further; in SA, some patients consulted the health facilities only on a 3 to 6-monthly basis, while some collected chronic medication at supermarkets and pharmaceutical retail stores. The span of recruitment should have been expanded; instead, it was limited to two health facilities. Limited resources posed challenges, and recruitment was initially restricted to one day per week per clinic.

The medicine collection point for some of the PLWD at the Lyttleton Clinic was a contractual arrangement between the provincial Department of Health and the various retailer outlets; and was implemented if the patients' health condition was under control. For this purpose, the Lyttleton Clinic issued an endorsed letter to the PLWD to collect their medication as per arrangement and to minimise their time away from work for convenience and not to spend

long waiting hours at the clinic. On the other side, the participants at the Laudium Health Centre collected their prescriptions from that specific pharmacy. The second limitation was the non-disclosure of information at both health settings. The absence of a diabetes patient profile and the non-disclosure policy and confidentiality laws (POPI Act) may be the causes of this. Finding volunteers among the hundreds of people using the waiting rooms was a very laborious process. Reluctance to participate occurs during Phases 2 and 3 was a constraint. There was no assurance that the participants would attend the focus group or that the volunteers for the Delphi survey would participate. The impact of hard-to-reach study population may be generalised in future studies.

Informed consent. One important tenet of ethical conduct of research is informed consent. Although standards varied during the pandemic and guidelines for obtaining informed consent was inconsistent, a practical approach was used, nonetheless, practical applications might hold ethical issues during the telephone interviews in Phase 2. However, authenticity is compromised and ethical problems might arise due to the absence of defined norms. Clear and useful rules that consider participants' capacities must be created for use in both routine and extraordinary situations.

Weaknesses of the Delphi. A few weaknesses impacted on Phase 3 of the investigation. The sample size was in the range, but for this Delphi, too small. While many committed to participate, a few specialists who represented a variety of different health fields failed to reply to the survey, resulting in insufficient information and data collection in different fields. Some limitations impacted on Phase 3. It was anticipated that a heterogeneous group could enable a broader perspective on self-care, but few experts did not complete the questionnaire. Because they represented different health disciplines and due to not participating, information is lost. Consequently, this phase lacked sufficient data from various domains on self-care. Diabetes self-care management is a complex issue where one domain of care influences the other. It is thus impossible to investigate only one domain of care. By doing so, questionnaires become too lengthy, leading to participation fatigue and influencing data generation.

Timing of the study. The timing of the Delphi survey was a limitation. The questionnaire had weak results and is subscribed to the country's academic programmes which were ending in preparation for the annual extended break. The experts were sent two reminders, but the response times would have remained the same whether there had been more participants, a longer response time, or just one domain to investigate. It is necessary to remind participants of the deadlines. The timing of the Delphi survey was a constraint. Due to the closing of

academic programs in the country, and the nearing long holiday, many did not respond to the questionnaire or e-mails. Two reminders were circulated to the experts, but even if there were more participants, even if the response time was longer, and even if there was only one domain to investigate, it would not have changed the response timings. Participants need to be reminded about the due dates. Diabetes self-care management is a complex issue where one domain of care influences the other. It is thus impossible to investigate only one domain of care. By doing so, questionnaires become too lengthy, leading to participation fatigue and influencing data generation. As for any other research, this study has limitations, as indicated below, but limitations can generate opportunities for future research. Delphi studies are dynamic and these incidents should not be generalised.

8.7 RECOMMENDATIONS FOR FUTURE RESEARCH

For the interdisciplinary groups, it is recommended that this tool be used in practice, education and research in the health industry.

8.7.1 Recommendations for DSME structures

People with diabetes and their families must have access to effective DSME self-care programs in order to ease the burden on medical institutions, lower the number of readmissions to hospitals, and save healthcare expenses. Given how many people rely on government assistance, this may be advantageous.

To establish self-care guidelines for nurses and others, it is recommended that the nursing fraternity be included in the Guideline committee of the new SEMDSA. Short courses for diabetes educators should be created. SANC, in collaboration with others should create an academic program to produce a Diabetes Specialist Nurse in order to guarantee consistent diabetes education. In order to enhance competences and guarantee uniform diabetes training, this is anticipated to be integrated into nurse education and practice training programs. Continuous professional development allows HCPs to share information and knowledge.

8.7.2 Recommendations for HCPs

Establishing and running a formal support group is advised for HCPs to facilitate peer meetings, self-care activities, DSME, group discussions, and question-and-answer sessions. Notwithstanding the collaboration with other role players, a psychologist, lifestyle coach, or

registered dietitian with expertise in diabetes treatment should lead the group. It is advised that the diabetes self-care management tool be promoted due to the benefits it offers the Department of Health. Piloting the tool after HCP, PLWD, and family structure training is a PHC-level technique for the NHI's implementation. It is expected that PHC and tertiary HCPs will suggest this tool to PLWD as a component of their personalised self-care treatment regimen.

8.7.3 Recommendations for research

It is recommended for future researchers to investigate diabetes mellitus self-care management for both PLWD and the family, there may be a discrepancy in the support that PLWD and their families would want to receive from HCPs.

The establishment of a diabetes register could be utilised to measure outcomes. It is imperative as it will facilitate the creation of a more precise health budget, identify the various aetiologies of diabetes, assess results, and identify strategies for enhancing self-care, all of which may contribute to the management of NCDs. In addition to reporting on a variety of topics, including population characteristics, risk factor control, complications and treatment, the register may identify areas where evidence-based guidelines are not being followed.

The DSSQ-family version proved to be trustworthy. This questionnaire was validated under varied socioeconomic conditions and with a different sample group in the US and SA. This DSSQ-Fv can be considered for similar future investigations.

Most of the software is inadequate for transcribing South African languages. This is an opportunity for information technology (IT) companies to develop academic transcribing programmes to remedy this deficiency.

This tool can become dynamic for ongoing activity change in this digital age. It is advised that IT create this tool in digital format to guarantee universal access and demonstrate its effectiveness in improving glycaemic management.

One important tenet of ethical research is informed consent. Although standards varied during the pandemic and guidelines for obtaining informed consent was inconsistent, a practical approach was used. In the absence of clearly defined guidelines, authenticity may be compromised and ethical problems might arise. It is suggested that practical guidelines in

consideration of the participant ability/capacity must be created for routine telephone consent and during extraordinary situations.

8.8 CONTRIBUTION TO THE NURSING BODY OF KNOWLEDGE

The significance of this study is the contribution of novelty and uniqueness. Initially this study contributes to the nursing body of knowledge in nursing practice and care. In recent years Diabetes Mellitus became a global health issue, suggesting that health promotion and the management of diabetes self-care management is too expanded for the nursing fraternity to function in isolation. Instead, it requires collaboration and consultation with a wider spectrum of role players and stakeholders beyond the healthcare industry. The uniqueness in this study was the direct engagement with PLWD in Phases 1 to 3, the family in Phase 2, and collaboration with service users during Phase 3.

Staggering estimates of diabetes prevalence is reported (Saeedi et al., 2019:1-2,4). It was noted that most of the diabetes self-care management research studies comprises clinical and pharmacological studies, suggesting that there is little support for PLWD and their families for self-care practices, this calls for diabetes self-care management interventions.

The 2017 SEMDSA guidelines is a comprehensive document comprising twenty-nine sections to provide broad guidelines on how type 2 diabetes should be managed (JEMDSA, 2017:1-196). Consequently, self-care management for type 1 diabetes was not addressed. Neither could SA guidelines for the management of type 1 diabetes be found which is viewed as a gap in knowledge regarding total diabetes care, but this gap was addressed by also including people diagnosed with type 1 diabetes in this study.

The latest version was issued around mid-2017. SEMDSA Type 2 Diabetes Guidelines Expert Committee for Chapter 5 deals with diabetes self-management education and support and suggests that education must be provided and managed by accredited HCPs and trained CWHs. Regrettably, as in most studies, there is a quietness on the involvement of PLWD or their family structure. This study has the potential to enhance diabetes self-care knowledge.

Narasimhan and Kapila (2019:76) stated that the Global Conference on Primary Health Care emphasised the empowerment of individuals to care for themselves and to empower those who provide care. Therefore, the aim of this study was to develop a diabetes self-care management tool that can be introduced for both PLWD and their supporting family without clinical or pharmacological interference at home.

Notwithstanding the adoption of the 2017 SEMDSA for the management of diabetes, none of the participants mentioned a structured program that would have improved their understanding and abilities to cope with the challenges of caring for PLWD. It is an unwritten duty for PLWD to accept responsibility for their own well-being and choose how to practise it with the support of their families and health support networks, to the contrary, this study suggested that self-care is generally weak. The approach to this study was different. The difference of this study comparing to previous research is the way how the gaps were filled. Most research of diabetes self-care management focuses mainly on clinical or pharmacological aspect whereby this study directly involved PLWD and their families. Through the lens of PLWD and the family, an easy-to-use diabetes self-care management tool was developed to enhance self-care practices with improvement in health.

This study demonstrates originality. The SEMDSA suggested guidelines on how type 2 diabetes should be managed (JEMDSA, 2017:1-196), focussing on the CCM. This study thus presented a modified conceptual model to show how the CCM and Orem's Theory of Self-care were integrated.

8.9 FINAL CONCLUSION

Phase 1. The study emphasises the necessity of better self-care routines and family participation in diabetes self-care management. In addition to assessing the degree of family support offered in Phase 1 diabetes self-care management, it seeks to gauge the opinions and experiences of PLWD. Clinical and pharmacological issues have been the subject of several studies on diabetes care; however, self-care management and family involvement are found to be below expectation.

The study aimed to improve family involvement in diabetes self-care management for people with PLWD. Results showed strong family relationships and high internal consistency. Improvements in self-care could be made through family assistance, revisiting appointment scheduling, and cooperation with healthcare providers. Factors such as limited diabetes-related information and resource shortages were highlighted.

Phase 2. Chapter 3 details research methodologies for all three Phases but Phase 2 is particularly highlighted for amendments due to insufficient data from focus groups amid the pandemic. The study's framework is diabetes self-care management, with the CCM being extracted from Orem's Model of Self-care Theory. The rationale for the DSSQ-Fv questionnaire pilot study and focus group is also discussed.

The research methodology for this study, based on the Self-care Theory, was revised after focus groups were inadequate. The study aimed to understand diabetes self-care management, incorporating elements from Orem's Model of Self-care Theory. The pilot study and focus group provided context for Phase 1, focusing on individual perceptions and family support. The study aimed to understand the psychological impact of diabetes on self-management and quality of life. The study reveals insufficient opportunities for diabetes self-management education (DSME) to help individuals with diabetes and their families learn new skills and advance their knowledge. Orem's self-care theory is helpful in DSME as it helps individuals with developmental disabilities and their families complete specific activities and evaluate self-care agency. The Theory of Self-Care advises individuals to perform self-care tasks with HCPs to improve their quality of life and life expectancy.

Chapter 5 presented the findings of Phase 2 Stage 1, where data were collected from PLWD through a focus group and telephone interviews. The data from both methods were merged and analysed through coding and thematic analysis. This study focussed on one of the recommendations of Chapter 5 of 2017 SEMDSA, which is dedicated to DSME/S, which implied that care should be “patient-centred, respectful and receptive to individual needs and values; and non-discriminatory towards cultural, ethnic language, socio-economic and educational differences” (Allie et al., 2017:22). From this recommendation, it was clear that patient/person-centredness, individual values and needs are key therefore individual account of their experiences were important. With a sound family support system assisted by HCPs, self-care practices might enhance on condition that PLWD receives adequate information through education and information sessions.

This study explained the challenges of establishing focus groups and interviews as qualitative data collection methods for a diabetes self-care management tool. The research faced challenges such as language barriers, hard-to-reach participants, and compromises during the COVID-19 pandemic. The study emphasised the importance of family support and self-management programs for PLWD. However, strategies were inconsistent and the family was not included in education sessions. The study also found mixed views on support from healthcare providers and the lack of professional trust. The study recommends rethinking data collection methods and implementing a pragmatic approach in future research. The results from Stages 1 and 2 inform the development of a diabetes self-care management tool. The study highlights the need for a more flexible and inclusive approach to support PLWD.

Phase 3. There are discrepancies in the literature about the Delphi process's essential elements of anonymity, iteration, controlled feedback, and statistical stability of agreement. Published research have used modified Delphi's, but details about methods like expert panels, consensus, and closing criteria are unclear. The treatment of diabetes self-care management is intricate and impacts every area. For this reason, the diabetes self-care management tool makes no claims to be comprehensive or authoritative. The structure just aims to provide ways that PLWD and their family might organise a schedule and choose how they wish to engage in self-care. The main objective was to develop a diabetes self-care management tool for PLWD, their families, including the benefit it holds for HCPs. This objective was achieved and it is anticipated that this tool can become dynamic if the above recommendations are considered.

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Annexure 1

Letters of permission to conduct the study

Annexure 1-A

Application to UP to conduct research for a proposed PhD

I intend to undertake the proposed research for the PhD Nursing Science degree at UP, entitled “A Mixed methods study to develop a self-care management tool for both people living with diabetes mellitus and their families”. With an interest in self-care management of people who are diagnosed with Diabetes, it is necessary to determine their demands and abilities for self-care, their requirements, how they practice self-care and how the family can be supported. This study aims to find out how PLWD, families and health care professionals are dealing with diabetes self-care management. It is hoped that the data collected will enhance self-care abilities, which ultimately should enhance the quality of life for PLWD and their families. This study will employ a Mixed methods research design, which allows different inquiry and analysis strategies (validated questionnaire Annexure 8A) in the quantitative component and focus groups (Annexure 10A and B, Annexure 11 A and B) in the qualitative components.

PLWD, their families and HCPs will participate voluntarily. All information will be treated as confidential, and no names will be revealed. Alphanumeric letters or pseudo names will be used to identify documents or participants. Sample selection will be based on the inclusion and exclusion criteria and Mixed methods design. This research is for academic purposes and is not related to the health settings or government. With this application, I am seeking authority from UP to conduct this research for the PhD nursing Science degree.

Jennifer Denise Jumat

September 2019

Researcher's signature

Date

Annexure 1-B

University of Pretoria Ethics clearance certificate for the study

A MIXED METHODS STUDY TO DEVELOP A SELF-CARE MANAGEMENT TOOL FOR BOTH
PEOPLE LIVING WITH DIABETES AND THEIR FAMILIES



710_2019_6_AR_Approval_00010_2024-04-11.pdf



Faculty of Health Sciences

Institution: The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
• FWA 00002567, Approved dd 18 March 2022 and Expires 18 March 2027.
• IORG # IORG0001762 OMB No. 0990-0279 Approved for use through June 30, 2025 and Expires 07/28/2028.

Faculty of Health Sciences **Research Ethics Committee**

11 April 2024

**Approval Certificate
Annual Renewal**

Dear Mrs JD Jumat,

Ethics Reference No.: 710/2019 – Line 6

Title: A mixed-methods study to develop a self-care management tool for people living with diabetes and their families

The **Annual Renewal** as supported by documents received between 2024-03-27 and 2024-04-10 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2024-04-10 as resolved by its quorate meeting.

Please note the following about your ethics approval:

- Renewal of ethics approval is valid for 1 year, subsequent annual renewal will become due on 2025-04-11.
- The Research Ethics Committee (REC) must monitor your research continuously. To this end, you must submit as may be applicable for your kind of research:
 - a) annual reports;
 - b) reports requested *ad hoc* by the REC;
 - c) all visitation and audit reports by a regulatory body (e.g. the HPCSA, FDA, SAHPRA) within 10 days of receiving one;
 - d) all routine monitoring reports compiled by the Clinical Research Associate or Site Manager within 10 days of receiving one.
- The REC may select your research study for an audit or a site visitation by the REC.
- The REC may require that you make amendments and take corrective actions.
- The REC may suspend or withdraw approval.
- Please remember to use your protocol number (710/2019) on any documents or correspondence with the Research Ethics Committee regarding your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

On behalf of the FHS REC, Dr R Sommers

MBChB, MMed (Int), MPharmMed, PhD

Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

Research Ethics Committee
Room 4-60, Level 4, Tswelopele Building
University of Pretoria, Private Bag X323
Gazina 0031, South Africa
Tel +27 (0)12 356 3084
Email: deepeka.behari@up.ac.za
www.up.ac.za

Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tsa Maphele

Annexure 2

Communication with the Tshwane Department of Health

Annexure 2-A

Tshwane Research Committee Clearance certificate (Laudium)



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr. Mpho Moshime-Shabangu
Tel: +27 12 451 9009
E-mail: Mpho.Moshime@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE

DATE ISSUED: 02/03/2020

PROJECT NUMBER: 14/2020

NHRD REFERENCE NUMBER: GP_202002_029

TOPIC: A mixed-methods study to develop a self-care management tool for people living with diabetes and their families

Name of the Researcher: Mrs Jennifer Jurnat

Name of the Co-researchers: Dr V. Bhana-Perna
Dr H. Sedibe

Facilities: Laudium CHC

Name of the Department: University of Pretoria

NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND

NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.

DECISION OF THE COMMITTEE: APPROVED


.....
Dr. Mpho Moshime-Shabangu
Acting Chairperson: Tshwane Research Committee

Date: 02/03/2020


.....
Mr. Mothomane Pitsi
Chief Director: Tshwane District Health

Date: 2020.03.02

Annexure 2-B
Request permission from Laudium CHC

E-mail: jd-vdh@hotmail.com

Ms J Jumat (Principle Investigator)

Cell: 082 555 8909

PO Box 12729

Hatfield

0028

November 2019

To: Sr Nancy Nkopane Clinic Manager (Facility Manager)

Laudium Community Health Care Centre

405 Bengal Street

Laudium

Centurion

0037

Re: Permission to do research at Laudium Community Health Care Centre.

I am currently studying PhD at the UP. I therefore request permission to conduct a study at Laudium Community Health Care Centre. The title of the study is: "A Mixed methods study to develop a self-care management tool for both people living with diabetes mellitus and their families".

I intend to publish the findings of the study in a research journal and be made available to Laudium Community Health Care Centre. I also intend to protect the personal identity of the persons by assigning each person a random code number. I undertake not to proceed with the study until I have received approval from the Faculty of Health Sciences Research Ethics Committee, UP.

Yours sincerely

Signature of the Principle Investigator

.....

Annexure 2-C
Request permission from Lyttleton Clinic

E-mail: jd-vdh@hotmail.com

Ms J Jumat (Principle Investigator)

Cell: 082 555 8909

PO Box 12729

Hatfield

0028

November 2019

To: Sr Rachel Pule (Clinic Manager)

Lyttleton Laudium Community Health Care Centre

892 Clifton Ave

Centurion

Gauteng

0163

Re: Permission to do research at Lyttleton Clinic (City of Tshwane Metropolitan Municipality).

I am currently studying PhD at the UP. I therefore request permission to conduct a study at Lyttleton Clinic. The title of the study is: "A Mixed methods study to develop a self-care management tool for both people living with diabetes mellitus and their families".

I intend to publish the findings of the study in a research journal and be made available to Lyttleton Clinic. I also intend to protect the personal identity of the persons by assigning each person a random code number. I undertake not to proceed with the study until I have received approval from the Faculty of Health Sciences Research Ethics Committee, UP.

Yours sincerely

Signature of the Principle Investigator

.....

Annexure 2-D
Permission received from Lyttleton Clinic



Annexure 1

DECLARATION OF INTENT FROM SKILLS DEVELOPMENT FOR TSHWANE MUNICIPAL CLINICS

I give permission to Jennifer Denise Jumat to do her Research on **A MIXED METHODS STUDY TO DEVELOP SELF-CARE FOR PEOPLE LIVING WITH DIABETES MELLITUS & THEIR FAMILIES.**

I know that the final approval will be from the Tshwane Regional Research Ethics Committee and that this is only to indicate that the clinic is willing to assist.

Other comments or conditions prescribed by the PHC Manager to the Researcher are

KINDLY MAKE AN APPOINTMENT WITH THE FACILITY MANAGER BEFORE VISITING THE CLINIC;

Lyttelton Clinic – Sr Rachel Pule – 012 358 3452/3289



Ms Pinkie Lesolang

Deputy Director: Skills Development

Date:

Annexure 3

Requesting permission to use DSSQ-FV questionnaire

Annexure 3-A

Permission requested to use DSSQ-Fv questionnaire

From: Jenny Jumat <jd-vdh@hotmail.com>
Date: Friday, March 22, 2019 at 2:51 AM
To: "La Greca, Annette M." <alagreca@miami.edu>
Subject: Fw: Permission requested

From: Jenny Jumat <jd-vdh@hotmail.com>
Sent: Thursday, 21 March 2019 12:12 PM
To: alagreca@umiami.edu.ac
Subject: Permission requested

Dear Ms. La Greca

I am registered for the PhD degree in nursing studies entitled Mixed Methods Study to Enhance Self-care Management for families living with diabetes at the UP in SA.

I have read the article "The Diabetes Social Support Questionnaire-Family Version: Evaluating Adolescents' Diabetes-Specific Support From Family Members. Article *in* Journal of Pediatric Psychology · January 2003, DOI: 10.1093/jpepsy/27.8.665 · Source: PubMed".

I am keen to use your questionnaire for possible data collection in my studies. I am requesting your permission to use the questionnaire and would like to ask for the complete questionnaire. All ethics will be observed when used in my studies.

Should you wish to have more information I will provide them without delay.

Greetings from SA

Jenny Jumat

Annexure 3-B
Response from Professor La Greca granting permission

Re: Permission requested

La Greca, Annette M. <alagreca@miami.edu>

Fri 2019/03/22 16:18

RESEARCH.docx

19 KB



Please see the attached document for a link to the measure and instructions.

That is all the information I have

Best

Annette M. La Greca, PhD, ABPP

Distinguished Professor of Psychology and Pediatrics

Cooper Fellow and Provost Scholar

Director of Clinical Training

University of Miami

Department of Psychology

Email: alagreca@miami.edu

Phone: 305-284-9146

RESEARCH

My research interests focus on adolescents' peer relations (including peer and cyber victimization), friendships, and romantic relationships, as they pertain to psychological and physical health, and on the impact of trauma, especially natural disasters (hurricanes), on the psychological and physical functioning of youth and parents. Within these areas, I adopt a “risk and resilience” perspective and am keenly interested in translating research findings into preventive interventions. My recent work also reflects an interest in developmental issues that affect the conceptualization of posttraumatic stress disorder in youth.

Quick Links to Research:

- My profile on Google Scholar can be found [here](#).
- Many of my publications are available on my [ResearchGate](#) page.

You may also be interested in visiting the FACEBOOK page for the [UM Peers Lab](#).

Manuals available for download include [Helping America Cope](#) and [After the Storm](#). For additional manuals, go to www.7-dippity.com.

Other Links:

- [Curriculum Vitae](#)
- [Members of my research lab](#)

Links to Available Self-Report Measures

- [Dating Anxiety](#)
- [Diabetes Social Support](#)
- [Peer Crowds](#)
- [Self-Care Inventory](#)
- [Social Anxiety Scales](#)

DATING ANXIETY

The Dating Anxiety Scale for Adolescents (DAS-A; Glickman & La Greca, 2004) assesses adolescents' anxiety in heterosocial and dating situations. For more information on this measure, consult the following articles:

- Adolescents' Anxiety in Dating Situations: The Role of Other-Sex Friends, Close Friends, and Romantic Partners. (La Greca & Mackey, 2007).
- The Dating Anxiety Scale for Adolescents: Scale Development and Associations with Adolescent Functioning. (Glickman & La Greca 2004).

DIABETES SOCIAL SUPPORT

The Diabetes Social Support Questionnaire (DSSQ) is a self-report measure with two parallel versions. The DSSQ Friends is a measure of friend's support for diabetes care. The DSSQ Family is a measure of family support for diabetes care. For more information on this measure, consult Bearman & La Greca, 2002, *Journal of Pediatric Psychology*.

PEER CROWDS

The Peer Crowds Questionnaire (PCQ; La Greca, Prinstein & Fetter, 2001) was designed to assess the extent to which adolescents identify with a variety of common peer crowd affiliations. For more information regarding this questionnaire, please consult the following articles:

- Adolescent Peer Crowd Affiliation: Linkages With Health-Risk Behaviors and Close Friendships. (La Greca, Prinstein & Fetter, 2001)
- Adolescents' Eating, Exercise, and Weight Control Behaviors: Does Peer Crowd Affiliation Play a Role? (Mackey & La Greca, 2007).

SELF-CARE INVENTORY

The Self-Care Inventory is a self-report measure designed to assess a person's level of adherence to diabetes self-care management recommendations over the previous 1 - 2 months. The SCI Manual can be downloaded here. A revised copy of the Self-Care Inventory (SCI-R) can be downloaded here. For information on the psychometric analyses of the SCI-R, please consult this article: Measuring Diabetes self-care management.

*PLEASE NOTE: The SCI and SCI-R are COPYRIGHTED materials. They are copyrighted by Annette M. La Greca, and may be used only with the written permission of the author. The author does not grant permission for publishing norms, alterations, or translations of the instrument without her written permission or collaboration in such efforts.

SOCIAL ANXIETY SCALES

The Social Anxiety Scale for Children-Revised (SASC-R) and the Social Anxiety Scale for Adolescents (SAS-A) are self-report measures designed to assess youths' levels of social anxiety. The SASC-R is appropriate for children ages 7 to 13 years (elementary school), and the SAS-A is appropriate for adolescents (middle school and high school). Each measure has 18 items (plus four filler items) that evaluate three aspects of social anxiety: Fear of Negative Evaluation from peers (FNE = 8 items), Social Avoidance and Distress around New Peers or in New Situations (SAD-New = 6 items) and Generalized Social Avoidance and Distress (SAD-General = 4 items). Items are rated on 5-point Likert scales and summed across relevant items to obtain scores for the SAS total and each of the three subscales. Substantial data supports the reliability and validity of these instruments.

The SASC-R and SAS-A are COPYRIGHTED materials. They are copyrighted by Annette M. La Greca and may be used only with her written permission. The author does not grant permission for publishing norms, alterations, or translations of the instrument without her written permission or collaboration in such efforts. The Manual for the Social Anxiety Scales contains detailed psychometric and normative information, information on translations, and copies of the scales and their scoring.

If you are interested in using the Social Anxiety Scales, please contact Adrienne Rondon (a.rondon@miami.edu). In order to obtain the manual:

- a) You must send a letter or email indicating in writing that you understand that the scales are copyrighted and that you will not publish norms, alterations, or translations of the instrument without Dr. La Greca's written permission or collaboration.
- b) You must also send a check or money order for \$15.00, payable to the Department of Psychology, along with your mailing address, to receive a copy of the manual with scoring and information on validity, reliability, etc.
- c) Please allow up to two weeks for processing. The manual is only available by mail.

Annexure 4

Pilot questions to determine the feasibility of DSSQ-Fv (Phase 1)

Annexure 4-A

Pilot questions to determine feasibility of DSSQ-Fv (Phase 1)

Question	Item	Rating scale		
		1	2	3
1	Rate the understanding of the questions	easy to understand	difficult to understand	very difficult
2	The sequence of the questions are easy to follow	acceptable	difficult	confusing
3	Rate the layout of the questionnaire	easy	difficult	complex
4	Would you prefer that the English questions should be translated to a language of choice?	Yes	No	Uncertain
5	Consider translations from English and indicate the time to complete the questionnaire	less than 1 hour	1 hour and more	
6	Do you require translation from English during completion of the questionnaire?	Yes	No	
7	How long did it take you to complete the questionnaire	Hours..... Minutes.....		



Pilot
questions.docx

Annexure 5

DSSQ-Fv questionnaire

How often does this happen?	<u>0</u> Never	<u>1</u> Less Than 2x a month	<u>2</u> Twice a Month	<u>3</u> Once a Week	<u>4</u> Several times a Week	<u>5</u> At least once a day
When this happens, how do you feel about it?	<u>-1</u> Unhelpful Or NOT Supportive	<u>0</u> Neutral	<u>1</u> A little Helpful or Supportive	<u>2</u> Helpful/ Supportive	<u>3</u> Very Supportive	

How often does a family member...

How does this make you feel?...
or How would you feel?

10. Let you know they appreciate how difficult it is to take Insulin Injections.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

BLOOD TESTING

11. Ask you about the results of your blood tests.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

12. Watch you test your blood sugars to see what the values are.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

13. Nag you until you do your testing.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

14. Remind you to test urine for ketones.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

15. Test your blood sugar for you.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

16. Remind you to test your blood sugar.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

17. Make sure you have materials needed for blood testing (e.g., chemstrips, etc).
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

18. Let you know that they appreciate how hard it is to test blood sugars every day.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

19. Set up the materials you need for testing your blood sugar.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

20. Praise you for testing your blood sugar on your own.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

21. Help out when you test your blood sugar.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

22. Keep track of testing results for you.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

23. Watch you for signs that your blood sugar is low.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

24. Help out when you might be having a reaction.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

MEAL PLAN

25. Encourage you to eat the right foods.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

How often does this happen?	<u>0</u> Never	<u>1</u> Less Than 2x a month	<u>2</u> Twice a Month	<u>3</u> Once a Week	<u>4</u> Several times a Week	<u>5</u> At least once a day
When this happens, how do you feel about it?	<u>-1</u> Unhelpful Or NOT Supportive	<u>0</u> Neutral	<u>1</u> A little Helpful or Supportive	<u>2</u> Helpful/ Supportive	<u>3</u> Very Supportive	

How often does a family member...

How does this make you feel?...
or How would you feel?

26. Let you know they understand how Important It is for you to eat right. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
27. Ask if certain foods are okay for you to eat, before serving them. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
28. Do the grocery shopping for your meals. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
29. Schedule meals at the times you need to eat. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
30. Remind you about sticking to your meal plan. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
31. Suggest foods you can eat on your meal plan. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
32. Join you in eating the same foods as you. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
33. Get on your case after you ate something you shouldn't. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
34. Avoid tempting you with food or drinks that you shouldn't have. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
35. Watch what you eat to make sure that you eat the right foods. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
36. Cook meals for you that fit your meal plan. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
37. Choose restaurants that serve food you can eat. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
38. Eat at the same time you do. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
39. Praise you for following your diet. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
40. Tell you when you've eaten too much or too little. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
41. Show they're pleased when you've eaten right. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3
42. Keep track of your meal plan for you. How often? 0 1 2 3 4 5	It feels: -1 0 1 2 3

How often does this happen?	<u>0</u> Never	<u>1</u> Less Than 2x a month	<u>2</u> Twice a Month	<u>3</u> Once a Week	<u>4</u> Several times a Week	<u>5</u> At least once a day
When this happens, how do you feel about it?	<u>-1</u> Unhelpful Or NOT Supportive	<u>0</u> Neutral	<u>1</u> A little Helpful or Supportive	<u>2</u> Helpful/ Supportive	<u>3</u> Very Supportive	

How often does a family member...

How does this make you feel?...
or How would you feel?

43. Buy special foods that you can eat.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

44. Tell you not to eat something you shouldn't.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

Exercise

45. Suggest ways you can get exercise.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

46. Remind you to exercise.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

47. Invite you to join in exercising with them.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

48. Get on your case when you haven't exercised.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

49. Congratulate or praise you for exercising regularly.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

50. Bug you about exercising.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

51. Encourage you to join an organized sports activity (e.g., little league, gymnastics).
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

52. Buy sports equipment for you (e.g., tennis racquet).
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

53. Exercise with you.
How often? 0 1 2 3 4 5

It feels: -1 0 1 2 3

General Items

54. Are available to listen to concerns or worries about your diabetes care.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

55. Give you things to read on diabetes care.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

56. Tell you how well you've been doing with your diabetes care.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

57. Encourage you to do a good job of taking care of your diabetes.
How often? 0 1 2 3 4 5 It feels: -1 0 1 2 3

58. Understand when you sometimes make mistakes in taking care of your diabetes.

Annexure 6

Socio-demographic questionnaire

Annexure 6-A

Self-developed questionnaire to obtain demographics

Here is an example of how to answer the questions in Part 1.

Question number	Question	Select your answer			
1	Age in years	20 and 30	31 and 40	~~41 and 50~~	51 and 60

2. Indicate your sex: Male Female

Part 1: Socio-demographic information involves answering some questions about you to obtain information about the characteristics of participants, for example, your age, marital status, where you live, etc.

“Family” refers to blood relatives, kinship or friends who are supporting you with self-care management of diabetes.

PART 1 SOCIO-DEMOGRAPHIC QUESTIONNAIRE

Number	Question	Select your answer				
1	Identify your type of diabetes	Type 1		Type 2		
2	Age in years					
3	Gender	Male		Female		
4	Language	Afrikaans	English	IsiNdebele	IsiXhosa	IsiZulu
		Sepedi	Sesotho	Setswana	Siswati	Tshivenda
		Xhitsonga	Other (specify)			
6	Do you understand English?	Yes		No		

Number	Question	Select your answer				
7	Do you speak English?	Yes		No		
8	Marital status	Single	Married or living with a partner	Divorced	Widow/widower	
9	Educational level	University graduate	Primary school	High school	Vocational skills	No formal education
10	Employment	Employed	Self-employed	Unemployed		
11	Duration of diabetes diagnosed in years	6 months to 5 years	6 to 10 years	Longer than 10 years		
12	Do you have a family to help you in managing the diabetes	Yes		No		
13	If your answer is "no" please indicate your response	I would like to be referred to a support group		I will find my own family/support group.		



Biographic
questionnaire.docx

Annexure 7

Statistician letter of support

Annexure 7-A

Letter of statistical support



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Curriculum • Learning Models • Organizational Structure

DEPARTMENT OF STATISTICS

LETTER OF STATISTICAL SUPPORT

Date: 12 July 2019

This letter is to confirm that **Ms JD Jumat**, studying at the University of Pretoria, discussed the project with the title **A MIXED-METHODS STUDY TO ENHANCE SELF-CARE MANAGEMENT FOR PEOPLE LIVING WITH DIABETES AND THEIR FAMILIES, IN TSHWANE** with me.

I hereby confirm that I am aware of the project and I also undertake to assist with the statistical analysis of the data generated from the project.

In Phase 1 of the study, patients diagnosed with Diabetes Types 1 and 2 for a minimum of six months, who have been visiting selected clinics in Tshwane will be approached to participate in the study. At this stage the researcher does not have access to the total number of patients who visit the clinics for treatment over a specific period yet. As soon as the numbers become available, a power analysis will be performed to ensure that the sample size is adequate for the purpose of the study.

The data analysis will consist of frequency analysis and descriptive statistics such as means, standard deviations and medians. Based on the manual for the questionnaire scores will be calculated for the sub scales of the DSSQ. The inferential statistics will include the calculation of Cronbach's alpha to gauge the internal reliability of the instrument. The mean scores for the sub scales will be compared across the demographic variables by performing independent t-tests or ANOVAs, if the data come from a normal distribution. If the data is not normally distributed, non-parametric statistical tests will be performed to compare the median scores of the sub scales.

Ms JC Jordaan
Research Consultant
Internal Statistical Consultation Service
Department of Statistics
E-mail address: Joyce.jordaan@up.ac.za

Annexure 7-B

Letter of statistical support (2)



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YUNIBESITHI YA PRETORIA
Deridolents • Leading Minds • Dikopolo tša Ditsoale

DEPARTMENT OF STATISTICS

LETTER OF STATISTICAL SUPPORT

Date: 12 July 2019

This letter is to confirm that **Ms JD Jumat**, studying at the University of Pretoria, discussed the project with the title **A MIXED-METHODS STUDY TO ENHANCE SELF-CARE MANAGEMENT FOR PEOPLE LIVING WITH DIABETES AND THEIR FAMILIES, IN TSHWANE** with me.

I hereby confirm that I am aware of the project and I also undertake to assist with the statistical analysis of the data generated from the project.

In Phase 1 of the study, patients diagnosed with Diabetes Types 1 and 2 for a minimum of six months, who have been visiting selected clinics in Tshwane will be approached to participate in the study. At this stage the researcher does not have access to the total number of patients who visit the clinics for treatment over a specific period yet. As soon as the numbers become available, a power analysis will be performed to ensure that the sample size is adequate for the purpose of the study.

The data analysis will consist of frequency analysis and descriptive statistics such as means, standard deviations and medians. Based on the manual for the questionnaire scores will be calculated for the sub scales of the DSSQ. The inferential statistics will include the calculation of Cronbach's alpha to gauge the internal reliability of the instrument. The mean scores for the sub scales will be compared across the demographic variables by performing independent t-tests or ANOVAs, if the data come from a normal distribution. If the data is not normally distributed, non-parametric statistical tests will be performed to compare the median scores of the sub scales.

Ms Gopika Ramkilawon
Senior Research Consultant
Internal Statistical Consultation Service
Department of Statistics
E-mail address: gopika.ramkilawon@up.ac.za

Annexure 8

Participants' information to participate in the DSSQ-Fv

Annexure 8-A

Participants' information to participate in the DSSQ-Fv

Dear Prospective Research Participant

1) INTRODUCTION

You are invited to volunteer for this research study. I am doing this research for the PhD Nursing degree purposes at the UP. The information in this document is provided to help you decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy with the kind of questions that will be asked.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of this questionnaire is to have an understanding of your knowledge and perception of diabetes self-care management , and by doing so; I wish to learn more about how you are practising self-care and how the family supports you to manage your diabetes.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM PARTICIPANTS

This study involves answering some questions regarding your management of diabetes. You will be asked to complete a questionnaire, which will take about 45 minutes. I will collect the questionnaire from you before you leave the venue. To maintain the integrity of the questionnaire, I will be present, but an assistant will translate the questions in your language to help you with the questionnaire; there will be no right or wrong answers. The researcher will keep the completed questionnaires in a safe place to make sure that only people working on this study will have access to it. Please do not write your name on the questionnaire. This will ensure that your answers are kept confidential (so nobody will know what you have answered).

The questionnaire will consist of the following parts:

- Part 1: Socio-demographic information, which involves answering some questions about you to obtain information about the characteristics of the participants, for example, your age, marital status, where you live, etc.

- Part 2: Health information which involves answering some questions about your diabetes self-care management and support by the families.

4) RISK AND DISCOMFORT INVOLVED

There is no foreseeable physical discomfort or risk involved. If there are questions that are too sensitive for you to answer, you do not need to answer them.

5) POSSIBLE BENEFITS OF THIS STUDY

This study may help yourself, your family and other PLWDs to enhance self-care of diabetes.

6) ETHICS APPROVAL

This Protocol will be submitted to the Faculty of Nursing Sciences Research Ethics Committee, UP, Medical Campus, Tswelopele Building, Level 4-59, Telephone numbers 012 356 3084 / 012 356 3085 and written approval will be granted by that committee. The study has been structured in accordance with the ethical principles which deal with the recommendations guiding researcher where human beings are participating.

7) INFORMATION

If you have any questions concerning this study, you may contact the researcher any time for clarity (Jenny Jumat at 082 555 8909).

8) CONFIDENTIALITY

All records from this study will be regarded as confidential. All results will be published or presented in such a way that it is not possible to identify you as the participant.

9) COMPENSATION

You will not be paid to take part in the study. However, any cost you have because of taking part in the study, for example transport costs, will be paid back to you only if it is outside your normal appointments.

Annexure 9

Leading questions for focus group discussions Phase 2

Annexure 9-A

Leading questions for focus group discussions Phase 2 stage 1

Central question:

- How do you experience caring for yourself in managing and living with diabetes?

Probing questions:

- With regards to diabetes, how do you experience the involvement of your family in managing and caring for you?
- How can your family better care and support you in your living with diabetes?
- How can health care professionals better care and support you in living with diabetes?

Annexure 9-B

Leading questions for focus group discussions Phase 2 stage 2

Central question:

- How do you experience caring for and supporting a family member who is living with diabetes?

Probing questions:

- What adjustments have you had to make in order to care for and support a family member living with diabetes?
- How can HCPs better support you in caring for and supporting a family member living with diabetes?

Central question:

- How do you experience caring for yourself in managing and living with diabetes?

Annexure 10

Permission to conduct telephone interviews Phase 2 Stages 1 and 2

Annexure 10-A

Information and informed consent (interviews Phase 2 Stage 1)

Dear Prospective Participant

1) INTRODUCTION

You are invited to volunteer for a research study. I am doing this research for PhD Nursing degree purposes at the UP. This document gives you information to help you decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about what we will be discussing during the interview.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of this study is to include the family to help enhance diabetes self-care management , and by doing so, the researcher wishes to learn more from you and the family about how you care for yourself and how the family support you with managing diabetes. “Family” refers to blood relatives, kinship or friends who are supporting People living with diabetes with self-care management. If there is a need for family support, assistance can be arranged with your permission. Part of the study will be an interview. The interview will be arranged at a time that is convenient to you and will take place via WhatsApp, Zoom, Skype, in-person or normal telephone line whichever is your choice.

3) EXPLANATION OF WHAT WILL BE EXPECTED FROM PARTICIPANTS

This study involves taking part in discussions about diabetes self-care management. If you agree to participate, you will be asked to be interviewed, which will take about 30 to 45 minutes. You and other participants will be asked some questions about your opinions, about your needs and your personal experiences with diabetes self-care management. With your permission, the discussions will be recorded on a recording device to ensure that no information is missed, and you will be required to give consent for the tape recording.

4) POSSIBLE RISKS AND DISCOMFORTS INVOLVED

There are no medical risks associated with the study. There will be no clinical procedures done. We do not think that taking part in the study will cause any physical or emotional discomfort or risk. You do not have to share any knowledge that you are not comfortable with. During the interview, you may find that some questions are sensitive; for instance, questions about how you think your family support you in dealing with diabetes. If questions feel too personal or make you feel uncomfortable, you do not have to answer them. If you need psychological support or counselling during or after the interview, I will be able to refer you to the relevant person. If there are people with poorly controlled diabetes and not managing the diabetes well, in consultation with them and the relevant clinics or persons, will they be referred for follow-up visits.

5) POSSIBLE BENEFITS OF THIS STUDY

This study aims to develop a tool to enhance self-care management for People living with diabetes and their families. Your participation is important for us to better understand your experiences of diabetes self-care management and the study results may onward benefit other People living with diabetes and their families.

6) COMPENSATION

You will not be paid to take part in the study.

7) VOLUNTARY PARTICIPATION

The decision to take part in the study is yours and yours alone. You do not have to take part if you do not want to. You can also stop at any time during the interview without giving a reason. If you refuse to take part in the study, this will not affect you in any way.

8) ETHICS APPROVAL

We will not record your name anywhere, and no one will be able to connect you to the answers you give. Your answers will be linked to a fictitious code number or a pseudonym (another name), and we will refer to you in this way in the data, any publication, report or other research output. All records from this study will be regarded as confidential. Results will be published in medical journals or presented at conferences in such a way that it will not be possible for people to know that you were part of the study.

The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the Research Ethics Committee of the University

of Pretoria. All of these people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study unless you give permission for other people to see the records. All hard copy information will be kept in a locked facility at the nursing department at the University of Pretoria for a minimum of 5 years, and only the research team will have access to this information.

9) INFORMATION

If you have any questions concerning this study, you should contact the researcher at any time with contact details at the end of the letter.

10) CONFIDENTIALITY

Although all participants of the interview will be requested to keep the discussion confidential, the researcher cannot guarantee that they will do so. I therefore request that you do not disclose any information of a very personal or sensitive nature.

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I give permission to be referred for family support and assistance.
- I give permission to be referred to the relevant clinic (s) or persons for consultation if I have problems to deal with the diabetes.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions, and I have no objections to participating in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to discontinue with the study, and my withdrawal will not affect my treatment and care.
- I am participating willingly.
- I am giving specific permission for the discussion to be recorded.
- I have received a signed copy of this informed consent agreement.
- Kindly complete the next part to give permission for the interview.

How to give permission two ways

1. Print the page, complete and send it back via e-mail to jd-vdh@hotmail.com

2. Write out on a normal piece of paper, complete only the part applicable to you. Please add your signature. Take a photo and send it via WhatsApp to 082 555 8909

Please indicate your preferred date and time for the interview by WhatsApp or e-mail. You can change at any time.

Thank you for giving permission.

Best regards

Researcher: J.D. Jumat

Cell: 082 555 8909

Email: jd-vdh@hotmail.com

Annexure 10-B

Leading questions for Phase 2 Stage 1 telephone interviews

Central question:

How do you experience caring for yourself in managing and living with diabetes?

- Insulin injections
- Blood testing
- Meal plan
- Physical activities
- General aspects (reading material and information on diabetes)

Probing questions:

- With regards to diabetes, how do you experience the involvement of your family in managing and caring for you?
- How can your family better care and support you in your living with diabetes?
- How can health care professionals better care for and support you in living with diabetes?

Annexure 10-C

Leading questions for Phase 2 Stage 2 telephone interviews

Central question:

How do you experience caring for and supporting a family member who is living with diabetes?

Reflect on the following:

- Insulin injections
- Blood testing
- Meal plan
- Physical activities
- General aspects (reading material and information on diabetes)

Probing question:

- What adjustments have you had to make in order to care for and support a family member living with diabetes?
- How can HCPs better support you in caring for and supporting a family member living with diabetes?

Annexure 11

Information and informed consent for Phase 3

Annexure 11-A

Information and informed consent to participate in Phase 3

Dear Prospective Participant

1. INTRODUCTION

You are invited to volunteer for this research study. I am doing this research for the PhD Nursing degree purposes at the UP. The information in this document is provided to help you to decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely willing to help in creating a self-care management tool for people living with diabetes mellitus and their families.

2. THE NATURE AND PURPOSE OF THIS STUDY

The aim of this diabetes self-care management tool is to assist the people living with diabetes and their families to enhance self-care management of diabetes at home.

3. EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM PARTICIPANTS

This study involves applying your expert knowledge in dealing with self-care management for people living with diabetes, and the families that provide support to them. You will be expected to assess and contextualise the information which the researcher will provide; this will be collected during the study. This mean that you will apply logic, knowledge, and skills specific to your health discipline (s) to make sound judgements when identifying indicators that should be included to develop a self-care management tool. Indicators should be considered according to its relevance to enhance diabetes self-care management for the PLWD and families. You will also be expected to provide guidance on how you as a health discipline will add value to enhance diabetes self-care management for families; this would lead to the creation of a comprehensive diabetes self-care management tool that will be distributed. The process will take place over 30 working days, but questionnaires will be done individually and at your own time.

4. RISK AND DISCOMFORT INVOLVED

None.

5. POSSIBLE BENEFITS OF THIS STUDY

This study may help yourself and other disciplines in dealing with self-care management by HCPs.

6. ETHICS APPROVAL

This Protocol was submitted to the Faculty of Nursing Sciences Research Ethics Committee, UP, Medical Campus, Tswelopele Building, Level 4-59, Telephone numbers 012 356 3084 / 012 356 3085 and written approval was granted by that committee. The study has been structured in accordance with the ethical principles which deal with the recommendations guiding researcher in the research where human beings are participating.

7. INFORMATION

If you have any questions concerning this study, you may contact the researcher at any time for clarity (Jenny Jumat at cell phone 082 555 8909 or email jd-vdh@hotmail.com).

8. CONFIDENTIALITY

All records from this study will be regarded as confidential. All results will be published or presented in such a way that it is not possible to identify you as the participant.

9. COMPENSATION

You will not be paid to take part in the study.

10. CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.

- I am aware that the information obtained in the study, including personal details, will be anonymously processed, and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to discontinue with the study and my withdrawal will not affect my employment or student status.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.

Participant's name (Please print)

Date

Participant's signature

Date

Researcher's name (Please print)

Date

Researcher's signature

Date

Annexure 11-B

Information and informed consent for Phase 3 Round 1

Dear Respondent,

You are invited to volunteer for the research study. I am doing research for a PhD Nursing Science degree at the University of Pretoria. You are invited to participate in this survey for this purpose. No right or wrong responses exist, only your personal opinion as an expert in your field counts. The aim of this study is to develop a self-care tool for PLWDs, also for use by the families to improve their knowledge and skills in dealing with the complexities of diabetes self-care management at home.

Your participation in the study is completely voluntary. All information will be treated as highly confidential, and the identity of respondents will not be disclosed and will remain anonymous. As an expert, you will be expected to respond to the information which the researcher provided and give your expert opinion of what should/could be included in a self-care tool and how you, as a health discipline, will add value to enhance diabetes self-care management. Your expert opinions will lead to the creation of the self-care tool. The process will take place over 30 working days, but questionnaires will be done individually and on your own time. The due date for this questionnaire, Round 1, is 24 November 2023. A date will be provided when you receive the following questionnaire, Round 2.

You will be asked to complete an online survey. We anticipate that it will take about 15 minutes to complete the online survey. By agreeing to participate in this study, your contribution will help with the development of the self-help tool aimed at improving the health of PLWDs and the scientific knowledge in this field. Please note that all answers will be recorded for further analysis by the investigators only. This research has been approved by the ethical board of the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria with reference 710/2019. Should you need any further information, please feel free to contact:

Principal investigator: Jenny Jumat; jd-vdh@hotmail.com

Supervisor: Dr Varshika Bhana-Pema; varshika.bhana@up.ac.za

Supervisor: Dr Heather Legodi; heather.legodi@up.ac.za

Do you consent to participate in this survey?

- ☐ Yes (1)
- ☐ No (2)

Q3 Please enter your name and surname.

Q4 Email

Q5 What is your gender?

- ☐ Male (1)
- ☐ Female (2)
- ☐ Other (3)
- ☐ Prefer not to say (4)

Q6 Select your age group

- ☐ 31 - 40 years old (1)
- ☐ 41 - 50 years old (2)
- ☐ 51 - 60 years old (3)
- ☐ 61 years or older (4)

Q7 What is your field of expertise?

Q8 What is your health discipline?

Q9 How many years of experience do you have?

Q10 If you have diabetes, what Diabetes type do you have?

- ☐ Type 1 (1)

☐ Type 2 (2)

Q11 If you have diabetes, what is your experience of being a diabetic in years?

Q12 If you have diabetes, what comorbidities do you have?

Q13 If you have diabetes, what diabetic-related complications do you have?

Q14 Should the following information be included in managing glycemic control during self-care?

Q15 How do PLWDs ensure adequate glycaemic control to avoid risks and complications, e.g., during exercise.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q16 How to use the glucometer, when to check the blood glucose, how to record the glucose reading, what it means, what to do if it is too low or too high.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q17 Advice on how to maintain a stable blood glucose level during physical exercises.

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q18 A peanut butter sandwich and a cup of tea can be given for the sudden onset of hypoglycaemia during self-care.

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q19 Should the following information be included to manage day-to-day activities during self-care?

Q20 To keep a journal/diabetic log to record glucose testing and reading, diet consumption (types of food), weight, medicine taken and reminders for follow-up consultations.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q21 Advice on how to establish and follow a daily routine.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q22 Should the following information be included to improve knowledge and skills for self-care?

Q23 How to ensure effective insulin storage when travelling by road, air or abroad?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q24 Training opportunities the PLWD and family can attend to understand the importance of glucose testing?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q25 According to your experience in your specific health discipline, what type of education would you provide to support self-care at home?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q26 How a support group for the PLWD can contribute to enhancing self-care?

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q27 How a support group for the family of a PLWD can contribute to enhancing self-care?

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q28 How a toll-free National Diabetes Hotline can add value with self-care advice?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q29 Should the following information be included to comply with a therapeutic diet during self-care?

Q30 What dietary information should be contained in hand-out pamphlets and diabetic menus to correlate with individual or cultural dietary preferences?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q31 How can a financial constraint family adjust a therapeutic diet to a healthy eating plan and ensure adequate glycaemic levels?

- ☐ Yes (1)
- ☐ No (2)

- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q32 Should the following information be included to improve self-care during medicine adherence and treatment?

Q33 How to prevent adverse drug events when taking medicine or insulin?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q34 How to dispose of used insulin needles.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q35 To ensure better medicine adherence in self-care, what information must be given to the PLWD?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q36 Advice that should be given when a PLWD receives medicine with new labels and packaging?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q37 What self-care practices the PLWD must follow when the prescribed high insulin dosage must be split for administering insulin, e.g., 76 units of insulin is prescribed, but an insulin pen only delivers 60 units?

- ☐ Yes (1)
- ☐ No (2)

- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q38 Should the following information be included to improve self-care for a diabetic with healthy teeth and mouth?

Q39 How to take care of the teeth and mouth at home to ensure a healthy mouth

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q40 What must be done if mouth and teeth problems occur due to diabetes?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q41 How the PLWD must prepare prior to dental work or surgery?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q42 Should the following information be included to improve self-care of the feet?

Q43 Advice about footcare inspection.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q44 How does the PLWD should wash the socks if foot fungus is present.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q45 When the PLWD should consult a podiatrist for a foot assessment.

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q46 How a PLWD can prevent cold feet?

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q47 Should the following information be included to identify possible problems during self-care of the eye?

Q48 Self-care practices that can help to prevent or delay the risks and complications of diabetic eye disease.

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q49 The intervals for an eye test to prevent diabetic eye disease?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q50 To know the signs and symptoms of diabetic eye disease?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q51 Should the following information be included to improve self-care during physical activities?

Q52 Which exercises can be recommended for a PLWD with physical restrictions, e.g., amputation?

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q53 Advice to balance the blood glucose before, during and after physical activities?

☐ Yes (1)

☐ No (2)

☐ Not applicable to my health discipline (3)

☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)

☐ Please provide suggestions for self-care improvement (5)

Q54 Should the following information be included to improve self-care during psychological influences?

Q55 What healthy coping skills and risk-reduction behaviours can the PLWD apply to improve self-care?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q56 How can a healthcare professional support the PLWD with self-care at home?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q57 How can a healthcare professional support the family with self-care of the PLWD at home?

- ☐ Yes (1)

- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q58 What advice should be given on how to manage the stress of self-care, fear of diabetes complications, anxiety or depression?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q59 What support can be given for sexual dysfunction?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Q60 What effective reminders can improve self-care behaviour?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Not applicable to my health discipline (3)
- ☐ Please provide your opinion even if it is not applicable to your specific health discipline (4)
- ☐ Please provide suggestions for self-care improvement (5)

Annexure 11-C

Information and informed consent for Phase 3 Round 2

Q1 Dear Respondent,

You are invited to volunteer for Round 2 of this research study. I am doing research for a PhD Nursing Science degree at the University of Pretoria. You are invited to participate in this survey for this purpose. No right or wrong responses exist. Only your personal opinion as an expert in your field counts. Your participation in the study is completely voluntary. All information will be treated as highly confidential, and your identity will not be disclosed.

This study aims to develop a self-care tool for PLWDs, also for use by families to improve their knowledge and skills in dealing with the complexities of diabetes self-care management at home. As an expert you are expected to respond to the information which the researcher provided. Your expert opinions will lead to the creation of the self-care tool.

Based on the responses from Round 1, and to obtain clarity, two questions need to be explored in greater depth. This is Round 2. You are requested to complete this online questionnaire to reconsider your response. You can rephrase the question or provide additional information; however, you are encouraged to respond by either selecting "yes" or "no".

We anticipate that it will take about 15 minutes to complete this online survey. This questionnaire will be done individually and at your own time. However, the due date for this questionnaire is 20 December 2023.

To finalise this part of the research, you will receive Round 3 during January 2024. Please note that all answers will be recorded for further analysis by the investigators only. This research has been approved by the ethical board of the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria with reference 710/2019.

Should you need any further information, please feel free to contact:

Principal investigator: Jenny Jumat; jd-vdh@hotmail.com

Supervisor: Dr Varshika Bhana-Pema; varshika.bhana@up.ac.za

Supervisor: Dr Heather Legodi; heather.legodi@up.ac.za

Q2 Do you consent to participate in this survey?

- ☐ Yes (1)
- ☐ No (2)

Q3 Please enter your name and surname

Q4 Email

Q5 What is your gender?

- ☐ Male (1)
- ☐ Female (2)
- ☐ Other (3)
- ☐ Prefer not to say (4)

Q6 Select your age group

- ☐ 31 - 40 years old (1)
- ☐ 41 - 50 years old (2)
- ☐ 51 - 60 years old (3)
- ☐ 61 years or older (4)

Q7 What is your field of expertise?

Q8 What is your health discipline?

Q9 How many years of experience do you have?

Q10 If you have diabetes, what Diabetes type do you have?

Type 1 (1)

Type 2 (2)

Q11 If you have diabetes, what is your experience of being a diabetic in years?

Q12 If you have diabetes, what comorbidities do you have?

Q13 If you have diabetes, what diabetic-related complications do you have?

Section B

Q14 How should the PLWD or family manage a sudden onset of low blood sugar at home if the PLWD is able to swallow and chew?

Yes (1)

No (2)

Not applicable to my health discipline (3)

Please provide your opinion even if it is not applicable to your specific health discipline (4)

Please provide suggestions for self-care improvement (5)

Q15 How should the PLWD or family manage a sudden onset of low blood sugar at home if the PLWD is unable to swallow and chew?

Yes (1)

No (2)

Not applicable to my health discipline (3)

Please provide your opinion even if it is not applicable to your specific health discipline (4)

Please provide suggestions for self-care improvement (5)

Q16 Can a diabetic log/journal be kept as a daily monitoring tool to record self-care activities?

Yes (1)

No (2)

Not applicable to my health discipline (3)

Please provide your opinion even if it is not applicable to your specific health discipline (4)

Please provide suggestions for self-care improvement (5)

Annexure 11-D

Information and informed consent for Phase 3 Round 3

Q1 Dear Respondent,

I am doing research for a PhD Nursing Science degree at the University of Pretoria. This study aims to develop a self-care tool for PLWDs. Your contribution will help with the development of the self-help tool aimed at improving the complexities of diabetes self-care management at home, to improve the health of PLWDs and to contribute to the scientific knowledge in this field.

By completing this final survey, your participation in the study is completely voluntary. All information will be treated as highly confidential, and your identity will not be disclosed. No right or wrong responses exist. Only your opinion as an expert in your field counts. As an expert, you will be expected to indicate to which level you agree or disagree with the items which the researcher provided and give your expert opinion of what information should/could be included in a self-care tool. Your expert opinions will lead to the creation of the self-care tool.

You will be asked to complete an online survey. We anticipate that it will take about 20 minutes to complete the survey. Please note that all answers will be recorded for further analysis by the investigators only. The questionnaire will be completed individually and on your own time from 1 March 2024. The closing date is 10 March 2024. This is the final Round. Thank you for participating.

This research has been approved by the ethical board of the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria with reference 710/2019. Should you need any further information, please feel free to contact:

Principal investigator: Jenny Jumat; jd-vdh@hotmail.com

Supervisor: Dr Varshika Bhana-Pema; varshika.bhana@up.ac.za

Supervisor: Dr Heather Legodi; heather.legodi@up.ac.za

Q2 Do you consent to participate in this survey?

Yes (1)

No (2)

Q3 Please enter your name and surname

Q4 Email

Q5 What is your gender?

Male (1)

Female (2)

Other (3)

Prefer not to say (4)

Q6 Select your age group

31 - 40 years old (1)

41 - 50 years old (2)

51 - 60 years old (3)

61 years or older (4)

Q7 What is your field of expertise?

Q8 What is your health discipline?

Q9 How many years of experience do you have?

Q10 If you have diabetes, what Diabetes type do you have?

Type 1 (1)

Type 2 (2)

Q11 If you have diabetes, what is your experience of being a diabetic in years?

Q12 If you have diabetes, what comorbidities do you have?

Q13 If you have diabetes, what diabetic-related complications do you have?

Q14 Manage the blood glucose during self-care

Q15 Always take the glucometer with you and have a healthy snack at hand.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q16 To prevent risks and complications, Type 2 PLWDs can manage their blood glucose by ensuring a reading not higher than 13mmol/L, or as suggested by the physician.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q17 To prevent risks and complications, Type 1 PLWDs can manage their blood glucose if they ensure a reading between 6 and 8.6 mmol/L, or as suggested by the physician.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q18 If the blood glucose is too high, a Type 2 PLWD can exercise, eat less carbohydrates and drink plenty of water.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q19 If the blood glucose is too high, a Type 1 PLWD can control the blood glucose with extra insulin as suggested by the physician.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q20 If the blood glucose is too low (3.9mmol/L), a Type 1 PLWD must take normal sugar, honey, Super-C sweets, Lifesaver sweets (it dissolves in the mouth), followed by a meal with carbohydrates and protein to restore the blood glucose levels.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q21 Do not exercise alone. If necessary, exercise under the supervision of a biokineticist.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q22 To maintain acceptable blood glucose level, do not to consume a heavy meal prior to exercise, but also do not exercise on an empty stomach. Monitor blood glucose levels before, during and after exercise.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q23 Recommended exercises for a PLWD with physical restrictions, e.g., amputation?

Q24 The diabetic amputee can do cycling with a prosthetic, swimming, walking with aid, etc.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q25 The value of a diabetic log

Q26 It is an important self-monitoring tool to ensure conclusive feedback to the HCP to make therapeutical decisions.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q27 To record the weekly blood glucose readings prior to the next consultation or during times when PLWDs make significant changes to their routine or are struggling with blood glucose control.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q28 To record diet consumption, weekly weight, urine testing, medicine or insulin taken or changes thereof.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q29 To record food items that affect blood glucose.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q30 Establish a daily routine

Q31 Daily routine could include foot care, dental care, blood glucose readings, physical activities (exercise and gardening), daily medication and insulin therapy, and prescribed dietary intake.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q32 Ensuring effective insulin storage when travelling by road, air or abroad

Q33 If travelling or on a day outing, ensure to keep the insulin out of direct sunlight.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q34 Where there are no fridge facilities or extended hours of load shedding, keep the insulin in a cooler bag with an ice pack or in a cool, dark place.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q35 Recommended DSME provided by HCPs

Q36 Individual healthcare providers should give an induction course about the most important aspects of self-care.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q37 Provide guidance for carb counting for pump patients and general low-carb education for diabetic people.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q38 Provide information and practical examples of portion control.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q39 Consider a pamphlet with simple self-care examples.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q40 Psychology sessions must include family therapy, cognitive behavioural therapy and general psychoeducation.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q41 The value of a support group for the PLWD or family

Q42 Members of the support group should meet on a regular basis.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q43 In the absence of a physical support group, a WhatsApp group can give access to telephonic conversations and questions, and it can be used as an online meeting platform.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q44 A dietitian can play a valuable role during dietary guidance and education in support groups.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q45 Encourage support groups for the family to minimise caregiver distress and burnout.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q46 Relevant dietary information to ensure healthy diets

Q47 List the food items which contain carbohydrates and how to eat them responsibly.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q48 Discuss the content of hand-out pamphlets and information with the PLWD and family.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q49 Other conditions, such as hypertension, hyperlipidaemia, etc., must be considered during dietary consultations.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q50 Simple and affordable diets could be seasonal/plant-based options, e.g. legumes.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q51 The dietitian can provide a list of low and high- GI products.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q52 Prevent errors with medicine or insulin

Q53 When receiving new medicine to which they were not exposed to previously, and to avoid mistakes, the HCPs must inform the patients about the differences and similarities accordingly.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q54 To prevent mistakes during medication intake, the pharmacist is responsible for providing advice and must check for drug interactions and potential allergic reactions.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q55 The pharmacist must ensure to issue the correct medicine to the correct person.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q56 The pharmacists should confirm the dosage, name of medication and interval of usage.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q57 Physicians or pharmacists should inform and explain when medicine prescriptions are changed.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q58 People must read the leaflets and ask questions when in doubt.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q59 Disposal of used insulin needles

Q60 Safety aspects of disposing of used needles are to collect used needles in a tin or thick, strong plastic container with a lid and store in a safe place. When it is nearly full, it could be taken to the health facility to add to their disposal.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q61 Needles should not be buried, burnt, or toilet flushed, nor throw used or unused needles loose in the dustbin.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q62 In the event that the PLWD administers very high dosages of insulin and needs to split the dosage due to the limited amount a pen takes, he/she can use two insulin pens, one to administer 60 units and the other for 16 units. Mark pens clearly with doses to be taken.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q63 Check the dosage of the insulin with a support person to ensure correct dosage to prevent mistakes.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q64 Dental care of the PLWD

Q65 Use a soft toothbrush, floss, toothpaste, and saltwater rinses.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q66 Visit the dentist and oral hygienist once a year to maintain good dental health.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q67 If mouth and teeth problems occur due to diabetes, consult the dentist earlier than scheduled.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q68 Report any problems such as bleeding or painful gums timeously to the HCP.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q69 Footcare to prevent complications

Q70 Poor foot care may lead to amputations. The person must always inspect the base of the foot on a daily basis.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q71 Ask for assistance with cutting nails to prevent ingrowing toenails or an injury.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q72 Wash the feet with lukewarm, soapy water and dry feet properly between the toes.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q73 Apply a moisturising cream to the feet but refrain from applying between the toes because the moisture between the toes may lead to infection.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q74 Daily foot inspection is recommended to early detect cuts, sores, blisters, redness, calluses, scratches, bruises, and circulation.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q75 Use a mirror to check under the feet or ask someone else to check the feet.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q76 Schedule annual foot assessments with the podiatrist to detect changes in the shape of the feet, which might affect movement.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q77 Consult the podiatrist for ingrowing toenails, injury, pins and needles, and pain.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q78 Wash the socks in soapy water or Milton solution if foot fungus is present.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q79 More than one pair of shoes is recommended, and it should be rotated on a daily basis. Ensure all shoes are comfortable.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q80 Ensure that wet shoes are properly dry before wearing them.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q81 Inspect inside the shoes for sharp objects, small pebbles or any damage to the inner shoe that may cause injury.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q82 Blood flow is very important for PLWD, and a foot and leg scan should be done as poor blood flow causes cold feet, numbness and slow healing sores.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q83 Due to peripheral neuropathy, hot water bottles are not recommended for cold feet, it may cause burns.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q84 Avoid wearing tight-fitting socks, it may cause injury and poor blood circulation.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q85 Refrain from smoking, it might affect blood vessels and can reduce blood flow to the feet.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q86 Eyecare to prevent diabetic eye disease

Q87 High blood glucose levels can damage the veins and arteries, maintain a satisfactory blood glucose level to prevent blurry and double vision.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q89 Consult the optometrist/ophthalmologist to check for glaucoma, redness, pain, discharge, blurred or double vision.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q90 Scheduled annual visits to the eye clinic, optometrist, or ophthalmologist are recommended for a comprehensive vision examination and dilated retinal examination to detect abnormalities and for treatment.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q91 Coping skills and managing risk-reduction behaviours

Q92 Avoid painful exercise as the pain might increase glucose levels and blood pressure.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q93 Identify a confidant to talk to when stressed or emotionally challenged.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q94 Consult psychologist for CBT, self-screening for diabetes distress, psychoeducation regarding comorbidities and referral pathways, strategies for fostering psychological resilience and emotional self-regulation.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q95 Follow a healthy eating plan and exercise regularly. Testing the blood sugar levels and using the outcome to facilitate treatment decisions.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q96 Always have the important contact numbers at hand, e.g. trauma hotline centre.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q97 Where possible and necessary, referrals to a psychologist must be made to recommend and implement intervention pathways to manage anxiety, stress and fear.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q98 Support for sexual dysfunction

Q99 Consult the dietitian for an improved diet to reduce blood glucose levels, which may improve blood flow and circulation.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q100 Obtain a referral note to a urologist.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q101 Do not self-medicate. Consult an HCP for medical therapy.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q102 Approach a psychologist for interventions such as cognitive-behavioural therapy, sensate-focused therapy, mindfulness-based interventions, and psychoeducation.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q103 Reminders to improve self-care

Q104 Utilisation of a clock on a cell phone, establish a self-care card and keep it on the fridge.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q105 Use a digital app that is set with certain reminders regarding health care routine.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q106 Use a written routine and enlist the support of family.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q107 Include the family and establish a workable routine.

Strongly disagree (7)

Disagree (8)

Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Q108 Set reminders for snack time to prevent hypoglycaemic incidences.

Strongly disagree (7)

Disagree (8)

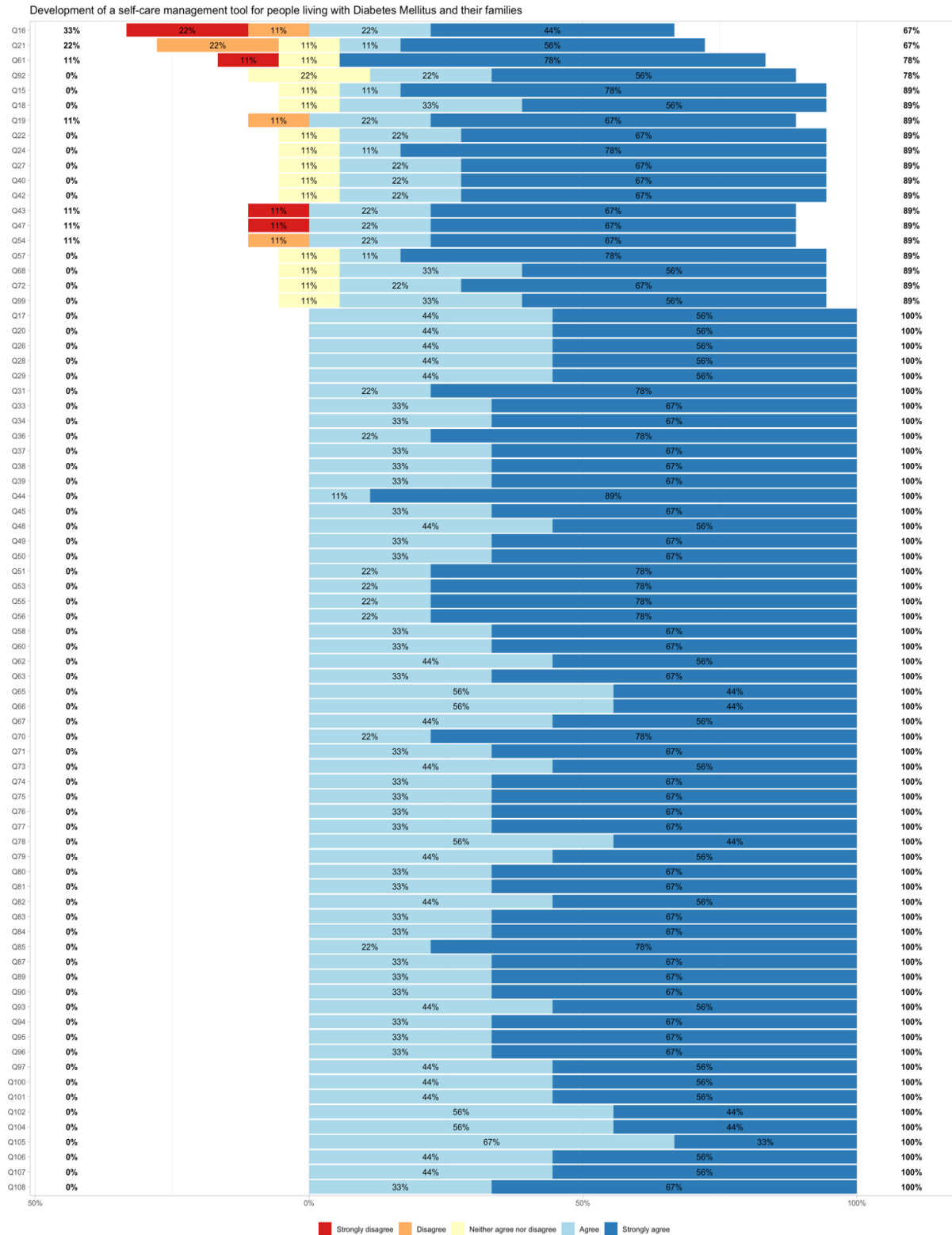
Neither agree nor disagree (9)

Agree (10)

Strongly agree (11)

Annexure 11-E

Likert Plots



Annexure 12-A

Diabetes self-care management tool text information Stage 3: Information to develop a self-care tool

You will never change your life until you change something you do daily. The secret of your success is found in your daily routine

John C. Maxwell

What you should know about diabetes self-care management

The World Health Organisation (2019:15) classified diabetes as a chronic metabolic disease under Type 1 and Type 2 diabetes, gestational and impaired glucose tolerance, and impaired fasting glycaemia. This document focuses on diabetes types 1 and 2. The non-production of insulin characterises type 1 diabetes due to the destruction of the β cells. Therefore, a type 1 diabetes person becomes insulin dependent. On the other side, type 2 diabetes occurs when the pancreas makes insufficient insulin or the body fails to use the insulin which is being produced effectively. In both cases, the person with the disease often leads to uncontrolled blood glucose.

Uncontrolled blood glucose may lead to a heightened risk of heart disease, stroke (clogging our arteries), and visually impaired problems such as blindness and glaucoma. People might have amputations of the lower limbs (toes, feet) and may experience kidney problems, etc. The positive thing is that by following a routine and changing certain habits, it is possible to maintain acceptable blood sugar levels most of the time, which might help to alleviate the difficulties of self-care. If you have type 1 or type 2 diabetes, it is recommended to establish a daily routine (morning, afternoon, and bedtime) and to be active. Do activities. Self-care requires a lifelong commitment, which can improve life quality. The PLWD has the authority to make decisions about living with diabetes, but the family and HCPs must be available to support them in their endeavours. These following guidelines are applicable to establish a routine

Manage the blood glucose

Effective self-care practices can prevent risks and delay complications such as stroke, blindness, heart attack, kidney failure, impotence, and amputations (Patino et al., 2017; Pinchevsky et al., 2017:2; Hilli et al. (2018:36). Persons diagnosed with diabetes must ensure

that the blood glucose levels remain between 7 or 8.6 mmol/, or as advised by the physician. PLWDs should ensure that they are empowered to manage their blood glucose (blood sugar) in all situations they might encounter, especially if the situation might directly impact their blood glucose levels. Some PLWDs use an automated glucometer (insulin pump), others self-administer the insulin with an insulin pen, and some use the vials and syringes. Although all ways of insulin therapy are used, the difference lies in affordability, regular testing and the correct dosage that is injected. Although Levitt and Dave (2017:S21) define a diabetes educator as "any healthcare worker who has completed, with competence, a SANC or SEMDSA-approved diabetes educators course, trained diabetes nurses too must provide diabetes education and support to effectively guide them through self-care practices with which they have difficulties, e.g. operating the glucometer, testing the blood glucose and administering the correct dosage of insulin subcutaneously. Always take the glucometer with you and have a healthy snack at hand. To prevent risks and complications, Type 2 PLWDs can manage their blood glucose by ensuring a reading not higher than 13mmol/L or as advised by the physician. If the blood glucose is too high, a Type 2 PLWD can exercise eating less carbohydrates and drink plenty of water.

Type 1 PLWD can manage their blood glucose if they ensure a reading between 7 and 8.6 mmol/L or as advised by the physician. If the blood glucose is too high, a Type 1 PLWD can control the blood glucose with extra insulin as advised by the physician. If the blood glucose is too low (around 3.9mmol/L), a Type 1 PLWD must take normal sugar, honey, Super-C sweets, and Lifesaver sweets (it dissolves in the mouth), followed by a meal with carbohydrates and protein to restore the blood glucose levels.

To always ensure that there is support available, it is advisable not to exercise alone. If possible, exercise under the supervision of a biokineticist, with friends or in a group. To maintain acceptable blood glucose levels, do not consume a heavy meal prior to exercise, but also do not exercise on an empty stomach. It is recommended to maintain good hydration (taking adequate water) during exercise. While some have the opinion that pure fruits or juices are better, they contain natural sugars, which might elevate blood glucose. PLWDs must be reminded to dilute the fruit juices with water. Monitor blood glucose levels before, during and after exercise to ensure that the blood glucose remains stable. It is worth the while to record the type of activities and duration thereof.

Maintain a stable blood glucose level during physical exercises

Physical exercise is not limited to a gym, a biokineticist or a physiotherapist. It includes any other physical activities at home, such as home chores, gardening, etc. When doing physical exercises, it is not advisable to exercise alone. The biokineticist can play a prominent role during physical exercise. With the focus on self-care, not all PLWDs are members of a formal gym or know which exercises to do. A biokineticist can recommend appropriate exercises to be done at home and in the presence of a family member. The blood glucose levels should be monitored before, during and after physical activities because energy is used which may influence the blood glucose, including the heart rate and blood pressure. Despite physical restrictions, exercises are encouraged and may include cardiovascular exercises (according to disability). A PLWD with an amputee can cycle with a prosthetic leg, swim, do deep breathing exercises, and walk (with aid).

Recording the blood glucose reading and other information

PLWDs should record their blood glucose readings and must know what to do when it is too low or too high. The signs and symptoms are very important. Those with type 1 diabetes should understand the importance of staying active to keep their blood glucose levels within an acceptable range. When the glucose levels are low, the person might experience sweating, or experience a sudden warm feeling, might feel anxious, nausea, a fast pulse rate and sometimes a bit confused. To increase blood glucose to a safe level, they should eat enough but not overeat. Follow the guidance for a low blood glucose level.

On the other hand, when the blood glucose is too high, they should use (extra) insulin and follow the guidance to manage high blood glucose. (Tanenbaum, Breland, Yu, Walker & Gonzalez, 2016; Iloh et al., 2017; Adegbola et al., 2016; Coughlin & Smith, 2017).

A person with type 2 diabetes can control glucose levels by exercising regularly and balancing calories and carbohydrates (carbs) with the prescribed medicine and physical activities. Both should make healthy food choices and pay attention to portion size; the dietitian could provide this. Each PLWD must confidently operate the glucometer and have sufficient supplies such as test strips, urine test strips, blood lancets and batteries to do a blood sugar test at home. Due to the variations in meal preparation and composition, the effect of medicine intake and insulin dosages, and frequently varying glucose readings, it is very important to interpret the readings and act accordingly.

Therefore, it is advisable and important to keep a record of the readings. The purpose of recording the reading is to discuss it with the HCP to make sense of the blood glucose patterns and to help the HCP facilitate treatment.

The value of a diabetes log

A diabetes log or diabetes journal is a valuable tool which can be used to record timings and readings of blood glucose tests, diet consumption, weight, medicine taken and a reminder for follow-up consultations. The log may aid when changes are required in treatment or medicinal therapy or when the PLWD struggles to keep the blood glucose under control. The views on the recording are inconsistent. Some found it a very important tool to ensure conclusive feedback to the HCP during follow-up consultations. Others find it tedious and recommend that recording should only be done for a few days prior to a follow-up visit or when significant changes are made to treatment and routine. The opinion is that the PLWD must be equipped with the knowledge of what and why they should record. It is suggested to include urine analysis to identify food items that affect blood glucose.

Reminders to follow through with activities and a routine

A daily routine is a habit. Older persons struggle to make lifestyle changes. Some need to change the ways of personal care, foot care, dental care, insulin administering, physical exercise and lifestyle changes (thought processes and behaviour (Tanenbaum, Breland, Yu, Walker & Gonzalez, 2016; Iloh et al., 2017; Adegbola et al., 2016; Coughlin & Smith, 2017).

PLWDs are sometimes confused. It is thus important that they be in control of their life in any situation and be allowed or encouraged to make decisions. They should know step-by-step what to do during a self-care activity. Therefore, a self-care tool that guides the day-to-day routine could foster a workable routine and alleviate uncertainties.

Reminders can form part of the routine to improve self-care behaviour. To establish a routine, it is recommended to use a self-thought-out, workable written routine and enlist the support of family. To prevent hypoglycaemic incidences, it would be useful to set reminders for activities such as glucose testing, snack time, exercise time, etc. Use a digital app (or ask assistance from the family) to set reminders of what to do and when to do certain tasks. An old-fashioned way is to use a clock or alarm on the cell phone or use a handwritten routine, place it against the fridge, and follow through with the tasks.

Suggestions for education by different health domains

A PLWD must understand what carb counting is. Carbohydrates (carbs) are food items, such as starches or sugary foods, which include bread, potatoes, spaghetti, soft drinks, beans, milk, etc. Carbs like sugary foods can increase the blood sugar. The dietitian can guide carbs. Carb counting is the number of grams of these carbohydrates in a meal. Carb counting is important for those on insulin pumps and a general low-carb education must be given for PLWD. They must read the labels on food item packaging and, in extreme cases, use measuring tools. They can change their carb intake to match the prescribed insulin dosage or vice versa. In view of a person-centred approach, the dietitian can detail the meal plan and inform about simple and complex carbs. Dietitians who are experienced in diabetes care can help to develop meal plans to help PLWDs make the right choices for healthy meal planning, nutrition, and weight control.

This HCP must consider the socio-economic circumstance, food preferences and lifestyle to control the blood glucose levels, to keep healthy and maintain an acceptable weight, or to prevent weight loss but instil healthy eating habits. The importance is to balance the meal according to portion size. Most PLWDs are advised to measure per plate by dividing the portions with about 50% non-starchy vegetables, 25% grains or starch and 25% proteins.

To embrace positive behaviour, the psychologist plays a valuable role if it is indicated in Family Therapy, Cognitive Behavioural Therapy and general psychoeducation. However, full diabetes education on a regular and ongoing basis is necessary. Education and skills development remains an extremely important factor in diabetes self-care management. This could be informal, formal, and practical activities, which could include how to use the glucometer or sphygmomanometer (blood pressure device) to be able to understand the readings. Amongst others, how to do foot care and how to manage hypo- and hyperglycaemia situations.

From a person-centred viewpoint, the blood glucose levels are different at any given time. For high blood glucose, the person can have a reading of more than 13.9 mmol/L, frequent urination, increased thirst and if the urine is tested, it can have more ketones. They might feel weak and sleepy, vomiting, blurry vision, stomach pain and feel warm. The PLWD should remain with the prescribed insulin dosage, remain within the portion size, be active avoid situations that cause stress or illness. Physical activity might lower blood glucose.

Where the blood glucose is too low, the PLWD might experience symptoms such as weakness, sweating, dizziness, shakiness, feeling sleepy, movement control and confusion or clumsy,

nausea etc. This situation must be avoided at all costs. The blood glucose must be checked immediately, and this can be temporarily reversed by taking normal sugar, honey, Super-C sweets, and Lifesaver sweets (it dissolves in the mouth), followed by a meal with carbohydrates and protein to restore the blood glucose levels. If the person is unable to swallow, they must not drink or eat anything but call for medical assistance immediately. While the person could be unconscious, turn him on the side and ensure the airways are not blocked. Call the ambulance to take the person to the nearest health facility. Family and friends must be trained on how to manage this emergency.

Managing stress with health coping skills to reduce risk behaviour

Stress can be managed through healthy coping skills, which may reduce risk-behaviour during self-care (Omisakin & Ncama, 2011:1734). Diabetes and self-care impact the psyche of a person. They need to be advised on how to manage the stress of self-care, fear of diabetes complications, anxiety, or depression. Exercise might help with stress management. The PLWD should always interact with the rest of the family. Acceptance of the health condition and knowing how to deal with it through self-care can alleviate anxiety and stress. DSME could address the stumbling blocks. A psychologist should be involved to guide them on how to manage certain aspects or situations. Coping mechanisms to reduce risk behaviour may improve self-care. Painful exercises elevate and increase blood glucose levels and must be avoided. In the case of stressful incidents which is emotionally challenging, it is recommended to discuss the matter with a confidant. Information leaflets issued to the person might be intimidating if they are not confident with the content, terminology, or interpretation. It is advisable that the HCP first discuss the content and ensure the person understands.

A psychologist may intervene and recommend the practice of cognitive-behavioural therapy, self-screening for diabetes distress, psychoeducation regarding comorbidities and referral pathways, and strategies for fostering psychological resilience and emotional self-regulation. Correct dietary habits in coordination with exercise may regulate uncontrolled blood glucose. It is recommended that the PLWD have available a contact number of the health facility, emergency ambulance, trauma centre, diabetes lifestyle coach, etc.

Join a support group

The value of a support group for the family and the PLWD may contribute to enhancing self-care and serve various functionalities. Apart from a face-to-face support group, there are other social media platforms where one can join. WhatsApp and Facebook groups can be

established. HCPs can also use these groups for training purposes. It is an ideal platform for sharing general information, motivating others, sharing easy, relevant recipes, and other practicalities. Support groups can change perceptions in either direction, so it is advisable for HCPs, especially dietitians, to lead those groups. It is suggested that such groups be non-threatening (not overwhelming) and at the level of the PLWDs or their families. Support groups may work well in communities where PLWDs need physical assistance with personal grooming, rides to retail stores, reading or listening to tales if a person is visually impaired, sharing of ideas, and visits to follow-up consultations, particularly where the person has physical limitations.

From a psychological view, a valuable part of support and self-esteem improvement may lead to mitigating problems associated with diabetes distress, which may foster resilience. Support groups must meet regularly to ensure its existence. It could be formalised for online meetings, informative discussions, and reminders. People who feel heard and understood may improve their mental health. Peer support is a valuable element. Any person wants to be in control of their life, wants to make informed decisions and be less dependent. The outcome is self-esteem improvement, lifestyle changes, and improved self-care. The more people in the support group contribute to group activities, the more a person gains leading to less liability on the healthcare system.

Healthcare support to the PLWD and family

HCPs can provide self-care support during follow-up consultations with the PLWD and the family about the self-care plan. It is therefore recommended for PLWDs to keep a diabetes log which could help to make relevant changes to the treatment plan. Through regular scheduled follow up consultations, it is advisable to discuss any uncertainties or ask for relevant assistance if it is required. HCPs could play an active role in support groups. The dietitian can share different meal plans, substitute food items, and recipes or ideas on how to put a healthy meal together. Psychological support, such as Family-based interventions, might be extremely valuable in terms of behavioural and relationship matters.

Biokineticist could arrange physical exercise sessions for a group, which could enhance social cohesion and minimise stress. Handouts and literature can be distributed, and a support group can be used for practical training sessions, reminders, and online discussions. A support /WhatsApp group for the family could be separate to give them freedom of voice when they discuss matters of PLWDs. This is a strategy to maintain good relationships with the rest of the household.

Adjusting a therapeutic diet for financially constraint families

With support from a dietitian, a financially constraint family can adjust a therapeutic diet to ensure a healthy eating plan, which in turn may ensure adequate glycaemic levels. Dietary advice is, however, not limited to financially constrained households but any person can read about dietary constraints, about what is healthy and allowed. Despite financial constraints, comorbidities and portion size should be considered. Anybody can consume seasonal availability, legumes, other plant-based wholesome and nutritious options if it is culturally accepted. There are affordable low-GI products available, and a list can be obtained from the dietitian, e.g. low GI rice is cheaply on the market. Under normal circumstances, pamphlets are freely available for self-service, but it would be advisable to first discuss the content before issuing the pamphlet to avoid misinterpretation. Hand-outs should take place after a support group discussion or presentation and individual follow-up diet consultation. The dietary information contained in hand-out pamphlets and diabetes menus must correlate with individual or cultural dietary preferences and consideration of socio-economic circumstances. The dietitian must consider portion control with emphasis on food items that contain carbs. It is advisable to list simple and complex carbs, including responsible consumption.

Preventing mistakes in drug events and medicine adherence

Medicine adherence is important (Adegbola et al., 2016:1-2,5). The onus of medication dispensing lay with the pharmacist who must check for drug interactions and potential allergic reactions. It is important to prevent these drug events. The pharmacist must ensure issues the correct medicine to the correct person and that the person knows why and how (dose, frequency, and duration) they should take the prescribed medication to prevent such events, e.g. the PLWD and family must understand that the blood glucose must be checked before insulin therapy to ensure insulin therapy. Knowledge of the prescribed medication is important to know how long it works in the body and the effects. Most PLWDs consult twice per year and should receive guidance on medication usage at each visit and medicine with new labels and packaging. Medication treatment can cause significant harm if it is used erroneously.

Several pharmaceutical companies supply medication to health facilities. Consequently, there are variations in packaging, generic names, and differences in the colour of the pills, which are common denominators for confusion. The names of some medications may sound similar and might even look similar but the pharmaceutical properties might be different. Patients and the support person must be able to identify the medication, not only to ensure the correct dose but also to identify any incorrect dispensed items. This should be discussed with the HCP.

PLWDs must be encouraged to not only depend on generic names of medication. When receiving new medicine that they were not exposed to previously, and to avoid mistakes, the pharmacist, physician, or nurse must inform the patients about the differences and similarities accordingly. A pill box might be of help to ensure that the person takes the correct medication at the right time. Pill boxes are popular amongst people who take different medicines at different times. The family can play a role in helping to “restock” the pills, e.g. routinely on a Sunday evening for the week. By preventing adverse drug events, PLWDs are not hospitalised, thus alleviating the ever-increasing burden on healthcare systems and increasing quality of life. It is an easy reference if the person is not sure whether the medication was taken or not.

Insulin storage when travelling

Problems with the availability of insulin and incorrect storage thereof might cause an increased risk of diabetes ketoacidosis. Insulin must be stored correctly. When travelling, it is advisable to take along an adequate amount of medication and to invest in a portable cooler bag with an ice pack to minimise side effects of exposed insulin, such as weight gain and depletion of vitamin B. At home, unused insulin must be stored in the fridge. In the event that there are no fridges or other cooling facilities at home and extended hours of load shedding, rather store the insulin in a cool, dark space to maintain efficacy but not be exposed to direct sunlight or extreme temperatures. Care must be taken not to use insulin which has reached the expiry date.

Administering of insulin

Some insulin-dependent persons use very high doses of insulin. A safe option for the PLWD is to split the dosage before administering insulin, e.g., 76 units of insulin are prescribed, while an insulin pen only delivers 60 units. This means that the person can have two insulin pens in use, one to administer 60 units and the other 16 units. The pens should be clearly marked with the dose that must be taken. Use of two injection sites is advised and should be rotated. The dosage can be divided in half in two pens and injected in equal amounts twice. The medicine chart indicates, for example, 60 units (1/2 hour before supper), with the second line indicating 16 units (1/2 hour before supper) etc. 16 units. The most important aspect is that the person does not overdose and must pay careful attention when preparing the insulin dosage. Alternatively, an insulin pump might be considered. Overdosing of insulin has its dangers. As a precautionary measure, it is recommended that the visually impaired, insulin-dependent person be issued with an insulin pen instead of a vial with insulin syringes and needles. To

ensure the correct dosage, it would be easy to turn the pen to the exact dosage because they can count and listen to the “clicking” sound of the pen.

Disposal of used insulin needles

Needle prick injuries occur unexpectedly and accidentally and are harmful to anyone. In most residential areas, projects or programs to dispose of sharp objects are non-existence. To prevent needle prick injuries and disposal thereof at home, used needles should be kept in a tin or thick, strong plastic container with a lid in a safe place. When it is full, it should be taken to the health facility and added to their disposal. Needles should not be buried, burnt, or toilet flushed, nor used or unused needles should be discarded loose in the dustbin.

Dental care

The PLWD must take care of the teeth and mouth at home to maintain good dental health. Ensure at least regular annual dental consultations and inform the dentist of the diabetes. Visit an oral hygienist at least once a year. Daily practical basic dental hygiene is inexpensive. Use a soft toothbrush, floss, toothpaste, and saltwater rinses. If mouth and teeth problems occur due to diabetes, insulin depletes vitamins needed for strong, healthy teeth, and consult the dentist even if it is earlier than scheduled. Report any problems such as bleeding or painful gums timeously. Seek immediate medical assistance and consult the dentist. The PLWD must be prepared prior to dental work or dental surgery. Depending on the patient’s general cardiac health, the dentist might order a prophylactic antibiotic regime to be taken within an hour of the planned procedure. The PLWD should take, if prescribed, the antibiotic regime prior to dental work to ensure good cardiac health. The dentist might advise on what the person can still eat, what to avoid and how to administer medication before and after the procedure. The sugar levels should always be in an acceptable range.

Footcare

People with diabetes must take special care of their feet to prevent neuropathy and to detect foot problems or complications early. It is important to avoid or reduce diabetes related complication (Hilli, et al., 2018:36; Reid, et al. 2018:122). Daily foot care must be part of the daily self-care routine. Poor care might lead to amputations. Wash the feet in lukewarm water and test the temperature with the elbow to ensure it is not too hot. Soaking of the feet might dry out the skin. Wash with soap and water and dry properly between the toes. Apply a moisturising cream to the feet but refrain from between the toes because the moisture between

the toes may lead to infection. Inspect the feet every day for cuts, sores, blisters, redness, calluses, or other problems. Check for any abnormalities, such as scratches, bruises, and cuts, including circulation. Use a mirror to see under the feet or ask someone else to check the feet. Report any changes in the feet to the HCP. Due to nerve damage, which might affect sensory (tingling sensation, pain, or weakness), check for poor circulation. Cuts may take longer to heal and is prone to infection. The podiatrist can detect changes in the shape of the feet, which might affect movement. An assessment is recommended annually. In the event that the PLWD is unable to cut the nails to prevent ingrowing toenails or injury, assistance should be asked from the podiatrist or a family member. If a podiatrist is affordable, book an appointment for foot care or use the health and beauty salon for the same purposes. Please refrain from smoking. It might affect blood vessels and can reduce blood flow to the feet.

Consult a podiatrist for a foot assessment annually or more often if required. Footcare should not only include an assessment of the feet; the Type and quality of comfortable shoes are equally important. Inspect inside the shoes for sharp objects, small pebbles or any damage to the inner shoe that can cause injury. Ensure to dry wet shoes properly before wearing them. Change the shoes every other day. Caring for the socks to prevent foot fungi is part of foot care. To promote better blood circulation, wear socks that are not too tight. Wear clean cotton or diabetes socks daily. It can be washed in water and soap or a Milton solution. Circulation is very important for PLWD, and a foot and leg scan should be done as poor blood flow causes cold feet, numbness and sores that heal slowly. Due to peripheral neuropathy, it is not recommended to use hot water bottles and heaters to prevent cold feet, as it might cause burns.

Eyecare

Self-care practices can prevent or delay the risks and complications of diabetes eye disease. A complication of uncontrolled high blood glucose is retinopathy, glaucoma, and cataracts. Annual visits to the eye clinic, optometrist, or ophthalmologist are recommended for a comprehensive vision examination and dilated retinal examination to detect abnormalities and for treatment. The PLWD must practice self-care eye screening to determine the effect of diabetes on the eyes. The diabetes eye is affected because of uncontrolled blood glucose; therefore, they should practice eye care as part of diabetes self-care management. It is recommended that they are aware of blurry eyes and double vision. They must adjust their diet to keep cholesterol levels in check, follow a healthy diet, exercise regularly, and drink adequate water to lower their blood glucose and keep fit and healthy.

Support for sexual dysfunction

Diabetes men are more prone than others to develop sexual dysfunction. More important is not to self-medicate. In view of potential cardiovascular problems and hypertension, the person must consult with a physician for medical therapy. The person can be referred to a urologist to determine the cause and for guidance or treatment. It might help if the person monitors and regulates blood glucose through an improved diet to increase blood flow and reduce blood glucose levels. High blood glucose levels might damage blood vessels and nerves. This is a sensitive complication and might be referred for psychological interventions such as cognitive-behavioural therapy, sensate-focused therapy, mindfulness-based interventions, and psychoeducation.

Thank you for taking the time to read this information

Author information and study:

University of Pretoria, PhD Nursing Science study (2020 – 2024)

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